Title
Leading a life with a terminal illness

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Publication Date
2004

Leading a Life With a Terminal Illness: An Interpretive Phenomenological Study of Patients' and Family Members' Experiences of Hospital End-of-Life Care

by

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DISSERTATION

Submitted in partial satisfaction of the requirements for the degree of

DOCTOR OF PHILOSOPHY

in

Nursing

in the

GRADUATE DIVISION

of the

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

Approved:

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This work is dedicated to my parents, Liseli and Erwin Spichiger-Wüthrich.

ACKNOWLEDGEMENTS

Several people have considerably contributed to this dissertation; their support has enabled me to accomplish the work. First, I want to express my great thanks to the patients and family members who participated in the study. During an extremely difficult period of their life, they spent time with me and shared their experiences of living with a terminal illness and being cared for in the hospital. Their willingness to talk to me made this project possible – a generosity that I appreciate tremendously.

I am grateful to the nurse managers and assistant nurse managers of the hospital who, in spite of tight work schedules, recruited patients, and to all the health care professionals for letting me observe their caregiving and for their cooperation.

It was a privilege to meet and work with Dr. Patricia Benner. Her never ending support as my advisor carried me through the years of course work, and she has been an extraordinary mentor throughout the course of this study as dissertation chair. She challenged and guided me, opening up new horizons and inspiring me to explore new ideas and deepen my interpretations. I am thankful for learning from such a brilliant and wise interpretive phenomenologist.

I wish to express my eternal thanks to Dr. Annemarie Kesselring, my Swiss mentor. She nurtured my interest in nursing research and encouraged me to go to UCSF. I thank her for her faith in my ability to succeed. As a member of my dissertation committee, she was an indispensable resource during data collection and analysis, providing scientific as well as personel support.

My thanks also go to the other members of the dissertation committee, Dr. Meg Wallhagen and Dr. Jeanie Kayser-Jones. I highly valued Meg's critical feedback and her

thoughtful suggestions as well as her support as chair of the committee for the Qualifying Exam. Jeanie's work with nursing home residents was a great source of inspiration for this project. I also wish to thank Dr. Kit Chesla who, during a research residency, introduced me to the practice of interpretation and was a very supportive member of the committee for the Qualifying Exam.

I want to thank my fellow students Heleen Prakke, Romy Mahrer Imhof and Lorenz Imhof. Our discussions were invaluable to me and the progress of this project. Other students and friends in the US and in Switzerland also contributed to this work, and I gratefully acknowledge their support and friendship. I also wish to thank my editor, Karla Lindgren, for her efficient and timely work.

Finally, my deep gratitude is extended to my family. They encouraged me to cross the ocean to pursue my goal, while they ran errands and took care of my affairs in Switzerland. No words can adequately express my thanks for their steadfast support.

Funding from the following sources is gratefully acknowledged: The Regents Fellowship, Nursing, of the Graduate Division, University of California San Francisco; the Non-Resident Tuition Scholarship of the University of California San Francisco; the Bernese Cancer Grant from the Bernese Cancer League; the Inselspital Berne, Switzerland; the Alumni Association of the Red Cross Nursing Foundation School for Registered Nursing, Berne, Switzerland; and the University of California, Nursing Alumni Association Scholarship.

ABSTRACT

Leading a Life With a Terminal Illness: An Interpretive Phenomenological Study of Patients' and Family Members' Experiences of Hospital End-of-Life Care

Elisabeth Spichiger

This interpretive phenomenological study explores terminally ill patients' and family members' experiences of hospital end-of-life care in one Swiss university hospital. Caring practices are considered from a theoretical perspective; palliative care is described as a caring practice and the gold standard in end-of-life care. Hospital end-of-life care, however, does not always meet this standard. The literature review shows that publications of patients' and families' experiences of hospital end-of-life care are limited and fragmented. This study aims at providing a local and particular, but more comprehensive picture.

Ten patients and their closest family members participated. Data were collected through repeated participant observations, conversations with patients, and interviews with family members during the patients' hospitalization and in a few cases post bereavement. Data were analysed using an interpretive phenomenological approach. The thematic analysis revealed four major themes that were illustrated with paradigm cases and exemplars.

People lead unique lives, and even when a terminal illness intrudes and brings about suffering and losses, patients and family members hold on to familiar background meanings and practices, while moving in the new worlds of illness, hospital and professional caregiving. Their life stories and illness experiences render their situation in the hospital more understandable and open up possibilities for the providers to personalize their care. The hospital is experienced differently, such as prison, heaven, or necessary sojourn and these experiences fluctuate over time. A caring stance of the professionals is crucial for patients and families to feel well cared for, whereas uncaring providers are experienced negatively. When care providers lack the needed skills, act inappropriately, do not know the patient and the family member, or do not recognize them as persons, patients and family members suffer unduly and care is experienced as routinized and devaluing. In contrast, adequate care and the families' integration decisively improve patients' and families' quality of life. Mundane care interventions become powerful recognition practices in the context of suffering and disability from a terminal illness. Skillfull emotional engagement and expertise in providing effective and attuned care hold many possibilities for humanizing the hospital setting. Implications for practice, education, and research are outlined.

Patricia Benner

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CHAPTER ONE: CARING PRACTICES AT THE END OF LIFE: A THEORETICAL PERSPECTIVE

The purpose of this chapter is twofold: To discuss caring practices in end-of-life care from a theoretical perspective, and to outline reasons to explore terminally ill patients' and their families' views of hospital end-of-life care. The chapter has four sections: First, the concepts of "caring," "practices," and "caring practices" are discussed. Second, end-of-life care is introduced, and it is claimed that palliative care is a caring practice. Third, hospital end-of-life care is explored further, and my experience with delivering such care is described. Finally, the apparent lack of terminally ill patients' and their families' perspectives on hospital end-of-life care is demonstrated, and the roots of my interest in this topic are outlined.

CARING PRACTICES

Caring practices are considered in three steps; caring and practices as distinct notions, followed by caring practices as a concept. A phenomenological view of caring is favored and contrasted with views influenced by the natural sciences. The discussion of practices is based on comprehensive, philosophical definitions of the term. The notions of caring and practices are then joined and illustrated with examples of private and public caring practices.

Caring

In this beginning section, numerous notions of caring are presented first. Then the call from some nurse researchers for quantification of the concept and why this is problematic is discussed. An exposition of caring from a phenomenological perspective follows. The discussions of Heidegger's and Kierkegaard's writings are, in addition to the referenced publications, based on Dr. H. L. Dreyfus' interpretation of Heidegger and Dr. J. Rubin's interpretation of Kierkegaard, both of which were provided during lectures at the University of California Berkeley.

Different Conceptualizations of Caring

Caring has been described in a myriad of different ways in the nursing literature. Meleis (1997), for whom caring is a component of what defines a nursing perspective, has also summarized views that contrast with her own: caring as the essence of nursing; caring as equal to the discipline of nursing; caring as the goal, mission, or both of nursing; caring as the moral ideal or central virtue of nursing; and caring as the art of nursing.

The numerous conceptualizations of caring have been constructed in different ways. Some were developed deductively, such as Watson's (1979) theory of human care. Others were formed inductively and represent different levels of abstraction (Walker & Avant, 1995). Examples are Leininger's (1991) grand theory of culture care diversity and universality that grew out of several ethnographic studies, or Swanson's (1991) middle-range theory of caring, which was empirically developed from three phenomenological studies. Many authors have provided descriptions of caring based on single studies. Their research included perspectives of patients, families, nurses, nursing students, nursing teachers, and other health care professionals (Swanson, 1999). The concept has been mainly investigated with qualitative methods, including phenomenology, grounded theory, content analysis, and ethnography. The few quantitative studies have mostly used caring behavior inventories with ranking scales.

Morse, Solberg, Neander, Bottorff, and Johnson (1990) explored various conceptualizations of caring and identified 35 explicit or implicit definitions of this concept. The authors analyzed the definitions and described five related perspectives on the nature of caring: caring as a human trait, a moral imperative or ideal, an affect, an interpersonal relationship, and a therapeutic intervention. Two outcomes of caring were identified as well: patients' subjective experiences of being cared for and patients' physical response to caring.

Sherwood (1997) performed a meta-synthesis of 16 qualitative studies that investigated caring from the client's perspective. The following four patterns of nurses' caring emerged from this synthesis: healing interaction (e.g., creating an overall healing milieu), nurses' knowledge (e.g., making knowledgeable decisions), intentional response (e.g., performing helpful interventions), and therapeutic outcomes (e.g., resolving physical and affective needs). The goal of the synthesis was the development of an operational model of caring, with relational statements and propositions that can be examined in practice for theoretical confirmation.

Swanson (1999) reviewed approximately 130 data-based, quantitative and qualitative investigations of caring to determine the current state of knowledge about the concept in nursing. These studies were mainly published between 1980 and 1996. This reviewer proposed to distinguish five levels of discourse when referring to the concept of

caring: Level I identified characteristics of persons with the capacity for caring; level II summarized concerns and commitments by focusing on the beliefs or values undergirding caring actions; level III identified patient-, nurse-, or organization-related conditions that enhance or diminish the likelihood of caring transactions; level IV described caring actions, behaviors, or therapeutic interventions; and level V focused on positive and negative consequences of caring. According to the author, the five levels of caring knowledge were hierarchical in order of level of assumption, not in order of significance.

For each level, study results were presented in extensive lists with categorized descriptors (Swanson, 1999). Caring capacities were summarized as compassionate, empathic, knowledgeable, positive, and reflective, with a total of 66 descriptors. Recognizing the dignity and worth of each person, focusing on the other's experience, connecting with the other, doing the right thing, and being present to the self summed up concerns and commitments. The conditions affecting caring were patients' communication, personalities, health problems, care needs, and relationships to nurses; nurses' personal and professional resources, constraints and demands; and organization-related conditions, namely personnel- and role-related, technological, administrative, and work- or practice-related conditions. Caring actions described under level IV included quantitative investigations (i.e. caring behavior ranking studies) and qualitative findings, which could be classified into the five caring categories of Swanson's (1991) middle-range theory of caring: maintaining belief, knowing, being with, doing for, and enabling. Finally, emotional-spiritual, physical, and social consequences of caring for clients and emotional-spiritual, professional, and social consequences of caring for nurses were listed.

The various conceptualizations of caring (Meleis, 1997; Morse et al., 1990) and the syntheses of knowledge about the concept (Sherwood, 1997; Swanson, 1999) show that it has been extensively described and explored; the relevance of caring for nursing is underlined. However, the numerous definitions and the research findings that include many distinct aspects, from caring as a characteristic of nurses to consequences of caring, also illustrate that authors do not share a common view of the concept and that, therefore, researchers need to carefully choose and describe their perspective.

A Quest for Quantification of Caring

Morse et al. (1990), Sherwood (1997) and Swanson (1999) agreed that nursing knowledge on the concept of caring needs further development. The latter two authors also shared a call for quantitative research. Swanson stated this most sharply:

> Nurse researchers working in a clinical arena need to expand (some may say constrict) their thinking to consider caring as a commodity that may be measured, rigorously applied, and tested for its effectiveness in promoting healing, recovery, or optimal well-being. (p. 55)

The request for quantitative research is based on the positivist assumption that caring can be operationalized into measurable features. This is in sharp contrast to the phenomenological view of caring adopted in this paper.

Dunlop (1994) provided an excellent discussion of the compatibility of the concept of caring with science. She stated that a traditional view of science, that is, a view following the natural science model, implies that caring can be described in a set of context-free, measurable variables. However, if stripped of their context, variables delineating caring (e.g., compassion) cannot be defined in measurable terms any better than caring itself. The human sciences are confronted with a fundamental problem when

emulating the natural science model because a description of human capacities in terms of context-free features, abstracted from everyday contexts, is impossible (Dreyfus, 1986). Taylor (1985a) made a similar point when saying that science cannot treat aspects of personhood in exactly the same way it approaches people's organic being. Swanson's (1999) meta-analysis on caring can serve as an illustrative example here. The author gave an all-embracing overview of the research on the concept. But for the reader, caring easily becomes elusive amidst the extensive lists of abstract categories and descriptors. With the removal of the study context through the process of meta-analysis, the meaning that caring held for a particular population situated in a specific context is lost.

Phronesis Versus Techne

Swanson's (1999) meta-analysis on caring serves to point out yet another relevant issue that is related to the call for quantification: the distinction between phronesis and techne. According to Dunne (1997), Aristotle made a distinction between practical knowledge or phronesis and productive knowledge or techne. Techne refers to the knowledge of an expert maker, that is, to the universal principles, means and ends underlying the production of something. The producer can provide a rational account of the artefact's production and teach others. The artefact, once produced, can stand on its own, independent of its maker.

Phronesis means embodied practical knowledge about how to act well. Good action itself is its end. Therefore, phronesis implies excellence and continual learning. Agents are engaged in their actions and act in relations with others. They attune universal knowledge to particular situations, but experience and perceptiveness have priority over formal knowledge. Actions cannot be separated from the agent or the particular context, and the agents can narrate about but not transform their actions into universal knowledge.

In relation to caring, an approach like Swanson's (1999) that breaks down the concept into means and ends, implies a view of caring that is based on techne, with a formulated body of knowledge, which, if applied correctly, will produce the desired outcomes independent of the applicant. The phenomenological perspective on caring discussed below, however, is rooted in phronesis and, therefore, considers caring as closely tied up with the actor who, based on experience and perceptiveness, applies formal knowledge in the best possible way to a particular situation.

A Phenomenological Approach to Caring

According to Dunlop (1994), a science of caring is only possible if one chooses a route that steps away from the natural science methodology with its quest for universal principles and prediction. She suggested hermeneutic inquiries as an appropriate way to articulate what caring means in a particular context. Benner and colleagues have published several hermeneutical studies with findings that express what caring means in nursing practice (Benner, 1984, 1994d; Benner, Hooper-Kyriakidis, & Stannard, 1999; Benner, Tanner, & Chesla, 1996). Their understanding of caring is rooted in Heideggerian phenomenology.

The Heideggerian Notion of Care

For Heidegger in "Being and Time," his fundamental work on the phenomenology of being, care is the ontological structure of being-in-the-world (Heidegger, 1927/1962). He defined care as:

> The Being of Dasein means ahead-of-itself-Being-already-in-(the world) as Being-alongside (entities encountered within-the-world). This Being fills in the signification of the term "care" (Sorge), which is used in a purely ontologico-existential manner. (p. 237)

Stated simply, by care, Heidegger meant, in a general way, "Sein geht mich an," or, being matters to me (Dreyfus, 1991). The form of mattering is not determined in this description; it may be in love or anger (Benner & Wrubel, 2001).

The ontological structure of care is threefold: 1) As human beings we take a stance on our being through our for-the-sake-of-whichs, what Heidegger (Heidegger, 1927/1962) called being ahead-of-itself. This concept means that what matters to us shows who we are. For instance, since nursing and the improvement of its scientific knowledge base matter to me, my for-the-sake-of-which is to be a nurse researcher. 2) Human beings are always already in a world. "To Being-in-the-world, however, belongs the fact that it has been delivered over to itself – that it has in each case already been thrown *into a world*" (p. 236). For Heidegger, the term world referred to the meaningful set of relationships, practices and language that human beings have because they are born into a culture (Leonard, 1994). Our shared skills and practices (e. g., walking, eating, dressing) provide meaning and intelligibility. As persons, we are always already situated (thrown, in Heidegger's term) into a particular, historical, and familiar world that then sets up which possibilities are open or precluded to us. This shared world is very much taken for granted, and therefore overlooked. It only becomes visible when smooth functioning breaks down. For example, as a woman of the 21st century, I can become a nurse researcher (my for-the-sake-of-which), but I cannot become a Greek heroine. 3) As human beings, with our for-the-sake-of-whichs (being ahead-of-itself), and our situatedness in a world (being-already-in-a-world), we manifest our being through our absorption in a world with shared norms and through our actual involvement in everyday activities, by coping with equipment. "Ahead-of-itself-Being-already-in-a-world essentially includes one's falling and one's *Being alongside* those things ready-to-hand within-the-world with which one concerns oneself" (Heidegger, 1927/1962). For example, as a nurse researcher I manifest myself through being absorbed in a world of research with shared meanings and norms, and through my research activities, such as performing interviews, entering data on the computer, and so forth.

Benner and Wrubel's View of Caring

In "The Primacy of Caring" Benner and Wrubel (1989) filled in Heidegger's yet empty ontological structure of care with their view of care, where caring means that

> persons, events, projects, and things matter to people. Caring is essential if the person is to live in a differentiated world where some things really matter, while others are less important or not important at all. "Caring" as a word for being connected and having things matter works well because it fuses thought, feeling, and action – knowing and being. And the term *caring* is used appropriately to describe a wide range of involvements, from romantic love to parental love to friendship, from caring for one's garden to caring about one's work to caring for and about one's patients. (p. 1)

Caring is "primary" (Benner and Wrubel's [2001] term for ontological) in three ways: 1) It sets up what matters, and therefore also what is stressful, to a person and also defines which possibilities are available and acceptable for coping with a situation. Caring (having a relationship, an event, etc. matter) makes the carer vulnerable to experiencing loss and pain, but may also result in joy and fulfillment. 2) Caring allows persons to focus on the event or the one cared for rather than on themselves. For caring persons in any given situation, certain aspects will show up as relevant, and these will enable them to recognize problems and possible solutions. These aspects will also help them to

implement the solutions (e. g., a caring person will nurse a loved one even under difficult conditions because this is just what she or he has to do). In this way, caring is enabling and therefore a necessary condition for expert human practice. 3) Caring sets up the ways in which giving help and receiving help are possible (Benner & Wrubel, 1989). An act performed in a caring relationship that allows trust will have more positive consequences than the same act performed in a noncaring manner.

Two Crucial Aspects of Caring

Qualitative distinctions and an absence of radical freedom of choice are two implicit yet crucial aspects of the above conceptualization of caring. They warrant further discussion.

Qualitative distinctions. Kierkegaard (1962) identified "levelling," his word for nihilism, as the striking problem of the modern age. "Our age is essentially one of understanding and reflection, without passion, momentarily bursting into enthusiasm, and shrewdly relapsing into repose" (p. 33). Here, passion stands for commitment and reflection for thought instead of action. In the modern culture, according to Kierkegaard, detachment had replaced commitments in human relationships (Rubin, 1989). Rubin provided an illustration of this modern, detached person:

> The prototypical contemporary man sits in front of the television set. He gossips about the latest scandals in the religious or political worlds but does not make any religious or political commitments of his own. He does not really care about anything, although he is very skilled at creating the illusion that he cares. (p. 133)

In a similar vein, Taylor (1991) described how the individualism of self-fulfillment, currently widespread in Western societies, centers on the self and concomitantly shuts out, or is even unaware, of the greater religious, political, or historical issues or concerns that transcend the self. Consequently, life becomes narrowed or flattened.

The consequence of this lack of commitments is a weakening of qualitative distinctions. Without a strong commitment, nothing will show up as more or less significant for human beings. Qualitative distinctions can only be maintained by a commitment to certain things or persons. For example, only a person to whom serious literature really matters is able to maintain the distinction between serious and trivial literature. This strong commitment will influence the person's world and self, and will thereby contain the risk of loss. The vulnerability that follows from strong commitments lets people shy away from getting involved (Kierkegaard, 1962; Rubin, 1989).

Rubin (1996) illustrated how nurses' inability to become deeply involved and make qualitative distinctions impeded caring. Contrary to expert nurses exhibiting excellent caring practices, these nurses, although experienced, could hardly remember particular patients and their specific situations. The nurses' disengaged stance prevented meaningful distinctions between patients and even between patients' experiences and their own. Rather, patients were stereotyped. The inability to experience patients as individuals hampered adequate care.

No radical freedom of choice. Human beings are always already in a world that provides background familiarity and meaning (Heidegger, 1927/1962). As noted above, this opens up possibilities. However, it also means that no human being can create his or her own self completely independent of others. Persons' identities crucially depend on their dialogical relations with others (Taylor, 1991). Caring precludes the autonomous, freely choosing individual so often embraced as the ideal in contemporary Western

societies. Kierkegaard's (1987) Judge William adeptly demonstrated that a position of radical freedom of choice is untenable. Taylor (1985a) underlined this position:

> The subject of radical choice is another avatar of that recurrent figure which our civilization aspires to realize, the disembodied ego, the subject who can objectify all being, including his own, and choose in radical freedom. But this promised total self-possession would in fact be the most total self-loss. (p.35)

Thus, from this phenomenological perspective, caring always involves human beings situated in a meaningful world and connected to other human beings through their significance-giving concerns. Caring actions are determined by this world and by the carers' commitments.

Noddings' Related, yet Distinct Notion of Caring

Noddings (1984) took a related stance on caring. Her discussion focused on the reciprocal relationship of the one-caring and the cared-for. She suggested that human beings in loving relationships naturally care (e.g., a mother for her child), and that their inclination to care for others (e.g., as nurses tend to patients) is grounded in the remembrance of positive feelings of caring and being cared for. Noddings and Benner and Wrubel (1989) agreed that caring happens in concrete situations, and that it involves making a commitment and taking the related risk.

Noddings' (1984) view is divergent in mainly two areas: First, she states that reciprocity in the caring relationship is indispensable. "Logically, we have the following situation: (W, X) is a caring relation if and only if i) W cares for X (as described in the one-caring) and ii) X recognizes that W cares for X" (p. 69). Second, Noddings distinguished natural caring (i.e., for a loved one) from ethical caring (i.e., for a "stranger"), claiming that ethical caring entails having a choice to accept or reject the

impulse to care. Acceptance is motivated by a concern about one's ethical self, by a desire to be moral.

> In caring, we accept the natural impulse to act on behalf of the present other. We are engrossed in the other. We have received him and feel his pain or happiness, but we are not compelled by this impulse. We have a choice; we may accept what we feel, or we may reject it. If we have a strong desire to be moral, we will not reject it, and this strong desire to be moral is derived, reflectively, from the more fundamental and natural desire to be and to remain related. (p. 83)

According to Benner and Wrubel's (1989) perspective, however, the carer's commitment will elicit caring actions unconditionally, that is, independently of the single care recipient's reaction, and choosing to accept or reject the impulse to care is not possible. Rather, the carers' thrownness and openness determine their capacity to understand and respond in caring relationships. How a caring relationship unfolds is beyond the carers' control (Benner et al., 1999). However, from both Noddings' and Benner and Wrubel's (1989) standpoint, caring can never be reduced to a mere set of therapeutic techniques. Rather, it provides a stance from which human beings can practice (Morse, Bottorff, Neander, & Solberg, 1991). The concept of practices is discussed next.

Practices

Some general understandings of practice are explained in the following definitions of the concept in Webster's Ninth New Collegiate Dictionary (1991): 1a) actual performance or application, b) a repeated or customary action, c) the usual way of doing something; 2a) systematic exercise for proficiency, b) the condition of being proficient through systematic exercise; 3) the continuous exercise of a profession. These definitions point out three issues, namely that practice may have to do with repeated activity, with

exercising this activity in order to improve performance, and that it may concern a professional activity. Some philosophers provided more comprehensive definitions of the concept. Notions of practice that extend beyond the general understanding of the word are presented in the definitions of Taylor, MacIntyre and Whitbeck.

Taylor's Notion of Practices

Taylor (1989) defined practice as

> something extremely vague and general: more or less any stable configuration of shared activity, whose shape is defined by a certain pattern of dos and don'ts, can be a practice for my purpose. The way we discipline our children, greet each other in the street, determine group decisions through voting in elections, and exchange things through markets are all practices. And there are practices at all levels of human social life: family, village, national politics, rituals of religious communities, and so on. (p. 204)

This definition highlights that such a practice is based in a cultural tradition (e.g., child education varies across cultures). Practices are found in the private as well as in the public area. Furthermore, a practice is constituted by meaningful actions. Moving a piece of wood on a checkered board becomes a meaningful action constituting the practice of playing chess, when performed by a chess player (Taylor, 1985b).

In a discussion of the relation between social theory and practice, Taylor (1985b) also pointed out that members of a society always have an implicit, pre-theoretical understanding of their practices (e.g., voting requires an independent decision by individuals). Social theory, concerned with providing an explanation of what is really happening in a society, first describes the central activities and norms of the society's practices, thereby making the members' self-understandings explicit. Second, social theory questions and challenges these self-understandings, and emphasizes some hitherto unrecognized aspects. Such a challenging theory may affect people's self-understanding.

In turn, an altered self-understanding may bring about changes in a practice (i.e. undermine, strengthen, or otherwise alter the practice), which then call for an adjustment of the articulation of the original practice. Consequently, practices and their articulations are always interwoven and influencing each other, thus bringing about changes over time (Taylor, 1985b, 1989).

MacIntyre's Notion of Practices

MacIntyre (1984) defined practice even more comprehensively as

> any coherent and complex form of socially established cooperative human activity through which goods internal to that form of activity are realized in the course of trying to achieve those standards of excellence which are appropriate to, and partially definitive of, that form of activity, with the result that human powers to achieve excellence, and human conceptions of the ends and goods involved, are systematically extended. (p. 187)

Giving an example, the author explained that the planting of turnips is not a practice; farming, however, is one. All practices require technical skills, but a practice is always more than a set of technical skills. A wide range of activities falls under the concept, for instance the arts, sciences, games, or the making and sustaining of family life.

MacIntyre (1984) distinguished goods external and internal to a practice. By goods external to a practice he meant such goods as prestige, status, and money. Engaging in a certain practice is only one way to achieve these goods, and there are always alternative ways to attain them. Goods external to a practice are objects of competition with losers and winners.

On the contrary, goods internal to a practice – the goods that are partly defining a practice – can only be achieved by engaging in a certain practice. MacIntyre (1984) called them internal for two reasons: They can only be specified in terms of a certain practice, and they can only be identified and recognized by the experience of participating in this practice. People who lack this experience are not capable of making judgments on the internal goods achieved. Typically, the achievement of goods internal to a practice is an achievement for all people participating in this practice. In a later publication where he discussed human vulnerability and disability, MacIntyre (1999) provided a fuller account of the goods internal to practices. The author now referred to internal goods as genuinely common goods acquired in a community of receiving and giving practitioners. A "normal looking" person can, for instance, gain insight from a relationship with a grossly disfigured person. By trying to neither feign unawareness of the disfigurement nor be totally distracted by the person's appearance, normal looking persons can gain insight into the values they place on a pleasing appearance and the errors inherent in these value judgments. It can serve as a way to discover yet unrecognized sources of error in their practical reasoning. Caring for physically or mentally incapacitated and totally dependent human beings, from this perspective, is not just a burdensome, one-sided relationship. It provides caregivers with the possibility of learning something essential, namely what it means to be fully responsible for the well-being of someone who is wholly entrusted to their care.

People entering a practice have to accept the standards of excellence featured within this practice, that is, the best standards achieved so far in this practice. Each practice has a history from which new practitioners have to learn. As MacIntyre (1984) stated, "To enter into a practice is to enter into a relationship not only with its contemporary practitioners, but also with those who have preceded us in the practice, particularly those whose achievements extended the reach of the practice to its present point" (p. 194). In striving to achieve excellence, practitioners have the potential to refine a practice and to work it out in new situations (Benner & Gordon, 1996).

Practices should not be confused with institutions (MacIntyre, 1984). Chess is a practice; the chess club is an institution. Institutions are involved in acquiring and distributing material goods such as money and power. They have to do so to sustain themselves and the practices they bear. Without the support of institutions, practices cannot survive. Practices and institutions – and consequently external goods and goods internal to a practice – are therefore closely related. The ideals and the creativity of a practice and the practitioners' cooperative care for common goods are always vulnerable to the acquisitiveness and the competitiveness of an institution.

Whitbeck's Feminist Standpoint

Whitbeck (1984), whose practice definition is based on MacIntyre's (1984) writings, added a feminist standpoint by regarding the "(mutual) realization of people" (p. 65) as the core practice, with a variety of particular forms which are mostly considered to be women's work, e.g., child rearing and education, or care of the ill and dying.

In summary, a practice is seen here as a culturally based, shared activity with a tradition. It has standards of excellence, which its practitioners strive to achieve. They, thereby, realize internal goods and extend their capacities to achieve these standards and the standards themselves. Practices, attending in some way to human beings and with practitioners who let these human beings matter to them, are considered as caring practices. Next, this notion of caring practices is explored further.

Exemplary Caring Practices

In this section, a discussion of caring practices is followed by illustrations of this concept. Mothering, a private caring practice, is described from a philosophical as well as a research derived perspective. Nursing patients and nursing patients' families, finally, serve as examples of public caring practices.

Caring practices, thus, refer to activities of people, activities they get involved in because other persons matter to them. Their commitment and their location in a meaningful world set up the possibility to engage in a practice, that is, to engage in a culturally based tradition, constituted of meaningful actions. This type of practice allows one to realize notions of good, is continually developed, and has the potential for being worked out in new situations (Benner, 1994b). Caring practices can be found in the private as well as the public area. Parenting, caring for sick family members, teaching, social work, and nursing are examples. The latter is seen as the paradigm case for a public caring practice in Western cultures, whereas mothering is paradigmatic for the private sphere (Benner, 1994b).

Although Noddings' (1984) distinction between natural and ethical caring is questionable, it points out that there are in fact differences between private and public caring practices. Public caring practices such as nursing are embedded in formal education and are institutionally structured (Benner, 1994b). In addition, the joys and losses involved in caring affect practitioners to a lower degree, since these experiences are not part of their personal world.

> Caring as a public practice does not have the same burdens as caring in one's private life since the growth, vulnerability and suffering of the one cared for does not threaten or damage the personal world of the care-giver. (Benner, 1994b, p. 142)

A Philosophical Perspective on Mothering

Ruddick (1995), a mother and daughter, an observer of other mothers, and a feminist, described mothering from a philosophical perspective. For her, maternal practice, that is, the work of a mother, starts when someone assumes the responsibility of caring for a child. The demands, imposed on the mother by the child and her social group, are threefold: 1) preserving the child's life through protective care, 2) fostering the child's growth by nurturing him or her emotionally and intellectually, and 3) training the child to become an acceptable member of the social group. "To be a mother is to be committed to meeting these demands by works of preservative love, nurturance, and training" (p. 17).

Mothering, for Ruddick (1995) is an ongoing, organized set of activities requiring discipline and active attention. However, these activities are not distinct techniques, but meaningful actions appropriate in particular situations, or, stated in Aristotle's words, phronesis not techne. Protective care, for instance, includes developing a watchful eye and learning when to intervene or look away. And fostering growth means providing support in unfolding more completely rather than promoting prescribed developmental steps. It is relational and particular.

A Research Derived Perspective on Mothering

Leonard (1993), in her interpretive study of first-time mothers with career commitments, described mothering as a caring practice. For some women in her study, having a baby was a "world-transforming experience" (p. 87), leading to a "world-defining commitment" (p. 96). In this transformation, the whole life (e.g., work, friends, leisure time) became centered around the baby, as when the mother, without hesitation, left the workplace earlier to take care of a sick baby or delayed returning to work after the birth because of a child's hospitalization. The backside of this strong commitment was the women's vulnerability associated with the potential loss of the baby. The baby became the focal point in the women's life and provided meaning, purpose, and identity. Their mothering practice also gave them great satisfaction. They hoped to support the child in growing according to his or her possibilities, rather than being concerned with the child's future achievements in education, and so forth. Nurturing and caring activities were based on meaningful family traditions, common sense, and the mothers' intuitive understanding of her child. By practicing daily, the mothers developed their skills and their understanding of mothering; they strove to be good mothers.

Leonard (1993) contrasted her notion of mothering as a caring practice with child rearing techniques, where the tasks of mothering are seen as technical procedures to deal with an object, the child. Successful child development as technique is then, for instance, measured in terms of walking and talking abilities. The internal goods embedded in mothering as a caring practice are lost.

Nursing Patients and Their Families

Benner and colleagues articulated, among other aspects, caring practices of the critical care nurses they observed and interviewed in a large, two-phased hermeneutic phenomenological study of critical care nursing (Benner, 1984; Benner et al., 1999; Benner et al., 1996). For instance, several domains of nursing practice were described, including the helping role, the teaching-coaching function, the diagnostic and patient-monitoring function, effective management of rapidly changing situations, and the

administration and monitoring of therapeutic interventions and regimens (Benner, 1984). For each domain, practices were articulated through narratives and interpretations that demonstrated nurses' caring for their patients. The helping role, among other practices, involved establishing a healing relationship, providing comfort measures, being with the patient, and maximizing the patient's participation in his or her own recovery. A nurse, for example, cared for a concert pianist who had suffered a mild stroke, was very depressed over the weakness in her right hand, and therefore refused to go to physical therapy. The nurse sat down with her patient and listened and talked to her without mentioning physical therapy. She pointed out in detail the day to day progress that the patient had made in moving her arm, hand and fingers since admission. While the patient only realized what she had lost, the nurse focused on the positive aspects. After this talk, the patient went to physical therapy. This nurse, truly concerned about her patient, was able to act in a meaningful way that fostered the woman's recovery.

Critical care nurses cared for patients' families primarily in three ways: They ensured that the family could be with the patient; they provided the family with information and support; and they encouraged family involvement in caregiving activities (Benner et al., 1999). For instance, recognizing families' fear of approaching a patient after surgery, a nurse would put the side rails down, give the family permission to go close and kiss and hug the patient.

In an often busy and turbulent intensive care unit nurses had to recognize and support the families' role in care to exhibit caring practices to families (Chesla, 1996). These nurses cared creatively and innovatively for families, and balanced family involvement with their efforts to care for and cure the patients. Nurses, who, for different

reasons, uniquely focused on the patients and the technical aspects of nursing, tended to see families as obstacles and tried to distance them.

Benner and colleagues articulated nursing as a caring practice mainly from the perspective of nurses (Benner, 1984; Benner et al., 1999; Benner et al., 1996). Patients' and families' perceptions were integrated only indirectly through nurses' narratives, which often detailed utterances of patients and family members, as well as the nurses' interpretations of care recipients' reactions and perceptions. To gain insight into patients' and families' views of caring practices, patients and families need to be included directly as research participants.

To sum up this section, the notion of caring practice, then, refers to a culturally based, shared activity with a tradition, which attends to persons and may be performed in the private or public area. Its practitioners are genuinely committed to these persons; they strive to achieve the practice's standards of excellence and, thereby, realize goods internal to the practice and extend their capacities to achieve excellence as well as their standards of excellence. The phenomenological view of caring provided by Benner and Wrubel (1989), combined with the comprehensive notion of practices given by Taylor (1989), MacIntyre (1984), and Whitbeck (1984) is advocated in this paper, because what constitutes a caring practice cannot be described as definite behaviors, actions, outcomes, and so forth. Rather, what is perceived as a caring practice depends on the particular situation of all people involved and on the specific context. The chosen conceptualization of caring practices is well suited to this perspective. The first part of this chapter discussed caring, practices, and finally, caring practices. The rest of the chapter will focus on end-of-life care as a potential caring practice.

END-OF-LIFE CARE – A CARING PRACTICE?

In this section, a brief introduction is followed by a discussion of end-of-life care that does not meet the criteria of a caring practice, and of palliative care, considered as the gold standard in end-of-life care. I suggest that palliative care is, in fact, a caring practice. The history of palliative care, its basic concepts, the continual refinement and articulation of methods, current standards of excellence, internal goods, challenges and emerging styles, and the practice's relation to institutions are described.

Introduction

For clarification, a description of how some key terms are understood in this dissertation is given first. Some general aspects of end-of-life care are discussed next.

Description of Key Terms

The term "terminally ill patients" refers to patients with progressive diseases expected to result in death, for which treatments may slow down progression for a limited time but are not anticipated to substantially change the course (Sachs, Ahronheim, Rhymes, Volicer, & Lynn, 1995). I decided to use "terminally ill" instead of "dying" after I had met the study participants and realized that these patients were mostly concerned with living on, not with dying. "End-of-life care" is used to relate to the care of these patients in general without specifying its content. "Palliative care" and "hospice care" have been used interchangeably for the specific form of care aiming at the best quality of life for terminally ill patients and their families. Palliative care is used here as the generic term, whereas hospice care refers to care provided through a hospice organization; and "supportive care," a notion that includes palliation during curative treatment, is not used (Barnard, Towers, Boston, & Lambrinidou, 2000; Doyle, Hanks, & MacDonald, 1998). I recognize that palliative care is not restricted to the last phase of a disease when no cure is available, but may also apply earlier in addition to curative treatment (Doyle et al., 1998; Radbruch & Zech, 1997; World Health Organization, 1990, 2003). Usually, the transition is fluid and the curative phase cannot be strictly separated from the last phase except in retrospect. For this dissertation, palliation in addition to curative treatment is not considered further; thus, palliative care refers to the best possible care during the last phase of a disease when cure in no longer an option. "Care providers" refers to the health care professional, while "caregivers" is used for family members who support patients. Finally, family is defined broadly to encompass all the individuals who the patient considers to be family (Ferrell, 1998).

General Aspects of End-of-Life Care

All human beings are dependent on the care of other human beings at birth and in early childhood. Many people require care later in life during episodes of illness, and, if one does not suffer from a sudden death, also for shorter or longer periods of time prior to death. Currently, end-of-life care is provided at home, in hospitals, nursing homes, or hospices. During most of the 20th century, hospital admissions for end-of-life care increased (Hunt, Bond, Groth, & King, 1991; McMillan, Mentnech, Lubitz, McBean, & Russell, 1990). Over the last three decades, this steady increase in hospital deaths and its corresponding decrease in home deaths have come to an end. The time frame may differ among countries, but the basic shift remains the same: Place of death has mainly moved from hospitals to nursing homes and hospices, while the number of home deaths has remained stable or increased slightly (Cartwright, 1991b; Higginson, Asin, & Dolan, 1998; Hunt, Bonett, & Roder, 1993; Hunt et al., 1991; Lerner, 1970; McMillan et al., 1990). Still however, approximately 50% of all deaths occur in hospitals (National Center for Health Statistics, 1998, 2000).

End-of-life care is delivered in many different ways. Family members may take it on alone, professional health care providers may support them, or the latter may be the only care providers. Family members and professionals may or may not be committed to caring for a terminally ill patient; their knowledge about and striving to achieve standards of excellence in end-of-life care may vary. Thus, end-of-life care may or may not qualify as a caring practice.

Uncaring End-of-Life Care

A classic study of end-of-life care and more recent research findings are discussed to illustrate uncaring end-of-life care. Major barriers to improve end-of-life care are mentioned.

End-of-Life Care, but not a Caring Practice

In the early 1960s, Glaser and Strauss (1965; 1968) investigated what happened in several American hospitals when people died. Although this now classic grounded theory study focused on interactions, a picture of end-of-life care appeared in the findings.

The primary goal for each patient was recovery, and only when physicians decided that nothing more could be done, meaning the patient had no chance of recovery, would the staff provide comfort care. This comfort care was seen as less rewarding, requiring reduced efforts and fewer skills, and was mostly delegated to nurses. Some of them volunteered to deliver this care, while others fled from it. Other providers (e.g., social workers, chaplains) got involved as needed.

The major goal of comfort care was painlessness. The staff at times also adapted their care according to a patient's wishes, and relaxed rules for the family. Families were mostly perceived as creating problems for the nurses, although some nurses let family members participate in care activities and tried to support families. Staff members were expected to keep themselves composed, and were therefore careful not to get too deeply involved with either the patient or the family.

Thus, in this study (Glaser & Strauss, 1965, 1968), end-of-life care was not described as a caring practice. Most care providers often purposefully avoided the commitment to terminally ill patients and their families that is required in order for their actions to qualify as caring. Although particular staff members tried to achieve valuable goals, the care providers lacked a shared view and common aims. And even though special needs were sometimes recognized, the related care activities were seen as "good will" care, and terminally ill patients and their families mostly had to fit into the hospitals' routines. End-of-life care was perceived as an unavoidable task, not as practice worthy of being improved through shared struggles for excellence. Consequently, inherent goods were rarely revealed, and the work was not recognized as rewarding.

Since the 1960s, end-of-life care has become a debated topic and, thanks to the hospice movement, a generally accepted picture of good end-of-life care exists (Wilson-Barnett & Richardson, 1998). However, the actual quality of this care varies greatly, and uncaring practices prevail. End-of-life care in hospitals has an especially bad reputation. People fear that inevitable death might be delayed by high technology interventions, which would prolong suffering and prevent human caring (George, 1999; Thomasma, 1992).

The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) provided some more recent, rather disturbing insights into dying in hospitals (Freeborne, Lynn, & Desbiens, 2000). Patients who died at the hospital (*n* = 1150 of 4301 enrollees) spent a median number of eight days in intensive care units (ICU). Physicians did not always know patients' care preferences regarding invasive treatments, and an intervention aiming at improving communication between patients and physicians on this matter failed to show any effect (The SUPPORT Principal Investigators, 1995). Pain and other symptoms were insufficiently controlled for many patients (Desbiens & Wu, 2000; Lynn et al., 1997). The characteristics of the local health care system were the strongest determinant of the place of death, whereas patients' wishes concerning place of end-of-life care were unrelated to the actual place of death (Pritchard et al., 1998).

Barriers to Improvement

Three major barriers to improving end-of-life care can be found: societal problems in dealing with the consequences of cultural changes and high technology medicine, insufficiently educated health care providers, and structural aspects of the health care system (Meier, Morrison, & Cassel, 1997).

Death in the High Technology Society

Our society has lost what the historian Ariès (1981) called the "tame death" (p. 5) of earlier centuries, a death that was tolerable, simple, familiar, expected and accepted without crippling fear, and one that happened within the family and community. (Although this picture may be appropriate for people dying quickly from infectious diseases, it is incomplete. Not everybody died in this peaceful way, due to lack of symptom control, epidemics killing whole families, abandonment of sick people, etc. [Callahan, 1993].) Instead, at the backside of its tremendous achievements, scientific medicine has created the wild death, which is technological, hidden, feared, and denied (Callahan, 1993). The civilization process, with modern medicine as one component, has taken more and more events, including birth and death, out of the public space (Elias, 1985). Dying has become an individual, often lonely experience occurring in institutions. Old rituals have been lost and our society does not yet have new ones.

Callahan (1993) stated that medicine has confused its power to alter, control, or eliminate disease with its power to banish death, and has blurred the lines between human being's and nature's power: "Death has been moved out of nature into the realm of human responsibility" (p. 64). With death as human responsibility on one side, and medicine with all its technological options on the other, human beings become slaves of technology. Nature has been replaced by human choices, and these are transformed by technology. Medicine engages in "technical brinkmanship" (p. 40), that is, it tries to push technology as far as possible to save lives, while at the same time it attempts to preserve a decent quality of life and cease treatment at the right time. However, in a high technology environment where the line between life and death is vanishing and ambivalence prevails in the wishes and values of patients, families, health care providers, and society, medicine does not master technological brinkmanship successfully. Uncaring end-of-life care and a wild, rather than a peaceful death are the consequences for many patients and families.

Lack of Education

The second obstacle to good end-of-life care is health care providers' lack of education. End-of-life care has not been an educational priority for physicians (Field & Cassel, 1997), and widely used textbooks provide little helpful information (Carron, Lynn, & Keaney, 1999). A review of 50 current and frequently used nursing textbooks, covering various subject areas, revealed that only 2% of the text was related to end-of-life care. Essential content was absent, and available information was often inaccurate (Ferrell, Virani, & Grant, 1999). Nursing research in end-of-life care during the 1970s, 1980s, and early 1990s, which focused on nurses' attitudes and experiences and on communication, showed that nurses were anxious and tended to avoid open communication with terminally ill patients and their families because of their insufficient educational background (Wilson-Barnett & Richardson, 1998). Lacking the knowledge, experience, and personal and technical skills required for high quality end-of-life care, these health care providers were deprived of experiencing some of the rewards from their work. They could only see this type of care as burdensome and stressful, especially if they were aware of their inadequacies.

An example from the study of critical care nurses mentioned before (Chesla, 1996) illustrates how terrifying uncaring end-of-life care can turn out. Nurses were caring for a baby who had looked perfectly normal at birth, but then quickly developed septic shock and disseminated intravascular coagulation. The infant was transferred to the tertiary-care hospital and died within 36 hours of birth. The ICU nurse stated that the parents, obviously frightened to death, were absolutely no problem at all because they were just sitting back in a little corner, doing everything to keep themselves out of the way.

Structural Barriers

Finally, as illustrated by the following examples, financial, organizational, and structural characteristics of the health care system greatly influence end-of-life care. Inadequate legal regulations for prescribing opioids inhibit timely access to pain medication for terminally ill patients (Meier et al., 1997). Staffing levels in hospitals are lower than in hospices, which creates a hurdle for good end-of-life care in hospitals (Seamark, Williams, Hall, Lawrence, & Gilbert, 1998). Whereas Canadians usually have free access to palliative care services, coverage for hospice care in the US is limited. This valuable alternative is, therefore, often unavailable to Americans (Barnard et al., 2000). Oregon has allocated more resources to provide end-of-life care at home, in hospices, or nursing homes. Consequently, the state has the lowest in-hospital death rate (31%) in the US (Tolle, Rosenfeld, Tilden, & Park, 1999).

For a variety of reasons, then, uncaring end-of-life care remains a reality in many settings, and terminally ill patients and their families suffer from this inadequate care. However, an alternative way of providing end-of-life care has been developed over the last three decades. It is claimed next that this alternative – palliative care – qualifies as a caring practice.

Palliative Care – a Caring Practice

Palliative care is first defined and presented as a caring practice. Then its components are discussed in more detail.

Palliative Care

As a consequence of the advances in modern medicine, health care providers often perceived patients whose diseases had become incurable as failures and their attitude was at times one of "nothing can be done." The needs of terminally ill patients and their families were thereby ignored. Palliative care evolved as an answer to this deplorable situation (Clark, 2000; Doyle, 1995). It refers to a philosophy of or an approach to care, not to any specific program or institution (Doyle, 1998). The World Health Organization (WHO; 1990) defined palliative care more than a decade ago and recently the definition was updated. According to the WHO (2003), palliative care is

> an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

The WHO (2003) further explained that palliative care

> provides relief from pain and other distressing symptoms; affirms life and regards dying as a normal process; intends neither to hasten or postpone death; integrates the psychological and spiritual aspects of patient care; offers a support system to help patients live as actively as possible until death; offers a support system to help the family cope during the patients' illness and in their own bereavement; uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated; will enhance quality of life, and may also positively influence the course of illness; is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

The WHO definition of palliative care has been widely recognized (Barnard et al., 2000; Doyle et al., 1998; Poor, 2001; Radbruch & Zech, 1997), and earlier descriptions of the concept mainly included the same components (Saunders & Baines, 1983; Zimmermann, 1986).

Leaders in palliative care consider three additional issues as relevant: Care should be provided in the setting most appropriate for patients and their families. The team delivering the care should be an interdisciplinary team, usually composed of nurses, physicians, social workers, chaplains, and volunteers, with additional specialists as needed. Also, research and education should be integral parts of palliative care (Barnard et al., 2000; Doyle et al., 1998; Saunders, 1984a, 1997; Zimmermann, 1986).

A Caring Practice

Although its practitioners are not explicitly mentioned in the WHO definition, it is obvious that palliative care takes place in human relationships, with health care providers who are concerned about and committed to caring for their terminally ill patients and their families. The British pioneer and founder of the first modern hospice, Dame Cicely Saunders, made this clear from the very beginning. In 1947 a terminally ill patient who was, according to her, the real founder of St. Christopher's Hospice told her "I want what is in your mind and in your heart." This remark let her realize that terminally ill patients "would need all the skills that could be developed, researched, and taught – together with the friendship and care of the heart" (Saunders, 1997, p. 4). Caring, thus, has always been and still is a requested feature of palliative care. Bearing witness and being with the terminally ill patient and the family is seen as essential, and palliative care practitioners commit themselves to never abandon patients and families, not even if confronted with overwhelming situations and seemingly intractable suffering (Byock, 1994; Quill, 1996).

Palliative care is described here as a public caring practice, mainly performed by trained professionals. It encompasses the private caring practice of family members caring for the terminally ill patient, which is, as Whitbeck (1984) showed, often overlooked. Nelms' (2000) study of mothers caring for their sons dying from AIDS provided a vivid illustration of their practice, and of its marginalization. It is paramount for palliative care practitioners to be aware of family members' private caring practice within their public caring practice, to fully acknowledge its worth, and to support family members in carrying on their work.

Palliative care practitioners have a basketful of technical and interpersonal know-how at their disposal to reach the goals of their practice. This knowledge base has been constantly enlarging since the 1960s through practitioners' experiences, research projects, and educational efforts. Palliative care therefore has a history and a tradition. The practice has the potential to let all people involved experience internal goods: an acceptable end of life for patients, better memories for their families, and satisfaction for the practitioners. The perceived rewards motivate the latter to continuously strive for excellence and to develop the practice further, with groups of practitioners advocating slightly different trends. A more detailed discussion of several aspects of palliative care follows.

Historical Development

Palliative care grew out of the hospice movement. The early history of hospices is mentioned, the evolvement of the hospice movement summarized, and the worldwide development of palliative care sketched.

Historical Hospices

Hospices were originally founded by monastic orders in the early Christian era throughout Europe and used as guesthouses for pilgrims and sick people (Saunders, 1993). Only much later, in the 19th century, was the term used to refer specifically to several institutions opened to provide care for terminally ill people (Clark, 2000; Saunders, 1993). The emphasis in these hospices, however, was on curing the soul rather than on sophisticated medical and nursing care (Clark, 2000).

The Evolving Hospice Movement

The hospice movement of the 20th century evolved as an answer to the neglect of terminally ill patients' and their families' needs by mainstream health care (Clark, 1999, 2000; Saunders, 1993). Dame Cicely Saunders was the foremost pioneer of the movement in Great Britain. She recognized the overlooked requirements of terminally ill patients while working as a nurse and later as a social worker and, determined to react, added medical training to her already broad education. In 1958 she started work as a physician and researcher at St. Joseph's Hospice in London (an institution for terminally ill patients, founded in 1905 by the Irish Sisters of Charity). She promoted the "around-the-clock" provision of drugs for effective pain control, in contrast to the routine use of an "on demand" schedule. She introduced medical and nursing reports and taped her conversations with patients. These recordings provided a rich data pool from which she lectured and published extensively for lay, nursing, and medical audiences over the next decade. Her intention was knowledge improvement as well as promotion of the idea and fund raising for a new hospice. She achieved the latter goal when the first modern hospice, St. Christopher's in London, opened its doors in 1967. Two years later, St. Christopher's pioneered a home care program.

Worldwide Development of Palliative Care

From the beginning, the St. Christopher's Hospice received visitors who were interested in this new model of end-of-life care and who subsequently embarked on endeavors to introduce improved end-of-life care elsewhere. The first hospice in the US was opened in 1974 (Kastenbaum, 1997; Wald, 1994), and in 1975, Mount founded the first palliative care service in Canada (Clark, 2000; Saunders, 1993). He also introduced the word "palliative," meaning alleviation of suffering without curing (Mount, 1997). In French, the term hospice did not seem advantageous; it had pejorative connotations, because it meant custodial or less than optimal care (Saunders, 1993). Palliative care was therefore the preferred term.

The hospice movement subsequently spread throughout Great Britain and the US, and since the 1980s, a worldwide growth of programs can be observed (Wilson & Kastenbaum, 1997). The principles of palliative care have been adapted to different cultural, socio-economic and religious contexts (Kastenbaum & Wilson, 1997). They are applied in a variety of settings and organizational structures: home care services; freestanding hospices; palliative care units in hospitals; palliative care teams in hospitals, nursing homes and home care; day care centers; palliative care services for children; and a combination of several of these services (Kastenbaum, 1997; Saunders, 1993; Wilson & Kastenbaum, 1997).

Several national and international organizations promote palliative care; for instance, the National Council for Hospice and Specialist Palliative Care Services in Great Britain, the Academy of Hospice Physicians in the US, and the European

Association for Palliative Care (Clark, 2000; Magno, 1992). In Great Britain, palliative medicine was recognized as a medical specialty in 1987 (Doyle et al., 1998).

The WHO has supported the worldwide development of palliative care since the 1980s with its Cancer Pain and Palliative Care Program (Stjernswärd, Colleau, & Ventafridda, 1996). A cornerstone of the program was the publication of standards and norms for palliative care (WHO, 1990), another was the development of the now widely recognized guidelines for cancer pain relief (WHO, 1996). Currently, the program focuses on pain relief as the most pragmatic, humane and achievable objective for cancer patients, especially in developing countries where curative treatments are often unavailable (Stjernswärd, 1997).

Basic Concepts of Palliative Care

Saunders' (1997) early perspective on palliative care already encompassed all the core aspects that later became the central concepts of palliative care in the WHO definition (WHO, 1990). Her view was based on her clinical experience and the descriptive work undertaken at St. Joseph's Hospice, as well as on her careful listening to patients' thought-stimulating and influential narratives (Clark, 1999). While symptom relief with a focus on pain control clearly was a major goal of palliative care, Saunders' concept of "total pain" made clear that pain, rather than having solely a physical dimension, also included a mental, spiritual, and social dimension (Clark, 1999; Saunders & Baines, 1983). She sought to provide care that would enable patients to live to their full potential as much as possible until death (Saunders, 1984a, 1997). The family was seen as the unit of care during a patient's illness and in bereavement. Freedom of spirit and individual care for each patient were perceived as paramount. Although the St.

Christopher's Hospice is a Christian foundation and Saunders is a strong believer, it was made very clear from the beginning that the institution was open for people of any faith or none. An interdisciplinary team provided care at St. Christopher's Hospice. Research and education were integrated from the onset. Summaries of each patient's case notes have been composed since the opening, and these have provided data for numerous studies (Haram, 1984). Saunders considered the hospice as a center for development and teaching, but also believed that the concepts of palliative care should be applied wherever terminally ill patients and their families are cared for (Saunders, 1984a, 1997; Saunders & Baines, 1983).

Continual Refinement and Articulation of Methods

Over the last three decades, the methods used to achieve goals flowing from the basic palliative care concepts have been continually refined and articulated. This becomes obvious when the three editions of "The management of terminal malignant disease" are compared (Saunders, 1978, 1984b; Saunders & Sykes, 1993). For instance, the physical examination was described in more detail in the second edition and new research findings were integrated. Regarding pain, the second edition added graphics explaining the effects of a drug regimen given every four hours, and the third edition finally discussed pain measurement instruments, presented the side effects of pain medications more prominently, and reported newly developed ways of administration (e.g., transdermal). Symptoms other than pain were more fully explored in the second edition and in the third edition, most symptoms even received a full chapter. The second edition was complemented by a chapter on the care of children dying from malignant disease. Finally, cross-cultural and spiritual aspects had been touched upon before, but were more explicitly discussed in separate chapters in the third edition.

Billings (2000) summarized the following recent advances in palliative care: improved management of chronic cancer pain, especially of neuropathic pain, and other symptoms; increased use of advance care planning to maintain patient autonomy; heightened comprehension of the role of artificial nutrition and hydration at the end of life; and general agreement that withholding or withdrawing life sustaining support as well as the rule of double effect (permission to use medication to relieve suffering even if it may hasten death) are acceptable. The founding of several palliative care journals in the 1980s and 1990s and the publication of numerous books also point to a growing body of knowledge (Quill & Billings, 1998).

This brief overview of the history of palliative care, its basic concepts and the continual refinement and articulation of methods illustrates that health care professionals entering the practice of palliative care find a tradition from which they can learn and discover standards of excellence they have to strive for. The best standards achieved so far in palliative care, that is, what palliative care practitioners do if their practice works at its optimum, is discussed next.

Current Standards of Excellence in Palliative Care

This section is based on the "Oxford Textbook of Palliative Medicine" (Doyle et al., 1998); therefore, only additional sources are referenced. The textbook is considered to be the most important scientific source in the field to date (Barnard et al., 2000; Quill & Billings, 1998).

Generally speaking, palliative care practitioners focus on improving the patients' and families' quality of life; stated otherwise, they care for individual patients and family members as whole persons, instead of treating the diseases. Consequently, the terminally ill patients' and their families' points of view are always taken into consideration and the patients' autonomy is paramount. Autonomy in this context mainly refers to patients' freedom of choice and this includes the option to delegate decisions to others. Practitioners are sensitive to cultural issues and respect different worldviews and value systems. At the basis of any intervention lies a thorough assessment of the whole situation. Interventions are either directed at eliminating the cause of a problem or at relieving the distress it causes. Treatment decisions are grounded in a careful balancing of potential benefits and adverse effects of any option, while keeping the overall goal in mind. Palliative care encompasses prevention of potential problems (e.g., pressure sores), prompt reactions in emergency situations (e.g., immediate treatment of a spinal cord compression), as well as rehabilitation, which mainly aims at helping a patient become a person again (e.g., by experiencing leisure and outside interests). Subsequently, palliative care for symptom distress, for psychological, social, and spiritual problems, and for the support of families is discussed in separate sections. However, these issues are in reality all interrelated and addressed as a whole by an interdisciplinary team.

Effective Symptom Management

The patients' subjective reports are the primary source of information for most symptoms, and their experiences are the decisive factor for any intervention. The whole range of possible treatments, invasive and non-invasive, is considered. Since, for instance, symptom control in cancer patients may be best achieved through the control of

neoplastic growth, or through the alteration of tumor biology or metabolic activity, disease-modifying interventions such as chemotherapy, radiotherapy, or surgery are included as components of palliative care provided that adverse effects do not outweigh potential symptom improvement and the patient's comfort may be enhanced. But it is also recognized that most symptoms are influenced by other than physical factors, and corresponding methods are integrated (e.g., relaxation).

Pain management. Pain control is seen as a primary concern in palliative care since unrelieved pain negatively affects every aspect of patients' and their families' lives. Pain treatment includes an individual approach with a careful assessment and ongoing evaluation to find a favorable balance between pain relief and adverse treatment effects, and to adjust treatment over time. Drugs are the most common treatment, and physicians prescribe, according to the WHO analgesic ladder (WHO, 1996), non-opioid analgesics, opioids for mild to moderate pain, opioids for moderate to severe pain, and adjuvant analgesics (any drug with primary indication other than pain). Oral administration is preferred and other routes of application are used when appropriate. To achieve continuous relief, controlled-release formulations are favored, as are rescue doses for break-through pain. Adverse pharmacological effects are prevented, monitored, and treated. Anesthetic techniques, neurosurgical procedures, and complementary methods such as acupuncture are available as well.

Management of other symptoms. The treatment of symptoms other than pain follows the principles of palliative care, which include thorough assessments and individually tailored interventions directed at treating causal factors, if reasonable, or at symptom alleviation only. Most of these symptoms have complex underlying mechanisms and, in general, the scientific knowledge base is smaller than that for pain control. As a result, current treatment standards are sometimes based on few studies or on clinical experiences. Furthermore, symptom interactions are not yet well investigated. Some special aspects of palliative care related to particular symptoms are mentioned below.

Terminally ill patients frequently suffer from gastrointestinal symptoms, such as nausea and vomiting, dysphagia, constipation, malignant intestinal obstruction, or cachexia, which are either induced by the disease or represent an adverse effect of some treatment. An adequate intervention takes this into consideration. Artificial hydration and nutrition are rarely seen as appropriate in palliative care, although hypodermoclysis is sometimes used. Palliative care practitioners are aware of asthenia, a combination of fatigue or lassitude, generalized weakness and mental fatigue, which is an often overlooked, but a very common symptom in terminally ill patients. They evaluate how disturbing the symptom is for the individual patient and suggest general or cause-specific measures to improve the patient's well-being. Respiratory symptoms (e.g., dyspnea, cough, hemoptysis) often become more prevalent when death approaches. Therefore, the question of reasonableness of any intervention has special relevance. Oxygen is used specifically in hypoxemic patients. To diminish secretions, anticholinergic drugs are used rather than suctioning (e.g., to prevent death rattle). Palliative care practitioners recognize that the visibility of skin problems, malodor from malignant wounds, or exudation from fistulas are extremely embarrassing for patients and their families, so they pay special attention to comfort and cosmetic appearance. Because oral problems such as xerostomia, infections, and ulcers interfere severely with patients' communication, social life, nutrition, and pleasure in eating, these symptoms have a detrimental effect on quality of life. Optimal mouth care is therefore perceived as highly important in palliative care. Once severe physical symptoms are treated, other needs can surface more readily and then be addressed. Sometimes physical symptoms remain intractable until other dimensions of suffering are addressed (Cassel, 1982).

Psychological, Social, and Spiritual Support

Practitioners engage in palliative care as whole persons and provide support beyond the physical dimension to terminally ill patients and their families through human relationships by using their self as an instrument for problem identification and interventions. Although psychological, social, and spiritual needs each have separate issues, most aspects of these needs overlap so they are difficult to disentangle. In providing psychological support, practitioners carefully evaluate if a problematic response lies within an expected range of reactions to a terminal illness, or if it constitutes a psychiatric complication (e.g., depression or a cognitive disorder). Interventions are chosen accordingly. Social support has a practical component: provision of legal, financial and resource related information; agency in tapping appropriate communal, governmental or charity resources for financial support, help with personal care and housekeeping; and help with planning for the future (e.g., with writing a will or organizing one's funeral). Spiritual support focuses on patients' search for existential meaning and transcendence of the self. It includes religious guidance and rituals of any faith when patients request this assistance (Lunn, 1993).

Palliative care practitioners are aware that terminally ill patients have a past, present, and future, are part of a social network within a cultural context, have been developing certain coping styles and strengths, and still have the potential for personal growth. Practitioners recognize that terminally ill patients show emotional reactions which are characteristic for each patient and may be displayed simultaneously, change over time, or both. These reactions are not limited to the denial, anger, bargaining, depression, and acceptance described by Kübler-Ross (1969), but also include others such as fear, guilt, hope, despair, (anticipatory) grief, and humor.

The primary interventions are communication and being there with the patient. Practitioners are skilled listeners and take the time to hear patients' stories. They provide adequate information and gently break bad news. Although truth telling and open awareness of the impending death is preferred, they are sensitive and do not force unwanted information onto patients. They support patients through therapeutic dialogue, which encompasses active listening, supportive verbal interventions (e.g., emphasize past strengths), and occasional interpretations. They know that at times staying with patients to witness their suffering is the best available action. If necessary, cognitive-behavioral techniques are used if patients are willing to try them. Examples are relaxation, distraction, meditation, hypnosis, biofeedback, and modeling. Complementary methods such as music, art, or aromatherapy are additional options. Practitioners know their limits, only use techniques when trained appropriately, and refer patients to specialists as needed.

The Family as Unit of Care

A terminal illness not only seriously affects the patient but also the family. In palliative care, therefore, the family is seen as the unit of care. Practitioners realize that family members' reactions are as varied as those of patients, that such reactions may match the patients' or may be different, and that family reactions may facilitate or complicate the situation. Psychological, social, and spiritual needs are evaluated and addressed with individual family members or the family as a whole in ways already described above for the patient. However, some needs, assessment strategies, and interventions are specific for families.

Family assessment includes drawing a genogram and evaluating both normal family functioning and changes that occurred as a result of the terminal illness of a member. Practitioners then facilitate communication among family members and with the patient, organizing family conferences to discuss complex issues or referring families for short-term psychotherapeutic interventions, if necessary (Strittmatter, 1997). Family members are continually given appropriate information regarding the patient's status, what to expect throughout the illness trajectory and when death occurs since many of them have never witnessed a death before. Practitioners encourage family members to be with the patient, and they teach the families needed nursing skills, validate their contributions to caregiving, and reinforce their commitment to care. They provide support or respite before family members become overwhelmed by the burden of caregiving. They are aware that bad experiences of family members during the patient's terminal illness will negatively influence their bereavement. Palliative care practitioners recognize the needs of non-adult children and that these needs depend on the children's age. They support parents in responding to these needs, and counseling for children is also made available before as well as after the patient's death.

At the time of death, practitioners allow final farewells according to families' wishes, answer any questions, and guide family members through necessary

arrangements. Practitioners can recognize vulnerable family members by knowing the risk factors for poor outcomes after bereavement (e.g. history of psychiatric illness, clinging or ambivalent relationship with the terminally ill patient, lack of social support). Bereavement care is offered to individuals or families, either proactively by inviting at-risk family members to accept the service or reactively when family members who were informed about the service subsequently seek help. Support may be provided over the telephone, at home, or in a hospital or hospice to individuals or groups. Palliative care practitioners have not yet reached consensus on any preferred form of bereavement care.

The Interdisciplinary Team

Patients and families face a myriad of issues when confronted with a terminal illness. To intervene adequately in each situation, a broad range of knowledge and skills is needed, and these assets cannot all be held by one person. Furthermore, different patients and families do not all talk easily to the same person. An interdisciplinary team, therefore, can unite all the required knowledge and skills, and can offer patients and families the opportunity to find an interlocutor who suits them.

The interdisciplinary team is defined as "a group of individuals with a common purpose working together. Each individual will have particular expertise and training, and will be responsible for making individual decisions within his area of responsibility" (Cummings, 1998, p. 19). The core team is composed of physicians, nurses, social workers, chaplains, and volunteers. Volunteers are seen as bridging the gap between an institution and the community it serves. Their role focuses on improving the quality of life for terminally ill patients and their families, and they may also support the administration, public relations or community education. The team is extended according to the needs of patients and their families, and may include physiotherapists, occupational, music, or art therapists, dieticians, pharmacists, or dentists. Patients and their families are recognized as team members and, for instance, included in care planning.

The common purpose, that is, the best possible quality of life for terminally ill patients and their families, is central for all team members at all times. To achieve this goal, the team works together efficiently, which means that role boundaries are often blurred (e.g., any member may talk with a patient about her religious doubts, not just the chaplain). The team communicates and interacts very well, conflicts are solved successfully, and the team leader is flexible enough to share leadership according to the task at hand.

In addition to being committed to the palliative care philosophy, team members are professionally competent, confident in their abilities, and secure enough to let others invade their specialties. Team members are mature individuals willing and able to trust, support, and respect others. They are also open and tolerant and show patience and sensitivity. The work of palliative care practitioners involves particular stresses (e.g., the repeated forming of relationships with terminally ill patients that are subsequently terminated by death). A staff support system, therefore, is in place for the interdisciplinary team (Harris, Bond, & Turnbull, 1990).

Given the premise that palliative care is a caring practice, and the standards of excellence outlined above, the question arises regarding what internal goods participants of the practice, namely terminally ill patients, their families, and practitioners, can achieve together.

Goods Jointly Achieved Throughout the Last Phase of a Terminal Illness

Internal goods are the goods that can solely be achieved by the terminally ill patients and all the people engaged in their care. Only a community of participants experiencing the practice of palliative care from within can accomplish and recognize internal goods. These goods reflect to a certain extent the issues discussed previously: The more completely palliative care goals (e.g., symptom control) are achieved, the greater the likelihood that notions of good can be identified within the last phase of a terminal illness.

A Good End of Life

In a very general way, experiencing an appropriate death (Weisman, 1984), a good death (Field & Cassel, 1997), or dying well (Byock, 1996) defines what might be positive about dying. These notions can be understood as either referring specifically to the moment when death occurs or as alluding to the whole dying process that unfolds over time, includes the actual death, and, for the family and health care providers, stretches beyond the patient's death (Payne, Langley-Evans, & Hillier, 1996). Clearly, when considering palliative care as a practice, the latter interpretation is the relevant one. A good death has been defined as one that is "free from avoidable distress and suffering for patients, families, and caregivers; in general accord with patients' and families' wishes; and reasonably consistent with clinical, cultural, and ethical standards" (Field & Cassel, 1997, p. 24). A peaceful death refers most frequently to the hoped for actual death event, and it has been described as gentle, calm, and beautiful, or as when the patient "just stopped breathing" (Keizer, Kozak, & Scott, 1992).

Internal goods achieved in palliative care, then, can be considered as terminally ill patients' experiences of effective relief of physical symptoms and of receiving the needed psychological, social and spiritual support at the end of life. This allows them to enjoy life as fully as possible until death and then also facilitates a peaceful death. Families bearing witness to their loved ones' journey are enabled to care for them according to family members' opportunities, and they feel supported by practitioners before as well as after the patients' death. Although they feel sad, families in these scenarios do not resent decisions and their memories are mainly good ones (Byock, 1997; Henderson, 1995; Lynn et al., 1997). Practitioners feel satisfied, because they have been able to achieve the goals of their practice. These remarks are intentionally kept very general since what particular patients, families and practitioners perceive as a good end of life is highly variable (Barnard et al., 2000).

Additional Internal Goods

In some situations, terminally ill patients, families and practitioners are able to commonly achieve additional goods. The following description of these types of experiences is drawn from numerous narratives in the palliative care literature, mainly from several collections of stories (Barnard et al., 2000; Byock, 1997; Kearney, 1996; Quill, 1996). Byock (1996) pointed out that dying is the last stage of living and that, according to developmental theories, such as that of Erik Erickson, human development is a lifelong process. Some patients are capable of achieving personal growth while their bodies are disintegrating from a terminal illness, some bring their life to an ultimate completion and others still contribute to the well-being of others while dying.

The personal growth that terminally ill patients may achieve takes different forms, such as reaching new insights or acquiring new patterns of behavior. For instance, a 30 year-old former top athlete and successful business man stated that the last year, during which he was slowly dying of metastatic cancer, had been the best of his life because he had gained a new awareness of the spiritual dimension of his human existence (Cohen & Mount, 1992). Another terminally ill patient was able to break out of his lifelong self-destructive behavior filled with anger and self-criticism, and could experience more intimacy with his children. He learned to be with them rather than trying to change them (Quill, 1996).

The palliative care literature is replete with examples of terminally ill patients who managed to complete relationships in creative ways, even reconciled broken relations successfully, and bid their farewells. Patients sometimes try to prepare their relatives emotionally for the finite departure, they prepare their own funeral, or they may initiate steps to safeguard their families' futures. Some terminally ill patients continue to contribute to the well-being of others by sharing their experiences and new understandings, for example as participants in a research project.

Family members may achieve additional positive aspects in different ways. They may experience growth as a family, for example by growing closer and dissolving tensions when confronted with the terminal illness of a member. From witnessing the dying process and death of a loved one, they can learn special lessons (e.g., about the meaningfulness of human existence), and can themselves grow as individuals. They may experience yet unknown inner strengths and develop unexpected capacities when a strong commitment enables them to provide care to or stay with the terminally ill even under

difficult circumstances. Finally, they can enjoy the satisfaction of making a positive difference as the companion of a patient at the end of life, and can feel comforted in their grieving by positive memories.

Similarly, practitioners of palliative care can achieve more than their usual goals. By being with patients and their families throughout the last phase of a terminal illness, they have the opportunity to witness and even help bring about extraordinary personal and familial accomplishments. They can learn and grow from these experiences as individuals and as teams. Lastly, they can take pleasure in the satisfaction of having positively influenced the end of life for patients, families, or both.

Striving for Excellence – Challenges and Emerging Styles in Palliative Care

Taylor's (1985b; 1989) notion that practices and their articulations influence each other and bring about changes over time can be applied to palliative care. From the beginning, palliative care practitioners have provided descriptions of their work through the report of particular patients' and family members' narratives and through the publication of experience- or research-based suggestions for interventions covering the whole range of the practice. As has been shown before, although the founders of palliative care already recognized the relevant concepts, these ideas have constantly evolved over time in order to address developments and emerging new issues. The articulation of their practice by palliative care practitioners influenced this process.

Major Challenges

Currently, palliative care is confronted with some major challenges, such as scarce resources, calls for quality improvement in end-of-life care through quality measurement, requests to extend palliative care beyond cancer patients, and a potential loss of characteristics relevant to the practice.

Scarce resources. The scarce financial resources within health care systems affect all components. Palliative care practitioners have to secure their share of funding if they want to perform the practice for all terminally ill patients, not only for a financially privileged elite (Barnard et al., 2000; Bosanquet, ; Doyle, 1995; Dush, 1993). Closely related to questions of resource allocation are quests for efficiency evaluation.

Quality improvement via measurement. Since deficiencies in end-of-life care have been widely recognized, efforts are currently made to improve it, and palliative care is seen as the standard to achieve (Field & Cassel, 1997). The definition and measurement of the quality of care, with quality of life for terminally ill patients and their families as an important outcome measure, is perceived as a relevant first step (Fowler, Coppola, & Teno, 1999; Teno, Byock, & Field, 1999). The challenge is to develop appropriate measurement instruments.

Researchers are aware that a problem-based medical model of care is too narrow as basis for instrument development; rather, all relevant aspects of palliative care are to be included (Byock, 1999; Fowler et al., 1999; Stewart, Teno, Patrick, & Lynn, 1999). Although researchers recognize the difficulties of measuring certain concepts and the fact that the relevance of concepts for terminally ill patients and their families may change over the course of an illness, they still assume that these metrics can be created. However, concepts relevant for terminally ill patients and their families, such as spirituality, personal growth, and even quality of life itself, pose the same measurement problems as measuring caring, discussed earlier in this paper. There seems to lie a certain risk ahead for palliative care concepts to be defined by the operations used to measure them (Clinch, Dudgeon, & Schipper, 1998). Practitioners need to pay close attention to the ongoing measurement endeavors and evaluate instruments critically.

Extension beyond cancer. Palliative care has focused heavily on cancer patients and, to some extent more recently, on patients dying from AIDS. There are requests from many people to also offer these services to other terminally ill patients, especially to the elderly dying from various chronic diseases (Bosanquet, 1999; George & Sykes, 1997). An additional challenge is the request to further promote palliative care internationally, particularly the extension to developing countries (Saunders & Kastenbaum, 1997).

Loss of relevant characteristics. Several authors have alluded to a possible "ossification" of palliative care, and more specifically of hospice care. The hospice movement may be losing its innovative character through the integration of its organizations into mainstream medicine via reimbursement systems, a move accompanied by routinization and bureaucratization (James & Field, 1992). Some palliative care organizations tend to institutionalize certain ideal notions, for example, what constitutes a good death (McNamara, Waddell, & Colvin, 1994). Consequently, practitioners widely accept conformity to these routinized ideals, which supports the smooth running of the organization. Patients and families deviating from the expected behavior are perceived as problematic and they disrupt the organizational flow (Barnard et al., 2000; McNamara et al., 1994). Finally, palliative care is seen as being at risk for medicalization because of the predominance of medicine and a shift from holistic care to symptom control and palliation only (Corner & Dunlop, 1997).

Emerging Styles

In addition to addressing the challenges mentioned above, the palliative care community continues to strive for improvement of the practice. Interventions related to the basic concepts are continually adapted, integrated, or developed according to experiences and research findings. Such innovations include the adaptation of psychological and art therapies to palliative care, the use of non-pharmacological interventions for symptom management, changes in the pharmacological management of symptoms (novel drugs, different routes of administration), and bereavement counseling for children (Davis & Sheldon, 1997).

In general, practitioners agree on the basic components of palliative care: symptom management and psychological, social, and spiritual support for the patient and family, including bereavement counseling for the latter. They share the scientific knowledge base and apply similar technical skills to achieve their goals. Most practitioners consider an approach that addresses the whole person as imperative and they define caring as the core of the practice. However, different styles have emerged among practitioners who concern themselves with the psychological, social, and spiritual suffering of terminally ill patients and their families. Many of them have adopted a generic approach, some concentrate on fostering personal growth for patients and families, while others emphasize patient autonomy and control.

The generic approach. Saunders and Baines (1983) have described what is seen here as generic approach. Their concept of total pain acknowledges that suffering may have other than physiological reasons. They stated that most terminally ill patients are capable of coming to terms with their circumstances and may even make the last phase of their life a fruitful time. In their view, practitioners can best support patients and families by showing concern and commitment, by providing excellent care, by listening to their experiences and stories, by communicating openly, by fostering communication among patients and family members, and – most importantly – by staying with patients and families. Other authors have confirmed the healing potential inherent in telling the story of one's illness experience (Frank, 1991, 1995; Kleinman, 1988).

Good palliative care and the passage of time, then, will often let terminally ill patients and their families find their way and will alleviate emotional suffering (Kearney, 1996). As Saunders (1993) put it:

> Care for the physical needs, the time taken to elucidate a symptom, the quiet acceptance of a family's angry demands, the way nursing care is given, can carry it all and can reach the most hidden places. This may be all we can offer to inarticulate total pain - it may well be enough as our patients finally face the truth on the other side of death. (p. 12)

However, some patients and families need additional help and a more direct approach to their struggles. Kearney (1996) described how he successfully used image work with terminally ill patients to relieve what he called existential dimensions of suffering or soul pain. He was careful in pointing out that image work is only one of several possible interventions and not adequate for all patients. Overall, the advocates of a generic approach to psychological, social, and spiritual suffering are aware that terminally ill patients and families embark on a journey towards the end of the patient's life and that this journey may entail positive achievements. They stress, however, that no kind of blueprint of this path should be imposed on patients or families.

Fostering growth. Without denying potential effects of a generic approach, some practitioners want to more actively foster growth in patients and families during the last

phase of a terminal illness. Byock (1997) is a well-known supporter of this stance. This author showed how the human potential to grow through the process of dying could be realized.

Byock (1997) first recounted the dying process of his father and how this affected him. With the stories of several hospice patients, he then illustrated that dying is not just a medical event. He described how family interactions can improve when members are caring for a terminally ill relative, how important relationships can be completed (e.g., conflicts solved), how physical symptoms can be relieved and extreme emotional suffering overcome, and how patients can maintain their dignity in the midst of dependence. He related the interventions that helped bring these changes about, mostly carefully challenging conversations that guided patients and families towards meaningful moves. He told a patient, for instance, "what hospice calls 'the five things of relationship completion' – saying 'I forgive you'; 'Forgive me'; 'Thank you'; 'I love you'; and 'Good bye'" (p.140).

Although Byock (1997) acknowledged that dying is always a difficult process, that patients will need physical care and that caregiving can become a burden, he optimistically focused on positive aspects. For example, he claimed that physical suffering can always be relieved, and described the fact that a dependent patient had to allow his family to care for him as the patient's final gift to his family. The author, as hospice director, referred to himself as conductor of the hospice "orchestra" and stated: "I have a strong sense of what the finished piece should sound like. I want patient and family to feel emotionally safe enough to regard the final weeks or days as an opportunity for meaningful interaction" (p. 161).

Byock (1997) made it clear that growth in terminally ill patients and families should be fostered as much as possible but never be expected or demanded. However, a clear picture of what constitutes dying well for him is discernible throughout the book. The possibility of using it in a prescriptive way and of imposing a blueprint of dying well on patients and families cannot be denied.

Advocating control. Other palliative care practitioners emphasize the maintenance of patients' autonomy and dignity at the end of life. Quill (1996), an advocate of this view, focused on the small group of terminally ill patients whose suffering could not be treated adequately, even with the best palliative care efforts. He reported several stories of patients who, short of totally losing personal integrity, at a certain point preferred death to life under the circumstances they were confronted with.

Some of these patients had the option of foregoing or withdrawing life support and, with the help of compassionate family members and palliative care practitioners, of choosing a dignified death. Others lacked this possibility and could only opt for terminal sedation when their symptoms became intolerable. Quill (1996) stressed the similarity of, for instance, terminal sedation to voluntary dehydration and physician assisted suicide with a prescribed high dose of barbiturates, and called for legalizing a way to help patients who suffer intractably but do not yet have an accepted opportunity to bring about their death.

Institutions and Palliative Care

As a practice, palliative care requires institutions in order to survive and flourish and it is, at the same time, vulnerable to corruption by institutional powers (MacIntyre, 1984). Understood as a particular approach to the care of terminally ill patients and their

families, the practice of palliative care, however, is not restricted to any specific institution (Doyle, 1998). Instead, the practice should be performed wherever it is needed, as Doyle explained: “To the question, ‘Who should provide palliative care?’, the answer must be every doctor and nurse. To the question, ‘Where should they provide palliative care?’, the answer must be where they work day-in, day-out” (p. 41). When St. Christopher’s Hospice was founded, Saunders (1984a; 1993; 1983) saw it as a center for knowledge development. The special environment would facilitate innovations and the testing of new approaches. Effective interventions could then be transferred to all settings.

Wherever end-of-life care is delivered – in the home, hospital, nursing home, or hospice – its quality is influenced by staffing levels, equipment, architecture, financial resources, payment systems, and so forth. But the decisive factor is whether or not health care providers are also palliative care practitioners who are knowledgeable of the practice and who strive to achieve its aims for the terminally ill patients and the families entrusted to their care. Applying palliative care in a setting that is established for this type of care is no doubt easier than in, for instance, an acute care hospital that focuses on cures. Practitioners encounter higher barriers in some institutions; however, it is still feasible to engage in palliative care and to improve end-of-life care as much as possible (Doyle, 1995).

This section has shown that palliative care is, in fact, a caring practice. Health care providers, committed to caring for terminally ill patients and their families, engage in the practice. The practice has a culturally based tradition in many Western countries, and local traditions are evolving in other regions of the world. The practice offers a broad

range of meaningful interventions to its practitioners. Palliative care allows terminally ill patients, their families, and practitioners to realize notions of good. The practice has been and still is constantly developed further by its practitioners. The next section will focus on end-of-life care in hospitals. Although it may be difficult to achieve the best standards of the caring practice in this environment, it will be shown that aspects of palliative care can be accomplished in acute care settings.

PALLIATIVE CARE TRACES IN HOSPITAL END-OF-LIFE CARE

In the first part of this section, illustrative descriptions of hospital end-of-life care from the literature are discussed. They show that aspects of palliative care have been actualized in hospital settings. In the second part, end-of-life care is described from a personal perspective and again contrasted with palliative care. My experiences also provide an account of my background understanding of end-of-life care from which my interpretations of the phenomenon evolve. In Heidegger's term, the account is part of the forestructure of interpretation (Dreyfus, 1991). This issue will be explored further in the chapter on methodology.

Hospital End-of-Life Care

Field (1984) studied nurses caring for terminally ill patients on a general medical unit, and described the end-of-life care approach favored by the staff. Nurses saw their terminally ill patients as individual persons with whom they were emotionally involved. They preferred an open awareness context (Glaser & Strauss, 1965), were allowed by physicians to inform patients about their diagnoses and prognoses and, therefore, tried to be honest and disclosed information when patients asked for it. Spending time with patients, and especially staying with them when death occurred, was valued. Some nurses made themselves available if bereaved relatives contacted them. The team had a flat hierarchical structure; team members supported each other and were strongly supported and fostered by supervisors. The nurse – physician collaboration ran smoothly.

Although this is obviously not the description of a comprehensive palliative care approach, aspects of it can be found: Nurses were committed to their patients and embraced care for the whole person. Open communication was encouraged, and even some bereavement care was provided. Nurses took responsibility, but worked with other staff members, supervisors, and physicians as a team.

Wros (1994) described how nurses even achieved notions of good in an ICU setting and with ongoing life-support. The nurses were caring for a young woman dying of complications of cancer treatment. The patient, who was still receiving curative treatment, was on a ventilator but had minimal chances of survival. The nurses, truly committed to the patient and her husband, were worried about the application of treatments that caused distress to the patient. However, they respected the patient's wishes and, when she became unresponsive, the husband's decision to continue treatment. But they tried to prevent or alleviate suffering as much as possible, for instance by negotiating pain treatment with the husband. They maintained a good relationship with the husband, although they at times disagreed with his perception of the patient's situation. Realizing the patient's need for touch, they stayed with her, and because they knew her preferences, they played the music and let her watch the TV shows she liked. And even though the nurses went along with the life-supporting treatment, they anticipated the patient's death and how harmful chest compressions and defibrillation would be. They successfully advocated against the use of these violent measures, and the patient finally died in peace from a cardiac arrest. The nurses described caring for this patient and her husband as rewarding and were satisfied with their achievements.

Researchers observed a consensus among ICU nurses to create dignified deaths for their patients and the families (Benner et al., 1999). For instance, when life-support was withheld or withdrawn, patients were not transferred out of the ICU if death was imminent, so as to secure care continuity. Nurses strove to allow completion of tasks, to make goodbyes and other leave-taking rituals possible, and to stay with patients. They followed the patient's or family's lead and were sensitive to cultural differences in approaching dying and death. These nurses' view of end-of-life care and their understanding of a dignified death reflected palliative care goals, such as respecting patients' autonomy and families' wishes, being with the patient, and meeting other than physical needs.

A Personal Perspective

In this personal account, the setting where I have been working as a nurse before I started studying nursing and engaged in this dissertation research is introduced, and my beliefs about as well as my practices in end-of-life care at that time are outlined. Traces of palliative care found in this description of hospital end-of-life care are highlighted.

The Site

For 20 years, I worked as a nurse in an acute medical clinic of a Swiss university hospital. The clinic had 75 beds on six acute care units and an intensive care unit. About 2000 patients were admitted per year, two thirds of them as emergencies. The mostly elderly patients suffered from diseases that encompassed the whole spectrum of internal medicine, with cardiovascular, neoplastic and respiratory diseases as the most prominent. Per year, 120 to 150 patients died at the clinic (Hess, Spichiger, Bucher, & Otto, 1997).

Some patients died suddenly from acute diseases, others unexpectedly from complications of chronic or terminal diseases. For a third group of patients, suffering from terminal illnesses, death was the expected end of their stay on an acute care unit where they had received care over days, weeks or even months. End-of-life care was, therefore, always an important component of my work as a nurse.

A senior consultant, six senior physicians, and 15 residents were in charge of the medical care for all hospitalized patients and for 50% of the patients admitted to the hospital's medical emergency room. The services of a social worker, a dietician, physiotherapists, and chaplains were available. A nurse manager, an assistant nurse manager, six charge nurses, staff nurses, and nursing assistants were mainly in charge of the nursing care. The clinic offered practical training to nursing and medical students.

Nurses worked in three shifts and all nurses took turns working all shifts. In a unit with 13 beds, the day shift team usually included four to five persons: two or three registered nurses, one or two nursing students, and one or two nursing assistants. One nurse or nursing student was working on evening shift, with one nursing assistant for two units; and one nurse or nursing student was responsible for two units during the night, with one nursing assistant for all six units.

Team nursing was used during the day shift, meaning that one registered nurse (charge nurse or staff nurse) was the team leader in charge of organizational aspects, and every nurse or nursing student, including the team leader, was responsible for the care of two to four patients. Whenever possible, nurses would care for the same patients over several days. Throughout the day, all nurses, nursing students, and nursing assistants attended reports, where patients' situations and problems were discussed.

I worked in this clinic first as a staff nurse, then as a charge nurse for many years, still mostly delivering direct patient care, but with the additional responsibility for the units' nursing team. Finally, I was the clinical nurse specialist for five years. My major task then became providing support for the registered nurses, and providing direct patient care in problematic situations was an important component.

I perceived the working atmosphere within the clinic's nursing team mostly as supportive. The team highly valued good nursing care, supported continuing education, and welcomed inputs and creativity; this climate encouraged reflection and learning through experiences. Since several nurses worked for many years at the clinic, we formed a strong team of experienced nurses who together learned from failures and successes and developed a pool of socially embedded knowledge (Benner et al., 1996). In particular, the team had a shared vision of good end-of-life care. This vision was expressed in a special section of the nursing goal statement written in 1990 and revised in 1999 (Pflegedienst Medizinische Abteilung Anna Seiler, Inselspital, 1999). The senior consultant, responsible for the medical care, also saw good end-of-life care as an important component of the clinic's task. He was very supportive of the nursing team in this respect.

My Beliefs About End-of-Life Care

Although it is my perception that the nursing staff had a common vision of what constituted good end-of-life care, I am writing here from my perspective because I cannot speak for my former colleagues. My image of good end-of-life care should not be understood as unchangeable, but rather as a set of beliefs and practices that developed through caring for many terminally ill patients and their families over time. And even though end-of-life care was recognized as a priority, the often turbulent daily life on an acute care, teaching clinic made it at times difficult to live up to the goals.

If a patient's disease had reached an incurable stage and death was imminent, for me, the worst that health care providers could say was that "nothing can be done anymore." On the contrary, from my perspective, the quality of patients' life during their last days, weeks or months depended to a great extent on the care they received, and as a nurse delivering this care, I could make a real difference for patients and their families. I considered end-of-life care, therefore, as a very rewarding task that called forth all my know-how and creativity.

As human beings we are mortal and, if we do not suffer sudden death, we will all face a terminal illness one day. I could not perceive a terminal illness as a battle lost by medicine, but rather recognized it as the end of many people's life trajectory – acceptable for some, incomprehensible for others. Medicine, I believed, was not the ultimate decision maker, and health care providers could never exactly predict the course of the terminal illness for any particular patient.

When caring for a terminally ill patient, my primary goal was to provide as much comfort as possible, whatever this meant to the patient, by attending to the patient's physical, psychological, social, and spiritual needs as thoroughly as possible. Individualized care seemed imperative to me. I believed that the family should be involved according to the patient's wishes and the family members' potential. An open and honest information policy fostered working towards these goals.

When caring for a terminally ill patient, the patient and his or her family mattered to me, and I understood caring as described by Benner and Wrubel (1989). From Liliane Juchli, one of my nursing teachers, I learned another philosophy that became very important to me in end-of-life care: Truly caring for patients and their families meant that I had to be there with them as a whole person, with my thoughts, my feelings, and my body.

Kübler-Ross (1969) described how patients, after learning they will die, might respond emotionally with denial, anger, bargaining, depression, and acceptance. These stages were always part of my background knowledge, although I saw these emotions as a mosaic of possible reactions rather than as stages through which patients might move back and forth (Buckman, 1998). It was my hope that terminally ill patients could come to a conclusion of their life that was acceptable for themselves and their families. However, I believed that as a nurse, I could only facilitate processes by making myself available and open for communication. Patients and families had to find their own way through a terminal illness, and I was careful not to impose my sense of dying well on them.

My End-of-Life Care Practices

When caring for terminally ill patients and their families, it was of prime importance to me to know them well, which meant that I had to learn as much as possible about the patients' bodies, their diseases and how they experienced the illness, related symptoms and treatments. I also had to be aware of psychological, social, and spiritual issues that mattered to or bothered the patients and had to explore family relationships and family members' potential to become involved.

On the practical level, my basic principles were that the patient was the main decision maker, and that there were no dogmas in end-of-life care. I did everything to achieve good symptom control, including using all medical technical options available to reach this goal. However, I tried to prevent discomfort during the administration of medical treatments. I made every effort to provide individualized physical care that comforted the patient. I showed patients that I had time to talk and tried to honestly discuss upcoming issues. I suggested the involvement of other professionals if I felt a need to do so. I approached family members, gave them the opportunity to ask questions or to talk to the physician, and informed them about their options. Family members were able to call and talk to the nurse at any time. During the final days, if they wished, they could visit around the clock and eat and sleep at the hospital. They were encouraged to be involved at a level that met the patient's and their needs, which included everything from just sitting at the bedside to providing care around the clock.

After the death, while I prepared the body according to hospital routines, it was important to me to still treat the body very respectfully. I decorated the bed with flowers and cleaned up the room before escorting family members to the deceased for a last visit. This visit was allowed to last for an unlimited period of time. Whenever possible, I had the family visit on the unit and only transferred the deceased to the chapel of rest afterwards. A lit candle outside the unit's nursing office conveyed the message of a patient's death to staff members.

Traces of Palliative Care

Again, this account of hospital end-of-life care does not represent the full picture of palliative care. Many nurses were committed to their terminally ill patients and the families. The nursing team had shared goals for end-of-life care, and nurses strove to achieve them. However, the cooperation with other professional groups was less intensive and not always well coordinated. The primary concern of the team was symptom control, but physicians and nurses at times lacked the special palliative care know-how to be as efficient as possible. Psychological, social, and spiritual needs were attended to whenever it was possible and seemed appropriate, mainly through what I earlier described as the generic approach (caring, providing good physical care, listening, and communicating). More direct approaches (e.g., psychotherapy) to patients' emotional struggles were rarely used, in part because their availability was very limited. Families were welcomed at the hospital and could be involved in the care to the extent that they and the patient wished. The clinic did not integrate a formal assessment of family needs into the practice, however, and it did not offer bereavement care. Hence, several aspects of palliative care were absent in the kind of end-of-life care I experienced and practiced as a nurse in this Swiss hospital. However, promising beginnings had been achieved and multiple traces of palliative care could be found.

The personal account provides the link to the final section of this chapter where I will point out the lack of patients' and families' perspectives on hospital end-of-life care, followed by an account that grounds my interest in this topic.

SEARCH FOR PATIENTS' AND FAMILIES' PERSPECTIVES

So far, different notions of caring were explored and a phenomenological view of caring was advocated. Comprehensive, philosophical definitions of practices were outlined. The concept of caring practices was exemplified, with mothering as a private and nursing as a public caring practice. In the next step, end-of-life care was introduced. Unsatisfying approaches to end-of-life care and barriers to its improvement were mentioned. Palliative care was then described, and it was claimed that it actually is a caring practice. Finally, the chapter focused on hospital end-of-life care, exploring traces of palliative care that can be found in the acute care environment.

The Providers' Perspective Prevails

The descriptions of caring, practices and, finally, caring practices originate from nurse researchers and philosophers. Health care providers who were deeply concerned about the insufficient care that terminally ill patients and their families received developed palliative care. Their activities were certainly influenced by patients and families. The writings of Saunders (1993; 1997; 1983) show that she in particular drew heavily on these experiences and let them guide her work. Nevertheless, the depictions of palliative care provided in journals and books represent the practitioners' view. Likewise, the above descriptions of hospital end-of-life care with traces of palliative care represent the nurses' voices.

Practitioners recounted most of the numerous narratives found in the palliative care literature retrospectively. Although authors tried to truly represent patients and families, it remained the authors' story and their choice to tell it for some reason (Arnold & Forrow, 1998). For instance, Byock (1997), Quill (1996), and Kearney (1996) each

published a collection of narratives. These stories provide excellent examples of palliative care situations and are highly instructive for practitioners. However, each author chose his stories to illustrate his special approach to palliative care.

To celebrate its anniversary, the St. Christopher's Hospice published an anthology that contains three narratives told by one patient and two family members (Holden, 1988; Murley, 1988; Rusling, 1988). These stories reported the patient's and family members' views of palliative care, and their experiences reflected the practitioners' goals. But contributions chosen for a jubilee book can hardly be expected to represent adverse examples.

Multiple Perspectives on Palliative Care

As an exception, Barnard et al. (2000) included patients' and families' perspectives in their study of palliative care in one American and one Canadian palliative care program, both of which had a home care service and an inpatient unit. These researchers chose a prospective, ethnographic design and in it they followed terminally ill patients and palliative care practitioners from admission to the patients' death, and they followed the families from admission to several months after bereavement. Data were collected through interviews with and participant observation of all people involved in any given situation. In addition, the practitioners kept journals. The results were reported in the form of narratives and short interpretations. Each story related the experiences of one terminally ill patient, his or her family, and the interdisciplinary team caring for them at home and in the inpatient unit.

The authors provided a realistic picture of palliative care and contrasted it with depictions of the ideal. The portrayals illustrated all the positive achievements attributed to palliative care: a caring interdisciplinary team, excellent symptom control, successful psychological, social, and spiritual support for terminally ill patients and their families, notions of good created throughout the terminal illness' trajectory (including a peaceful death), and good bereavement care.

However, the narratives also showed limitations of palliative care. Some patients experienced patronization instead of empathy and invasion of their privacy rather than solicitude of practitioners. Pain control was at times less than optimal. Not all psychological, social, and spiritual problems could be named and dealt with. One patient never talked about her feelings; another one struggled emotionally, did not respond to alternative approaches, and did not have her suffering relieved by the team. Whereas palliative care services were covered by their health insurance for Canadian patients, the situation of American patients and families were often complicated by financial constraints.

The study also revealed disagreements related to truth telling. For instance, the team told one patient, for whom palliative care was the only option after a diagnosis of incurable cancer, his diagnosis and prognosis, despite the fact that this went against the wishes of his family. Since the man died within a few weeks, neither he nor his family had the time to adapt to the situation. After bereavement, the family still resented that the patient had been informed about his impending death.

Several patients were caught between ideologies. Even though they needed palliative care, they still struggled to find a cure in an attempt to gain time. Palliative care practitioners were troubled by these situations. For some of them, it was easier to care for patients and families who matched their expectations. The less patients and families

corresponded to the image of palliative care clients, the more questions arose within the interdisciplinary teams. Not all long-lasting family struggles could be solved and sometimes relationships remained strained. Some family members never received bereavement care even though they had problems during this time.

Divergent Perspectives?

The above study (Barnard et al., 2000) also highlighted an additional issue, namely that terminally ill patients' and their families' perceptions of the care they received might differ from the providers' perceptions. Morse et al. (1990) made a similar point when explaining that comparisons of patients' and nurses' perspectives on care differed and that the two groups expressed distinct caring behaviors as most relevant. Dunlop (1994), in her discussion of caring, stated that the point of view of care recipients was still missing.

This theoretical exploration of caring practices in end-of-life care is predominantly based on the care providers' perspective, and representations of patients' and families' views seem limited. The hospital setting in particular appears to be susceptible to providing insufficient end-of-life care, but it remains the place of death for many patients. As a former hospital nurse, I felt challenged to further investigate end-of-life care in this setting and especially to discover terminally ill patients' and their families' perceptions of the care they receive. My interest in the perspective of end-of-life care recipients was originally raised through a previous research experience.

Roots of my Research Interest

In 1993, to conclude my postgraduate education (Higher Education in Nursing Level II) in Switzerland, I had to pursue a small research project and write a thesis. Because of my great interest in end-of-life care, I decided to explore a question in this area. One of the criteria in the nursing goal statement for terminally ill patients stated that nursing interventions might be limited in favor of the patients' well-being and comfort (Pflegedienst Medizinische Abteilung Anna Seiler, Inselspital, 1999). When discussing potential themes for my thesis with colleagues, we agreed that this criterion was important, but it became evident that none of us knew how this statement was translated into practice, and it seemed worthwhile to learn more about this issue. Therefore, the research question for my thesis read: How do nurses react and feel about the wish of dying patients to refrain from nursing care activities in favor of their well-being (Spichiger, 1995)? I collected data through participant observation and interviews with nurses and used a grounded theory approach for data analysis.

The findings showed that since nurses tried to individualize nursing care, terminally ill patients quite frequently refused interventions such as mouth care, bathing, or turning. These situations constituted dilemmas for the nurses if they considered a certain intervention as necessary to prevent future problems that might cause discomfort to the patient (e.g. mouth infections, pressure sores). The nurses showed a wide range of possible reactions, from accepting the patients' decision to not offering choices to the patients. The prevailing feeling among nurses when dealing with such situations was uncertainty.

For my thesis, I only looked at the nurses' part in delivering end-of-life care. I also realized that nurses sometimes acted based on assumptions they made, for instance on assumptions of what family members expected. But I wondered how terminally ill patients and their families really experienced nursing care, and what they felt and thought about nurses' work. I became aware that I did not know much about their perspectives and wanted to explore it further. Several years later, when I had to find a topic for my dissertation research, I decided to take up the theme and learn more about terminally ill patients' and their family members' experiences of hospital end-of-life care.

CHAPTER TWO: TERMINALLY ILL PATIENTS' AND THEIR FAMILIES' EXPERIENCES OF HOSPITAL END-OF-LIFE CARE: REVIEW OF THE LITERATURE

Approximately 50% of patients still die in hospitals (National Center for Health Statistics, 1998, 2000). Most hospital units provide end-of-life care without specializing in palliative care. Publications that represent the terminally ill patients' own reports of their care experiences are scarce, and reports on the families' perceptions of the patients' care, as well as on their own experiences with hospital end-of-life care, are limited.

This literature review focuses on terminally ill patients' and family members' experiences of hospital end-of-life care, that is, on their perspectives as they related them in personal interviews or reports and as participants in qualitative and quantitative research projects. Publications on terminally ill patients' experiences are discussed first, followed by a description of the literature on families' experiences. Conclusions from the review are drawn, findings are contrasted with the practice of palliative care, and research questions are stated.

The Medline and CINAHL databases and Dissertation Abstracts International were searched and reference lists of publications reviewed. The literature was reviewed when this study was planned in 2001, and the review was updated after data collection and analysis were completed in 2004. Research projects, personal reports and case studies with data from adult patients dying of various diseases and from their families or from both are included. Experiences with any form of specialized palliative care services are excluded, although some study samples may include palliative care patients. The publications do not only report data from the patients' last hospitalizations but from the whole terminal phase, which may include several hospitalizations. Some studies report findings derived from patient and family member data, without clearly distinguishing experiences. These studies are included in the section on patients' experiences if patients contributed substantially to the findings. Studies comparing hospital care to care provided in other settings or through a specialized palliative care service are included if data on patients' and families' hospital experiences are reported.

Regarding qualitative research, there is no agreed upon list of criteria for evaluation (Smith & Deemer, 2000), and, according to Bochner (2000), it would be disadvantageous to have one, because such a list would reinforce static standards and limit new developments. Rather, the reader should consider the goal and the methodological approach of a study and evaluate it accordingly. My appraisal of qualitative studies is influenced by my background as an experienced nurse and by my understanding of end-of-life care. My evaluations focus on three questions: Does the research process make sense? Do I trust the results? Do the results contribute to my understanding of the phenomenon?

Patients' Experiences of Hospital End-of-Life Care

A few articles reported personal experiences of particular patients in various forms (Foley, 1999; Schmele, 1995; Veatch & Veatch, 1994). A few quantitative studies investigated symptom prevalence (Hockley, Dunlop, & Davies, 1988; Levenson, McCarthy, Lynn, Davis, & Phillips, 2000; Lynn et al., 2000; McCarthy, Phillips, Zhong, Drews, & Lynn, 2000; Roth, Lynn, Zhong, Borum, & Dawson, 2000; The SUPPORT

Principal Investigators, 1995). A qualitative study explored terminally ill patients' experiences of communication with hospital nurses (Weinandy, 1997), two others communication with physicians (McCormick & Conley, 1995; Wenrich et al., 2001). Several qualitative studies focused on related aspects, namely, patients' concerns, wishes and fears, physicians' skills needed to provide good end-of-life care, elements of quality end-of-life care, and lived experiences of approaching death, rather than on patients' experiences of hospital end-of-life care (Carline et al., 2003; Curtis et al., 2001; Ryan, 2003; Singer, Martin, & Kelner, 1999; Tanaka, Iwamoto, Kaneyasu, & Petrini, 1999). Three publications described potential outcomes of care, and two of these compared different care settings (Greer et al., 1986; Grond, Zech, Schug, Lynch, & Lehmann, 1991; Kane, Wales, Bernstein, Leibowitz, & Kaplan, 1984). The findings of these outcome studies provided some indirect clues to understanding terminally ill patients' experiences of hospital end-of-life care.

Personal Accounts

Veatch and Veatch (1994) published an interview with a terminally ill patient in order to raise a previously underexplored problem in hospital care: the selection of roommates. This 72-year-old cancer patient had gone through several hospitalizations and had, at one point, observed a roommate who died of cancer and suffered uncontrolled pain. His experiences with roommates rose concerns about his future care: Would he have to die in pain as well?

Ivan Hanson, an American health care professional and scholar who was dying of cancer at age 59 after being diagnosed with the disease about 4 years earlier, related some of his experiences as a hospital patient in an interview with a colleague (Schmele, 1995).

For him, health care providers were often caught up in the system and, as a result, the suffering patient's perspective was lost. Nurses were often so busy dealing with technical aspects of care that they tended to overlook the patient behind the machines, or they lacked the time to get to know the patient as a person. He experienced casual conversations with nursing assistants who relied on their personal life experiences as more caring than some conversations with highly educated and well-read providers.

Hanson considered spiritual aspects of dying to be very personal (Schmele, 1995). He therefore became resentful when some health care providers, who he barely knew, wanted to discuss such issues. At times he even felt that nurses intruded his privacy with their own religious beliefs, and that they lacked the sensitivity to realize that he did not appreciate these conversations.

Other health care providers thought of themselves as the experts and did not assess his real needs (Schmele, 1995). Asked what quality care would mean for him, Hanson stated that an accurate assessment of his situation throughout the dying trajectory was important. He wanted to be treated as a human being and make his own informed decisions. Finally, he suggested that the health care providers should work as a team.

In a case study of a 44-year-old American woman who was admitted with unclear symptoms, diagnosed with metastatic lung cancer, and died after only 25 days in the hospital, an interview with the patient on the day before her death was summarized (Foley, 1999). This patient experienced the dying process as humiliating and suffered severe pain, partly in order to stay lucid as long as possible. She stated that physicians needed to listen to patients. Her biggest fear was dying alone. She wished for someone to tell her that it was all right to let go when her time came.

These interviews with terminally ill patients pointed out relevant issues in hospital end-of-life care on different levels. Medical-technical aspects, such as accurate diagnostics and effective symptom control, were of concern to the patients. Not being recognized and met as a particular person was alienating and difficult to tolerate. The organizational structure of the hospital should be flexible (e.g., it should take individual needs for rooms into account) and promote teamwork.

Two of the patients also illustrated the tremendous variability among patients and illness trajectories. On the one hand, there was Hanson, a knowledgeable health care professional whose trajectory from diagnosis to death extended over 4 1/2 years. This relatively long period of time gave him the opportunity to reflect upon and come to terms with his dying. He was hospitalized several times, but finally died at home, where he was cared for by his family. On the other hand, there was the woman (her personal circumstances were not fully reported) who was diagnosed after hospital admission. She underwent numerous diagnostic tests, interventions and pain treatments, was constantly challenged to catch up with her rapid decline, and died after only 25 days. A particular terminally ill patient and her family, consequently, experience the care provided by health care professionals who are challenged to come to terms with many different people and a wide range of situations, and to do so within a system that tries to delimit its escalating costs.

Patients' Experiences of Symptoms

Hockley et al. (1988) monitored both physical and mental distress in 26 terminally ill patients admitted to one of five units in two British hospitals. Two chest physicians and a rheumatologist consented to have their patients with a prognosis of less than 3 months consecutively included in the study. The sample consisted of 15 patients with cancer and of 11 patients with a non-malignant disease. On the 7th day after admission, the patients' physical symptoms were assessed using a list of 16 symptoms. In addition, anger, anxiety and depression were assessed in 22 of 26 patients. Both instruments were based on 4-point rating scales. A few findings provided direct insight into patients' experiences, but most only provided indirect insight.

Anorexia was the most common symptom, in that only 2 patients had good appetites. A sore mouth was distressing for 21 of the patients. Of the 26 patients, 23 did not sleep well. They identified noise, disturbing roommates, and being turned in bed too often as causes. Patients did not expect to sleep well in the hospital. Twenty patients suffered from cough and 18 from dyspnea, with breathlessness causing the most distress to patients. The frequency of cough and dyspnea was related to the fact that two of the three admitting physicians were chest specialists. Pain was found in 18 patients, with 11 describing it as moderately or severely distressing. Sixteen patients had pressure sores, and 10 of them had developed these pressure sores in the hospital. Of the 19 patients who felt depressed, the 6 most affected had all reported several distressing physical symptoms. Patients who did not know their diagnoses experienced anxiety.

This study does not allow for generalizations because of the small sample size, the somewhat special group of participants (i.e., patients who were dying from chest or rheumatologic diseases), and the lack of any report of patients' characteristics. The interview process, the data collection tools, and the analysis were not described thoroughly. It is not clear how the qualitative data were gathered. The researchers did not explain how symptoms and the amount of distress they caused were measured, so what counted as distressing remains unclear. These limitations make it difficult to evaluate the validity and reliability of the reported results.

This study aimed at reporting symptom prevalence in terminally ill hospitalized patients and, in addition, reported a few associations. The study's potential to increase the understanding of patients' experiences is limited because it largely only provided indirect indications of care experience. Given the high prevalence of anorexia, nutritional care might have been of special importance to patients. Effective but not distressing measures for mouth care and pressure sore prevention might have been absent. Effective symptom control and the provision of adequate information were missed for several patients. Knowing patients' symptoms and emotional states does not necessarily improve insights or open up possibilities for amelioration or consolations. Additional information about the context and the concerns of particular patients is needed. For instance, the contextual information provided in relation to sleep raises interesting questions regarding how preventive nursing interventions and patients' need for uninterrupted sleep should be balanced, or how patients who start out with very low expectations will evaluate care experiences.

Symptom prevalence was also investigated in the SUPPORT (The SUPPORT Principal Investigators, 1995). This study aimed at improving decision making and care for seriously ill hospitalized patients. Patients with one or more of nine life-threatening diagnoses from five teaching hospitals in the US were enrolled (*N* = 9105). The project had two phases; the first was a prospective, observational study (*n* = 4301), the second a clinical trial (*n* = 4804). The goal of the intervention was to improve interactions between physicians and patients regarding the latter's preferences for comfort care or aggressive treatment. Symptoms were evaluated during the second week of patients' hospitalization or at discharge. When possible, patients were interviewed; otherwise, surrogates' answers were substituted. During the first phase, 22% of the patients reported having moderate to severe pain at least half the time. The trial intervention did not bring about any improvement for the intervention group; that is, pain levels did not decrease during the second phase of the study.

Several secondary analyses of subsamples of patients participating in both phases of the SUPPORT provided further information on symptom prevalence (Levenson et al., 2000; Lynn et al., 2000; McCarthy et al., 2000; Roth et al., 2000). Each of these studies included patients with a specific diagnosis, who died within one year of study entry and had provided data within the last six months of life. Patients or surrogates were asked about the severity and frequency of pain, nausea, confusion, and dyspnea. Subscales of the Profile of Mood States were used to evaluate anxiety and depression. Data were summarized for different time periods prior to patients' death. Among 539 patients hospitalized with an acute exacerbation of congestive heart failure, about 20% to 40% were suffering from severe pain, and about 30% to 60% from severe dyspnea, severe meaning moderately or extremely severe for at least half of the time. Symptom prevalence increased as death approached. About 10% of the patients were severely confused (Levenson et al., 2000). In the subsample of 416 patients with chronic obstructive pulmonary disease (COPD), about 25% suffered severely from pain, about 75% from dyspnea, and 10% to 20% from confusion (Lynn et al., 2000). Of 1063 patients with either advanced colon or lung cancer, about 25% to 45% experienced severe pain, up to about 30% experienced severe confusion, with an increase as death approached,

and 5% to 10% felt severely nauseated (McCarthy et al., 2000). Finally, in the subsample of 575 patients with end stage liver disease with cirrhosis about 30% to 40% suffered severely from pain, about 5% to 30% from confusion, with an increase closer to death, up to about 10% from nausea, and about 25% to 45% from dyspnea (Roth et al., 2000). In all subsamples, patients suffered only modestly from anxiety and depression.

Although the focus of the SUPPORT was not on symptom prevalence, the results of the main study and of several secondary analyses illustrated that substantial groups of patients experienced severe symptoms in the second week of a hospitalization during the last six months of their life. The total study sample included adults of all ages ($M = 65$ years), men and women, different ethnicities, and patients with different diseases. A few selected symptoms were evaluated with rather rough measures, and it does not become exactly clear, how often patients' answers were substituted by surrogates' responses. No data were collected regarding symptom management or changes of symptoms over time in the hospital. Thus, no detailed conclusions about patients' experiences of hospital end-of-life care can be drawn from this group of studies. However, it can still be deduced that many terminally ill patients with various diseases experienced insufficient symptom management in the hospital.

Patients' Experiences of Communication

Weinandy (1997) researched how hospital nurses and terminally ill patients experienced their communication. He interviewed 15 hospital staff nurses and 15 hospice patients who had experienced hospital care before. The 9 women and 6 men were American, all but one patient suffered from cancer, and their ages ranged from 41 to 84 years ($M = 67$). An extended list of open-ended questions, derived from the literature, guided the interviews. Constant comparison was used for data analysis.

Ambiguity was a recurrent theme in the results. Patients experienced ambiguity and confusion about what to expect from their diseases, the nurses, and themselves in their roles as terminally ill patients. They made big efforts to be "good" patients, that is, to need nurses in what they thought was the right way. Nurses and patients often used indirect language, and patients interpreted nurses' utterances and behavior in order to assess their realities, a situation that opened the door to frequent misinterpretations. Physicians, families and the hospital environment influenced the communication between nurses and patients. Patients used nurses to compensate for unsatisfactory communications with physicians. They tried to protect family members by revealing emotions or questions to nurses rather than to their families. Time constraints frequently negatively impacted communications between nurses and patients. Patients saw rapport with nurses as a prerequisite for talking about serious issues. The establishment of this rapport depended on the continuity of care, which was often not given because of the hospital organization. Nurses could damage rapport when a patient perceived a nurse's utterance or behavior as offensive. Patients also experienced ambivalence about who was in control of the communication between nurse and patient.

In this dissertation, Weinandy (1997) discussed grounded theory as a qualitative method for developing knowledge inductively. However, when describing his method, he only mentioned constant comparison for data analysis. Thus, it is not easy to understand to what extent he followed the analytic techniques of grounded theory. He clearly did not translate the inductive approach of grounded theory into action, since he derived the interview topics from the literature and the results seem to reflect and be limited to these issues. Nurse and patient data were presented together, and nurses' views were somewhat more present in the results. It is not always easy to understand which results represented the patients' genuine contributions. However, the study pointed out an important aspect: Terminally ill patients experienced tremendous ambiguity about their role as patients.

McCormick and Conley's (1995) study focused on how terminally ill patients experienced their communication with physicians from the diagnosis of cancer to the beginning of the terminal phase of the illness, mainly in terms of the breaking of information regarding the disease and its progress. Two women and 4 men were interviewed. They were American, between 34 and 75 years old ($M = 62.2$), and all had accepted hospice assignments. Only a small component of the interviews concerned patients' experiences of hospital care.

Most patients experienced two distinct levels of awareness during the last phase of their illnesses. When cure was no longer an option, they considered themselves as incurable, as having to live with the illness, but not as terminal yet. Only later, after further deterioration, did they realize that death was imminent. They got the information about their status in different ways, but rarely through a direct discussion initiated by their physicians. Yet all patients wanted to be informed about their impending death so as to be able to plan their remaining time. Some patients experienced hospital nurses as being more comfortable than physicians when talking about dying, and they regretted the latter's reluctance to discuss the topic.

The interview process was not thoroughly discussed, and the analysis of data was not described in this publication. However, the authors introduced each participant, and their interpretations seemed grounded in the data and were supported by lengthy quotes. The findings highlighted interesting points, namely that these patients did not equate being incurable with dying and that they wished for ongoing communication about their changing situation.

Wenrich et al. (2001) reported findings regarding communication between terminally ill patients and physicians. These results are part of a more comprehensive study described below (Curtis et al., 2001). From focus group discussions with terminally ill patients, bereaved family members, health care providers, and physicians, the researchers learnt that physicians need the following competences in order to communicate adequately with terminally ill patients: talk with patients in an honest and straightforward way, listen to patients, give bad news in a sensitive way, be willing to talk about dying, encourage questions from patients, and be sensitive to when patients are ready to talk about death. The first three competences were seen as most relevant by patients.

Qualitative Studies Focusing on Related Aspects

Curtis et al. (2001) developed a conceptual model of the domains of physicians' skills at providing excellent end-of-life care. They collected data through focus group discussions with terminally ill patients suffering from COPD, AIDS, or cancer (11 groups, $n = 79$), bereaved family members (3 groups, $n = 20$), nurses and social workers (4 groups, $n = 27$), and physicians with expertise in end-of-life care (2 groups, $n = 11$). Female and male patients participated, their age ranged from 27 to 78 years, about half of the AIDS patients were African American, and most others were white. Based on the literature and experts, the researchers drafted a preliminary framework of domains. Focus group transcripts were then coded and the domains were constantly revised using a grounded theory approach. The researchers worked first in pairs, they reviewed results and then developed the model as a group. Twelve domains of physicians' skills were identified and specific components within each domain described. Patients' and families' language was used to label components and illustrate them with quotes. The coded passages for each domain were counted and domains were ranked according to frequencies for each group of participants.

According to this conceptual model, to provide excellent end-of-life care, physicians need cognitive and affective skills, the former relating to professional competence, pain and symptom management, the latter to giving emotional support and recognizing the patient as a person. Physicians also must have communication skills in order to communicate adequately with patients, educate them, and include and recognize the family. Patient-centered values are relevant, that is, physicians must pay attention to patient values, show respect and humility, and support patient decision making. Finally, a patient-centered care system is needed, with physicians ensuring accessibility and continuity, team communication and coordination. Communication with patients, emotional support, and accessibility and continuity were most frequently mentioned by most patient groups and families.

Carline et al. (2003), in an additional publication on this project, provided further details regarding the domains of accessibility and continuity as well as team communication and coordination. The components of the domain accessibility and continuity were the following: the physician takes as much time as needed with patients, ensures that he is accessible to patients and families in a timely manner, makes patients feel confident that they will not be abandoned prior to death, avoids keeping patients waiting without explanations, continues to be involved with patients after referral to hospice, minimizes interruptions and focuses on patients during visits, and has contact with families after patients' death. All patient groups and families mentioned the first and second component most frequently. Team communication and coordination referred to physicians' respecting other team members, ensuring consistent information from the entire team, and letting patients and families know who is available. These components were infrequently mentioned by patients and families.

The study by Curtis et al. (2001) did not focus on physicians in hospitals, but on physicians working in different settings, including hospitals. Although patients, family members, and health care providers participated in focus groups, the terminally ill patients were the biggest group of participants, and the researchers took care to give them a prominent voice. Data collection and analysis were carefully described, and the domains were illustrated with meaningful quotes. The authors were aware of the study's limitations: The focus group included participants from one geographical region of the US only, they were mostly white, and patients were suffering from three specific conditions. Thus, with other groups of participants, additional issues might surface. In addition, the rankings of domains and components according to the number of coded passages in the transcripts might be influenced by group dynamics and seems, therefore, somewhat questionable. Nevertheless, the study highlights that physicians need affective and communicative skills in addition to cognitive skills in order to give high-quality end-of-life care. It also points out the relevance of physicians' accessibility and of the continuity of care.

Singer, Martin, and Kelner (1999) described elements of quality end-of-life care as identified by Canadian patients. These authors performed a secondary analysis of interviews with three patient groups: 48 dialysis patients (mean age 48.3 years, 18 non-white), 40 persons infected with HIV (mean age 39.6 years), and 38 residents of a long-term care facility (mean age 76.3 years). The latter two groups mostly included white people, and all groups included men and women. The in-depth interviews with open-ended questions had focused on patients' control at the end of life and on advance care planning. A systematic analysis of content and frequencies revealed five relevant domains. Quotes were elicited to support each theme.

For these patients, receiving adequate pain and symptom control was a great concern. They wanted to avoid an inappropriate prolongation of dying and achieve a sense of control over their end-of-life care decisions. Patients were afraid of burdening their families and wished to strengthen relationships with loved ones.

Again, the study did not focus on hospitalized patients, but patients had experiences with hospital care. Unlike many others, this study included non-cancer patients. Data collection and analysis were well outlined. Each domain was described further and illustrated with quotes. Thus, the authors reached a coherent account. However, the study is restrained by the limits inherent in content analysis methodology. As Silverman (2000) noted, researchers performing content analyses usually take meanings of words and experiences for granted. They categorize the content and sometimes count frequencies without attempting to further explore and interpret the text. They may reach a coherent and comprehensive description of the data, but rarely articulate new insights beyond quotes from participants.

In addition, the fact that these results are based on a secondary analysis has to be considered. Given the interviews' focus on control and advance care planning, aspects related to these issues may be overemphasized in the findings, while other aspects, which are also relevant to quality end-of-life care, were not mentioned by these patients.

Tanaka et al.'s (1999) study focused on the patients' concerns, wishes, and fears. These Japanese researchers interviewed 8 hospitalized and terminally ill cancer patients, 4 women and 4 men, aged 51 to 93 (*M* = 63.3). All patients knew their diagnoses. Three of the authors jointly performed a content analysis of the transcribed interview texts.

Patients' fears of pain were most prominent, and maintaining pain control was a major concern of these patients. They wished to live ordinary lives and were pleased when they could perform normal activities (e.g., eating at the table). They voiced economic and family concerns and hopes to return to work. The patients also hoped for improvement in their physical conditions. They wanted to have family nearby and felt supported by family members.

The issues concerning content analysis also apply to Tanaka et al.'s (1999) study. In addition, the way in which subthemes were linked to the four main categories seems debatable. The authors subsumed under "living an ordinary life," for instance, patient satisfaction with performing daily self-care activities, economic and family concerns, and wishes to return to work. As reader, I feel left with a list of concerns and hopes rather than with an auditable description. Yet my Western perspective may prevent me from understanding what may be obvious for the Japanese authors because the Japanese concept of family differs from Western concepts.

Ryan (2003) explored the lived experience of approaching death among elderly persons with advanced cancer. She interviewed five participants repeatedly at home or in the out-patient clinic. The participants were white Americans, their age ranged from 65 to 83 years. They had experienced care in out-patient clinics as well as during hospital admissions. Using Munhall's approach to phenomenology for data analysis, the author provided five narratives of individuals' experiences and a summarizing interpretation of these narratives.

Regarding their care experiences, these terminally ill patients stated that being recognized as a unique person by care providers was important. They valued kindness, genuine caring, and relationships to care providers that were based on trust and respect. Listening and giving information with compassionate honesty, without being harsh, was also relevant for these patients.

In this dissertation, the methodological approach is well described. The author did not address differences between Husserl's and Heidegger's phenomenology; therefore, the philosophical background remains a bit blurred. Although the study did not focus on experiences of hospital care, the narratives and the interpretation provide some hints to aspects that contribute to positive or negative interactions with health care professionals.

The qualitative studies investigating communication or focusing on related aspects all included women and men. Their age ranged from 20 to 93 years. Most study participants were white, and with one exception (Tanaka et al., 1999), studies were performed in the US or Canada. The results do not allude to any differences in patients' care experiences related to gender or age, which is not surprising given the small sample sizes of most studies. However, Weinandy (1997) rightly stated that potential influences

of gender and age need to be explored in future research. Ethnic and cultural aspects should be considered as well.

Studies Focusing on Outcomes

Grond et al. (1991) analyzed pain treatments in cancer patients during the last days of life and tested the utility of the WHO guidelines for cancer pain relief (1986). Over 6 years, all cancer patients treated in a German pain clinic and followed until death were included in the total sample (*N* = 401), with 199 women and 202 men, and an age range from 16 to 90 years (*M* = 58, *SD* = 12). Of 319 patients who either died on a general hospital unit or on the hospital's palliative care unit, 262 were able to rate their pain on the day preceding their death. Eleven patients suffered from severe pain, 22 reported moderate, 53 mild, and 176 no pain. Since there were no reports of data on pain from the time period prior to the implementation of the WHO guidelines or from a control group, the study does not allow for comparisons or generalization. However, the researchers still demonstrated that with the rigorous application of the guidelines in their clinic, they achieved good pain control for a majority of patients at the end of life.

A randomized clinical trial compared hospice and standard care provided in an American Veterans Administration Medical Center to cancer patients with a prognosis of 2 weeks to 6 months (Kane, Klein, Bernstein, Rothenberg, & Wales, 1985; Kane et al., 1984). The sample included 247 consecutively admitted patients. They were almost all male and their age ranged from 34 to 92, with a mean age of about 64 years. Characteristics of the hospice and control groups did not differ significantly. Previously validated measurement tools were adapted for this study and administered through interviews. The analysis of data from repeated patient interviews did not reveal significant differences in control of pain and other symptoms or in effects of treatments for depression and anxiety. Hospital patients were, however, less satisfied than hospice patients with interpersonal care and involvement in care. Regarding the lack of significant differences, the authors suggested that either the role of hospice care in symptom management may be smaller than expected, or conventional care may have learned from hospices and improved to their standards. The latter seems quite likely in an institution that incorporated both a hospice inpatient unit and a consultation team. However, since no symptom scores are reported, it is not possible to evaluate the level of symptom control that was achieved for these patients.

The National Hospice Study (NHS) assessed whether hospice attained its goals, and the study provided a database for health care policy formulations in the US (Greer et al., 1986). Patients were admitted to either hospices without beds (home care, HC), hospices with beds (hospital based, HB), or conventional hospital care (CC). A convenience sample composed of 1754 patients with advanced cancer was investigated. It showed only minor differences among the groups. CC patients were younger and more functionally impaired, and HC patients were less likely to have been hospitalized in the 2 months prior to study entry and less likely to live alone. The majority of patients in the CC group ($n = 297$) were aged 55 to 74 (58.9%), 26.6% were younger and 14.5% older and women represented 52.7% of patients in this sample. An adapted satisfaction measurement scale was used and data were gathered from patients at entry into the study and in a follow-up interview. These patients reported high levels of satisfaction with health care. No significant differences among settings were found.

The first of the three studies discussed above evaluated pain control (Grond et al., 1991) and the latter two compared symptom control and satisfaction with care among various settings (Greer et al., 1986; Kane et al., 1985; Kane et al., 1984); that is, all of the studies focused on outcome measures. However, knowing the outcomes of care does, by no means, fully illuminate the patients' experiences of this care. A terminally ill patient, for instance, may be in pain, but his experience of care, and more specifically of pain management, will vary greatly depending on the circumstances of his particular situation.

Overview of the Studies on Patients' Experiences

The personal accounts related individual patients' experiences of hospital end-of-life care. None of the studies focused directly on this theme. Rather, the publications addressed certain aspects of hospital care, such as symptom prevalence or outcomes, or they focused on another theme, for instance on communication, and patients' experiences of hospital care were only indirectly described. While some studies included cancer patients only, others included patients suffering from different diseases. The age of study participants encompassed the whole range of adulthood. Women and men were equally represented in all projects except that of Kane et al. (1984). Researchers who followed the patients over time investigated different time periods prior to death, and one-time interviews were performed at various times relative to death. Most projects were carried out in the US, but some were done in various countries and were influenced by different cultures and different health care systems. Furthermore, several studies had methodological shortcomings.

The review provides, at best, some glimpses of terminally ill patients' experiences of hospital end-of-life care. In summary, the reports and study findings highlight

somewhat arbitrarily aspects of this population's care experiences without allowing for any definite conclusions. The following themes were touched upon: influential experiences with roommates; patients' relationships to, and communication with health care providers; patients' autonomy; individual care; symptom control; nursing interventions related to activities of daily living; spiritual and psychological support; family presence and family burden; physicians' competence, accessibility, continuity of care, and teamwork of health care providers. The relevance for care providers of recognizing patients as persons, of a caring stance towards patients, of listening to and informing patients adequately has been pointed out repeatedly. The studies also show that many patients experience insufficient symptom control in hospitals. All of these issues except that of experiences with roommates have been recognized as relevant aspects of palliative care, and best practices have been described in the literature for these issues. In hospital end-of-life care, these practices are not always applied thoroughly and successfully.

Patients' Unexplored Experiences

Comprehensive descriptions of hospital end-of-life care from the patients' perspective are lacking in the literature. For many terminally ill patients, the hospital, sometimes even the hospital room or bed, is their last place to stay and be cared for, perhaps by family members, but mostly by professional health care providers. The following have not yet been explored: what this reality means to terminally ill patients in various cultures and health care systems; how these patients experience daily life and the receiving of care in the unfamiliar hospital world; which experiences are common or vary among patients; and how their experiences and their perceptions of the hospital environment change over time and in relation to patients' health status.

Families' Experiences of Hospital End-of-Life Care

The body of literature on families' experiences of end-of-life care in hospitals is more extensive than that on patients' experiences, but it is still somewhat limited. Most publications represent particular projects that applied a variety of research methods and are widely unrelated to each other. For discussion, studies using a similar approach are grouped together; however, group affiliation is ambiguous for some publications, and in these situations the best fitting group was chosen. The summary of a few personal accounts is followed by an in-depth discussion of projects that focused on families' experiences. The next group of studies investigated families' needs. Then, studies that focused on outcome measures of hospital end-of-life care and provided some indirect insights into families' experiences are summarized. Finally, studies comparing hospital to hospice care are outlined.

No attempt is made to discuss separately what family members reported as the patients' experiences of hospital end-of-life care and family members' own perceptions of the care. This section shows that the terminally ill patients' well-being was the most important issue for family members. Families' care experiences depended to a great extent on the patients' experiences. Any separation would, therefore, seem artificial and the review would become repetitious. If not stated otherwise in the included studies, family member meant the spouse, significant other or next of kin of the terminally ill patient, and one person represented the family as a research participant.

Personal Accounts

In several reports of particular situations, family members recalled very good as well as very bad experiences with the end-of-life care that patients had received in hospitals. In one case, staff suggested and helped organize a hospital wedding for a dying woman's daughter in order to fulfill the mother's great wish to see her only daughter's wedding (Montague, 1995). In other situations, a daughter complained about the insufficient pain control that her demented father experienced (Absolon, 1998), and the companion of a patient dying from AIDS reported how his partner suffered from care discontinuities, symptom treatment delays, and staff's lack of training in palliative care (Masterson, 1996). The lack of experience with end-of-life care was also problematic for a consultant in palliative medicine who witnessed the dying from metastatic prostate cancer of his father-in-law. Nursing care was excellent, but communication with physicians was poor, and the family had problems with getting adequate prescriptions for pain control. These providers were not used to care for terminally ill patients, and the author wondered what happened to patients who did not have a professional as advocate (O'Neill, 1999). A nurse recounted that her terminally ill friend had perceived the nurses as rough when they were bathing her (Petit de Mange, 1998). Furthermore, before and after the death of this African American Muslim woman, the nurses proceeded according to hospital routines without taking full account of this patient's and her family's religious and cultural background. Two other health care professionals, after the death of their mother who had suffered from Alzheimer's disease and pneumonia, complained about the disregard of the patient's advance directives, and that she was kept alive at the cost of insufficient pain relief. When they suggested the involvement of hospice two weeks prior to the patient's death, the attending physician said it was not yet time for hospice care; she expected the patient to live for more than six months (Larson & Larson, 2002).

These personal accounts pointed out some aspects of families' experiences of hospital end-of-life care that went unnoticed in research projects: 1) the initiative of staff members to attend to a terminally ill patient's special need that exceeded hospital routines; 2) hospital staff's lack of education in palliative care; 3) the disregard of advance directives, and 4) the disrespect for religious and cultural issues.

Studies Investigating Families' Experiences

In most of the studies discussed below, several aspects of hospital end-of-life care were included, and the investigation of families' experiences was either the main purpose (Abt, 2001; Atwood, 1977; Czerwiec, 1996; Ogasawara, Kume, & Andou, 2003; Pierce, 1999; Rogers, Karlsen, & Addington-Hall, 2000) or one component of a more comprehensive study (Berns & Colvin, 1998; Herd, 1990; Hess et al., 1997; Hockley et al., 1988; Jacobs, Bonuck, Burton, & Mulvihill, 2002; Teno, Casey, Welch, & Edgman-Levitan, 2001; Vachon et al., 1977; Wilkes, 1984). Two research projects focused on specific themes: family involvement (Andershed & Ternestedt, 1998, 1999) and family members' perceptions of communication (Krant & Johnston, 1977). Finally, some studies that compared hospital to hospice care provided some details on families' experiences with the former. These findings are summarized.

Studies With a Broad Perspective Focusing on Families' Experiences

Atwood (1977), in a grounded theory study, investigated the kinds of nursing care that were helpful and unhelpful, as well as nursing care that was needed but not received.

Twenty-three family members, 15 women and 8 men, were interviewed during different stages of their relatives' terminal illness. Two families were Mexican and all others were Anglo-American. All of the patients suffered from cancer and were inpatients of the oncology unit of a hospital. Three family members were interviewed a second time after their relatives' deaths.

The most important finding was summarized in the following hypothesis: "The greater the difference between the amount of nursing care effort expected by the family and the amount of effort made by the nursing team, the greater the magnitude of selective neglect" (Atwood, 1977, p. 344). Selective neglect meant "failure to carry out an aspect of a role because it has much lower priority than other aspects" (p. 345). Family members identified three areas of selective neglect: nutrition, person-centered care, and environment. While some families perceived the patient as having been fed well, other families complained that the nursing staff did not pay enough attention to patients' nutritional needs. The environment was of concern for families, especially the high level of noise, a lack of privacy, and the moving of patients from one room to another without prior explanations. In the area of person-centered care, the staff met or exceeded most of the families' expectations. Some concerns were, however, raised about the lack of patience and compassion from some nurses.

Atwood (1977) followed the grounded theory research process well. He acknowledged, however, that he did not reach a saturation of categories because he could only perform a few post bereavement interviews as a consequence of the patients' wide ranges of life expectancy and the inaccessibility of family members who lived far away. In addition, the term selective neglect was based on role theory and not grounded in data.

It was assumed that nurses' conceptions of their roles allowed them to prioritize medical needs over basic needs such as nutrition. Without data from the nurses to confirm this assumption, other potential reasons for neglect cannot be excluded, and the notion of selective neglect, therefore, seems debatable. In spite of these limitations, the findings showed that family members considered careful attention to basic needs, especially nutrition, as highly relevant in end-of-life care.

In Czerwiec's (1996) study, 30 American next-of-kin were interviewed by phone approximately 3 to 5 months after the death of a relative in one medical center. Participants were asked open-ended questions regarding their satisfaction or dissatisfaction with hospital care. Respondents also rated their overall satisfaction on a numerical scale.

Ninety-two percent of the participants were satisfied or very satisfied with the care their relatives had received. Family satisfaction was most positively affected if the staff was perceived as having a caring attitude. Dissatisfaction was mainly caused by a lack of information about the patient's condition. Of all of the comments about nurses, 87% were positive. Family members particularly appreciated actions that provided comfort, relieved pain, and kept the patients clean and dry. One nurse who was perceived as unfriendly and rough with the patient elicited a negative comment. Nurses' caring for family members during families' presence in the hospital was highly appreciated. Family members valued when nurses were available, open, compassionate, and willing to listen. Unavailability of the nurses was experienced negatively, but was often excused by family members as being a product of the time constraints of nurses.

Although this author did not outline the data analysis method used or name what appears as content analysis, she provided a coherent and credible description of the data and supported it with numerous quotes. Her findings underlined the relevance of caring in end-of-life care. Caring referred to showing concern and commitment for individual patients and their families.

Pierce (1999) interviewed 29 randomly selected bereaved family members and asked them to describe their reactions to experiencing the death of a loved one in an American tertiary care facility, and to make suggestions for improving end-of-life care. The participants' age ranged from 30 to 80 years ($M = 53$), and 21 were female. Although 27 informants had a generally positive view of the care they and their terminally ill relatives had received, 18 of them made suggestions for improvements. These 18 interviews were transcribed and analyzed using a constant comparative method. Percentages and numbers of participants for each category were reported.

In the Pierce (1999) study, family members identified two common, recurrent experiences: the positive impact of individual care providers (41%, $n = 12$) and the persistence of regrets and sadness (35%, $n = 10$). Of concern for the families was the routine nature of a complex hospital system (79%, $n = 23$). Even though families sometimes recognized that there was inadequate staffing or training, a lack of personalized attention and caring was distressful to the families. Family members stated that the bureaucratic system left them and the patient feeling powerless, ill informed, and disrespected (72%, $n = 21$). Families suggested three ways in which end-of-life care could be ameliorated: 1) facilitate interaction between the terminally ill patient and the family by facilitating closeness and talking, and by maintaining the patient's personal hygiene (24%, $n = 7$); 2) improve interaction between care providers and the patient, family or both by providing information, listening, and recognizing the uniqueness of the situation for the patient, family or both (62%, $n = 18$); and 3) create an aesthetically pleasing setting that allows for caring (35%, $n = 10$).

The research procedure for this study was outlined quite clearly, except the process in which the 11 non-transcribed interviews without suggestions were integrated into the analysis. The author's interpretations were undergirded by examples and seem plausible. The negative impact of a bureaucratic system on participants is a thought-provoking aspect of these findings. The bureaucratic routines seem to be experienced by families as a particular kind of social annihilation, which, in the time of patients' physical demise, allows physical and social death to collude.

Rogers et al. (2000) researched sources of dissatisfaction with hospital care during the last year of cancer patients' lives. The authors reported family members' answers to 14 open-ended questions that were part of a more comprehensive survey, and they invited participants to comment on their experiences with hospital care during the terminal illness of a loved one. Data were collected from a random sample of a British inner city health district via interviews conducted or postal questionnaires sent 7 months after bereavement. A 53% response rate was achieved ($N = 138$). The content of the data was analyzed and organized into common themes and categories. Two researchers independently generated the themes first and then together reconsidered differences.

Hospital care by physicians was rated excellent or good by 74%, and this number increased to 80% for hospital care by nurses. Even family members who made negative comments about medical or nursing care contributed to these high ratings. Much of the dissatisfaction expressed by family members related to hospital staff's communication, especially to the way bad news was given. Respondents resented if such communication took place in public areas, at a time when they or the patients were not prepared for it, or if physicians appeared insensitive. Several respondents felt that medical students and junior physicians should not engage in this type of communication because they lacked the necessary skills. At times, a patient's implicit or explicit wish not to be told about the impending death was disrespected. Seventeen family members experienced problems in getting adequate information about the patients' conditions and prognoses. A few acknowledged that their own inaction played a role in this respect.

Personal care was dissatisfying for 45 family members because either patients were not treated as individuals or patients' specific needs were not recognized (e.g., patients were not helped with food, left for long periods in wet linen, or not dressed properly). Twenty-eight respondents felt that only their presence at the hospital ensured that basic nursing care was given. This lack of individual care compromised the patients' dignity. Several family members explained these shortcomings with limited resources.

For some respondents, bureaucratic requirements overrode patients' care needs. Others reported that the patients' complaints had not been taken seriously, resulting in late diagnoses of the terminal conditions. Some dissatisfaction was related to the malfunctioning of medical equipment or to the hospital environment (e.g., a family member cleaned the bathroom before allowing the patient to use it).

The researchers pointed out that overall high satisfaction levels with care might mask shortcomings. Therefore, giving an option to research participants to freely comment on their experiences was seen as a valuable additional data source. The authors suggested that these family members' dissatisfaction was mainly a response to situations that threatened the patients' or family members' selves or identities. The findings fit well with those of Coyle (1999) who, in a grounded theory study, explored the meaning of dissatisfaction with health care, and found that the concept of "personal identity threat" was the basis of people's dissatisfaction with health care. The findings also support those of Pierce (1999), namely that there are harmful effects of not being met as a person, of not having one's personal concerns recognized at the end of life.

Rogers et al. (2000) reported an excellent content analysis, which, although it showed the limitations of this method, provided comprehensible results. Their publication shed some light on the discrepancy between the common reports of high satisfaction levels with hospital end-of-life care and the ongoing complaints about such care by showing that the concept of satisfaction is too vague to include the whole range of family members' experiences.

Abt (2001) explored bereaved family members' experiences of care in one private hospital in Switzerland. The survey included three subscales of the modified City of Hope Questionnaire (spirituality, care environment, and communication) and open questions regarding hospital rooms and services. Participants could also make suggestions for improvement. The questionnaire was mailed to the closest family member of oncology patients who had died in the hospital. With a response rate of 55.5%, 76 family members participated in the study. Their age ranged from 31 to 95 years (M = 63.3), 48 were women, and 57.9% were spouses. The group of responders did not significantly differ from the group of non-responders. Descriptive and explorative statistics were used for data analysis.

On a scale from 1 to 11, spirituality was rated on average at 6.71 and had minimal influence on family members' satisfaction with care. Care environment reached 8.23 points; respecting privacy, respecting wishes regarding care, the possibility of being present around the clock, the knowledge of nurses, symptom management, and nursing care in general were positive aspects for the family members. Care for the family members was lacking. Communication was rated at 7.65; as strengths appeared the presence of nurses and physicians when needed, the nurses' empathy, consideration, and caring, and physicians' adequate communication. Family members missed the opportunity to talk to physicians or nurses during the dying process and to physicians after the patient's death. Most family members experienced the patient's death as dignified. Hospital services were not well known and rarely used. Suggestions for improvement included actively approaching families, and integrating patient and family member as partners.

Although the questionnaire was carefully translated, several questions seemed difficult to answer; therefore, data were missing, which affected the statistical analyses. The answers to the open-ended questions revealed a great willingness of family members to share experiences. The author rightly concluded that a qualitative approach might have been as valuable. The study resulted in a profile of strengths and weaknesses; however, it has to be considered that the questionnaire did not cover all aspects of end-of-life care. The findings showed potential for improvements within this hospital, they cannot be transferred to other settings.

Ogasawara, Kume, and Andou (2003) examined how bereaved families of patients with cancer perceived the care and how satisfied they were. The authors also identified barriers to the best care in a Japanese university hospital. Prior to their death, patients had been hospitalized on average for 95.7 days. The researchers mailed a self-developed survey questionnaire to a convenient sample of family members. The response rate was 55%, with 73 participants. Participants age ranged from 28 to 85 years (*M* = 56.1), 57% were women, and 69% were spouses.

Among the participating family members, 74% were satisfied with the medical treatment, 90% were satisfied with nursing care, and 80% were satisfied with information at admission, while this number dropped to 63% at the end of the patients' life. Family members experienced pain, breathing problems and loss of appetite as the most difficult symptoms to deal with. The study revealed misconceptions of family members regarding the use of opioids. Finally, family members expected patient-centered, rather than cancer-centered care from nurses and physicians.

The authors alluded to limitations of the study, such as the low response rate, the self-constructed questionnaire, and the inclusion of only one hospital, and to cultural aspects that have to be considered: In Japan, telling the truth to terminally ill patients is not common, and decisions are mostly left to the family, not to the patient. Furthermore, the group of respondents was not compared to non-respondents. Again, the results of this study were valuable for the particular hospital; they cannot be generalized to other settings.

Projects With Different Aims, Families' Experiences Being One Component

As part of a larger study of living with cancer from the widows' perspective, Vachon et al. (1977) interviewed 73 Canadian widows of cancer patients 1 to 2 months after the death. The participants' age ranged from 22 to 69 years (*M* = 53). Among other results, these authors highlighted negative family experiences with hospital care. These widows reported that patients were neglected and received poor care, admission to the hospital was sometimes denied, and staff became less available as the time of death approached. It is difficult to evaluate how credible these results are since the data collection procedure was not described completely. In addition, the method of data analysis was not mentioned and results were not supported by quotes.

Wilkes' (1984) purpose was to achieve, in a single project, a broad picture of end-of-life care both in the hospital and at home in Great Britain. He investigated a random sample of 262 deaths, two thirds of which had occurred in hospitals, by performing interviews with family members 1 to 2 months after bereavement. When relating their hospital experiences, the family members criticized the difficulty they had getting adequate information from physicians, poor symptom control and overtreatments for their relatives, and the uncaring attitude of the hospital. Special gratitude for physicians was expressed by 29% and for nurses by 34% of family members.

Hockley et al. (1988), in the descriptive study already discussed in the section on patients' experiences, also performed semi-structured interviews with 20 family members. The researchers asked them to fill in a mood check list with adjectives describing fatigue, anxiety, depression, and anger on a 4-point rating scale. The family members related that they experienced problems in getting adequate information. However, they expressed understanding that pressure experienced by staff prevented communication. Family members who received unclear information about the patients' prognosis were more depressed and anxious.

Herd (1990) compared end-of-life care in rural areas with that in urban areas of one district of Great Britain. The views of family members, physicians and nurses were compared. The researcher investigated 157 consecutive deaths, 74 of which had occurred in hospitals. The results concerning families' perspectives on hospital end-of-life care were based on 41 interviews. Participants were encouraged to talk freely about their experiences. Many family members had not recognized that the patient was dying (41%). Respondents expressed generally high satisfaction with care, with 86% rating nursing care as good or excellent and 76% rating medical care as good or excellent. Between 7% and 14% experienced problems with nurses, physicians, transport, or lack of support. Acute units were seen as busy and noisy.

The last three studies discussed (Herd, 1990; Hockley et al., 1988; Wilkes, 1984) share some limitations. Descriptions of interview procedures and contents were lacking or insufficient. It remains unclear how comprehensive the interviews were or to what extent issues were elicited by researchers versus being raised spontaneously by participants and, therefore, how relevant the studied experiences were for family members. The data analysis methods were not mentioned. The reported results imply content analyses and frequencies. However, it is impossible to evaluate how rigorous the analyses were and, therefore, how credible the results are.

Hess et al. (1997) identified the view of family members, physicians, and nurses regarding end-of-life care, as well as medical and nursing interventions applied before death. They derived areas of care improvement for the Swiss acute medical clinic where this survey was conducted. Fifty consecutive deaths were investigated. Questionnaires with open-ended questions concerning the provision of information, medical and nursing care, and the family's options in caring for the patient were mailed to family members after the death. The response rate was 82%. The answers were subjected to content analysis, and frequencies were evaluated where appropriate. The analysis was performed by two authors and then reviewed by all of the authors.

The majority of the family members were informed of the impending death. Half of the family members were satisfied with the presence of physicians, the information physicians had provided, and the care physicians had given to the patient and family. A minority of family members was critical of these aspects and 15 answers were missing. Three fourths of the family members were satisfied with nursing care, and all considered the nursing interventions to be appropriate. Twenty-nine family members were satisfied with their opportunities to be with the patient. The options of calling the nurses or visiting the patient around the clock were especially appreciated. Some family members could not care for the patient as they wished, mainly because the death was unexpected or occurred earlier than expected, or because no single room was available.

The research and analysis process were adequately described. However, the results were heavily summarized and not backed up with quotes, which reinforced the limitations inherent in the content analysis. It is therefore difficult to achieve a deeper understanding of families' perspectives from this survey. However, two aspects seem relevant: Unrestricted access improved family members' abilities to care for the patient as they wished, whereas the unexpected nature of a death hampered their possibilities.

As part of a larger study, Berns and Colvin (1998) interviewed 416 bereaved family members within 1 month of the patients' death. Death had occurred in different settings, including hospitals, in the US. The researchers heard many unsolicited stories and

recognized the need of the families to tell their stories. The researchers included an open-ended question in the interview. The participants were asked if they would like to share anything that happened during the 24 hours prior to the death. Approximately 50% of the interviewees responded to the question. A constant comparative method was used for the data analysis.

Berns and Colvin (1998) summarized their results in the following six propositions:

> 1) Being present or absent at the death of their loved one was a significant memory for survivors. 2) Survivors need and expect honest and open communication from a consistent health care provider during the dying process. 3) Families want information about the dying process and want to know what to expect during this time. 4) Keeping promises and wishes made to the dying person helps families cope with the death. 5) Giving a patient the permission to die is a powerful directive that families feel should be in their control. 6) Families will remember details of the events surrounding the death and will describe their loved ones' death as either peaceful and comfortable or as painful and struggling. (pp. 584-585)

These researchers' recognition of participants' needs and their openness to provide bereaved family members with an opportunity to share experiences while gaining valuable data at the same time is remarkable. The analysis process was well described and the propositions seem grounded in the data. The interview question focused on the last 24 hours of patients' lives and prompted participants to recount the most relevant issues, thereby limiting somewhat the range of care experiences, but still allowing valuable insights about events immediately preceding death.

Jacobs, Bonuck, Burton, and Mulvihill (2002) assessed end-of-life care in an urban teaching hospital in the US with the goal of developing a plan to improve care. Among other measures, they interviewed 31 bereaved family members, mostly adult children, within 3 to 6 months after the patient's death. A structured telephone interview was used for data collection.

A majority of family members agreed that the staff tried to keep the patient physically comfortable (83%) and pain free (73%). Only 53% felt that the patient's and the family's emotional needs were addressed. While 50% did not expect the patient's death until the final week, 60% were involved in decisions regarding end-of-life care. Pain relief was preferred (50%) over extending life (20%). Many family members did not feel able to make judgments regarding the adequacy of medical procedures, whereas 27% reported excessive testing and efforts to keep the patient alive. Family members frequently experienced communication with providers, especially with physicians, as insufficient.

This project provided a picture of families' experiences in a particular hospital, although the structured questionnaire limited the aspects about which family members could relate their perceptions. Clearly, the goal was an evaluation of end-of-life care in this hospital and the interviews with family members were a small part, yet the latter's perceptions reinforce issues that have been pointed out in other studies, for instance, general satisfaction with care and problems with communication.

Teno, Casey, Welch, and Edgman-Levitan (2001) aimed at developing a conceptual model of good end-of-life care as a basis for an instrument to evaluate end-of-life care as perceived by bereaved family members. They reviewed professional guidelines and collected data from six focus groups of bereaved family members. Patients had been cared for in different settings, including hospitals, and had died 3 to 12 months before family members were contacted. Forty-two family members participated, their mean age was 61 years, 70% were women, 17% were African American and 13% multiracial. The focus groups were conducted in different regions of the US. A grounded theory approach was used for data analysis.

According to these family members, quality end-of-life care would provide patients with the desired physical comfort, help them take control of decisions regarding medical treatment and daily routines, relieve families of the burden of feeling that they must be constantly present to advocate for the best care of the patient, educate families so that they would feel confident to care for the patient at home, and provide emotional support to families before and after the patient's death. Family members also wanted patients to be treated with dignity and respect.

The goal of this project was the development of a survey questionnaire, and it is not discernable to what extent families' experiences relate to hospital care. In contrast to other studies, however, family members from different areas and ethnic minorities were included. The results allude to relevant aspects of end-of-life care mentioned elsewhere as well, and point to the burden of family advocacy, an issue not stated so clearly in other studies.

Studies Focusing on Specific Aspects of Families' Experiences

In order to study the involvement of relatives and their sense of coherence, Andershed and Ternestedt (1998; 1999) followed 6 spouses, 5 women and 1 man, of patients with incurable cancer for 2 weeks to 9 months prospectively and for 1 to 3 months after the patients' death. The spouses' age ranged from 46 to 84 years. At the time of inclusion in the study, all patients were hospitalized on a surgical unit. Fifteen in-depth interviews and 23 informal conversations with spouses, observations of care on the surgical unit and on a hospice unit, and home visits provided the data, which were all collected by one of the authors. These Swedish researchers used inductive and deductive methods for data analysis (Andershed & Ternestedt, 1998). They derived interpretations from the data by moving between the parts and the whole (the hermeneutic circle) and by comparing the data with Antonovsky's concept of coherence.

Andershed and Ternestedt (1998) described relatives' involvement in care as either involvement in the light or involvement in the dark. Involvement in the light was a trusting relationship in which relatives were well informed, meaningfully involved, and incorporated as natural members of the care team. Involvement in the dark included insufficient interplay and collaboration whereby relatives lacked information and were not seen or acknowledged by the staff. In the course of their illness, all of the patients had been hospitalized on a surgical unit. The relatives' involvement in this acute care setting was characterized as involvement in the dark. The authors suggested that a sense of coherence, a rapid or appropriate course of illness, and the presence or absence of humanistic care influenced relatives' experience of involvement.

Using a grounded theory approach, these authors later published a secondary analysis of the data (Andershed & Ternestedt, 1999). Their new aim was to develop a theoretical understanding of the relatives' involvement. The result described the relatives' involvement in three main categories: 1) to know, that is, to understand the patient's situation by gathering information from the patient, staff and others; 2) to be, that is, to be present and immersed in the patient's world; and 3) to do, that is, to act on the patient's behalf, to be the patient's spokesperson in contacts with medical services, and to maintain contact with family and friends.

Andershed and Ternestedt (1998; 1999) provided a detailed description of the data collection and both analyses processes. Although the number of participants was small, repeated interviews before and after the deaths, as well as additional observations provided a rich data set. The interpretations seem well grounded in data and the theoretical underpinnings were outlined. The authors could have improved the reader's understanding through a description of the particular study context and their own backgrounds. The memorable metaphors of "involvement in the dark" and "involvement in the light" summarized the different care cultures experienced by family members extremely well.

Krant and Johnston (1977) aimed at identifying family members' perceptions of medical and family communication. These researchers interviewed 126 family members who were related to 75 patients. The majority of participants were white, their mean age was 43.8 years, and 78 were female. The participants were the spouses, children, siblings, or mothers of the patients. A semi-structured instrument with 78 variables guided interviews. Physicians of medical oncology units of an American hospital referred patients with a prognosis of less than 6 months. The terminally ill relatives of 65 family members were hospitalized. The interview encompassed several topics of which only family members' perceptions of medical communication are of interest in this review. Content, frequencies and correlations of answers were reported.

Forty percent of family members could not identify the physician currently in charge of the patient. Many close family members did not feel that they had a communicative link to the medical staff. Family members who did not establish communication with a physician at the time of diagnosis had problems doing so with subsequent physicians. Accordingly, physicians were not perceived as helpful by two thirds of family members.

These findings may be partly a result of the fact that physicians tend to communicate mainly with only the closest family member of each patient. The interview procedure and data analysis are not easily understood from this report, which prevents a thorough evaluation. The findings highlighted the importance of continuing communication among family members and physicians.

Comparison Studies Providing Details on Families' Experiences

Several studies mainly focused on comparing different care settings but, in addition, provided some details on family members' experiences of hospital end-of-life care. The major findings of most of these studies are discussed later. Here, family members' specific experiences with hospital care are summarized.

A group of 65 family members of terminally ill cancer patients commented on the health care services they received (Higginson, Wade, & McCarthy, 1990). Participants' age ranged from 22 to 82 years (*M* = 60). In terms of hospital care, several participants specifically complained about communication problems (e.g., physicians were perceived as having difficulty talking about dying or surgeons were perceived as seeing terminally ill patients as failures). Some family members experienced coordination problems (e.g., staff was ill informed). The third issue was overworked staff. Physicians and nurses were seen as too busy and lacking the time to care.

A sample of 461 bereaved family members were asked to comment on positive and negative aspects of end-of-life care (Hanson, Danis, & Garrett, 1997). One participant highly valued the hospital staff's balance between caring for patients and being medically excellent. Others complained about treatment delays (e.g., a long waiting time in the emergency room before the patient was admitted to die) and inadequate pain control (e.g., insufficient evaluation of pain management by nurses). Physicians who were open, communicative, and collaborative were praised, whereas other physicians' insensitive communication styles, poor judgment about diagnoses and treatments, and reluctance to use pain medication were experienced negatively by family members.

Another group of bereaved family members pointed out the need for a special room that would allow privacy for conversations and for the family to meet after the patient's death (Seale & Kelly, 1997). They also mentioned that roommates who behaved inappropriately or were noisy at night troubled patients.

Cartwright (1991a) surveyed general practitioners, hospital consultants, community nurses, and family members in a random sample of 639 deceased patients in order to compare hospital and home care services. Some family members thought that the patient had been admitted to the hospital too late (23%) or discharged from the hospital too soon or inappropriately (11%). Several felt that the patient had needed more treatments (e.g., a patient's diabetes mellitus was not followed up properly) or that the patient was overtreated (e.g., blood transfusions made one patient feel a bit better but prolonged her agony). Family members' opinions about the adequacy of treatments might have derived from patients' views or might be debatable, but their comments show that these families were either not well informed about the patients' treatments or did not understand or accept explanations given to them.

Fragments of Families' Experiences

The publications on families' experiences with hospital end-of-life care are somewhat more comprehensive than those on patients' experiences in several respects. Although some samples were comprised of cancer patients only, many included patients who were dying or had died from other diseases. Researchers used a variety of methods for data collection and analysis. Interviews that used different approaches, from open-ended to structured questions to measurement scales, provided most of the data. For most studies, data were collected at one point in time, either during the patient's terminal illness or at different times in the bereavement period. Only two projects included repeated pre-and post-bereavement interviews. The preferred analysis method for qualitative data was content analysis. However, a few researchers used a grounded theory or interpretive approach. Most studies were carried out in the US or Great Britain, though a few were in other countries.

Although the body of literature on families' experiences is more extensive than that on patients' experiences, it provides only fragments of families' experiences of hospital end-of-life care, not a comprehensive picture. While some studies specifically examined families' experiences of hospital care, most focused primarily on other aspects of end-of-life care. Overall, many family members expresses general satisfaction with hospital care, whereas at a closer look, problematic aspects surfaced.

Family members highly praised caring health care providers who showed concern and compassion, were sensitive and open, took the time to listen, treated terminally ill patients and their family members with respect and as individual human beings, and recognized their unique situations. Uncaring staff members, perceived as unfriendly,

rough, or insensitive, had a negative influence on families' experiences. Families' expressions of sadness, regrets, and anxiety call to mind that these states, in relation to the (imminent) loss of a member, are human feelings to be lived through rather than symptoms to be managed.

Communication among terminally ill patients, their families and health care providers appeared as an aspect that greatly influenced families' care experiences. Family members valued ongoing and open communication with staff if it provided them with honest and appropriate information, was timed to their needs, respected their standpoints, and allowed them to ask questions and make contributions. Often, however, they experienced the contrary or, at the very least, problems with communication that overshadowed the whole experience of care. These problems may also explain complaints about, for instance, overtreatments or undertreatments and untimely admissions to or discharges from the hospital.

Family members expected health care providers to attend without delays to the terminally ill patients' symptoms and to provide as much comfort as possible. Family members were distressed by a lack of symptom control. Furthermore, individual care was valued. These families considered the patients' basic needs (e.g., nutrition and body care) as relevant and were concerned when they perceived a lack of attention to individual needs. The patient's dignity was compromised when these aspects were disregarded. The maintenance of patients' personal hygiene also facilitated family members' being present at the bedside. Family members saw themselves as patient advocates and felt burdened when they perceived the care as insufficient.

Families appreciated the availability of health care providers, but frequently excused a provider's unavailability as being a result of heavy workloads, staff shortages, and a lack of resources. The hospital environment influenced families' experiences. Privacy and access to the terminally ill patients around the clock were welcomed. But sometimes patients and families experienced a lack of privacy, unexpected moves from one room to another, or problems with roommates. Some units were perceived as unaesthetic, noisy, and not well maintained. The hospital bureaucracy occasionally overrode care needs of patients and families. Finally, the circumstances of a patient's death (e.g., an unexpected versus an expected death or a quick versus a slow illness trajectory) influenced family members' experiences.

Several studies did not provide any sample characteristics, while others provided limited information on these factors. The family member samples included both women and men of a wide age range, but few included ethnic minorities. If and how family characteristics related to and influenced family members' care experiences were not explored. An array of questions in this area has yet to be answered. For instance, how do the patients' diseases (e.g., diagnoses or types of cancer) and how do their illness experiences relate to family members' experiences? How do care experiences vary according to the family members' relationship to the patients (e.g., as a spouse or daughter)? How are the age and gender of both the patient and family member associated with the family member's care experiences, and how does the family member's own health status make a difference? How do the families' ethnic, economic, and educational backgrounds influence the care experiences?

Studies Investigating Family Needs

Five studies, four of which were carried out in the US (Freihofer & Felton, 1976; Hampe, 1975; Irwin & Meier, 1973; O'Brien Abt, 1983) and one of which was in Canada (Wright & Dyck, 1984), investigated the needs of families of terminally ill hospitalized patients.

The Needs Studies

Hampe (1975) investigated whether spouses of terminally ill patients hospitalized in a university medical center recognized their own needs, and if health professionals met the spouses' needs. She derived eight needs from the literature. A cancer nurse specialist confirmed the validity of the needs, which then provided the basis for open-ended interview questions. Using a convenience sample, 27 spouses were interviewed prior to the death of the patients. Eighteen patients died before the completion of the study. Fourteen of their spouses were reinterviewed 3 to 12 weeks after the patients' death. The investigator analyzed the interviews, rating needs as perceived or not perceived and as met or not met. A second researcher rated 25% of the data independently. Rater agreement was 90%. Quantitative as well as qualitative results were reported.

All eight needs were experienced and reported by 93% of the participants. For the majority of the spouses, their needs to be with (63%) and to be helpful to (74%) the patient were met. The need to be assured of the patient's physical comfort was not met for 67% of the spouses; and the need to be assured of the patient's emotional comfort was not met for 52% of the spouses. Uncontrolled pain and emotions and lack of cleanliness were of concern. All spouses expected information from physicians about their mates' condition, but only 48% had this need met. Nurses were expected to relate daily progress.

The need to be informed of the impending death was met for 75% of the spouses. In most cases (81%) this information was given in public areas of the hospital. Thirty-two percent of the spouses could ventilate their emotions. Forty-one percent of the spouses received the desired comfort and support from other family members, and 15% received the needed acceptance, support and comfort from health care professionals. For most spouses, the primary responsibility of health care professionals was the patient's care. Health care professionals were seen as too busy to be concerned with the spouses' difficulties, but the spouses expected health care professionals to behave at least decently towards them. There was an 87% agreement between pre- and post-death interviews.

The procedures of data collection and analysis were not clearly outlined for this study. It would have been helpful to be provided with the interview questions. In addition, an explanation of the method in which qualitative findings were derived would have been informative. Nevertheless, the results confirmed the spouses' perceptions of the eight needs and also identified the needs that were not met consistently.

Hampe's (1975) study was successfully used by an intensive care unit (ICU) nursing team (Dracup & Breu, 1978). First, spouses of critically ill patients were interviewed using Hampe's questions. Next, based on the unsatisfying interview results, on Hampe's eight needs, and on continuing education, the staff devised a standard care plan to improve the support for spouses. Finally, after the implementation of the plan, a second group of spouses were interviewed and results were compared with the first group. The findings revealed that significantly more needs were met in the second group.

The primary purpose of Irwin and Meier's (1973) study was to operationalize "support" for family members of terminally ill patients. As a first step, the authors

gathered approximately 600 descriptive statements from survey interviews with health care providers and bereaved family members. These statements were then reduced to 60 items. With these 60 items, a Q-sort-technique was developed. Each of the nine predetermined piles was assigned a score from 0 (least supportive) to 8 (most supportive). A convenience sample of 20 family members of terminally ill patients who were hospitalized on the oncology-hematology unit of a general hospital and 20 health care providers sorted each item according to its importance in providing support. The mean score for each item was then calculated. Items concerning honest information provided to the family members and patients' comfort were ranked most important.

The strongest element of this project (Irwin & Meier, 1973) was the collection of statements describing supportive behaviors from health care providers and affected family members. However, minimal information regarding the content of these statements is available in the paper. Data analysis and reported results are not easily understood. Shannon (1973) rightly criticized the pervasive inconsistencies in this publication. For instance, the literature review did not lead up to the study and the purpose of the study (i.e., operationalize "support" for relatives of terminally ill patients) and the method used (i.e., a Q-sort that rates supposedly supportive behaviors into most and least supportive) were incongruent.

Freihofer and Felton (1976) searched for the most helpful nursing behaviors to use with family members of hospitalized and terminally ill adult cancer patients. A Q-sort-technique was used with statements derived from the literature and from expert nurses. The items covered three areas: behaviors promoting the patient's comfort and hygiene, behaviors indicating that the patient's emotional needs are understood, and behaviors indicating that the impact of grief, grieving, and loss on the family member is understood. Twenty-five family members of terminally ill patients hospitalized in a military medical center sorted the 88 items according to perceived helpfulness into nine piles with assigned scores from 1 to 9. Mean scores for each statement were calculated and ranked according to desirability for the total group, for males and females, and for Protestants and Catholics. No explanation was given for the inclusion of the latter groups.

Results were similar for all groups. The total group ranked "keep the patient well groomed," "allow the patient to do as much for himself/herself as possible," "give the pain medication as often as possible," and "keep the patient physically comfortable" as extremely helpful. "Encourage me to cry," "hold my hand," "cry with me," and "remind me that the patient's suffering will be over soon" were rated as least helpful. All of the most desirable nursing behaviors were directed toward support and comfort of the terminally ill patient, whereas nurses' support for family members to ventilate emotions was perceived as least desirable.

O'Brien Abt (1983) investigated families of terminally ill hospitalized patients by having family members identify the importance of 45 needs, if their needs were met, and by whom. The structured interview schedule of Molter (1979) was slightly adapted and used in the study. (Molter had developed her need statements for family members of critically ill ICU patients from the literature and from a survey of graduate students.) A convenience sample of 20 family members was interviewed during the patients' hospitalizations in two general hospitals. The 10 needs identified as most important by O'Brien Abt (1983) were related to being informed honestly and thoroughly, and to knowing that the patient is given the best care possible and is kept comfortable. Thirty of the 45 needs were met more than 50% of the time. Most frequently, both physicians and nurses met these needs. An open-ended question at the end of the interview did not reveal any new needs.

Wright and Dyck (1984) investigated the needs of cancer patients' family members across the diagnostic, recurrent, and terminal stage of the disease. The authors also studied family members' perceptions of nurses and nursing care (Dyck & Wright, 1985). They conducted an exploratory descriptive study using a semi-structured interview developed by the researchers based on clinical experience, a review of the literature, and consultation with colleagues. In addition, a 12-item Likert scale questionnaire adapted from the eight needs identified by Hampe's (1975) study was administered. A convenience sample was drawn from two units of a referral hospital. Included were 45 family members of cancer patients who were either in the diagnostic (n = 15), recurrent (n = 15), or the terminal (n = 15) stage. The analysis of interview data was not described. It can be assumed from the reported results that a content analysis was performed. Mean scores were calculated for the Likert scale items. Results were reported for the whole group as well as for the three subgroups.

Insufficient symptom control (53%) and difficulty obtaining information were the most frequently mentioned concerns of family members of terminally ill patients. The need scale responses reinforced these findings. The need to be assured of the patient's comfort was rated the highest, followed by the need to be kept informed of the patient's condition and of any changes, and the need to be with and to communicate with the patient (Wright & Dyck, 1984). At the terminal stage, 60% of the family members indicated that nurses did not do anything for them, nor did they expect nurses to do anything for them since nurses were seen as being too busy. Family members felt that they were helped if nurses were friendly and made them feel welcomed at the hospital. Family members also felt that they were helped if the nurses included them in providing care to the patient. One third of the family members expected nurses to explain the patient's current status and procedures, whereas another third of them believed that providing information was beyond the scope of the nurse's role. When asked for suggestions to improve care, 40% of the family members said that more adequate care, including more personalized care, should be provided. Compassion and competence were most frequently mentioned as valued traits in nurses (Dyck & Wright, 1985).

Patients' Comfort Is the Priority

This group of studies focused on identifying needs of families of terminally ill hospitalized patients. The needs were derived from the literature, expert nurses, and from surveys of health care professionals. Only one survey included families (Irwin & Meier, 1973). These needs may, to a certain extent, represent theoretical perspectives (e.g., grief and crisis theories) and opinions of professionals rather than the views of the persons affected. For each study, a new instrument was developed or an existing one was adapted. Only content validity, namely face validity through expert consultations, was addressed. No reliability data were provided with the exception of Freihofer and Felton's (1976) report of rater agreement.

The use of questionnaires constrained family members to the needs listed. Only two studies allowed them to include additional issues (O'Brien Abt, 1983; Wright & Dyck, 1984). Perhaps it was difficult for participants to recall additional needs after having answered 45 questions (O'Brien Abt, 1983). The second study provided additional insight into what families expect from nurses (Dyck & Wright, 1985; Wright & Dyck, 1984). Furthermore, the evaluation of needs, because of the limited information on the context in which those arose and on their concrete content, does not yet allow for an understanding of the meaning these needs may have for particular families.

The Q-sort-technique used in two studies (Freihofer & Felton, 1976; Irwin & Meier, 1973) is a system of weighing items to indicate degrees of importance of behaviors. The results may be somewhat artificial because participants are forced to put a certain number of items in each pile. The number of piles and the number of items per pile are chosen by the researchers so as to build a bell shaped curve with few items in the piles at each end and most items in the middle. Participants can neither assign equal importance to all items they might consider equally relevant, nor can they eliminate items that they might consider adversarial rather than just least desirable.

Most studies used a cross-sectional design and collected data prior to the patients' deaths. This method has the advantage of gathering more immediate experiences of families than the data collection in the bereavement period. However, the distress experienced by families during this time of terminal hospitalization of a loved one and the one-time interview may be limiting.

All studies used a convenience sample. The sample sizes were small (from 20 to 45 participants). Only Freihofer and Felton (1976) reported ethnic background; it is speculated that most participants were Caucasian. Comparisons across studies are difficult. Although the studies built upon each other to a certain extent, they each used a different type of need questionnaire.

Despite the studies' numerous limitations, results were similar across studies. Some general conclusions can, therefore, be drawn: 1) Families were most concerned about the terminally ill patients' comfort. 2) Families wanted to be present at the bedside. 3) Families needed honest, thorough, and ongoing information. 4) Families perceived support from nurses for family members as less important and perceived nurses as too busy to provide it.

Outcome Surveys

In this section, several studies are summarized that focused mainly on outcomes of end-of-life care and provided mostly indirect clues on families' experiences. These surveys investigated large random or convenience samples of bereaved family members. Most decedents had been elderly; they had died from various diseases, including many from cancer. They had received care in different settings, including hospitals. Data collection occurred via mail or personal or telephone interviews. Most researchers used structured questionnaires or measurement tools.

Satisfaction Surveys

Several studies reported family members' satisfaction with end-of-life care. Addington-Hall, MacDonald, Anderson, and Freeling (1991) investigated family members' views of terminally ill cancer patients' experiences with end-of-life care. Half of the family members were satisfied with the hospital care. Dissatisfied family members' concerns were related to insufficient information, inadequate staffing, lack of coordination among staff members, and inadequate pain control.

Sykes, Pearson, and Chell (1992) evaluated satisfaction with end-of-life care services for cancer patients. Overall, 53% of spontaneous comments of family members were positive. The highest proportion of adverse comments concerned information. Sixty-two percent of family members felt there had been a delay between the patient's recognition of a problem and the receipt of treatment. In 13% of the cases this delay was attributed to the hospital. All of the 9 patients who had been admitted to the district general hospital as well as to the smaller district hospital during the course of their illnesses preferred the smaller hospital. Only 40% of the family members were present at the hospital when death occurred due to various reasons (e.g., some had been asked to leave by staff), whereas 91% of the family members were present when it occurred in the home.

Addington-Hall, Lay, Altmann, and McCarthy (1995), as part of a larger study, questioned family members of patients who had died from stroke about families' satisfaction with care during the last year of the patient's life. Concerning hospitals, 29% rated physicians' and 46% nurses' care as excellent, 37% thought physicians had been too rushed, and 25% felt that the patient had not had enough choice in treatment options. Sizeable minorities complained about the lack of privacy, or the lack of a peaceful and quiet room, or felt treated with indifference or even hostility when visiting the deceased. In reference to all services, 39% of family members experienced a lack of information.

McCarthy, Lay, and Addington-Hall (1996) reported family members' satisfaction with hospital care in another subsample of the larger study mentioned above. The sample was composed of patients who had died from heart disease. The participants rated 81% of physicians and 84% of nurses as excellent or good. Thirteen percent of family members mentioned that physicians had not had enough time for the patient, and 29% thought that the patient had not had enough choice in treatment options.

Baker et al. (2000) assessed family members' satisfaction with the dying experience from a subsample of the SUPPORT (The SUPPORT Principal Investigators, 1995). Eighty-four percent of the family members expressed no dissatisfaction with patient comfort, and 69.5 % expressed no dissatisfaction with communication or decision-making. Satisfaction with comfort was significantly lower for family members who experienced a negative financial impact of the patient's illness on family finances, among male family members, and when the patient's preference for care was followed to a lesser extent. Finally, patients had been hospitalized in different institutions, and family members' satisfaction varied among those.

Tolle, Tilden, Rosenfeld, and Hickman (2000) examined the final month of life of Oregon decedents from the families' perspective. Decedents' preferences concerning the amount of life-sustaining treatments were respected to a great extent. Overall, satisfaction with support from clinicians was fairly high. Family members were dissatisfied with the availability of physicians (20%), the availability of nurses (8%), the information and instruction given by clinicians (12%), and the received emotional support (10%).

Symptom Surveys

Inadequate symptom control was a recurrent finding in the surveys. In Addington-Hall et al.'s (1991) study, more than 50% of patients had experienced symptoms, including loss of appetite, breathlessness, constipation, pain, insomnia, and depression, during the last week of their lives, according to family members' recall. Only pain, constipation, and itchy skin were effectively controlled for the majority of patients.

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Continuous symptom control problems in patients (e.g., pain, anorexia, nausea or vomiting) were remembered by 66% of the family members participating in Sykes et al.'s (1992) research. At least half of the patients in Addington-Hall et al.'s (1995) sample had experienced pain, urinary incontinence, low mood, and mental confusion; and one third had suffered breathlessness, insomnia, loss of appetite, constipation, and loss of bowel control. In the group of hospitalized patients, physicians' treatments achieved relief of pain, breathlessness, nausea and vomiting, and constipation for 50%, 67%, 60%, and 84% of patients respectively. A majority of family members thought that physicians had tried hard enough to relieve the symptoms. In patients dying from heart disease, the most common symptoms were pain, dyspnea, and mental disturbances (M. McCarthy et al., 1996). Pain was not under control for 34% nor was dyspnea for 24% of hospital patients.

Using a subsample of family members participating in the SUPPORT or Hospitalized Elderly Longitudinal Project (HELP), Lynn et al. (1997) reported symptoms experienced by patients during the last 3 days of their lives. According to family members, 45% of the patients were unconscious. Eighty percent of conscious patients suffered from fatigue, over half from dyspnea, almost 40% from pain, and almost 25% from confusion. One fourth of the patients were anxious and depressed, and 17% felt alone and isolated. A majority of the patients found it difficult to tolerate their symptoms.

Miettinen, Tilvis, Karppi, and Arve (1998) investigated family members' opinions on pain relief. Moderate to severe pain prior to death was prevalent in 57% of patients, and pain was more common in patients who died in hospitals than at home. Pain relief was unsuccessful for 22% of patients. Pain relief was related to aspects of good care, for instance, treatment of other symptoms, care of daily needs, atmosphere of the environment, and communication.

Bucher, Trostle, and Moore (1999) described cancer pain and its relief during the last 4 weeks of patients' lives. Family members recalled pain in 86% of patients. Of these, 70% had a great deal to quite a bit of pain, and 30% had some or a little pain. Interventions usually stopped the pain in 9% of the cases, made it much better for 37%, made it a little better for 39%, achieved no relief in 14%, and made pain worse in 1% of patients.

Tolle et al. (2000) reported moderate to severe pain during the last week of life in 34% of patients, and pain was more prevalent in hospitals. This difference between settings was the result of an increase in pain reports for hospitalized patients that occurred during the last 3 months of data collection (33% to 57%). A follow-up study after one year revealed a comparable result, with 54% of hospital patients experiencing moderate to severe pain in the last week of life (Tolle, Tilden, Hickman, & Rosenfeld, 2000). In spite of these high numbers, over 85% of family members rated clinicians' attention to comfort needs as excellent or good in both studies.

High Satisfaction, Unrelieved Symptoms

Each of the satisfaction surveys had a somewhat different focus. A common finding was that a majority of the families were generally satisfied with the care their patients had received. In addition, some family members perceived the information that they had received as insufficient. Unavailability of health care providers, mainly physicians, was problematized. Finally, the studies showed that the quality of care was perceived differently at different sites. This fact raises questions regarding the nature of differences among institutions. Which aspects of a setting influence families' care experiences and in which respects? And, in taking the question one step further, how are families' experiences similar or different in various health care systems, countries, and cultures?

Patients suffering from terminal illnesses are certainly expected to experience a variety of symptoms. Palliative care practitioners, however, have demonstrated that with effective management, adequate symptom control can be achieved for most patients. The symptom surveys showed, in fact, that family members remembered patients as exhibiting many symptoms. These symptoms were often unsatisfactorily controlled and caused undue suffering in a great number of terminally ill patients.

In spite of the numerous problems they raised and the high prevalence of unrelieved symptoms that patients had experienced, family members still reported great overall satisfaction with care, and even with symptom management. This shows again that satisfaction measures are an insufficient means to explore care experiences. Most family members have had no or limited experiences with end-of-life care. Therefore, they usually lack comparisons and have only vague expectations. Not knowing what could be achieved, for instance, in terms of symptom control, they may easily be satisfied with insufficient care. In addition, acknowledging that the patient is receiving or received unsatisfactory care may increase feelings of grief and guilt. In order to come to terms with their losses, families may like to think of the terminally ill or deceased member as having been well cared for. Seale (1998) suggested that bereaved interviewees, through telling their stories, might protect their moral reputation (e.g., by giving explanations why they were not present when death occurred), as well as try to repair distress and disruptions caused by the death.

Studies Comparing Hospital Care to Hospice Care

Several studies compared settings, mainly hospital to hospice care. Researchers collected data from matched pairs of family members and from family members who had experiences with either one or a number of different settings. Prospective and retrospective designs were used.

The Comparison Studies

Parkes and Parkes (1984) evaluated changes over 10 years in end-of-life care at one hospice and at local hospitals by replicating an earlier study. The authors compared spouses' perceptions during 1967-69 and 1977-79, using 34 and 30 matched pairs of family members respectively. Patients' pain and distress decreased in both settings, but more so in hospitals. This result showed that the hospitals had improved their level of symptom control to hospice standards by 1979. Although spouses spent more time at hospital bedside in 1979 than 1969, spouses in the hospice were more involved in the patients' care and had more contact with health care providers before and after the death. The attribute most often given to the hospice was "like a family."

In 1994, Seale and Kelly (1997) used a similar design and partially replicated the study of Parkes and Parkes (1984) by interviewing 33 matched pairs of family members of patients who had died in the same hospice and local hospitals as the patients in the previous study. The results showed that relief of symptoms (i.e., pain, breathing problems, nausea and vomiting) had mostly been achieved with no differences between settings. Family members in the hospital group were more likely to experience staff as very busy, and less likely to describe the atmosphere as "like a family" than family members in the hospice group. However, 5 participants from the hospital group stated that either they or the patient purposefully avoided hospice services because of an unwillingness to accept the awareness of death.

Kane et al. (1985), in the randomized clinical trial already discussed in the section on patients' experiences, also interviewed family members repeatedly before and after bereavement. Family members of patients receiving regular care at the hospital experienced more anxiety and were less satisfied with care involvement than family members of hospice patients. Needs concerning involvement with the patient and interaction with professionals were less often met for family members of hospital patients than for family members of hospice patients.

In the NHS, already mentioned in the section on patients' experiences, family members provided extensive data (Greer et al., 1986). They were interviewed when they entered the study, 7 days later, and every 14 days thereafter until the patient's death, as well as in the bereavement period. A series of tools was used to measure overall quality of life, social quality of life, pain and symptoms, and satisfaction with care. The use of medical and social services was assessed as well. Only a few measures differed significantly between hospital and hospice care. Three weeks and 1 week before death, CC patients experienced more medical interventions than HC or HB patients did. Family members' satisfaction with care was generally high, yet significantly higher in the HB group than in the CC group. One week before death, HB and HC patients were significantly less likely to experience persistent pain than CC patients were. Three weeks prior to death, this was true for HB patients only (Morris et al., 1986).

Wallston, Burger, Smith, and Baugher (1988) suggested that the measures used in the NHS were not sensitive enough to reveal more significant differences between hospital and hospice care. For their secondary analysis of NHS data, they constructed a Quality of Death (QOD) score from patients' wishes concerning their last 3 days of life and from data gathered from family members during the post bereavement interviews regarding patients' actual last 3 days of life. A subsample of the NHS was investigated (*n* = 880). The QOD scores for CC patients were significantly lower than the scores for HB and HC patients, showing that hospice care optimized the quality of death for these patients.

Higginson et al. (1990) compared family members' views of the quality of palliative care received from hospitals, community services, and supportive teams specialized in palliative care. Hospital services were rated lowest. Negative comments concerned communication with staff, mostly in that they broke bad news in insensitive ways; unsatisfactory coordination of services with waiting times and ill informed providers being the most frequently reported problems; and overworked staff.

Dawson (1991) evaluated the effectiveness in meeting the emotional needs of family members of different programs offering end-of-life care by comparing three hospice programs and a conventional care hospital program. The hospital group had more unmet needs, a lower degree of satisfaction with the psycho-social support received from nurses, and a lower level of overall satisfaction with care than any of the hospice programs.

Wakefield and Ashby (1993) studied attitudes to end-of-life care of 100 family members, comparing five places of death (i.e., public hospital, private hospital, hospice, nursing home, and home). Overall satisfaction with care was rated as good or excellent by a vast majority of family members, with hospices receiving the highest ratings.

Hospice physicians were perceived as more accessible than physicians in other institutions. The level of satisfaction with care by physicians was lowest in hospitals. At all sites, most family members were very satisfied with nursing care. Over 50% of the family members felt sufficiently informed; however, hospices and nursing homes were rated higher than hospitals in this respect.

Hanson et al. (1997) studied 461 bereaved families' perceptions of the treatment their elderly relatives had received prior to dying of common chronic diseases. Participants were also asked for positive or negative comments on any aspect of end-of-life care. Of 474 comments, 64% were positive. The proportion of positive comments varied, with 91% for hospices, 69% for hospitals, and 51% for nursing homes. Most positive comments about hospital care praised the skills of compassionate and attentive nurses, whereas negative comments concerned treatment delays and inadequate pain control.

Seamark et al. (1998) compared perceptions of 161 family members of patients who had died of cancer in community hospitals or in a hospice. Although the results did not differ in several areas between the settings, the hospice group perceived professionals as easier to talk to, was more often able to spend the night with the patient and be present at death, was more involved in the patient's care, perceived the total care as better, and felt more supported after death. For both settings, positive spontaneous comments centered mainly on the caring nature of the staff and the concept of holistic care. Negative comments were more frequently given for community hospitals, and these statements concerned poor communication, inadequate nursing care, and lack of bereavement care. Nurse staffing levels were reported for both settings. The hospice had 1.1 whole-time equivalents per bed, the community hospitals had 0.4 whole-time equivalent per bed. This difference may well account for some of the problems experienced by family members with end-of-life care in community hospitals.

Teno et al. (2004) aimed at providing national estimates of the dying experience and at examining whether family members' perceptions of end-of-life care differed by the last place of care. They surveyed a probability sample of 1578 bereaved family members of patients who had died in the US during the year 2000. Overall, family members reported high rates (21% to 50%) of unmet needs regarding symptom control, concerns with physician communication, lack of emotional support for themselves, and a belief that patients were not always treated with respect. When compared with home hospice care, family members reported that patients were more often not treated with respect in hospitals, hospital staff was less likely to provide emotional support to the family, and family members' overall assessment of the quality of care was lower for hospitals.

Hospice Care Is Slightly Better

Although hospital care may have improved over time (Parkes & Parkes, 1984; Seale & Kelly, 1997), hospice care was perceived by family members as better than hospital care. The main reasons were 1) the greater presence and involvement of families; 2) better interactions with staff; and 3) more psychosocial support for families before and after death. Lack of staffing seemed to be a major obstacle for hospitals. The "like a family" attribute of hospices most likely refers to family members' feelings of being met as persons, and to having their particular concerns, needs and wishes recognized while caring for and closing down the relationship with the terminally ill patient.

However, Seale and Kelly's (1997) findings showed that hospice care was not the best solution for everybody. Hospices' emphasis on open communication seemed threatening to some patients and family members. These families, therefore, preferred hospital care. Families' expectations regarding the illness trajectory and how they and the patient should be cared for will affect their care experiences. A family who is still hoping for a cure will probably be less likely to perceive medical interventions as causing unnecessary suffering than a family who has accepted the patient's impending death. Families may perceive hospice goals as an ideology to which patients and families are expected to live up to, and may reject such care because it seems to threaten their ways of living.

Furthermore, the dissimilarities of hospital and hospice care perceived by family members were not tremendous, and two large studies, the NHS (Greer et al., 1986) and Kane et al.'s (1984, 1985) randomized clinical trial, revealed only minor differences. The findings of a secondary analysis of NHS data alluded to potential measurement problems (Wallston et al., 1988). In fact, either the selection of measured outcomes or a lack of sensitivity of the measurement tools may partly explain these results. It can also be speculated, however, that by separating means and ends and considering only the latter, the relevant differences between hospice and hospital care were missed. Stated in Aristotle's terms, a major problem of these large comparison studies might have come from their focus on techne and disregard of phronesis (Dunne, 1997). In a grounded theory study that investigated the desirable outcomes of people using palliative care services in different settings, Devery, Lennie, and Cooney (1999) concluded that patients and families did not necessarily value certain outcomes but, rather, the way of care delivery, based on a trusting relationship with providers. Accordingly, the authors argued that studies that only focus on the evaluation of quantifiable outcomes miss the unique contribution of palliative care services. The results of Teno et al. (2004), which revealed some differences between hospice and hospital care, might be attributed to the fact that these authors used an instrument that included items related to the care process.

Families' Experiences – a Reflection of Patients' Views?

Data provided by family members definitively represent their perceptions of hospital end-of-life care and their interpretations of how patients experience or, if in retrospect, experienced the care. Every terminal illness and death within a family is unique to its members and causes distress and lasting memories. Families' experiences, therefore, warrant attention and further research (Lynn et al., 1997).

But to what extent do family members' accounts reflect patients' experiences, that is, how much would patients' descriptions differ from those of their families? The question has been investigated but not yet answered conclusively, as a recent review of studies examining the agreement of patient and family member responses showed (McPherson & Addington-Hall, 2003). Most of these studies used prospective designs, only a few compared patients' responses with those of family members provided after the patients' death.

Study findings suggest that information on concrete, observable phenomena, such as use of services, tend to reach good levels of agreement between the terminally ill patients and family members. There is also more agreement regarding overt symptoms, such as vomiting, and aspects of patient's functioning, such as activities of daily living. Agreement tends to be poor for patient experiences that are more subjective, like pain or

mood. Family members had a tendency to overestimate pain, the severity of mood disturbances and distress from symptoms. Family members' prospective ratings are more in agreement with patient responses than retrospective ratings (McPherson & Addington-Hall, 2003).

Family members living closest to the patients seemed better informed; their ratings were in more agreement with patient ratings than responses of more distanced relatives. The potential influence on agreement of patient and family member demographics, the level of patients' impairment, caregiver burden, expectations and beliefs, and coping strategies were discussed by the authors of the review, but no consistent conclusions can be drawn from the body of available literature. Other aspects, for instance, the assessment period, the timing of the assessment or the measurement instrument may also affect agreement. Finally, some discrepancies between patients' and family members' responses may be related to the research projects themselves; that is, agreement may be poor, because researchers missed to compare like with like, used questionable measures of association, examined convenient and small samples, or because measurement instruments lacked reliability and validity (McPherson & Addington-Hall, 2003).

Thus, many questions regarding to what extent family members' reports reflect patients' experiences remain unanswered. However, when potential discrepancies are taken into account, family members can still provide meaningful data on care experiences during the terminal phase, when patients cannot speak for themselves anymore. But it seems valuable to gather data directly from patients whenever this is feasible.

Conclusions

In this final section, terminally ill patients' and their families' experiences of hospital end-of-life care are contrasted with the practice of palliative care outlined in chapter one. Then, the research questions, guiding this qualitative study, are stated. These questions were derived from the discussion of caring practices and from this literature review.

Caring Practices in End-of-Life Care: Research Findings Revisited

The practice of palliative care described in chapter one calls for health care providers who allow terminally ill patients and their families to matter to them, who strive to achieve excellent symptom control, and who provide adequate psychological, social, and spiritual support in order to accomplish the best quality of life possible for patients and their families. Interestingly, terminally ill patients' and their families' perceptions of what constitutes satisfactory end-of-life care seem to point to the same issues.

The aspects of end-of-life care revealed as relevant for terminally ill patients match the aspects of palliative care. Caring staff was praised or desired by patients and families in many studies. Caring, that is, showing concern and being committed, allows health care providers to recognize terminally ill patients and their families in their unique situations and to encounter them as particular persons. Caring, then, appears as a major prerequisite for good hospital end-of-life care. The fact that families did not always expect to be cared for by hospital staff and repeatedly excused the lack of attention as being a product of inadequate staffing levels does not mean that their needs do not exist. Rather, it may allude to the fact that families prioritized patients' comfort and, consequently, neglected their own needs; that families accepted as unavoidable the conditions of the health care system and the subsequent lack of resources for adequate end-of-life care; or that families had very low expectations. Improved involvement of hospice staff with families was one of the most valued qualities that differentiated hospice care from hospital care. Since the patients' comfort was paramount for families, symptom control was an important issue for them. Families perceived end-of-life care as better if their needs to be informed, to be present at the bedside, and to be involved in the patients' care were honored by staff. Palliative care practices offer the technical and interpersonal know-how that is required to appropriately care for terminally ill patients and their families.

Statement of Research Questions

This review of the literature on terminally ill patients' and their families' experiences with hospital end-of-life care has shown that little is known about patients' experiences and that the knowledge about families' experiences, even though more extensive, is incomplete. Most studies focused on specific components of care experiences and many elicited data on satisfactory or unsatisfactory aspects. Missing are comprehensive pictures of everyday hospital end-of-life care as it is experienced by terminally ill patients and their families throughout the course of a terminal illness, and of the changes in experiences that may occur over time. Each such description would necessarily be local and would depict the experiences of a particular population. However, it would broaden health care providers' understanding of terminally ill patients' and their families' experiences of hospital care during a period of time that concludes patients' lives and will remain memorable for family members.

Thus, the study described in the subsequent chapters aimed at exploring the following research questions: 1) What are adult terminally ill patients' lived experiences of being cared for by an interdisciplinary team of health care providers in a Swiss university hospital over the course of their terminal illness? 2) What are families' lived experiences of caring for a terminally ill member in a Swiss university hospital over the course of the terminal illness, given that the patient also receives professional care from an interdisciplinary team of health care providers who may also see family members as care recipients? The next chapter describes interpretive phenomenology as a suitable research method used to explore these questions.

CHAPTER THREE: A PASSAGE TO TERMINALLY ILL PATIENTS' AND THEIR FAMILIES' LIVED EXPERIENCES OF HOSPITAL END-OF-LIFE CARE: DESCRIPTION OF THE METHODOLOGY

For professional health care providers, the hospital is the everyday workplace with which they are very familiar. People who enter the hospital as patients or family members, however, leave their familiar homes and workplaces behind and are confronted with a situation where shared meanings are limited. Charon (1996) provided a vivid description of this situation:

> To outsiders, hospitals are dream sequences where alien languages and customs are used, where rules that apply everywhere else are suspended, where human interchange is replaced by a peculiar set of commands: take off your clothes, hold your breath, don't move. The boundaries that customarily exist between public and private or between acceptable and taboo break down. (p. 294)

Nevertheless, patients, families and hospital workers still have some common understanding, because they usually share a cultural background, habits, and language. In addition, patients and families, over time, discover and become more familiar with the hospital world.

However, each hospitalization also means that patients and families have to come to terms with a change in the patient's health status, and they most likely will encounter an as yet unknown language, interventions, and health care providers. Furthermore, the patients' bodies are exposed, their everyday habits and activities concerning, for instance, eating or body care, are explored, changed, or taken over. Frank (1991), narrating his experiences with being seriously ill, stated that "in becoming a patient – being colonized as medical territory and becoming a spectator to your own drama – you lose yourself"

(p. 56). Terminally ill patients and their families are, on top of all other obstacles, confronted with the patient's imminent death.

Given the context of health care providers working in their taken-for-granted world of the hospital, and of patients and their families who are thrown out of their worlds into a more or less unfamiliar situation where they may face the patient's death, the research questions already raised in the literature review are repeated here: 1) What are adult terminally ill patients' lived experiences of being cared for by an interdisciplinary team of health care providers at a Swiss university hospital over the course of their terminal illness? 2) What are families' lived experiences of caring for a terminally ill member at a Swiss university hospital over the course of the terminal illness, given that the patient also receives professional care from an interdisciplinary team of health care providers who may also see family members as care recipients?

These questions call for an account that gives a voice to terminally ill patients and their families and has the potential to deepen health care providers' understanding of the care recipients' perspective. However, given the vulnerability of terminally ill patients, the question arises of whether or not a research project searching for such an account should even be initiated.

The purpose of this chapter is threefold: To discuss the appropriateness of doing research on terminally ill patients, to show that interpretive or hermeneutical phenomenology is a suitable research method to explore the research questions stated above, and to outline how the method was used for this study. Accordingly, ethical issues regarding research on terminally ill patients are discussed first, followed by a description of interpretive phenomenology and the methodological aspects of this research project.

Research on Terminally Ill Patients – Is it Ethical?

The question of whether or not research that involves terminally ill patients is ethically justifiable has been raised. Arguments as well as counter-arguments for doing research on terminally ill patients are discussed, and a practicable approach is outlined.

Arguments Against Research on Terminally Ill Patients

Terminally ill patients are a very vulnerable group (Roy & MacDonald, 1998). They are usually dependent on professional health care providers and may be unduly reluctant to reject research participation, fearing that this will negatively influence their care. The terminally ill patients' competence to give informed consent is of special concern (Roy & MacDonald, 1998). They must be able to understand relevant information, grasp its meaning for themselves, make the choice, and communicate their decision (Appelbaum & Grisso, 1988). The sicker the patients, the more likely it is that their competence may be jeopardized. However, researchers may not always be aware of this fact. Bruera, Spachynski, MacEachern, and Hanson (1993) reported that 13 of 67 patients with advanced cancer who had signed a consent form for participation in clinical trials scored less than 24 on the mini-mental state examination. This instrument, which assesses cognitive status, is considered reliable and valid, and a score below 24 is evidence of cognitive impairment (Frank-Stromborg & Olsen, 1997). Neither the principal investigator nor the research nurse had discovered their prospective subjects' impaired mental status. The finding indicates that the competence of terminally ill patients who are prospective research participants must be evaluated carefully. The clinical situations of terminally ill patients are often unstable and their needs are prone to

changes at any time (Roy & MacDonald, 1998). Sudden changes in patients' status and their needs may interfere with research interests.

De Raeve (1994) argued that all researchers, to some degree, treat participants as a means to the research end. Referring to the Kantian principle that a person should never be treated as a mere means, she stated that it is unacceptable to use terminally ill patients as research participants. Furthermore, in qualitative research designs that imply a relationship between participant and researcher via interviews and participant observation or both, role confusions may occur (e.g., the researcher is perceived as a visitor or friend), the termination of the relationship may harm the patient, or it may become difficult for a patient to withdraw research participation because it means losing an attentive listener. In addition, the reflection on experiences may be distressing for terminally ill patients. The author expressed concern that researchers, in order to achieve valuable results, may not pay sufficient attention to the processes that produce the information. This is an ethical risk that is increased by the inability of vulnerable patients to defend themselves.

De Raeve (1994) concluded that investigations into terminally ill patients' experiences could be seen as an affront to their dignity. She stated, in referring to research questions about death and the dying process that "one wonders whether they should ever be asked by the living of the dying? Maybe the only respectful position is to simply and gratefully receive what is generously and spontaneously offered, rather than to ask" (p. 302).

Arguments for Research on Terminally Ill Patients

The ethical issues raised by critics of research on terminally ill patients are not unique to this group, but rather apply to every study that involves human beings. The fact that these patients are confronted with the ultimate loss makes them vulnerable, but it does not preclude their participation in research. Provided that the patients' well-being is clearly seen as priority at all times (Roy & MacDonald, 1998), and that researchers are aware of potential problems, carefully observe and reflect on the research process, and deal appropriately with difficulties while respecting the patients' and families' concerns and vulnerabilities, research on terminally ill patients is ethically justifiable.

In alluding to potential benefits of research participation, some authors argued that terminally ill patients should maintain the right to participate in studies that might have positive effects for themselves or others (MacDonald, 1995; Roy & MacDonald, 1998). Even terminally ill patients who are no longer able to give written informed consent because they, for instance, lost the physical ability to sign a form or suffer from mild cognitive impairment do not necessarily have to be excluded. Other procedures could be considered. For example, a terminally ill patient's verbal assent could be supplemented with the valid consent of a surrogate decision-maker (Thévoz, 1994). Kennedy (1991) critiqued the exclusion of older patients from cancer research, which results in a lack of scientific knowledge for this group. By drawing an analogy, it can be argued that without research in end-of-life care, the currently deficient body of scientific knowledge will never be corrected.

A Practicable Way of Doing Research on Terminally Ill Patients

Barnard et al. (2000) provided an example of how researchers can proceed appropriately when studying terminally ill patients' experiences. These authors followed palliative care patients until death and their families through the bereavement period, gathering data via interviews and participant observation. A member of the palliative care team first asked patients if they would be willing to meet with a researcher and hear more about the study. Patients who agreed were contacted by one of the researchers and family members were contacted only with the patients' permission. Potential participants were informed in detail about the project, its purpose, the methods used, and what participation would entail. They also received written descriptions of the study. The researchers frankly told patients and family members that discussions might touch on painful or private experiences, but also assured them that the patient's best interest would always have priority over research needs. The researchers informed patients and families that they were prepared to stop interviews, cancel visits or withdraw from the patient's room at any time. The researchers explained to potential participants the planned publication of data in the form of narratives. They were told that their identity would be disguised so as to maintain confidentiality. People involved in the cases would be likely to recognize themselves, but it would be unlikely for outsiders to identify participants. Patients were assured confidentiality, but the researchers made two exceptions. They would report to the palliative care team explicitly stated suicidal intentions and patient abuse or situations that seemed to put the patient in imminent physical danger.

The researchers received few refusals. Two families withdrew shortly after study inclusion, one because of concerns about the emotional nature of the interviews, the other because of the patient's extreme fatigue. The researchers did not encounter situations that forced them to break confidentiality. Even though these researchers had carefully considered potential problems and discussed these issues with participants in advance, it became clear in the process of data collection that, at the beginning, participants could not fully appreciate the impact that the study would have on them. When painful memories emerged, researchers had to decide if they should and how to proceed with the interview. Participants did not know the outcome of their stories and sometimes worried about how readers would interpret their words and actions.

In spite of these risks, many patients and family members appreciated participating in the project for different reasons. Some experienced it as their opportunity to contribute to the improvement of end-of-life care; some enjoyed regular visits by an attentive listener; and for others the study provided an opportunity to gain posthumous public recognition or to redeem their misunderstood lives and actions. Several participants stated that they valued the opportunity to tell their perspectives and to learn from their reflections. With their detailed report of how they experienced and handled ethical challenges, these researchers (Barnard et al., 2000) illustrated that the critics' concerns about research in end-of-life care are justified. However, their project also demonstrated that procedures to deal with problems are available and that research participation can even benefit terminally ill patients.

Interpretive Phenomenology

In this section, an outline of interpretive phenomenology and its delimitations as a research method is followed by a discussion that begins with people's everyday understanding, leads to interpretation, and to the articulation of meanings and self-understandings.

Sketch of the Method and its Delimitations

Phenomenology literally means the description or study of appearances (Lacey, 1996). The essence of this approach is to pay close attention to things (i.e., phenomena),

to let them show up (Moran, 2000). The term "hermeneutical" originates from the name of Hermes, the messenger of the Greek gods, and refers to interpreting (Packer & Addison, 1989). Interpretation in this context means to explain or tell the meaning of a phenomenon, to present it in understandable terms (Webster's ninth new collegiate dictionary, 1991). Interpretive phenomenology as a research method, then, refers to the study of a text or text analogue, with the goal of describing the phenomena that manifest themselves in the text and to elucidate their meanings.

The terms hermeneutical and interpretive have been used interchangeably (Benner, 1994a). In this dissertation, interpretive is used. The discussion of the method is based on Benner and her colleagues' use of interpretive phenomenology for nursing research. Their approach is built on the philosophical works of Kierkegaard, Heidegger, Merleau-Ponty, Wittgenstein, Dreyfus, and Taylor (Benner, 1994d).

Interpretive phenomenology is most suitable for exploring questions about human issues and concerns (Plager, 1994). The method allows researchers to uncover common meanings and everyday experiences, habits, skills and practices in a specific context, which often get overlooked because they are aspects of human beings' taken-for-granted background (Leonard, 1994). Interpretive phenomenology was, therefore, well suited to researching terminally ill patients' and their families' experiences of end-of-life care in a particular hospital.

Interpretive phenomenology assumes that researchers are part of the study context, that their pre-understandings shape the project and that interpretations unfold from a dialogue with the text. These assumptions delimit interpretive phenomenology from approaches that are based on Husserlian phenomenology. For Husserl, the founder of phenomenology, the goal of the method was to go "to the things themselves" and to intuitively grasp the essence of phenomena as they appeared in consciousness (Moran, 2000; Van Manen, 1990). Interpretation had to be avoided through the "bracketing" of the actual world and naturalistic assumptions. The latter is, according to Heidegger (1927/1962), impossible because human beings are self-interpreting and always already situated in a world with shared meanings (Dreyfus, 1991). World in a Heideggerian sense is "the meaningful set of relationships, practices, and language that we have by being born into a culture" (Leonard, 1994, p. 46). This world, since it is so familiar, is taken for granted and often overlooked. For employees, for instance, the hospital, with its equipment, practices, medicalized language, professional relationships, sights, smells, and so forth, is their everyday, taken-for-granted workplace world. Passing over the world is not desirable when the goal is to better understand persons in their worlds.

Improving the understanding of research participants' worlds is different from the search for causal explanations and theoretical propositions, which is usually the aim in the natural sciences (Benner, 1994a). Research in the natural sciences is widely based on Cartesianism, which presupposes 1) a dualism of body and mind, with human beings as subjects looking at objects; and 2) that entities can be broken down into measurable units from which knowledge can be abstracted and generalized (Dreyfus, 1991; Plager, 1994). Research on human beings is limited if reduced to this approach only, because people's worlds, their experiences, their concerns, their common meanings, and the context are left out, as Taylor (1985a) explained:

> A being who exists only in self-interpretation cannot be understood absolutely; and one who can only be understood against the background of distinctions of worth cannot be captured by a scientific language which essentially aspires to neutrality. Our personhood cannot be treated scientifically in exactly the same way we

> approach our organic being. What it is to possess a liver or a heart is something I can define quite independently of the space of questions in which I exist for myself, but not what it is to have a self or be a person. (pp. 3-4)

An interpretive approach such as interpretive phenomenology is called for in order to explore human beings' worlds beyond measurable organic units.

An interpretive phenomenological study provides, as its result, an account that illuminates the participants' world (Benner, 1994a), a coherent account that replaces and makes sense of the original text (Taylor, 1985b). The rest of this section will discuss how researchers can arrive at such an account. It is, in addition to the referenced sources, based on Dr. H. L. Dreyfus' interpretation of Heidegger provided during lectures at the University of California Berkeley, and on Dr. P. Benner's and Dr. C. Chesla's teachings of interpretive phenomenology at the University of California San Francisco School of Nursing.

From Everyday Understanding to Articulation

Heidegger (1927/1962) discussed three types of understanding: coping, interpreting and asserting (Dreyfus, 1991). These types of understanding are related to three ways in which people can be involved with equipment when they perform some activities. Heidegger (1927/1962) described these three modes of engagement as ready-to-hand, unready-to-hand and present-at-hand. Ready-to-hand means that people are absorbed in their activities, the equipment they use functions smoothly and, therefore, remains mostly unnoticed. If some sort of breakdown occurs in the smooth functioning, the mode of engagement turns to unready-to-hand. The equipment becomes conspicuous. Finally, present-at-hand refers to the engagement of an observer who stands back and reflects on the situation, for instance, on properties of equipment.

Understanding as Know-How

At its most basic level, understanding is not seen as cognition but as know-how that allows skillful coping. Heidegger (1982) stated:

> In German we say that someone can vorstehen something – literally, stand in front of or ahead of it, that is, saying that he versteht sich darauf, understands in the sense of being skilled or expert at it [has the know-how of it]. The meaning of the term "understanding" [Verstehen] as defined above is intended to go back to this usage in ordinary language. (p. 276}

This kind of understanding, this know-how, enables human beings to master their everyday activities in their worlds as the persons they are. For instance, as a healthy person in my own bathroom, I know how to brush my teeth. I do not have to think about this activity, I just do it. This know-how relates to the ready-to-hand mode of engagement (Dreyfus, 1991). I use the toothbrush without explicitly noticing it.

Interpretation and Assertions

From understanding as know-how derive, according to Heidegger (1927/1962), the other types of understanding, interpretation and assertions. Interpretation, in the sense of laying something out, occurs when smooth functioning is disturbed and people need to pay attention and act deliberately (Dreyfus, 1991). To use the example of brushing my teeth again, when the water tap does not function, I notice that it is the device that, when working properly, allows me to mix cold and hot water so as to reach the temperature at which I like to rinse my mouth. Or, as a bedbound hospital patient, I have to become conscious of my teeth brushing habits and tell the nurse about them, in order to continue with my usual practice.

Such everyday interpretations, then, may or may not be articulated, that is, put into language. Heidegger (1927/1962) referred to the articulation of interpretations as

assertions, and distinguished between hermeneutic and theoretical assertions. The former relate to a context-bound articulation of something that has been noticed, that is, laid out or interpreted (e.g., I like lukewarm water to rinse my mouth); the latter relates to context-free statements about objects and their properties (e.g., fluoride is included as a component of toothpaste because it prevents caries). Everyday interpretations and hermeneutic assertions are connected with the unready-to-hand mode of engagement, and theoretical assertions relate to a present-at-hand way of involvement (Dreyfus, 1991). The malfunctioning water tap or my bedboundedness bring teeth brushing to my notice. As a detached observer, I can reflect on the components of tooth paste and on the reasons for its composition.

A hermeneutic assertion has the following three aspects: 1) It points something out, that is, in a shared context it points out an aspect of an ongoing activity that needs attention. 2) It predicates, that is, it attributes a predicate to a subject (these terms are used in their grammatical sense here), thereby focusing only on the relevant aspect. 3) It communicates, that is, something that people already shared gets explicitly shared. For example, if, as a patient about to brush my teeth in bed, I say to the nurse, "the water is too hot," I am pointing to an aspect that needs the nurse's attention, namely the water temperature, which is the relevant aspect of the water for me at this moment. My utterance also makes explicit what both the nurse and me were implicitly aware of before, namely that each person likes water of a certain temperature to rinse the mouth.

Heideggerian interpretations and hermeneutic assertions can be extended beyond everyday activities and used as a method to interpret texts, practices and so forth.

Heidegger (1927/1962) has illustrated this with "Being and Time," which is his interpretation of the meaning of being.

The Influence of Researchers' Pre-Understandings

Interpretation presupposes, in both an everyday practical context and the context of a research project (the context focused on here), a pre-understanding that links basic understanding or know-how with interpretation (Plager, 1994). This is Heidegger's (1927/1962) three-fold fore-structure of interpretation.

The first aspect is a fore-having, which refers to the taken-for-granted background, the familiar world. It also circumscribes the area of the questions asked. I have outlined my pre-understanding of hospital end-of-life care as a nurse in chapter one. Additional aspects influenced my interpretations, namely, that I spent three years studying nursing at the University of California San Francisco; that I encountered an unfamiliar health care system through readings, discussions and observations; that I was absent from my former workplace for three years prior to the data collection and, therefore, only learned about the changes that had occurred in the hospital and in the Swiss health care system and the effects of these changes on end-of-life care after my return; and that I experienced a terminal illness and the death of a close family member, but not in the hospital. Finally, my background as a hospital nurse led me to explore a research question in this context.

The second aspect of the fore-structure is a fore-sight, meaning that researchers have a certain perspective from which to approach the interpretation. The research questions or lines of inquiry (Benner, 1994c) that are established at the beginning of a study, along with the reasons for these particular questions, provide the starting point from which the interpretation evolves.

In chapter one, I described my reasons to explore terminally ill patients' and their families' perspectives on hospital end-of-life care. The broad research questions, which guided this study, were stated at the beginning of this chapter. My interpretations started from the following more specific tentative lines of inquiry: 1) What interaction (micro)practices do the terminally ill patients and their families describe and which practices do I observe? Which interaction (micro)practices of health care providers are remembered by terminally ill patients' and their families' as helpful or not helpful? Which of these practices do satisfy patients' and families' needs to be recognized and met as persons? Micropractices refer to the sometimes very subtle nuances in gestures, tone of voice, use of words, and so forth. 2) What measures do health care providers use to support and enhance terminally ill patients' comfort? How are these measures implemented? How do patients and families experience these measures? 3) How do health care providers shape the support in or taking over of activities of daily living according to individual patients' needs? How do patients and families experience health care providers' practices? 4) Which (micro)practices of health care providers and what conditions give rise to terminally ill patients' and their families' feelings of being cared for or not being cared for?

The third and final aspect of the fore-structure is a fore-conception. Given the researchers' background and the taken perspective, they can have some expectation of the interpretation. In reflecting on my anticipations, I expected that terminally ill patients' and families' views of hospital end-of-life care would differ from the health care providers' views described in the literature, and I wondered in which respects and to what extent; I believed that caring and uncaring would be key words in the interpretation; and I could imagine that the daily hassles and joys would show up as influencing experiences more frequently than "big" topics, such as advance directives.

The notion that researchers' pre-understandings will influence their interpretations and, therefore, need to be spelled out as much as possible parallels postmodernism's view of the researcher as a historically and locally situated human being rather than as an objective detached observer (Lincoln & Denzin, 2000).

Moving in the Hermeneutic Circle

Because the researchers' pre-understandings to some extent govern their inquiries and predetermine their interpretations, answers are found in light of what is already known (Moran, 2000), which makes interpretation circular. Also there is no ground zero for human understanding and interpretation, that is, for every topic in the foreground of attention some background taken-for-granted pre-understanding made this particular foreground possible. Researchers enter this so-called hermeneutic circle via their research questions. While interpreting, they constantly move from the background (i.e., their pre-understandings) to the foreground (i.e., the text they are interpreting), as well as between the whole text and parts of it (Leonard, 1994). Lines of inquiry, in the form of research questions, put some boundaries to the interpretation; however, these boundaries have to be tentative (Benner, 1994c). The challenge for interpreters is to make explicit as many of their pre-understandings as possible; to stay open, be reflective and be able to hear questions; and to be willing to have their assumptions and initial questions challenged, altered, extended and transformed by the text. The goal is to create a true dialogue between researchers and the text, a dialogue that departs from the researchers' pre-understandings and enlarges and deepens their understandings. The analysis of parts of

the text sheds light on the whole text, and vice versa. Internal to the interpretive project is experiential learning on the part of the interpreters.

Interpreting is similar to practical reasoning, which is reasoning in transitions such as in clinical situations (Benner, 1994c; Taylor, 1989). Practical reasoning does not attempt to establish one correct interpretation, but rather generates comparative interpretations and tries to show that one is better than another. Taylor's (1993) discussion of practical reasoning is well captured in the following description: "Practical reasoning moves one's understanding to a better or clearer understanding and resolves contradiction or confusion. Moving through a transition from a poorer to a better understanding is error-reducing, enlarges one's sense of possibility, or clarifies limits" (Benner et al., 1999, p. 10). During the process of giving voice to various interpretations, researchers may reach out and even speculate, but they always need to return to and evaluate suggested interpretations in light of the text. The best interpretation is the one that provides the most plausible explanation of the text.

In addition to closely looking at what is in the text, or the text's content, interpreting also involves considering how the text unfolds, that is, considering the structure of the text in various ways (Fontana & Frey, 2000). Researchers may, for instance, ask why a certain story was told at a certain point of time in an interview, reflect on factors that influenced an interview or observational situation, search for concrete narratives, take into account the variation in immediacy of experience between often told and fresh stories, or recognize their stances towards participants (e.g., rejection or idealization usually means that a good grasp of the participants has not yet been achieved) (Benner, 1994c).

The interpretive process continues until researchers are satisfied with the depth of their interpretations (Leonard, 1994). There is, consequently, no clear end-point, and it is assumed that the participants' world can never be articulated completely (Benner, 1994c). Furthermore, the option of a deeper, more comprehensive or more convincing interpretation always remains available (Leonard, 1994).

Articulating Interpretations

The most common way interpretations are shared with others is through articulation, through putting them into spoken or, in the case of research, into written language. The aim of articulating findings in interpretive phenomenology is to provide a coherent account that makes sense of the original text (Taylor, 1985b). Stated otherwise, the articulation of findings should allow readers to enhance their understanding of the participants' world and experiences, without the reader spending time in the field, interviewing people, and so forth.

What, then, does the content of such an account look like, given the research project aims of exploring the world and experiences of participants? The researchers present the participants' voice and then comment on it from different view points in order to enlighten it (Benner, 1994c). The commentary, although it is on a more abstract level, remains true to the original text.

Researchers seek to show commonalties and differences, yet they do not describe phenomena as oppositional, but rather focus on presenting the phenomena as they are lived by participants in a particular context and in a variety of ways, with contradictions, qualitative distinctions and changes over time (Benner, 1994c). Researchers do not apply theoretical models or terms to their account, but enter into a dialogue (again, similar to practical reasoning) with the literature by comparing and contrasting their findings with other publications.

However, in order to enhance the readers' understanding of a phenomenon, simply articulating the thematic content of the original text in a clearer fashion will not suffice. Readers can only gain access to an interpretive phenomenological account if it resonates to some extent with their understanding, not so much on a cognitive but rather on an experiential level (Taylor, 1985b; Van Manen, 1998). Researchers need to consider not only what the account says, that is, the thematic aspects, but also how the articulation of these aspects speaks to the reader. Van Manen (1998) stated that in order to address the latter aspect, an account must be concrete and evocative and have intensity, tone, and epiphany. The phenomenon should be made so concrete that it can be recognized and experienced. The description must be vivid enough to evoke reflection, to let the reader wonder, question, or understand. Intensification refers to carefully choosing key terms and to fully explaining their meanings; key terms should, so to speak, paint a picture for the reader. Through its tone, an account speaks to the reader on a noncognitive level. Researchers want to give their articulations a tone that allows the reader to grasp aspects that attend to significance and meaning. An articulation with epiphany, finally, transforms the readers' understanding; it lets them suddenly "see" or intuitively grasp the meaning of something.

Taylor (1985a) discussed three aspects that make articulation valuable for human beings; these aspects extend Heidegger's (1927/1962) notions of pointing out, predication and communication. First, people formulate things through articulation and bring what has been implicit to explicit awareness and full consciousness. The formulation of a particular matter allows people, subsequently, to focus properly on it and to draw some boundaries, that is, to make distinctions. Second, articulation creates a rapport between people, similar to what they do when they strike up a conversation. The reader may have experienced that the sleep of a hospital patient is often interrupted. The researchers discover this in their text. By articulating the fact in the interpretive phenomenological account, it is put out there, between reader and researcher. "Language creates what one might call a public space, or a common vantage point from which we survey the world together" (Taylor, 1985a, p. 259). Finally, language allows specifically human concerns to be articulated, that is, concerns that only human beings can, but animals do not, have. Only people generate these concerns, because they alone are able to discriminate and to apply standards (e.g., shame is a human concern, because people can recognize shameful situations, animals cannot). Accordingly, this interpretive phenomenological account of terminally ill patients' and their families' experiences of hospital end-of-life care articulates and makes explicit these experiences and, therefore, permits the reader to focus on them and make qualitative distinctions. Their articulation creates public space for these experiences and allows for highlighting of terminally ill patients' and families' specific concerns.

Dunne (1997), referring to his account of phronesis in teaching, explained that:

> A good teacher might find that a work such as this did little, directly, to improve her practice – other than to help her to articulate it better. The value of such articulation, however, is not to be underestimated. For even good teachers can easily be intimidated by the sophistication, apparent power, and high prestige of technicist approaches. (p. 368)

By analogy, the goal of this interpretive phenomenological account of terminally ill patients' and their families' experiences was to strengthen their voice and to raise the attention of health care providers and the public (i.e., prospective patients and family members) to the concerns and experiences of the terminally ill and their families (Benner, 1994c).

Study Methodology

In this section, an overview of the study context is followed by an outline of the methodology used in this study. The theoretical considerations, which guided the research process, are mentioned. The methodological procedures are described, and relevant experiences with applying the method are pointed out.

The Study Context

This study was conducted in one Swiss university hospital. Thus, it provides a local and particular account of patients' and family members' experiences of hospital end-of-life care. The context of the study is outlined briefly, in order to enhance understanding and to allow judgments regarding comparability with other settings. This section is based on an article I wrote on health care in Switzerland (Spichiger, 2003).

Switzerland is a small European country bordered by Germany, France, Italy, Austria, and Lichtenstein. The country covers 41,285 square kilometers, and has just over seven million inhabitants. Switzerland is multilingual, with 65% speaking German. About 48% are Roman Catholics and 44% are Protestants (European Observatory on Health Care Systems, 2000). Foreigners make up approximately 20% of the population (Bundesamt für Statistik, 2000). Service trade is the biggest line of business besides industrial production and farming. Switzerland is not a member of the European Union.

Politically, Switzerland, officially the Swiss Confederation, is a federal republic. The country is made up of 23 cantons, 3 of which are divided into semi-cantons, and has about 2900 municipalities (European Observatory on Health Care Systems, 2000). The cantons are 26 entities, sovereign in all matters that are not, according to the constitution, dealt with at the federal level. Rights and duties of municipalities vary according to cantonal laws. The Swiss population is frequently directly involved in political decision-making through popular petitions, referendums, and ballots. Although the rather conservative parties have a majority, coalitions are changing, and decisions are often based on compromises.

The Swiss Healthcare System

Switzerland has a well developed healthcare system, which is accessible for all inhabitants. Health care is expensive, though, with expenditures of 10.2% of the gross domestic product (Domenighetti & Quaglia, 2001). Life expectancy is high, with 76.5 years for men and 82.5 years for women (Bisig, 2001). Leading causes of death are malignant neoplasms, ischemic heart disease, and cerebrovascular disease (European Observatory on Health Care Systems, 2000).

Like Swiss politics, healthcare is characterized by liberalism and federalism. Responsibilities for healthcare are shared, in accordance with the political system, among the Confederation, the cantons, and the municipalities. The healthcare system has developed over decades in a rather uncoordinated fashion, resulting in a complicated system with many actors and 26 different subsystems. The federal constitution regulates health insurances. The cantons implement federal law and are the main providers of

healthcare, since they are responsible for hospitals and nursing homes. Municipalities are usually in charge of home health care.

Ambulatory healthcare is mostly delivered by physicians in office-based, independent practices. People have free choice of physicians and access to specialists. However, most have a general practitioner who will refer them to a specialist or for hospitalization. Home health care coverage is fairly comprehensive, and the country has a well-developed infrastructure for the delivery of acute care, with 378 hospitals, that is 6.3 beds per 1000 inhabitants. The occupancy rate of 86% is high, and patients stay on average 13.7 days in the hospital (Undritz, 2001). High technology medicine is mostly provided by the five university hospitals.

Switzerland has a long tradition of health insurance for most people and a compulsory health insurance since 1996, meaning that all inhabitants are covered for basic care. This includes medical and nursing care at home as well as in the hospital and nursing homes, medications, equipment, transport, and some alternative therapies. About 100 public and private companies offer compulsory health insurance. These companies are not allowed to make profits, and premiums are community related. In addition to the basic care, companies offer supplementary health insurance. The premiums for these various packages are risk-related. The most common are supplementary policies for a free choice in hospitals and superior inpatient accommodation, with two levels: private or semi-private, entitling the patient to a single or double hospital room.

Healthcare is mainly financed by compulsory health insurance, subsidies from the Confederation, the cantons and municipalities, patients' out-of-pocket payments, and supplementary health insurance. The prevalent payment system is fee-for-service, although other systems are in use, for example, global budgeting. Fees are negotiated between service providers (medical associations and associations of hospitals) and payers (insurance companies and cantons) and are decided upon by governmental bodies.

The Study Site

The study was conducted in a university hospital in the German speaking part of Switzerland. The hospital has about 1000 beds. It provides specialized as well as basic care. It is a public institution, but has also private beds at its disposal. In 2002, about 50,000 patients were hospitalized for a mean of 7 days. In addition, about 146,000 outpatients were treated (Inselspital, 2002).

Data were collected in the clinic for general internal medicine, the clinic where most patients died from terminal diseases. The clinic had 140 beds, with two departments for acute care and one department for rehabilitation. During 2002 and 2003, about 2500 patients were cared for per year; mean duration of hospitalization was about 12 days for acute care and 42 days for rehabilitation; 147 respectively 162 patients died. The clinic had 11 units, with one or two residents per unit, senior physicians as supervisors, and three senior consultants, each in charge of one department. Regarding nursing care, a charge nurse was responsible for each unit, while a nurse manager and an assistant nurse manager were supervising each department. Staffing levels were about 0.9 nurses and 0.2 nursing assistants per bed. Team nursing or primary nursing were used, and nurses worked in three shifts. The clinic offered practical training to nursing and medical students. The services of social workers, dieticians, physiotherapists, occupational therapists, and chaplains were available.

Other clinics that, according to their clinical nurse specialists, also occasionally cared for terminally ill patients were asked for participation in the study. Three clinics declined for different reasons, such as lack of eligible patients, recent participation in another study on dying, or sensitivity of the research topic. One surgical clinic participated, but no patient agreed to take part in the study.

Selection of Participants

In order to find shared experiences and meanings, commonalties as well as differences, the participating patients and family members needed to have some similarities. However, research on terminally ill patients' and their families' experiences of hospital end-of-life care had not yet considered patient and family characteristics as potentially influential factors. It was, therefore, difficult to set inclusion criteria. I assumed that the Swiss context, with its rather homogeneous population and an obligatory health insurance for basic care for all, as well as the collection of data within one hospital would already provide some homogeneity in the sample. Thus, no criteria were set regarding the patient's diagnosis, the patient's and family member's age and gender, as well as the patient's and family member's formal relationship.

Terminally ill patients who fulfilled the following criteria were included in the sample: 1) The patient was 18 years or older. 2) The patient could designate a close family member who visited regularly. 3) The patient was hospitalized in one Swiss university hospital and expected to die during this hospitalization by the medical and nursing team. 4) The patient and the family member spoke German. 5) The patient and the family member were, according to the care providers, able to give informed consent and agreed to participate.

The first months of data collection showed that it was extremely difficult for the care providers to predict which patients would die in the hospital. In addition, these patients were often too sick to be approached or refused study participation because they felt too exhausted. Therefore, inclusion criteria were adapted: Patients were eligible, if they were no longer treated curatively and were expected to die within weeks or a few months.

Ethical Considerations

The study and the modifications were approved by the Committee on Human Research, the Institutional Review Board of the University of California San Francisco. The Ethics Committee of the State of Berne was approached. But in 2001, this recently established committee focused on clinical trials, and a review and approval of this qualitative study was not considered necessary. The university hospital approved the study, and a letter of support was obtained.

Procedures on the Clinic Level

Within the university hospital, clinic management teams were approached and informed about the study first. After a clinic management team had approved participation of their patients, the professional health care providers (nurses, nursing aides, physicians, physiotherapists, occupational therapists, dieticians, social workers, and chaplains) were informed verbally about the study. Flyers with written information were provided as well (see Appendix A for English and Appendix L for German version).

When a patient agreed to participate, I informed the nursing team and the responsible resident, explained the study as needed, and provided them with the written information again. During data collection, I stayed in contact with the nursing team in order to coordinate observation sessions and interviews with the patient's and the unit's schedule.

During participant observation, roommates were aware of my presence. I informed them about the purpose of my observation and offered them to leave the room at any time if they wished so. All roommates readily agreed with my presence, and I was never asked to leave.

Participant observation also involved the health care providers. Providers who preferred not to participate could notify me and would not have been observed. However, no provider refused to be observed. I had planned to get verbal consent on the spot from health care providers to tape informal conversations, but such conversations turned out to be casual and brief, so that I wrote field notes instead of using the tape recorder.

Recruiting Study Participants

When I met potential study participants first, I did not know if they were aware or willing to acknowledge the patient's terminal stage. Therefore, the procedure to obtain informed consent did not directly mention this fact. The terms "terminally ill patient" and "end-of-life care" were not used in the consent forms for cultural reasons. The terms "seriously ill patient" and "hospital care" were used instead. Circumlocutions are common in conversations about diagnoses and prognoses in Switzerland and the above terms are frequently used by lay persons and professionals. It seemed inappropriate for me to risk confronting potential participants in a first meeting with words that might be too strong and explicit to be experienced as polite and respectful.

A patient who met the inclusion criteria was first approached by the nurse manager or assistant nurse manager. She briefly explained that a nurse researcher was conducting a study that explored patients' and their families' experiences of care in this hospital (see Appendix B for English and Appendix M for German version). I only contacted patients who were willing to meet with the researcher and wanted to hear more about the project. When first meeting with a patient, I provided written information (see Appendix C for English and Appendix N for German version) and carefully explained the study and what participation would mean for the patient and family member. If a patient agreed to participate, I contacted the family member, provided written information (see Appendix D for English and Appendix O for German version) and explained the study. If the family member also agreed to participate, I let both, patient and family member sign the informed consent forms (Appendixes C and D for English and Appendixes N and O for German version) and gave them a copy of the forms. When a patient was physically unable to sign, he or she gave verbal consent in the presence of the family member and had the family member sign for him or her.

During the first phase of data collection, when a patient was expected to die in the hospital, I asked the family member during one of the interviews, if I could contact him or her again later. I explained my interest in a post bereavement interview to family members who acknowledged the patient's impending death. I had planned to tell the family members that I would like to talk about the hospital stay in retrospect, should they not be aware of the patient's terminal status. However, this was never the case. Such a verbal agreement seemed culturally appropriate, since in Switzerland a verbal consent is considered valid in many situations. Approximately 3 months post bereavement, I called

the family member who had agreed to be contacted again, asked if he or she would be willing to participate in a follow-up interview, and explained the purpose of the post bereavement interview to a family member who might participate. If he or she verbally consented to an interview, an appointment was made at a time and place convenient to him or her. At the beginning of this meeting, I explained the purpose of the interview again as needed, had the family member sign a consent form (see Appendix E for English and Appendix P for German version) and gave him or her a copy of the form.

Since it was problematic to predict which patients would die in the hospital, several patients who participated in the study were discharged. The procedure described above did not allow me to ask these patients and their family members for a post discharge interview. Therefore, the procedure was modified. The possibility of a post discharge contact was now mentioned in the consent forms for patients and family members (see Appendixes C and D for English and Appendixes N and O for German version). If the patient was discharged, I asked the patient and the family member during an interview if I could contact them by phone about one month post discharge to check in how they were doing. I planned to ask the patient and/or the family member for a follow-up interview during this phone call, if this would seem meaningful and sensible. This flexible approach took into account that a patient might have died or was dying at the time of the phone call, and that asking for an interview might be inappropriate. I planned to provide the needed information regarding a follow-up interview on the phone and, if the patient and/or the family member were willing to participate, make an appointment. At the beginning of this meeting, the patient and/or the family member would sign the consent forms and get a copy of the forms (see Appendixes F and G for English and Appendixes

Q and R for German version). If the patient was discharged to another health care institution, no post discharge interview was planned, since doing so would have required approval from this institution.

Confidentiality

All participants were assured that their contributions would be kept as confidential as possible. Tapes were stored in a secure place and will be destroyed after completion of the dissertation. Codes were used instead of names. In the dissertation as well as in publications flowing from it, identities were and will be disguised, so that participants will not be recognized. I informed the health care providers of one exception: Should I perceive that the action of a health care provider put a patient at risk, I would notify this provider and, if necessary, the supervisor. I was never forced to do so.

The Study Sample

Recruitment of Participants

Data for this study were collected during 2002 and 2003. The nurse managers or assistant nurse managers approached 44 patients, 33 of them agreed to meet with the researcher, 8 refused, 2 were too sick to understand the information, and 1 did not meet the inclusion criteria. I contacted 32 patients. One patient was asked when I was absent and died before I could meet him. Of the 32 patients, 18 refused participation, the health status of 2 patients deteriorated rapidly so that it was not possible to get informed consent, and 2 patients did not meet the inclusion criteria. Patients who did not meet inclusion criteria either spoke French or did not have a close family member.

Ten patients and 10 family members participated in the study. The brother and sister-in-law of a patient wished to participate together, and the mother of another patient withdrew from the study prior to the first interview, whereas in all other cases, the closest family member of each patient participated.

Patients were not asked, but most spontaneously gave a reason for refusing study participation. The majority said that they felt extremely exhausted and participation would be too burdensome. A few patients stated other reasons, namely that they were preoccupied with coming to terms with their illness, preferred to spend their time with the family members when they visited rather than for interviews, did not wish to burden family members with study participation, or would not be able to read the results.

Contacting patients and family members to inform them about the study and get their decision regarding participation was a demanding process. It often required several visits, because patients felt sick or were sleeping or otherwise unavailable, and patients and family members wanted to think over or discuss participation with other family members, so they frequently postponed their decision. Thus, the decision-making process usually expanded over about 3 days.

The nurse managers and assistant nurse managers, who first contacted eligible patients, took on this task in addition to their already full work schedule. This fact rendered recruitment more difficult. The day's work and the smooth running of the clinic's nursing service were rightly given priority over the research project. Therefore, eligible patients were repeatedly not recognized or not contacted during busy times, even though I regularly communicated with the responsible persons.

Characteristics of Participants

Information regarding the study participants' characteristics is provided in Table 1. All patients and family members were white, and all but one were Swiss. One patient was an immigrant from Eastern Europe.

The patients were hospitalized on average for 33 days, with a range from 5 to 72 days (median = 31). Patients and family members participated in the study for a mean of 16.4 days, with a range from 2 to 56 days (median = 9.5).

Data Collection

From the discussion about interpretation and articulation of a text arises the question of how an appropriate text or text analogue is generated. Stated otherwise, how and what kind of data do researchers gather and then transform into a text for interpretation? Interpretive phenomenology aims at articulating everyday taken-for-granted meanings and practices, as well as how participants experience breakdowns in this taken-for-grantedness. Accordingly, a data collection method is chosen that allows as good an approach to the participants' world as is feasible. A pure, unaffected access to taken-for-granted aspects is never possible because by drawing attention to any unnoticed issue, this issue becomes noticed.

For this study, data collection included participant observation, conversations with patients, interviews with the closest family members, and reviewing medical and nursing records. I was aware that with this approach, the families' experiences were represented from the patients' and closest family members' perspectives only. The inclusion of several or all family members would have provided a richer picture but seemed less feasible from a practical point of view.

Table 1

Characteristics of Study Participants

	Patients	Family members
Age in years, mean (range)	62.7 (38-85)	64.6 (41-82)
Gender		
Women/Men	3/7	7/3
(Former) occupation		
Housewife	1	4
Service sector	1	1
Blue-collar worker	2	1
Public employee	3	3
Business owner	2	1
Scientist	1	
Religious affiliation		
Protestants	7	7
Catholics	3	2
None		1
Relationship to the patient		
Spouse		4
Partner		3
Mother		1
Brother		1
Sister-in-law		1
Diagnosis		
Metastatic cancer of the lung	4	
of the prostate	2	
of the oesophagus	1	
of unknown origin	1	
Multiple myeloma	1	
Glioma	1	

In postmodern qualitative research, assumptions are made concerning participant observation and interviewing (Angrosino & Mays de Pérez, 2000). The researcher as observer or interviewer is always part of the situation and affects it in some way. A researcher never observes what would have happened in her or his absence, nor hears the same story that the participant would tell to another person. The gender, age, ethnicity and class of the participant and researcher are influential factors in their relationship. At the beginning of an observation session or an interview, it is crucial for researchers to establish a rapport with and gain the trust of the participants in order to gather valuable data. The course of an observation or interview is not predetermined but develops over time and is shaped through the interaction of participant and researcher. Finally, the description of a phenomenon that a participant provides is co-created by both, participant and researcher (Fontana & Frey, 2000).

A good interpretive phenomenological account is well grounded in data. To achieve this, an amount of text is required that provides the richness, redundancy and clarity that researchers need to feel confident in their interpretations (Benner, 1994c). The sample size for an interpretive phenomenological study, then, depends on the quality and amount of data gathered from each case.

For this study, I planned to include 10 to 20 terminally ill patients and their closest family members, depending on the amount of data collected from each dyad. Due to the problems with recruitment, only 10 dyads provided data. However, a sufficient body of text was generated to feel confident in the interpretations. Many aspects that are discussed in the following result chapters and illustrated with quotes, can be discovered

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in other quotes as well, which speaks to the required redundancy in the data. Table 2 provides an overview of the collected data.

Table 2

Overview of the Collected Data

Case No.	Conversations/Interviews			Observations	Post discharge phone calls	Post bereavement interviews
	Pat.°	FM°°	Pat.+FM			
1	1	1		1		
2	2		1	1		
3	3	1		2		
4	1	5		8		1
5	2		2	2		
6	1	2		2		1
7	2	1	2	1		
8		1		1	1	
9	2	2*		3		
10	1			1		
Total	15	13	5	22	1	2

Note: ° Patients; °° Family members; * 1 Interview was with 2 family members

After getting informed consent, a date for the first participant observation was set with the patient and an appointment for the first interview was made with the family member. I was aware of patients' and family members' vulnerability and that the patients' health status might change frequently. Throughout the data collection process, I paid great attention and made sure that the patients' and family members' best interests and well being had priority over the research needs. I left the room of a dying patient, for instance, when the physician was about to talk through personal issues with the family member, because I felt that observation would be intrusive.

Participant Observation

Observation helps to make visible the context of patients' and families' experiences, for instance, the hospital structure, smells and noises (Benner, 1994c). Observing what patients, family members and health care providers actually do and how they interact, provides a more immediate access than a dialogue alone would. Observation also provokes interview questions. During participant observation, it seems especially important to stay open to new upcoming issues and various aspects of a situation (i.e., the what and how, its content) and to remember observations well in order to write comprehensive fieldnotes.

Repeatedly, I spent some time with the patient and observed the care he or she received. Duration and timing of observations were first adapted to the patient's situation, and second varied according to the research needs and my schedule. During participant observations, I talked informally with health care providers in order to clarify questions. Since I wanted to observe from the patient's perspective, I did not usually participate in care interventions. However, I helped out occasionally if immediate support was needed, and I assisted patients in the absence of other health care providers, if they asked for help or seemed at risk for harm. I intervened, for instance, when a patient tried to transfer on his own from the wheelchair to the bed and risked to fall.

I took notes during observation sessions if I could do so in an unobtrusive way, and I wrote extensive fieldnotes as soon as possible after observation sessions. These fieldnotes described the patients, the care they received and their reactions, as well as contextual aspects such as the environment. The fieldnotes were reviewed for missing observations and open questions for subsequent conversations with patients or interviews with family members. Repeated observations provided the opportunity to fill in discovered gaps. In my view, being an experienced nurse and returning to the units for observation after an absence of 3 years was a good combination. It allowed me a fresh look, while I was still able to understand what was going on.

Interviewing for Interpretation

Interviews provide the option of asking open-ended questions regarding the phenomena of interest. Researchers who generate a text for interpretive phenomenology are most interested in rich, concrete narratives because such narratives are closer to lived experiences and meanings. Such narratives may be considered indirect discourse in the tradition of Kierkegaard because they indirectly disclose the persons concerns, meanings and know-how, whereas opinions, beliefs and ideology disclose knowing that and more formalized explicit knowledge (Benner, 1994c). Collecting both opinions and narratives allows the interpreter to create a discourse between lived experiences and explicit beliefs. Therefore, researchers mainly encourage participants to tell stories of real situations, but also question them about opinions and beliefs. Interviewers first listen carefully to the story and then ask probing questions in order to fill in gaps and get as many details as possible, with the goal of achieving "thick descriptions" (Geertz, 1973). Repeated interviews are preferred because it allows researchers to review interviews for gaps and overlooked questions (Benner, 1994c).

A good text is a prerequisite for a valuable interpretive phenomenological account and, therefore, researchers must be able to generate such a text. For Kvale (1996), the ideal interviewer knows the interview theme very well; structures the interview with an outline at the beginning and a rounding off at the end; asks clear, simple, and understandable questions; allows participants to gently proceed at their pace; signals openness to different views; is an empathic, active listener and sensitive to the how-aspects of the interview; is open to new issues and follows them up; steers the interview according to its purpose; critically questions participants' utterances; remembers what has been said throughout the interview and can ask for elaboration on earlier statements or related parts of the interview; and clarifies meanings by providing interpretations that the participants can confirm or disconfirm.

Conversations With Patients

During participant observations, I talked informally with the patients. This allowed capturing their immediate understanding of a situation. If the patients' health status allowed doing so, I had longer conversations with them. Most of these conversations were embedded in an observation session. Occasionally, I arranged additional times for conversations. The place for conversations was chosen according to the patients' wishes and needs for privacy; conversations took place in the patient's room, in a separate room at the hospital, or in a corner of the smoking area.

With the patients' permission, all conversations were taped. I asked open-ended questions and encouraged the participants to tell stories of real situations, but also questioned them about opinions and beliefs, and followed up with probing questions. The content of conversations focused on the patients' experiences of care during the current hospitalization, but also included related aspects (e.g., the patients' illness trajectory and experiences, their life history, their family) that allowed me to get to know the patient as a person (for potential questions see Appendix H for English and Appendix S for German version). The goal was to cover over time as many of the questions as the patients' situation allowed and to follow up with topics if possible. Conversations were reviewed for gaps and overlooked questions, and missed information was gathered later if feasible. With most patients, I was able to cover all topics to some extent, even though the length of study participation at times only permitted one conversation. Two patients were too sick for a longer conversation, and the health status of another patient deteriorated unexpectedly, which prevented further conversations.

Since I did not know if patients were aware or willing to acknowledge their terminal illness when I met them first, I did not disclose this fact, but followed the patients' lead and spoke in their words about the illness. All patients knew their diagnosis and were aware of their shortened life expectancy. Some talked openly about these issues, while others just alluded to them occasionally. In general, talking to the patients was easy, because they showed a great willingness to share their stories. Some patients, however, were a bit forgetful and could not provide narratives of real care situations, because they did not remember concrete events.

After the modification of data collection procedures, only one patient was discharged home. I met this patient and the family member to make an appointment with the family member, but learned from them that the patient would be discharged the next day, that the family member was no longer interested in study participation, and that both wanted to focus on organizing discharge. It seemed inappropriate to ask for a post discharge interview in this situation. Thus, no post discharge interviews were done.

Family Member Interviews

The interviews with family members that were performed during the patients' hospital stay took usually place in a separate room. The family member was interviewed separately unless he or she did not want to leave the patient. Thus, two interviews took place in the patients' presence. In three cases, the patient and the family member preferred to talk to me together. The post bereavement interviews were done in a place convenient to the family member, that is, one in the family member's home and one in my office at the hospital.

With the family members' permission, all interviews were taped. The interview style was the same as outlined above for the conversations with the patients. The content focused on the family members' experiences of the care that the patients and the families received during the current hospitalization, but also included related aspects (e.g., the family members' perception of the patients' illness trajectory and experiences, social support within and for the family, their own health status) that allowed me to get to know the family member as a person (for potential interview questions see Appendix J for English and Appendix T for German version). Data on the family members' characteristics were also collected. The family members were interviewed repeatedly until the patients' death or discharge. Duration and timing of interviews first depended on the patients' and the family members' situation and on the latter's availability, and second varied according to the length of study participation and research needs. I was

able to cover all topics to some extent with most family members, although I talked to three of them only once.

Again, the patients' terminal status was only mentioned if the family member acknowledged it. All family members knew the patient's diagnosis, and, in the absence of the patient, most talked openly about the patient's impending death. Most family members seemed eager to relate their stories; some even stated that talking to me had been a positive experience for them.

Approximately 3 months post bereavement, a follow-up interview was done with two family members. It focused on the care experiences during the patients' last days of life and their death, as well as on reviewing retrospectively the experience of hospital end-of-life care as a whole (for potential interview questions see Appendix K for English and Appendix U for German version). One family member was contacted by phone after the patient's discharge to a palliative care unit where he died a few days later. I did not ask for a post bereavement interview, because this family member had provided comprehensive information before and answered the few open questions I still had on the phone. One patient died unexpectedly on the day of his planned discharge. This couple had told me before that they preferred not to be contacted at home; thus, I did not ask for a post bereavement interview.

In Switzerland, when a patient is discharged from the hospital, care responsibility is usually turned over to the general practitioner. The hospital does not get further information regarding the patient's trajectory. Death certificates are not publicly available. Therefore, it was not possible to follow up the patients who were discharged for time of survival.

Transcription of Conversations and Interviews

Conversations with patients and interviews with family members were conducted in the participants' everyday language, which was Swiss German for all but one participant who spoke in broken High German. I transcribed all conversations and interviews into High German. The transcription was as close as possible to the spoken language. The Swiss German version was maintained for special expressions that are not used in High German, or added in parentheses if the High German version did not transmit the meaning clearly enough. Nonverbal aspects (e.g., pauses, emotional reactions) were integrated in the transcripts.

Review of Medical and Nursing Records

The following information concerning the patient was gathered from the medical and nursing records: date of admission, age, gender, occupation, religious affiliation, diagnosis, medical history, current medical and nursing interventions, course of hospitalization and major events from the providers' perspective.

Data Analysis

Theoretical Considerations

From a practical perspective of doing interpretive phenomenology, data analysis, that is, interpretation, begins as soon as text is available, parallels further data collection and extends beyond data collection to the final interpretation and articulation. The interpretive process involves three strategies: paradigm cases, thematic analysis and exemplars, all of which are also used as presentation strategies (Benner, 1994c). Interpretation usually starts with the close analysis of one case. A paradigm case that conveys a strong pattern of meanings is chosen. "Paradigm cases embody the rich descriptive information necessary for understanding how an individual's actions and understandings emerge from his or her situational context: their concerns, practices and background meanings" (Leonard, 1994, p. 59). The analysis process consists of reading and dwelling with the text and writing, or, in other words, of moving in the hermeneutic circle. After one case is fully interpreted, another is explored and compared and contrasted to the first one. Paradigm cases are helpful because they allow researchers to recognize meaningful patterns that can subsequently be discovered in cases that represent them more subtly.

Thematic analysis means not only reading the whole text across cases for common themes in relation to the pre-established lines of inquiry, but also challenging and extending these lines. An interpretive plan emerges and major themes are developed further and refined (Leonard, 1994).

Exemplars are "stories or vignettes that capture the meaning in a situation in such a way that the meaning can then be recognized in another situation that might have very different objective circumstances" (Leonard, 1994, p. 59). Exemplars are searched for and developed throughout the interpretive process and used to discover and convey qualitative distinctions (Benner, 1994c).

The final report of an interpretive phenomenological study presents major themes, together with paradigm cases that convey the richness of participants' world and experiences, and with exemplars that highlight similarities and distinctions for the reader. Benner (1994a) has summarized what is required of a good account:

> The interpretation must be auditable and plausible, must offer increased understanding, and must articulate the practices, meanings, concerns, and practical

> knowledge of the world it interprets. Good interpretation is guided by an ethic of understanding and responsiveness. One must not read into the text what is not there. Self-knowledge is required to limit the interpreter's projection of his or her own world onto the text. The extremes of idealizing and villainizing are to be avoided. (p. xvii)

Steps in Data Analysis

For data analysis in this study, I followed the steps outlined above. Transcribing already let me become familiar with the text. I read transcripts of one case several times and wrote a first interpretation of the case. This procedure was repeated with several cases. I also read transcripts across cases, searching for common themes. In a next step, I delved deeper into a few cases in order to come up with more meaningful interpretations. I dwelled with the whole data set to find major themes. With a provisional interpretive plan, I finally started writing a result chapter; that is, I interpreted one major theme, using paradigm cases and exemplars to convey meanings and qualitative distinctions. Subsequently, I wrote the other result chapters, while, in a parallel process, the interpretive plan was constantly developed further. Interpretations were deepened, that is, chapters were re-written, until a satisfactory account was achieved.

To keep track of the interpretive process and the transitions of my understandings, I used practical devices to support my work, for instance, a "map" of each transcript, that is, a shorthand outline of the content according to line numbers that helped to find text fragments quickly. I wrote short notes throughout the interpretive process to remind me of personal responses to the text, theoretical perspectives, alternative interpretations, and so on. When working on specific topics, I created files containing the text fragments of all cases that were related to a topic.

Interpretive phenomenology should not be a lonely adventure. Other researchers' input is valuable to reveal gaps and blind spots, to offer alternative interpretations, and to provide feedback on how the text, especially its tone, speaks to them. Therefore, I discussed interpretations of the text repeatedly with two other doctoral students during the early phase of data analysis. In addition, I got feedback from the Swiss member of the dissertation committee, and we discussed interpretations, especially influences of the Swiss culture, throughout the analysis. Cultural aspects were also reflected upon with other Swiss nurses. Finally, the dissertation chair supported and challenged me to deepen interpretations.

The original text for data analysis (fieldnotes and transcripts of conversations and interviews) were in German, whereas the dissertation was written in English. Thus, interpretations were written in English from the beginning. Quotes were translated. An attempt was made to stay as close as possible to the German text, with the goal to convey the real meaning. The Swiss member of the dissertation committee, who is fluent in both languages, checked all translations in order to improve their credibility.

Respondent Validation

The best interpretive phenomenological account is one in which participants or people who share participants' situation recognize themselves, an account that puts into words what they already understood but lacked the words to express (Benner, 1994a). Thus, researchers may present findings to participants and get their feedback (Chesla, 1994). For this study, no validation of results through participants was planned. It was expected that most patients would have died. Since the analysis was written in English, and I was in the US while the family members were in Switzerland, presenting findings to them was not feasible for practical reasons. However, I tried to validate interpretations as much as possible during data collection; that is, I reflected my understanding of their stories to participants during conversations and interviews as often as possible, asking them to comment on my view. I also thought about possible interpretations and took up these topics in subsequent interviews.

Some Explanatory Comments on the Results

In the following result chapters, all names are pseudonyms. In order to increase confidentiality, the male form is consistently used for physicians and the female form for other professional groups, regardless of the persons' real gender. For the same reason, descriptions of the context, of treatments, and so on, are purposefully kept vague. Details are only provided when needed to understand the situation.

Quotes were slightly edited if this seemed necessary to make them more readable and improve understanding. In the quotes, three dots at the end of a sentence mean that the speaker did not finish the sentence, but left it open ended. Within a quote, three dots in parentheses (…) mean that a part of the quote was left out, because it would not contribute to the understanding of the topic; put at the beginning of a line between the quoted text, (…) means that the following part of the quote is taken from another interview section.

Conclusions

In the first section of this chapter, I showed that, in spite of the vulnerability of terminally ill patients, research in end-of-life care is feasible if researchers carefully prepare the data collection, explain the study as thoroughly as possible to enable prospective participants to make informed decisions, always give priority to patients' and their family members' well-being and needs, are flexible, continue to reflect on the process and deal appropriately with problems. If the style of the researcher is one of empathic listener and observer, the research process itself can be less intrusive and more attuned. My experiences with conducting this study confirm that research in end-of-life care is possible, if the described precautions are carefully considered throughout the research process. However, researchers have to take potential problems into account, for instance, the difficulties with prognoses and recruitment, or the impact of a busy acute care setting on research procedures.

In the second section, I discussed interpretive phenomenology as an appropriate method to study terminally ill patients' and their families' experiences of end-of-life care in a particular hospital setting, and in the third section, I explained how the method was used for this study. The literature review shows that so far, most studies focused on specific components of patients' or families' experiences with hospital end-of-life care and many described satisfactory or unsatisfactory aspects. Missing are comprehensive pictures of everyday hospital end-of-life care as experienced by patients and their family members over the course of a terminal illness. This study presents a broader picture. Patients and family members were recruited as pairs and, as far as possible, followed throughout the hospital stay. Conversations and interviews were guided by broad, open-ended questions, which allowed study participants to elaborate on their concerns rather than focus on aspects predetermined by the researcher. Interpretive phenomenology proved to be a very suitable method to increase the understanding of terminally ill patients' and family members' lived experiences of being cared for in a Swiss university

hospital. Interpretive phenomenology allowed challenging the research questions and discovering that care experiences are embedded in patients' and family members' more comprehensive view of the hospital and influenced by their way of leading their life.

CHAPTER FOUR: LEADING A LIFE WITH A TERMINAL ILLNESS

"A day at the hospital is also just a day of life."

„Ein Tag im Spital ist halt auch ein Tag des Lebens." (5a, 5b 254-255)

From a phenomenological perspective, people are born into a culture and are always already situated into a particular, historical and familiar world, that is, in a meaningful set of relationships, practices and language. This shared world sets up which possibilities are open or precluded, and it provides shared norms and meanings. People are, through their actual involvement in everyday activities, absorbed in the world of their family, the world of their work, the world of camping, and so on. While embedded in these shared worlds, persons, couples, or families lead their own unique, biographical life in a specific historical time. Leading a life means doing or experiencing things that give life its particular quality (Sinclair, 1987), or to be or become a certain kind of human being (Taylor, 1997). Leading a life encompasses the feeling that one's life is moving somewhere, in one or more directions, in various rhythms of regular and critical phases and passages. Leading a life also involves trying to guide these movements to some extent.

When a terminal illness breaks into peoples' lives, their familiar lifeworlds are shattered. Life moves into a critical phase, a passage that brings life's finitude to the foreground. Peoples' possibilities to continue living their usual life, let alone guide their life, are now very limited; carrying on everyday taken-for-granted activities becomes difficult or even impossible. With the onset of illness, people are forced to enter new worlds – the world of illness, the hospital world, the world of professional care. But, as stated in Gadamer's words (1960/1995), even when life changes rapidly, as during revolutionary times – or when a terminal illness intrudes – more of the old is preserved than anybody expected or is aware of, and the old merges with the new. Peoples' everyday horizons get clouded, new prospects appear, their horizons shift and fuse into new ones, but do not close down completely. Thus, people facing a terminal illness still rely as much as possible on the familiar worlds of their home, family or work for shared meanings, language and practices, even though they are compelled to enter unfamiliar worlds and move on to new horizons.

My research question focused on patients' and family members' care experiences in the hospital, as I wanted to explore the world of professional care from their perspective. However, from conversations and interviews, it became clear that care experiences can only be understood in the context of patients' and family members' experiences of the hospital stay and of leading their life with a terminal illness. Patients and family members were continuing to live their life, however, now their life had become a life with a terminal illness, which forced them to search for professional care at the hospital. One family member poignantly explained that "a day at the hospital is also just a day of life." („Ein Tag im Spital ist halt auch ein Tag des Lebens." 5a, 5b 254-255). For patients and family members, the overarching experience was facing the terminal illness. This experience shaped their experiences of the hospital stay and of the professional care they received. When asked about good and bad experiences at the hospital, one patient bluntly stated that it was bad to have the illness and that nothing was good because no cure was available (9b 2. 62-76).

From the study participants' accounts, it became obvious that the research questions were stated too narrowly. While the questions focused on patients' and family members' experiences with their care in the hospital, these experiences were firmly grounded in the experience of being in the hospital and of leading a life with a terminal illness for patients and family members. Thus, they did not relate detached accounts of single care episodes, but quite extensive stories of their life with a terminal illness. Episodes that stood out for patients and family members became understandable against the background of their whole story, while the meaning of the whole story was illuminated through specific experiences. In accordance with the hermeneutic circle, the whole rendered the parts more comprehensible and vice versa (Gadamer, 1960/1995).

The following presentation of findings takes this enlarged perspective into consideration. In this chapter, patients' and family members' experiences of leading a life with a terminal illness are described. The next chapter outlines experiences of being in the hospital. Chapter six thematizes commitment and caring as decisive aspects of the relationship among patients, family members and care providers. Chapter seven, finally, addresses patients' and family members' experiences with care interventions.

Going on With Life

In conversations during observation and in interviews, patients and family members talked at length about their lives, relating stories about their families, their work, their experiences, about good and bad times. The slightest hints triggered these stories, such as a demographic question or one about their business, or even no question at all. It seemed that patients and family members needed to share more than care experiences; they wanted to share the fuller picture of their life stories. From these accounts, it becomes clear that patients and family members, some as couples, continued living their lives, even though a terminal illness had broken in. As mentioned in the introduction, these life stories are illuminating; the study participants' accounts of their experiences, their actions and behavior at the hospital become more comprehensible. Background knowledge renders the present more understandable. The stories of two couples, as far as they related them, are outlined below as illustrative examples.

Confidence and Enjoying Life

Mr. Blum was 85 years old, his wife three years younger. They had been married for almost 60 years. Mr. Blum, although Swiss, grew up in Germany where the couple met and got married during World War II. Their first plan of building up their own business in the services industry failed; the designated house got destroyed during a bomb raid. Later, Mr. Blum's parents' house, where the couple had been living, was also bombed out. With their one year old daughter, the couple moved to Switzerland in 1945, and after some time the family moved on to the small town where they were still living. Their son was born there, and they started up their own business and ran it successfully for over 30 years. They lived in their own house, with the business on the first and their living space on the second, third and fourth floors. Along with caring for the family and the household, Mrs. Blum was always assisting in the business. Although she was not professionally trained for her job, she learned by doing and was soon able to take on every required task. While the children were small, she had an aide for the household. When the couple retired 18 years ago, the business was carried on by someone else who was renting the rooms. The second floor was turned into a separate flat and rented out, and the couple since then have been living on the third and fourth floors.

Mr. and Mrs. Blum were active members of the Catholic Church. Thirty years ago, they were decisively involved in building up the community around the newly constructed church in their home town. Mrs. Blum had participated over the years in social work for the church. The couple liked hiking; after retirement, and until recently, they organized hiking tours for the elderly in the community. They maintained close contact with their daughter who was single, working and visiting regularly, and with the son and his family. They greatly enjoyed seeing their first great-granddaughter grow up.

For some time, Mrs. Blum had been developing more and more problems with walking. The big flat and the numerous stairs had become a burden. However, Mr. Blum, who was still agile and felt healthy, took on household chores, like preparing breakfast and shopping. He also supported his wife with her body care. They employed a cleaning lady, and the couple got support from their children or neighbors, if needed. They have been, therefore, able to live on in their own house so far.

The Terminal Illness Breaks in

About 18 months ago, Mrs. Blum realized that her husband was losing weight. Only after several months, was she able to convince him to see his general practitioner. Mr. Blum was diagnosed with metastatic prostate cancer eight months before his hospitalization; he underwent an orchiectomy and started on chemotherapy. The latter had to be discontinued, because he did not tolerate the medication. After treatment, Mr. Blum felt as well as before and did not experience any symptoms until about one month prior to his hospital admission. For four weeks, he suffered increasingly from back pain. Eventually, one morning, he was unable to get up; his right leg was no longer under his command. The general practitioner immediately organized admission to the regional hospital. A few days later, when vertebral metastases causing paraparesis had been diagnosed, Mr. Blum was admitted to the university hospital for radiotherapy.

A Positive Stance Towards Life

The couple, but especially Mr. Blum, radiated a positive attitude. When looking back, they seemed satisfied with their life. While talking to me and together, reminding each other of special experiences, they appeared to re-enjoy good moments, for instance their hiking tours in the Black Forest. Their marriage, although not without disagreements, was a good one, as Mr. Blum stated:

> My wife and me, we made a good team. The sun was not always shining, those who pretend this… that isn't true. Yes, we had some quarrels, but we stuck together. (pause) And this is important in life.
>
> Meine Frau und ich, wir waren ein gutes Gespann. Es schien nicht immer die Sonne, diejenigen, die das vorgeben… das stimmt nicht. Ja, es hat manchmal „Chritz" gegeben, aber wir hielten zusammen. (Pause) Und das ist wichtig im Leben. (2a 2. 155-161)

They had gone through difficult times during the war and when building up their business. With support and hard work, however, together they managed to slowly improve their situation. Both acknowledged the other's contribution to their success.

> Patient: And then, of course, it wasn't exactly the land of milk and honey. It was a hard way, at that time. But we always had good people. And so we also started up our own business… and together… my wife was the soul of the business. She went so well along with people (his speech is faltering, he is moved). Many only came because of her…
> Wife: Oh, this is not true; they came because of you…
> Interviewer: Well, this doesn't really matter, they came anyhow (laughing)…
> Wife: Main point, they came…
> Patient: Well, yes… and slowly we were doing better and better. We stuck together through thick and thin… yes!
>
> Patient: Und danach flogen uns natürlich die gebratenen Tauben nicht in den Mund. Das war ein harter Weg, damals. Aber wir hatten immer wieder gute Menschen. Und so haben wir dann auch ein eigenes Geschäft angefangen… und zusammen… die

> Seele war meine Frau, von dem Geschäft. Sie konnte es sehr gut mit den Leuten (er spricht stockend, ist gerührt). Es sind viele nur wegen ihr gekommen...
> Ehefrau: Ach, das ist nicht wahr, die kamen wegen Dir...
> Interviewerin: Das ist ja egal, sie kamen jedenfalls (lachend)...
> Ehefrau: Hauptsache, sie kamen...
> Patient: Ja, ja... und langsam ging es uns dann immer etwas besser. Wir hielten zusammen durch dick und dünn... jawoll! (2a, 2b 167-181)

Mr. and Mrs. Blum's marriage was traditional: Mrs. Blum clearly saw her husband as the head of the family, responsible for their business and all money issues, while she took care of the kids and the household. Her remarks about her husband's generosity underlined this. It could easily be argued that it was their, not just his money, and that she was as generous as he was. In this sense, she relied on her husband. Recently, her disability had made her even more dependent upon him; without his support, she would have been unable to stay at home. When her husband was admitted to the hospital, the general practitioner organized a temporary bed in a nursing home for her.

When Mrs. Blum mentioned her husband's generosity, he stated that he had experienced generosity himself:

> Wife: He was always generous, towards me and also towards the children... only too generous.
> Patient: One can never be generous enough.
> Wife: You know, rarely does a father give his children the inheritance during his lifetime. What we had worked for, the house, also to the daughter...
> Patient: Well, yes... but I had experienced the same from my parents, you know. (...) She (his mother) gave the last thing... (...) From the little she had, she still gave to our children.
>
> Ehefrau: Er war immer grosszügig, zu mir und auch zu den Kindern... nur viel zu grosszügig.
> Patient: Das kann man gar nicht genug sein.
> Ehefrau: Wissen Sie, das gibt es selten, dass ein Vater schon zu Lebzeiten den Kindern schon das Erbe gibt. Wofür wir geschafft haben, das Haus, der Tochter auch...
> Patient: Ja, ja... aber ich hatte auch von meinen Eltern das Gleiche erfahren, nicht wahr. (...) Sie (seine Mutter) hat auch das Letzte... (...)Von dem wenigen, das sie hatte, hat sie unseren Kindern noch gegeben. (2a, 2b 313-327)

Mr. Blum related that, many years ago, he lent money to a former employee, even though he could hardly afford doing so. This was the beginning of a lifelong friendship; the whole family, including the great-granddaughter, still greatly enjoyed visiting this former household aide and her husband on their farm. Mr. Blum explained that, whatever you do, it will come back one day in a direct or indirect way. He experienced this again and again, for instance, from the church community during his current hospital stay (2a, 2b 493-498).

The couple stated that their life had never been guided by any scheme; both valued spontaneity and enjoyed what ever came up (2a 2. 365-371).

> Wife: Sometimes I cooked, sometimes he said: „The weather is so nice, let us go out."
> Patient: Well you know, in this respect, my wife was always ready to go along with; I already did this when we were still running the business. It could be that, when I came upstairs, the tea water was on the stove and so on, and then I could say: "Come on, turn this stuff off, now we are going out." (...) All of this was so... just spontaneous...
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> Ehefrau: Manchmal habe ich gekocht, manchmal hat er gesagt: „Es ist so schönes Wetter, komm wir gehen weg."
> Patient: Also wissen Sie, in dieser Beziehung hat meine Frau immer schnell mitgezogen, das hatte ich schon, als wir noch das Geschäft betrieben. Da konnte es sein, dass ich am Abend rauf kam, da war das Wasser auf dem Herd für Tee und so, und dann konnte ich sagen: „Komm, stell das Zeug ab, jetzt gehen wir aus. (...) Das war alles so... einfach spontan... (2a, 2b 300-312)

Mr. and Mrs. Blum, as practising Christians, were grateful for their achievements in life.

> Wife: And we say this, we also had good luck, could stay healthy, could always work, could acquire something, did get something. And yet one easily forgets that one has help from above (points to heaven), not just good luck.
> Patient: Well, yes... I just don't know... for me as a Christian it is just... There is someone else who shows you the way. And these are not always easy ways for us, but I accept them. But I am also grateful for everything.
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> Ehefrau: Und wir sagen das, wir haben auch Glück gehabt, konnten gesund bleiben, konnten immer schaffen, haben etwas erworben, sind zu etwas gekommen. Und

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> dabei vergisst man ganz, dass man Hilfe hat von hier oben (zeigt zum Himmel), nicht nur Glück.
> Patient: Ja, ja… also ich weiss nicht… für mich als Christ ist einfach… da ist ein anderer da, der zeigt, wo es lang geht. Und das sind für uns nicht immer bequeme Wege, aber die nehme ich an. Ich bin aber auch dankbar für alles. (2a, 2b 335-343)

One not so easy way that Mr. Blum was, nevertheless, willing to take on was his illness. He was aware, from the time of diagnosis, that the treatment was not curative, that the cancer would grow, although, according to the surgeon, no-one could predict when and how (2a, 2b 387-392). From reading about cancer, he anticipated a downward journey, and from repeated questions of and comments by his physicians regarding pain and the availability of pain medication, he expected to suffer pain (2a, 2b 694-700).

> I was just grateful that for a long, long time I did not need any pills. I did not take this for granted. They (the physicians) did not ask without any reason… It seems to be the normal state that this proceeds with pain.

> Ich war nur dankbar, dass ich lange, lange Zeit keine Tabletten brauchte. Ich habe gefunden, das sei gar nicht selbstverständlich. Umsonst haben die (die Ärzte) nicht gefragt… Das scheint der Normalzustand zu sein, dass das dann schon mit Schmerzen weitergeht. (2a 195-203)

Mr. Blum was accepting the cancer diagnosis as an issue that had to be expected at his age. He did not spend much time thinking about it and basically continued to live as before, gratefully enjoying, as the above quote shows, every pain free day that was still granted to him.

> I said: "I also know, how old I am, you know." It is not the same, if I am 50 years old or 85, so there is a little difference. And we just went on living afterwards, as usual. When it was a nice day, I said: "Oh, I feel like, shall we go to the "Hogerbeizli?" (a tourist café).

> Ich sagte: „Ich weiss auch, wie alt ich bin, nicht wahr." Es ist nicht das Gleiche, ob ich 50 Jahre alt bin oder 85, das ist schon ein kleiner Unterschied. Und wir haben danach weiter einfach gelebt, normal. Wenn ein schöner Tag war, habe ich gesagt: „So, jetzt habe ich Lust, wollen wir aufs „Hogerbeizli?" (ein Ausflugsrestaurant). (2a, 2b 392-409)

The couple, when talking about Mr. Blum's illness and what it meant for them, agreed on their goal: maintaining the best possible quality of life, for both, for as long as possible.

> Just over the last days we could really talk well together. She has it now... accepted, the fact that it is incurable, and that no-one knows how quickly or slowly it will proceed, and what dimensions it will take on. So, I am not thinking about it anyway. Why shall I think about this in advance? We then talked together saying that for us, it is now a matter of maintaining our quality of life as much as possible and as long as possible, that we can, for instance, drink a glass of wine together, may be even two, mainly in the evening, of course.
>
> Gerade in den letzten Tagen haben wir wirklich gut miteinander reden können. Sie hat das jetzt... akzeptiert, also dass es unheilbar ist, und dass niemand weiss, wie rasch oder wie langsam dass es weiterschreitet, und was es für Ausmasse annimmt. Also, ich selber mache mir da sowieso keine Gedanken. Was soll ich schon im voraus da studieren? Dann haben wir so zusammen geredet, für uns geht es jetzt einfach darum, die Lebensqualität so gut wie möglich und so lange wie möglich zu erhalten, dass wir zusammen zum Beispiel ein Glas Wein trinken können, vielleicht auch mal zwei, hauptsächlich am Abend, natürlich. (2a 2. 337-349)

Mr. Blum, who was looking back on a full and satisfying life, was able to accept that at age 85, the end of his life was approaching. Although he was aware of potential future troubles, he refused to worry in advance about problems that might or might never come up. Instead, he was thankful for the good time left and enjoyed every symptom free day with his wife. Throughout their marriage, besides working hard, the couple had always appreciated joyful moments, be it their hiking holidays or going out spontaneously. They had always known and still knew what quality of life meant for them and could now agree on realistic goals for their near future. They had experienced their faith as a strong resource and could confidently trust in this guidance. As parents, they had maintained a good relationship with and supported their children, and now they felt supported by their family. Over many years, they had built up strong ties with neighbors and within the community; now they could rely on this network. Therefore, although struck with Mr.

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Blum's terminal illness, the couple was mostly able to keep up a positive attitude towards their situation and their life even during Mr. Blum's hospital stay.

Facing Losses and Uncertainty

It goes without saying that the couple's situation also comprised sorrow and problems. As stated above, Mrs. Blum depended on her husband, and Mr. Blum was deeply concerned about his wife's future. Both were aware that Mr. Blum was better able to continue living alone and had silently hoped and prayed for him to be the surviving partner. Confronted with her husband's terminal illness and his sudden deterioration, Mrs. Blum wished to follow him should he die. She withheld her appeal to the general practitioner from her husband, however, knowing that it would only increase his concern.

> When my husband was in the regional hospital, he said that he had always prayed: „Dear God, let me survive my wife. I am better able to be alone than my wife." (...) But you know, I pray every day that my husband may not die before me, but if he dies, I said to the physician: "Doctor, give me an injection so that I can follow my husband right away." And I told him: "I am serious about this." I am 100% serious about this. I did not talk about this to my husband.
>
> Als mein Mann im Regionalspital war, hat er gesagt, er habe immer gebetet: „Lieber Gott, lass mich meine Frau überleben. Ich kann besser alleine sein als meine Frau." (...) Aber wissen Sie, was ich jeden Tag bete, dass mein Mann nicht stirbt, vor mir, aber wenn er stirbt, da habe ich zum Arzt gesagt: „Herr Doktor, machen Sie mir eine Spritze, damit ich gleich mit meinem Mann gehen kann." Und ich habe zu ihm gesagt: „Das ist mein Ernst." Das ist mir 100% ernst. Zu meinem Mann habe ich das nicht gesagt. (2a, 2b 798-803, 856-862)

The couple who had shared this life and stuck closely together for 60 years was aware that separation through death was coming. Mr. Blum, as the head of the family for 60 years, still felt responsible for his wife and wished to care for her until her death. He was willing to undergo the sorrow of losing her for the sake of saving her the experience of being left behind alone. Mrs. Blum, as the dependent partner who had happily accepted her husband's guidance over 60 years, could not imagine a life without her husband.

The couple was attached to their house and Mr. Blum was especially fond of staying at their home. He had gained some insight into old people's homes when accompanying his wife for visits and could not imagine himself in one of them. He thought that for him, with his still active mind, this would be a horror (2a 2. 416-420).

Since Mrs. Blum's disability made living in their flat more and more difficult for her, she would have been willing to move to an old people's home. The general practitioner brought up and debated the topic of moving to a more convenient place repeatedly with the couple. They had not, however, taken any further steps, because Mr. Blum was still able to support his wife and did not see the need for change. The deterioration of his illness with bone metastases causing paraparesis and great pain made the problem suddenly an urgent one.

> Wife: I have often told my husband: "I wouldn't mind going to an old people's home." (...) But my husband always mentioned: "I am not ripe for the old people's home, so we just won't go to the old people's home." And the physician always pushed that, eh, we should take a smaller flat with an elevator, one that would not cause so much trouble anymore, where one does not have to climb stairs. But this was always only because of me. And my husband always said: "Listen, doctor, I am doing fine, and my wife doesn't have to climb stairs unnecessarily," and as he also told you, "we go out eating, I am shopping," that's what he always said. Then I have a cleaning lady who does the cleaning, and then... well. Then once, I probably wasn't in a good mood and he neither, so I told him: "I will go to the old people's home on my own, and you can stay in your hut on your own." When I had said this, he said: "Okay, go search for a flat, but on your own, without me. You can choose the one that you like, and we will move there." And then he pointed up the finger like that: "But no complaints later about the neighbors, or because the TV is too loud." You know, in your own house you never experienced this. "Or that you complain, now it's their turn to do laundry today, we cannot do any laundry now. So, no complaints, I will move with you." Then we did not say anything anymore. Then we were at the physician's office again, and he asked, if we had been able to decide for something. He then told the physician the same. And I asked: "Doctor, would you

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> search for a flat under this condition?" (…) Yes… later this came up (hospital admission), now it is this moment.

> Ehefrau: Ich habe schon oft zu meinem Mann gesagt: „Mir macht es nichts aus ins Altersheim zu gehen." (…) Aber der Mann hat immer gesagt: „Ich bin nicht reif fürs Altersheim, also gehen wir auch nicht ins Altersheim." Und der Arzt drängte immer darauf, eh, wir sollten eine kleinere Wohnung nehmen mit Lift, die nicht mehr so viel Arbeit gibt, wo man nicht mehr Treppen steigen muss. Aber immer nur wegen mir. Und mein Mann sagte immer: „Hören Sie, Herr Doktor, mir geht es ja gut, und meine Frau muss nicht unnötigerweise Treppen steigen," und wie er Ihnen auch gesagt hat, „wir gehen essen, ich mache die Einkäufe," das hat er immer gesagt. Dann habe ich eine Putzfrau, die kommt zum Putzen, und danach…also. Dann einmal, wahrscheinlich war ich nicht gut aufgelegt und er auch nicht, da habe ich zu ihm gesagt: „Ich gehe jetzt dann alleine ins Altersheim, und Du kannst alleine in Deiner Hütte bleiben." Als ich das gesagt hatte, hat er gesagt: „Also gut, geh Du jetzt eine Wohnung suchen, aber ganz alleine, ohne mich. Du darfst die auslesen, die Dir gefällt, und da gehen wir hin." Und dann hielt er so den Finger auf: „Aber ja keine Reklamation nachher wegen der Nachbarn, oder weil der Fernseher zu laut laufe." Gellet, im eigenen Haus hat man das gar nicht empfunden. „Oder dass Du reklamierst, jetzt haben die heute Wäsche, jetzt können wir nicht waschen. Also, keine Reklamationen, ich zügle mit Dir." Dann haben wir nichts mehr gesagt. Dann waren wir wieder beim Arzt, und er fragte, ob wir uns für etwas hätten entschliessen können. Da hat er dem Arzt das Gleiche erzählt. Und ich fragte: „Herr Doktor, würden Sie mit dieser Auflage eine Wohnung suchen gehen?" (…) Ja…nachher kam das (die Spitaleinweisung), jetzt ist dieser Moment. (2a, 2b 706-740)

With Mrs. Blum depending on her husband's support and Mr. Blum's current health deterioration, the future was very unclear for the couple. Although radiation therapy was effective, the pain relieved, and Mr. Blum had started walking training again, a return home seemed unfeasible. Pressured to find a solution and taking into consideration her husband's strong wish to stay in their house, Mrs. Blum finally came up with the idea of moving to the smaller flat on the second floor.

> Because he is so attached to the house, and told the physician: "It is my biggest wish, that they will once carry me out dead from here," so I was lying in bed at night in the nursing home and couldn't sleep. And then, this certainly was an inspiration: What if we would move to the second floor? Then we would only have one flight of stairs… and would install a stair-elevator, we would then at least be at home and together. I thought about this at night, and when I came the next day, I said to him: "Listen, what if we would move to the second floor? We then would not have to go to the old people's home." (…) Then he said: "Well, would you move to the second floor" I

> said: “Of course.” “Then we will move to the second floor, this is big enough for us.” And, you know, perhaps I am only thinking this, but I believe it 100%, that from then on, he was livening up.

> Weil er so an dem Haus hängt, und zum Arzt gesagt hat: „Es ist mein grösster Wunsch, dass sie mich hier mal tot hinaustragen,“ da lag ich im Heim nachts im Bett und konnte nicht schlafen. Und dann, das war sicher eine Eingebung: Und wenn wir zügeln würden, in den ersten Stock? Dann hätten wir nur eine Treppe… und würden da einen Treppenlift einbauen, dann wären wir doch zu Hause und beieinander. Das habe ich in der Nacht überlegt, und als ich am nächsten Tag kam, habe ich zu ihm gesagt: „Du, höre, und wenn wir in den ersten Stock runter zügeln würden? Dann müssten wir nicht ins Altersheim.“ (…) Da sagte er: „Ja, würdest Du in den ersten Stock gehen?“ Sagte ich: „Klar.“ „Dann gehen wir in den ersten Stock, das ist gross genug für uns.“ Und, wissen Sie, vielleicht meine ich es auch nur, aber ich glaube es 100%ig, von da an hat er etwas aufgelebt. (2a, 2b 1026-1043)

Mr. Blum picked up his wife’s suggestion as the best available option: “That is not as it was before, but still ten times better than being in a home.” („Das ist nicht mehr so, wie es vorher war, aber immer noch zehnmal besser, als wenn wir in einem Heim wären.“ 2a 2. 414-416). He stated that they would be able to organize themselves and be ready to get help if needed. He anticipated that, in the future, they would need the support of professional home health care. But he was not willing to bother about these future issues now (2a 2. 434-439).

Mr. Blum also refused to worry about potentially missed decisions or changes in the past. He never used to do so; he would not do it now. In fact, three weeks after his hospital admission, his health status had improved so much that he was again able to climb as many stairs as he had to climb at home. The couple, therefore, decided against moving. They planned to return home again after a three week stay in a health resort. Although their living arrangement appeared to lie on shaky grounds, any change seemed unnecessary at the moment; they would deal with upcoming problems at that time.

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Holding on to Their Way of Living

This couple's life story enlightened their current situation, their actions and experiences. Faithfully and confidently, they had taken up their life and, after a difficult start, successfully built up their family and their business together. They worked hard, but also enjoyed their life and were active, caring members of their community. When the terminal illness intruded, they could rely on their positive experiences. They, but especially Mr. Blum, were able to continue living and still get the best out of their situation. Given her dependency on her husband, Mrs. Blum's greater concern was understandable. The couple's final decision against any change and for a return home became comprehensible, when Mr. Blum's perspective on leaving his house for an old people's home was considered, and given his trust that things would fall into place at the right time.

Mr. and Mrs. Blum led their life with great confidence. Once they had established their family and business, their life was marked by continuity and integrity, and embedded in a stable context. Within a shared world, they had found their unique way of leading a life that was very meaningful to them. Even when the terminal illness intruded their life, they were at first able to go on living. The sudden deterioration of Mr. Blum's health status and his hospital admission, however, shook up the couple's world and forced them to adjust their way of living to the restrictions that the illness put upon them. They took up the challenge, searching and finally opting for a solution that allowed them to keep as much continuity as possible.

Next, the story of a second couple is described. This couple was chosen as a contrasting example. Both couples had been living in Switzerland during the 20th century, that is, they shared a cultural and historical world. Both had been married for decades and ran a business successfully. However, their worlds of family and work, the way they led their lives and took up the man's terminal illness differed greatly. While these contrasts make lived life and lifeworlds more visible, they also show how both couples held on to their respective way of leading their life when the terminal illness broke in, and how their life perspective shaped their experiences with the stay and care in the hospital.

Going Ahead With Work While Ignoring the Illness

Mr. and Mrs. Alder were both 75 years old. They had been married for 50 years. Both grew up in the same village. While Mrs. Alder, after training at a commercial college, completing a housekeeping apprenticeship and working in an office, took on the responsibility for their household and cared for the family, Mr. Alder entered the company that his father had founded. Later he took over the company. First, he worked for many years together with two other family members. As the youngest, he then took over on his own, and about seven years ago, he handed the company over to his eldest son. However, he had still been working for the company on a daily basis and dealing with several other business mandates ever since.

The couple had five children, all of them successful professionals, and nine grandchildren. Two sons were currently living and working abroad with their families. One daughter was a physician. Mr. and Mrs. Alder greatly enjoyed their family and stayed in contact with all of its members.

Mrs. Alder, besides caring for her big family and their own house, had for years been caring for her parents and later for an aunt who had been living with the family until her death. She had many interests, used to play tennis until two years ago, played the piano and was an eager reader. For some years, she had suffered from Parkinson's disease, which slowed down her movements a bit, gave her a monotonous voice and flattened her facial expression.

The Illness Trajectory

Mr. Alder had been diagnosed with prostate cancer nine years ago. He got hormone therapy subsequently for two years. One year later, he underwent aortocoronary bypass surgery for his coronary heart disease. He also underwent a cholecystectomy. A transurethral prostatectomy was performed five years ago. Continual problems with the passing of urine let to the insertion of a suprapubic indwelling catheter one year later. This catheter was not without problems; it got blocked and had to be changed pretty frequently. When bone, lung and liver metastases were diagnosed a year ago, radiotherapy to the right hip and chemotherapy for three months followed. Three months ago, a metastasis on the forehead was treated with radiation. Mr. Alder was admitted to the hospital in a generally bad condition with fever, severe pain in the upper abdomen and a blocked suprapubic catheter. After the exclusion of any heart problem, the pain was attributed to tension in the liver capsule due to multiple metastases and the temperature to a urinary tract infection. The latter was treated with antibiotics, urinary flow was secured, and the patient got fentanyl patches for pain. Because the patient had strongly opted for it prior to his hospitalization, a palliative chemotherapy was started with the goal of reducing liver metastases and thereby the pain. Surprisingly, Mr. Alder survived this crisis and recovered enough to be discharged home again two weeks later.

Working is Living

Mr. Alder mentioned that he would no longer have any direct responsibility in the company, but that he kept helping out wherever he was needed (1c 102-104). Relating what he did on a usual day at home, he stated:

> At six o'clock, or a quarter to six, I get up, and then I am on my way, go shopping for my wife. First I go to the office, and then I go shopping, this and that and for the company, if they have something, bank or so. At noon, I go home and sleep for one to one hour and a half, then I get up again and do something for me privately or go to the office once more, it depends. At five, six o'clock, I go home.
>
> Um sechs Uhr, viertel nach sechs, stehe ich auf, und dann bin ich unterwegs, mache Einkäufe am Morgen für meine Frau. Zuerst gehe ich ins Büro und dann mache ich Einkäufe, dies und jenes und im Geschäft, wenn sie etwas haben, Bank und so. Am Mittag gehe ich nach Hause und schlafe eine bis anderthalb Stunden, dann stehe ich nochmals auf und mache für mich privat etwas oder gehe nochmals ins Büro, je nachdem. Um fünf, sechs Uhr gehe ich nach Hause. (1a 252-260)

Mrs. Alder provided a different picture of her husband's work pattern. She said that the company was his hobby, he was at his office every day, served as a member on several boards of directors, and still travelled abroad for the company; only two weeks prior to his hospital admission, he visited Germany driving himself (1b 269-270).

> He would be in retirement for ten years now, but he was in the office each morning at half past six, until almost the last day, on Monday. (...) He just wanted to hang on until the end, and he said: "I will turn over this mandate or that next year." He was always clinging to his profession, to his work. (...) It was his hobby, the company. (...) Only a few weeks ago, he was in the United States for final discussions, France, Italy, Germany, he wanted to take part everywhere. Until the last day, he did not admit defeat.
>
> Er wäre ja seit 10 Jahren pensioniert, aber er war jeden Morgen um halb sieben im Büro, bis fast auf den letzten Tag, am Montag. (...) Er wollte einfach dran sein bis zuletzt, und er sagte: „Das Mandat und jenes gebe ich dann ab nächstes Jahr." Er hat sich immer so an seinen Beruf geklammert, an seine Arbeit. (...) Das war sein Hobby, der Betrieb. (...) Noch vor einigen Wochen war er in Amerika für Abschlussbesprechungen, Frankreich, Italien, Deutschland, überall wollte es dabei sein. Bis auf den letzten Tag gab er sich nicht geschlagen. (1b 94-102, 127-134)

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It seems that Mr. Alder was rather downplaying his work involvement; in fact, working for the family company appeared to be such a relevant aspect of his life that he could not imagine continuing to live without his work, even while facing the terminal phase of his illness. Two weeks after his admission, the man who had admitted to his wife that he might not have survived the night without being admitted to the hospital (1b 121-123), and who was expected to die by his daughter (1b 195-199), was again making plans for returning to work. According to his wife, he assumed that the family had deliberately planned his discharge just before a holiday, so that he would not be able to go to the office for some days (1b 140-142). He stated that, during the upcoming holiday, he would get himself organized again at home and work on his tax declaration. The following week, he might then go and have a look at his office to see what work was waiting for him (1a 351-356).

Having a Disease

Mr. Alder stated that he had rarely been sick (1a 285-290). He seemed to associate being sick with lying in bed rather than with any disease. When referring to the myocardial infarction he had suffered 20 years ago, he doubted that it would still be considered an infarction today (1a 565-567). He related what had happened prior to his admission as follows:

> Patient: Well, before I had seen the urologist, you know, and then, it started, well, in fact… because of the passing of urine. From the general practitioner to the urologist, but that was a long, long time ago, almost ten years, or eight years probably. In between, I had other health related issues that were in the foreground, had bypasses, five bypasses, and gall bladder, so this moved a bit to the background… I don't really remember, what in fact then… if one just with medication, probably… and the PSA value got controlled, and it decreased, rapidly, below zero four, or what is the dividing line, the limit…
> Interviewer: Yes, something like that…

Patient: And everything was under control, and suddenly… one and a half year ago it went up above 40, and then these reports also go to the general practitioner and to Alice (daughter, who is a physician), and then Alice said: "You know, something has to be done now. I will make an appointment for you with one of my colleagues, Prof. Muller (oncologist)." Then I said: "Well, but this has to be done by the general practitioner or by the urologist." She said, she would sort this out, she would talk to him. But he then had to make the appointment, just in order to go somewhat through the proper channels… Yes, and this worked out in any case. And then I had the first invitation and examination… And my wife always joined me, when we had an audience with him. And then we started with chemotherapy… Program of the chemotherapy, there were, I believe, six or eight sessions, where I just got these infusions, that was ambulatory. And I tolerated it very well, and… eh at the same time, or straight afterwards, one did a radiation program with Prof. Meyer (radiologist). I can't remember now, what came first, just in succession… also about nine sessions… I had pain, here, in the hip, and here, on the side and here… and even up here… And this was also done, very strictly, each week, on the same day, at the same time, was this done. In the middle of the year both programs were finished. And in autumn, I had a check-up with Prof. Muller, just wellbeing, blood and so… and that was alright from the chemotherapy, and the pain was gone. But we had already seen this hump in spring (bone metastasis on the forehead). Then he said he wanted to show this to his colleague, Prof. Meyer. In spring he said, it would not have priority, it would not be dramatic, one should just observe it, and in summer… In autumn, we finally passed this on, and Prof. Meyer looked at me and then I had six sessions of radiotherapy. And afterwards one had a final meeting with Mr. Meyer, and he just said, this in fact impressed me: "Mr. Alder, as soon as you feel something, pain somewhere or a prickling in the leg, something abnormal, not just up here (forehead), elsewhere as well, you have to come immediately… as an emergency… not wait another three weeks, because one has an appointment or so, but immediately." This in some way…this stuck with me. And now… I had a check-up again with Prof. Muller, a regular one, where one drew blood, and this was on Monday… this was two weeks ago. And then one made an appointment for one week ago, for a first chemotherapy, with the intention to program this for every week. That was two weeks ago, and on Tuesday, one day later, I just didn't feel well anymore. I had pain; I couldn't go on, almost over night.
Interviewer: Before you did not have this trouble?
Patient: No, in fact not. I… well, it is possible that perhaps, around the weekend something had shown up, and I probably did not tell Prof. Muller clearly enough… Or I don't remember… In any case on Tuesday… on Wednesday nothing went anymore. Then I thought that we had now reached the point, where Prof. Meyer had wagged his finger at me.

Patient: Ja, also vorher war ich beim Urologen, nicht wahr, und dann, es hat angefangen, ja, eigentlich… wegen dem Wasserlösen. Vom Hausarzt zum Urologen, das ist aber schon lange, lange zurück, das sind fast zehn Jahre, oder acht Jahre wahrscheinlich. Dazwischen hatte ich andere Sachen, die im Vordergrund standen gesundheitlich, hatte Bypasse, fünf Bypasse, und Gallenblase, da ist das

etwas in den Hintergrund getreten... Ich weiss gar nicht mehr, was eigentlich damals... ob man einfach nur mit Medikamenten, wahrscheinlich... und hat einfach den PSA-Wert verfolgt, und der kam runter, rapide, auf unter null vier, oder was ist da die Schmerzgrenze, so eine Richtgrenze...

Interviewerin: Ja, so etwas...

Patient: Und das war alles im Griff, und plötzlich... vor anderthalb Jahren ging der rauf auf über 40, und dann gehen jeweils diese Berichte auch zum Hausarzt und zu Alice (Tochter, die Ärztin ist), und dann sagte Alice: „Du, jetzt muss etwas gehen. Ich melde Dich bei einem meiner Kollegen an, bei Prof. Müller (Onkologe)." Dann sagte ich: „Ja, das muss aber über den Hausarzt gehen, oder über den Urologen." Sie sagte, ja, sie werde das schon in Ordnung bringen, sie werde mit ihm reden. Aber er musste mich dann anmelden, aber nur damit der Dienstweg einigermassen eingehalten war... Ja, und das hat jedenfalls geklappt. Und dann hatte ich die erste Einladung und Untersuchung... Und dann kam auch meine Frau immer mit, wenn wir Audienz hatten bei ihm. Und danach haben wir mit der Chemo angefangen... Programm der Chemotherapie, das waren, glaube ich, sechs oder acht Sitzungen, wo ich einfach diese Infusionen hatte, das war ambulant. Und die habe ich sehr gut vertragen, und...eh gleichzeitig, oder gleich anschliessend, hat man Strahlenprogramm gemacht bei Prof. Meyer (Radiologe). Ich weiss jetzt nicht mehr, was zuerst war, einfach nacheinander... auch etwa neun Sitzungen... Ich hatte Schmerzen, da, in der Hüfte, und da, in der Seite und da ... und sogar da oben... Und das hat man auch, ganz strikte, jede Woche, am gleichen Tag, um die gleiche Zeit, ist das gelaufen. Auf Mitte Jahr letztes Jahr waren die zwei Programme durch. Und im Herbst mal hatte ich einen Kontrollbesuch bei Herrn Prof. Müller, einfach Wohlbefinden, Blut und so... und das war gut von dieser Chemo, und die Schmerzen waren weg. Aber wir haben schon im Frühling da den Buckel gesehen (Knochenmetastase an der Stirne). Dann sagte er, er wolle dies seinem Kollegen zeigen, Herrn Prof. Meyer. Im Frühling sagte er, dies habe nicht Priorität, es sei nicht dramatisch, man müsse es einfach beobachten, und im Sommer... Im Herbst haben wir das dann doch weitergegeben, und Herr Meyer hat mich angeschaut, und dann hatte ich sechs Sitzungen, um das zu bestrahlen. (...) Und danach hat man dort auch noch eine Schlussbesprechung gehabt mit Herrn Meyer, und er hat einfach gesagt, das hat mir eigentlich Eindruck gemacht: „Herr Alder, sobald sie etwas spüren, einen Schmerz irgendwo oder ein Kribbeln im Bein, irgendetwas Abnormales, nicht nur da oben (Stirne) auch sonst, dann müssen Sie sofort kommen... als Notfall... nicht noch drei Wochen warten, weil man einen Termin hat oder so, sondern sofort." Das hat mir irgendwie... das ist hängen geblieben. Und jetzt... hatte ich wieder einen Kontrolltermin bei Herrn Müller, normal, wo man Blut genommen hat, und das war am Montag... das war heute vor 14 Tagen. Und dann hat man abgemacht für heute vor acht Tagen, eine erste Chemotherapie, mit der Absicht, das dann jede Woche zu programmieren. Das war heute vor 14 Tagen, und am Dienstag, am Tag danach, war es mir einfach nicht mehr gut. Ich hatte Schmerzen, ich mochte nicht mehr, fast über Nacht.

Interviewerin: Vorher hatten Sie diese Beschwerden nicht?

Patient: Nein, eigentlich nicht. Ich...gut, es kann sein, dass vielleicht, gerade so ums Wochenende sich etwas eingestellt hat, und ich habe es wahrscheinlich Herrn Müller

> zuwenig deutlich gesagt am Montag… Oder ich weiss nicht mehr… Auf jeden Fall am Dienstag… am Mittwoch ging es einfach nicht mehr. Da habe ich gedacht, jetzt seien wir am Punkt, an dem mir Prof. Meyer den Finger aufgehalten hatte. (1a 87-167)

In his account, Mr. Alder provided a list of the medical treatments he underwent over the last 18 months, explaining that the elevated prostate-specific antigen value caused his daughter to refer him and how she organized the referral to the oncologist, who was treating him and how many sessions of chemotherapy and radiotherapy he had, etc. He briefly summarized the time since the diagnosis of the prostate cancer, stating that the latter was moving into the background because other health issues were more prominent. He did not mention the urinary catheter, although it had frequently caused problems over the last four years. Symptoms only appeared as reasons to search for treatment. Suffering and emotions were absent in his story. He often used the impersonal "one" form when referring to himself, his wife or a physician. His report sounded very rational, almost like a medical record; however, he never used the words cancer or metastases or spoke about his prognosis, nor did he mention that it had been his choice to start once more with chemotherapy. According to his wife, the oncologist had clearly informed him about the latest findings and stated that not getting the chemotherapy was also an option given his severely advanced disease (1b 216-225). Mr. Alder, nevertheless, knew his diagnosis and that he was seriously ill. He admitted this occasionally, for instance, when he told the resident on his round that he would not forget his message. "Which message?" "If I would really be aware of the seriousness of my illness; topic settled." ("Was?" "Ob ich mir bewusst sei, dass ich wirklich sehr schwer krank sei, Thema erledigt." 1c 213-216). The patient immediately went on talking about something else, making it very clear that he was not willing to discuss the issue further.

Mr. Alder's statement that "we finally passed this on" ("wir haben das dann doch weitergegeben" 1a 134-135) could as well be about a piece of equipment that is taken to the mechanic for repair instead of concerning the metastasis on his forehead. Possibly influenced by his lifelong involvement with machines at work, Mr. Alder seemed to adhere to a rather mechanistic world view, a view that compares the human body to a machine, which, if causing problems, can get fixed by medicine.

Mr. Alder did not see any need for talking about his disease with his family. He stated that since the early 1990s his daughter, who was a physician, had taken on this task. Whatever came up, she would inform her siblings in a timely manner. He experienced this as a relief.

> Patient: From the 90s… Alice was in fact professionally already so involved that she took charge of the information. (…) When I was admitted to the hospital here, all had an e-mail the next day or in the evening. Dad is in the hospital, there and there, it is this and that, if something interests you, call me. That was of course ideal, she was the minister of information, you know.
> Interviewer: And this was okay for you?
> Patient: Yes, all have the same information and do not pass around things that are not true, and this worked actually well. They come, and then one talks openly about it and so, and then they say, when I want to get started: "You don't need to say anything, we know already everything." That is convenient. It has been relieving.
>
> Patient: Ab den 90er Jahren… war Alice eigentlich schon beruflich so involviert, dass sie die Information übernommen hat. (…) Als ich hier ins Spital kam, hatten alle am nächsten Tag oder Abend ein E-Mail. Vater ist im Spital, dort und dort, es ist das und das, wenn Euch etwas interessiert, ruft mich an. Das war natürlich ideal, sie war der Informationsminister, oder.
> Interviewerin: Und das ist gut so für Sie?
> Patient: Ja, alle haben die gleiche Information und reden nicht etwas im Zeug rum, das nicht stimmt, und das hat eigentlich gut funktioniert. Sie kommen daher, und dann redet man offen darüber und so, und dann sagen sie, wenn ich anfangen will: „Du musst gar nichts sagen, wir wissen schon alles." Das ist noch angenehm. Das hat schon entlastet. (1a 570-587)

In addition, he mentioned that three of his closest friends were physicians. Should his wife need any information, she could also call one of them (1a 587-597). For Mr. Alder, disease-related information had always been and still was the relevant issue; he had never considered talking about his approaching death, nor about the illness as a straining experience for him, his wife and his children, and he did not do so during his hospital stay. He felt relief when he did not have to pass on information, that is, when he did not have to talk about his disease.

Mr. Alder was talking about his hospital stay as he talked about the time before. He stated that he had several medical tests and then got medication, pain medication and others; he did not know what it was. In the beginning, he slept a lot so that the first days went by without him noticing much. Now, the pain was gone, he was improving and ready to return home (1a 171-215, 266-270). It has to be added here that the patient seemed a bit forgetful. He could, for instance, not remember my appointment with his wife or that all the hospital employees were informed about data collection for the study. This forgetfulness likely influenced his perception of the hospital stay. Nevertheless, he did not concern himself with problems or admit any suffering from symptoms. He got physiotherapy for shoulder pain after a contortion. However, since no injury was apparent on the X-ray, the issue did not concern him greatly.

> This was in fact done on the side. They did an X-ray to see if anything was pulled or broken. That was not the case. Then they said, it would take some days or weeks for the pulling, or whatever it is, inflammation, to go away. Well, I don't spend much thought on it. The exercise tomorrow will be the last one that I will be doing.
>
> Das ging jetzt eigentlich so nebenbei. Sie haben es ja geröntgt, um zu sehen, ob etwas gezerrt oder gebrochen ist. Das war nicht der Fall. Da haben sie gesagt, es gehe ein paar Tage oder Wochen, bis diese Zerrung oder was es ist, Entzündung, weg ist. Ja, darauf gebe ich nicht so viel. Morgen wird die letzte Übung sein, die ich mache. (1a 515-521)

During observation, the patient had been grimacing and rubbing his forehead several times. His breathing was at times audible (1c 108-110). Asked if he experienced pain or any other symptom, he answered with a surprised look: "No, absolutely not… I am feeling excellent." („Nein, absolut nicht… Mir geht es ausgezeichnet.“ 1a 19) When the nurse stated that he was a bit short of breath after body care, he agreed, adding that it was only temporary (1c 164-165).

It was hard to believe that Mr. Alder felt excellent, given his health status. However, from the standpoint that pain, or any other symptom, is what the patient experiences, his view has to be understood as true for him. The situation offered various interpretations: My observation might have been wrong; I might have misinterpreted the patient's facial expressions; he might have been unwilling to acknowledge any symptoms and simply ignored them; pain and shortness of breath only reached a level below his "suffering-threshold;" or the opioid was effective and took care of any symptoms. It seems impossible to find out which interpretation was the best fitting one. However, from the wife's above statement regarding Mr. Alder's attitude towards working and from her illness story below, it can be deduced that the patient dealt with his illness at the hospital as he had done over the preceding years: He was hushing it up, ignoring problems as much as possible and planning to go on with working.

Experiencing a Terminal Illness

Kleinman (1988) described disease as a pathophysiological problem seen from the professional caregivers' perspective, disease relating to changes in body structures and functioning. Illness, in contrast, is the patient's and family member's lived experience of symptoms and suffering. This distinction comes to mind when the stories of Mr. and Mrs. Alder are compared: While Mr. Alder provided a report of his disease, Mrs. Alder related the story of her husband's illness.

Well, it started with troubles with the prostate, that was in 92, 93. Then he went to see the physician for the first time, and he diagnosed cancer cells when they did the tests. And then he got injections, first every sixth week and pills, so almost a chemotherapy, to scotch the cancer cells, as he told us at that time. The general practitioner told me, when I related it to him, I should not be anxious, dad would be able to live on for ten years with this, and when I am now looking back, then he almost had these ten years. It actually began with him complaining, perhaps last year or so, for the first time, that he had pain in the hip, or perhaps two years ago. And one said that it was sciatica and treated it with injections. But in autumn last year it deteriorated considerably. And we were still in the United States, and there I saw that he did not eat anymore. At night, he went up, and he had pain in spite of pain killers, they were not effective. And then we came home, and then the daughter organized an appointment with Prof. Muller for us. And suddenly I suspected that this could be related to the prostate, that it might not be rheumatism, but something quite different, and this got later confirmed. When we returned from the United States, that was in February, we had the first meeting with Prof. Meyer, and he said that he would like to give radiotherapy. And then they gave radiotherapy to the hip, and I believe about 14 times, I believe over two weeks he had to go to the hospital every day. Subsequently he had chemotherapy. Now I have to think, if this was before… first he had the radiotherapy and then the chemotherapy. And, contrary to expectations, he got very well through it, he was not even nauseated, and he did not lose his hair. With this, he was pretty happy, and so one then said that one would not do anything for the time being. And then he certainly had a good time. And now last autumn, it seemed to me that he would start to deteriorate again, and each day he looked greyer to me, but he did not want to say anything. But somehow… we went through the treatment, made an appointment again and we probably had the latest meeting with Prof. Muller in November. And he said that it was quite well, and that it was unaltered, and that nothing had changed. And so we were pleased. About in January it seemed to me that he would again eat less, and he was not hungry. (…) It seemed to me that he lost weight and that his abdomen got bigger and bigger. (…) And then I said: "Well, I will just not wait any longer, if this is not improving." Because Prof. Meyer had said that in case he would get some pain, we should come immediately, sometimes it would be already too late after 12 hours. Then one morning he said that his shoulder was hurting. My first thought was immediately: Does it have metastases in the bones up there as well? Because the physician had told me that prostate cancer would usually make bone metastases first. Later, last week, before we came to the hospital, he said: "Uh, I have such a stitch." And there was something else, the third, I am not sure anymore where it was, most likely also in the abdomen. He said if the appendix would be there. But before he had never ever said anything. It just seemed to me that he was more tired every day when he came home, and that the shoulder would almost hang to the ground, but he did not want to admit it. And on Tuesday morning he went to work at half past six and for the first time he came back home at eight and said that nothing went anymore. And I had for a long time, it was such a nightmare for me. When will this blow up? He then was in bed on Tuesday… and went to the office once more in the evening, dragging himself, one could hardly watch him, and looked so badly. Wednesday morning the same, he wanted to go up on Wednesday morning, tried and then went back und went to the bathroom, then he came back and lay down again, three times the whole thing. Then I said: "Well, now I am not watching any longer, the physician has to come now," and he then was glad.

Ja, es hat angefangen mit einem Prostataleiden, was war das, 92, 93. Da ging er das erste Mal zum Arzt, und der hat dann Krebszellen festgestellt, als sie untersucht haben. Und danach hat er Spritzen bekommen, zuerst alle 6 Wochen und Tabletten, also fast eine Chemotherapie, um die Krebszellen abzuwürgen, hat er uns damals gesagt. Der Hausarzt sagte mir, als ich es ihm erzählte, ich solle nicht Angst haben, damit könne Vater noch zehn Jahre leben, und wenn ich jetzt zurückschaue, sind das einfach fast die zehn Jahre, die er jetzt noch gehabt hat. Angefangen hat es eigentlich damit, dass er geklagt hat, vielleicht letztes Jahr oder so, zum ersten Mal, er habe Schmerzen in der Hüfte, oder vielleicht auch schon zwei Jahre. Und man hat gesagt, es sei Ischias und hat Spritzen gemacht. Aber letzten Herbst hat es sich ziemlich verschlechtert. Und wir waren noch in Amerika, und dort habe ich gesehen, dass er nichts mehr gegessen hat. Nachts stand er auf, und er hatte Schmerzen trotz Schmerztabletten, es hat nichts genützt. Und dann kamen wir heim, und dann hat die Tochter organisiert, dass wir zu Prof. Müller gehen konnten. Und plötzlich ist mir der Verdacht gekommen, ob dies eventuell die Auswirkung sein könnte von der Prostata, dass es nicht Rheuma sei, sondern etwas ganz anderes, und das hat sich dann bestätigt. Als wir von Amerika heim kamen, das war im Februar, hatten wir eine Besprechung mit Prof. Meyer, und er hat gesagt, er möchte bestrahlen. Und dann haben sie die Hüfte bestrahlt, und ich glaube etwa 14mal, ich glaube zwei Wochen lang musste er jeden Tag ins Spital. Anschliessend hatte er noch eine Chemo. Jetzt muss ich überlegen, ob dies vorher … zuerst hatte er die Bestrahlung und danach die Chemo. Und die hat er wider Erwarten sehr gut überstanden, nicht mal schlecht war ihm, und die Haare hat er auch nicht verloren. Da war er ziemlich glücklich, und so hat man danach gesagt, jetzt mache man vorläufig nichts. Und dann hatte er gewiss eine gute Zeit. Und jetzt letzten Herbst dünkte mich, er fange wieder an schlechter auszusehen, und jeden Tag schien mir, er werde grauer, und er wollte aber nichts sagen. Aber irgendwie… haben wir die Behandlung gemacht, haben uns wieder angemeldet und zwar sind wir wohl im November zum letzten Mal bei Prof. Müller gewesen. Und er sagte, es sei recht gut, und es sei stabil und habe sich nicht verändert. Und da haben wir uns gefreut. Etwa im Januar schien mir, er fange wieder an, weniger zu essen und hatte einfach keinen Hunger. (…) Es schien mir, er nehme ab und der Bauch werde immer grösser. (…) Dann sagte ich: „Also jetzt warte ich dann einfach nicht mehr, wenn es nicht besser wird.“ Weil Prof. Meyer gesagt hatte, wenn er irgendwie Schmerzen habe, sollten wir sofort kommen, manchmal sei es in 12 Stunden schon zu spät. Dann sagte er eines Morgens, die Achsel tue ihm weh. Mein erster Gedanke war gleich: Hat es auch Metastasen in den Knochen da oben? Weil der Arzt mir gesagt hatte, in der Regel mache Prostatakrebs zuerst Ableger in den Knochen. Nachher, letzte Woche, bevor wir ins Spital kamen, sagte er: „Uuh, ich habe jetzt auch Seitenstechen.“ Und dann war noch etwas, das Dritte, ich weiss nicht mehr sicher, wo das war, wohl auch noch im Bauch. Er sagte, ob man da den Blinddarm habe. Aber vorher hat er

> nie, nie etwas gesagt. (…) Es schien mir einfach, er sei jeden Tag, wenn er heim komme, müder und die Achsel hänge ihm fast bis zum Boden runter, aber er wollte es nicht zugestehen. (…) Und am Dienstagmorgen ging er arbeiten um halb sieben und kam das erste Mal um acht wieder nach Hause und sagte, es gehe nicht mehr. Und ich habe schon lange, es war mir so ein Alpdruck. Wann eklatiert jetzt das Zeug? Dann war er am Dienstag im Bett… und ging gegen Abend nochmals ins Büro, hat sich geschleift, also man durfte kaum hinsehen, und sah schlecht aus. Am Mittwochmorgen dasselbe, am Mittwochmorgen wollte er aufstehen, hat probiert, und dann ging er wieder zurück, und er ging ins Badezimmer, dann kam er zurück und legte sich wieder hin, das Ganze dreimal so. Dann habe ich gesagt: „So, jetzt schaue ich nicht mehr weiter zu, jetzt muss der Arzt her," und er war dann froh. (1b 31-114)

In Mrs. Alder's story, Mr. Alder's suffering as well as her big concerns about her husband's wellbeing surfaced. She repeatedly observed deterioration in his health status, which she related to a progression of the illness. She was talking freely about cancer, and any unknown pain let her assume new metastases, while her husband was wondering if his abdominal pain might be related to the appendix. She also mentioned how pleased they were about successful treatments and the lack of side effects, and that her husband could enjoy a good time after the first treatment of the recurrence. Interestingly, both partners mentioned Prof. Meyer's remark; their interpretation of when the time for another appointment was reached, however, differed remarkably. For Mrs. Alder, this point was reached when she again observed signs of deterioration about two months prior to her husband's hospital admission. For Mr. Alder, the point was only reached when he was absolutely unable to go on, on the day of his admission.

Mrs. Alder added that the years since diagnosis had not passed by without problems. Especially, since her husband had had the urinary catheter, they constantly had to take care of it (1b 354-367). However, her husband never ever complained about any problem. She admired him for this, and also showed understanding for his occasional bad mood. But she, unlike her husband, acknowledged the burden that his illness caused for him and the family.

> But I must admire him, he has not yet complained *once* that he would be annoyed or so. So, this was in fact astonishing for me, I really must admire him for this. At times he was in a somewhat bad mood, but then I put myself in his place and thought: How would it be for you to live with this burden? It is just, it was a burden for all of us.
>
> Aber ich muss ihn bewundern, er hat noch nicht *einmal* geklagt, dass es ihm verleide oder so. Also, das hat mich schon verwundert, da muss ich ihn also wirklich bewundern. Manchmal war er etwas „uliidig," aber dann habe ich mich an seinen Platz gestellt und gedacht: Wie wäre es für mich, mit dieser Belastung zu leben? Es ist einfach, wir hatten alle eine Belastung. (1b 281-287)

Over all the years, Mr. Alder concealed having cancer from the people in his village. His family was not allowed to mention it. Only recently had he opened up on this fact. Imagining herself in the same situation, his wife understood his standpoint, especially when she was confronted with the consequences of the news.

> He for the first time told someone, perhaps around the New Year: "I am a cancer patient." Before he just hushed it up, one was not allowed to say anything. But I can understand this; perhaps I would not have wanted this either. And now, after it got known, it spreads like wildfire. I almost wanted to say that I cannot go shopping anymore; it is the topic of the hour in the village.
>
> Er hat zum ersten Mal, vielleicht um Neujahr rum, zu jemandem gesagt: „Ich bin ein Krebspatient." Vorher hat er es einfach totgeschwiegen, man durfte nichts sagen. Aber das kann ich auch verstehen, vielleicht hätte ich das auch nicht gewollt. Und jetzt, nachdem es ausgekommen ist, ist ein Lauffeuer im Dorf. Ich hätte fast gesagt, ich kann nicht mehr Einkäufe machen gehen, das ist das Dorfgespräch. (1b 287-295)

It becomes clear from Mrs. Alder's story that her husband had been extremely reluctant to acknowledge symptoms, suffering, or any deterioration throughout the journey of his illness. He constantly refused to talk about his cancer or any other concerns. Going on with his beloved work was on his agenda rather than giving in to the illness, and this way seemed to work best for him. Taking this background into account, it does not seem surprising that Mr. Alder stuck to his way of living with the illness during his hospital stay.

While his way of taking up the illness seemed worthwhile for Mr. Alder, it was more problematic for his family, especially for his wife. At times, Mrs. Alder regretted that she could not enjoy her husband's companionship more often after his retirement. But she knew what to do with herself, was used to his work focus and recognized that he was happier at work. Therefore, she accepted his choice as being adequate for him and supported him, even though she could imagine a different approach.

> And I thought, I would let him do it. He was happy and looked forward to his work every morning, it was right for him like that. And I knew what to do with myself anyway. At times, I regretted it, when I saw how others could go walking together, and he just has his company. But what else shall I do… He was satisfied, and Saturday, Sunday, he usually felt worse, he then kept thinking and touched his forehead repeatedly. That is where he got this hump…
>
> Und ich dachte, ich lasse ihn machen. Er war glücklich und freute sich jeden Morgen auf seine Arbeit, dann stimmte es bei ihm. Und ich wusste schon, was mit mir anfangen. Ich habe es manchmal bedauert, wenn ich sah, wie andere zusammen spazieren gehen können, und er hat einfach nur sein Geschäft. Aber, was will ich anderes… Er war zufrieden, und Samstag, Sonntag ging es ihm meistens schlechter, da hat er studiert und immer wieder an den Kopf rauf gegriffen. Er hat ja dann da eine Beule bekommen… (1b 236-245)

Aware that her husband's death was not far away, Mrs. Alder stated that, even though the most relevant issues were settled, much was still left to talk about. However, she was reluctant to bring up any topic that would make her husband realize that the family expected him to die soon. After he had just overcome the crisis and felt well again, she was not willing to risk a breakdown and stated: "What dad needs now is love and care, everything else is irrelevant." („Was Vater jetzt braucht, ist Liebe und Zuwendung, alles andere spielt keine Rolle." 1b 554-564). With the support of her sh

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children, she felt able to later reorganize her life as a widow and deal with all the upcoming issues.

Mrs. Alder explained that now and throughout her life, her actions were guided by what felt right in her heart. For instance, she never regretted her decision to care for her aunt, although this care lasted for 14 years, much longer than she had expected. She could have done a lot of other things during this time; however, she felt that caring had been more important (1b 637-654).

> Just always making sure that it is right for me. And what others do or don't, I think, doesn't have to bother me. Although something might be difficult for me at times, or I have to admit that something does not work… just that I feel well here (points to her heart). That's what I am looking for.
>
> Einfach immer drauf schauen, dass es für mich stimmt. Und was andere tun oder unterlassen, denke ich, kann mir gleich sein. Wenn ich auch manchmal unten durch muss, oder etwas zugebe, das nicht stimmt… einfach dass es mir da wohl ist (zeigt auf ihr Herz). Auf das schaue ich. (1b 656-660)

The nursing record stated that Mr. and Mrs. Alder were in denial. Furthermore, one of the nurses mentioned that it was somewhat problematic for her to see how the patient bossed his wife around (1 Pfl 9-14). I had a similar experience when I met the couple to get their informed consent. Mr. Alder asked his wife to just sign the form; I had to insist that she could take the time to read it first. In addition, Mrs. Alder was dressed simply and her appearance somewhat marked by Parkinson's disease. It was easy, therefore, to see her as a little housewife under the thumb of her husband at first glance. During the interview, however, I got to know a woman who had guided her own life at the side of her beloved but workaholic husband. A woman who had always known and still knew what she was doing and why she did it. From her account, it became crystal clear that she was not in denial; she was fully aware of her husband's diagnosis and prognosis as well as of his imminent death. She was, however, unwilling to force this truth upon her husband and refused to talk about these issues in his presence. Mr. Alder's way of taking up his terminal illness may be considered denial; he certainly denied the implications of his illness. Nevertheless, he knew his cancer diagnosis and was aware of the seriousness of the illness; he did not, however, openly acknowledge these facts. For him, over many years it seemed to have worked best to ignore and hush up the illness; he did not change this approach during his hospitalization. The couple's life story made his standpoint more comprehensible; it could now be understood as the continuation of the way of taking up his illness that had worked best for Mr. Alder so far. The care providers' perspective was limited and somewhat distorted, because it did not take this life story into consideration.

Going on With Unique Lives

The life stories of these two couples, as far as they were revealed during data collection, were outlined to illustrate that each couple brought unique life experiences to the hospital, and to show that patients' and family members' actions and behaviors at the hospital were more comprehensible in the light of these stories. The findings of a study on terminally ill patients' perspective on death were similar (Yedidia & MacGregor, 2001). These patients' outlooks on dying differed greatly, but the view of individual persons was consistent over time and firmly grounded in their life trajectories. The authors concluded that neglecting patients' biographies might undermine individualized and effective care interventions.

The two stories provide quite different perspectives on living a life as a couple as well as on taking up a terminal illness. They should be seen as examples of the uniqueness of life stories. From each study case, a story could be told, and each would be a unique one and differ from all the others in many aspects. All cases would, however, show that patients and family members were continuing to live their particular lives, in spite of the patient's terminal illness.

The two life stories also allude to the joy, richness, satisfaction, doubts, troubles, pain, sorrow, anxiety, and uncertainty of lived life – to life's inexpressible density and chaotic vitality (O'Brien, 2003). The stories point to a challenge for care providers: A science on the search for universal truth and generalizable theory can never exhaust the fullness of a unique life. Patients' and family members' lived experiences cannot be captured in abstract lists of medical and nursing diagnoses. Denial as a label for Mr. and Mrs. Alder's coping with the terminal illness, for instance, does not convey the complexity of their way of taking up the illness in their life. While the natural sciences greatly contributed to progress in medicine and nursing, their abstractions also distanced the care providers from patients' and families' lived experiences of illness and suffering, and dehumanized patients and family members (McWhinney, 2001). Thus, care providers are challenged to bridge this gap by attending to patients and family members as persons, and by skillfully applying their scientific knowledge to the individual situation of each patient and family (Benner, 2001b; Gadamer, 1996).

While patients and family members continued living their lives after the onset of the terminal illness, their lives did not go on unaffected by the illness. The next section discusses new and troubling experiences that the illness brought along.

Living with a Terminal Illness

When a person is diagnosed with a terminal illness, life changes for the patient and the family. They face many losses and experience the illness' unpredictable journey. Patients have the experience that reality does not always match their expectations. Family members are affected as witnesses to the patients' suffering and as caregivers. The illness may, however, also bring about positive experiences for some patients and family members.

Losses From the Terminal Illness

"At this moment, for my hushand a world broke down, of course," („Da fiel für meinen Mann natürlich eine Welt zusammen," 8b 227) stated one wife when remembering the time when his incurable cancer was diagnosed. And a patient, referring to her illness, said: "It is always there, it is never again not there." („Es ist immer da, es ist nie nicht mehr da." 5a 494). When a terminal illness intrudes people's lives, their world is shattered. The affected person, who is now considered a patient, and the family are confronted with a new reality. The illness takes its toll; everyday life can no longer be taken for granted. Going on with life means living with the terminal illness until the patient's death.

Gadamer (1996) described health as a general feeling of well-being, which means being open to new things and ready to embark on new enterprises, barely noticing demands and strains. Health as a state of equilibrium, as an experience of weightlessness, chiefly resides in the background and remains hidden from conscious self-awareness. Undisturbed health escapes peoples' attention. Illness, however, forces itself upon them. Illness means disturbance and dysfunction; sick people fall out of their normal lifeworld.

With a terminal illness, the balance is thrown off definitely; restoring the equilibrium of health has become unattainable.

The Loss of a Common Future

With the onset of a terminal illness, patients and families face the shortened lifespan of the patient and the (early) termination of their relationship through death. With a shrinking future, life plans are threatened or destroyed. Adaptation or giving up are called for, both painful processes for patients and families. One patient, for instance, experienced the changes forced upon her partnership as burdensome and felt a great uncertainty regarding future life plans with her partner (5a 540-543, 554-556).

The New Year's Eve party was extremely painful for one couple who had received the man's terminal diagnosis shortly before and were fully aware that they would never celebrate the New Year together again.

> And then the holidays came up, Christmas, New Year, I would never want to experience that again, such a New Year. That was the most brutal, New Year's Eve at midnight, that was unbearable. Christmas was okay, but this was absolutely unbearable. My husband was still reacting very emotionally at that time. He had always been a bit sensitive, but then he had awful troubles.
>
> Und dann kam ja die Festzeit, Weihnachten, Neujahr, das möchte ich nie mehr erleben, so ein Neujahr. Das war das Brutalste, Silvester um 12 Uhr, das war unerträglich. Weihnachten ging, aber das war absolut unerträglich. Mein Mann hat damals noch sehr emotional reagiert. Er war immer ein wenig sensibel, aber da hatte er also wahnsinnig Mühe. (8b 239-245)

For another couple, the woman's severely advanced cancer, diagnosed only one month prior to her death, completely ruined their life plan; and through this immigrant's illness and subsequent death, her family back home lost the support she had provided before. Her partner explained that they had planned to return to her country together and build up a business:

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> Partner: Yes, that was in fact our plan. Now it's not put into action. Well, now I can't, we would have had to marry because of the papers and all the fuss and bother, so that I could have emigrated with her. Then we could have built up the stuff there. With my pension, that's already 100,000 SFr., with that one can already start something nice there. Well, we had said that we would invest 50,000 SFr. Then we would already have what we wanted, and still have 50,000 in reserve, if it should not work out. We could easily survive one or two years, or three, until we would make money with the campsite that we had in mind.
> Interviewer: Ah, you had such concrete plans.
> Partner: Yes, we did have plans. We had said, two or three more years in Switzerland, till I am divorced, till she is divorced. And then get married, and then just scrape as much money as possible, and then simply get away, that would be the end of it.
>
> Partner: Ja, das war eigentlich unser Plan. Jetzt ist halt nichts draus geworden. Also, jetzt kann ich ja nicht, wir hätten ja heiraten müssen, wegen den Papieren und allem Drum und Dran, damit ich mit ihr hätte auswandern können. Dann hätten wir das Zeug dort aufbauen können. Mit meiner Pensionskasse, das sind schon 100'000 Fr., damit kann man dort schon etwas Schönes anfangen. Also, wir hatten gesagt, dass wir 50'000 Fr. investieren würden. Dann hätten wir schon das, was wir haben wollten, und haben 50'000 Reserve im Rücken, wenn es nicht gelingen sollte. Ein Jahr oder zwei könnten wir gut überleben, oder drei, bis es anziehen würde, der Campingplatz, der eigentlich unsere Idee war.
> Interviewerin: Ah, so konkrete Pläne hatten sie.
> Partner: Ja, Pläne haben wir gehabt. Wir hatten gesagt, noch zwei, drei Jahre in der Schweiz, bis ich geschieden bin, bis sie geschieden ist. Und dann heiraten, und dann einfach noch Geld zusammensammeln, soviel wie möglich, und dann abhauen, fertig. (6 po 182-200)

For this couple, the terminal illness was a clear and abrupt closing down of an imagined and planned future. With this abrupt cut off from a common future, the terminal illness was differently experienced than in the cases of the Blums and the Alders. These two elderly couples had lived in stable relationships for decades and led well worked out lives. Both couples had known the men's cancer diagnoses for an extended period of time, when recent deterioration required hospital admission. They were still granted some more time together and were able to go on with their lives, although under more constraints. This is very different from the experience of this middle-aged couple, who had met after stormy times for both, had only lived together for about one year, and were planning for a sha

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challenging new life and future. With the terminal illness, their plans became radically impossible, and with the woman's death after only one month in the hospital, their partnership ended abruptly.

Forced Adaptations in Everyday Life

While living with a terminal illness, patients and families experience many losses and distressing situations. The illness causes disability; patients are no longer able to carry on their usual activities or to work. Family tasks have to be reorganized. For example, one patient explained:

> If something had to be carried around in our house, I did it. I transported things and went shopping. There I must also organize myself differently. (...) So that we may get a car, that we did not need a car so far, but that now a car may be adequate, for instance...
>
> Wenn jemand etwas tragen musste bei uns, war ich es. Ich habe Sachen rumtransportiert und Einkäufe gemacht. Da muss ich mich auch anders organisieren. (...) Dass wir uns halt vielleicht ein Auto zulegen, dass wir bisher kein Auto brauchten, aber jetzt dann ein Auto am Platz ist, zum Beispiel... (5a 772-792)

A man in his forties, suffering from brain metastases, greatly regretted the impossibility of returning to work. Although he had been off sick for 14 months, he still expressed some hope of resuming his job and discussed work related issues enthusiastically. He was glad that the pension the disability insurance granted him was only provisional.

> Now they even granted a disability pension to me, which I do not really like, however. My goal would be, of course, to go back to work one day. (pause) Eh, that's how it changes. (...) The disability pension is only provisional. And I am not unhappy about this, because eh... I do not feel like a pensioner, I am still too young. And well, now I am already feeling a bit better again. (...) I had just thought, that I would be able to resume working again this year, but it was not possible. You know, with the chemotherapies and stuff and so on. One is just exhausted. One just can't. And then it is also a question of concentrating.

> Jetzt haben sie mir noch eine IV-Rente gesprochen, was mir allerdings nicht so zusagt. Mein Ziel wäre natürlich schon, gelegentlich wieder arbeiten zu gehen. (Pause) Eh, so ändert es halt. (…) Die IV-Rente ist ja nur provisorisch. Und da bin ich nicht unglücklich, weil eh… ich fühle mich nicht als Rentner, ich bin noch zu jung. Und eben, jetzt geht es mir ja schon wieder etwas besser. (…) Ich hatte eben gedacht, ich könnte dieses Jahr wieder mit arbeiten anfangen, aber es war nichts. Oder, mit diesen Chemotherapien und Zeug und Geschichten. Man ist einfach fix und fertig. Man mag einfach nicht. Und dann ist es auch eine Frage der Konzentration. (10a 54-61, 85-99)

Disability not only interferes with running errands or working, but with leisure time as well. Many pleasurable activities are no longer possible. Patients and family members are left with nostalgic memories and have to find out which options might still be open for them. A patient mentioned that, when alone and looking at the mountains, he had the blues. He remembered his trips round the mountains that were now a thing of the past (7c 55-61). His partner related that for some time, they had not been able to hike, because they were caring for her mother. But after her death, they resumed and greatly enjoyed hiking together. Sighing, she stated that now, with the partner bound to a wheelchair, this option was once more precluded, and they would have to find out what was still possible (7a 7b 2. 284-286). In addition, the couple had spent almost all their weekends in their trailer at a campsite. They remembered this wonderful time:

> Partner: It was nice in the little garden each time, to sit on the corner seat, and the titmouses sat on the table, and about 30 sparrows in the lilac tree that wanted something for breakfast together with us… wasn't it nice each time?
> Patient: Yes.
>
> Partnerin: Es war jeweils schön im Gärtli, auf der Eckbank zu sitzen, und die Meisen kamen auf den Tisch, und etwa 30 Spatzen auf dem Fliederbäumchen, die etwas zum Frühstück wollten mit uns zusammen… gell, das war jeweils schön?
> Patient: Ja. (7a 7b 2. 240-248)

Now, the patient was no longer able to drive, the partner was afraid to take up driving again after years of no practice, and the trailer had no wheelchair access. Therefore, the couple would be restricted to short day trips to the camp when another family member was willing to give them a ride.

The Loss of Independence

With progressive illness and increasing disability, patients lost their independence and the ability to care for themselves. For one patient, the consequence was the transfer from the hospital to a nursing home, since living alone in his flat had become impossible. He lost his independence, his flat and access to most of his personal belongings. His brother and sister-in-law, who had taken on the task of vacating the flat, were confronted with the patient's years of accumulated belongings, with his wish to keep many things including furniture, and with limited storage space. They were aware of the patient's limited life expectancy and thought that he would neither need most of his belongings anymore nor would it be possible to bring them to the nursing home. From his reluctance in getting rid of these things, they concluded that the patient had not yet truly realized the seriousness of his illness and still expected to use them again.

> Brother: I have the feeling that he does not yet take his illness as seriously as it actually is. I have this feeling, because… eh… Now regarding the vacating of the flat, keeping this and keeping that. I just think that he will never again be able to use it. That's how I see the whole story. That's brutal, but that's how I see it.
>
> Bruder: Ich habe das Gefühl, er nehme seine Krankheit noch gar nicht so ernst, wie sie eigentlich ist. Das Gefühl habe ich, weil… eh… Jetzt gerade die Wohnungsräumung, das noch behalten und jenes noch behalten. Ich bin einfach der Meinung, dass er das nie mehr brauchen können wird. So schaue ich die ganze Geschichte an. Das ist brutal, aber ich sehe es so. (9b 51-57)

The family's conclusion, however, might be too rational; it neglected the fact that many things have unique meaning for the owner. For this patient, after losing his independence and his flat, getting rid of most of his belongings might just have been going too far. He

still needed some connection to his earlier life. Although stored at his brother's house, these things still belonged to him and were still there rather than sold or thrown away, which made every thought about them qualitatively different for the patient. Even with limited or no access, the loss had not yet become irrevocable. The stored belongings may have held open his past life and kept a future possibility open for this patient.

Thus, with the terminal illness, a new force comes into people's lives. A force that disrupts peoples' familiar worlds and shatters life plans. If the illness forces radical changes upon patients, they may be partly or fully cut off from their past. The illness interferes with patients' and family members' present everyday activities, they experience distress and multiple losses. Their current life is bothersome. Patients and families move on to new horizons, but instead of the planned and hoped for developments, illness and suffering appear on these horizons. The future becomes fundamentally uncertain and unpredictable.

Living With Unpredictability

After the terminal illness has intruded into their lives, patients and family members have to live with unanswerable questions: How will the illness proceed and how rapidly will it proceed? What will be done and when will something be done? How will their life be affected?

The Unpredictable Journey With the Terminal Illness

Patients and families are confronted with an unpredictable illness trajectory and an unclear prognosis. A patient with impaired balance, for instance, fell at home and was admitted to the hospital with burns from the electrical heater. Some patients survived serious crises and recovered enough to return home again, while another patient died on the day of his anticipated discharge from the hospital after an unexpected rapid decline. Even though patients and family members were searching for clear answers, these were rarely available, as one family member explained:

> I think we will call his neurologist, because no-one is telling me... They keep saying: "It changes, it changes, it changes, once like this, once like that...," and this doesn't tell me anything. It is really something special, such a brain tumor is something special. I think, we will just call the neurologist and ask him, if he can explain how this... Although it is possible, that one does not know how this is developing... That is also possible.
>
> Ich glaube, wir werden seinen Neurologen anrufen, weil mir niemand erzählt hat... Sie sagen immer: „Es wechselt, es wechselt, es wechselt, einmal hier, einmal so...," und das sagt mir einfach nichts. Es ist wirklich etwas Besonderes, so ein Hirntumor ist etwas Besonderes. Ich glaube, wir werden den Neurologen einfach anrufen und fragen, ob er erklären kann, wie sich das... Obwohl es auch möglich ist, dass man nicht weiss, wie sich das entwickelt... Das ist auch möglich. (4b 2. 398-405)

She later added that the neurologist in fact had not been able to provide a prognosis either, it might go on for weeks or months, or her son could suddenly die within a few days. "And we must live with this," („Und mit dem müssen wir leben," 4b 4. 200-205) she concluded.

Another family member tried to interpret the physician's utterances on the basis of her knowledge and prior experiences, but was also left with uncertainty.

> Well, the physician said, this astonished me a bit: "We go ahead with the chemotherapy, see how he tolerates it on Monday, Tuesday, then it should be alright until after Easter," he said. I do not quite know, I can imagine that, if the liver doesn't work sufficiently anymore, that the whole body gets poisoned pretty quickly? But one cannot predict that? (...) I just know that the liver is eliminating toxic substances, and when it doesn't do this anymore... I had an uncle who died within a few days. (...) But well, with the chemotherapy they are perhaps still able to... the blood was alright, that's what I also don't understand... that this is not decisive.
>
> Also, der Arzt hat noch gesagt, was mich etwas erstaunt hat: „Wir machen noch Chemo, schauen wie er es verträgt am Montag, Dienstag, danach sollte es dann gehen bis nach Ostern," sagt er. Ich weiss ja auch nicht, ich kann mir vorstellen, dass, wenn die Leber nicht mehr genug arbeitet, dass es schnell eine Vergiftung

> geben kann im ganzen Körper? Aber das kann man nicht voraussagen? (...) Ich weiss nur, dass die Leber doch dafür da ist, Giftstoffe herauszuschaffen, und wenn sie das nicht mehr tut... ich hatte einen Onkel, der starb dann innert ein paar Tagen. (...) Aber eben, mit der Chemo können sie es vielleicht noch etwas... das Blut sei gut, das verstehe ich eben auch nicht, ...dass nicht dies massgebend ist. (1b 310-328)

Uncertainty regarding illness trajectories and prognoses is often combined with a lack of clarity regarding treatment for patients and families. Further treatment decisions depend on effects and side effects of the current therapy and are, therefore, frequently postponed until these effects become apparent, leaving patients and families in limbo. One couple, facing the woman's very advanced cancer with an unknown primary tumor, could only hope that either palliative chemotherapy or radiotherapy would give them some more time. The partner, who observed the constant physical deterioration of the patient explained:

> They don't know it, the cancer, and the only thing that they can try now is to stop, try to fight it back, they already said that it is not possible to get rid of it. But they don't know which cancer... And now we just hope that something works of this chemistry, or that the radiotherapy has some effect. But well, each week she becomes weaker. I know that, I see that...
>
> Sie kennen ihn nicht, den Krebs, und das einzige, was sie jetzt probieren können, ist zu stoppen, versuchen, ihn zurückzudrängen, wegmachen haben sie schon gesagt, geht nicht. Aber sie wissen nicht, welcher Krebs... Und jetzt hoffen wir einfach, dass irgendetwas anschlägt, von dieser Chemie, oder dass das Bestrahlen etwas nützt. Aber eben, jede Woche wird sie schwächer. Ich weiss das, ich sehe das... (6b 231-239)

The husband of another patient stated, in relation to further treatment options: "It is a constant back and forth and unclear, how it will go on," („Es ist ein ständiges Hin und Her und unklar, wie es weitergeht,“ 3b 191-192) while his wife explained that further decisions would depend on the effect of radiotherapy.

> I don't know if anything else is coming up, I haven't a clue. I must now just take what's coming up day by day. And if after radiation the physician will find that the

> vertebrae are still stable enough, if I could get the chemotherapy ambulatory at the regional hospital, I don't know. Or if even surgery is necessary first... One just doesn't know more at the moment.
>
> Ich weiss nicht, ob noch anderes kommt, keine Ahnung. Ich muss jetzt einfach einen Tag nach dem anderen nehmen wie es kommt. Und ob dann nach der Bestrahlung der Arzt findet, die Wirbel seien immer noch stabil genug, ob ich dann schon ambulant im Regionalspital die Chemo machen könnte, ich weiss es nicht. Oder ob es zuerst eine Operation auch noch braucht... Man weiss jetzt einfach noch nicht mehr. (3a 161-169)

For some patients and family members, the consequences of the terminal illness, mainly physical disability, jeopardized current living arrangements, leaving them insecure about where they would have to go. The man who was unable to return to his flat, for instance, was enrolled by his brother and the social worker in five nursing homes. He then had to take the first available place; luckily the place he finally got was a good option for him. But even when he was informed that a place was now available, he still did not know for several days if he would get a single room or would have to share it.

Taking One Day After the Other

Throughout their journey with the illness, patients and families were time after time confronted with unexpected incidents; plans repeatedly turned out to be impracticable. Patients and families suffered from living in limbo. This was described poignantly by one wife when she said:

> You just feel constantly under pressure, and you cannot get rid of it, like a bomb which you do not know when it will explode.
>
> Es ist einfach immer ein Druck auf Ihnen, den Sie nicht loswerden, wie eine Bombe von der Sie nicht wissen, wann sie platzt. (1b 394-396)

This uncertainty was not a constant, however. Unpredictability increased with every downturn of the illness; the sicker the patient, the shorter became the foreseeable future.

With an improvement, the time frame slowly got extended again. Patients and family members who were kept in limbo regarding their near future adopted a "day by day" approach; that is, they stopped planning ahead and just lived through each single day as it came up for them. Statements similar to the next one were made in many conversations with patients and families.

> I just want to take it day by day and be glad when he is saying good morning after waking up and is breathing again next to me.
>
> Ich will einfach einen Tag nach dem anderen nehmen und froh sein, wenn er am Morgen guten Tag sagt und wieder neben mir atmet. (1b 578-580)

When a patient's health status slowly improved after a serious crisis, patients and family members cautiously began to think again about their near future.

> And now for me the future is coming up slowly a bit more again. Until now, I did not find it hard at all to live in the present only, but now I start thinking a bit again: Well, how will this go on now?
>
> Und jetzt kommt bei mir einfach langsam schon die Zukunft wieder mehr. Bis jetzt ist es mir überhaupt nicht schwer gefallen, nur in der Gegenwart zu leben, aber jetzt überlege ich mir schon wieder ein wenig: Ja, wie geht das jetzt weiter? (5a, 5b 2. 67-71)

Conversations mostly centered around discharge planning and care at home. Necessary new arrangements were discussed. However, patients and family members remained aware that the illness might render their plans useless before they could put them into practice, and that new illness-related problems would come up sooner or later. Therefore, patients and family members guarded against high expectations; they would still take it day by day and carefully explore their options, as one partner explained:

> And then everything is open. It will just come one after the other, see, how it goes. I know that something is coming up for me, I know that. But it is not the same every day.

> Und dann steht einfach alles offen. Es kommt einfach dann nach und nach, schauen, wie es geht. Ich weiss, dass etwas auf mich zu kommt, das weiss ich. Aber es ist nicht jeden Tag gleich. (7b 411-414)

For patients and families living with the terminal illness also means living with great uncertainty. Even the near, let alone the far future has become radically unforeseeable. Thus, patients and families live in the present, taking one day after the other. Projecting into the future is restricted or even precluded. Charmaz (1991) also mentioned living one day at a time in her study of living with a chronic illness. She described this approach as a strategy, which helped chronically ill people to get through troublesome periods. This strategy enabled them to control emotions, manage life, relinquish future goals, and manage stress and illness. They were dealing with things – each day – but only one day at a time. Like patients and family members in this study, the chronically ill focused on the present when the illness became overwhelming; their future was shrinking during these difficult times.

Anticipations and Realities

Repeatedly, patients talked about what they had expected to do or how they had imagined feeling under certain circumstances. When these circumstances materialized during the course of the illness, however, their experiences were quite different from any prior anticipation. A scientist, for instance, had reflected on high technology medicine and wondered which medical treatments and technology would be acceptable and what she would refuse in case of a serious illness. She stated with some surprise that, when she was actually diagnosed with severely advanced multiple myeloma, such questions never even came up for her. Agreeing on radiotherapy and chemotherapy was just self-evident.

> Theoretically I considered occasionally in relation to school medicine, to high technology medicine: How much advantage would I take of high technology medicine, what would be acceptable, what would not be acceptable for me? And funnily enough this is now a dimension that doesn't come to fruition at the moment. What is acceptable or not. Well, I did not ask myself for one second, radiotherapy yes or no. (…) Chemotherapy yes or no, I in fact never asked myself, I never reflected upon it. It was absolutely clear, one tries it. (…) I find it quite remarkable that this wasn't a dimension at all.

> Theoretisch habe ich mir ab und zu in Zusammenhang mit der Schulmedizin, mit der Spitzenmedizin Überlegungen gemacht: Wie weit würde ich die Spitzenmedizin überhaupt in Anspruch nehmen, was würde drinliegen, was würde für mich nicht drin liegen? Und das ist jetzt komischerweise eine Dimension, die zurzeit überhaupt nicht zum Tragen kommt. Was drin liegt oder nicht. Also ich habe mich eigentlich keine Sekunde gefragt, Bestrahlung ja oder nein. (…) Chemotherapie, ja oder nein, habe ich mich effektiv nie gefragt, das habe ich nie hinterfragt. Das war ganz klar, das versucht man. (…) Ich finde es noch bemerkenswert, dass dies überhaupt keine Dimension war. (5a, 5b 465-495)

The partner, in contrast, explained that she had always expected such a reaction; as children of our time and society, when confronted with a terminal illness, we reach for all the available treatment options (5a, 5b 496-500).

Other patients related similar experiences when they had been anticipating care needs or disability. One patient explained that, while feeling well, being bed bound for two weeks seemed absolutely impossible to him. However, he had just gone through this experience and found it astonishingly easy. Seriously ill and under strong pain medication, he slept a lot and the days went by almost unnoticed (1a 247-281). Another patient stated how horrified he had always been by the thought of sitting in a wheelchair. Admitted with vertebral metastases and unable to walk, he now was in fact sitting in the wheelchair at the hospital. There was no other way of moving around. Asked how he experienced being wheelchair bound after this had been such a horror-filled vision for him, he stated: "Now I am in there, now I don't know anything else anymore!" („Jetzt bin ich drin, jetzt weiss ich nichts anderes mehr!" 7a 217) He added that there was no other way and that fighting against it was impossible (7a, 7b 255-256).

When reality catches up with patients, when the inconceivable turns into a fact, the inevitable is accepted and lived through as one or as the only possible way of living in the given situation. Imagining an illness experience is quite different from being immersed in one. The reality of the body's limitations and demands that illness brings about make the concessions doable and even tolerable. Stated otherwise, the patients' world has been shattered through the diagnosis of a terminal illness or through deterioration of their health status. They find themselves in a new, yet unfamiliar world, where anticipated options are turned into non-options that may not even be recognized anymore. In addition, patients do not necessarily experience all the terrifying aspects they had anticipated, once they live in their new reality. While some people are aware that, in any given situation, they may not act or feel as imagined previously, for others, it comes as a surprise when they realize retrospectively the gap between their anticipations and the reality they are living now.

The man in the wheelchair, who had been a manual worker and was now quite forgetful and not very talkative, was unable to further articulate his experience of sitting in the wheelchair. For him, it had become a fact to live with, period. This example illustrates that articulation has limits; study participants could not put all their feelings or experiences into words. Such situations came up several times during conversations. They might have had different reasons: I may have asked the wrong probing questions or asked them in the wrong way; some consequence of the illness, such as forgetfulness or aphasia, may have rendered further explanations impossible; study participants may have been unwilling to share more; or their feelings and experiences eluded in fact any articulation.

Family Members' Experiences

While living with the terminal illness, patients and family members share many experiences. Their perspectives, however, differ. While the patients are directly affected by and suffer from symptoms and disabilities, the family members are witnesses to the suffering and provide care. Witnessing and caring bring about further experiences unique to the family members.

Witnessing Suffering

Being a witness to the beloved patient's suffering is extremely demanding for family members. Although they do not experience symptoms or disability themselves, they live with or visit the patient frequently so that the problematic situation is constantly on their mind, they watch the patient closely, they know the diagnosis, and they imagine vividly how the patient may feel. Observing and imagining the patient's distress is in deed very distressing for the family member. The following quotes from a partner illustrate this. The man had witnessed his partner's back pain at home over many weeks before she was admitted to the hospital and was diagnosed with terminal cancer. His workplace was in sight of the hospital.

> She never complained, also at home she never complained that she was in pain. At the most, she said that she had back pain, but nobody knew how severely she suffered from back pain. One only learned that here, how much back pain she had suffered, because, well, when they found out that it was a tumor, one can then imagine what pain she endured so far.
> (...)
> Before, at home, she was screaming from pain at night. And I didn't know... you know, if one cannot help, one would like to, but cannot.

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> (...)
> When she is speaking so softly, then I know, aha, it's not good at the moment. Usually she speaks more powerfully, but when she is speaking so softly... then it is hurting my heart, when I hear her like that, and I think: Oh you poor soul. Why she after all?
> (...)
> And then it is of course also hard for me, I am working just down there. And throughout the whole night shift, I am seeing this hut here (the hospital). That's not necessarily empowering... She likes it of course. She can come here for smoking and watch me at work. Then she asks: "Which engine are you driving?" Then I give her a light sign, then she sees, which engine I am driving. It is interesting for her, but for me... I somewhat fly into a rage. I go home to sleep, then I come here, then I go to work, and then I see this hut all the time and know how much pain she suffers and everything...
>
> Sie hat dann schon nie gejammert, auch daheim hat sie nie gejammert, sie habe Schmerzen. Sie sagte höchstens, sie habe Rückenschmerzen, aber wie stark sie Rückenschmerzen hatte, das wusste kein Mensch. Das hat man ja dann erst hier erfahren, wieviel Rückenweh sie gehabt hatte, weil, ja, als sie dann rausgefunden hatten, einen Tumor, da kann man sich ja vorstellen, was sie bisher für Schmerzen ausgehalten hat. (6 po 374-382)
> (...)
> Vorher war sie drin, zu Hause, da hat sie geschrien vor Schmerzen in der Nacht. Und ich wusste nicht... oder, wenn man dann nicht helfen kann, man möchte, kann aber nicht. (6b 283-286)
> (...)
> Wenn sie so leise redet, dann weiss ich, aha, jetzt ist es nicht gut. Sonst kann sie schon kraftvoller reden, aber wenn sie dann so leise redet... dann tut es mir wieder weh im Herzen, wenn ich sie so höre, dann denke ich: Oh Du arme „Cheib." Wieso überhaupt sie? (6b 388-396)
> (...)
> Und dann ist es natürlich auch hart für mich, ich arbeite gerade da unten. Und ich sehe den lieben, langen Nachtdienst hier die Hütte (das Spital). Das ist auch nicht unbedingt aufbauend... Ihr gefällt es natürlich. Sie kann hierher kommen zum Rauchen und zusehen, wie ich arbeite. Dann fragt sie: „Mit welcher Lok fährst Du?" Dann gebe ich ihr ein Lichtzeichen, dann sieht sie, mit welcher Lok ich fahre. Für sie ist es interessant, aber für mich... Ich bekomme dann etwas den Koller. Ich gehe nach Hause zum Schlafen, dann komme ich hierhin, dann gehe ich arbeiten, und dann sehe ich die ganze Zeit diese Hütte und weiss, wie sie Schmerzen hat und alles zusammen... (6b 180-193)

These words may not sound very impressive; however, these are the words of a manual worker who spoke a rough slang and was more used to taking action than in expressing himself verbally. Showing his suffering and sorrow openly, let alone talking about his fe

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feelings, was not his way. During the post bereavement interview he excused his tears by saying he had a cold, and in the first interview he desperately tried to keep up his morale by repeatedly stating in a very different and self-convincing voice: "But otherwise, everything is alright." („Aber sonst geht es gut." 6b 28-31) His words, therefore, should be taken as hints alluding to the tremendous suffering that transpired during the interviews, but remained unarticulated.

Not being able to do something for the patient or, as the example below shows, for the family, added to the suffering of family members. Witnessing the patient's suffering works as a strong call to action for family members; they want to provide help in relieving the suffering. Being robbed of this option and condemned to only stand and watch is very distressing.

> And the brother who is abroad now was very close to him, likes him incredibly and... Now he cannot talk to him on the phone... He called every day. Now he cannot call anymore. Instead, he is calling me every day, and I must tell how it goes. And he suffers, he suffers, because he cannot help. Also not me and his father... because he knows that he cannot do more.
>
> Und der Bruder, der jetzt im Ausland ist, war ihm sehr nahe, hat ihn wahnsinnig gerne und... Jetzt kann er nicht mehr mit ihm telefonieren... Er hat jeden Tag telefoniert. Jetzt kann er nicht mehr telefonieren. Dafür ruft er mich jeden Tag an, und ich muss erzählen, wie es geht. Und er leidet, er leidet darunter, weil er nicht helfen kann. Auch mir und seinem Vater gegenüber... weil er weiss, er kann nicht mehr tun. (4b 2. 294-301)

The illness takes its toll on patients; symptoms and disability may let them react with impatience or anger, for instance, when a well-intended care action causes pain. At times they are in a bad mood or even depressed. Family members, committed to caring for the patients and doing the best they can, experience such negative reactions as painful and hurting. They show, nevertheless, great understanding for the patients' behavior; they can imagine themselves reacting similarly under the same circumstances. However, understanding the patient's response does not prevent suffering from it. One partner, for example, decided to leave the room for a smoking break, stating that it would hurt him when the patient was grousing during body care (6c 2. 192-196). Thus, family members come up with rational, logical explanations of patients' negative reactions, words, or moods. They imagine themselves being in the patient's situation and understand that they might react in the same way. Knowing why the patients react negatively and understanding it works as a coping strategy for the family members. Knowing why, however, does not prevent family members' immediate suffering in the situation.

Meeting the Patient as a Different Person

In some patients, their mental capacity or even their personality was directly affected to some degree by the illness, especially in those suffering from a brain tumor or brain metastases. The family then met a patient who was no longer exactly the person they had intimately known. Their close relative showed some strange and at times incomprehensible characteristics. One family member explained:

> He is not wholly my son, he is another son, even though at times he says exactly what he would have said in the past.
>
> Er ist nicht mehr ganz mein Sohn, er ist ein anderer Sohn, obwohl manchmal sagt er genau, was er früher auch gesagt hat. (4b 650-652)

The brother and sister-in-law of another patient also related a problematic situation. The patient, a man in his fifties suffered from brain metastases. Prior to the metastases, he had been living independently, spending his leisure time mainly with colleagues. The family members laughingly acknowledged: "We only got a look-in when he was not feeling well." („Wir kamen nur zum Zug, wenn es ihm nicht gut ging.“ 9b 500-501) Family relations had been strained occasionally in the past; the patient, the younger brother, had never easily accepted his elder brother's suggestions. However, the brother and sister-in-law had cared for him when he had been sick before, and it was natural for them as his closest relatives to again commit themselves to caring for him when he became terminally ill (9b 2. 283-331). They visited regularly and were running errands for the patient. But this was not an easy task for the brother. Frictions were common as his wife mentioned:

> Sister-in-law: My husband has troubles with him at the moment. Whenever he visits… He has to ask him about money and correspondence and so on, and then he is always so spiteful. (…) And then he comes home angry and says that one could do everything "and then it isn't right anyway, he knows it all better" (laughs quietly).
> Interviewer: Mhm, not an easy situation…
> Sister-in-law: No, this is not so easy. And I feel sorry when my husband comes home so angry. You know, I regret that, I then think that he would not need this on top. Since he is doing everything for him, that at least they would be able to talk together decently.
>
> Schwägerin: Mein Mann hat jetzt Mühe mit ihm. Jedesmal wenn er geht… Er muss ihn ja fragen wegen Geld und Korrespondenz und so, und dann ist er immer so gehässig. (…) Und dann kommt er auch sehr verärgert nach Hause, und sagt, da könne man machen und tun, „und dann ist es doch nicht recht, und er weiss doch alles besser" (lacht leise).
> Interviewerin: Mhm, keine einfache Situation…
> Schwägerin: Nein, das ist nicht so einfach. Und ich bedauere es dann, wenn mein Mann so verärgert nach Hause kommt. Oder, das bedauere ich dann, ich habe dann das Gefühl, das müsste er jetzt nicht auch noch haben. Wenn er ihm schon sonst alles macht, dass sie doch anständig miteinander reden könnten. (9b 2. 61-86)

The sister-in-law further explained that some friction had been common between the brothers, but she felt that the patient's behavior was now accentuated through the illness. For her, the burden was doubled: Not only was she concerned about the patient's well-being, she also worried for her husband. In addition, she had to act as mediator.

The brother was disappointed by the patient's unwillingness to deal with anything. Asked to turn in applications to the social worker, the patient did not do so, but just left it to his brother. The brother went on:

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> He also got forgetful. He said: "You brought me a whole pile of things," but it was only the application form for the disability pension. (...) The second was the application for the nursing home. "Yeah, I cannot do this, you brought me a whole lot of mail." "Okay, give me the stuff, I'll take care of it."

> Er ist auch vergesslich geworden. Er hat gesagt: „Du hast mir ja einen ganzen Stoss Sachen gebracht," und dabei war es einfach das IV-Formular. (...) Das zweite war die Anmeldung für das Pflegeheim. „Jää, das kann ich nicht machen, Du hast mir einen ganzen Haufen Post gebracht." „Also gib mir das Zeug, ich erledige es." (9b 304-330)

Thus, even though the brother was aware of the patient's forgetfulness, he did not fully connect this to his behavior, that is, he did not fully realize that the patient's forgetfulness interfered with his ability to perform the requested task. From the nursing record and my observations, however, it was clear that forgetfulness was a serious problem for the patient. From a professional perspective, unwillingness was unlikely to be the reason for not taking on the requested task, it seemed much more likely that the patient forgot what he was asked to do and that he was asked to do it. In fact, the patient stated that he did not know what was going on regarding applications and gratefully acknowledged the support of his brother and sister-in-law. Since friction-laden conversations had not been unusual between the brothers before, any challenging issue in their conversations probably let them slip into this pattern again. While the patient was partly unaware of his forgetfulness and did not easily acknowledge his memory problems, for the brother it was difficult to fully discover the impact of the patient's memory loss as a major reason for their strained conversations since this was a familiar although now somewhat intensified pattern.

Experiencing Additional Burden

Besides witnessing suffering and facing negative reactions of and changes in the patient, some family members experience an additional burden. The terminally ill patient

may not be the only family member in need of care. Family tasks may pile up and become overwhelming, as one woman acknowledged:

> At the moment, I also frequently visit my mother who is in a nursing home. And she is not doing so well either. She is badly down in the dumps at times. But well, I just have to accept that. (…) My sister and I, we arrange so that each of us visits once a week, or I sometimes take her home or she takes her home for a meal so that she has some diversion. Well, now for a while it seemed to be a lot for me. My mother felt so badly, was depressed, and well, then going to her in the nursing home and then again coming here in the hospital. Then I thought, well now… "Now I will not go anywhere for one week," I said, but I didn't manage it in the end, and went to visit both again.
>
> Ich habe im Moment auch noch die Mutter, die auch in einem Pflegeheim ist, die ich auch viel besuchen gehe. Und es geht ihr eben oft auch nicht so gut. Moralisch ist es bei ihr manchmal schlimm. Aber gut, ich muss es einfach hinnehmen. (…) Meine Schwester und ich, wir sprechen uns ab, dass jede einmal pro Woche geht, oder ich nehme sie manchmal zu mir heim oder sie zu ihr zum Essen, damit sie etwas Abwechslung hat. Gut, jetzt eine Weile schien mir, ich hätte schon viel. Die Mutter war letzte Woche auch so schlecht zwäg, hat „gmoralet," und eben, dann zu ihr ins Pflegeheim und danach wieder hierher ins Spital. Da dünkte mich, also jetzt… „Jetzt gehe ich dann einmal eine Woche nirgends hin," habe ich gesagt, aber ich habe es dann doch nicht fertig gebracht, und ging dann doch wieder beide besuchen. (9b 2. 306-327)

Disagreements, not with the patient, but within the rest of the family also cause trouble. One wife felt deeply hurt by her son who blamed her for not having organized a more accessible flat.

> But, you know, when the physician told me to search for a flat and I did not do so, then the son once gave me a ride to the city and said to me: "It is your fault that dad cannot return home. If you had searched for a flat, with an elevator, dad could return home now." This hurt me.
>
> Aber, wissen Sie, als der Arzt sagte, ich solle eine Wohnung suchen und habe keine gesucht, da hat mich der Sohn einmal in die Stadt gefahren und zu mir gesagt: „Du bist schuld, dass Vater nicht nach Hause kann. Hättest Du eine Wohnung gesucht, mit Lift, könnte Vater jetzt nach Hause." Das hat mir weh getan. (2a, 2b 1014-1020)

Consequences for Family Members

While all family members share the distress of being witnesses to the patients' suffering, several family members have to deal with additional burdens depending on the patient's and family's specific situation. The multiple burdens that family members experience have consequences for them on different levels. Accompanying a terminally ill patient, sometimes over a long period of time, is exhausting. Family members get tired. The patient, the illness and caregiving become the focus of thoughts, feelings and actions, family members are completely taken up by their concerns and commitments. Prior everyday activities and pleasures move to the background. The following quote illustrates how a wife's life was affected by her husband's illness.

> I was just unenthusiastic over the last time, I had no pleasure anymore playing the piano, I didn't feel like reading, could not concentrate...
> (...)
> Whatever I did, my thoughts were with the illness and the family, and I could just not concentrate anymore, not even on a book. I have books at home that I started reading three times... and I am just not proceeding. And sometimes, I just sit and think...
>
> Ich war einfach in der letzten Zeit lustlos, ich hatte keine Freude mehr Klavier zu spielen, ich mochte nicht lesen, konnte mich nicht konzentrieren... (1b 376-379)
> (...)
> Bei allem was ich tat, war ich immer mit einem Gedanken bei der Krankheit und der Familie, und ich konnte mich einfach nicht mehr konzentrieren, nicht mal mehr auf ein Buch. Ich habe Bücher daheim, die ich dreimal angefangen habe... und ich komme einfach nicht weiter. Und manchmal sitze ich einfach da und studiere... (1b 610-615)

At times, nagging thoughts bothered family members. For instance, the parents of the patient who died from his third cancer stated that they had given him their genes, and they were brooding over the cause of his terminal illness: Was it their genes? Or the radiotherapy he got for the first tumor? And the mother added that as terrible this terminal illness was, what bothered them most was the thought that he had been sick so often

throughout his life (4b 5. 267-271). She also suspected that her son had suffered more than they ever knew.

> I was on the bus, on the streetcar, and he (went to work) by bus or streetcar before he stopped working… and I don't know how, you know. Because he… The leg did not work anymore. He had crutches, and I don't know how he managed this. And I think, he fell from time to time, he never mentioned that, but I am sure.
>
> Ich war im Bus, im Tram, und er ist in der letzten Zeit, als er noch arbeitete mit Bus und Tram… (zur Arbeit gegangen), und ich weiss nicht wie, oder. Weil er hat… Das Bein lief nicht mehr. Er hatte Krücken, und ich weiss nicht, wie er das gemacht hat. Und ich denke, er sei hie und da umgefallen, er hat das nicht erzählt, aber ich bin sicher. (4b 5. 283-289)

Tormented by her son's suffering, this mother came to think about death as a release, as an acceptable and even preferable alternative to an agonizing life. At least, her son's suffering would be over for ever, he would not get another serious illness.

> At times I think, if he had recovered somewhat, he would have gotten a fourth tumor or something tragic… And I think now that in a way nothing can happen anymore… I assume that afterwards he will be… released from all that troubled him, and free…
>
> Ich denke manchmal, wenn er wieder einigermassen gesund geworden wäre, hätte er vielleicht noch einen vierten Tumor gehabt oder etwas Tragisches… Und ich denke jetzt, es kann irgendwie nichts mehr passieren… Was ich vermute, nachher ist er einfach… erlöst, von allem, was ihn plagen konnte, und frei… (4b 5. 277-283)

Caring for a terminally ill patient does often not leave space and time for social activities, contacts are reduced, and family members' social life is put on hold.

> And the problem is that we almost don't have any social life, at the moment. It is also hard to do it for me. I must say… We have good friends who call and say: "Come for dinner," but now, it is difficult, because our world is a different one at the moment. And it might be good, but I think that what they are doing at the moment, travelling and things like that, it is almost of no interest to me. And I cannot talk about my son all evening, perhaps a bit, but that's it. It is not even my goal. And… therefore it is difficult. I already declined several times.
>
> Und das Problem ist, dass wir praktisch kein Sozialleben daneben haben, jetzt. Ich kann es auch fast nicht. Ich muss sagen… Wir haben gute Freunde, sie telefonieren und sagen: „Kommt zum Nachtessen," aber jetzt, es ist schwierig, weil unsere Welt ist im Moment eine andere. Und es wäre vielleicht gut, aber ich denke, was sie

> machen momentan, reisen und Zeug und Sachen, es interessiert mich fast nicht. Und ich kann doch nicht von meinem Sohn erzählen den ganzen Abend, vielleicht ein bisschen, aber dann fertig. Es ist auch nicht mein Ziel. Und... deshalb ist es schwierig. Ich habe schon einige Male abgesagt. (4b 5. 431-443)

Family members' everyday world has been shattered; they are now living in a world that is dominated by caring for the patient. The worlds of their friends, which they shared with them in the past, seem estranged and have become irrelevant at the moment. While friends are looking at and moving on to their familiar horizon, with occasional glimpses into illness and caregiving, the horizon of family members who care for a terminally ill patient appears dull and narrow. Looking beyond and discovering new horizons are postponed to a yet unforeseeable future.

Experiencing Death

With the patient's death, family members face the final loss of a loved one and the suffering and sorrow that comes with it. One wife related that she first wanted to be strong and not let her sorrow surface, but after a while she suffered a breakdown. She got excellent support from her physician, family and friends, and learned that she could mourn and had to live through her sorrow (8 call 67-82). The mother who lost her son said three months later that she felt supported by family and friends, by the funeral service and many, many conversations with her husband. She felt she was in a special place during the first few weeks when a lot had to be done and her other sons were visiting. She was very sad but felt sustained. Later this changed. She was extremely tired and had health problems. It was a difficult time, and she still experienced ups and downs after three months, although on the whole, she was recovering.

The man who lost his partner within one month after the diagnosis of her terminal cancer could not rely on a sustaining social network, but got some support from a counsellor at the hospital. He related the most dreadful experiences: He had spent the last six days with the patient at the hospital, and when she died, suicide was his first thought, and he was unable to resume sleeping after a week with no more than short naps.

> In the beginning, well, I jump down somewhere or so, that was the first thought. And then I talked to the counsellor, yes… and then it went somehow. I could not sleep, napped for an hour, and then awake all the time. I was somewhat too tired to sleep. Then I finally could… well, he (the counsellor) gave me two pills so that I could finally sleep through the night.
>
> Am Anfang zuerst, ja, ich springe irgendwo runter oder so, das war der erste Gedanke. Und dann habe ich eben mit dem Berater geredet, ja… und dann ging es einigermassen. Ich habe nicht schlafen können, eine Stunde etwa eingenickt, dann die ganze Zeit nur noch wach. Ich war irgendwie zu müde zum Schlafen. Dann konnte ich endlich… also er (der Berater) hat mir dann zwei Tabletten gegeben, damit ich endlich mal durchschlafen konnte. (6 po 1200-1208)

That first month was marked by constant high distress. He had to organize the funeral service and all the paperwork related to the death of an immigrant. Since his partner had been on the lease, he had to find a new place and move within two weeks. He was so continually stressed that he had no time to think. When looking back, he stated that this stress actually helped him to overcome this first month. Once he was somewhat settled again, a low set in, but at least one month had already passed since his partner's death. After three months, he related that he was doing quite well as long as he kept himself busy. But he still experienced sleeping problems and bad dreams.

> Well, I feel quite well, as far as my health is concerned… Some rebounds from time to time of course, now that I am living alone, you know, and… I still have a photo at home, and… then one is of course still reflecting a lot, especially if one has an early shift and can't sleep at night… (…) One should be able to turn it off in the head, because it is always the same, always the same. And then I also have stupid nightmares of the whole story, but very brutal stuff. Not about the cancer, but I would like to save her, and someone is in her back with a small knife and stabs her

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> back all the time, and I can't bring her up until she is just dead. I am dreaming such nonsense at times.
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> Ja, mir geht es einigermassen gut, vom Gesundheitlichen her… Ab und zu natürlich wieder etwas Rückschläge, jetzt wo ich alleine wohne, oder, und... Ich habe noch eine Foto zu Hause, und… dann denkt man natürlich noch viel nach, vorallem wenn man dann Frühdienst hat, und nachts nicht schlafen kann… (…) Man sollte es mal abstellen im Kopf oben, weil es ist immer das Gleiche, immer das Gleiche. Und dann habe ich auch blödsinnige Alpträume von der ganzen Geschichte, aber ganz brutales Zeug. Nicht vom Krebs her, sondern ich möchte sie gerne retten und einer ist hintendran mit einem kleinen Messer und sticht die ganze Zeit in den Rücken rein, und ich kann sie nicht raufziehen, bis sie einfach tot ist. Solchen Mist träume ich ab und zu. (6 po 52-74)

He kept going on, convincing himself that his life was going on after all, but he had a hard time finding any new meaning in life.

> Now I must start fighting again all over, now when I get bored, I must fight, tell myself that it will go on anyway. But I'm really fed up when I'm sitting at home. Why should I go to work at all? For what, you know? From time to time, it doesn't make any sense to me. What shall I be doing there now?
>
> Jetzt muss ich wieder anfangen zu kämpfen rundum, jetzt wo es mir langweilig wird, muss ich kämpfen, mir selber sagen, es gehe ja trotzdem weiter. Aber es scheisst mich an, wenn ich zu Hause hocke. Weshalb soll ich überhaupt arbeiten gehen? Für was, oder? Ich sehe ab und zu den Sinn nicht mehr dahinter. Was soll ich da jetzt noch machen gehen? (6 po 1038-1045)

In conclusion, he admitted that, prior to his partner's death, he had not known how much he loved her. Resuming life without her and their common plans was extremely difficult for him.

> Eh, I just loved this woman more than everything… (…) I didn't even know that I loved this woman so much.
>
> Eh, ich habe diese Frau einfach über alles geliebt… (…) Ich wusste gar nicht, dass ich die Frau so gerne hatte. (6 po 1055-1056)

With the patient's death, family members suffer the final loss of a beloved person. The world they had shared with the patient collapses; the deceased will never again be part of their everyday world. Only after mourning this tremendous loss can family members slowly settle in their new world and begin to explore which possibilities are now open for them.

Rewarding Experiences

As difficult as it was to accept having a terminal illness and living with it, as much suffering as the illness caused to both patients and families, they, nevertheless, also related positive experiences that the illness had brought about for them. The diagnosis of a terminal illness threw people's life plans off. Patients were confronted with a shortened life span and concerned about partners who would have to go on with life alone. One patient, when relating how difficult it was to come to terms with this new life perspective, nevertheless said that it also had a positive and liberating side to it:

> The positive of it is also that it releases resources, that I can allow myself to think things, which I never allowed myself to think before. That I am telling myself: My life is more limited, probably, than I thought it would, and now I can set priorities for myself, which I did not allow myself to set before. That I suddenly tell myself: Well, do I have to do this yet? Do I need this? Do I want this? That it can as well get advantages going; that it does not only have to be negative.
>
> Das Positive ist aber auch, dass dies Ressourcen freisetzt, dass ich mir erlauben kann, Sachen zu denken, die ich mir vorher nie erlaubt habe zu denken. Dass ich mir sage: Mein Leben ist begrenzter, wahrscheinlich, als ich das Gefühl hatte, es sei, und jetzt kann ich mir Prioritäten setzen, die ich mir vorher nicht zu setzen erlaubt habe. Dass ich mir plötzlich sage: Du, muss ich das noch? Brauche ich das? Will ich das? Dass es sehr wohl auch Vorteile in Gang setzen kann, dass es nicht nur negativ sein muss. (5a 501-510)

Patients and family members experienced great support from their families and friends, emotional support as well as assistance with practical issues such as running errands. For some, the extent of this support was surprising and a very rewarding experience. The following quotes from a woman and a man underline this. The man

stated that he had not expected the colleagues from his group of regulars to visit him at the hospital, but they did, giving him the certainty that he was not yet forgotten.

> Patient: They came, yes, and this in fact, how shall I say it, lifted me up a bit. One is not forgotten, you know. Recently, a colleague was calling and said: "You are driving around in the wheelchair, I heard." "Well yes, not far of course, just around here." "Well, if you would like to come to the favorite pub, we will come and pick you up at noon and bring you there." (...)
> Interviewer: That is a good offer.
> Patient: Very, very good, I quite appreciate that.
> Interviewer: Nice...
> Patient: Something I had never expected.
>
> Patient: Die sind gekommen, ja, und das hat mich effektiv, wie soll ich sagen, so etwas aufgestellt. Man ist nicht vergessen, oder. Letzthin kam ein Telefon von einem Kollegen, der sagte: „Du fährst mit dem Rollstuhl rum, habe ich sagen gehört." „Ja schon, nicht weit natürlich, so etwas im Zeug rum da." „Also, wenn Du gerne in die Stammbeiz kommen willst, kommen wir Dich holen mittags und bringen Dich her." (...)
> Interviewerin: Das ist ein gutes Angebot.
> Patient: Sehr, sehr, das schätze ich noch so.
> Interviewerin: Schön...
> Patient: Was ich nie gedacht hätte. (7a 2. 217-235)
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> Female patient: And what I experienced as very good is the sympathy of all my friends, family, at work. The many, many people who ask, show concern, call, and give me strength. Ask: "How are you? What are you doing? I will quickly pass by." I could not imagine how many people would provide support to me. This is a very good experience, to feel this.
>
> Patientin: Und was ich ganz gut erlebt habe, ist die Anteilnahme von all meinen Freunden, Freundinnen, Familie, am Arbeitsplatz. Die vielen, vielen Leute, die nachfragen, betroffen sind, telefonieren, und mir auch Kraft geben. Fragen: „Du, wie geht es? Was machst Du? Ich komme schnell vorbei." Ich hatte das nicht für möglich gehalten, wie viele Leute mir Unterstützung geben. Das ist ganz ein gutes Erlebnis, das zu spüren. (5a 510-518)

The terminal illness of one family member affected the extended family, and all shared their sadness. It could bring families closer together; family ties got strengthened, as the mother of a patient explained:

> It is of course on the minds of the whole family, we are all sad. And it also somehow creates... a connection. I see that all cousins are coming, they are sad too.

> For years they did not have any contact... no contact is perhaps... yes, very little contact, now they are all coming at once.
>
> Es beschäftigt natürlich die ganze Familie, wir sind alle traurig. Und es schafft irgendwie... auch eine Verbindung. Ich sehe, dass alle Cousinen kommen, sie sind auch traurig. Jahrelang haben sie keinen Kontakt... keinen Kontakt ist vielleicht... ja, sehr wenig Kontakt, jetzt auf einmal kommen sie. (4b 2. 311-316)

The parents who lost their son only realized during his terminal illness what a reliable network of friends he had built up (4b 3. 394-415). And the mother explained that, even though it had been tremendously hard to accompany their son through the last weeks of his life, they also learned a lot from their relationship with him and from his friends.

> It is a difficult illness, I have to say, but it also has a lot... And my husband also said that he learned a whole lot. He said: "I did not believe that at 70 I would learn so much, but I learned a whole lot." From the relationship we had with him, from all the friends we met.
>
> Es ist eine schwierige Krankheit, muss ich sagen, aber es hat auch sehr viel... Und mein Mann hat auch gesagt, er habe sehr, sehr viel gelernt. Er hat gesagt: „Ich habe nicht mehr geglaubt, dass ich mit 70 noch so viel lernen würde, aber ich habe sehr viel gelernt." Von der Beziehung, die wir mit ihm hatten, von allen Freunden, die wir getroffen haben. (4 po 721-727)

This patient, who had suffered tremendously from his terminal illness, eventually died peacefully in the presence of his father. His quiet death was very comforting for the family.

> Mother: My husband was with him for one and a half hours. And he said that he was quiet, that he in fact fell asleep, in a way, suddenly... The head lay on the side, and he then realized that he was not breathing anymore. And then he got the nurse or rang the bell. And when I came, he was still lying on the side, and we were allowed to stay with him just like that, a bit longer. And that was good, because... He was totally relaxed, quiet; there was no fight, nothing. And I must say that this was consoling. How he died is consoling, one could almost say that it was beautiful. After the whole illness...
>
> Mutter: Mein Mann war noch eineinhalb Stunden bei ihm. Und er hat gesagt, er war ruhig, er sei wirklich eingeschlafen, auf eine Art, auf einmal... Der Kopf lag auf der

> Seite, und er habe dann gemerkt, dass er nicht mehr atme. Und dann hat er die Schwester geholt oder geläutet. Und als ich kam, war er immer noch auf der Seite, und wir durften mit ihm bleiben einfach so, etwas länger. Und das war schön, weil … Er war total entspannt, ruhig, und es hat keinen Kampf gegeben, nichts. Und ich muss sagen, das war ein Trost. Wie er gestorben ist, ist ein Trost, man kann fast sagen, es war schön. Nach der ganzen Krankheit… (6 po 262-272)

Living with a terminal illness, then, is not necessarily only laden with many burdens; positive aspects may be experienced by patients and family members. Facing a shortened life expectancy may be liberating, bring forth hidden resources and open up new possibilities. New insights may be gained from caring or being cared for. Witnessing a peaceful death after a painful illness journey can bring consolation.

Going on With Life After the Onset of a Terminal Illness

As shown in chapter one, the palliative care literature is replete with examples of patients and family members for whom the terminal illness brought new and rewarding experiences. The participants in this study occasionally touched on this theme, relating some aspects that made living with the terminal illness or continuing to live after the patient's death more bearable. While their world had been shaken up and possibilities were diminished in their current world fuelled with illness, they had still been able to recognize new horizons of possibilities that opened up for them in this new unstable world. However, these study participants' stories primarily show how their everyday worlds collapsed when the terminal illness broke in and how they were, nevertheless, continually relying on familiar background practices and language, while moving in the new worlds of illness, hospital and professional caregiving. The participants' accounts also illustrate that patients' and family members' life stories render their decisions, actions, and behavior in the hospital more understandable. Thus, knowing patients and fam

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families as persons is crucial for care providers, who aim at giving optimal care. Knowing patients and families life stories, concerns, and illness experiences opens up possibilities to improve and individualize care interventions.

These participants' stories also give evidence to the suffering that a terminal illness causes. Cassell (1982) defined suffering as "the state of severe distress associated with events that threaten the intactness of the person" (p. 640). Thus, suffering is, but is not solely, related to symptoms that can be related to some pathophysiological changes in the patient's body. Rather, for terminally ill patients and their families suffering is also related to loss: the loss of their everyday taken-for-granted way of living, the loss of life plans and of a common future. Patients lose social roles, and their integrity as a person is threatened by physical and mental disabilities. Family members suffer as witnesses to the patients' suffering and experience the strains of caring and caregiving; their world is closing in. Eventually, with their death, the patients face the final collapse of their world, the definite closing down of horizons. The family members are confronted with the definite loss of a loved one and, while mourning the loss, must resume life without the beloved person. They have to take up life again and move on to new horizons. They must lead a new life in a forever altered world.

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CHAPTER FIVE: EXPERIENCES OF BEING IN THE HOSPITAL

The experience of being in the hospital encompasses more than care provided by professional care providers. Patients and family members provide a whole picture of what it means to live in a hospital over time. In this chapter, three major ways of experiencing the hospital are outlined. Patients and families describe existence in the hospital on a continuum from prison to heaven, or somewhere in-between. For most of the hospital stay, patients occupy some place in-between and can be described as "guests of necessity." Guests of necessity experience the hospital as the right place to be, even though they long for home. The quality of hospital life is not constant, rather, patients move back and forth on a continuum, and some experiences are transitory and fade away. Lasting connections to home and everyday life make the hospital stay bearable. In other words, temporary life in a hospital is dependent on the larger existence and dwelling place of home.

For patients, being in the hospital means being in the hospital for 24 hours a day. For family members, it means visiting the patient regularly; most of them spend several hours per day at the hospital. Some time during these hospital days is taken up by diagnostic tests, treatments and nursing care. However, patients spend many hours on their own or in the company of a family member, occupying themselves, lying or sitting idly in their beds or hospital rooms, or sleeping.

The Hospital Experienced as Prison

Mr. Dolder was transferred for palliative care from another unit of the hospital to the unit where he died nine weeks later. In the beginning, Mr. Dolder's feelings alternated between great sadness and fury, he cried a lot, and he reacted rather aggressively at times (4b 398-406, 433-438). In summary, he said: "I am feeling like in prison." („Ich fühle mich wie im Gefängnis." 4a 41) Mr. Dolder expressed the most negative view of all study participants regarding his experience of being in the hospital. In order to make his feelings understandable, it is necessary to explore his situation in detail. Interviews with the patient's mother and observations provided most of the data, since only one short conversation with the patient was possible.

Mr. Dolder suffered from a glioma that had been diagnosed about nine months earlier. Chemotherapies had failed and palliative radiation therapy had to be stopped due to brain edema. At admission, he had a paresis of the right side, some difficulty with speaking, and problems with his short term memory. His health status deteriorated constantly. He became hemiplegic, aphasic, and suffered from an almost total memory loss.

Mr. Dolder was in his late thirties. His life had been marked by illness: As a child, he had been treated successfully for another brain tumor, but as a consequence suffered from epilepsy. In his twenties, a lymphoma was diagnosed and treated with success. Although the epilepsy had at times hampered Mr. Dolder's education and working life, he had been able to work full time in an office over the last few years. He was active in sports and traveled around the world. He was living on his own, but maintained close cor

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contact with his parents and siblings. He also had a big circle of friends. Both parents were retired and living comfortably in another city.

Mr. Dolder related his feelings of imprisonment to the loss of his independence. Asked if he had also felt like in prison on the unit where he had been hospitalized before, he stated: "Less so, because I was still more independent there." („Weniger, da ich dort noch selbständiger war.“ 4a 44-45) His mother confirmed that being dependent was the biggest problem for her son. He had, therefore, fought for his independence at home for as long as possible. After admission to the first unit, he was in a transitional stage, still hoping for some improvement from radiotherapy. With the transfer to palliative care, his dependency had become absolutely definite.

> Interviewer: I understand that your son at the moment… this is my impression, that he mainly suffers from being so dependent…
> Mother: Yes, this is probably the biggest… for every little thing he is dependent, and he cannot stand this. And he had fought for months, in his flat. He did not want to become dependent, and, therefore, he always went to work, did everything, went shopping, although he could hardly walk anymore; because he did not want to become dependent. But it happened suddenly. And in the hospital (on the first unit) it still was a transition, for him, it probably wasn't really true yet, but now it is true, and it is a fact.
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> Interviewerin: Ich verstehe, dass Ihr Sohn im Moment… das ist mein Eindruck, dass er vor allem darunter leidet, dass er so abhängig ist…
> Mutter: Ja, wahrscheinlich ist das die grösste… für jede Kleinigkeit ist er abhängig, und er verträgt das nicht. Und er hat monatelang gekämpft, in der Wohnung. Er wollte nicht abhängig werden, und deshalb ging er immer arbeiten, hat alles gemacht, ging einkaufen, obwohl er fast nicht mehr gehen konnte, weil er nicht abhängig sein wollte. Aber auf einmal kam das. Und im Spital (auf der ersten Abteilung) war es noch eine Transition, es war noch nicht ganz wahr, wahrscheinlich für ihn, aber jetzt ist es wahr, und es ist da. (4b 413-424)

Due to his aphasia, Mr. Dolder's utterances were limited to a few sentences; he could not further explain what contributed to his feelings of imprisonment in the hospital. However, by

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by closely considering his situation, it is possible to point out several aspects that most likely imprisoned his spirit.

Freedom of Decision-Making

Despite the many obstacles that cancer and epilepsy had put in his way, Mr. Dolder had coped with education and managed to live independently, and to work, first part time, and then even full time for several years. The years prior to the onset of the terminal illness were the best years of his life. He had defeated cancer for the second time and did not suffer any epileptic attacks. He was a very active traveler, climbing mountains and trekking in Africa, South America and Asia (4b 533-625). And he made his own decisions, including the decision to take a risk, for instance, when he decided to climb Kilimanjaro against the advice of his neurologist.

> Mother: After the first cancer 10 years ago, he went to Kenya and he said he would climb up the Kilimanjaro. And the neurologist said: "No, this is too high, don't go." So he said he would climb up Mount Kenya. And he was on Mount Kenya, which is 1000 meters less, 5000 or so. Then he said, if I can make 5000, I can also make 6000. In February, he returned to Kenya and was on the Kilimanjaro.
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> Mutter: Nach dem ersten Krebs vor 10 Jahren, ist er nach Kenia gegangen und hat gesagt, er gehe auf den Kilimandjaro. Und der Neurologe hat gesagt: „Nein, es ist zu hoch, gehen Sie nicht." So sagte er, er gehe auf den Mount Kenia. Und er war auf dem Mount Kenia, das ist 1000 Meter weniger, 5000 oder so. Dann hat er gesagt, wenn ich 5000 machen kann, kann ich auch 6000 machen. Im Februar ging er wieder nach Kenia und war auf dem Kilimandjaro. (4b 605-613)

In contrast, in the hospital, the decisions that Mr. Dolder could still make, were very constrained, as the following observation illustrates:

> Mr. Dolder is sitting in the wheelchair at the sink, a nurse is helping him with body care. The nurse asks him, if he wants lotion or eau de toilette for his face. Both bottles are standing on the sink, and the nurse tells Mr. Dolder that he may say or show it. He chooses eau de toilette. Some time later, the nurse asks him where he would like to eat breakfast, in his room or outside at the table in the corridor. He chooses to stay in the room. The nurse suggests washing his hand, because he still

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> has some eau de toilette on it and, therefore, the food might not taste well. Mr. Dolder rubs his hand on his track-suit. He does not want to wash it. The nurse accepts this. She mentions that she would now like to put up the wheelchair table. Mr. Dolder states that this was not necessary in his view. The nurse explains that it is necessary from the nurses' perspective; otherwise it would be dangerous for him. She asks if he could accept this. His answer remains unclear, and the nurse puts up the table.

> Herr Dolder sitzt im Rollstuhl am Lavabo, eine Pflegende hilft ihm bei der Körperpflege. Die Pflegende fragt ihn, ob er Lotion oder Eau de toilette wolle für das Gesicht. Beide Flaschen stehen auf dem Lavabo, und die Pflegende sagt zu Herrn Dolder, er könne es sagen oder zeigen. Er wählt Eau de toilette. Etwas später fragt die Pflegende ihn, wo er das Frühstück essen möchte, im Zimmer oder draussen im Gang am Tisch. Er will im Zimmer bleiben. Die Pflegende schlägt vor, noch die Hand zu waschen, da er noch Eau de toilette dran habe, das Essen werde deshalb vielleicht nicht gut schmecken. Herr Dolder reibt die Hand am Trainer. Er will sie nicht waschen. Die Pflegende akzeptiert dies. Sie sagt, jetzt möchte sie noch das Rollstuhl-Tischli montieren. Herr Dolder sagt, aus seiner Sicht sei dies nicht nötig. Sie erklärt, es sei nötig aus der Sicht der Pflegenden, da es sonst für ihn gefährlich sei. Sie fragt, ob er dies akzeptieren könne. Seine Antwort bleibt unklar, und die Pflegende montiert das Tischli. (4c 54-81)

The nurses were aware that the patient suffered from being dependent and tried to reduce his feeling of dependency by letting him make as many decisions as possible. But his decision-making was now reduced to choosing between lotion or eau de toilette for his face, between eating breakfast in his room or outside. He had the freedom to rub off his hand instead of washing it, but the table was fixed on the wheelchair against his wish. Given an earlier fall and the patient's neglect of his hemiplegia, this fall prevention intervention was easily comprehensible from a nursing perspective, but remained, nevertheless, incomprehensible for the patient and a far cry from his own perceived "acceptable risks."

For Mr. Dolder who had made relevant decisions in his life, such as climbing Kilimanjaro against his physician's advice, the decisions he could still make at the hospital were trivial ones. He was only allowed to make certain decisions, and some of

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his wishes were disregarded. It seems understandable that he still felt heavily restricted in his freedom of decision-making (4a 54-58), and that this added to his feelings of dependency and consequently of imprisonment. The nurses' endeavors to allow Mr. Dolder to make decisions whenever possible hardly influenced his sense of his comparative loss of agency and freedom.

The Unable Body

Photos showed Mr. Dolder as a slim and athletic young man with full, brown hair. In the hospital, he was heavily marked by his illness and treatment side effects. He had gained some weight and showed the typical moon face from high dose cortisone therapy, he appeared awkward (schwerfällig); his hair was thin and grey. On the whole, he looked much older than in the photos taken before the onset of his terminal illness.

The eager mountain climber, skier, and swimmer was losing command over the right side of his body, and his paralysis was progressing as a consequence of the growing brain tumor. He was now bound to wheelchair and bed, unable to get up and move around on his own. Furthermore, the tumor robbed him of parts of his self-awareness, language and memory. He was not always aware of his physical limitations and would, unobserved and without the side rails on his bed or the table on his wheelchair, try to get up as he usually did prior to the onset of his illness and fall. Communication was severely restricted; although the patient still mostly seemed to understand, his speech was limited to single words or an occasional sentence, which deprived him from clearly uttering his view or his wishes and from engaging in discussions. Accordingly, the care providers adapted, and thereby limited, their verbal interactions with the patient to his abilities, for instance, by asking questions that he could answer with yes or no. Finally, th

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the patient's short term memory was affected and worsened constantly. Reading had become impossible, because he lacked the needed concentration (4b 58-59). He felt restless, sad, and misunderstood, was bored and depressed, as his mother explained:

> And it is almost always something else, but he is restless and not happy, clearly. (...) Now he said, for instance: "I am so bored." Then we say: "You have lots of visitors, and you have therapy, occupational therapy once, and once you may listen to music." It is clear that he can do less. He cannot read anymore, he cannot concentrate for reading, he said that. (...) And today it is... it is not aggressive, but it is always: "I can't do this, I don't want to do that and yes..." I said: "When I am here, you are not bored, I am here and we are both together." And he said: "Yeah, you don't understand." I asked: "Shall I not come?" "Yes you should, but you don't fully understand me..." It is the depression, the deep depression, it can't go on.
>
> Und es ist praktisch jedesmal etwas anderes, aber er ist unruhig und nicht glücklich, eindeutig. (...) Jetzt hat er gesagt, zum Beispiel: „Es ist mir so langweilig.“ Dann sagen wir: „Du hast viel Besuch, und Du hast Therapie, einmal Ergotherapie, und einmal kannst Du vielleicht Musik hören.“ Es ist klar, er kann weniger machen. Er kann nicht mehr lesen, er kann sich nicht mehr konzentrieren zum Lesen, das hat er gesagt. (...) Und heute ist es... es ist nicht aggressiv, aber es ist immer: „Ich kann das nicht mehr, ich will das nicht mehr und ja...“ Ich habe gesagt: „Wenn ich da bin, ist Dir nicht langweilig, ich bin da, und wir sind beide miteinander.“ Und er sagt: „Ja, Du verstehst nicht.“ Ich habe gefragt: „Soll ich nicht kommen?“ „Ja, doch, aber Du verstehst mich nicht ganz...“ Es ist die Depression, die tiefe Depression, es geht nicht mehr. (4b 49-69)

Mr. Dolder, this very active, well trained man who had overcome severe illness and gone out to discover the world, now experienced bodily deficits and was becoming increasingly unable to move, speak, remember, and occupy himself. His world was literally shrinking, and he was still painfully aware or constantly reminded of his losses. His feelings of dependency and imprisonment become comprehensible when one grasps his comparative base and his desires.

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The Hospital Environment

Mr. Dolder would have preferred to be at home, and once he asked to be cared for at his parents' house. However, these possibilities were precluded, given his physical and cognitive limitations and that his flat was located on the second floor without wheelchair access. His mother reflected repeatedly on the option of caring for him at home and stated that, had he suffered from a different cancer and still been able to walk, for instance, home care might have been possible. But she was aware that he needed much physical care and the presence of caregivers around the clock, seven days a week. She realized that the demands would be too high, and the general practitioner as well as the nurses at the hospital supported her opinion. For the son and the mother, this was one more aspect of the tragedy of his illness.

> Mother: If he had, for instance, a different kind of tumor, if he could still walk, then one could care for him in his flat with the support from the professional home health care. It is a kind of tumor that makes caring for him difficult.
> Interviewer: Yes, there are always two nurses for getting him up.
> Mother: Yes, there are always two of them… A nurse said to me: "Look, we are always two and we work three shifts. If you want to do this at home, you will also need almost three shifts with the night," and therefore… I knew this, it is virtually impossible.
> (…)
> And I think, I prefer to come and then I can give him something. Being with him, not nurse him, but be there. His general practitioner pointed this out to me very clearly: "You must not nurse him; you must accompany him, but not nurse him," and I believe, he was right.
>
> Mutter: Wenn er zum Beispiel eine andere Art von Tumor hätte, wenn er noch etwas gehen könnte, dann könnte man ihn mit Spitex in der Wohnung betreuen. Es ist eine Art, wo es schwer ist, ihn zu pflegen.
> Interviewerin: Ja, die Pflegenden sind immer zu zweit zum Aufnehmen.
> Mutter: Ja, sie sind immer zu zweit… Eine Schwester hat mir gesagt: „Schauen Sie, wir sind immer zu zweit und wir sind drei Schichten. Wenn Sie das privat machen wollen, brauchen Sie auch fast drei Schichten, mit der Nacht," und deshalb… Ich habe es gewusst, es ist praktisch nicht möglich. (4b 3. 554-571)
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> Und ich denke, ich komme lieber, und dann kann ich ihm etwas geben. Bei ihm sein, ihn nicht pflegen, aber da sein. Das hat mir sein Hausarzt sehr deutlich gesagt: „Sie müssen nicht pflegen, Sie müssen ihn begleiten, aber nicht pflegen," und ich glaube, er hatte recht. (4b 4. 428-459)

Mr. Dolder was not always fully aware of his disabilities, as his mother related:

> He knows that he is terminally ill, but he does not know that he is heavy, that one has to lift him and so on, this, I believe, he does not realize.

> Er weiss, dass er todkrank ist, aber er weiss nicht, dass er schwer ist, dass man ihn heben muss und so, das, glaube ich, realisiert er nicht. (4b 236-238)

It was, therefore, difficult for the patient to understand and accept that returning home or being cared for at his parents' house was not an option. Therefore, he had to stay in the hospital or, according to his feelings, was being imprisoned.

Mr. Dolder's hospital world included his single room, the common areas at the hospital (e. g. corridors, physiotherapy), the park, and a hospital restaurant nearby. In describing his room, Mrs. Dolder stated that it was a typical hospital room, rather cold and lacking bright colors (4b 76-85, 4b 5. 27-44). To make things worse, the hospital's outer wall was under reconstruction. It was, therefore, noisy during the day, and the window of the room was covered. Nevertheless, the room was beautifully decorated with photos from Mr. Dolder's trips. His mother always brought flowers, and the room was well equipped with TV, CD player, books, etc.

Mr. Dolder could sit in the corridor outside his room, and visitors or the nursing assistants took him frequently to the park or at times to the restaurant. Mr. Dolder never gave his opinion about the hospital room (4b 5. 84-85). He did say, however, that the noise was bothering him, and he could neither really enjoy visits to the restaurant nor the park. Regarding the visits to the restaurant, he said: "It is always the same, no big cha

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change." („Es ist immer das Gleiche, keine grosse Abwechslung." 4a 68-70) And when his mother admired the trees in the park, he reacted cynically, as she recounted:

> I said: "Look how beautiful the trees are." And he said: "Yes, the trees are very beautiful, yes, mum, the trees are very beautiful." And I understood that I had said something wrong. He does not care about the trees.
>
> Ich habe gesagt: „Schau mal, wie schön die Bäume sind." Und er hat gesagt: „Ja, die Bäume sind sehr schön, ja, Maman, die Bäume sind sehr schön." Und ich habe verstanden, dass ich etwas Falsches gesagt hatte. Die Bäume sind ihm egal. (4b 5. 71-76)

Mr. Dolder spent most of his time either in bed with the side rails up or in a wheelchair with a fixed table. Even though this table was later taken off when he had company, he remained bound to the wheelchair and depended on others to take him wherever he wished to go. Thus, he was literally imprisoned either in the hospital bed or in the wheelchair. Furthermore, when his visitors took him outside to the – in their view – pleasant environment intending to provide a nice change, he did not experience the diversion they were hoping for.

Waiting for Death

Mr. Dolder had been a fighter throughout his life. He had fought for his education, for work and travel; he had fought successfully against his epilepsy and twice against cancer. He had also fought against his third cancer, as his mother stated, but this time, he had lost the fight. This situation seemed unacceptable to him, he just wanted to die.

> He thought he could do it a third time, like crazy. He always went to the physiotherapy, strength training, he made everything that one can do, and he said to the physician: "Give me more chemotherapy, I tolerate it well…" and it was useless. He had a lot of strength at once, but now it came to an end. Now he only has the strength to say that he wants to die.
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> He says that this was no life anymore, that he would vegetate, like a baby. "And I can't do anything… and I have enough now. I just have enough, and I fought very hard, but now I don't want anymore."

> Er hat gemeint, er könne es ein drittes Mal, wie verrückt. Er ging immer in die Physiotherapie, Krafttraining, er hat alles gemacht, was man machen kann, und er hat dem Arzt gesagt: „Geben Sie mir noch mehr Chemotherapie, ich vertrage es gut…" und es hat nichts genützt. Er hatte auf einmal sehr viel Kraft, aber jetzt ist diese zu Ende. Er hat nur noch die Kraft zu sagen, er wolle sterben. (4b 640-647)
> (…)
> Er sagt, das sei kein Leben mehr, er vegetiere, wie ein Bébé. „Und ich kann nichts mehr machen… und ich habe jetzt genug. Ich habe einfach genug, und ich habe sehr gekämpft, aber jetzt will ich nicht mehr." (4b 33-37)

For a while, Mr. Dolder, from time to time, considered committing suicide with the help of Exit (an organisation that provides assistance in suicide for terminally ill people). However, he was informed that this was not possible in the hospital, and his parents, although they finally got the information brochures for him, were not actively supporting him. The patient never took any further steps in this direction. Given his forgetfulness and aphasia, he was most likely unable to do so (4b 31-45).

Mr. Dolder was aware of his approaching death and hoped that the end would not be too far away. He said:

> I think that my life is coming to an end, perhaps within a few months, perhaps within some weeks. I hope that it will not last for months anymore.

> Ich denke, dass mein Leben zu Ende geht, vielleicht in einigen Monaten, vielleicht in einigen Wochen. Ich hoffe, dass es nicht mehr Monate geht.

And he added in a resigned tone of voice: "What can one do…" („Was kann man machen…" 4a 47-52) Mr. Dolder, the fighter, was now condemned to idly wait for death.

Summary

Mr. Dolder, although his life had been marked by illness, had experienced several very good years, where he could work full time, traveled around and lived independently.

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He was fully enjoying his life, when one day he recognized a problem with moving his right foot, the first symptom of the deadly glioma (4b 593-597). Within a few months, his world broke down unstoppably; his life was taken over by the illness. Two months prior to his death, limited to irrelevant decisions, with severe physical and cognitive disabilities tying him to bed and wheelchair, and forced to remain in the hospital, inactively waiting for death, he experienced the hospital as prison. Given this young man's life situation and the severe consequences of his illness and the treatment side effects he suffered from, his feelings are understandable. His mother summarized: "If one considers this from his perspective, it was absolutely right. I understood the word prison." („Wenn man das aus seiner Sicht betrachtet, hat es absolut gestimmt. Das Wort Gefängnis habe ich verstanden." 4b 5. 76-80)

Mr. Dolder's severe suffering was mainly caused by the illness that had thrown him suddenly out of his hard-won, full life, destroyed his future plans, and compelled him into living at the hospital until death. Stated otherwise, his experiences in the hospital were predominantly shaped by his terminal illness and the consequences it had on his life situation. It can even be argued that Mr. Dolder might have felt imprisoned regardless of the place of care. But being in the hospital certainly added to this negative feeling. He could still imagine his home as a place of wider possibilities and capacities. Home became a symbol of his earlier capacities and life. The decisive factor for his feelings of imprisonment was, however, the illness that robbed him more and more of his abilities and trapped him in his wheelchair and bed. The care providers' options for alleviating his existential suffering were clearly limited. On the contrary, understandably

concerned about his safety, the care providers restricted his decisions and thereby further contributed unwillingly to his feeling of imprisonment.

The Hospital Experienced as Heaven

Several patients and family members experienced admission to the hospital as a huge relief, because at home, the patient had suffered severe symptoms that were not diagnosed correctly or treated effectively. Upon arrival at the hospital, symptoms were treated immediately, so that patients felt recognized and very well cared for. The sudden alleviation of their tremendous suffering let them feel like they were in heaven, as one patient stated when talking about her admission to the emergency department:

> At home I kept vomiting, but in the emergency department this was remedied within half an hour, an hour. They probably gave me morphine. And the restless legs didn't bother me any longer, I didn't vomit anymore, I wasn't nauseated. I felt like in heaven during this afternoon, because I had improved so much.
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> Ich habe daheim nur noch erbrochen, aber in der Notfallstation war das innert einer halben Stunde, einer Stunde alles behoben. Sie haben mir wahrscheinlich Morphium gegeben. Und die restless Legs haben mich nicht mehr geplagt, ich habe nicht mehr erbrochen, es war mir nicht mehr schlecht. Ich fühlte mich an diesem Nachmittag wie im Himmel, so viel wohler fühlte ich mich. (3a 180-189)

As an example, one case will be explored further in order to show how the patient's life situation and the illness trajectory prior to admission resulted in the patient's feeling of being in heaven at the hospital post admission. Ms. Egger, the patient, was a biologist and working at a hospital. Her partner, Ms. Egli, was a lawyer. Both women were about 60 years old. They had been partners for a long time and had been living together for three years.

In Search of the Diagnosis

For about nine months, Ms. Egger had experienced unclear thoracic problems and tiredness. She first considered her tiredness as normal and interpreted her symptoms as muscle tenseness, because she usually reacted with muscle tenseness if she felt under pressure.

> For about three quarters of a year, I have had problems with the thorax. But this was so undefined. I was also tired, you know, but who is not tired? And then I thought that regarding the thorax, this would be muscle tenseness. I react with muscle tenseness if I am under pressure.
>
> Ich habe seit etwa einem Dreivierteljahr Probleme mit dem Thorax gehabt. Aber das war so undefiniert. Ich war auch müde, oder, aber wer ist nicht müde? Und dann dachte ich beim Thorax, das seien so Verspannungen. Ich reagiere, wenn ich unter Druck bin, mit Muskelverspannungen. (5a 292-297)

When Ms. Egger's symptoms got worse, she saw the general practitioner who diagnosed blocked rib joints that he treated with manipulation. Although the treatment at first seemed successful, the situation remained unclear, with fluctuating symptoms.

> And when it got worse, I went to see the physician, but then he said that some rib joints were blocked, he manipulated and that helped, but two days later it was at another place. Or I almost bit the dust over the weekend, and on Monday when I saw the physician, I didn't feel it anywhere anymore.
>
> Und als es dann immer schlimmer wurde, ging ich mal zum Arzt, aber dann hat er auch gesagt, es seien blockierte Rippengelenke, hat manipuliert und das ging dann auch, aber zwei Tage später war es an einem anderen Ort. Oder ich ging fast drauf über das Wochenende, am Montag zum Arzt, dann spürte ich es nirgends mehr. (5a 298-305)

When manipulation did not bring about the desired effect, patient and physician together came to the conclusion that her symptoms might be stress related. In consequence, Ms. Egger reduced her working time, hoping for some improvement of her well-being.

> But after a while, he said that he would not go on with manipulating, because he had the feeling that it wasn't it, and that it might affect the vertebral joints. And so we came to the conclusion that I should probably change my working style. The age, reduce distress. And so I reduced my working time a bit in order to see if this might help.
>
> Und dann sagte er nach einer Weile, jetzt manipuliere er nicht mehr, weil er auch das Gefühl hatte, es sei nicht das, und es mache die Wirbelgelenke kaputt. Und so kamen wir auch dazu, dass ich wahrscheinlich etwas an meinem Arbeitsstil ändern müsse. Das Alter, weniger stressen. Und dann habe ich etwas reduziert mit der Arbeit, mal zum Schauen, ob das etwas bringt. (5a 305-312)

However, when Ms. Egger realized that working less did not make her situation better, her general practitioner was unavailable. She then saw a rheumatologist, but he concentrated on the spinal column, and his diagnosis was not convincing for Ms. Egger.

> And when I realized, after two weeks, that this did not bring about anything and wanted to go back to the physician, he was on vacation. (…) And so I did not know what to do. I was treated by a physiotherapist who always said that I had something, that she wanted a diagnosis, that she feared to do something wrong. (…) And so I went to see her physician, a rheumatologist, and he did not find anything. He did not say that I had nothing, but gave me such a commonplace diagnosis, sacralspondylosyndrome. And I kept telling him that it was not a problem of the spinal column, stated that it hurt here (points to her thorax). He did not even look.
>
> Und als ich gemerkt habe, nach vierzehn Tagen, dass dies nichts bringt, und wieder zum Arzt wollte, war er in den Ferien. (…) Und so wusste ich nicht, was soll ich. Ich war bei einer Physiotherapeutin, die immer sagte, ich hätte etwas, sie möchte eine Diagnose, sie habe Angst, sie mache etwas Falsches. (…) Und dann ging ich zu ihrem Arzt, einem Rheumatologen, und der hat nichts rausgefunden. Er hat nicht gesagt, ich hätte nichts, aber gab mir so eine Allerweltsdiagnose, Sakralspondylosyndrom. Und ich sagte ihm immer, ich hätte es nicht an der Wirbelsäule, habe gesagt, hier (zeigt auf Thorax) tue es mir weh. Er hat gar nicht geschaut. (5a 317-333)

Ms. Egger did not feel taken seriously by this physician and decided to stop seeing him. With this decision, she was again left without medical care and her suffering continued undiagnosed and untreated.

Turn to the Worst

Ms. Egger then suffered rib fractures on a trip to France without having any accident. She went to an emergency department where spontaneous fractures were diagnosed. She was, therefore, advised to return home for further investigations. She saw another rheumatologist who, still missing the correct diagnosis, focused on osteoporosis in spite of Ms. Egger's differing view. The patient felt unable to make the physician recognize the seriousness of her pain.

> And then I went to France for a vacation, got spontaneous rib fractures on the journey there, went to the emergency room in France, and there they immediately diagnosed that, four broken ribs, and said, since I had not had any accident, that I had to go home. And then I made an appointment here with a rheumatologist. (...) But this rheumatologist did not react either. He had actually seen these X-rays, the spontaneous fractures, but thought of osteoporosis... And I always told him, I remember this, that I did not have the feeling that it was osteoporosis. I have a too robust bone structure, and I am too young. And it is not inherited. I don't have the osteoporosis bone, this must be something else. I was somehow unable to make him understand that I was almost biting the dust from pain.

> Und ich ging ja dann nach Frankreich in die Ferien, machte spontane Rippenfrakturen auf der Hinreise, ging auf den Notfall in Frankreich, und dort haben sie das sofort diagnostiziert, vier Rippen gebrochen, und haben gesagt, weil ich keinen Unfall gehabt hatte, ich müsse nach Hause. Und dann vereinbarte ich hier etwas mit einem Rheumatologen. (...) Dieser Rheumatologe hat einfach auch nicht geschaltet. Der hat zwar diese Röntgenbilder gesehen, die spontanen Frakturen, hat aber auf Osteoporose... Und ich habe ihm immer gesagt, das weiss ich noch, ich habe nicht das Gefühl, dass es Osteoporose ist. Ich habe einen zu robusten Knochenbau, und ich bin noch zu jung. Und ich bin nicht erblich belastet. Ich habe nicht den Osteoporoseknochen, es muss etwas anderes sein. Ich konnte irgendwie nicht rüberbringen, dass ich fast draufgehe vor Schmerzen. (5a 339-357)

Finally, Ms. Egger was unable to sleep, unable to get up; her situation had turned intolerable, and her partner was at a complete loss as to what to do.

> I could not get up; they didn't know anymore what to do with me at home. I was unable to get up from the bed. (...) And for two or three weeks, I didn't really sleep. I was then sitting in the easy-chair for two hours, went to bed for one hour, up again walking around a bit, you know, and always had the phone in my bed, because I was unable to get up on my own.

> Ich konnte nicht mehr aufstehen, die wussten zu Hause nicht mehr, was machen mit mir. Ich kam nicht mehr vom Bett auf. (...) Und vierzehn Tage oder drei Wochen habe ich gar nicht mehr richtig geschlafen. Dann bin ich zwei Stunden im Lehnstuhl gesessen, eine Stunde ins Bett, wieder etwas rumgelaufen, oder, hatte immer das Telefon im Bett, weil ich nicht mehr selber aufstehen konnte. (5a 362-373)

Hospital Admission as Huge Relief

At this point, Ms. Egger talked to her sister-in-law, a physician, who confirmed that she was not quite wrong about her situation and that she was rather seriously ill. The sister-in-law suggested that she should organize her admission to the hospital through the emergency physician (5a 357-362). Ms. Egger followed the advice of her sister-in-law, and the emergency physician admitted her immediately to the hospital via the emergency department. There, physicians and nurses took care of her right away; she got excellent care. For her, the hospital admission had terminated an untenable situation and was, therefore, experienced as a huge relief.

> And then the emergency physician immediately said, he did not even visit me at home, I should go to the hospital. And then it worked. (...) They recognised my pain, gave me morphine immediately... (...) Then I got a soft bed, which was already the paradise on earth. Nursing care and medicine, that was so well coordinated, they treated me like a raw egg, and really totally well.
>
> Und dann sagte der Notarzt sofort, er kam nicht mal zu mir heim, ich solle gleich ins Spital. Und dann lief es. (...) Sie haben das mit meinen Schmerzen realisiert, gaben mir sofort Morphium... (...) Dann bekam ich ein weiches Bett, das war auch schon das Paradies auf Erden. Die Pflege und die Medizin, das hat so ineinander gegriffen, und mich wie ein rohes Ei behandelt, und wirklich total gut. (5a 364-385)

The Partner's Experiences

The hospital admission not only was a big relief for the patient, but also for her partner, Ms. Egli. Having accompanied Ms. Egger through all these months with unclear, but increasing symptoms, which ended in a true nightmare, she had always perceived a discrepancy between Ms. Egger's trouble and the temporary diagnoses. Ms. Egli also realized how problematic it was for her partner, when her symptoms were not taken seriously. After Ms. Egger had suffered spontaneous rib fractures and an internet search had revealed a multiple myeloma as a possible diagnosis, Ms. Egli got into a panic. Relief only came with admission, when the care providers at the hospital immediately took steps for symptom control and a diagnostic work-up. Although still in fear regarding the diagnosis, Ms. Egli felt that her partner was now in good hands and very well cared for. Asked how she had experienced the time prior to admission, Ms. Egli related the following:

> Well… as absolutely tormenting. And already since months, for a long time before it intensified, it was frightening for me. "You know that, I mentioned that to you." I thought that such trouble could not just be related to muscle tenseness or… a blocked rib joint. So I could not imagine this, because I know she is not dramatizing, we now know each other long enough. In the end, when we were on vacation, one couldn't watch this anymore. She had to try lying down, and once she was lying, she could not get up anymore, and you could not help. So that I was finally relieved when she made the decision to go to the hospital. And there was also the experience with a physician who did not realise… well, obviously… it was easier, once the fractures were there. After that, there were not many options left, but before… I just believe that it was a nightmare for her, with severe troubles, and then to hear that it was nothing. (…) But I panicked since they had diagnosed bone fractures at the hospital, then I started to float about. (…) That is why, on the day you left for home, I already went to the internet. I had my laptop there, and just entered what it was about spontaneous bone fractures. And apart from osteoporosis, which would also be a possibility, but you had always said that this was not your problem, there was only one alternative, and this was the multiple myeloma. From then on, I in fact developed almost panic anxiety. (…) And I was then somehow absolutely relieved when she was admitted to the hospital. From then on she also had the experience that at least the people concerned with her care gave her full attention. And from then on she was actually in good hands.

> Ja… als absolut beklemmend. Und zwar schon seit Monaten, längst bevor sich das zugespitzt hat, war mir das unheimlich. „Du weisst es, ich habe Dir das auch gesagt." Mich dünkte, solche Beschwerden, das gebe es doch einfach nicht als Muskelverspannung oder… blockiertes Rippengelenk. Also ich konnte mir das

> nicht vorstellen, weil sie dann nicht dramatisiert, wir kennen uns jetzt lange genug. Am Schluss, als wir noch in den Ferien waren, war es nicht mehr zum Zusehen. Sie musste probieren, sich hinzulegen, und wenn sie mal lag, kam sie nicht mehr auf, und helfen konnte man nicht. So dass ich schliesslich froh war, dass sie den Entschluss gefasst hat, jetzt müsse sie glaub wirklich ins Spital. Und es gab ja auch eine Erfahrung mit einem Arzt, der nicht realisiert hat… ja also, offenbar… es war einfacher, nachdem die Brüche vorlagen. Danach gab es nicht mehr sehr viel Auswahl, aber vorher… Also ich glaube, es war für sie ein Alptraum, mit massiven Beschwerden, und dann zu hören, es sei nichts. (…) Aber ich hatte Panik seit es im Spital geheissen hat, es seien Knochenbrüche, da hat es bei mir angefangen zu rumoren. (…) Deshalb ging ich am Tag, an dem Du heimgereist bist, schon ins Internet. Ich hatte mein Laptop da, und gab mal ein, was es auf sich habe mit spontanen Knochenbrüchen. Und also abgesehen von Osteoporose, was auch möglich ist, aber Du immer gesagt hattest, das sei nicht Dein Problem, gab es nur eine Alternative, und das war das multiple Myelom. Von da an habe ich effektiv fast panische Angst entwickelt… (…) Und ich war dann irgendwie, absolut erlöst, als sie ins Spital kam. Von da an hat sie dann auch die Erfahrung gemacht, dass auf jeden Fall diejenigen, die mit der Pflege befasst waren, voll auf sie eingegangen sind. Und von da an war sie eigentlich gut aufgehoben. (5a, 5b 169-250)

Within a few days at the hospital, Ms. Egger was diagnosed with severe advanced multiple myeloma, a diagnosis that fully explained all her symptoms.

Summary

Prior to Ms. Egger's hospital admission, she and her partner had gone through an odyssey of increasing pain, inappropriate diagnoses, inadequate treatment trials, and non-recognition by physicians. While the partner doubted the harmlessness of the situation almost from the beginning, the patient first agreed with her general practitioner's diagnosis. Later, although she did not feel recognized by the rheumatologist, she still denied the seriousness of her illness (5a 414-435). Only when, after the rib fractures, she was unable to convey her intolerable pain to the second rheumatologist and the situation turned unbearable at home, she took action and organized her hospital admission. Unclear symptoms, problematic interactions with physicians, and the patient's own initial misinterpretations of her problems contributed to the fact that her painful journey lasted

several months and ended in an intolerable situation. After admission, the patient's suffering was fully recognized and taken care of immediately. It is not astonishing, therefore, that hospital admission was experienced as a huge relief by both patient and partner.

The hospital is usually a place that provokes rather negative feelings and thoughts, a place that people prefer to see from the outside. However, at times, the hospital can be experienced very differently, that is, in a positive way by ill people and their families. After a journey laden with uncertainty and unrelieved symptoms, hospital admission may come as a big release. Given that people are recognised, well taken care of and their suffering from symptoms is relieved, the hospital may well be experienced as heaven on earth. In contrast to when the hospital was experienced as prison, in these situations the care providers at the hospital had a decisive influence; their adequate and immediate actions were of prime importance for the patients' and families' positive experiences.

Guests of Necessity

So far, two extreme experiences of patients and family members – the hospital as prison and the hospital as heaven – have been described. However, throughout their hospital stays, the experiences of most patients and their family members lie somewhere between these two poles. Hospital admission was accepted as necessary or even desired, as one family member related:

> And he (the patient) said: "I can't walk anymore, it just isn't possible anymore, I don't know how to do it." And then he (the general practitioner during a home visit) said: "In this case it is probably better for you to go to the hospital." And then he said: "I have the feeling, doctor, that I would belong there for a long time now."
>
> Und er (der Patient) sagte: „Ich kann nicht mehr laufen, es geht einfach nicht mehr, ich weiss nicht mehr wie." Und da hat er (der Hausarzt, während einem

> Hausbesuch) gesagt: „Dann ist es wahrscheinlich doch gut für Sie, ins Spital zu gehen." Und dann hat er gesagt: „Ich habe das Gefühl, Herr Doktor, dort würde ich schon lange hin gehören." (7b 60-65)

Patients felt mostly well cared for in the hospital. Over time, the, at first, unfamiliar hospital world, the unfamiliar faces of the care providers became familiar. One family member, when discussing the hospital unit, stated that for the mentally handicapped patient "it had become somewhat familiar. He probably knows the employees, I believe, the nurses. He knows them." („es ist für ihn etwas familiär geworden. Er kennt wahrscheinlich auch das Personal, glaube ich, die Krankenschwestern. Er kennt sie schon." 4b 4. 106-115) Another patient, on returning to the same hospital unit, was pleased to meet the known care providers again and felt like she was coming home (5a, 5b 2. 46-57).

However, even though patients and family members acknowledged the necessity for the hospital stay, felt well cared for, and became more familiar with the hospital over time, most hoped to return home as soon as possible. As soon as possible meant, as soon as the care at home was well organized, so that the patient and family member felt able to go along with the situation, as one wife explained: "I like to take him home, but I must be able to take on the responsibility." („Ich nehme ihn gerne heim, aber ich muss es verantworten können." 1b 136-164). Some patients, for whom a discharge home was no longer or not yet an option, got the care providers' permission for a leave of absence; that is, they were allowed to visit their home for a day or for a weekend. Patients and family members greatly enjoyed this opportunity.

The patients who were forced by their illness to stay in the hospital and the family members who, consequently, had to visit patients regularly at the hospital can

appropriately be described as "guests of necessity." Their hosts, the professional care providers, tried their best to make the hospital stay agreeable. Patients and family members, as guests, tried to conform and come to terms with the rules and standards of their hosts' house as guests usually do, to adjust to the structures of the, at least in the beginning, unfamiliar environment. In addition, if the patient did not have a single room, they had to live with other patients and their visitors. Even with the best individualized care, however, patients and family members remained guests of necessity who lived in their hosts' house and depended on them, while they would have preferred to be at home, as masters of their own house, living on their own terms.

Longing for Home

Being at home provoked feelings that the hospital could hardly substitute for. Just being there, within one's own four walls, surrounded by one's own belongings, drinking one's own brand of tea, and eating a home-made meal made *the* difference, and allowed patients and family members to reconnect with their familiar world that they had taken for granted prior to the patient's illness. The following story of Ms. Egger and Ms. Egli who spent one day at home illustrates this.

> Partner: First, we had a good cup of tea and a bit of a different bread, just something different. Listening to music, just being there, sitting together, reading the newspaper. Actually, not much happened, just what one usually does at home.
> Patient: What we usually do on Saturday…
> Partner: Just being there for a while, I can't say it otherwise, what I had so much hoped for that it might once be possible again. Just being there for a while… And later I invited our neighbors who help to look after the house, whom we usually undertake a lot with, I invited them for dinner.
> Patient: They made the salad.
> Partner: They brought the salad and the fruit juice for the aperitif, and I just cooked something she liked to get. Just something different, because even if everything is alright and well here, the longing for being at home once again remains, the longing

> for a different taste and for something else to eat, for having something else around you. Actually not much happened, nothing. Don't you think so?
> Patient: Nothing… (…)
> Partner: (…) So in fact nothing, but I believe that was the good of it. It was helpful for everybody…
>
> Partnerin: Zuerst hatten wir eine Tasse guten Tee und etwas anderes Brot, einfach etwas anderes. Musik hören, etwas da sein, etwas zusammen sitzen, Zeitung lesen. Eigentlich ist nicht viel gelaufen, halt das, was man zu Hause so macht.
> Patientin: Was wir sonst am Samstag machen…
> Partnerin: Einfach ein bisschen da sein, ich kann es nicht anders sagen, das was ich so gehofft hatte, dass es dann wieder einmal möglich sei. Einfach ein bisschen da sein…Und nachher habe ich unsere Nachbarinnen eingeladen, die auch zum Haus schauen helfen, mit denen wir auch sonst viel machen, die habe ich zum z'Nacht eingeladen.
> Patientin: Sie haben den Salat gemacht.
> Partnerin: Sie haben den Salat mitgebracht und den Fruchtsaft zum Apéro, und ich habe einfach etwas gekocht, worauf sie Lust hatte. Einfach etwas anders, denn auch, wenn alles hier stimmt und gut ist, gibt es halt trotzdem die Sehnsucht, wieder mal zu Hause zu sein, einen etwas anderen Geschmack zu haben und etwas anderes zu essen, etwas anderes um sich zu haben. Eigentlich lief nicht viel, nichts. Gell nicht?
> Patientin: Nüt… (…)
> Partnerin: (…) Also eigentlich nichts, aber gerade das hat gut getan, glaube ich. Es hat allen gut getan… (5a, 5b 102-139)

In addition, being at home also meant being at home *together*, living together. One partner related in an exemplary way how she experienced the patient's absence from their home: She was annoyed, missed their conversations, and, at times, even neglected cooking for herself. Stated otherwise, he was alone at the hospital, she was alone at home, and they greatly missed each other.

> Partner: Especially in the evening, when one comes home and no-one is in the flat. Boring, if you sit around on your own. Before, when we watched TV, one could discuss a bit or with sports, soccer or ice hockey of course, what we liked to watch, we could talk about it.
> Patient: Yeah.
> Partner: Now, each time I think, he is alone over there and I am alone here, you know… yes, that is this. Yes, because I am not a person who likes to be alone.
> Patient: Neither am I.
> Partner: That is nothing for me. I must just have someone to talk to and have someone around me. (little pause) And also regarding the cooking, before, you

> could at least ask: "What would you like? What should I prepare? I just do not know what at the moment." Now, just for myself, my god, I must look deeply into the pot to discover something (laughs).
> Interviewer: And each time, you have to decide yourself what you will have.
> Partner: At times I prepare something, at times I don't, at times I think, oh, I just don't feel like, that is so boring. That's it actually. Because, during the 11 years that we have been together now, we have had a good time together.

> Partnerin: Vorallem am Abend, wenn man heimkommt und niemand in der Wohnung ist. Langweilig, wenn man so alleine da hockt. Sonst, wenn wir ferngesehen haben, konnte man etwas diskutieren oder beim Sport, Fussball oder natürlich Eishockey, das wir gerne sehen, konnten wir doch etwas darüber reden.
> Patient: Jaja.
> Partnerin: Jetzt denke ich jeweilen, er ist dort alleine und ich bin hier alleine, oder… ja, das ist das. Ja, weil ich bin nicht ein Mensch, der gerne alleine ist.
> Patient: Ich eben auch nicht.
> Partnerin: Das ist nichts für mich. Ich muss schon jemanden haben zum Reden und ein wenig jemand um mich rum haben. (kleine Pause) Und auch was das Kochen anbelangt, vorher konnte man doch etwa noch fragen: „Du, was hättest Du gerne? Was soll ich machen? Ich weiss jetzt gerade nicht was." Jetzt nur für mich, Jesses Gott, da muss ich ja weit in die Pfanne runterschauen, damit ich etwas sehe (lacht).
> Interviewerin: Und Sie müssen jedes Mal selber entscheiden, was es gibt.
> Partnerin: Manchmal mache ich etwas, manchmal mache ich nichts, manchmal denke ich, ja phh, ich mag doch nicht, das ist doch langweilig. Das ist eigentlich das. Weil wir haben es eigentlich in den elf Jahren, die wir jetzt zusammen waren, schön gehabt miteinander. (7a, 7b 2. 240-279)

Another partner related how difficult it was for the patient to return to the hospital after they had spent the weekend at their little house in the country and enjoyed happy hours together and with their friends. It took the patient a long time to get ready in the morning, a fact that the partner interpreted as showing her reluctance to leave and go back to the hospital (6b 250-256), although she felt very well cared for there.

> They do all that is humanly possible to make her feel better. From this perspective, she is satisfied, you know. Well, she doesn't like to come, that is clear to me. But once she is here again, it's alright. But till she gets here, that's the same game each time. "Now just get on, get dressed, get your hair done." "Just don't hurry me." "I don't hurry you, but you got up at half past six, now it's almost half past eight, two hours, and you are still nowhere."

> Sie machen alles Menschenmögliche, damit es ihr besser geht. Von dem her ist sie zufrieden, oder. Gut, sie kommt nicht gerne, das ist mir auch klar. Aber wenn sie

> dann wieder hier ist, ist es wieder gut. Aber bis sie hier ist, das ist jedes Mal das gleiche Cabaret. „Jetzt mach mal vorwärts, zieh Dich an, mach die Frisur." „Jetzt hetze mich nicht." „Ich hetze nicht, aber jetzt bist Du um halb sieben aufgestanden, jetzt haben wir dann halb neun, zwei Stunden, und Du bist noch nirgends." (6b 379-390)

Parting From Home

As an exception, one patient decided that a discharge home would not be an option for him; instead, he wished to be transferred to a palliative care unit where he died after a few days. His wife stated later that he had absolutely wanted to go there because he knew that she considered this as a good option. He had thought that, if he were there, things would be alright for her. This was a priority for him, because caring for her had always come first for him (8 call 40-48).

For yet another patient who had been living alone, returning home was no option. He suffered from severe dizziness and impaired balance due to brain metastases, which bound him to the wheelchair. He was admitted to the hospital after a sudden decline and then realized that a return home would be impossible. This was very hard for him.

> Patient: This is bad. And the second time, it got so bad that I can't live on my own, in my flat, impossible.
> Interviewer: Yes, I agree, from seeing you here, this is not possible anymore.
> Patient: Cooking and shopping myself, that is… Forget it.
> Interviewer: Mhm… that is difficult.
> Patient: That is terribly difficult.
>
> Patient: Das ist schlimm. Und das zweite Mal kam es eben so schlimm, dass ich nicht mehr alleine leben kann, in der Wohnung, unmöglich.
> Interviewerin: Ja, das sehe ich auch so, wenn ich Sie hier sehe, das geht nicht.
> Patient: Selber kochen und einkaufen, das ist… Vergessen.
> Interviewer: Mhm… das ist schwierig.
> Patient: Das ist „huere" schwer. (9a 45-53)

Although this patient greatly enjoyed leaving the hospital for a meeting with colleagues at his favorite restaurant and might well have been able to go home just for a visit, he preferred cutting all ties and never went back. He asked his brother and sister-in-law to vacate the flat. However, he was supposed to go to a nursing home and still hoped to move some of his furniture to his future room there (9a 175-190, 329-341; 9a 2. 167-177; 9c 135-138).

Behind the Walls

During an observation period, a nurse was checking on the patient and stated that she would return later. The patient then spontaneously mentioned that it was difficult for her not to know what "later" would mean, it could be two minutes or an hour. She later added:

> The lack of transparency, that I do not know when they will come, this disturbs me sometimes. But if I want to be objective… well, what am I actually waiting for? So from this perspective, this is a detail. I mostly did not even mention that it bothered me.
>
> Das nicht Transparente, dass ich nicht weiss, wann sie kommen, das stört mich manchmal. Aber wenn ich dann objektiv sein will… also, auf was warte ich eigentlich? Also von dem her ist das ein Detail. Ich habe es meistens auch nicht gesagt, dass es mich gestört hat. (5a 606-614)

This patient fully recognized that, from a cognitive point of view, it did not matter for her, at exactly which point in time the nurse would come back. The lack of transparency and the uncertainty it brought along, was a minor issue and not worth mentioning. However, on an experiential, emotional level, it was disturbing and remained problematic for her to cope with.

A family member related a similar experience. The patient was in tremendous pain, and they were waiting for the pain specialist. The family member explained that he was aware of the specialist's multiple cases, that he had to treat other patients, and that these might have priority. Nevertheless, idly waiting without knowing when the specialist would finally come, so that something could be done about the patient's pain, made him extremely impatient (6b 2. 50-62).

Patients and family members were confined to the patient's room most of their time in the hospital. Their knowledge of the hospital organization and the nursing care system was limited; they were mostly left in the dark regarding other patients' needs. Thus, they experienced real bother by this lack of transparency. They could literally not see through the door and walls of their room and therefore hardly notice what happened outside. Contrarily, the care providers had an overview of all the patients on the unit and of their workload; they were in a position to set priorities and allocate time adequately. They were in control and, as patients and family members readily acknowledged, in fact, had to be in control from a rational standpoint. The emotional hassle that the lack of transparency, and probably also the lack of control, caused was added to the patients' and family members' overall uncertainty. The terminal illness rendered their future life unpredictable, and they were in limbo regarding treatments during their hospital stay. Now, they experienced additional uncertainty on the microlevel of the daily hospital routine.

Summary

Patients and family members mostly considered the hospital as a necessity, as the place to get adequate care. However, during the patients' hospital stay, both, patients and family members, were deprived of the others' company and of the closeness in their everyday living together at home. For the family members who were aware of their partners' limited life span, being alone at home may have, in addition, provoked sad visions of a lonely future.

In addition, while patients usually felt well cared for, and experienced symptom relief and at times some improvement in their health status as positive aspects of the hospital stay, they missed the familiarity and intimacy of their homes. Unless a patient was forced to or had a clear reason for choosing another solution, patients were longing and hoping to return home. Svenaeus (2001), in his discussion of health and illness, describes health as being at home in one's world. In illness, people are no longer at home; illness is seen as a pervasive homelessness. The patients' longing for returning home may also be understood as longing for the one step towards being at home that is still open to them, living in their familiar home, while their more fundamental homelessness cannot be alleviated due to their terminal illness.

Alternating and Fading Experiences

Whatever way patients experienced the hospital – as prison, as heaven, as the unloved, but right place to be – two additional aspects showed up: Patients' experiences fluctuated over the course of their hospital stay, and some patients and family members later could not clearly remember all phases of that stay.

Alternating Experiences

Even when admission had been very welcomed due to the immediate symptom relief, after a while, longing for home took over; patients became guests of necessity. For instance, the patient who felt like she was in heaven after her admission to the emergency unit related that after one month in the hospital she was impatient to return home. She was longing for the silence of her balcony and stated that she would not postpone her discharge in spite of remaining symptoms. The hospital had become unbearable to her (3a 3. 181-204).

On the contrary, Mr. Dolder, the young man who compared the hospital to a prison after admission, later experienced joyful moments. His brain tumor and its consequences – hemiplegia, aphasia, forgetfulness – had brought him to this prison and caused his great sadness and fury. Over time, the disease progressed, that is, the growing brain tumor robbed Mr. Dolder more and more of his memory. He seemed to solely live in the present; the connections to past and future seemed to fade away. "Seemed" is relevant here, since Mr. Dolder had become almost unable to express himself verbally due to his aphasia, it was impossible to truly know how the world looked for him. The only remaining option was to observe and interpret his behavior, his facial expressions, and his utterances. With an apparently vanishing past and no anticipation of a future, the tremendous losses that he had suffered earlier seemed to become less prominent; he could enjoy the moment, for instance staying with visitors or picnicking with his family. For Mr. Dolder's mother it was on the one hand, difficult to realize that her son forgot more and more, that he seemed to retreat slowly into a world that was inaccessible to others, and on the other, she recognized with relief that his suffering seemed to be diminishing.

> Mother: I have the feeling that he is not making any distinction now, regarding who… he is satisfied with the nurses, with me, with the father, with Doris, with friends… it is about the same. For him, how shall I say it, it is just, he just takes, if he knows… He knew her (a friend who offered to feed him), one could notice that. And I thought, okay, I will take the earlier train then. And I must say, I was less sad for the first time on the train, calmer, and it was less hard, because I noticed, I said: "Goodbye, I will come again in two days." "Yes, Yes." "Your father is coming tomorrow." "Yes, Yes." I want to say… It doesn't not matter to him, but something in this direction. Well, then he is suffering less, although… I do of course not know what he still thinks.
> Interviewer: We all do not know this… But by looking from the outside, one now gets the impression that he is suffering less than two weeks ago.

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> Mother: Yes, definitely.
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> Mutter: Ich habe das Gefühl, er mache jetzt nicht mehr einen Unterschied, wer… er ist zufrieden mit den Schwestern, mit mir, mit dem Vater, mit Doris, mit den Freunden… es ist einfach etwa das Gleiche. Für ihn, wie soll ich sagen, es ist einfach so, er nimmt einfach, wenn er sie kennt… Er hat sie (eine Freundin, die anbot ihm das Essen einzugeben) gekannt, das hat man gemerkt. Und ich habe gefunden, na ja, dann gehe ich etwas früher auf den Zug. Und ich muss sagen, ich war das erste Mal weniger traurig im Zug, ruhiger, und es war mir weniger schwer, weil ich gemerkt habe, ich habe gesagt: „Adieu, ich komme in zwei Tagen." „Ja, ja." „Der Vater kommt morgen." „Ja, ja." Ich möchte sagen…Es ist ihm nicht gleich, aber etwas in diese Richtung. Ja gut, dann leidet er nicht, obwohl… Ich weiss natürlich nicht recht, was er noch denkt.
> Interviewerin: Das wissen wir alle nicht… Aber von aussen gesehen, hat man jetzt den Eindruck, er leide weniger als vor zwei Wochen.
> Mutter: Ja, eindeutig. (4b 3. 163-183)

In the post bereavement interview, the mother related that, as difficult as the last phase of her son's life had been, they had still been able to share beautiful moments.

> It was a difficult time, but there were beautiful moments, I must say. (…) We went for a walk in the garden, sat in the beautiful garden. And of course, I knew, he is dying, but it was quite comfy. We drank Coca Cola, and the garden was beautiful. And when I am remembering, I say to my husband: "It was quite a beautiful time there." We used to share our bottle of Coke, and the garden, the sun and… It was almost a beautiful time.
>
> Es war eine schwierige Zeit, aber es gab schöne Momente, muss ich sagen. (…) Wir gingen im Garten spazieren, sassen im schönen Garten. Und natürlich, ich habe gewusst, er stirbt, aber es war noch gemütlich. Wir haben Coca Cola getrunken, und der Garten war schön. Und wenn ich mich erinnere, sage ich zu meinem Mann: „Es war noch eine schöne Zeit da." Unsere Flasche Coca haben wir immer geteilt, und der Garten, Sonne und… Es war fast eine schöne Zeit. (4 po 727-738)

Fading Experiences

At this time in the course of his illness, Mr. Dolder seemed to forget his experiences almost instantaneously. The experiences of some other patients were also dulled, though to a lesser extent. For instance, an elderly patient with metastatic prostate cancer, admitted for emergency radiation therapy to treat a beginning paraparesis of his legs, wondered what had happened during his first days at the hospital. He had lived

through some days with pain, fear, and dependency, but aspects of these bad days had disappeared from his memory.

> Patient: So what I thought of this morning, for instance, when I was admitted to the hospital, even here… how was this now…? You certainly had to go to the toilet, did you? So, how this happened, if I used the bedpan, or if they brought me outside… that is completely gone.
> Interviewer: You cannot remember?
> Patient: No. This came up last night, I believe… hey, how… what happened, you certainly had to go to the toilet? It is not possible that you did not go to the toilet for eight days, you know.
>
> Patient: Also was ich zum Beispiel heute morgen schon überlegt habe, als ich hier ins Spital eingeliefert wurde, selbst hier… wie war das jetzt…? Du musstest doch auf die Toilette, nicht wahr? Also, wie das gegangen ist, ob ich auf der Schüssel war, oder ob sie mich raus… das ist vollständig weg.
> Interviewerin: Können Sie sich nicht daran erinnern?
> Patient: Nein. Das ist mir gestern abend, glaube ich… Du, wie… wie war das jetzt, Du musstest doch aufs WC? Das ist ja nicht möglich, dass Du acht Tage nicht auf dem WC warst, nicht wahr. (2a 131-144)

Another patient stated that during the first days at the hospital, he could not remember where he was when waking up. He related this confusion to the opioids he got for pain (1a 29-40).

Due to the distress caused by the illness and hospital admission, the disease itself, medication side effects, or a pre-existing forgetfulness, some experiences slipped from patients' memories. Many of these experiences were rather unpleasant; forgetting them, therefore, may not have been the worst option.

Some family members could not clearly remember what happened during certain phases of the patient's hospital stay. One husband, for instance, stated that he first met his wife at the hospital unit after her admission, while the patient said that he had spent many hours with her in the emergency department. He had a complete lack of memory regarding the emergency department (3a 267-282, 3b 83-86). This husband had been extremely distressed because he had been unexpectedly confronted with the diagnosis of cancer recurrence and hospital admission for his wife. The partner of a patient who died in the hospital had stayed with and cared for her around the clock during her last days. He stated in the post bereavement interview that he could hardly remember this time, because he did not get any sleep over the whole time (6 po 286-288). The tremendous distress that these family members had experienced clouded their memories.

Helpful Lasting Connections to Home and Everyday Life

While patients and family members were confronted with a new, mostly unfamiliar world in the hospital, patients were not completely cut off from their prior life and their homes, some connections were maintained, mainly through family members. These connections helped to make the hospital stay more bearable.

Patients still had a few personal belongings (7c 32-33); bedside tables and walls were decorated with photos, postcards (8c 47-48; 4a 32-34, 4b 2. 527-533), or with special items like the drawing that the grandson living abroad had given his father to take to his grandpa (1 c 64-67). Patients, who used to listen to the radio or read a certain journal regularly, were happy to keep up these customs. Patients were allowed to carry on their habits, as one partner stated:

> He also has his glass of wine that he is allowed to drink. And the physician gave him permission for smoking. And I appreciate that. That one can actually carry on the things one used to have before.
>
> Er hat auch sein Gläschen Wein, das er haben darf. Und er darf auch vom Arzt aus rauchen gehen. Und das finde ich gut. Dass man die Sachen, die man vorher auch gehabt hat, eigentlich weiterführen kann. (7b 211-215)

Staying in contact over the phone or meeting with family and friends was a great source of satisfaction and pleasure for the patients. A patient, who had not seen her

daughter and two-year old grandson for several months, because her family was living abroad, enjoyed daily phone calls with them.

> Patient: When I am talking to the daughter, he always wants to speak with mum, and takes the phone and sometimes, I do not understand what he is saying, but he speaks (patient and interviewer laugh). Today he told me: "Do you see, do you see?" And then I asked: "What? I can't see over the phone." He got crazy and gave the phone back, because I did not see what he was saying. And then his mother said: "Sun glasses." Put on and wanted to show me on the phone. But I couldn't see it over the phone… (patient and interviewer laugh).
>
> Patientin: Wenn ich mit Tochter spreche, dann er will immer telefonieren mit der Mama, und nimmt Telefon und manchmal verstehe ich gar nicht, was er sagt, aber er spricht (Patientin und Interviewerin lachen). Heute erzählte er mir: „Siehst Du, siehst Du?“ Und dann habe ich gefragt: „Was? Ich sehe nicht im Telefon.“ Er ist verrückt geworden, Telefon zurückgegeben, ich sehe nicht, was er sagen will. Und dann Mutter gesagt: „Eine Sonnenbrille.“ Direkt aufgemacht und dann zeigt das mir am Telefon. Aber im Telefon ich habe das nicht gesehen… (Patientin und Interviewerin lachen). (6a 320-338)

One wife observed that her husband's well-being improved as soon as their sons, visiting from abroad, entered his hospital room (1b 748-752). Another partner related how much the patient enjoyed the company of his family while sitting in the hospital restaurant and drinking a cup of coffee:

> His son with the family, with the two daughters and myself were there, together we went downstairs for a coffee, sat around this table. When they left, he said: "This was nice, don't you think so." "Yes, that was comfy." He liked that.
>
> Sein Sohn mit der Familie, mit den zwei Töchtern und ich waren da, wir gingen zusammen runter einen Kaffee nehmen, sassen um dieses Tischli rum. Als sie gingen, hat er gesagt: „Gell, das war jetzt schön.“ „Ja, das war jetzt gemütlich.“ Das hat ihm gefallen. (7b 414-419)

Family members, in addition, were allowed to eat at the hospital, that is, patient and family member could share meals as they would at home, an option that was very much appreciated by both.

> We also appreciate that my husband, that is, acquaintances, relatives can eat here. My daughter, who is working here, now joins me for lunch, and my husband has

> lunch or dinner with me. This takes care of his problem. He has one complete meal per day, and we have more time together, and it also increases my appetite.
>
> Was wir auch ganz gut finden, ist, dass der Mann, also die Bekannten, Verwandten hier essen können. Meine Tochter, die hier arbeitet, kommt jetzt zu mir zum Mittagessen, der Mann kommt zum Mittag- oder Abendessen mit mir. Damit ist sein Problem gelöst. Er hat einmal im Tag eine vielseitige Mahlzeit, und wir sind länger beieinander, und ich habe auch mehr Lust zum Essen. (3a 295-302)

At times, special aspects of normal life at home were also lived in the hospital, for instance, when the patient organized a birthday gift for his partner who highly valued this gesture (7b 438-442). Another couple celebrated the patient's birthday at three o'clock in the morning, only two days prior to the woman's death (6b 2. 76-80). One family member related that her family had picnics with the patient in the hospital garden or took him to the restaurant for lunch:

> I bring something from home, and when we have a picnic on top of the little hill, he likes that. And next Sunday, if the weather isn't nice, we may go to the coffee shop or something like that, where we can eat together.
>
> Ich bringe etwas von daheim, und wenn wir picknicken oben auf dem kleinen Hügel, hat er es gerne. Und am nächsten Sonntag, wenn das Wetter nicht schön ist, gehen wir vielleicht ins Café oder so etwas, wo wir miteinander essen können. (4b 3. 602-606)

Another member of this family even organized a garden party with grilling at the hospital for the patient and his friends. They celebrated for several hours, and the patient greatly enjoyed it (4b 3. 66-87).

When confronted with the, at first, strange hospital world, it was helpful for patients to maintain some connections to home and to their normal life. Family members mostly took on the task of establishing and maintaining these connections. First of all, they did so by visiting patients regularly or by talking to them on the phone. In addition, connections were maintained through personal belongings that were brought to the

hospital. Carrying on with personal habits or with celebrating events that one would also celebrate at home was supportive as well.

The ability to share a drink or even a meal was especially valued by patients and family members. In Switzerland, socializing is very much tied to sharing a drink or a meal. Chatting with family members or friends usually means chatting while eating together. Visitors are invited for lunch or dinner, and even unexpected visitors will almost always be offered a drink, be it a glass of wine or a cup of coffee. At the hospital, sharing a meal or a drink is, therefore, qualitatively different from just visiting and talking for both patients and visitors. Just being together in the foreign environment of the hospital room may have a disassociating effect. The patient is receiving visitors, but is deprived of his role as host. The visitors are confronted with an ill person who may even be lying in bed. Taking up conversations as usual may not be easy under these circumstances. If the patient and his or her visitors can share a meal or a drink, the situation may seem much more familiar and improve their feelings of connectedness.

Grill parties for patients at the hospital were uncommon. Several of the above examples show that the care providers were well aware of the patients' terminal stage of illness and aimed at achieving the best possible quality of life for patients and family members, in accordance with the goals of palliative care. In order to accomplish this goal, the care providers adapted care and hospital standards accordingly and supported unusual endeavors. While usually not allowed, smoking was made possible on the units for these patients. Drinking a glass of wine with the main meal of the day is common for quite a lot of people in Switzerland. However, most people would not expect to drink alcoholic beverages at the hospital and would not carry on this habit while hospitalized. Care

providers might allow this glass of wine if asked for it, but only took the initiative and suggested it if the patient's quality of life clearly had priority. And even though visiting hours were handled generously for all patients and every patient could order meals for family members, the nurses usually only offered to order meals and allowed visits around the clock for family members of terminally ill patients. The patients' possibilities for maintaining or re-establishing connections to their homes and their everyday life, although mainly facilitated by family members, depended to some extent on the care providers willingness to go along with or support these endeavors.

Summary

Patients and families experience the hospital in different ways, as prison, heaven, or a necessary sojourn. Their perceptions may alter or fade away over time, but are decisively influenced by sequelae of the illness, for instance, symptoms or the degree of the patient's dependency, by the illness trajectory, as well as by their relationships with and the interventions of the care providers. Remaining connected to their home through families' visits, familiar rituals or meals and artefacts, supports the hospital experience and may bring about a sense of homelike familiarity for patients and family members dwelling in the hospital. In addition, as has been shown in chapter four, the experience of being in the hospital is interrelated and depends on patients' and family members' way of leading their life with the terminal illness and of going on with their life in the hospital.

CHAPTER SIX: COMMITMENT AND CARING AS DECISIVE ASPECTS OF THE RELATIONSHIP AMONG PATIENTS, FAMILY MEMBERS AND CARE PROVIDERS

> "One could say that 90% of all who are here anticipate ones every wish. And are concerned."
>
> „Man könnte also sagen, dass 90% von allen, die da sind, einem die Wünsche von den Augen ablesen. Und tüe mitchummere'." (3a 2. 840-842)

With their hospital admission, the terminally ill patients and their families who participated in this study left their familiar homes and workplaces behind and entered a more or less unfamiliar situation. The patients had to undergo examinations and interventions as well as accept being cared for by professional health care providers; patients and family members met numerous yet unknown health care providers. A common understanding and shared meaning could no longer be taken for granted. For the professional health care providers, however, the hospital was their everyday, familiar workplace, their taken-for-granted world. These study participants' accounts show how the health care providers' commitment or lack of commitment to caring for them made the alien hospital world more or less bearable to the patients and family members "thrown" into it.

While the previous chapters outline patients' and families' experiences of leading their life with a terminal illness and of being in the hospital, this chapter finally turns to patients' and families' experiences of the care they received in the hospital. It discusses the attitudes of care providers that, according to patients and family members, essentially influence their perception of these care providers as persons who are more or less

committed to caring for them. The relationship of patients, family members and care providers is described as reciprocal, and the influence of the frequent rotation of care providers as well as the unit's atmosphere on this relationship are considered. The committed care providers' alertness to patients' and family members' needs is addressed. Finally, using body care as an example, it is shown how the care providers' commitment and caring opens up the possibility for patients to accept care and feel well cared for.

Health Care Providers' Attitude

"Oh yes, he is a *human being*, yes!"

„Oh ja, das ist ein *Mensch*, ja!" (2a, 2b 527)

This statement of a patient about his general practitioner summarizes in one word what patients and family members highly value or miss in the professional care providers in the hospital. Of course, they are looking for competent professionals, but in addition, they also hope for caring human beings. Forced by the illness to stay in or visit the hospital regularly, patients and family members describe the attitudes of their hosts – the professional care providers – as a decisive influence on their care experiences. Friendliness, cheerfulness, and good manners, firmly grounded in empathy (Einfühlungsvermögen), consideration (Rücksichtsnahme), patience, and respect form the basis of a provider attitude that is experienced positively by patients and family members and lets them perceive care providers as committed and caring.

Being Kind and Nice

In all their accounts, patients and family members referred to the nice care providers. Friendliness, smiling, cheerfulness and good manners were praised repeatedly.

A friendly and pleasant voice, a smile, or a cheerful face were rays of hope for vulnerable human beings who found themselves in the alien hospital world. Patients and family members appreciated care providers who introduced themselves, said "hello" and "goodbye," and engaged occasionally in everyday conversations. Excerpts of a conversation with a patient and his wife illustrate this:

> Patient: Everybody here… they are wonderful people (his speech is faltering, he is moved). You know, if you are helpless, and before you were active and independent all your life.
>
> Patient: They are all so *unbelievably nice*, almost every evening, yesterday for instance, the nurse stayed with me for half an hour, and we talked about everything under the sun. And as I said before, they all come with a smile, and when they end work, they come and say goodbye…
> Wife: Say goodbye, give you their hand, say: "Good night, I will come again tomorrow," or "I will not come for two days, just to let you know."
>
> Patient: Already when you see her (the physiotherapist), she always shows such a smile, and this already lifts you up.
> Wife: And also the men who bring you to the radiotherapy, they are all so nice and ready to help.
>
> Wife: He says: "Whoever comes in, they smile and talk to me," and he of course also talks to the nurses. Our daughter says each time, as a joke: "Do you have a new girlfriend?" (laughs).
>
> Patient: Alle hier… sind wunderbare Menschen (spricht stockend, ist gerührt). „Gället," wenn man hilflos ist, und vorher das ganze Leben aktiv und selbständig war. (2a, 2b 82-85)
>
> Patient: Es sind alle so *unerhört nett*, fast jeden Abend, gestern abend zum Beispiel, war die Schwester sicher noch eine halbe Stunde bei mir, und wir redeten zusammen über Gott und die Welt. Und wie gesagt, die kommen alle mit einem Lächeln, und wenn sie Feierabend haben, kommen die meisten und verabschieden sich…
> Ehefrau: Sagen gute Nacht, geben die Hand, sagen: „Gute Nacht, ich komme morgen wieder," oder „ich komme zwei Tage nicht, damit Sie es wissen." (2a, 2b 584-596)
>
> Patient: Wenn man sie (die Physiotherapeutin) nur schon sieht, so ein Lächeln hat sie stets auf sich, und schon das stellt einem auf.

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> Ehefrau: Und auch die Männer, die Dich holen zum Bestrahlen, die sind alle so nett und hilfsbereit… (2a, 2b 624-628)
>
> Ehefrau: Er sagt: „Es kann reinkommen, wer will, sie lachen mich an und reden,“ und er redet natürlich auch mit den Schwestern. Unsere Tochter sagt jeweils, aus Spass: „Hast Du heute eine neue Freundin?“ (lacht) (2a, 2b 996-999)

An everyday conversation between a patient and a care provider could just be a nice chat, a welcomed way of passing the time; it might have, however, other positive aspects as well. For patients and care providers, such a chat could distract attention from a rather unpleasant nursing activity, for instance, when patient and nurse exchanged their hiking experiences while the nurse was performing his perineum care (2c 120-123). An informal conversation also opened up the opportunity to step out of their respective hospital role as patient or care provider and get to know each other as private persons. And it might bring an aspect of normal life to the hospital world for patients. They could engage in everyday conversations at the hospital as they would at home or at work. An example was the patient who had interesting conversations with the nurses during a special treatment and stated that she had met particular people there who were able to philosophize a bit (5a 2. 60-119). These normal talks of life had a way of humanizing the hospital experience and the caregivers. They served as “recognition practices” (Taylor, 1991) that went beyond the bounds of the tasks and the clinical therapeutics of the hospital.

Being or not being recognized as a person is a major aspect of patients’ and family members’ experiences. A recent study on “How are you?” by Cameron (2002) also demonstrates its relevance. The author investigated the use of “How are you?” This is usually a common greeting, part of everyday behavior and not reflected upon. However, in patient – nurse encounters, “How are you?” is a major question. Thus, nurses’ “How

are you?" can be extremely ambiguous for patients. Is it meant as a ritualized greeting or a question demonstrating concern for the patient's well-being? Patients who long for the question, but only get the greeting do not feel met, they are not recognized.

The Nice Nurses

Patients and family members experienced different professionals (e. g. physicians, physiotherapists, social workers) as nice; however, the kindness of the nurses was especially emphasized several times. One family member said:

> Each new nurse is even nicer than the one before. The one on duty tonight is like an angel, *so* kind!
>
> Jede neue Pflegende ist noch netter als die vorherige. Diejenige von heute abend ist wie ein Engel, *so* lieb! (3b 174-176)

And another stated that:

> Each was perfect, each enjoyed coming in, you never saw anyone in a bad mood. Go and take a look at my workplace and see, how these office animals run around there.
>
> Jede war perfekt, jede hatte Freude, wenn sie reinkam, man hat nie jemanden gesehen, der einen „suure Stei gschrisse" hat. Gehen Sie mal in meine Bude schauen, wie diese Bürohengste dort rumlaufen. (6 po 839-842)

Another family member was impressed because she had never observed any sign of distress in the nurses, although they must have been under time and work pressure (5a, 5b 275-282). The receptivity, warmth and good humor of the nurses were encouraging, and made being dependent and requiring care seem less burdensome for the patients.

With patients and family members relying upon their background meanings, it can be assumed that nurses are expected socially to be warm and friendly with patients out of deference to their illness and suffering. "Nurses are kind and nice" (lieb und nett). This is a frequently heard statement in Switzerland. Rather negative reactions of several

colleagues come to my mind: They were frustrated and felt diminished by these apparently simple attributes, not recognized as professionals. What is often referred to publicly, but rarely recognized as an achievement, not even by nurses themselves, has been called "emotional labor" by Hochschild (1983/2003). Emotional labor "requires one to induce or suppress feeling in order to sustain the outward countenance that produces the proper state of mind in others" (p. 7). Taking up Hochschild's concept, Smith (1992) has described emotional labor as a relevant component of nursing care. The patients and family members in this study again emphasized how decisive such attributes as being kind, nice and good mannered in nurses were for them; nurses' positive emotional labor is highly valued. Nursing is obviously more than being kind and nice, but the lack of such attributes will threaten nurses' relationships to patients and families, and the latter may feel degraded. Why do nurses not proudly acknowledge that friendliness, cheerfulness and good manners are indispensable conditions for good nursing care, and that it is a professional achievement to embody these attributes even under difficult and stressful circumstances?

Particular Experiences

While patients and family members shared the positive experiences related to care providers' friendliness, smiles, cheerfulness and good manners, they, nevertheless, differed in some respects. Several patients and family members mentioned other, somewhat surprising, characteristics of providers that influenced their experiences of hospital care. One patient especially valued care providers who she experienced as outstanding personalities, like one of her nurses (3a 2. 720-725) or the well known specialist who was involved in her care (3a 2. 133-136). A family member stressed the

appearance and aura (Ausstrahlung) of care providers as an influential aspect (8b 95-107), while another patient stated that the resident would radiate youth; he liked him for that, because with five children and nine grand children, he was used to being surrounded by young people (1a 441-447).

Such individual perceptions are quite common in everyday life. Since patients and family members, while in the hospital, still rely as much as possible on the background practices and meanings of their familiar world outside the hospital, it is not astonishing that their experiences with care providers are shaped by the same individual perceptions that shape their experiences with people in everyday life. All such particular utterances of patients and family members about care providers had a positive connotation; issues that might be socially unacceptable, for example racist thoughts, were not mentioned. It can be assumed, however, that people with such feelings would also bring them to the hospital.

Uncaring Providers

While patients and family members mostly praised the friendliness and cheerfulness of the hospital care providers, they, nevertheless, also talked about some exceptions to the overall positive picture of the care providers' attitudes. One family member described impressively the difference in attitude she experienced in her contacts with the physicians on two different units of the hospital:

> These were different worlds, the time there and the time here. There are just extremely big differences. (…) I can tell you exactly what it was. First… Not all the people have the same aura, not all the people look equally good, not everybody is equally self-confident, and if one is content with oneself, overall, then one may radiate more positive aspects. Dr. Smith, he is a small, unpretentious man, he certainly also has his chances with women, but I can imagine that Dr. Summer on the whole is a greater success with people, because he has an attractive appearance,

> he has a very pleasant voice. Mr. Smith always put on an unwilling face and walked around looking dejected. He never smiled. (…) On the corridor, he might or might not greet. Dr. Summer greeted me with my name from the second day on.

> Das waren verschiedene Welten, die Zeit dort und die Zeit hier. Da sind also schon extrem grosse Unterschiede. (…) Ich kann Ihnen genau sagen, woran es liegt. Als erstes… Es haben ja nicht alle Leute die gleiche Ausstrahlung, es sehen nicht alle Leute gleich aus, sind nicht alle gleich selbstsicher, und wenn man mit sich selber zufrieden ist, mit allem, dann strahlt man vielleicht mehr positive Sachen aus. Herr Dr. Schmid, das ist ein kleiner, unscheinbarer Mann, der hat sicher seine Chancen auch bei den Frauen, aber ich kann mir vorstellen, dass Dr. Sommer allgemein besser bei den Leuten ankommt, weil er ein ansprechendes Äusseres hat, er hat eine sehr sympathische Stimme. Der Herr Schmid hat immer so eine „Mougere" gemacht und lief so ein bisschen „vertschaupet" rum. Er hatte nie ein Lächeln. (…) Im Gang hat er vielleicht gegrüsst und vielleicht nicht. Dr. Sommer grüsste mich vom zweiten Tag an mit Namen. (8b 78-112)

This family member easily got in touch with Dr. Summer, because his appearance facilitated conversations and she felt recognized as the patient's closest relative. Dr. Smith's non-recognition and depressed appearance, in contrast, made coming into contact with him more difficult. It could be said that Dr. Summer engaged in a reassuring relationship with this family member, whereas Dr. Smith could not be seen as a resource in this respect.

Mrs. Dolder related a few situations where she and her husband experienced physicians as brusque, their language as rather rude and the tone of their conversations as inadequate with a mentally handicapped patient. (4b 89-100, 4b 3. 478-492, 4b 5. 500-513) Mrs. Dolder also met a nurse who never talked to her and stated: "Too much is in fact too much, but not a single word is not enough." („Zuviel ist auch zuviel, aber kein Wort ist zu wenig." 4b 5. 460) A patient who praised all the other nurses, talked about the one exception she had encountered, a nurse on the night shift:

> (The nurse did)… just the absolute minimum that she had to do. That was the medications at night. Just… barely greeting. Now, when I was in the single room, entered, didn't say good evening, did something with the equipment and "good

> night," and out and gone. Didn't ask: "How are you," didn't say, as the others, "call me, ring the bell, if you don't feel well or so." And two days ago, I asked, if she would be as kind as to air my room for five minutes. Because it was hot. And then she said: "Yes, I am going to the room next door, but then I have to go to another unit, eh, I am now going next door, and then I will come back and just close it again." And she in fact... just turned around and came back. "It's just not yet five minutes." Bang. And later I heard her in the corridor for hours...
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> (Die Pflegende machte)... einfach das absolute Minimum, das sie machen musste. Das waren die Medikamente in der Nacht. Einfach... kaum grüssen. Jetzt als ich da im Einzelzimmer war, reingekommen, nicht guten Abend gesagt, etwas am Apparat gemacht und „gute Nacht," und raus und weg. Nicht gefragt: „Wie geht es," nicht gesagt, wie die anderen, „melden Sie sich, läuten Sie dann, wenn Ihnen nicht gut ist oder so." Und vor zwei Tagen habe ich gesagt, ob sie so gut wäre und mir fünf Minuten lüften würde. Weil es heiss war. Und dann hat sie gesagt: „Ja, ich gehe noch ins Zimmer nebenan, aber dann muss ich noch auf eine andere Abteilung, eh, ich gehe jetzt nach nebenan, und komme es halt dann gleich wieder schliessen." Und sie ist wirklich... einfach umgekehrt und wieder gekommen. „Jetzt sind es halt nicht fünf Minuten." Peng. Und dann habe ich sie aber später stundenlang im Gang gehört... (3a 323-339)

While this patient rarely showed emotion when she talked, her dismay about the nurse's behavior clearly surfaced in the way she was speaking. In the first part of the story, she only used verbs and did not address this nurse as a person, something that she did not do throughout the rest of my conversations with her.

The study participants related few stories of unfriendly behavior. Those who did, however, talked repeatedly about these bad experiences. The patient quoted above, for instance, told me her story twice and her husband mentioned it as well. These situations were experienced very negatively and are not easily forgotten. From the standpoint of a healthy person, the lack of a greeting or a friendly remark, a window that is closed too soon, may seem trivial. For worried family members, for a terminally ill patient who was unable to get up on her own, unable to sleep in a hot room and craving fresh air, unfriendliness or being disregarded by the only available nurse at night was upsetting and hurtful. Experiencing brusqueness and inconsiderate behavior in the context of feeling

vulnerable and needy heightens the patients' sense of vulnerability and disrupts trust and confidence. Their expectation to be cared for is not met.

A Note on Swiss Culture

While the care providers' friendliness, cheerfulness and good manners are highly valued and experienced very positively by patients and family members, unfriendliness and non-recognition is perceived very negatively. These facts may also be, to some extent, related to the cultural background of this study. Swiss people tend to a common middle ground; by adhering to unwritten societal norms, people tend to do "what one usually does." Behaviors lying above or below a certain threshold are easily considered with suspicion and recognized as extraordinary. In unfamiliar situations, such as in the hospital, people silently try to adapt to the unknown norms; stepping over the threshold is avoided whenever possible. Assumptions are guiding peoples' behavior; there is a tendency to non-explicitness in Switzerland. Furthermore, Swiss people are regarded as rather reserved; opening up to someone else takes time, and disagreeing openly is avoided if possible. People may, therefore, be used to a certain "normal" distanced friendliness when meeting professionals in their everyday life. When patients and family members meet care providers in the hospital who are friendlier, more cheerful and readily willing to get in touch, this may be experienced as extraordinary and extremely helpful in a situation where people are feeling very vulnerable. For a patient who is reluctant to break any unknown rules and, for instance, avoids ringing the bell too frequently, receiving explicit permission to call for help is supportive. Any unfriendliness or unwillingness to fulfil a simple request is, thus, experienced in sharp contrast to this overall positive contact with care providers. The woman quoted above who already felt disregarded by the nurse and

did, as an exception, not get that particular nurse's permission to call for help, still roused herself to ask for a favor that she considered justified. She must have experienced the reaction of the nurse as a slap in her face. The nurse, from the patient's perspective, used a flimsy excuse, disdained her request, and stated this openly. From a cultural perspective, it can be said that the nurse stepped over the threshold of acceptable behavior in a negative sense.

Empathy, Consideration, Patience, and Respect

Patients and family members in this study were not talking about a superficial exposure of provider characteristics. "Putting on" a friendly, cheerful face and exhibiting good manners would not suffice. Rather, to be experienced positively, these attitudes had to be rooted in empathy, consideration, patience, and respect for patients and family members.

Experiencing or Missing Empathy and Consideration

Patients and family members highly valued empathic and considerate care providers. "They are so… empathic, from what I see, and considerate," („Sie sind etwas von… einfühlsam, was ich sehe, und rücksichtsvoll," 5a, 5b 275-282) said one family member. And others mentioned that the nurse expressed her understanding for an episode of incontinence, because she was able to put herself in the patient's place (6 po 759-765), and that the care providers showed understanding for the exceptional situation of family members (8 call 98-102). Such care providers were also described as available, good listeners, engaged, able to feel some of the unsaid and to talk adequately with patients and family members. Patients and family members felt understood by them. These care

providers showed the expected *professional* stance, as one family member summarized (8 call 89-97).

What patients and family members appreciated in care providers has been called "emotional reasoning" by Halpern (2001). This notion refers to her understanding of empathy. She described empathy as a skillful emotional engagement, where care providers as listeners use their emotional associations to provide a context that allows them to imagine patients' and family members' distinct experiences. This is very different from the detached concern that is expected for allowing care providers to grasp patients' emotions objectively, which is so often recommended in the health sciences.

However, patients and family members experienced care providers differently; while most were empathic and considerate, some were rather cold and distanced or even insensitive. Mr. Dolder's mother related a whole range of positive and negative experiences with different physicians that the patient and family had met during her son's terminal illness. She mentioned that her son had been treated over the years by the same neurologist and went on:

> He is neurologist and psychiatrist for him. He liked him, also admired him for the resistance he showed towards the illness, and he just was like a real father, he also kept visiting him.
>
> Er ist Neurologe und Psychiater für ihn. Er hat ihn gerne gehabt, hat ihn auch bewundert, wie er immer Widerstand gehabt hat, der Krankheit gegenüber, und er war also wie ein richtiger Vater, ging ihn auch immer besuchen. (4b 2. 479-492)

This physician visited Mr. Dolder a few times in the hospital, talking to him as well as to the family.

Regarding the general practitioner, Mrs. Dolder said that "he had a very good contact, and he was very good." („er hatte einen sehr guten Kontakt, und er war sehr gut."

4b 2. 496-526) On one of the hospital units, she observed that "they were always so kind and so correct and so nice," („sie waren immer so lieb und so korrekt und so nett," 4 b 136-137) and "there, conversations always ran smoothly and very nicely." („da sind Gespräche immer sehr rund und sehr schön gelaufen." 4b 153-154) She added:

> I was also astonished that the specialist gave him his phone number. "If you need me at some point in time, you can call me." I found that super.
>
> Ich war auch erstaunt, dass der Spezialist ihm seine Telefonnummer gegeben hat. „Wenn Sie mich mal brauchen, können Sie mich anrufen." Das fand ich super. (4b 2. 496-526)

Providing one's private phone number to a patient stands, in fact, for great commitment, because, in the hospital, health care providers usually transfer responsibility for patient care to the professionals on duty during their spare time.

Even the resident who had to break bad news – the stopping of radiation therapy – was able to do so in an acceptable way, although he appeared colder and more distant than the neurologist or general practitioner.

> All of that was said very gently. (...) The resident is gentle, cold but gentle, they must have some distance, certainly... (...) He does not show any feelings, but it is gentle, and that is important as well.
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> Das wurde alles sehr sachte („fiin") gesagt. (...) Der Assistent ist sachte, kalt aber sachte, sie müssen ja etwas Distanz haben, sicher... (...) Er zeigt keine Gefühle, aber es ist sachte, und das ist auch wichtig. (4b 163-172)

Mrs. Dolder also observed a rather business-like conversation between her husband and a senior consultant, which was still acceptable to her:

> He shows understanding, generally understanding, well, he is a typical man with a big business that he has here... yeah... that was alright. I found that he is a businessman and my husband is a businessman, and so they went along well with each other, in a way, it ran smoothly...
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> Er hat Verständnis, generell Verständnis, doch, er ist ein typischer Mann mit einem grossen Geschäft, das er da hat... jaja... das hat gestimmt. Ich habe gefunden, er ist

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> ein Geschäftsmann und mein Mann ist ein Geschäftsmann, und da kamen sie gut zusammen aus, auf eine Art, ja, es lief rund… (4b 216-222)

After mainly positive experiences, Mrs. Dolder was shocked when physicians occasionally acted insensitively, for instance, after the patient's fall off his wheelchair.

> But then a physician came… He was probably just on duty. And he came, "hello," we (the parents) were at his left and right. I can't remember if he greeted or ignored us, but this doesn't matter. He is the patient. Then he asked: "What happened?" Well, a fall. "Do you have any pain? No? Otherwise you can get pills." And of course, he said something… We found him in the room… And then the nurses came, and one just put him back into the wheelchair. He said: "Why did you not let me die on the floor?" And this is of course not logical. And then he said this again to him, I don't know how he formulated it. And he said: "What do you think, it will take three days for you to die, and we do not leave anybody on the floor for three days in the hospital." Like that… bang. For me, this is not right, it is not… what I expect of a physician towards a patient who is not so able anymore… who is sick and not so able anymore to go on discussing, at times yes, but at times not. And eh… well, and "goodbye." My husband also thought that, it is somewhat hard for the family who is sitting next.

> Aber nachher kam ein Arzt… Er hatte wahrscheinlich einfach Dienst. Und er kam, „grüezi," wir (die Eltern) sind links und rechts. Ich kann mich nicht erinnern, ob er uns begrüsst oder ignoriert hat, aber das macht nichts. Er ist der Patient. Nachher hat er gefragt: „Was ist passiert?" Ja, gut umgefallen. „Haben Sie weh? Nein? Sonst können Sie Tabletten haben." Und natürlich, er hat etwas gesagt… Wir haben ihn gefunden im Zimmer… Und dann kamen die Schwestern, und man hat ihn einfach wieder in den Rollstuhl gesetzt. Er hat gesagt: „Warum habt Ihr mich nicht am Boden sterben lassen?" Und das ist natürlich nicht logisch. Und dann hat er das bei ihm wieder gesagt, ich weiss nicht, wie er es formuliert hat. Und er sagte: „Was meinen Sie, bis Sie gestorben sind, geht es drei Tage, und drei Tage lassen wir niemandem am Boden im Spital." So… tatsch. Für mich ist das nicht recht, es ist nicht… was ich erwarte von einem Arzt einem Patienten gegenüber, der nicht mehr so fähig ist… der krank ist und nicht mehr so fähig, weiter zu diskutieren, manchmal schon, aber manchmal nicht. Und eh…ja, und „adieu." Mein Mann fand es auch, es ist etwas hart für die Familie, die daneben sitzt. (4b 105-128)

Given her son's cognitive impairment, Mrs. Dolder experienced the resident's statement as brutal and his tone as inadequate (4b 470-499). She was aware of her and her husband's hypersensitivity and wondering if the physicians had to speak in this candid manner for some reason:

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> We are of course the family… We suffer from the illness of our son. I am of course hypersensitive, but my husband too, yes, he shows it less, but it is exactly the same. And they are the physicians with their experience, buff… It is of course not the same level… And I was asking myself: Does one have to talk to a patient like this? I don't have any experience. Does one have to be a bit strict, so that…?
>
> Wir sind natürlich die Familie… Wir leiden unter der Krankheit unseres Sohnes. Ich bin natürlich überempfindlich, aber mein Mann auch, ja, er zeigt es weniger, aber es ist genau gleich. Und sie sind die Ärzte mit ihrer Erfahrung, baff… Es ist natürlich nicht die gleiche Ebene… Und ich habe mich gefragt: Muss man so mit einem Patienten reden? Ich habe keine Erfahrung. Muss man ein bisschen so streng sein, damit…? (4b 139-147)

Although this mother of a dying son experienced the confrontational conversational style of some physicians negatively, she did not just condemn it as inadequate. Rather, she took the families' dismay and lack of experience into consideration and searched for justification for the physicians' behavior. However, she was aware that other professionals had conveyed difficult messages to her son in a gentle manner, and she could not find any satisfactory explanation for this candid approach. It did not fit her understanding of palliative care. In fact, with individual care of patients and their families being a cornerstone of palliative care, the resident in the example above clearly missed relevant aspects: As resident on duty, he did not know the patient as a person and took neither his despair nor his cognitive impairment into consideration when talking to him. Furthermore, he did not integrate the family members in any way.

Patients and family members noticed that, although in general, they had good relationships with, they did not have equal connections to all care providers, and they had their favorites. Mrs. Dolder, for instance, said that she experienced the nurses who were also mothers as especially understanding, because they could identify with her situation (4b 4. 512-543). Another family member stated:

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> Clearly, one does not have the same good connection to everybody, but that is quite clear. Someone who is not so young anymore, perhaps one meets them on a different level, that is quite clear.
>
> Ganz klar hat man nicht zu allen den genau gleich guten Draht, aber das ist ja ganz klar. Jemand der nicht mehr ganz jung ist, da begegnet man sich vielleicht auf einer anderen Ebene, das ist ganz klar. (8b 582-585)

Thus, care providers with some life experience or those who shared an experience such as motherhood with patients or family members were highly appreciated, if they were able to bring their experiences to the care situation in a fruitful way.

Patient Care Providers

Patience was another provider attitude that was needed by the terminally ill, at times slow, forgetful, confused, or depressed patients, and valued by patients and families. The partner of one patient related the following observation:

> An example was the former roommate, she did, from my perspective, well, she just got on my nerves. (…) She just had something… how would you say… the mountain people would say, "Oh, she is complaining a lot." She was just complaining, and it seemed to me that the nurses, (…) when they came, they were always patient and able to get involved with her in this situation, without having to demonstrate in any way that this was difficult. They tried, with patience, and, "Yes, look, and let us do this…" So simply extremely well.
>
> Ein Beispiel habe ich auch mit der früheren Nachbarin, also die hat, nach meinen Dafürhalten, also mir hat sie einfach auf die Nerven gegeben. (…) Die hatte einfach so etwas… wie sagt man… die Oberländer sagen, oh sie ist „grüüsli chlagsam." Sie hat einfach gejammert, und da schien mir, dass die Pflegenden, (…) wenn sie kamen, immer mit Geduld und ja, einfühlend sich auf diese Situation einlassen konnten, ohne dass sie irgendwie zeigen mussten, dass das schwierig ist. Probierten, mit Geduld, und, „Ja, schauen Sie, und jetzt tun wir doch…" So einfach ausgesprochen gut. (5a, 5b 317-331)

Experiencing Respect and Disrespect

Finally, respect was pointed out as an additional relevant characteristic of care providers. Experiencing respect or disrespect at the hospital was an issue for those

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patients and family members who either had been treated disrespectfully in their everyday life, or were in a situation that might provoke disrespect in society, or had actually experienced disrespect at the hospital.

One patient was a forty-year-old immigrant. She had been working as a waitress in a pub. For several months, she had been suffering severe back pain before she was admitted and then diagnosed with severely advanced metastatic cancer. Her partner said that people had been talking badly about her because she was a foreigner. "Yeah, before she just was a malingerer who did not want do work..." („Ja, vorher war sie eben nur eine Simulantin, die nur nicht arbeiten wolle..." 6 po 1246-1259) And he stated:

> She simply only was a dirty foreigner, in the pub. This is quite usual there, you know, foreigner is foreigner, is just dirt.
>
> Sie war ja eben nur eine Drecksausländerin, in der Beiz. Dort ist das gang und gäbe, oder, Ausländer ist Ausländer, ist einfach Dreck. (6 po 1299-1323)

Asked if they had experienced hostility to foreigners at any time in the hospital, the partner stated clearly:

> Partner: No, no.
> Interviewer: You never had this feeling?
> Partner: No, as I said before, she was in good hands here, for her this was almost like heaven, you know, for her it was nice here...
>
> Partner: Nein, nein.
> Interviewerin: Das Gefühl hatten Sie nicht?
> Partner: Nein, wie gesagt, hier war sie so gut aufgehoben, für sie war das fast der Himmel, oder, für sie war es schön hier... (6 po 1299-1323)

The patient mentioned that all the care providers were looking after her extremely well, much better than she had expected (6a 35-36). To be fully respected as a person by everyone at the hospital – an experience that she had been lacking in her daily life before – contributed to her positive care experience.

From admission and throughout the hospitalization, the lesbian partnership of Ms. Egger and Ms. Egli was taken-for-granted and respected by all the care providers. The partner's status as significant other was never questioned.

> From the beginning, I was just accepted as Eva's partner, my access was never questioned. This has always been respected. I believe that we never talked further about the situation, but nothing ever arose that would have made this necessary. I always experienced a natural attitude of "she is here and part of it." So just a big taken-for-grantedness.
>
> Von allem Anfang an wurde sehr selbstverständlich akzeptiert, dass ich die Lebenspartnerin von Eva bin, und es wurde nie hinterfragt, dass ich Zutritt habe. Man hat das immer respektiert. Ich glaube, näher geredet über die Situation haben wir, glaube ich, nicht, aber es hat sich auch gar nicht ergeben, dass man dies hätte tun sollen. Ich habe immer eine sehr selbstverständliche Haltung von „die ist da und gehört dazu" vorgefunden. Also eigentlich, so eine grosse Selbstverständlichkeit. (5a, 5b 582-599)

The family of Mr. Dolder greatly appreciated that, until death, the care providers approached him always as a person, calling him by his name and talking to him as if he could understand everything. The respectful attitude of the care providers was also recognized during several observation periods. An example will illustrate this: The hospital provides paper bibs for protecting the clothes of patients who have problems with eating. These bibs can be put over the patients head. However, all the nurses and nursing aids who fed the patient, referred to these bibs as "big napkins" and never put them over the patient's head, instead they opened them and arranged them around the patient's neck. The care providers, thereby, avoided words and gestures that are acceptable for little kids but might provoke feelings of humiliation in adult patients. Mentally handicapped persons as well as gay people belong to groups which may still be discriminated against in society. Acceptance and respect in the hospital was experienced very positively, but not taken-for-granted and, therefore, stressed in the interviews.

One family member and one patient mentioned that they felt disrespected at the hospital at certain times. For a wife who was about 20 years younger than her sick husband, good looking and well dressed, it was not possible to build up a viable relationship with certain care providers. When she met them at first, she assumed prejudices from their look and tone of voice: "Something like, she must have married him for his money." („Der muss Geld gehabt haben, dass sie ihn geheiratet hat, so in dem Sinn." 8b 114-127) This was unacceptable to her and caused her to withdraw from these providers:

> When I notice this, then I hide myself away, I don't need this. (...) Let it be noted that, whom I wanted to marry, is a private matter.
>
> Wenn ich das merke, dann igele ich mich ein, das muss ich nicht haben. (...) Das ist ja meine Privatangelegenheit, wen ich heiraten wollte, notabene. (8b 114-127, 672-682)

From this wife's perspective, a few care providers allowed themselves to make an immediate judgment about the couple's relationship that they were not entitled to, and she experienced this as an insult. This judgmental behavior would be in bad taste in any setting, but stands out as almost cruel in the hospital when the patient and his wife both feel vulnerable.

A man with spinal cancer metastases causing paralysis and, thereby, bowel incontinence, stated that his worst hospital experience was with special therapy. If he was not clean on arrival for therapy, the therapists would complain, although they knew that he was unable to control his bowel movements. In addition, they informed the nurses on the unit (7a, 7b 2. 366-417). For this man who already greatly suffered from his bowel incontinence, overhearing remarks and phone calls about his uncleanliness was very

humiliating. Moving his hidden, private lack of ordinary control of the bowels into a public discussion diminished his sense of pride and dignity.

Summary

Patients as well as family members appreciate friendly, cheerful, good mannered care providers who demonstrate empathy, consideration, patience, and respect. However, this is more than everyday courtesy; it must take into consideration the particular vulnerabilities of the patients and their families during a time of illness, disability and suffering. The care providers' attention is naturally directed first towards the patients in need of medical and nursing care. But the care providers also, at different levels and more or less successfully, take steps to address family members' needs and to integrate them. This topic is discussed next.

Family Members' Integration

Family members valued their integration into the hospital environment, which meant that they felt welcomed, well informed, and had access to the patient and unit whenever possible, in other words, they felt cared for. Comparing her experiences on two different units of the hospital, one wife stated:

> There, I had the feeling that I was not recognized as wife. Perhaps shortly reduced to a denominator. Here yes, but there, I wasn't taken seriously, they just didn't recognize me as wife. And this bothered me a bit.
> (...)
> No information was provided, or I had to ask. Here one told me from time to time: "Dr. Summer would like to talk to you briefly." There I always had the feeling that I had to fight, when I wanted to know something. And here it was so natural that I got informed. There, one would never ask... Of course they have our particulars. They did not ask, for instance in our time I think that, "don't you have a cell phone?" That's just part of it for me. (...) Here they asked me: "Between what hours are you in the office?" There, they couldn't care less. And so here I could say: "From half past six, I'm there." One also never told me that I could call the

> unit, at night, if I had the feeling that it wasn't so good. Here the card was provided spontaneously: "You can."
>
> Ich hatte dort das Gefühl, ich werde gar nicht als Ehefrau wahrgenommen. Vielleicht kurz auf den Nenner gebracht. Hier ja, aber dort wurde ich nicht für voll genommen, die haben mich einfach irgendwie als Ehefrau nicht wahrgenommen. Und das hat mich ein bisschen gestört. (8b 151-156)
> (...)
> Es kam nichts an Informationen, oder ich musste fragen. Hier hat man mir ab und zu gesagt: „Dr. Sommer möchte dann noch schnell mit Ihnen reden." Ich hatte dort immer das Gefühl, ich müsste noch kämpfen, wenn ich etwas wissen wollte. Und hier war es so selbstverständlich, dass man mich informiert. Man hätte dort auch nie gefragt... Klar haben sie unsere Personalien. Sie haben nicht gefragt, zum Beispiel in der heutigen Zeit finde ich das, „haben Sie nicht ein Handy?" Das gehört für mich etwas dazu. (...) Hier haben sie mich gefragt: „Von wann bis wann sind Sie im Büro?" Das war doch denen dort wurst. Und so konnte ich hier sagen: „Von halb sieben an bin ich dort." Man hat mir dort auch nie gesagt, dass ich auf die Abteilung telefonieren könne, nachts, wenn ich das Gefühl hatte, es sei nicht so gut. Hier kam spontan das Kärtli: „Sie können." (8b 127-149)

The possibility of calling the nurses on the unit at any time, to receive timely information on the phone in a courteous and friendly manner, and never to be turned down, was also mentioned as a very positive experience by Ms. Egli. She used to call her partner every morning. When she could not reach her, she got worried because, for a while, the patient had suffered one complication after the other. In these situations, she tried to find out what was going on by calling the unit, for instance, on the day when the patient had fallen. Ms. Egli stated:

> They could have told me... turn me away, that would be an option, they in fact also have a lot to do. But really very friendly and patiently, and they brought her the phone. They said, yes, she fell, and they would let me talk to her... That is why I too feel in good hands.
>
> Sie hätten mir ja sagen können... mich abwehren, das wäre ja noch drin, sie haben ja wirklich auch zu tun. Aber wirklich ganz freundlich und geduldig und dann ihr das Telefon gebracht. Gesagt, ja, sie sei gestürzt, und sie würden sie mir geben... So fühle ich mich eben noch mit aufgehoben. (5a, 5b 353-388)

Usually, family members had access to the patients outside visiting hours. One patient said that her husband could stay with her all day in the emergency department (3a

273-282). A family member stated that she was allowed to stay with the patient during procedures, that the nurses exhausted all options (e. g. divider, curtain) to let her be present even when a second patient was in the room (8b 571-577). A partner related that the nurses gave the patient and her undisturbed time together (5a, 5b 582-599).

Several family members were approached by the nurses, offered a drink or informed about the option of ordering meals at the hospital. An elderly wife stated:

> Often they also ask: "How are *you*?" or "Would you like a cup of coffee?" Once they even asked if I would like to eat lunch here together with my husband, I could do this as well.
>
> Oft fragen sie auch: „Wie geht es *Ihnen*? oder „Möchten Sie einen Kaffee?" Einmal haben sie mich sogar gefragt, ob ich hier zu Mittag essen möchte mit meinem Mann, das könnte ich auch. (2a, 2b 899-907)

Three approaches to family members can be differentiated in their experiences. Non-recognition as the patient's closest family member and the related lack of information was experienced as problematic and caused the family member to feel excluded or disregarded. Family members who had experienced a liberal handling of visiting hours, received the requested information at any time, and were treated kindly by care providers felt welcomed and accepted as significant person for the patient. Their experiences were positive. Finally, care providers who approached family members actively and showed concern for their well-being, for instance, by explaining their options at the hospital, were greatly appreciated, and family members felt not only recognized but in addition cared for themselves. Patient and family member were considered as the unit of care; an important concept of palliative care was put into practice.

Reciprocity

Patients and family members were aware that the care provider – patient/family member relationship was not a one-way affair, that they played their part in shaping it. A man expressed this succinctly by stating: "You get as much as you give." („Wie man in den Wald ruft, so kommt es zurück." 2a, 2b 629-650) He illustrated his view with the following story that shows how a patient and an employee could share a joyful moment on their way to radiation therapy:

> Just as an example, employees responsible for transportation of patients are they called. Then such a nice guy came, and I was thinking, (…) from where he might be, you know. And then… on our way I said: "Listen, that may be a bit cheeky, but where are you actually coming from?" Then he told me from where he came. Yes, and then I mention… that we had travelled around this country once… (…) And then I mention: "And then we also were in this place with the famous temples." Then he said at once: "This place, I born there." The man enjoyed this like a kid. That was for both, somewhat… these are short moments, but beautiful moments.

> Nur ein Beispiel, Transporteure sagen sie denen. Da kam so ein netter Typ, da habe ich studiert, (…) wo kommt der her, nicht wahr. Und dann… unterwegs sagte ich: „Hören Sie, das ist vielleicht etwas frech, aber wo kommen Sie eigentlich her?" Da sagte er zu mir, woher er komme. Ja, und dann mache ich… wir hätten auch schon eine Reise durch dieses Land gemacht… (…) Und dann mache ich so: „Und dann waren wir auch in diesem Ort mit den berühmten Tempeln." Da sagt er aufs Mal: „Dieser Ort, ich dort geboren." Der Mann hatte eine Freude wie ein Kind. Da ist beiden, irgendwie… das sind kurze Momente, aber schöne Momente. (2a, 2b 629-650)

Successful and Unsuccessful Interactions

Of course the illness put limits on patients' interactions; some patients were at times too sick, unable to communicate verbally, or suffering from a dimming of consciousness. Their ability to influence their relationship with care providers were minimal during these time periods.

In addition, patients and family members brought their everyday, more or less distinct interaction skills to the hospital. For instance, Mr. Blum who had had his own service business, had organized hiking trips for groups after his retirement, and was an engaged member of his church, easily struck up communications with care providers at the hospital, just as he did in his everyday life. (2c 120-123; 2a, 2b 996-999) Another patient, suffering from an advanced cancer with multiple bone metastases, described how she was unable to interact effectively. She had experienced an earlier mammography as painful and only reluctantly agreed to another one. She was taken by ambulance to another hospital for the X-ray. The nurses on her unit handed over a syringe with pain medication to the ambulance men, instructing them to give the injection if the patient should suffer from pain. Already the shaking during transportation was painful for this frail, emaciated woman. The examination was worse; in order to place her very small breasts correctly for the X-ray, the radiology assistants pulled and pushed her so that she was in severe pain afterwards and asked for the injection. However, the radiology assistants were not allowed to give it and the ambulance men had left for a coffee break. And even upon their return the urgently needed and promised pain medication was not provided to the patient.

> Patient: I was already complaining a bit, and when I was in bed again, I said: "Uh, now I need this injection." Then they (the radiology assistants) said: "They (the ambulance men) will come, they will come." And I said: "Well, where are they?" "Drinking coffee." Then I said: "Can't you give me the injection?" "No, we are not allowed to do it." And well, after a while they came back, and the nurse, to excuse them, immediately said: "You deserved this cup of coffee." But that I would have deserved an injection… I am stupid, I do not react, I don't fight at the moment. At least, I should have, in a decent way, of course, but I should at least have asked why I did not deserve an injection. (…) And then this was of course again a long way, until I finally was lying in bed here and got the injection.
> Interviewer: Well… didn't they give you the injection?

> Patient: Mm, no way. I realized that they probably don't know how to do it, or don't want… nothing… They just transported me afterwards. And I knew that it would not take so much time anymore: Shut up! But that was not satisfying.

> Patientin: Ich habe schon etwas gejammert, und als ich dann wieder im Bett war, sagte ich: „Uh, jetzt muss ich diese Spritze haben." Dann sagten sie (die Röntgenassistentinnen): „Ja, sie (die Sanitäter) kommen dann, sie kommen dann." Und ich sagte: „Ja, wo sind sie denn?" „Beim Kaffee." Dann sagte ich: „Können denn nicht Sie mir die Spritze geben?" „Nein, das dürfen wir nicht." Und ja, nach einiger Zeit kamen sie dann, und die Schwester hat sofort, um sie zu entschuldigen, gesagt: „Den Kaffee habt Ihr verdient." Aber dass ich eine Spritze verdient gehabt hätte… Ich bin eine Blöde, ich reagiere nicht, ich wehre mich nicht im Moment. Das hätte ich wenigstens, im Anstand klar, aber das hätte ich wenigstens fragen sollen. Warum ich denn keine Spritze verdient hätte. (…) Und dann war das halt wieder ein langer Weg, bis ich dann schlussendlich hier im Bett lag und die Spritze bekam.
> Interviewerin: Ja… die Spritze haben sie Ihnen nicht gegeben?
> Patientin: Mm, wohin denken Sie. Ich habe gemerkt, dass die das wahrscheinlich gar nicht können, oder nicht wollen … nichts… Die haben mich danach transportiert. Und ich wusste ja, es geht nicht mehr so lange: Schweig! Aber das war nicht befriedigend. (3a 3. 85-107)

In this awkward situation, the patient - in pain, weak and dependent - was unable to effectively communicate her need. She felt silenced (mundtot gemacht) by the care providers and, as she stated herself, lacked the quick-wittedness to react and take up the conversation, instead, she resigned and decided to keep quiet. From a provider perspective, it remains unclear, why the pain medication was not given, since the ambulance men did not refuse the request, when asked by the nurse.

Thoughtful and Guarded Interactions

In the interview excerpt above, the patient mentioned what she should have asked and added "in a decent way, of course." Another patient, used to have the saying as boss of his company, stated:

> I accept how they do it, that is clear. When I say something, then this is a wish, you know, not in any way a command.

> Ich akzeptiere es, wie sie es machen, das ist ganz klar. Wenn ich etwas sage, so ist dies ein Wunsch, oder, dann ist das nicht irgendwie ein Befehl. (1a 388-391)

As far as possible, given the illness and their social background, patients and family members are very considerate in their interactions with care providers. Patients and family members, aware that they are the vulnerable partners in these interactions, may not want to put their mostly good relationships with the care providers at risk. They do not know the care provider network from the inside and can not judge if and how far a complaint about one care provider might spread and potentially damage their future care. As guests of necessity, forced by the illness to stay at their hosts' house, they may adapt as much as possible to the terms of the care providers in the hospital. Patients' and family members' carefulness may also be seen as typically Swiss, as an unwillingness to risk an open disagreement.

Patients and family members took care to show their appreciation to care providers. "I hope that we in fact show that we are satisfied," („Ich hoffe, dass wir auch zeigen, dass wir zufrieden sind," 4b 4. 317-322) stated a family member, and a patient uttered: "I take some trouble to express my thanks." („Ich gebe mir Mühe, ihnen auch zu danken." 1a 406-411) Some patients tried to please the care providers. One was wondering if he would have to exercise with the walking aid on the stairs and decided to ask the physiotherapist. He added: "They even like being asked." („Sie haben es sogar gerne, wenn man sie fragt." 7a 189-198) A wife related how her husband continued breathing therapy for the sake of the physiotherapist, even though he considered it useless.

> He kept blowing to please her (the physiotherapist), you know. He doesn't want to be the one who annoys somebody. He still kept blowing into it, but when she left, he said, that blowing was just nonsense.

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> Er hat schon noch geblasen, um ihr (der Physiotherapeutin) einen Gefallen zu tun, oder. Er will ja nicht der sein, der jemanden aufregt. Er hat schon noch reingeblasen, aber wenn sie ging, hat er gesagt, das sei doch ein „Chabis." (8b 505-513)

And even though patients and family members valued providers who approached and informed them spontaneously, they acknowledged their part in searching for the needed information.

> Of course, I must also ask if I want to know something. I really cannot expect that it is always them who approach me.
>
> Ich muss natürlich auch fragen, wenn ich etwas wissen will. Ich kann ja nicht erwarten, dass sie immer nur kommen. (8b 594-605)

Thus, patients and family members are not only thoughtful regarding their interactions with care providers; as far as the illness allows them to do so, they actively contribute to good relationships, for instance, by valuing the care providers' professional knowledge and endeavors, or by initiating the search for information themselves.

When interactions with care providers were experienced as problematic, patients and family members carefully considered their options and decided how to proceed. The family member who did not feel recognized as the patient's wife, for instance, explained that she did not communicate her bad feelings to any care provider, even though she was well-known outside the hospital for her apt statements. But she was aware that her husband would return home again and kept silent (8b 156-161). This wife's realization that her husband would not die on this unit but was still in need of care let her decide to simply go along with not being acknowledged, rather than speaking up. She might have acted differently, if her husband had been dying and less able to express himself.

The mother of Mr. Dolder had been greatly hurt, because a nurse did not allow her to give the regular pills to her son when she was feeding him. Later she felt somewhat

compelled to discuss the issue with this nurse, and a friend encouraged her to do so. However, she realized that thinking about a possibly useless dispute caused her distress. Her husband advised against starting such a conversation by putting things into perspective: The bad experience with this nurse had become irrelevant, relevant was the well-being of their son. She agreed and decided to just distance herself from this nurse, a strategy that worked well for her (4b 414-415; 4b 5. 419-451).

Thus, when patients and family members actually face problematic interactions with care providers, and even when they feel entitled to speak, they may be hesitant to assert themselves. They carefully think over the situation and may decide rather to keep silent than to utter criticism, because they are unwilling to risk jeopardizing the patient's care. This demonstrates the power differential that patients and families feel with the care providers, their fear of abandonment, or even retaliation, of disrupting or damaging their relationship with the care providers if they offend them. Family members seem especially aware of the patients' vulnerability and dependency on the care providers and the hospital. They clearly prioritize the patients' well being over their own concerns and try to avoid any negative influences on the care. Yet another reason for not speaking up may be the unwillingness of the already distressed family members to face additional negative experiences that any dispute with care providers might cause.

Interestingly, patients and family members seem to expect primarily negative consequences, should they utter any criticism to the care providers. It can be argued, however, that criticism, if stated as a feedback on facts rather than an accusation of persons, may yield positive consequences, that is, an improvement in the care provided. The question arises why this aspect is not mentioned by patients and family members. It

is of course possible that this issue just did not come up in the interviews. It seems also possible, however, that people lack the experience of giving critical feedback in an effective way when they are reluctant guests in an unfamiliar house and in the context of feeling vulnerable. The Swiss cultural tendency to avoid arguments and make implicit assumptions may suppress rather than foster critical feedback.

Rotating Care Providers

An additional issue influenced the patient/family member – care provider relationship: the frequent rotations of care providers. At the hospital, due to the division of labor among multiple specialists (e. g. physiotherapists, social workers, dieticians), the shift-work of nurses, and the frequent rotation of residents, a great number of persons were involved in the care of each patient. Patients and family members were, therefore, frequently confronted with new faces. For instance, a patient who was first admitted to the emergency department met the responsible resident and senior physician as well as several nurses of this department. After his transfer to a medical unit, another resident, senior physician, and nursing team took over responsibility, and additional professionals got involved according to the patient's needs. During the day shift, one nurse was mainly responsible for the patient's care, but other team members might assist her, and the responsible nurse usually changed every second or third day. Yet other nurses cared for the patient during evening and night shifts. Different physicians were on duty at night and on weekends, and physicians as well as other professionals might rotate during a patient's hospital stay.

These frequent changes of care providers were experienced differently by different patients and family members. One family member stated that the frequent changes among

the nurses at the hospital were no problem, because all of them were qualified professionals. The patient agreed, saying that all of them cared equally well for him (1a 361-371; 1b 854-877). For other patients, the rotations were a problem, but one that was inevitable under current working conditions. An elderly patient, for instance, mentioned his problems with remembering the care providers' names:

> Nowadays it's just like that, there is a terrible amount of rotations. I have troubles with the names, for instance. I already had troubles with names before, but until I really got the name, someone else comes along, and also different people. That's just how it is nowadays.
>
> Es ist heute einfach so, es ist wahnsinnig viel Wechsel. Da habe ich dann zum Beispiel Mühe mit den Namen. Damit hatte ich vorher schon Mühe, mit den Namen, aber bis ich dann den Namen hier richtig aufgenommen habe, kommt schon lange wieder jemand anderes, und auch verschiedene. Das ist heute einfach so. (2a, 2b 577-584)

Another patient greatly regretted that with the transfer to a different unit his relationship to the consulting specialist was cut. This specialist had accompanied the patient through palliative treatments and had supported him in coming to terms with his illness and approaching death. Even though the members of the new care team were supposed to continue counselling, a long-term and trusting relationship to a particular care provider cannot simply be replaced by new relationships to other providers.

Patients' experiences regarding the continuity of their care also depended on verbal and written reports of the care providers. One patient recognized that the residents responsible for her special therapy rotated very quickly, but that continuity was ensured due to good documentation (5a 2. 149-155). In regard to nursing, she explained:

> And what I also experience as good, I believe that in their report they inform each other well so that continuity is ensured. Other people are assigned to the room again and again, but they are informed. They also know when I had been moaning the day before, that I did not feel so well, and they start from there, and ask: "Are you

> feeling better now?" You do not need to tell them at length, they actually know more or less…
>
> Und was ich auch noch gut finde, ich glaube, im Rapport, sie erzählen sich gut, so dass Kontinuität da ist. Es sind ja immer wieder andere Leute im Zimmer zugeteilt, aber sie sind orientiert. Oder sie wissen auch, wenn ich am Tag davor „glieret" habe, dass ich es nicht so gut hatte, und gehen davon aus, und fragen: „Geht es jetzt besser?" Man muss nicht lange reden und erzählen, sie wissen eigentlich ungefähr… (5a 846-866)

Another patient related contrasting experiences. She found it difficult to meet new nurses and residents so often, because each had to get to know her as a patient, and she in turn had to explain and answer questions repeatedly (3a 2. 914-926). The different experiences of these patients are likely due to the changing quality of verbal reports and documentations. Not all care providers are equally able to report or write down concisely relevant information about a patient. Different patient experiences may also be related to the fact that not all care providers are equally talented in being considerate about information when caring for a patient.

Interestingly and in contrast to others, one patient welcomed some rotation among the nurses, stating that every nurse had her personal strengths and by meeting several of them, she could profit from all.

> By the way, I also find it good that the nurses rotate, because each of them has her specialty, her strengths, and by now, I already know them a bit. It is exciting for me how each nurse reacts differently, has strengths, one can give you this, another one that… I find this totally exciting.
>
> Ich finde es übrigens auch noch gut, dass die Pflegeperson wechselt, weil jede wieder ihre eigenen Spezialitäten hat, ihre Stärken, und ich kenne sie jetzt schon etwas. Ich finde das noch spannend, wie jede Pflegende wieder anders reagiert, Stärken hat, einem Sachen geben kann, eine andere das… das finde ich total spannend. (5a 846-866)

This patient's perspective may to some extent be related to the length of her hospital stay. She was hospitalized for two months and readmitted later for chemotherapy. She had a better chance, therefore, to get to know the members of the nursing team and their individual strengths than patients who spend a few weeks or days in the hospital. Having different care providers may also have made her feel less obligated and less burdensome to the nurses.

In summary, it can be said that patients and family members accept the frequent changes of care providers as a given fact under current working conditions. Rotations can even be seen as an advantage, if a patient is able to profit from the different strengths of different providers. However, as a requirement for good care, care providers have to guarantee an adequate flow of verbal or written information so that patients do not have to repeat their whole story with each new provider. Being asked to do so is experienced negatively. The very act of giving personal information frequently, may also lead to the patient feeling insecure about being "known" and recognized. Over time, repeated introductions demonstrate lack of continuity and a lack of being remembered.

The Units' Atmosphere

The hospital, a huge multi-storey building constructed in the late 1960s and early 1970s, is often seen as a factory by outsiders. After having experienced the hospital from the inside, however, the image of a factory had proved to be wrong for study participants (3a 3. 147-149; 1b 517-521; 4 po 620-641). Their experiences were on the one hand shaped by the care providers they met, but on the other hand by the units where they were hospitalized or treated. Patients and family members were aware of differences among the units; each had its own atmosphere. That is, patients' and family members' hospital experiences did not solely depend on encounters with individual care providers, but also on the units' atmosphere (2a 486-524; 5a 2. 60-119; 8b 78-85; 8 call 104-111).

One patient, for instance, expressed her astonishment about the personal treatment in a specialized department, given the number of patients treated there daily:

> Astonishingly personal, because, if one thinks, it takes five, at most ten minutes, such a treatment. Theoretically, they can treat x people per day. And they know the name, they give you the name. They know what it is about, (…) perhaps inform themselves quickly in advance. But they don't give you the feeling that one is a number and that they have to check, ah, that's why she is coming.
>
> Erstaunlich persönlich, weil, wenn man denkt, es geht fünf, höchstens zehn Minuten, so eine Behandlung. Sie können theoretisch x Leute behandeln pro Tag. Und sie wissen den Namen, sie geben einen den Namen. Sie wissen, worum es geht, (…) erkundigen sich vielleicht vorher schnell. Aber sie geben einem nicht das Gefühl, man sei eine Nummer und sie müssten jetzt nachsehen, ah, die kommt deswegen. (5a 2. 178-185)

A patient who had been transferred from another hospital impressively described the difference he experienced between the two units where he had been cared for:

> Patient: Well that is crazy, well, I have to say that this is incredible the whole care. In the other hospital, I was of course unlucky, because it was over Easter, the personnel was reduced, but the whole ambiance, just of these women, it is on a totally different level, I thought.
> Interviewer: That is in comparison to the other hospital?
> Patient: Yes, I mean, they did a good job, you must understand me rightly, I'm not criticizing. I was very satisfied there, but when I now experienced this here, well, these are worlds.
> Interviewer: That's interesting, what is it then that makes up these worlds?
> Patient: The worlds? … Well, first, when the door opens, no rule without an exception, but they come in with a smile, and I just call this ambiance. That is exactly as if when we go out to eat. It depends, if I just need something because I am hungry, then it doesn't matter, then I'm glad if it comes as quickly as possible. But if one goes out for a pleasant evening, then, the service, you know. Not that I'm very demanding, but that it is just nice, the price comes only later. If that then costs a bit more, well, is it worth it ten times. One will remember this evening.
>
> Patient: Also das ist wahnsinnig, also da muss ich sagen, das ist also unerhört, die ganze Betreuung. Im anderen Spital hatte ich natürlich Pech, weil es über Ostern war, das Personal war reduziert, aber die ganze Ambiance, gerade von diesen Frauen, ist auf einer ganz anderen Ebene, fand ich.
> Interviewerin: Das heisst im Vergleich mit dem anderen Spital?
> Patient: Ja, ich meine, die machten ihre Sache recht, Sie müssen mich recht verstehen, ich kritisiere nicht. Ich war dort sehr zufrieden, aber als ich jetzt das hier erlebte, also, das sind Welten.

> Interviewerin: Das ist interessant, was macht denn diese Welten aus?
> Patient: Die Welten?... Also erstens schon, wenn die Türe aufgeht, keine Regel ohne Ausnahme, aber die kommen mit einem Lächeln, und ich sage dem einfach Ambiance. Das ist genau so, wie wenn wir auswärts essen gehen. Es kommt drauf an, wenn ich nur etwas haben muss für den Hunger, dann spielt es keine Rolle, dann ich bin froh, wenn es so schnell wie möglich kommt. Aber wenn man am Abend so gemütlich geht, dann, der Service, nicht wahr. Nicht dass ich grosse Ansprüche stelle, aber einfach dass es nett ist, dann kommt erst der Preis. Ob das dann ein Fränkli mehr kostet, ja, das ist es zehnmal wert. An den Abend denkt man zurück. (2a 486-524)

This patient mentioned one possible reason for the difference between units he experienced: He had been admitted to the former unit during a holiday when the number of staff had been reduced. A family member was wondering about potential causes for the huge differences between units that she had experienced: Did it depend on the unit per se, on the kind of diseases treated there, on the supervisor, or on the senior physician (8b 78-85)? Another patient had observed the functioning of a specialized unit and recognized that the nursing team had great autonomy in organizing its work, especially on weekends, and was fully using its freedom. She always experienced the unit as radiating a very good spirit, even during an emergency treatment on the weekend, and related this pleasant atmosphere to the liberal working conditions of the nursing team (5a 2. 60-119).

It is suggested that the atmosphere on a unit is co-created by the care providers, staff and supervisors, of the respective team within the given structural and organizational conditions. Benner et al. (1996) described how caring knowledge is socially embedded and stated: "The unit subculture also has taken-for-granted ways of thinking and being with patients that get transmitted" (p. 222). A team that highly values kindness, empathy, consideration, patience, and respect towards patients and family members, and lives out these attitudes daily, provides role models to new team members

and, thereby, transmits and sustains what is taken-for-granted on the unit. New team members learn what is expected and what may be sanctioned.

Caring Providers

In order to describe in detail what patients and family members regard highly or dislike in their encounters with care providers, specific characteristics of the latter have been addressed and outlined. The description of a range of care provider characteristics should not be misunderstood, however, but seen as a matter of articulation. Thus, care providers are not experienced as people with certain characteristics. A particular person is always more than the sum of his or her characteristics. That is, patients and family members do not meet care providers who expose a combination of arbitrary characteristics. An unfriendly, empathic nurse is hardly conceivable, for instance. Rather, patients and family members meet care providers as persons who take on a certain attitude or stance towards them.

The patient who called his general practitioner a *human being* (Mensch) meant that as a patient, he had not only met a knowledgeable professional, but a human being; furthermore, not a distanced and disinterested human being, but an involved and concerned one, or stated otherwise, a caring human being. Caring, according to Benner and Wrubel (1989) means that “persons, events, projects, and things matter to people” (p. 1). In the context of health care, caring means that patients and family members matter to the care providers. The study participants’ experiences reflected this view of caring; they felt best cared for when the providers showed their recognition and concern (3b 86-88), as the following statement of a patient illustrates:

> One could say that 90% of all who are here anticipate ones every wish. And are concerned. I now realized that with my nausea. They almost suffered themselves. One told me that the whole unit was preoccupied with me in the mean time... (...) and that is nice. One feels how they discuss together. That's good. And it is good that one realizes it.
>
> Man könnte also sagen, dass 90% von allen, die da sind, einem die Wünsche von den Augen ablesen. Und „tüe mitchummere." Ich habe das jetzt gemerkt mit meinem Schlechtsein. Es hat sie selber fast mitgenommen. Eine hat mir gesagt, ich beschäftige inzwischen die ganze Abteilung... (...) und das ist schön. Man sieht, wie sie miteinander beraten. Das ist ja gut. Und es ist gut, dass man es merkt. (3a 2. 840-851)

Situations that were experienced as problematic, however, were related to uncaring providers, that is, to providers who distanced themselves from patients and families. These providers focused on the medical task at hand and tended to ignore patients and family members as persons, which may be experienced as dehumanizing by the latter (Toombs, 2001a). Caring cannot be separated from the necessary medical and nursing tasks, because having any of these tasks done with disregard or lack of concern changes the experience for the patient and family member.

Caring, that is, letting patients and family members matter to them, allows the care providers to focus on the one cared for and enables them to be constantly alert (Benner & Wrubel, 1989). For the caring providers, the terminally ill patients and their families have priority; they are eager to recognize their needs and wishes.

Alert Providers

Caring providers constantly showed great alertness (Aufmerksamkeit, Wachsamkeit) and recognized (potential) needs of the patients. They also observed details, such as a patient's dry mouth (1c 221-227) or the newly acquired non-slip shoes

(2c 141-144). As one family member stated, the nurses had their antennas out and nothing escaped them regarding the patient's situation.

> And… each has her own way of being, but I always perceive again, that they refer to wishes, and they virtually have their antennas out and notice that.
>
> Und… jede hat ihre eigene Art, aber immer wieder merke ich, sie gehen auf Wünsche ein, und sie haben so quasi die Antenne draussen und nehmen das auf. (5a, 5b 273-275)

Attending to Physical Needs

Caring providers were aware of physical needs, and they recognized progresses and adapted their actions to the patients' changing situation. This required attentiveness and concern on the part of the care providers. For instance, one patient related that the therapists recognized her pain and her regained abilities:

> They work very carefully. They know that they might hurt you and always ask: "Is it okay like that?" Move you carefully. Yes, move you very consciously and ask: "Is it okay like that?" They also notice when you make progresses, that they do not need to help anymore with certain things, where they helped before. They notice that, they are aware of that.
>
> Sie arbeiten sehr sorgfältig. Sie wissen, dass sie einem weh tun könnten und fragen immer zurück: „Geht das so?" Bewegen einen sorgfältig. Ja, bewegen einen sehr bewusst und fragen: „Geht das so?" Sie merken auch, wenn man Fortschritte macht, dass sie mit gewissen Sachen nicht mehr helfen müssen, wo sie vorher geholfen haben, das merken sie dann, das ist ihnen dann bewusst. (5a 2. 171-178)

And regarding her constipation, the same patient stated:

> So how they look, like with the enema, it was actually them who pushed and said that something had to be done. Thus, I did not have to moan that I did not feel well anymore.
>
> Also wie die schauen, eben das mit dem Einlauf, das waren eigentlich sie, die gedrängt haben, die gesagt haben, es müsse etwas gehen. Also musste ich gar nicht lamentieren, mir sei es nicht mehr wohl. (5a, 5b 765-774)

Recognition of Patients' Whole Situation

Caring providers did not solely focus on physical needs. Their alertness was comprehensive, directed towards their patients' whole situations. The partner of a younger woman, who died in the hospital more quickly than expected from metastatic cancer, illustrated this. Their flat lacked wheelchair access, and during the patient's hospital stay, the landlord gave them notice to move from the apartment. The patient wanted to divorce her husband who was in jail, and she had lost work. This was a devastating situation for this immigrant and her current partner – but the hospital provided support with all the problems and, had the patient survived, things would have been organized in ways that they would have been able to continue living together in a convenient place.

> Well, as I said before, where do you still find this? Everything is considered and done. And Fiona did in fact not just enter with the cancer, she also had a problem with her separation, a problem with the workplace, because she had just started and lost the job again. And they were taking care of everything. (...) If she could have been discharged, everything would have been organized, and one could have lived on.
>
> Eben, wie schon gesagt, wo finden Sie das sonst noch? Es wird ja für alles geschaut und alles gemacht. Und Fiona kam ja nicht nur mit dem Krebs rein, sie hatte ja auch noch ein Problem mit der Trennung, ein Problem mit dem Arbeitsplatz, weil sie gerade frisch angefangen und ihn wieder verloren hatte. Und sie haben für alles geschaut. (...) Sie hätte ja rauskommen können, und es wäre alles organisiert gewesen, man hätte weiterleben können. (6 po 927-940)

In the following story, recounted by Ms. Egger and her partner, the nurses recognized the patient's emotional problem and suggested the transfer to another room. The nurses' attentiveness and their taking action greatly relieved the patient who had suffered, but had not considered asking for the change herself. In the patient's and her partner's view, this would have been an excessive demand.

Patient: And then the old woman, for example, she drove me crazy. Each time, when I got up, she said: "Oh, you are still so fit, you are *still going up so easily*." And she could repeat this ten times. And I could tell her each time that I was not yet 90, after all, you know, she is over 30 years older than I am. In addition, she is quite fit given her age and how she was still able to move around. I would be glad if I would ever get to be 90 and could still move around like that.
Partner: It drives you… It makes you angry…
Patient: Yes… (…) But actually, I should not have become furious. It somehow shows again that my vigor is not that great. That's why I am in this room now. They noticed that she got on my nerves. Or last night, each time, when I was about to fall asleep, she asked: "Are you sleeping?" (partner and interviewer laugh) Until I put Oropax in my ears and said: "No, if you keep asking, I cannot sleep." You know, she is turning off the light at half past seven and doesn't do anything anymore, and then she is wondering that she cannot sleep after two o'clock. She slept from eight to two o'clock, and in fact very well! In the morning, she complains that she could not close an eye.
Partner: Yes, I just believe that in this situation the energy resources are not that big anymore…
Patient: She was the third or fourth old woman with whom I shared the room, each again with a different pattern, and now I cannot bear it anymore.
Interviewer: So, you said that you could not bear it anymore, or did they notice it?
Patient: No, no, no, they have…
Partner: They noticed it…
Patient: I would never have taken the liberty, I would never have taken the liberty to say that I would not want to stay in that room.
Partner: Yes, one would never take this liberty…
Patient: The nurses suggested it. They had an empty room and told me that they would move me. (…) They somehow noticed that I was irritated.
Partner: They are always feeling this…
Patient: I would never have taken the liberty, I was ashamed, actually, that I was not better able to master this, with more sovereignty. Because she is also a pitiful, you know…

Patientin: Und dann die alte Frau, zum Beispiel, die hat mich verrückt gemacht. Sie hat jedes Mal, wenn ich aufgestanden bin, gesagt: „Oh, Sie sind dann noch fit, Sie mögen dann noch gut." Und das konnte sie zehnmal nacheinander sagen. Und ich konnte ihr jedes Mal sagen, ich sei auch noch nicht 90, also immerhin, oder, die ist also über 30 Jahre älter als ich. Und so unfit ist die gar nicht, das kommt dann nämlich noch dazu. Also für ihr Alter und wie die sich noch bewegen konnte. Ich wäre froh, wenn ich jemals 90 würde und mich noch so bewegen könnte.
Partnerin: Es geht einem… Es macht einen hässig…
Patientin: Ja… (…) Aber eigentlich hätte ich ja gar nicht wütend werden müssen. Es zeigt irgendwie wieder, dass meine Spannkraft nicht so gross ist. Deswegen bin ich ja jetzt in diesem Zimmer, die haben gemerkt, dass ich mich über die aufrege. Oder letzte Nacht, jedes Mal, wenn ich wieder am Einschlafen war, fragte sie: „Schlafen Sie?" (Angehörige und Interviewerin lachen.) Du, bis ich die Oropax

> reintat und sagte: „Nein, wenn Sie mich dauernd fragen, kann ich nicht schlafen.“ Weisst Du, da löscht sie um halb acht das Licht und macht nichts mehr, und wundert sich dann, wenn sie ab zwei Uhr nicht mehr schlafen kann. Die hat von acht bis zwei Uhr geschlafen, und zwar bestens! Am Morgen klagt sie, sie habe kein Auge zugetan.
> Partnerin: Ja, ich glaube eben, dass dann da die Kräftereserven nicht mehr so gross sind...
> Patientin: Sie war die dritte oder vierte alte Frau, die ich im Zimmer hatte, jede wieder ein anderes Muster, und jetzt kann ich es wie nicht mehr ertragen.
> Interviewerin: Und jetzt haben Sie gesagt, Sie könnten es nicht mehr ertragen, oder haben sie es gemerkt?
> Patientin: Nein, nein, mm, das haben...
> Partnerin: Sie haben das gemerkt...
> Patientin: Ich hätte mich nie dafür gehalten, ich hätte mich nie dafür gehalten zu sagen, ich wolle nicht mehr in diesem Zimmer sein.
> Partnerin: Ja, da hätte man sich doch nie dafür...
> Patientin: Das haben mir die Pflegenden vorgeschlagen. Und sie hatten hier ein freies Zimmer und haben gesagt, sie würden mich zügeln. (...) Die haben irgendwie gemerkt, dass ich mich nerve.
> Partnerin: Das spüren die immer...
> Patientin: Ich hätte mich nie dafür gehalten, ich habe mich geschämt, eigentlich, dass ich das nicht besser meistern konnte, irgendwie etwas souveräner. Weil das ist ja auch eine arme, oder... (5a, 5b 2. 84-152)

Lack of Attentiveness

Ms. Egger vividly described the difference between attentive and unobservant care providers, when relating her experiences with a physiotherapist and a rheumatologist prior to admission.

> And she (the physiotherapist) had also localized it correctly. I had a soft tissue tumor exactly where she had always said she would feel something. And this shows me that people who listen to what you say, where it would hurt, and who listen to their hands... She localized it correctly. Could not interpret it, but said there is something. This seems a phenomenon to me. And the physician to whom I wanted to say where... he did not even look. This was not on his scheme. On his scheme, there was the spinal column. No, really...

> Und sie (die Physiotherapeutin) hatte es auch richtig lokalisiert. Genau dort hatte ich einen Weichteiltumor, wo sie gesagt hatte, sie spüre etwas. Und das zeigt mir einfach, dass Leute, die zuhören, was man sagt, wo es weh tue, und die auf ihre Hände hören... Sie hat das richtig lokalisiert. Konnte es zwar nicht deuten, sagte aber, dort ist etwas. Das dünkt mich ein Phänomen. Und der Arzt, dem ich sagen

> wollte, wo… der hat gar nicht geschaut. Das war irgendwie nicht in seinem Schema. In seinem Schema war die Wirbelsäule. Nein, also… (5a 402-413)

The rheumatologist, according to the patient, remained attached to his diagnostic scheme and the spinal column. She experienced him as unable to retreat from his preconceived view, and was left with her pain and the undiagnosed multiple myeloma. Stated otherwise, this rheumatologist was focusing on an organ instead of caring for the person; he lacked the attentiveness to recognize the whole problem and, thereby, missed the right diagnosis. In contrast, the physiotherapist listened to the patient, and understood listening as using all her senses in order to receive and interpret verbal and bodily signals from the patient. She, and later the care providers at the hospital, showed concern and attentiveness; consequently, the patient and her partner felt well cared for.

However, also at the hospital, care providers did not always demonstrate a caring stance and at times lacked alertness. Observation revealed the following episode: The patient, an elderly man with an advanced metastatic lung cancer, was hardly able to walk a few steps with a walking aid and was moving around in the wheelchair. He also suffered from prostate cancer and had a suprapubic indwelling catheter, which was connected to a urinary bag. The patient seemed a bit forgetful. He was sitting at the table in his room with the urinary bag lying on the chair, when the nursing aid came in with the scale on wheels to take his weight. She asked him to transfer to the scale. He slowly got up and moved with difficulty to the scale, without taking any notice of the urinary bag, thereby risking stretching the catheter. Finally, the nursing assistant drew his attention to the bag and he dragged it over to the scale. When his weight had been taken, the patient got up again, thereby letting the urinary bag hang to the floor and risking stepping on it. After a while, the nursing assistant intervened again. The patient mentioned that on the

days before, the nurse had fixed the urinary bag on his thigh, but that the device had disappeared. The nursing assistant suggested bringing him a clamp, but when she realized that he was about to go to the smoking room in the wheelchair, she told him to ask for a clamp in the nursing office, which was on his way. The patient left his room in the wheelchair and moved through the corridor to the office. He hesitated, obviously, he did not know where to ask; no-one was in the office. He moved to the next door, to the office of the neighboring nursing team. A nurse was preparing an injection. The patient asked for a clamp, she said "Please ask someone next door, I am busy." Hesitantly, the patient moved further and mentioned to me (observer) that he would ask again on his return from the smoking room. In the smoking room, the patient was bothered by the urinary bag, which he had to reposition. He mentioned that he did not like it, if the bag would hang around visibly (7a 382-383). On the way back to his room, the patient met the nursing assistant again and said:

> "You did not yet bring me a clamp." "Didn't you ask for one at the office?" "Yes I did, but they did not have time."
>
> „Sie haben mir noch keine Klemme gebracht." „Haben Sie nicht im Büro nach einer gefragt?" „Doch, aber sie hatten keine Zeit." (7c 239-244)

The patient moved on, and the nursing assistant muttered to herself that certainly someone would have given him a clamp, if...

In this situation, the best solution, that is, fixing the urinary bag invisibly and securely on the patient's thigh, was discontinued. Even though the nursing assistant had observed the patient's risky dealing with the urinary bag, she did not really get involved and did not solve the problem satisfactorily, instead, she asked the patient to help himself and, thereby, overestimated his abilities. She lacked the caring stance towards the patient

and the alertness to fully recognize his situation. The nurse who sent the patient next door, was not a member of the team responsible for him and, therefore, did not care any further for him. This example illustrates how loss of continuity and attentiveness can be experienced as a lack of care and even recognition of the patient.

In summary, the care providers' commitment to caring for patients and family members enables them to show great alertness towards patients' and family members' needs. The providers' caring subsequently enables patients and family members to receive support and feel cared for.

Caring and Receiving Body Care

Benner and Wrubel (1989) stated:

> Caring is primary because it sets up the possibility of giving help and receiving help. The same act done in a caring and noncaring way may have quite different consequences. A caring relationship sets up the conditions of trust that enable the one cared for to appropriate the help offered and to feel cared for. (p. 4)

How the patients who participated in this study experienced receiving help from caring providers and how caring enabled them to feel cared for is clearly illustrated in receiving body care.

All the seriously ill patients received, at some time during their hospitalization, support with body care by the nurses, for instance with bathing and perineum care, acts that people usually do themselves in private. Accepting help, therefore, means accepting an intrusion into one's privacy. Some patients said that, the first time, they had to force themselves a bit to let it happen, but they soon realized that it was natural for the nurses to provide body care, and they experienced receiving help later as unproblematic, as the following interview excerpt shows:

> Patient: I remember that a nurse once told me, when it got started (perineum care), when I said: "I will do it myself and so…" "Do you think that I have never seen a man?" Well yes, she is actually right, you know. She told me this to my face (laughs a bit). And then, that was it… it is no problem anymore for me.
> Interviewer: That means that you first had to realize…
> Patient: Yes, it took some overcoming…
> Interviewer: …that this is a daily task for the nurse?
> Patient: Well yes, you can say so.
>
> Patient: Ich weiss noch, einmal hat mir eine Krankenschwester gesagt, als es los ging (mit Intimtoilette machen), als ich sagte: „Das mache ich dann selber und so…" „Denken Sie eigentlich, ich hätte noch nie einen Mann gesehen?" Ja so, sie hat eigentlich recht, oder. Sie hat mir das direkt ins Gesicht gesagt (lacht etwas). Und dann, das war es… es ist kein Problem für mich.
> Interviewerin: Das heisst, dass Sie am Anfang realisieren mussten…
> Patient: Ja, hat es Überwindung gebraucht…
> Interviewerin: …dass dies für die Krankenschwester das tägliche Brot ist?
> Patient: Ja, ja, so kann man es sagen. (1a 291-318)

Other patients just accepted support with body care; they were unable to do it themselves, and the help by the nurses seemed taken-for-granted or even welcomed:

> Patient: I just accepted that. I can't do it myself now, that is, I did not even think about it…
> Interviewer: It was just natural that they did it?
> Patient: Yes, exactly.
>
> Patient: Ich habe das einfach angenommen. Ich kann das jetzt nicht selber machen, das heisst, dass ich das nicht mal so gedacht habe…
> Interviewerin: Es war wie selbstverständlich, dass sie es gemacht haben?
> Patient: Ja, genau. (2a, 2b 660-682)
>
> If I am unable to do it myself, I am really glad when it gets done. For instance, I can hardly perform certain movements… As long as I can stand or sit at the sink, it is okay, but reaching back somehow… I cannot, for instance, clean myself after I was on the toilet, I cannot reach back, then I am glad that they are doing it. And if I cannot or feel too tired, if somehow I am lacking breath, then this does not bother me.
>
> Wenn ich nicht mag, bin ich ausgesprochen froh, wenn es gemacht wird. Zum Beispiel kann ich gewisse Bewegungen nicht gut machen… Wenn ich am Lavabo stehen oder sitzen kann, dann geht es gut, aber irgendwie so nach hinten langen und so… ich kann mich beispielsweise nicht säubern, nachdem ich auf der Toilette war, ich kann nicht nach hinten reichen, dann bin ich froh, wenn sie das machen. Weil

> ich gar nicht kann. Und wenn ich nicht kann oder nicht mag, wenn irgendwie der Atem nicht reicht, dann stört mich das auch nicht. (5a 678-743)

One patient opened up a different perspective on the topic by pointing to the issue on the nurses' side: In the beginning, she thought that delivering an enema was an unreasonable demand on the nurses. Over time, she realized that it was quite natural for the nurses, or at least they gave her the feeling that it was natural for them. She made this conclusion partly from the fact, that the nurses reminded her that it was time for an enema, she did not have to ask for it.

> Patient: And with the enema, I first thought that this was a totally unreasonable demand on the nurses, and over time, I realized that it is not that bad, I believe. I do not know, I do not see it, I turn to the other side... But they make me understand... they do the manipulation in such a way that I get the feeling, it would not be so...
> Interviewer: That it was quite natural for them?
> Patient: Yes. Because they always tell me that it would be time for it again, that we should do it again.
>
> Patientin: Und beim Einlauf habe ich zuerst gefunden, es sei eine totale Zumutung für die Pflegenden und habe jetzt mit der Zeit gemerkt, dass es, glaube ich, nicht so schlimm ist. Ich weiss nicht, ich sehe es ja nicht, ich kehre mich ja ab... Aber sie geben mir zu verstehen... sie machen die Manipulation so, dass ich das Gefühl habe, es sei für sie nicht so...
> Interviewerin: Es sei für sie selbstverständlich?
> Patientin: Ja. Weil sie sagen mir ja auch immer, es wäre wieder nach, wir sollten es machen. (5a 678-743)

In addition, patients stated that it was easy to accept help because the nurses were kind and nice (3a 2. 279-301) and worked carefully and discreetly (1a 291-318). Consequently, rather than being bothered by receiving body care, patients could enjoy a shower or being bathed. "Showering invigorates, one feels a bit like a different person again," („Das Duschen stellt noch so auf, man ist danach wieder etwas ein anderer Mensch," 3a 2. 279-301) said one of them.

Body care by the nurses is accepted under the condition that patients are unable to do things themselves. They have no choice, the only alternative, no care, would be worse. The need for care has priority over privacy concerns. The nurses are kind, they clearly signal that providing body care is natural for them, and they perform their tasks carefully and discreetly. They show the tact required to make receiving body care feel "natural" to adults who are accustomed to doing this in private. The nurses' tact and caring stance makes it possible for patients to experience a probably awkward situation as unproblematic or enables them to easily overcome their embarrassment when confronted with the situation for the first time. The patients who are too sick to care for themselves allow, even welcome, a nurse to enter their private sphere. She provides body care as a taken-for-granted component of her work and maintains the patients' privacy towards the rest of the world, so that they feel well cared for.

Summary

The relationship among care providers, patients and families is mainly experienced by the latter in terms of the care providers' commitment and caring for them. Patients and families greatly appreciate kind and nice care providers who show empathy, consideration, patience and respect, while they experience a lack of this caring stance in care providers as problematic and disruptive. Family members feel integrated and even cared for in the hospital if they are welcomed, well informed, and have access to the patient whenever possible. Patients and family members are aware of their influence on interactions with care providers; they try to improve and take great care not to damage their relationships with care providers. In addition, patients' and families' experiences depend on the perceived continuity of care and on the atmosphere of the units where they

are treated or cared for. The care providers' commitment and caring enables them to show constant alertness to the felt needs of patients and families, whereas a lack of concern leads to inattentiveness. The providers' caring subsequently enables patients and family members to receive support. The mood, tact and style of the care providers sets up a disclosive space where patients and families feel cared for, or neglected or even treated with disrespect and a lack of consideration for their vulnerability and felt needs. Both giving and receiving care can feel burdensome. Care providers and patients and family members must negotiate this intimate space in and through their relationship.

This chapter focused on the relationship among patients, families, and care providers, and the next chapter will describe care providers' actual practices. However, the final section of this chapter shows how closely intertwined the care providers' relationship to patients and family members is with their caring practices. This also becomes obvious in several of the quotes throughout this chapter. The taking apart of the patient/family member – care provider relationship and care providers' practices should be understood primarily as a matter of articulation. Any caring practice requires a relationship between the one caring and the one cared for. Thus, patients' and family members' lived experiences always reflect this whole situation.

CHAPTER SEVEN: PATIENTS' AND FAMILY MEMBERS' EXPERIENCES WITH CARE INTERVENTIONS

> Now I believe, that we will finally gain control over it. When I am not nauseated, I am a completely different person. One day I would like to die and the next I feel well. When it is like that for two days… then I don't have much resistance anymore. Sorry… then I tell my husband: "Oh, I would like to die, then everything would be over." If one just feels so horribly wretched… Well, then I recovered during the day yesterday, and ate a nice dinner. (…) And this morning I could eat half a muesli and some bread and coffee. It goes upwards like that.
> Interviewer: And as soon as you feel better, you don't want to die anymore…
> Patient: No, no (laughs).
>
> Jetzt glaube ich, dass wir es dann schon in den Griff bekommen. Wenn mir nicht mehr schlecht ist, bin ich ein total anderer Mensch. An einem Tag möchte ich sterben und am nächsten geht es mir gut. Wenn es während zwei Tagen nur so ist… dann habe ich nicht mehr grossen Widerstand. Tut mir leid... dann sage ich schon zum Mann: „Oh, ich möchte doch am liebsten sterben, dann wäre alles vorbei." Wenn einem einfach so schauderhaft elend ist... Ja, jetzt habe ich mich dann auf gestern im Laufe des Tages ganz erholt wieder, und habe gut z'Nacht gegessen. (…) Und heute morgen mochte ich auch ein halbes Birchermüesli und etwas Brot und Kaffee. Es geht aufwärts so.
> Interviewerin: Und sobald es Ihnen besser geht, möchten Sie nicht mehr sterben…
> Patientin: Nein, nein (lacht). (3a 2. 14-83)

The patients who participated in this study were admitted to the hospital for different reasons. Some were admitted with severe symptoms and then diagnosed with a terminal illness; for others, the diagnosis was known, and they were admitted because of a serious deterioration in their health status or a complication. While some patients died in the hospital and one was transferred to a palliative care unit, others recovered enough to return home once again. Patients underwent diagnostic tests and various medical treatments. Seriously ill, they were not able to fully care for themselves and needed support in their activities of daily living.

This chapter focuses on how patients and family members experience the activities of the professional care providers in the hospital, the activities of the physicians, nurses, physiotherapists, social workers, and other professionals, who examine and observe patients, order and perform tests, prescribe and deliver medications and other treatments, provide nursing care, and inform and counsel patients and family members.

The patients' well-being has priority for family members as evidenced by their care for patients throughout their hospital stay. Caring in this context means more than showing concern and being committed, it includes actively contributing to the patients' well-being in different ways, from keeping company to nursing the patient. The caring stance that most care providers showed towards patients and family members and their endeavors to integrate family members allowed the latter to get involved in the patients' care as much as they wished or were able to. Patients also showed concern and cared for their family members, within the boundaries that the illness set upon their efforts. Family members' and patients' caring and how family members experienced caregiving is addressed in the second section of this chapter.

Experiencing Professional Care

In general, patients and family members were satisfied with the care in the hospital. When asked if they had experienced problems with getting the needed professional care, or if they felt that additional occupational groups should have been involved in their care, all patients (with the exception of Mr. Dolder who could not answer such a question) and all family members clearly denied any difficulty; they felt that all the needed professionals had been involved. Looking more closely, positive as well as negative experiences with care interventions surfaced. They are described in detail below. They

should be understood as outstanding against a background of overall positive experiences.

In this section, the care providers' efforts to achieve the best possible quality of life for patients and their families, to balance advantages and disadvantages of medical procedures and to manage symptoms are discussed. Next, the adequacy of the care that is provided, how the care is attuned to individual patients' and families' needs, and how giving information and counselling is experienced by patients and family members is addressed. In this section, it is also described how, on the one hand, care providers prevent problems by removing some stumbling blocks, but, on the other, at times put others right in patients' and family members' paths. Finally, aspects that influence the adequacy of care interventions are outlined.

Achieving the Best Possible Quality of Life

The professional care providers tried hard to achieve the best possible quality of life for their terminally ill patients and their families; that is, they tried to alleviate symptoms, ameliorate patients' health status if feasible, respect the patients' autonomy, and also take patients' and families' psychological, social, and spiritual needs into consideration. In some situations, the goal of the best possible quality of life was explicitly stated in the medical and nursing record, for others it was implicit, but could be derived from the care activities, such as endeavoring to improve pain control. The care providers' activities focused on the patients' well-being rather than, for instance, on rehabilitation. They showed great consideration for the patients and were willing to do more than just the requested tasks. They also acted as patients' advocates. The following examples illustrate these positively experienced care interventions.

During observation, a nursing assistant was weighing a patient, who had experienced a constant loss of weight as the first sign of his cancer. The nursing assistant told him his current weight and he asked what his weight had been on the previous day. She did not know that and the patient was wondering if he had lost weight again. The nursing assistant offered to check and the patient was pleased with this. She soon returned and informed the patient that he had in fact lost 200 g during the last two days (2c 171-184). The task at hand for this nursing assistant was weighing the patient. She could have left the patient wondering. Instead, she was willing to take the extra step to let the patient know his previous weight – clearly a contribution to the patient's overall positive impression of his care. Similarly, when responding to the alarm of the infusion pump, a nurse carefully arranged and fixed the patient's intravenous lines by slipping the bottles through the private clothes that the patient was wearing. She found a solution that prevented further line blockings that was satisfactory for the patient (3c 2. 11-26).

Another patient with brain metastases, suffering from balance problems, was a bit forgetful and at times confused at night. His nurse talked to him to find out what would be the best solution for him regarding the side rails on his bed. She explained her dilemma; he had side rails put on after a fall as a measure to prevent him from getting up on his own and falling again, but he had still got out of bed on his own by climbing over the side rail. Did he feel more secure with the side rails or did he rather feel imprisoned? After some discussion, it became clear that the patient preferred to have the side rails up at night (10c 92-108). In this situation, the best solution was not obvious. Without side rails, the patient was at risk for further falls, and the side rails might remind him not to get up without assistance. However, he might well be too confused to recognize his situation and the consequences of a fall over the side rails might be worse. Instead of just making a decision in this dilemma, the nurse took the patient's feelings into consideration and respected his perspective.

One patient highly valued the complementary measures that the nurses offered. She suffered from severe constipation due to hypercalcemia and opioids and was treated with laxatives, enemas, and rosemary compresses.

> Patient: I actually only have a bowel movement with an enema, not otherwise. They do this every second day. Then it works. And with laxatives… this certainly also helps, in order not to get hard stool, but laxatives are not sufficient. And they are unpleasant, these laxatives, I appreciate them more, the enemas. And rosemary compresses, which aid, which stimulate the peristalsis, this is very pleasant.
> Interviewer: They are doing this as well?
> Patient: They are doing it here. The nurses buy it themselves or let the family bring it, and that is incredibly pleasant, these rosemary compresses. (…) It stimulates, it frees a bit, and it smells wonderfully.
>
> Patientin: Ich kann eigentlich nur mit einem Einlauf stuhlen, sonst geht es nicht. Das machen sie alle zwei Tage. Dann geht es. Und mit Abführmitteln… das hilft sicher auch, damit es nicht hart wird, aber Abführmittel alleine bringen es nicht. Und sie sind unangenehm, diese Abführmittel, ich schätze es mehr, die Einläufe. Und Rosmarinwickel, die das fördern, die die Darmbewegung anregen, das ist sehr angenehm.
> Interviewerin: Das machen sie auch?
> Patientin: Das machen sie hier. Die Pflegenden kaufen es selber oder lassen es von den Angehörigen bringen, und das ist wahnsinnig angenehm, diese Rosmarinwickel. (…) Es regt an, es befreit etwas, und es riecht wunderbar. (5a 52-77)

The family member acknowledged the contribution of this complementary therapy to the patient's well-being and was surprised that it was offered in a university hospital. She stated that she would expect this rather in an institution specializing in alternative medicine (5a 5b 688-700). The nurses in this situation took the initiative and extra effort to provide a very welcomed treatment that improved the patient's well-being as well as the patient's and the family member's satisfaction with care.

The care providers were also experienced as patient advocates, for instance, when a patient was extremely embarrassed and felt she was a trouble-maker in the room she shared with five other patients.

> And then I got this phase with vomiting, vomiting. I was vomiting when the others should eat at the table, which was extremely embarrassing for me. They had to do the enema in bed, they said, they couldn't do it otherwise than in the bed. And the others were in the mean time again eating. Uh, that was embarrassing for me. And then the nurse (...) said: "We are not going on like that, we move you out of the six-bed room, this is untenable."
>
> Und dann bekam ich die Phase mit Brechen, Brechen. Ich war am Erbrechen, wenn die anderen essen sollten am Tisch, das war für mich äusserst peinlich. Sie mussten mir den Einlauf im Bett machen, sie sagten, sie könnten nicht anders als im Bett. Und sie waren mittlerweilen halt auch wieder am Essen. Uh, das war mir peinlich. Und dann hat die Schwester (...) gesagt: „So machen wir nicht weiter, wir zügeln sie aus dem Sechser-Zimmer, das ist unhaltbar." (3a 2. 712-727)

The patient was transferred to a single bedroom for the rest of her hospital stay, which she and her husband greatly appreciated.

During observation, another nurse gave the patient's need priority over the work flow in the X-ray department, when she refused to send the patient there without pain medication:

> The patient tells me (observer) that the X-ray department wanted her to get there earlier this morning, but that this would not have been possible. The nurse says, yes, they had asked if she could come earlier, but she denied, because she had agreed with the patient to give her an injection against pain prior to transportation. She did not want to deviate from this.
>
> Die Patientin bemerkt zu mir (Beobachterin), das Röntgen habe sie heute morgen früher aufbieten wollen, dies sei aber nicht möglich gewesen. Die Pflegende sagt, ja, sie hätten gefragt, ob sie früher kommen könne, aber sie habe abgelehnt, da sie mit der Patientin abgemacht habe, dass sie ihr vor dem Transport eine Schmerzspritze geben werde. Davon habe sie nicht abweichen wollen. (3c 39-44)

Thanks to this injection, the patient was then pain free during transportation to the X-ray department and the computer tomography she had to undergo.

These examples show the care providers' successful efforts to improve the situation for patients and family members, to achieve a better quality of life for them. Achievement of the best possible quality of life is a major goal in palliative care. Thus, the care providers acted in accordance with this goal. While "the best possible quality of life" has a positive connotation, the other side should not be overlooked. The word "possible" points it out; only the possible can be achieved, not the impossible. The patient in the first example got his question answered; however, he and his wife still had to come to terms with his constant weight loss from the metastatic cancer. And although another patient's autonomy was respected when he was allowed to make the decision regarding the side rails, he remained unable to safely get up on his own. The constipated patient enjoyed the rosemary compresses, but she still suffered from her condition and had to swallow horribly tasting laxatives. The patient who got a single room was saved from the embarrassment of bothering her roommates, but her vomiting continued. Hence, the care providers could do their best to improve patients' and family members' situations, however, they could not offer a cure for the terminal illness that robbed the patients of their physical and sometimes of their cognitive abilities, provoked symptoms that were at times uncontrollable, and rendered them dependent on the care and support of others. The suffering from physical and mental disabilities and symptoms is added to the painful losses that the terminal illness brings about in patients' and families' lives and to the inconvenience of an enforced hospital stay. The existential suffering that accompanies a terminal illness cannot be remedied; patients and families must somehow endure it and live through it.

Balancing Medical Procedures

When no cure is possible and care aims at the improvement of patients' well-being, advantages and disadvantages of any diagnostic measure and medical treatment have to be considered. For instance, for a patient diagnosed with vertebral metastases causing severe pain and paralysis, radiation therapy was suggested. The patient agreed and later stated that his pain completely disappeared after the first treatment, while he never mentioned any problems with side effects from radiotherapy (2a 2. 223-228). When another patient got diagnosed with a severely advanced esophageal cancer, neither surgery, nor radiotherapy, nor chemotherapy, nor the insertion of a stent was suggested, because, according to the specialists' judgment, none of these treatments would contribute anything to the patient's quality of life. This was acceptable for the patient and his wife (8b 301-309).

The decision for or against diagnostic tests and medical treatments or the choice between available therapies, however, was not always easily made. The patient who related the story of her painful mammography, for instance, stated that she first refused the test:

> First, I was against it, because I just don't have a breast anymore. I remember, many years ago, when this was done, one pulled the little bit of breast so much to place it between the plates… This was painful for a long time afterwards, and I had the feeling, that perhaps something would be torn apart rather than that it would be useful.
> (…)
> Not that I could not bear this for a moment, but I just had the feeling that they would almost rip them off. And then they even don't see much, on this little bit…
>
> Da war ich zuerst dagegen, weil ich ja keine Brust mehr habe. Ich weiss, vor vielen Jahren, als man das machte, da hat man an dem bisschen Brust so gerissen, um es zwischen die zwei Platten… Das hat mir noch lange weh getan, und ich hatte das Gefühl, da gehe vielleicht eher noch etwas kaputt als dass es etwas nütze. (3a 150-156)

> (...)
> Nicht, dass ich mich da nicht einen Moment leiden könnte, aber ich hatte einfach das Gefühl, die würden einem diese fast wegreissen. Und sie sehen doch auch nichts, an diesem bisschen...(3a 2. 625-628)

The physicians, however, persuaded her to do the test, explaining that it was absolutely necessary to subsequently decide upon a palliative chemotherapy. The patient had undergone surgery for lung cancer two years ago and was now diagnosed with bone metastases. The goal was to exclude breast cancer as the primary tumor of these metastases. Since the patient and her husband were hoping for the chemotherapy as a measure to slow down tumor growth, the patient finally agreed to the mammography. It turned out to be a tremendously painful experience for her, and her doubts were fully justified. The report stated: No breast cancer, but due to the very small breasts, dorsal parts were not depicted for technical reasons (3 KG 59-61).

Another patient suffered from shortness of breath due to aspiration pneumonia and pleural effusions. Shortly after his admission, a tube was inserted to drain pleural effusions. This first drainage worked quite well and the patient's breathlessness was relieved to some extent, but only for a rather short time. Two weeks later, the physicians suggested a second drainage. At this time, the patient left decisions more or less to his wife, and she only reluctantly agreed, fearing that the patient would suffocate otherwise. Thus, a tube was inserted again and left in place for a week.

> Wife: And they inserted the tube once more. Well, at this moment I did not fully agree anymore first. I said: "Well, does it have do be done?" "Yes, in order for him to breathe more easily." Then I had to say, yes, because suffocating, that must be horrible.
> Interviewer: And did you get the impression, that the tube had some effect?
> Wife: Not at all. Well, I don't know how it would be, if they had not inserted it. But what the effect was... The physician just told me one could not say that it had been useless, but what effect it had?

> Ehefrau: Und sie haben ja den Schlauch nochmals reingetan. Gut, da war ich dann nicht mehr so ganz einverstanden zuerst. Habe gesagt: „Ja, muss das sein?“ „Ja, damit er besser atmen kann.“ Dann musste ich sagen, ja, weil das Ersticken, das muss ja grässlich sein.
> Interviewerin: Und hatten Sie dann den Eindruck, der Schlauch habe etwas gebracht?
> Ehefrau: Überhaupt nicht. Ja, ich weiss nicht, wie es wäre, wenn sie ihn nicht reingetan hätten. Aber gebracht hat es offenbar… Der Arzt hat mir vorhin gesagt, man könne nicht sagen, es sei für nichts gewesen, aber was es gebracht hat? (8b 515-525)

The second drainage was problematic and hardly effective, because the effusions were encapsulated. The pain from the tube was well controlled; the patient did not suffer from the treatment. However, it did not alleviate his shortness of breath. The patient died a few days later. In retrospect, any positive effect of this second drainage seems very questionable, and this was clearly also the view of the family member. It can be speculated that without the drainage, breathlessness would have increased. But given this patient's clear statement for palliative care and his wish to die as soon as possible, symptom control might as well have been possible with opioids.

While in the two situations described above the physicians had a clear treatment plan and presented it convincingly, the next example reveals some disagreements among care providers. The patient was diagnosed with severely advanced metastatic cancer and suffered from an obstruction of the superior vena cava. She hoped for some more time and was willing to adhere to any treatment that might help achieve this.

> And I really have many things that are not yet dealt with, and I want to deal with. I must go on living together with the illness, there is no other way. Just try how it goes best. (…) And now I cooperate with all therapies that are there and help a bit, and I hope it will go well.

> Und ich habe schon viele Sachen, das noch nicht erledigt, und ich will das erledigen. Ich muss weiter leben, mit der Krankheit zusammen, es geht nicht anders. Einfach versuchen, wie geht das besser. (…) Und da jetzt ich mache mit alle Therapien, was gibt, ein bisschen helfen, und ich hoffe, das geht gut. (6a 228-234)

The patient had palliative radiation and chemotherapy. Given her terminal situation, it was first decided not to insert stents now or even if she got worse, but to treat the obstruction of the superior vena cava with cortisone and low dose heparin. Two weeks later, with another senior consultant on duty, this decision was overthrown, two stents were inserted and heparin was given intravenously. From the medical record, the reason for this change was not clear; a nurse later explained that they had hoped to alleviate the patient's feelings of suffocation, and that the stents had been effective in this respect (6 Pfl. 79-95). The treatment was extremely painful for the patient and she felt very bad for the next two days. Her nurse questioned the procedure, stating that the patient had agreed without being fully aware of what it would entail. She said that they hoped to improve the patient's health status enough to allow her to return home once more for a few days, but was wondering if the price was not too high (6 Pfl. 41-56). After five days, the heparin was stopped in the morning to allow the insertion of a central venous line. Two hours later, the patient's upper body parts turned livid; an angiography confirmed the thrombosis of the stents. In this hopeless situation, it was decided to stop treatments (with the exception of heparin) and to provide comfort care only, with high doses of opioid and phenobarbiturates for symptom control (6 KG). The patient died two days later. While the care providers disagreed on the best course of action, the patient's partner never questioned the decisions regarding her treatments. He was convinced that the patient had gotten the best possible treatment, as he explained in the post bereavement interview:

> They did all that was humanly possible, you know. And finally, they just didn't want to go on, because it had just been a torment and wouldn't have any effect. It would have come to nothing. It was just very clear that she would die. One didn't know exactly which day, but that she would die was clear. And they had not expected it to happen so quickly, here in the hospital. And I believe that they did all they could. And if they had had more options, they would have done more. (...) They just did

> what seemed to have a chance. If it is effective, okay, if not, we stop it again. (…) They really tried everything, but I don't believe that they fiddled about or so. (…) They always said what they did, they explained, to me also, everything they did, and why they did it, and why they hoped for an improvement.
>
> Sie haben alles gemacht, was menschenmöglich war, oder. Und schlussendlich wollten sie einfach nicht mehr weitermachen, weil es doch nur eine Quälerei gewesen wäre und nichts gebracht hätte. Es hätte zu nichts mehr geführt. Es war ja ganz klar, dass sie stirbt. Man wusste nicht genau, an welchem Tag, aber dass sie stirbt war klar. Und damit, dass es so schnell ging, haben sie auch nicht gerechnet, hier im Spital. Und ich glaube, dass sie alles gemacht haben, was sie machen konnten. Und wenn sie mehr gehabt hätten, hätten sie auch mehr gemacht. (…) Sie haben einfach das gemacht, wo sie eine Chance gesehen haben. Wenn es etwas bringt, ist es gut, wenn nicht, klemmen wir gleich ab. (…) Probiert haben sie ja alles, aber ich glaube auch nicht, dass sie rumgetüftelt hätten oder so. (…) Sie haben ja immer gesagt, was sie machen, sie haben mir ja auch immer alles erklärt, was sie machen und wieso sie es machen und die Hoffnung haben, dass es besser wird. (6 po 415-425, 438-457)

The patient's view regarding the insertion of the stents remained unknown, because she never felt well enough for another conversation with me after this procedure.

The examples above throw some light on the difficulties involved in balancing advantages and disadvantages of diagnostic tests and medical treatments. In some situations, the decision for or against a procedure seems straightforward, because of a clear judgment that the advantages (e. g. pain relief) would outweigh the disadvantages (e. g. side effects of radiotherapy) or vice versa. However, such a clear judgment is not always possible; the consequences of procedures cannot always be predicted equally well. In addition, it is of course easier to judge the adequacy of any intervention in retrospect, but tremendously more difficult to do so prospectively, because it is impossible to fully know an individual patient's reactions and illness trajectory in advance.

But even though the last three situations outlined above are recognized as problematic and the difficulty in making the best decisions is acknowledged, some questions arise. For instance, was the patient's individual situation, his statement against any life prolonging measures taken into account, when the second drainage was suggested? Were the care providers fully aware of his view? Were the technical problems and the unsatisfactory result of the mammography not foreseeable, given the woman's very small breasts, her prior bad experience and her severe back pain? Were no other measures available to diagnose a lump? Were the need for and the sequence of procedures carefully considered prior to the insertion of the stents?

The care providers seemed to err mainly on the side of intervening. One questions whether they did so, in part, to deal with their own need to act and their experience of helplessness in the face of death. Without doubt, witnessing patients' suffering is not only painful for family members, it is also difficult for the professionals, and they feel equally compelled to doing something. Taking action may too often mean initiating medical procedures, while other options may not be considered as "doing something." However, caring relationships, being with and talking to patients and families, recognizing them as persons, and providing excellent comfort care have been shown to be powerful measures to improve patients' and families' well-being in the hospital. In fact, although often overlooked, these aspects are challenging for professionals; they require the courage to get emotionally involved and the skill to find an adequate level of engagement. Reacting to problems by prescribing and carrying out medical procedures may be the easier route for some professionals.

These rather problematic examples highlight yet another aspect, the perceptions of patients, family members and care providers may differ. The patient and family member may hesitate, while the care providers are convinced as to the best option, or the patient and family member may fully agree with every step, even though the care providers are moving back and forth with suggestions. It becomes obvious from the above examples, however, that the care providers have the upper-hand. They have the medical knowledge from which they can argue convincingly, while the lay persons, that is, most patients and family members, depend on the information that is provided to them for their decisions. Not astonishingly, patients and family members usually, albeit at times reluctantly, follow the professionals' advice. This fact leaves the care providers with the responsibility to fully consider and carefully balance advantages and disadvantages of any medical procedure they suggest, taking patients' and families' whole situation into account and keeping the goal in mind: the best possible quality of life for patients and family members. To do this fully, the care providers must be aware of their own sense of helplessness when confronted with suffering and death, and reflect on their coping strategies, on their reasons for acting.

Managing Symptoms

In healthy people, a new symptom can be seen as a warning signal drawing attention to a disease. It alerts people to seek medical care for diagnosis and treatment. In the terminal phase of an illness, however, symptoms mostly lose this useful aspect. With no cure available, a symptom may still point to a complication that should be treated in the best interest of the patient. But mostly, symptoms are now nagging concomitants of the illness, causing suffering to patients. Consequently, a major goal of palliative care is excellent symptom management. For symptom control, the full range of medical options is considered. But like with any medical procedure, advantages and disadvantages of available treatments have to be balanced to find the best option for an individual patient. With a progressing disease, often causing more and increasing symptoms over time,

achieving satisfactory relief for an array of diverse symptoms is a major challenge for care providers.

The patients who participated in this study experienced a variety of symptoms, with pain as the most frequent. Other symptoms included constipation, nausea and vomiting, shortness of breath, cough, weakness, fatigue, forgetfulness, confusion, paralyses, aphasia, apraxia, urinary and bowel incontinence, loss of appetite, swallowing problems, dizziness, and excessive sweating. Care providers were eager to alleviate symptoms, although their success varied. Symptom control depended on the cooperation of patients, family members and care providers, and while effective treatment was readily available for some symptoms, there was none for others.

Effective Symptom Management

Some patients experienced efficient symptom management that was effective within a short period of time. For instance, early paralysis and pain were at times very successfully treated with radiation. One patient explained:

> And here in the shoulder, I have a pretty big… such a hole that also causes me pain, they now give radiotherapy to it, and that helps a lot. So one can almost watch how the pain disappears during radiotherapy, and the hole fills up.
>
> Und hier in der Achsel hatte ich ein ziemlich grosses… so ein Loch, das mir auch Schmerzen machte, das bestrahlen sie jetzt, und das hilft sehr. Also da kann man fast zuschauen, wie die Schmerzen weggehen während der Bestrahlung, und das Loch füllt sich auf. (5a 104-108)

This patient further related that she could follow the progress from radiotherapy on a daily basis. She already felt an improvement in pain after a few treatments. With no therapy over the weekend, her pain increased again over the first weekend, but did not do so during later breaks (5c 2. 216-226).

Another patient related how her pain regimen was effectively adjusted in the hospital. Prior to admission, her excruciating back pain from a not yet diagnosed metastatic cancer was treated with non-steroid anti-inflammatory drugs, which were ineffective and caused side effects. In the hospital, her pain was satisfactorily controlled with fentanyl patches as an around-the-clock medication, supplemented with morphine as needed.

> Yeah, before it was very bad, before I had very, very bad pain everywhere. Only had weak pills, it doesn't help at all, and it also ruins the stomach, when I swallow many pills. But now I get the right ones, and not so incredibly many, but it's effective. First week not yet quite alright, but then, they tried which were the right ones. Now it is the right one, so it gets well. (...) And now I also don't have to swallow so many, just with the pain patch, that is very good, (...) and only drops, and that doesn't hurt the stomach so much anymore. Before I can't eat, because of the many pills, always stomach aches, but now this is good. And I can eat again, not an awful lot, but always a bit, every day. Sometimes I also feel hungry again. (...) I think that's nice.
>
> Ja, vorher war sehr schlimm, vorher habe ich sehr, sehr grosse Schmerzen gehabt überall. Habe ich nur sehr schwache Tabletten gehabt, das nützt gar nichts, und das macht den Magen schon kaputt, wenn ich viele Tabletten schlucke. Aber hier bekomme ich richtige, und nicht wahnsinnig viele, aber das nützt. Erste Woche noch nicht ganz gut, aber dann, probierten sie, welche ist die besseren. Jetzt das ist die Richtige, da kommt es gut. (...) Und jetzt muss ich auch nicht so viel schlucken, einfach mit dem Schmerzpflaster, das ist sehr gut, (...) und nur Tropfen, und das macht nicht mehr so viel für Magen. Vorher kann ich gar nicht essen, wegen so viele Tabletten, immer Magenschmerzen, aber jetzt ist das gut. Und jetzt ich kann wieder essen, nicht wahnsinnig viel, aber ein bisschen immer, alle Tage. Manchmal ich spüre auch wieder Hunger. (...) Das finde ich schön. (6a 55-86)

Following the standard for palliative pain treatment, the care providers prescribed a strong opioid around-the-clock and a short acting one for break-through pain, and then titrated the dose upwards until sufficient pain relief was achieved for the patient. Her quality of life was definitively improved, not only was her pain relieved, she also could enjoy meals again.

Struggling for Symptom Control

Unfortunately for several patients, good symptom control was not always achieved. Some symptoms proved to be intractable, for instance, a patient's dizziness and tendency to fall to the right side from brain metastases. Neither radiotherapy nor cortisone brought about any positive effect. The world kept turning around the patient – an endless ride on the merry-go-round (9c 95-96). He could only walk in the company of another person. He learnt to move around in the wheelchair, and walking and balancing exercises somewhat increased his ability to cope with the symptoms. Thus, physiotherapy slightly improved his situation, but dizziness and loss of balance confined him to the hospital and nursing home.

Another patient suffered from severe pain from vertebral metastases. In addition, she was nauseated, vomited repeatedly and was constipated. Although her pain was fairly well controlled through radiotherapy and medication, the other symptoms were not. Throughout the four weeks of her hospital stay, the patient's experiences alternated between good and bad times. She was nauseated, unable to eat, and vomited frequently for one or two days, and then she felt much better for a couple of days, before she started vomiting again. Constipation was an ongoing problem; the patient never achieved good bowel function.

> Interviewer: You wanted to tell me how it went on last Monday. You needed an enema again, and you hated them, you said.
> Patient: Ah yes, from then on I felt of course again miserable. (...) This is working tremendously, mainly it is working where I have the sore point from the back... And they also told me, that if radiation would affect other organs, it would be the stomach and the intestines, and that is here just so closely together, and in the end one does not know where the pain comes from. Then of course I again vomited, vomited, vomited... (...) Yesterday it eased, but I didn't really have a bowel movement. (...) Now I believe, that we will finally gain control over it. When I am not nauseated, I am a completely different person. One day I would like to die and the next I feel well. When it is like that for two days... then I don't have much resistance anymore. Sorry... then I tell my husband: "Oh, I would like to die, then everything would be over." If one just feels so horribly wretched... Well, then I

> recovered during the day yesterday, and ate a nice dinner. (…) And this morning I could eat half a muesli and some bread and coffee. It goes upwards like that.
> Interviewer: And as soon as you feel better, you don't want to die anymore…
> Patient: No, no (laughs).
>
> Interviewerin: Sie wollten mir erzählen, wie es am Montag weiterging. Sie hätten dann wieder einen Einlauf gebraucht, und die hassten Sie, haben Sie gesagt.
> Patientin: Ah ja, von da an ging es mir dann natürlich wieder mies. (…) Das tut da unheimlich werken, vor allem tut es da so werken, wo ich den wunden Punkt vom Rücken habe… Und sie haben mir auch gesagt, wenn die Bestrahlung andere Organe treffe, wären es der Magen und die Gedärme, und das ist hier gerade schön beieinander, und man weiss dann zuletzt nicht, wovon die Schmerzen sind. Dann habe ich natürlich wieder erbrochen, erbrochen, erbrochen… (…) Es hat sich dann gestern ausgependelt, aber richtig stuhlen konnte ich nicht. (…) Jetzt glaube ich, dass wir es dann schon in den Griff bekommen. Wenn mir nicht mehr schlecht ist, bin ich ein total anderer Mensch. An einem Tag möchte ich sterben und am nächsten geht es mir gut. Wenn es während zwei Tagen nur so ist… dann habe ich nicht mehr grossen Widerstand. Tut mir leid... dann sage ich schon zum Mann: „Oh, ich möchte doch am liebsten sterben, dann wäre alles vorbei." Wenn einem einfach so schauderhaft elend ist... Ja, jetzt habe ich mich dann auf gestern im Laufe des Tages ganz erholt wieder, und habe gut z'Nacht gegessen. (…) Und heute morgen mochte ich auch ein halbes Birchermüesli und etwas Brot und Kaffee. Es geht aufwärts so.
> Interviewerin: Und sobald es Ihnen besser geht, möchten Sie nicht mehr sterben…
> Patientin: Nein, nein (lacht). (3a 2. 14-83)

This patient demonstrated how common symptoms – nausea, vomiting, pain – closed down her world; she lost the desire to live in the midst of suffering. But she resiliently returned to life as soon as the symptoms were resolved.

The care providers and the patient identified multiple potential reasons for the symptoms: the patient's proneness for constipation before her illness, her immobilization from pain, opioids interfering with bowel movement, fecal impaction, radiotherapy affecting the gastro-intestinal tract, psychological problems, and even a basiliaris syndrome. The patient was treated with anti-emetics. A range of laxatives was tried; taking them was, however, problematic for the patient, given her nausea and vomiting. She got enemas, a very painful procedure for her. The patient was allowed to eat whatever she

liked, and she suggested taking black olives and plums, her household remedy for constipation. The nurses offered rosemary compresses. The patient got a tranquilizer before meals with her husband, because he seemed to force her to eat, which then apparently caused her vomiting. For some time, the patient even wore a collar to stabilize her neck, when a basiliaris syndrome was suspected to precipitate her vomiting. After a while, the care providers thought that they might be talking the patient into a problem by focusing too much on her bowel movements and tried to avoid that. According to the nursing care plan, the patient's well-being had priority, and the nurses were supposed to decide with the patient what measures should be initiated for her bowels every second day. However, all these endeavors did not bring about the hoped for symptom relief. In fact, shortly before the patient's discharge, the medical record stated optimistically that bowel functioning had finally been achieved, while the patient vomited again the next day, and an X-ray revealed fecal impaction.

The interrelatedness and the multiple potential causes of this patient's symptoms made effective symptom management very difficult. Undoubtedly, the care providers tried their best, yet this seems somehow not good enough in this situation. The patient's accounts and the medical and nursing record provide a somewhat confusing and fractured picture of a repeated trial and error approach. What seems to be missing is a comprehensive consideration of the patient's situation and a rigorous, stepwise approach to symptom management, which is suggested in palliative care (Twycross, 2003). Despite the limits imposed on symptom management by a terminal illness, clearly the care providers' effectiveness depends on a meticulous assessment of each symptom and their

interactions, on individualized treatment and on steadfastness in treatment efficacy evaluation and treatment adaptation over time.

Effective symptom management requires the cooperation of all persons involved. The care providers depend on the patients' and sometimes on the family members' verbal or nonverbal feedback for the evaluation of symptoms, for setting goals, and for the reviewing of treatment impacts. Patients may be more or less willing or able to relate symptoms. Family members' views and suggestions may influence the patients. For instance, one family member strongly encouraged the patient to ask for sufficient pain medication, while another expressed worries about side effects of laxatives. Mr. Dolder's urinary incontinence provides an example that illustrates the patient's and the care providers' interaction in symptom management and its influence on the outcome.

From the beginning of his hospital stay, Mr. Dolder had a problem with urinary incontinence. He either was unaware that he was urinating or, when he still felt the urge to pass water, he tried to do so unsuccessfully and also got wet. With his hemiplegia, he was unable to go to the toilet on his own or to handle the urinal. He was wearing absorbent pads, but since he neglected at times his hemiplegia, he tried to take off his clothes, including the absorbent pads, as one usually would to urinate. Thus, not only the absorbent pads got wet, but his clothes or the bed as well. The nurses tried to prevent his wetting himself by having the patient pass urine at regular intervals. But this meant a transfer from wheelchair to bed or toilet chair and back each time – a bothersome action for the patient, and often an unsuccessful one. Mr. Dolder was extremely embarrassed by his incontinence. After a while, the care providers, the patient and his parents opted for the insertion of a suprapubic indwelling catheter to prevent incontinence episodes and save

Mr. Dolder useless transfers and the shame of getting wet. Unfortunately, Mr. Dolder's cognitive disability and technical problems repeatedly interfered with this goal. He still recognized that something was different and used to take off the dressing or pull the catheter. Once he actually pulled it out, and it had to be replaced. When the patient was sitting in the wheelchair, the thin tube got easily misplaced and clamped. Therefore, urine drainage was quite frequently interrupted and Mr. Dolder got again wet. According to his mother, the situation improved, but not at all as much as everybody had hoped for.

In conclusion, symptom management depends on the interaction of symptoms, patient, family, and care providers. Some symptoms can be well or at least satisfactorily controlled, while others resist any treatment. Patients' physical and cognitive abilities, as well as patients' and family members' attitudes may either limit or promote symptom control. There is also a risk that intimate bodily problems such as incontinence, are perceived as extremely debilitating and humiliating, even as interfering with their desire to continue living their life by patients, while the care providers consider the symptom as mundane and uninteresting, because it does not qualify as physically threatening. Thus, the care providers' perceptions, skills and knowledge appear to be the crucial factors in symptom management. They explore and suggest available options and the best way to act. They build up a relationship and communicate with patients and family members. Their know-how, their concern for patients and families, and their communicative and social competencies affect the quality of symptom management they are able to provide. With care providers who lack expertise in palliative care, patients receive suboptimal symptom management.

The experience of the vomiting and constipated patient highlights the importance of optimal symptom control. With ongoing and unrelieved symptoms, suffering becomes overwhelming and death seems a preferable alternative. When symptoms are under control and the patient feels better, life seems worth living again. Mr. Dolder also wished to die when he experienced his dependency as unbearable and felt imprisoned, and his mother accepted death as relief when she faced his tremendous suffering. With untreated or untreatable symptoms, suffering can become overpowering and take up the patients' whole life. The horizon of the patients' world closes down; going on with life means suffering on. Life becomes pointless, and death – the end of suffering – is welcomed. With effective symptom management, suffering is forced back; with symptom relief, the patients' world opens up again, their horizon widens and life regains meaning. Leading their life seems worthwhile once more.

Providing Adequate Care

All the patients needed nursing care, some had physiotherapy, and for some, additional professionals were involved, such as the occupational therapist or the social worker. Patients and family members experienced the interventions of these professionals mostly as adequate, but some also experienced episodes of inadequate care.

Adequate Care

Patients and family members repeatedly related satisfying episodes of care, which brought about positive outcomes. For instance, when Mr. Dolder was bedridden and rather spastic, the massage of the physiotherapist helped him relax, according to his mother (4b 5. 230-240). Another patient stated that she got all the needed information promptly:

> I can just always ask the nurses, and they give me addresses, or call someone to come by, or organize something. And actually always very promptly. They would have called someone for a wig, but I thought, perhaps my imagination is insufficient, but I didn't think that this was currently my problem. (...) And should it become one, I can still, they would have appropriate addresses, they told me.
>
> Ich kann die Pflegenden einfach immer fragen, und sie geben mir Adressen, oder schicken jemanden vorbei, oder organisieren etwas. Und eigentlich immer sehr prompt. Sie hätten jemanden geschickt wegen einer Perücke, aber ich habe gefunden, vielleicht reicht die Phantasie nicht, aber ich fand nicht, dass dies jetzt mein Problem sei. (...) Und wenn das dann noch kommt, kann ich immer noch, sie hätten entsprechende Adressen, haben sie mir gesagt. (5a 832-843)

The partner of a patient who was allowed to return home for the weekend felt secure, because they got enough pain medication and could return to the hospital at any time in case of a problem.

> Uh... we get whole packages of pills and morphine, everything, drops and everything. In this respect, we are well equipped for the weekend. And anyway, we have the phone number of the unit, in case something happened, I can put her in the car and just drive to the emergency entrance and bring her up. (...) That's well organized.
>
> Uh... paketweise erhalten wir da Tabletten und Morphium alles zusammen, Tropfen und alles zusammen. Von dem her sind wir gut ausgerüstet über das Wochenende. Und sowieso, wir haben die Telefonnummer der Abteilung, wenn etwas wäre, kann ich sie ins Auto packen, gleich zum Notfalleingang fahren und sie gleich raufbringen. (...) Das ist gut organisiert. (6b 259-266)

Other positively experienced aspects of the care were the good coordination among providers, the flexibility of the nurses, and the focus on details. For instance, one patient realized with some surprise that the nurses from a unit providing special treatment visited her repeatedly on the regular unit in order to take care of her special shunt. While the nurses on the unit were responsible for the port-a-cath, the special unit nurses were responsible for the shunt, and they never forgot its care (5a 155-196). A family member explained that the nurses did not work according to a fixed schedule, but were flexible and would, for example, postpone bathing when the patient was too tired. They could cope

with sudden changes and were nevertheless able to do their work (5a, 5b 347-352). The care providers' observance of details was also valued, for instance, the timely changing of sweaty bed linen (5c 128-132) or the fact that for transportation, beds were always moved foot first, so that the patients could look ahead (5a 2. 125-130).

Inadequate Care

While patients and family members considered most care interventions as adequate and experienced positive outcomes, some interventions were seen as inadequate and brought about negative feelings. A patient with obstructive esophageal cancer and, therefore, unable to swallow solid food, got inadequate meals a few times, as his wife related:

> I found everything to be good here, except for two meals. This made me grumpy. Yesterday I'm coming, and he has green salad and little beetroot cubes on the table. That is not the right thing. And once he had a strawberry dessert, and then there was half of a strawberry in there, or even a whole.
>
> Ich habe hier alles gut gefunden, ausser zweimal beim Essen. Da wurde ich muff. Gestern komme ich, und er hat grünen Salat und Randenwürfeli auf dem Tisch. Das kann es nicht sein. Und einmal hatte er ein Erdbeerdessert, und dann war eine halbe Erdbeere drin, oder sogar eine ganze. (8b 559-563)

The nurse who tried to assess Mr. Alder's living situation at home for discharge planning did this in a way that seemed unacceptable to the couple.

> I was actually only almost shocked when a nurse said, well, when my husband wanted to go home now, she told me, well, she had to... what the social situation would look like. She also asked my husband, and of course he got furious. He said that this was his problem. If I would have help, how I would see this, and how our living situation would look like, and how this should work out. It just seemed a bit arrogant from such a young... to me. So I said: "Listen, the daughter and the physicians, we will discuss this all together, and you don't need to bother about this." That's just how it is. "Well, how will he go up and down the stairs?" she said. I said: "He cannot do this, he will have a stair elevator." "When will he get it?" Then I said: "It will be installed in about... I don't know." Then I said: "Listen, we will deal with this within the family." I don't know, if they have to ask that, but I thought it was

> arrogant and hurting that she asked me how the social situation, and so… such a young girl. Excuse me…

> Mich hat eigentlich nur, fast, schockiert von einer Krankenschwester, als sie sagte, eben, wenn der Mann jetzt heim wolle, sagte sie zu mir, eben, sie müsse da… wie das soziale Umfeld sei. Das hat sie auch den Mann gefragt, und der wurde natürlich wütend. Er sagte, das sei sein Problem. Ob ich Hilfe hätte, wie ich das sähe, und wie wir wohnen würden, und wie das gehen solle. Es dünkte mich also etwas arrogant von so einem jungen…, mir gegenüber. Also sagte ich: „Hören Sie, das wird die Tochter mit den Ärzten, alle zusammen besprechen wir das, und Sie müssen sich nicht darum sorgen." Das ist doch wahr. „Ja, wie geht er denn die Treppe rauf und runter?" hat sie gesagt. Ich sagte: „Das kann er nicht, er bekommt einen Treppenlift." „Wann kommt der?" Dann sagte ich: „Der kommt dann etwa… ich weiss nicht." Dann sagte ich: „Hören Sie, das lösen wir dann in der Familie." Ich weiss nicht, ob sie das fragen müssen, aber ich fand das arrogant und verletzend, dass sie mich fragte, wie das soziale Umfeld, und so… so ein junges „Tüpfi." Excusé… (1b 470-499)

For people in Switzerland, the word "social" may still be closely connected to the concept of "welfare." This certainly was the case for this financially well situated upper class couple. Thus, the nurse's question regarding their social situation made them see red. Furthermore, they likely experienced the young nurse's questions as an intrusion into their privacy and as non-recognition of the family's abilities to deal with upcoming problems. The couple did not consider discharge planning as a nursing task. Therefore, this incursion into their private life seemed inappropriate and illegitimate – especially from a young woman. For them, it was clear that physicians were in charge of planning. With their daughter as the physician in the family who maintained close connections to the patient's physicians in the hospital, they obviously expected these physicians to decide about discharge together, and they took on the responsibility to organize the needed support at home themselves. The nurse's routine approach to discharge planning and her use of standard professional language were completely misunderstood; her way of dealing with the problem at hand did not fit the individual situation of the Alder family.

Some nursing teams in the hospital used to light a candle in the corridor after a patient's death. A family member who had observed burning candles repeatedly, felt bothered by this tradition; lighting a candle for the patient seemed inappropriate to him.

> And then there was the discussion about the candle outside. I asked why a candle was outside the door from time to time. And they said, if someone had died. And then I said: "Well, I would not necessarily want a candle outside the door." And when the time came, just a few days later, the topic came up again, and I knew, now, it will end, you know. I talked to the specialist about the candle. What it meant for the nurse. Then I thought, okay, put it up, but in fact it is not for me. Well, afterwards I didn't care anymore, but at this moment it just seemed to me, well, a death candle, I don't need that. (…) It seemed just brutal to me. Because I saw it often burning while I was there. And I thought, it does not necessarily have to burn outside her door.
>
> Und dann kam die Diskussion wegen der Kerze draussen. Ich habe gefragt, weshalb ab und zu eine Kerze vor der Türe stehe. Und sie haben gesagt, wenn jemand gestorben sei. Und dann habe ich gesagt: „Also ich möchte nicht unbedingt die Kerze vor der Türe.“ Und als es dann soweit war, also ein paar Tage später, kam halt das Thema dann nochmals hervor, und ich habe gewusst, also jetzt, es geht ja fertig, oder. Ich habe mit dem Spezialisten darüber geredet über die Kerze. Was das für die Krankenschwester sei. Dann fand ich, also gut, stellt sie auf, aber es ist eigentlich nicht für mich. Gut, nachher war es mir gleichgültig, aber damals dünkte mich einfach, ja, eine Todeskerze, das brauche ich nicht. (…) Mir schien das einfach brutal. Weil ich die oft brennen sah, während ich da war. Und ich habe gedacht, die muss nicht unbedingt vor ihrer Türe brennen. (6 po 495-511)

This family member who faced the death of his partner only one month after the diagnosis of the terminal cancer and who had to deal with an array of other problems, was pained by the thought of a candle lighted for his partner. For this family member, a burning candle did not bear any positive meaning, rather it had become a sign of the frequent deaths on the unit, whereas for the nurses, the candle may have symbolized respectful commemorations. The nurses were careful not to just disregard his wish; they involved the specialist who then reviewed the situation with the family member. With individual care as a cornerstone of palliative care, the question arises, was it necessary to open a discussion of this issue and get the family member's permission to adhere to the custom, instead of simply accepting his wish and do without a candle for once.

Mrs. Dolder was dissatisfied with how her deceased son was dressed. She did not like to see him first in a hospital nightrobe and later, in the chapel of rest, in a shroud with a bow tie.

> After he had died... We then went to the restaurant for a while. When we came back, he was of course stiff, with the nightrobe, with the bandage... I don't remember, in any case, he effectively was a dead person now, before not yet, he was sleeping. And when my son came, he looked like that, and I thought that it was a pity that he had not seen him before the laying out. But it is... one probably has to do it like that. I found it very nice, they placed a sun flower on the bed, I found that very nice. (...) And then my son from abroad came. (...) He said, he wanted to see him again, he had to bid farewell. And there he was just... I don't know, why they do this, but they dressed him with a bow tie or so, completely unnaturally. And I think, in death one should remain as natural as possible. From the beginning, I said: "Could you dress him in a polo shirt?" And they said that it was difficult.
>
> Als er gestorben war... Wir gingen dann etwas ins Restaurant. Als wir zurückkamen, war er natürlich steif, im Nachthemd, mit der Bandage... Ich weiss nicht mehr, auf alle Fälle, er war jetzt effektiv ein Toter, vorher noch nicht, er hat geschlafen. Und als mein Sohn kam, da war er so, und ich habe gedacht, das ist schade, dass er ihn vor dem Aufbahren nicht gesehen hat. Aber es ist... wahrscheinlich muss man das so machen. Ich habe es sehr schön gefunden, sie haben ihm eine Sonnenblume hingelegt, das habe ich sehr schön gefunden. (...) Und dann kam mein Sohn aus dem Ausland. (...) Er hat gesagt, er will ihn noch sehen, er müsse noch Abschied nehmen von ihm. Und dort ist er einfach... Ich weiss nicht, warum sie das machen, aber sie haben ihm eine Masche oder so, total unnatürlich angezogen. Und ich finde, im Tod sollte man möglichst natürlich bleiben. Ich habe von Anfang an gesagt: „Können Sie ihm ein Polo anziehen?" Und sie haben gesagt, es sei schwierig. (4 po 649-674)

Mrs. Dolder stated that the inadequate dress was a hassle at the time, it became irrelevant later. The issue can be seen as a drop of bitterness in what the family otherwise experienced as a peaceful death – an avoidable drop of bitterness, since the hospital guidelines allowed personal clothes for the deceased.

In summary, patients and family members experience most care interventions as adequate. They highly value care providers' consideration of details, flexibility and good coordination. However, at times care providers miss the point; for different reasons, such as lack of experience, poor attention to details, or adherence to routines, their interventions are experienced as inadequate by patients and family members.

Attuning Care Activities Individually

The care providers aimed at individual care for patients and families. With the wide range of situations they encountered, the frequent and at times rapid changes in patients' health status, the care providers were constantly challenged to adapt their activities in order to fine tune them to the shifting needs of patients and family members. The care providers' abilities to live up to this challenge varied, as illustrated below. Care providers mainly faced the challenge to do the right thing in specific care situations, of constantly and adequately adapting supporting care interventions to the improving or diminishing abilities of patients, and of sharing the responsibility of decision making about care activities with patients.

Doing the Right Thing

The wife of the patient who was transferred to a palliative care unit shortly before his death later related that the resident, when saying goodbye, said that he hoped things would happen according to their wishes. The wife thought that this was a very appropriate wish (8 call 33-38). How does one bid farewell to a dying patient and his wife? This resident found exactly the right words in an extraordinary situation, where commonplace hopes for getting better were clearly inadequate and a simple goodbye somewhat insufficient.

This wife also recounted how a nurse convinced her husband to accept pain medication. Throughout his life, the man had been very reluctant to take pain killers. His

wife, eager to assure good pain control for him, unsuccessfully tried to persuade him to ask for enough pain medication. Then, the insertion of a tube for drainage of a pleural effusion brought about a change in his attitude.

> He already went crazy in the past when he was supposed to take an aspirin occasionally. That was terrific. A pain killer, an alcacyl? No. And with this, he had some resistance first. Only after he got here did he now accept this. I had him again and again a bit, in doses, again and again a bit… He just would have preferred to have no pain, he would have liked to go immediately, without having pain. But with taking pain killers over a longer period of time, he still had some resistance. And then the nurse was just really, really fantastic. He had to get this tube inserted. And when I said, but this would certainly hurt horribly, she said: "No, you know, they render it insensitive." And he said: "They will give me something." And I said that, nevertheless, everybody would say how painful this was. Then she said, it would in fact be somewhat unpleasant. "But not that it hurts," I insisted. And then she told him: "Listen, if it's okay for you, I can of course give you drops in advance so that you will certainly not feel anything. Because, you won't get dizzy or nauseated, or so. But only if you want." She really asked him, and she asked *him*. (…) And then he said: „Well, yes, okay." Just like that, well, okay. (…) And from then on… since then he even asked for it at night. (…) And at this moment he probably realized… The acceptance was there, it was a key experience. She did this so well.

> Er hat früher schon ein Cabaret gemacht, wenn er mal ein Aspirin nehmen sollte. Das war sagenhaft. Eine Schmerztablette, ein Alcacyl? Nein. Und dort hat es zuerst etwas geharzt. Erst seit er hier ist, hat er das jetzt akzeptiert. Ich habe ihm immer wieder so etwas, in Dosen, immer wieder so ein bisschen … Er hätte einfach lieber keine Schmerzen gewollt, er hätte gleich sofort gehen wollen, und keine Schmerzen haben. Aber über längere Zeit Schmerzmittel zu nehmen, da hatte er noch etwas einen Widerstand. Und dann hat die eine Schwester das ganz, ganz toll gemacht. Er musste diesen Schlauch reintun gehen. Und als ich sagte, aber das tue doch sicher wahnsinnig weh, sagte sie: „Nein, wissen Sie, die machen das unempfindlich." Und er hat gesagt: „Die geben mir dann etwas." Und ich sagte, aber es sagten doch alle, das sei so schmerzhaft. Dann sagte sie, es sei schon etwas unangenehm. „Aber nicht, dass es dann weh tut," habe ich insistiert. Und dann sagte sie zu ihm: „Hören Sie, wenn es Ihnen recht ist, kann ich Ihnen natürlich vorher schon Tropfen geben, damit Sie dann sicher nichts spüren. Weil, da wird Ihnen nicht schwindlig oder schlecht, oder so. Aber nur wenn Sie wollen." Sie hat ihn wirklich gefragt, und sie hat *ihn* gefragt. (…) Und dann sagte er: „Ja, doch, also." Einfach so, na, dann halt. (…) Und von da an… seither hat er sogar selber am Abend immer verlangt. (…) Und da hat er wahrscheinlich gemerkt… Da war die Akzeptanz, das war so ein Schlüsselerlebnis. Sie hat das so gut gemacht. (8b 431-479)

This nurse, aware of the patient's reluctance to take pain killers, skillfully picked up the wife's cue and offered pain medication preventively, assuring the patient that he would not experience side effects, and making sure that he understood that he could make his own decision. The nurse's action not only achieved a pain free tube insertion for the patient, but also a change in his attitude towards pain medication. After he had experienced its effect once, he was finally willing to continue taking it. What the nurse actually did does not seem extraordinary. She was successful, because she did the right thing at the right time and used an approach that was suitable for this patient.

When caring for patients and family members, care providers are challenged repeatedly to react to uncommon situations. The better they succeed in doing the right thing at the right time in the right way, the better are the patients' and families' experiences of their care. Doing the right thing requires the care providers to recognize patients and family members as persons, to know their story and to share an understanding of the situation with them.

Providing Adequate Support

The care providers, especially the nurses, frequently provide support, for instance with activities of daily living, because the patients are too sick to perform certain tasks for themselves. However, being dependent is a problematic experience for patients, and they are eager to remain as independent as possible or regain independency as much as and as soon as possible. With patients' well-being as the major goal, the care providers are challenged to provide exactly the needed amount of support, without expecting too much or too little of the patients. Attuning care activities to patients who are either cognitively impaired, or whose health status changes frequently, or both, is especially challenging.

The care of Mr. Dolder provided a good example of this, and the following three care episodes illustrate how this challenge was taken up by different nurses and how their success varied.

About six weeks prior to his death, Mr. Dolder was hemiplegic and suffered from some apraxia; he rarely spoke, but could still answer questions with yes or no. During observation in the morning, the nurse responsible for him entered his room, introduced herself and asked, if he would like to take a shower. Mr. Dolder agreed. Together with a colleague, the nurse transferred the patient to the shower chair on wheels and drove him to the bathroom. When the patient was ready, she placed the chair in the shower and started showering the patient.

> She turns on the water and asks if the temperature is alright, lets the patient feel if it is good. She asks him, if he wants to rub the face himself. She gives him the towel and then guides his left hand, because the patient is unable to do it on his own. Then she tells him that he could now wash the breast and the tummy. When he does not react, she mentions: "Shall I?" and takes over. Subsequently, she finishes washing the patient. In the mean time, she asks if the water temperature was still alright. Then she says that she would like to wash his hair as well, if that would be okay. The patient agrees. Eventually she moves the shower chair out of the shower. She starts wiping the patient and has him help as much as he does on his own. She wipes him carefully. Together with the colleague, she then pulls up his track-suit trousers and transfers him to the wheelchair. The nurse then helps the patient to put on the track-suit coat by slipping her hand backwards through the right sleeve, taking his hand and pulling up the sleeve. On the left side, she has the patient put it on himself. Subsequently, she brings the patient back to his room and places the wheelchair in front of the sink. She asks him to comb a bit and gives him the comb. He tries, he partly manages to comb his hair on the left side, on the right side, he "combs" his ear. The nurse picks up the comb and starts the hair-dryer.

> Sie stellt das Wasser an und fragt, ob die Temperatur stimme, lässt den Patienten spüren, ob es gut ist. Sie fragt ihn, ob er selber das Gesicht waschen wolle. Sie gibt ihm den Waschlappen und führt dann seine linke Hand, weil der Patient es alleine nicht schafft. Dann sagt sie zu ihm, jetzt könne er die Brust und den Bauch waschen. Als er nicht darauf reagiert, meint sie: „Soll ich?“ und übernimmt es. Anschliessend wäscht sie den Patienten fertig. Dazwischen fragt sie nach, ob die Wassertemperatur noch gut sei. Danach sagt sie, sie wolle ihm gerne die Haare auch waschen, ob das gut sei. Der Patient ist einverstanden. Schliesslich fährt sie den Duschstuhl aus der

> Dusche. Sie beginnt, den Patienten abzutrocknen und lässt ihn dabei helfen, soviel er von sich aus tut. Sie trocknet ihn sorgfältig ab. Danach zieht sie zusammen mit der Kollegin dem Patienten die Trainerhosen an und transferiert ihn in seinen Rollstuhl. Die Pflegende hilft dann dem Patienten, seine Trainerjacke anzuziehen, dabei geht sie mit ihrer Hand rückwärts durch den rechten Ärmel, fasst seine Hand und zieht den Ärmel so an. Links lässt sie den Patienten selber reinschlüpfen. Anschliessend bringt die Pflegende den Patienten in sein Zimmer zurück und platziert den Rollstuhl vor dem Lavabo. Sie fordert ihn auf, sich etwas zu kämmen und gibt ihm den Kamm. Er versucht es, auf der linken Kopfseite schafft er es zum Teil, die Haare etwas zu kämmen, rechts „kämmt" er das Ohr. Die Pflegende nimmt ihm den Kamm ab und beginnt, die Haare trocken zu föhnen. (4c 2. 18-153)

The nurse respected Mr. Dolder's wishes: He could make decisions regarding the shower, the washing of his hair and the water temperature. She encouraged him to do as much as possible himself. As soon as he got stuck, she guided him or took over, passing silently over his disabilities. The patient, when asked if he had enjoyed the shower, said yes. He could not utter his experiences more precisely, but the showering went by smoothly, and he never appeared unhappy. The approach of this very experienced nurse seemed appropriate, mainly because she focused on the patient's remaining abilities rather than on his disabilities. The patient's well-being had priority over any attempt of training or rehabilitation. Through her respectful attuned care the nurse recognized Mr. Dolder as an independent person.

About two weeks later, a less favorable approach by a nursing student was observed. Mr. Dolder was sitting in his wheelchair at the table in the hospital corridor. The student was sitting next to him, feeding him breakfast.

> The nurse cuts the patient's roll in two halves and spreads them with butter. She prepares a feeding cup with Ovo. She gives one half of the roll to the patient and asks him: "Take a bite!" This is difficult for him, he repeatedly succeeds only after several demands. The nurse explains: "You don't have to open the mouth that much, like that is sufficient (demonstrates it). And now bite. Doesn't it work?" In addition, she pulls the rest of the roll until it breaks apart. She alternates with feeding roll and Ovo, feeding the Ovo to the patient with the feeding cup. She does not ask him to drink himself. In the beginning, the nurse asks questions, for instance, if he had

> already had a shower. "Do you still remember? No? Or can't you say it?" She does not get any answer. Later she asks less and looks out of the window at times. Then she prepares the gathering device of the napkin to protect the patient's clothes from food and Ovo. She mentions to the patient that everything would fall into it, and in the end one could eat dessert out of it. Finally, the patient has eaten the whole roll and almost finished the Ovo. The nurse leaves the cup within reaching distance and carries the tray away. The patient grasps the cup and drinks.
>
> Die Pflegende schneidet das Weggli des Patienten in zwei Hälften und bestreicht diese mit Butter. Sie bereitet einen Schnabelbecher mit Ovo zu. Sie reicht dem Patienten die ganze Wegglihälfte und fordert ihn auf: „Beissen Sie ab!" Dies fällt ihm sehr schwer, es gelingt immer erst nach mehrmaliger Aufforderung. Die Pflegende erklärt: „Sie müssen den Mund nicht soweit öffnen, nur so reicht auch (zeigt vor). Und jetzt abbeissen. Geht es nicht?" Zudem zieht sie dann jeweils am Reststück, bis das Weggli entzwei geht. Sie gibt abwechselnd Weggli und Ovo ein, wobei sie die Ovo dem Patienten im Schnabelbecher eingibt. Sie fordert ihn nicht zum selber Trinken auf. Am Anfang stellt die Pflegende dem Patienten Fragen, zum Beispiel, ob er schon geduscht habe. „Wissen Sie es noch? Nicht mehr? Oder können Sie es nicht sagen?" Sie erhält keine Antwort. Später fragt sie weniger und schaut zeitweise aus dem Fenster. Die Pflegende öffnet dann die Auffangvorrichtung am Esslatz, um die Kleider des Patienten vor Essresten oder Ovo zu schützen. Sie meint zum Patienten, da falle alles rein, am Schluss könne man das Dessert da raus essen. Schliesslich hat der Patient das ganze Weggli gegessen und die Ovo fast getrunken. Die Pflegende lässt den Becher in Reichweite stehen und bringt das Plateau weg. Der Patient ergreift den Becher und trinkt. (4c 5. 73-154)

This nursing student did obviously not know Mr. Dolder well, she was unaware of his abilities and disabilities. For weeks, his rolls had been cut into bite-sized pieces, but he was still able to drink himself, although he needed some guidance at times. He was unable to answer her questions. Furthermore, her questions probably distracted Mr. Dolder from eating. It seems likely that she was not always focusing her attention on the patient and the task at hand since she was either talking about unrelated issues or staring out of the window. Her demanding way of talking to Mr. Dolder and her repeated requests to do things he was no longer able to do had the potential of bringing his deficits fully to his attention and may have caused unnecessary distress. Finally, her remark about eating dessert out of the napkin highlighted his spillage and was simply tactless. This nursing student clearly lacked the knowledge, empathy, and experience required to feed a patient like Mr. Dolder in an adequate way. She was unable to attune her care to his needs. This care episode illustrates that a task such as feeding someone, so often thought of as simple and doable by anybody, becomes a complex and challenging nursing intervention in the context of physical and mental disability and suffering from dependency.

A week prior to his death, Mr. Dolder was one day cared for by a nurse from another unit who had never met the patient before. Mr. Dolder was now mostly bedridden, completely aphasic and unable to move purposefully. At times, he could still swallow and seemed to react to people, but he was sleeping or in a nonresponsive state most of the time.

> 7.45 am: The nurse goes to the patient. He sleeps; the nurse lets him sleep and leaves the room. The patient is lying in a foetal position on his right side. He appears to be spastic. Shortly after the nurse left the room, he begins to move. He lifts his head, opens his eyes a bit, grasps the cover and the bed linen, pulls them or folds them back. Then he lies down again in the original position and is quiet for a while. Then the whole episode starts all over again. It seems very stereotypical. Sometimes, the patient grasps his right arm and from time to time he moves the latter with his left hand.
> 8.00 am: The nurse enters the room with the breakfast tray. The patient is moving. The nurse addresses him: "I am Ms. Perren, I will accompany and assist you today." The patient does not react, he keeps moving in the same stereotypical pattern. The nurse asks: "Do you want to turn on your back?" She goes to the other side of the bed and tells the patient that he could now turn. No reaction. She tries to help by pulling his shoulder slightly, but without success. She mentions to the patient that he seems too spastic, that turning is not possible like that. She leaves the room. Soon she returns and tells the patient that she asked a colleague for advice and would now bathe him a bit for relaxation. She bathes his legs and back, and massages him with slow circling movements using oil of roses. Then she asks the patient again to turn. No reaction. The nurse tells the patient that she would go to another patient and would be back in ten minutes. It is now 8.15 am. The patient is again lying in an unchanged position on his right side, from time to time he moves stereotypically, in between he is quiet.
> 8.30 am: The nurse returns, she observes the patient for a moment and then says that she would get a second nurse for turning, and leaves the room.

8.35 am: The nurse returns again and tells the patient that she could not yet find someone to help, but would keep looking and come back.
8.45 am: The nurse is standing for several minutes at the patient's bedside and observes him, she then leaves the room again.
9.00 am: The nurse returns and tells the patient that she now found someone, so that they would be able to turn together – the three of them, they would be here in a short moment. She leaves the room again.
9.10 am: The patient is now quiet, he seems to sleep.
9.15 am: The nurse and a colleague enter the room. They realize that the patient is now sleeping and decide to let him sleep.

7.45 Uhr: Die Pflegende geht zum Patienten. Er schläft, die Pflegende lässt ihn weiterschlafen und geht wieder raus. Der Patient liegt in einer fötalen Stellung auf der rechten Seite. Er wirkt sehr spastisch. Kurz nachdem die Pflegende das Zimmer wieder verlassen hat, beginnt der Patient sich zu bewegen. Er hebt jeweils den Kopf, öffnet die Augen halbwegs, greift mit der linken Hand nach Decke und Leintuch, zieht daran oder schlägt diese zurück. Dann legt er sich wieder in der ursprünglichen Lage hin und liegt einen Moment ruhig da. Dann beginnt das Ganze von vorne. Es wirkt sehr stereotyp. Manchmal fasst der Patient nach dem rechten Arm und ab und zu bewegt er diesen mit der linken Hand.
8.00 Uhr: Die Pflegende kommt mit dem Frühstücksplateau ins Zimmer. Der Patient bewegt sich. Die Pflegende spricht ihn an: „Ich bin Frau Perren, ich werde sie heute begleiten und unterstützen." Der Patient reagiert nicht, er bewegt sich weiter im gleichen stereotypen Muster. Die Pflegende fragt: „Wollen Sie auf den Rücken drehen?" Sie geht auf die andere Bettseite und sagt zum Patienten, er könne jetzt drehen. Keine Reaktion. Sie versucht nachzuhelfen, indem sie leicht an der Schulter zieht, jedoch ohne Erfolg. Sie meint zum Patienten, er sei so verkrampft, dass das Drehen so nicht gehe. Sie verlässt das Zimmer. Bald kommt sie zurück und sagt zum Patienten, sie habe eine Kollegin um Rat gefragt und werde ihn jetzt etwas waschen zur Entspannung. Sie wäscht ihm die Beine und den Rücken, und massiert mit langsamen, kreisenden Bewegungen Rosenöl ein. Danach fordert sie den Patienten erneut zum Drehen auf. Keine Reaktion. Die Pflegende sagt zum Patienten, sie gehe zu einer anderen Patientin und komme in zehn Minuten wieder. Es ist inzwischen 8.15 Uhr. Der Patient liegt weiter in unveränderter Haltung auf der rechten Seite, ab und zu bewegt er sich stereotyp, dazwischen ist er ruhig.
8.30 Uhr: Die Pflegende kommt zurück, sie beobachtet den Patienten einen Moment und sagt dann, sie hole eine zweite Pflegende zum Drehen und verlässt das Zimmer.
8.35 Uhr: Die Pflegende kommt wieder ins Zimmer und sagt zum Patienten, sie habe noch keine Helferin gefunden, sie schaue weiter und komme wieder.
8.45 Uhr: Die Pflegende steht einige Minuten am Bett des Patienten und beobachtet ihn, verlässt dann das Zimmer wieder.
9.00 Uhr: Die Pflegende kommt zurück und sagt zum Patienten, sie habe jetzt jemanden gefunden, damit sie zu zweit – zu dritt drehen könnten, es dauere nur noch einen kurzen Moment. Sie verlässt das Zimmer wieder.
9.10 Uhr: Der Patient ist jetzt ruhig, scheint zu schlafen.

> 9.15 Uhr: Die Pflegende und eine Kollegin kommen ins Zimmer. Sie stellen fest, dass der Patient jetzt schläft und beschliessen, ihn schlafen zu lassen. (4c 8. 31-150)

This nurse did not know her patient; she met Mr. Dolder for the first time on this morning and relied on the information in the nursing record and on the advice of her colleagues – a very challenging situation indeed. She did not find a way to connect to the nonresponsive patient verbally or nonverbally. Subsequently, she could not adapt her interventions to his situation. The recommended bathing procedure did not have the hoped for relaxing effect on the patient. The nurse was not able to turn Mr. Dolder on her own and for some time could not find anyone to help her. As a result, Mr. Dolder did not get cared for (with the exception of bathing his legs and back), that is, he got no mouth care, no attempt to let him drink or eat was made, and he remained in the same clenched position during the one and a half hours he was "awake." It is impossible to say how Mr. Dolder experienced this situation. From observation, he did not seem comfortable during this phase. When he finally fell asleep again, the nurses assumed that sleeping would be more comfortable for him than being awake. They prioritized his present well-being and postponed care interventions, which might, nevertheless, improve well-being in the longer run. Continuity of care was valued by patients and families. By assigning this dying patient to a nurse who was only helping out temporarily, the continuity of his care was not ensured anymore. The nurse who neither knew the patient nor his story was unable to attune her care to his needs.

These three care episodes illustrate how the nurses' abilities to fine tune their interventions to the patient's situation varied. They also highlight that the care providers' expertise and their knowledge of the patient as well as the latter's health status heavily influenced this attuning. Fine tuning activities to an unknown, nonresponsive patient is definitively much more demanding than doing so when the patient is well-known and can agree or disagree; and responding adequately to care needs is a much bigger challenge for a nursing student than an experienced nurse. The latter, the expert, intuitively relies on her extensive theoretical knowledge, practical know-how, and on comparisons with prior similar cases, while the former, the novice, may rely on textbook knowledge about brain tumors as well as hemiplegia, aphasia, and apraxia, but has never met a patient with a specific and frequently changing pattern of symptoms from these conditions (Benner, 1984).

Sharing Responsibility

For the care providers, fine tuning care activities to the patients' needs also meant sharing or taking on the responsibility together with the patients, or to either assume full responsibility for or leave decisions to the patients. The patients' satisfaction with their care depended on how well the providers managed this task. Ms. Egger's experiences serve as an example.

When admitted, Ms. Egger was seriously ill and in severe pain. Over the first weeks, her situation worsened with one complication following another. Only after several weeks, did she begin to recover slowly and was finally well enough to start planning discharge. Depending on her illness situation and stamina (Spannkraft), her strength and willingness to take on responsibility and make decisions were changing over time. The providers had to constantly attune their care to her present situation by either deciding on the patient's behalf, providing counselling, or giving information and letting the patient decide herself.

For instance, Ms. Egger got her yoghurt for breakfast even though she had forgotten to order it; an attentive nurse took care of the order (5c 151-163). As to pain medication, on admission the care providers took over and provided pain treatment quickly and efficiently to the patient's satisfaction. Later, Ms. Egger was more involved and decided for herself if, when and what kind of pain treatment she needed. When the nurse who assisted her with body care in the morning asked about pain in her arm, Ms. Egger said that she had some pain in the right arm, but the left arm was better. The nurse offered pain medication, but Ms. Egger did not want any at the moment. Instead, she thought that Kytta (an anti-inflammatory ointment) would be good. The nurse got it and rubbed it in for her (5c 96-108). The same morning, Ms. Egger was about to get up and walk to the bathroom on her own. The nurse asked her gently to wait for her assistance, since Ms. Egger had fallen a few days before. The patient agreed to wait for the nurse's company (5c 65-69). With regard to discharge planning, Ms. Egger just requested information from the care providers and decided to organize the needed support herself. She was now ready again to take on responsibility, and at times, she even felt conflicted, because she felt responsible although she knew that the issue at hand was clearly the nurses' business. For instance, she had an appointment and was waiting for transportation. The responsible employee was later than usual and she did not want to be late.

> Well, but now they should really come. In principle, it is not even my problem, but it is my problem nevertheless. (...) Now, I have a dilemma. Should I call and ask if transportation is really ordered?
>
> So, aber jetzt sollten die dann kommen. Im Prinzip ist es ja nicht mein Problem, und trotzdem ist es mein Problem. (...) Jetzt bin ich im Dilemma, ob ich läuten soll und fragen, ob er wirklich bestellt sei. (5a 2. 263-272)

With her condition rapidly going up and down, Ms. Egger felt at times unclear about what might be the best course of action for her. One morning, when she felt too tired to do anything, the nurses let her stay in bed quietly, and they did without bathing.

> When I once really did not feel like doing anything, they just let me be. That was difficult on one side, because it was not planned; on the other side they really let me in peace, because they noticed that I was too tired. That was ambivalent, letting me be, on the one hand, I thought: What is this, they just let me lie here. On the other hand, I found it good that I was not forced to do anything. So, there were really both sides. At the moment when I was so tired, I would say in retrospect, not exerting pressure but doing the possible was the right reaction.
>
> Als ich mal wirklich nicht mochte, haben sie mich wirklich auch sein lassen. Das war einerseits schwierig, weil es nicht planbar war, auf der anderen Seite haben sie mich dann auch in Ruhe gelassen, weil sie einfach gemerkt haben, dass ich nicht mag. Das war ambivalent, einerseits mich sein zu lassen, ich habe gefunden: Geht es eigentlich noch, die lassen mich einfach so liegen. Auf der anderen Seite fand ich es wieder gut, dass ich nichts musste. Eben, es waren wirklich beide Seiten da. Im Moment, als ich so gar nicht mochte, war es, würde ich rückblickend sagen, die wirklich gute Reaktion, dort nicht Druck zu machen, sondern einfach zu machen, was möglich ist. (5a, 5b 332-346)

Had Ms. Egger judged this situation differently in retrospect, she might have related a different story, one of being abandoned and not cared for. In a moment when her patient was unable to figure out what she really needed, the nurse took on the responsibility to make a decision for her. Thus, the nurse took a risk; she expected to know the patient well enough to make the right decision on her behalf. And although Ms. Egger felt some ambivalence at the moment, she considered the nurse's reaction as the best option retrospectively. This example illustrates the phronesis – judgment, attunement and wisdom – in body care. Under ordinary circumstances, body care remains in the taken-for-granted background, but with profound disability and suffering, assistance in body care requires the embodied practical knowledge of an expert.

In the situations described so far, the care providers seemed willing readily to let the patient participate in or take over responsibility. At times, however, care providers set clear limits in order to avoid potential harm for the patient, regardless of the fact that she was willing to accept responsibility. They were unwilling to let her take the risk. This prevented them from fully attuning their actions to the patient's wishes, and therefore she felt deprived of some options. Nevertheless, the providers' decisions might have been well justified from their perspective.

> They (the physiotherapists) also fear very much, somehow, they do not allow me the use of other equipment… I believe that insurance cases are a huge sword of Damocles in all these institutions. I was also not allowed to use the bicycle on my own in the health resort. Those are just there, and Saturday and Sunday, one could actually have used them. But they are extremely afraid that one would fall, and that they would have a liability case. And therefore, I was not allowed to swim, they were afraid; yes, it is slippery in the indoor swimming pool, and with my bone fragility, and that it would give a liability case. (…) But I think this is crazy; if I am falling, I actually fall myself. I would, for instance, never have thought about accusing someone when I had the accident, when I fell, that the care in the hospital had not been good. That was me! I went up and expected too much of myself.
>
> Sie (die Physiotherapeutinnen) haben auch sehr Angst, irgendwie, sie wollen mich auf keine anderen Geräte lassen, sie haben irgendwie… Ich glaube, so Versicherungsfälle, das ist ein riesiges Damoklesschwert in all diesen Institutionen. Ich durfte auch nicht alleine aufs Velo in der Rehabilitationsklinik. Die stehen ja rum und Samstag und Sonntag könnte man doch eigentlich gehen. Aber die haben wahnsinnig Angst, man falle, und es gebe einen Haftpflichtfall. Und ich konnte nicht baden gehen deswegen, weil sie Angst hatten. Ja, es ist rutschig in einem Hallenbad, und ich mit meiner Knochenbrüchigkeit, und das gäbe einen Haftpflichtfall. (…) Aber ich finde das verrückt, wenn ich umfalle, falle ich doch selber um. Mir wäre es beispielsweise nie in den Sinn gekommen, als ich den Unfall hatte, als ich fiel, irgend jemandem die Schuld zu geben, dass die Pflege im Spital nicht gut gewesen sei. Das war ich! Ich bin aufgestanden und habe mich überfordert. (5a, 5b 2. 566-588)

Regarding responsibility, the care providers frequently seem to be in a position of standing-by, informing and counselling, while letting patients decide on their own behalf about care interventions. But they are ready to step in as soon as necessary to either share responsibility or take it on themselves. The patients' autonomy is respected, but terminally ill patients are not always able or willing to take on (full) responsibility. The care providers are required to walk a fine line between providing enough support, accepting responsibility, even making decisions and respecting the patients' will and wishes. Making decisions for the patients also means acting in the patients' best interest at any time. Not granting a decision to patients who are willing to be responsible may constitute an offense to their autonomy, or care providers may just adhere strictly to institutional rules and not consider the option of an exceptional case, or they may be unwilling to take any risk or, as Ms. Egger suspected, fear legal consequences, but it can in fact also be an act in a patient's best interest.

Providing Information and Counselling

For patients and family members in limbo, with tormenting thoughts floating about their mind and tremendous insecurity, adequate information and counselling were extremely helpful. Mrs. Dolder related that her son had talked a lot about death with a specialist. He had reassured him not to be afraid, he would likely sleep more and more and die in his sleep. Thinking about death as falling asleep for ever was very comforting for Mr. Dolder, he hoped for this development, and in fact did die in his sleep (4b 4. 267-282; 4 po 273-284).

A couple, who faced the recurrence of the woman's lung cancer and several diagnostic tests to decide upon a palliative chemotherapy, experienced the counselling of a specialist as very supportive and clarifying.

> He says it would be very important for us to ask questions and that he could explain everything to us. Only a patient, who understands what is going on, would be able to cooperate and participate. The dreadful unknown that floats ones mind is bad.

> And so he now explained us why, each time when a new diagnostic test was done. Of course, we were frightened when they said that the lungs were also affected. Now we will get an X-ray of the head, and the mammography. We then said: Now it's probably a hopeless case, now it has likely spread everywhere. And then he explained, why. It goes now, in my view, a bit the other way around. They now do not examine to find as much as possible, they examine to see what can be excluded. To adjust the chemotherapy correctly.
>
> Er sagt, es sei sehr wichtig, dass wir Fragen stellen würden, und dass er uns alles erklären könne. Nur ein Patient, der die Sache begreife, könne diese mittragen und mitmachen. Das furchtbar Ungewisse, das einem im Kopf rumschwirrt, ist schlecht. Und so hat er uns jetzt von Fall zu Fall, wenn wieder eine neue Untersuchung war, hat er uns erklärt, warum. Natürlich sind wir gewaltig erschrocken, als es hiess, auf der Lunge sei auch noch etwas gefunden worden. Jetzt werden wir noch den Kopf röntgen, und die Mammografie. Da haben wir gesagt: Jetzt ist wohl Hopfen und Malz verloren, jetzt ist es denk in allem rum. Und dann hat er erklärt, warum. Es geht, für meine Augen, jetzt etwas den umgekehrten Weg. Sie untersuchen jetzt nicht, um noch möglichst viel zu finden, sie untersuchen, um zu sehen, was man ausschliessen kann. Um die Chemotherapie richtig einstellen zu können. (3a 2. 603-618)

This couple especially valued the specialist's profound medical and psychological knowledge, as well as his honesty.

Another couple acknowledged that a counselling session helped them realize the necessity of sharing illness experiences and concerns.

> What was also very important is that we could take into account that one can actually tell each other what we are concerned about, and that we must do this, because otherwise it undermines the relationship.
>
> Was auch sehr wichtig war, dass wir uns dort Rechenschaft geben konnten, dass man sich eigentlich gegenseitig sagen kann, was uns beschäftigt, und das auch muss, weil es sonst die Beziehung untergräbt. (5a, 5b 523-527)

Even though this couple did not meet regularly with the counsellor, they agreed that it was reassuring to be aware of this resource and to know that they could ask for another session whenever necessary (5a, 5b 2. 369-378).

The partner of a patient who died in the hospital experienced bereavement counselling as helpful, because it was his only opportunity to talk through certain issues.

> Now I am more or less over it, but I was glad that I could meet with the counsellor, because there are issues that you just cannot talk about with colleagues. I don't have my parents anymore, so that I could go to mum or dad to complain or so. And with the colleagues… eh, they certainly all are nice guys, but you cannot just discuss this with colleagues. And with female colleagues it wasn't possible either, because when I discussed with them, they cried. Then I told myself: This is not helpful when they cry, I would like to howl, you shouldn't howl.

> Jetzt bin ich einigermassen drüber, aber ich war froh, dass ich zum Berater gehen konnte, weil es Sachen gibt, über die Sie mit den Kollegen einfach nicht reden können. Und Eltern habe ich keine mehr, wo ich eben zu Mami oder Papi hätte klagen gehen können oder so. Und mit den Kollegen… eh, es sind alle zusammen sicher gute Kerle, aber man kann nicht einfach mit den Kollegen darüber diskutieren. Und mit den Kolleginnen ging es auch nicht, weil wenn ich mit denen diskutiert habe, waren die nachher in Tränen aufgelöst. Da habe ich gesagt: Das nützt mir auch nichts, wenn die in Tränen aufgelöst sind, ich möchte heulen, nicht ihr sollt heulen. (6 po 1330-1346)

This man lacked the social network, which, for instance, the parents of Mr. Dolder experienced as very supportive in their bereavement. While Mr. Dolder's parents could and felt compelled to talk about her son together and with other family members and friends after his death, this man had lost his intimate partner, had no close family members, and did not find another person within his circle of colleagues who was able to provide comforting support. For him, counselling opened up a window that would otherwise have been closed, a window to talk freely about his tremendous loss. Talking was an important aspect in living through his sorrow and preparing himself for taking up his new life.

Not all consultations were experienced as supportive, however. One family member, when asked if she felt supported by repeated conversations with the patient's physicians, explained that these meetings brought along an agreement on the best care for the patient, but nothing for her.

> The first conversation brought along only negative feelings. (…) The second was absolutely correct, neutral… And then… I would like to say that the physicians were not relevant for me, and they did not give me what I would have needed.
>
> Das erste Gespräch hat nur Negatives gebracht für mich. (…) Das zweite war absolut korrekt, neutral… Und nachher… Ich möchte sagen, für mich waren die Ärzte nicht wichtig, und sie haben mir auch nicht gebracht, was ich nötig gehabt hätte. (4b po 523-528)

She experienced the information regarding the patient's prognosis as unsatisfactory, and stated that following the advice to have her own life besides caring for the patient was just impossible for her (4b po 489-493).

The partner, who stayed at the bedside of the dying patient over several days and only occasionally slept for short periods of time, related a similar story. He had some disputes with the night nurse. She was concerned about his well-being and wanted him to sleep at night. She repeatedly offered him another room and suggested that a student would stay with the patient. However, the partner was determined not to abandon the patient, but to care for her until she died, and strictly refused to take a real break.

In the context of leading their lives while the patient was hospitalized with a terminal illness and, in these two cases, actually dying, the well-meant advice to either live their own life besides caring for the patient or leave the patient for sleeping was misguided. Such advice fails to recognize that the family members' and the patients' world and life are strongly intertwined. Being distant and attempting to live a separate life is untenable. For the first family member, living her life at this moment meant accompanying the patient through his terminal illness, for the second staying with the patient was the only available option from his perspective. These family members were fully committed to caring for the patients. Caring, that is, being concerned about the patients and actively contributing to their well-being, in fact defined these family

members' current world. Caregiving filled out their horizon; moving beyond was precluded at this time.

Patients and family members highly value adequate information and counselling; meaning understandable, honest, and timely information provided by a knowledgeable provider, and counselling that meets and takes into account their individual situations. These findings confirm what the review of the literature on patients' and family members' experiences revealed, namely that information contributes as a major aspect to patients' and family members' experiences in the hospital, positively if adequate, negatively if lacking or inadequate.

Removing Stumbling Blocks

At times, the care providers intervened skilfully on behalf of patients and family members to prevent difficulties or the escalation of a problematic situation. The following story of a patient illustrates this.

> One morning, I almost freaked out. Then, they also helped me. There was another patient, and her husband arrived at seven in the morning. Put up the divider, and then he just was in the room. I was waking up, had not yet been on the toilet, nothing, and he was just walking around the room. And the nurses could not get rid of him. He said that he was a private payer and had the right to be in the room, that was it. And I almost freaked out. I could not go to the toilet, I could not do anything, after all, I was still trying to realize where I was. And when they had brought him out, after five minutes, he was back again. But they did... With a saintly patience, they did... I would have freaked out as a nurse. And they ushered him out again and again with a saintly patience. And there, I realized that after all, I lacked any vigor, I had... I just said: "He has to leave." I was out of myself, I really freaked out.

> Einmal an einem Morgen, da bin ich fast ausgeflippt. Da haben sie mir auch geholfen. Da war eine andere Patientin, und ihr Ehemann fuhr am Morgen um sieben ein. Paravent hingestellt und dann war er einfach im Zimmer. Ich war am Erwachen, ich war noch nicht auf dem WC, nichts, und der lief einfach im Zimmer rum. Und die Pflegenden brachten den nicht raus. Er sagte, er sei Privatzahler, er habe das Recht, im Zimmer zu sein, fertig. Und da bin ich fast ausgeflippt. Ich

> konnte nicht aufs WC, ich konnte nichts machen, bis ich überhaupt realisiert habe, wo ich bin. Und wenn sie ihn fünf Minuten draussen hatten, stand er wieder da. Aber die haben das… Sie haben mit einer Engelsgeduld… Ich wäre ausgeflippt, wenn ich Pflegende gewesen wäre. Und sie haben ihn mit Engelsgeduld immer wieder rauskomplimentiert. Und dort habe ich gemerkt, da habe ich also überhaupt keine Spannkraft mehr, da habe ich… Da habe ich einfach gesagt: „Der soll raus.“ Ich war ausserhalb meiner selbst, da bin ich richtig ausgeflippt. (5a 628-646)

Within two hours, the nurses organized a private room for the second patient and moved her out. The patient and her partner praised the nurses for their prompt and successful action, stating that the situation might well have escalated.

> Patient: I found that the nurses had reacted with total sovereignty. It was also for them a relatively new phenomenon, but somehow friendly, not insulting, and they reached the goal, finally. This seemed good to me. And I simply did not have the vigor to react well. But I did not have to. This did not even bother me, because they in fact attended to my interests.
> (…)
> Partner: It could have escalated.
> (…)
> Interviewer: But they could deal with it so that the situation did not escalate?
> Patient and partner: Yes, they could deal with it.
> Partner: And it has to be extremely professional, otherwise you cannot manage this, otherwise you do not find the adequate tone.
>
> Patientin: Ich habe gefunden, die Pflegenden hätten total souverän reagiert. Es war auch für sie ein relativ neues Phänomen, aber irgendwie freundlich, nicht beleidigend, und kamen auch zum Ziel, oder. Das hat mich gut gedünkt. Und ich hatte da einfach nicht die Spannkraft, gut zu reagieren. Aber das musste ich auch nicht. Es hat mich dann auch nicht gestört, sie haben ja meine Interessen vertreten. (5a 660-667)
> (…)
> Partnerin: Es hätte eskalieren können.
> (…)
> Interviewerin: Aber sie konnten damit umgehen, ohne dass es eskalierte?
> Patient and Partner: Ja, sie konnten damit umgehen.
> Partner: Ausgesprochen professionell muss ja das sein, sonst schafft man das doch nicht, sonst findet man doch nicht den angemessenen Ton. (5a, 5b 287-315)

In both the patient's and the family member's view, the nurses showed great social competencies in dealing with an awkward situation. The patient was very relieved that they acted on her behalf and saved her from the additional distress of an escalating

conflict. Nurses might understand this kind of action as an ordinary form of patient advocacy.

The care providers, and especially the nurses, often act preventively. Prevention is frequently mentioned as one of their tasks, but it is usually related to preventing physical problems, for example, pressure sores. The story told above and a few other examples in the data highlight that care providers also act preventively in other realms. They use their social competency to deal with upcoming interpersonal problems and ensure the smooth running of the units; stumbling blocks are removed. A parallel can be drawn to pressure sore prevention: If the nurses implement prevention measures successfully, the fact that the patient does not suffer from a pressure sore is often taken-for-granted and is rarely acknowledged as an outcome of good nursing care. Disputes with patients, family members, other visitors, or among care providers can be very disruptive and cause considerable distress. However, the brewing storm in the air whose breakout was competently prevented is easily overlooked. In other words, the competent social interactions of the care providers remain almost invisible to other care providers, the hospital management or the public. Yet in the context of the distress of terminal illness and an enforced hospital stay, such social competence is essential for patients and families, thereby making their life easier.

Putting Stumbling Blocks in the Way

Patients and family members mostly felt well cared for in the hospital. They also related some negative experiences, which were more or less tolerable. Usually, patients and family members found a way to cope with these negative aspects; for instance, time might remedy the issue, they considered it as a minor aspect in the context of their overall

positive experiences, or they found an acceptable explanation or excuse such as a staffing shortage. However, patients and family members also related a few care episodes that affected them very negatively. These situations hurt them deeply and were neither easily forgotten nor forgiven. They stuck in peoples' memories and came up again and again in conversations as stumbling blocks put in their way by care providers.

Experiencing a Tribunal

For Mrs. Dolder, a round table conversation was such a situation. Her son, both parents, two physicians, a nurse, and a medical student were present. When he recognized the context, her son immediately said: "That is like a tribunal." („Das ist wie ein Tribunal." 4b 226-227) The conversation turned around the patient's illness and the options for care. The patient and his parents were asked to utter their views and guided to negotiate a solution acceptable for both sides.

> And sometime he said: "I cannot return to my flat, but I could go to my parents." Then the physician said: "How do you imagine this?" And so and so. "You force your parents to take you home. Ask them, if this is possible. " And I said: "No, we cannot do this, we are too old." And he was then very aggressive. But before, he had never said that he would like to come home. In his flat, yes. And then, what bothered me most, he said: "After all it is not your parents' fault that you are sick." Then I said: "It's even less his fault." (...) This really hurt me very much, very much, I almost left, but then I thought, no, that's not good for him, and stayed.
>
> Und irgendwann hat er gesagt: „In die Wohnung kann ich nicht mehr, aber ich könnte zu meinen Eltern." Dann hat der Arzt gesagt: „Wie stellen Sie sich das vor?" Und so und so. „Sie zwingen ihre Eltern, Sie heim zu nehmen. Fragen Sie, ob es geht." Und ich habe gesagt: „Nein, wir können das nicht machen, wir sind zu alt." Und er war da sehr aggressiv. Aber er hat vorher nie gesagt, dass er heim möchte. In seine Wohnung schon. Und dann, was mir am meisten ausgemacht hat, er hat gesagt: „Schliesslich können Ihre Eltern nichts dafür, dass Sie krank sind." Da habe ich gesagt: „Er kann noch weniger dafür." (...) Und das hat mich natürlich sehr gemocht, sehr gemocht, ich bin fast rausgegangen, aber ich habe gedacht, nein, es ist nicht gut für ihn, und bin geblieben. (4b 239-261)

The mother further explained why she considered the context of this conversation as inadequate:

> It is bad. It was the only time when he was aggressive with me… He certainly felt: I am just attacked, I am in a tribunal. It is not right. (…) They should consider that the people are weak, very weak. This was the case with my son, he could not think logically anymore. It was just not good.
>
> Es ist schlecht. Es war das einzige Mal, wo er mit mir aggressiv war… Er hat sicher gespürt: Ich bin einfach attackiert, ich bin in einem Tribunal. Es ist nicht richtig. (…) Sie müssten bedenken, dass die Leute geschwächt sind, sehr geschwächt. Das war der Fall bei meinem Sohn, er konnte nicht mehr logisch denken. Es war also nicht gut. (4 po 425-449)

The round table conversation including patient, family, physicians and nurse was constituted to involve the most relevant partners in the discussion and decision making regarding Mr. Dolder's care. It was intended to elucidate the different partners perspectives, to bring reality to the patient's and his family's awareness, to clarify possible and finally agree upon the best available options for the patient and his parents. However, Mr. Dolder and his parents experienced the meeting very differently from the professionals' intent, for them it was an unbearable tribunal. The setting of the meeting was unexpected, never before had they talked to so many care providers at once. The picture of a tribunal seems quite comprehensible, if one considers that the conversation was mainly a dialogue between one physician and the patient and his parents, with three other providers listening. The questions the patient was supposed to answer seemed too demanding given his cognitive impairment. The physician's conversational style was experienced as confrontational, which added to the patient's distress. Feeling under great pressure, he reacted with aggression. The physician guided or even forced the parents into a debate with their son and used a, in their view, totally unjustifiable argument to convince him that his wish to return home was unreasonable. With the patient reacting

aggressively out of helplessness and the parents shocked and hurt by the physician's statement, this round table conversation was certainly not the most favorable method to choose when looking for a solution to providing the best care for Mr. Dolder.

For care providers, the round table appears to be a convenient setting for involving patient and family and respecting their perspectives, and a confrontational conversational style seems adequate for leading patient and family to accepting reality regarding the consequences of the illness. However, this setting can be experienced as a nightmare by patient and family, if the social demands of the situation are too complex for the patient, the family, or both. Carefully taking the patient's and family's individual situation and experiences into consideration and fine tuning setting and conversational style accordingly might help to avoid such undesirable experiences for patients and families.

Sliding Into Economic Language

Another patient and his family were told that the patient had to apply for a place in several nursing homes, because he could not stay in the hospital. The patient had been admitted with a recurrence of brain metastases. He had been treated with a cycle of palliative radiotherapy. Together with the physicians, he had decided against palliative chemotherapy, because its side effects would likely outweigh any benefit. His health status was quite stable, an unlimited hospital stay, therefore, was not justifiable. Since the patient had been living alone, was now wheelchair bound and in need of nursing care, returning home was also not an option. The patient was very satisfied with his care in the hospital and wished to stay on the unit. It was very hard for him to accept that this was not possible, but he finally came to terms with this fact and looked forwards to the

transfer to the nursing home. What he could not cope with was the physician's message.

He remembered the conversation with the physician:

> Patient: Well, I just have to leave. Cost-and-effect calculation, that's it. The physician told my brother.
> (...)
> Patient: Well, how was it? Well, explained the disease, and that radiotherapy did not react, and that chemotherapy would be useless, ineffective, and well, that I cannot stay here. When there were no tests, treatments, therapies.
> (...)
> Patient: Cost-and-effect. That shocked my brother.
> Interviewer: That shocked him...
> Patient: Yes, that is impudent, cost-and-effect, exactly like in a butcher's shop.
> Interviewer: Well, and how was it for you to hear that?
> Patient: In any case I did not forget it so far!
>
> Patient: Ja, ich muss einfach hier raus. Kosten-Nutzen Rechnung, eben. Hat der Arzt gesagt zum Bruder.
> (...)
> Patient: Ja, wie ging das ab? Eben, die Krankheit erklärt, und dass die Bestrahlung nicht reagiert hat, und dass Chemo für die Füchse sei, nichts nützt, und eben, dass ich nicht hier bleiben könne. Wenn keine Untersuchungen, Behandlungen, Therapien mehr seien.
> (...)
> Patient: Kosten-Nutzen. Das ist meinem Bruder eingefahren.
> Interviewerin: Das ist ihm eingefahren...
> Patient: Ja, das ist eine Frechheit, Kosten-Nutzen, gerade wie in einer Metzgerei.
> Interviewerin: Ja, und wie war es denn für Sie, das zu hören?
> Patient: Ich habe es auf jeden Fall nicht vergessen! (9a 69-70, 195-199, 211-221)

For the patient's brother and sister-in-law, this conversation was also a disturbing experience:

> Brother: The physician really gave us a piece of his mind. That bothered me in some way, in the brother's presence. He suddenly started to talk about cost-and-effect relations. I got a bit outraged, I must say. Well, I know that it just has to be like that, but it seemed brutal to me that this was said in the brother's presence. You are no longer profitable for us, we want to get rid of you. Or we cannot help you...
> Sister-in-law: The chemotherapy would be too expensive, would cost too much for the effect it would have. (...) He mentioned the cost-and-effect relation several times. And that seemed rather disturbing to me. That one just says this so frankly, you know, cost-and-effect for a human being... the relation of cost and effect isn't right anymore.

> Brother: He can let me know this, that is absolutely okay. But there was no need to say this frankly in my brother's face.
> Sister-in-law: Yes, and that shocked him.
> Brother: He mentions it each time I visit him...
>
> Bruder: Der Arzt hat echt Klartext geredet. Das hat mich auf eine Art etwas gestört, in Gegenwart des Bruders. Der hat da plötzlich angefangen, von Kosten-Nutzen Verhältnis zu reden. Da war ich etwas aufgebracht, das muss ich sagen. Ich weiss ja, dass das einfach so sein muss, aber es dünkte mich brutal, dass man dies in Gegenwart des Patienten selber sagt. Du rentierst uns nicht mehr, wir wollen Dich weg haben. Oder Dir können wir nicht helfen...
> Schwägerin: Die Chemo komme zu teuer, es koste zuviel zum Nutzen, den es bringe. (...) Das Kosten-Nutzen Verhältnis hat er mehrmals angesprochen. Und das dünkte mich also auch noch stark. Dass man das gerade so einfach sagt, oder, Kosten-Nutzen für einen Menschen... das Verhältnis stimmt nicht mehr von Kosten und Nutzen.
> Bruder: Mir darf er das sagen, das ist absolut in Ordnung. Einfach dem Bruder hätte er es nicht an den Kopf werfen müssen.
> Schwägerin: Ja, und das ist ihm also schon eingefahren.
> Bruder: Das erwähnt er fast jedes Mal, wenn ich zu ihm gehe... (9b 265-289)

For the patient, when talking about cost-and-effect, the physician seemed to make a comparison with, for instance, a butcher calculating which goods might be profitable for his shop, with the patient as the goods. Stated otherwise, the patient extended the cost-and-effect appraisal to his own worthiness; he felt objectified and dehumanized. The family members experienced the message as inadequate and reacted angrily, but coped by rationalizing: Health care costs had to be taken into account. They were mainly concerned about the negative consequences of the message for the patient. As they mentioned, the degrading message remained a sting in the flesh for the patient.

Regardless to whom it is given, patient or family, a message with such an unbeneficial outcome seems unjustifiable from an ethical perspective. The sister-in-law is right: Talking about cost-and-effect in relation to a human being is harmful. The discussion of costs in relation to the effectiveness of interventions for specific groups of people is necessary for health care policy. This discussion must not be taken, however, to the level of individual patients. The message, as perceived by patient and family, heavily damaged the relationship between the patient and his physician. In ethical terms, it can be seen as an offence against the rule of non-maleficience. The slide into economic language leaves behind the care provider's concern for the patient's well-being. The physician neither takes fully into consideration the patient's vulnerability and dependency, nor the responsibility that acting from the more powerful position comprises.

With increasing health care costs and limited resources, it is obvious that patients who do not need hospital care, have to be discharged. The care providers have to comply with health care insurance and hospital guidelines in this respect. From this perspective, the physician was obliged to inform his patient about the impossibility of an unlimited hospital stay and the necessity of nursing home applications. However, it was up to him to formulate this message in an acceptable way, to choose the right words. Definitely, this physician did not find the right words. The patient felt kicked out by the care providers for financial reasons, rather than learning what the consequences of insurance and hospital guidelines were in his case, what was required for compliance, how the care providers could support him in finding an acceptable solution, and that he would still be cared for in the hospital until the transfer to the nursing home.

Experiencing Mistrust

In the following example, the intervention of a nurse was experienced very negatively. When visiting her son, Mrs. Dolder always fed him and also gave him the medications he got with meals. She used to wrap the pills in food, or break them in halves to facilitate swallowing, and gave them one by one. With this procedure, she did not experience problems with administration; Mr. Dolder always took all of them. One day, a

nurse brought the pills and stated that she would give them to the patient herself. She explained that they had recently found a pill on the floor, and that she had to make sure the patient got all his medication. She then had the patient swallow all the pills quickly, without any supporting measures.

> She said that a pill had been on the floor the day before or at noon… I don't remember, if I was here then… in any case, she would have to make sure that he would take the medications. Then she shuffled five or six pills into his mouth within a few… not even minutes, because she thought… she did not trust me and that just… bfff… (…) If I consider that I brought him pills to the classroom, because he had forgotten them… That hurt me deeply. (…) It hurt me, because my son is epileptic and what a mother has to watch, it is crazy… (cries) She hurt me. As mother of an epileptic one must always make sure that he takes the medication, it is almost an obsession.
>
> Sie hat gesagt, am Vortag oder Mittag sei ein Medikament am Boden gewesen… Ich weiss nicht mehr, ob ich dann da war… auf alle Fälle, sie müsste schauen, dass er die Medikamente nimmt. Dann hat sie fünf oder sechs Medikamente reingeschaufelt innerhalb von ein paar… nicht mal Minuten, weil sie gefunden hat… sie hat kein Vertrauen in mich und das hat mir… bfff… (…) Wenn ich denke, dass ich ihm Medikamente ins Schulzimmer nachgebracht habe, weil er sie vergessen hat… Das hat mich zutiefst getroffen. (…) Es hat mich getroffen, weil mein Sohn ist Epileptiker und was eine Mutter schauen muss, es ist verrückt…(weint) Sie hat mich verletzt. Als Mutter eines Epileptikers muss man immer schauen, dass er die Medikamente nimmt, es ist fast eine Obsession. (4b 366-388)

As a mother who had been responsible for her son's medication regimen for many years, Mrs. Dolder felt deeply hurt by the nurse's reaction, which she experienced as unjustified mistrust. In addition, she considered her way of giving the pills as less burdensome for her son, that is, she felt deprived of a task that she thought she could do better than the nurse. What exactly happened regarding the pill on the floor did not become clear. The nurse obviously connected the problem to the visitors who used to feed the patient, and considered herself as fully responsible for delivering the medication. She did not take the mother's special situation into consideration and was unwilling to share responsibility and, thereby, caused great suffering to Mrs. Dolder.

Summary

The three situations described above show how blatant failures in attuning care interventions to individual patients and families are experienced extremely negatively. An inadequate setting and conversational style, inappropriate words, or not granting responsibility should be considered as examples; such failures may occur with whatever intervention care providers deliver. Such situations are problematic, because they add avoidable burden to the already distressed patients and families; stumbling blocks put in their way by awkwardly acting care providers. Furthermore, the care providers may not learn how badly their actions affected patients and family members. For instance, Mrs. Dolder, according to the interviews with her, never told the care providers that they experienced the round table conversation as a tribunal or told the nurse or anyone else how deeply hurt she was by the nurse's mistrust. Thus, putting stumbling blocks in patients' and family members' way may occur with the same invisibility as the removing. Sub-optimal care may not be noticed by the professionals, but nevertheless be strongly experienced by patients and families.

Aspects Influencing the Adequacy of Interventions

The adequacy of care interventions and consequently patients' and families' experiences are related to the care providers' abilities to improve the quality of life for patients and family members, to balance medical procedures, to fine tune their activities to the patients' and families' needs, and to provide information and supportive counselling. However, the adequacy of interventions does not solely depend on care providers' skills. It is also influenced by some aspects that are not under their control. Due to their health status, patients' abilities to express their needs vary, and any decrease

in expressiveness increases the care providers' challenge to attune actions to needs. In addition, fully conscious patients' willingness and ability to articulate their needs differ. Furthermore, patients and families bring different expectations to the hospital and their experiences depend on how far care providers meet these expectations. Finally, structural and organizational factors may limit or promote the care providers' endeavors to provide the best possible care to patients and families.

Articulating Concerns and Needs

In general, when patients or family members uttered a concern or a need, the care providers tried their best to respond adequately. Some family members, however, related that the patients just kept silent instead of expressing their wishes. Subsequently, their needs were not fully met, because the care providers were unaware of them. For instance, patients did not get the preferred food, because they did not take advantage of the available selection. The patients who did utter their needs were not all equally capable of explaining themselves.

For the foreign patient, German was not her mother tongue, which meant that she lacked the words to go beyond a description of her pain as very bad, bad, not so bad anymore or as well controlled. In addition, the care providers and her partner noticed her unwillingness to admit pain. Her partner related this to her reluctance to bother others and to the fact that she did not want to lose her mind from too many drugs.

> She doesn't tell me everything. But I see how she feels from watching her face. I notice it from that when she lies to me or so. When I ask: "How are you?" and she says: "Well." Then I say: "Don't tell rubbish, I can see it anyway."
>
> Sie sagt mir ja auch nicht alles. Aber ich sehe es ihr immer am „Gring" an, wie sie sich fühlt. Ich sehe es so, wenn sie mich anlügt oder so. Wenn ich frage: „Wie geht

> es?“ und sie sagt: „Gut.“ Dann sage ich: „Du musst nicht Quatsch erzählen, ich sehe es Dir ja an.“ (6b 299-303)

The woman's language barrier and her unwillingness to fully acknowledge the amount of her pain increased the care providers' problems in adjusting her pain medication regimen, although they were eager to do so (6 PD 109-114).

In contrast to the example above, the following quote shows how a scientist vividly described her altered body feeling in the first conversation and about one week later after she had started physiotherapy.

> At the moment I have a terrible problem with the body feeling. I have the feeling that the digestion would be somewhere below, that it does not belong to me, below the stomach. And here, the thorax does not belong to me either, it is like an alien element, like a block that does not belong to me. (…) I know about the body feeling in theory, but I have never experienced it myself, and I think, that is a phenomenon. Because I have somehow the feeling to be cut up…
>
> The body feeling and just this block of thorax, which is like a stone, is on the foreground of what bothers me a lot. (…) I started with physiotherapy, and that helps. So, with this I have the feeling to be on the way to gently bring about some flow, when I sometimes feel, after all, something is moving now. The stone comes out of its immobility, it begins to flow a bit. But it is clear to me that this will probably still last for some time.
>
> Also mit dem Körpergefühl habe ich wahnsinnig Mühe zurzeit. Ich habe das Gefühl, die Verdauung sei irgendwie da unterhalb, das gehöre gar nicht zu mir, unterhalb des Magens. Und hier, der Thorax gehört auch nicht zu mir, das ist wie ein Fremdkörper, so wie ein Klotz hier, der nicht mir gehört. (…) Theoretisch weiss ich das mit dem Körpergefühl, aber ich habe es noch nie selber erlebt, und ich finde, das ist ein Phänomen. Weil ich irgendwie das Gefühl habe, ich sei zerstückelt… (5a 98-104, 482-486)
>
> Das Körpergefühl und einfach der Klotz von Thorax, der wie ein Stein ist, steht im Vordergrund dessen, was mich massiv stört. (…) Ich habe mit Physiotherapie angefangen, und das hilft. Also, dort bin ich auf dem Weg, habe ich das Gefühl, ganz sanft ein wenig Flüsse reinzubringen, wo ich dann manchmal merke, doch, jetzt bewegt sich etwas. Der Stein kommt aus seiner Unbeweglichkeit raus, es fängt etwas an zu fliessen. Aber es ist mir klar, das wird wahrscheinlich noch lange gehen. (5a, 5b 632-646)

It does not seem astonishing that this woman got a physiotherapy program that suited her very well and from which she profited regarding her body feeling.

This final example shows how Mr. Dolder's cognitive disability interfered with the fine tuning of his care. His mother repeatedly realized that he got food he disliked, because he was no longer able to make informed decisions and just said yes to anything.

> They respect the personality, and I think that is nice. But at times it goes almost too far. I don't know exactly, how it works, he can choose meals for the whole week or for three days. And they continue with that, and he says, yes, yes for semolina, but he loathes semolina. But he said yes for semolina, and he had semolina twice. And I said: "For God's sake, don't give him semolina, he disliked it already as a child."
>
> Sie respektieren die Persönlichkeit, und das finde ich schön. Obwohl es manchmal fast zu weit geht. Ich weiss nicht genau, wie das geht, er kann am Morgen für die ganze Woche, oder für drei Tage das Menü wählen. Und das machen sie weiter, und er sagt, ja, ja beim Griessbrei, aber er hasst Griessbrei wie die Pest. Aber er hat ja gesagt für Griessbrei, und er hatte zweimal Griessbrei. Und ich habe gesagt: „Um Gotteswillen, geben Sie ihm keinen Griessbrei, den hatte er schon als Kind nicht gerne.“ (4b 3. 434-443)

The care providers seemed to overestimate Mr. Dolder's cognitive capacity; according to his mother, they still took a yes as a yes without questioning, when he had already lost the ability to make distinct decisions.

The providers' abilities in delivering adequate care interventions to an individual patient or family member depend to some extent on the information they get from the person affected. Patients' and family members' willingness and ability to articulate their concerns and needs vary for different reasons. Thus, the adequacy of care interventions depends on the interaction of care providers' expertise and patients' and family members' readiness to express themselves.

Differing Expectations

Patients' and families' prior experiences with receiving care from professional health care providers and with hospital stays differed greatly. Accordingly, their expectations regarding the current hospitalization varied.

Asked for his perspective on how the patient experienced her care in the hospital, the partner of the foreign patient answered:

> Well, let us say it like that: When I brought her to the hospital, she asked: „Did you pack cutlery? Did you pack a glass?" "Are you crazy, cutlery and a glass?" Well, in her country you must bring this all, you know. As far as the care is concerned, she is satisfied. One cannot compare this. Here someone is there, one can call, one can get something. One can say, I am in pain, and then one gets something against pain. One can say, I am thirsty, and then a glass of tea arrives. This does not exist there... The physicians come, they talk to her. They do all that's humanly possible to make her feel better. So, with this, she is satisfied, you know.
>
> Also, sagen wir es mal so: Als ich sie ins Spital gebracht habe, hat sie mich noch gefragt: „Hast Du das Besteck eingepackt? Hast Du ein Glas eingepackt?" „Was spinnst Du, Besteck und Glas?" Ja, in ihrer Heimat musst Du das alles mitnehmen, oder. Von der Pflege her und so ist sie zufrieden. Das kann man nicht vergleichen. Hier ist jemand da, man kann läuten, man kann etwas haben. Man kann sagen, ich habe Schmerzen, dann bekommt man etwas gegen die Schmerzen. Man kann sagen, ich habe Durst, dann kommt ein Glas Tee. Das gibt es dort nicht... Die Ärzte kommen, sie reden mit ihr. Sie machen alles Menschenmögliche, damit es ihr besser geht. Von dem her ist sie zufrieden, oder. (6b 410-426)

The patient agreed, she got more than she had ever expected:

> And here everybody cares about me, nurse, physician, all, very well. Much more than I expected. And always ask questions and always help well. I feel very well now.
>
> Und mir hier schauen alle, Schwester, Arzt, alle, sehr gut. Viel mehr wie ich erwartet. Und immer Fragen stellen und immer gut helfen. Ich fühle mich jetzt sehr gut. (6a 35-39)

That this 40-year-old woman who had been diagnosed with terminal cancer only three weeks before, suffered from pain and shortness of breath, was wheelchair bound, underwent palliative radiation and chemotherapy, and faced a very shortened life span

and destroyed plans for a better future with her partner, could say she felt very well seems unbelievable. Her statement becomes more comprehensible when her expectations are taken into consideration. She had never been hospitalized in Switzerland before and relied on experiences from her home country. She did not expect to be cared for or to get medication for free in the hospital. What seems obvious for Swiss people, therefore, far exceeded her expectations. Accordingly, she was very satisfied with her care.

While this immigrant did not know what to expect, the other patients and family members had prior experience with the Swiss health care system and, therefore, more realistic expectations. Some even had a clear vision of palliative care and, correspondingly, specific expectations. For instance, a family member wondered on what kind of a unit the patient was. She mentioned that she would expect a softer approach and more active listening on a palliative care unit (4b 459-462). Another family member said that from the moment they got the terminal diagnosis, adequate pain control for the patient had been her major concern. She was aware of options, had read information brochures on cancer pain treatment, and expected care providers to keep the patient pain free (8b 56-67, 426-431).

"Nobody is perfect," added one patient (10a 525), when he said it would not be worth mentioning the few times during several stays in the hospital when he was not served the meal he had actually ordered. Patients and family members did not expect perfection in the hospital. They could put up with minor mistakes or misunderstandings. For instance, a patient who only got a blood transfusion on Monday instead of Friday, because the order got stuck somewhere between the prescribing specialist and the unit, stated that such a delay seemed acceptable to her, given the size and complex organization of the hospital.

The varying expectations of patients and families influence their care experiences. When expectations are met or even exceeded, they are satisfied and feel well cared for, while unmet expectations dampen down their experiences. Since patients' and family members' expectations vary greatly and because they do not all expose the same level of tolerance for inconsistencies, the challenge for care providers to meet felt needs varies as well. What may perfectly satisfy one patient may seem insufficient to another. Patients and family members expect what they assume to be available based on their knowledge and experiences. This aspect may also apply for symptoms like pain. Patients who expect to suffer pain from cancer may be unaware of effective measures for pain control. The unknown cannot be expected, and subsequently cannot be requested. Therefore, patients and family members, who remain unaware of additional care options that might benefit them, may not get the best possible care. Furthermore, patients and families may be totally satisfied with their care, while the latter may appear sub-optimal if palliative care is taken into account as the desirable standard. This brings up the question, if the study participants who stated that they did not miss anything in the hospital, did in fact not need anything else, or if they were not aware of additional resources. In this respect, the care providers are asked to provide enough information to allow patients and family members adequate decisions.

Limiting or Promoting Structural and Organisational Factors

Care providers were working on a certain unit or department of the hospital with a given structure and setting. Their ability to adapt structural aspects to individual patients'

and families' needs was very limited. There was, for instance, no way around having six-bed rooms, although these were not at all popular for patients and families. The nurses were, nevertheless, successful in getting magnet stripes on the walls, which allowed them to decorate rooms individually with patients' photos or pictures.

Thus, structural barriers at times interfered with optimal patient care. A patient related that she preferred transportation in her bed, because it was more anonymous, she could hide a bit and close her eyes. Following a fall, she was brought to the dental clinic in a wheelchair. She experienced this as very embarrassing, because her smashed face was exposed. However, although the dental clinic is located just across the street, transportation to this building in a hospital bed is not usually possible and was not an option in her case.

The care providers were also embedded in an organizational system with its rules and limited resources. At times, patients and families were aware of staff shortages and showed some understanding for the consequences, such as minor hassles or delays. However, one patient was very disappointed, because she had to wait 12 days for the beginning of her radiotherapy. Without signs of paralysis, she was not eligible for emergency radiation and had to wait for a regular treatment slot. An intervening holiday further exceeded the waiting time. The patient, imagining rapidly growing metastases, thought that the delay was harming her.

> It was day number 12, when I got it for the first time. And… when it is growing so explosively, I really consider this as a disadvantage, that it could go on raging during this time.

> Es wurde Tag Nummer 12, bis ich das erste Mal drankam. Und… wenn es eben so explosionsartig wächst, schaue ich es schon als Nachteil an, dass es während dieser Zeit weiterwüten konnte. (3a 125-129)

In this situation, the care providers obviously could not immediately increase the capacity of the radiotherapy department. Under these conditions, treating patients according to pre-established rules, that is, according to symptom severity or in sequential order seemed a reasonable and ethically justifiable solution, even to the patient. In fact, she complained about the lack of equipment, not about the care providers, and decided to bring the problem to the attention of the federal minister responsible for health care through a letter.

For other patients, organizational regulations brought advantages. On the in-patient units, terminally ill patients in need of a single room were given high priority and mostly got one, even though their insurance would not pay for it. In addition, family members were allowed to visit around the clock, they could order meals and were offered a couch if they stayed over night.

Thus, the hospital's structure, organization and resources may both limit or promote care providers' endeavors to deliver the best suitable interventions to individual patients and family members in a timely manner. The care providers are challenged to fully use the available options and to deal creatively with limitations. For instance, in the case of the patient who was embarrassed by her smashed face, a scarf might have been a solution to her problem. In addition, care providers who aim at improving care could take even further steps and go beyond the individual patient's or family member's needs to initiate required changes on the unit, hospital or health policy level.

Summary

Patients' and families' experiences with care interventions are best when the latter match their concerns and felt needs, and their experiences are closely interrelated with their expectations. Meeting the patients' and families' needs and achieving good care calls for skillful and experienced care providers. But the care providers also rely on patients and families; the latter's abilities to express themselves are critical. Furthermore, care providers must act within the boundaries of the hospital structure and its organizational system. Finally, while caregiving is mainly the task of the professionals in the hospital, families also have a share in supporting patients. This theme is taken up in the following section.

This study makes the significance of finely attuned care visible. Aspects of care that people do for themselves when healthy, such as body care, eating, or toileting, are usually taken for granted and reside in the background. With illness and disability, such aspects of care become prominent. Thus, giving care that is well attuned to patients' and families' needs and concerns acts as a powerful recognition practice. Care providers who bear witness to suffering and stand along side patients and family members as skillful helpers, counsellors and advocates acknowledge personhood (Benner et al., 1999).

Family Members' and Patients' Caring for Each Other

"Our goal is really to help him, to make everything easier for him."

„Unser Ziel ist wirklich, ihm zu helfen, ihm alles leichter zu machen." (4b 85-86)

This statement summarizes the family members' perspective: They primarily want to ease the patients' suffering from their terminal illness. The patients, on the other hand, are concerned about the burden on their families.

The Patients' and Family Members' Well-Being Has Priority

For the family members the patients' well-being has priority, and they are willing to take a lot upon themselves to achieve the best options for patients. Their experiences are shaped by the patients' experiences and depend on the comprehensibility of the care they observe. The patients also show concern and care for their families within the limits set by the illness. With the goal not to burden the other, patients and family members carefully consider what they talk or do not talk about. These issues are outlined further below.

The Patient Comes First

For the family members who lived with the terminally ill patients and accompanied them through the hospital stay, the patients' well-being was their major concern. They clearly stepped back and put the patients' wishes and needs first. Mrs. Alder respected her husband's unwillingness to talk about cancer or the consequences of his impending death and did without, knowing that she would be able to rely on her children for support after his death. Mrs. Blum, who had to go temporarily to a nursing home during her husband's hospitalization, reassured him:

> And I am in good hands, I am not missing anything, you don't need to be anxious for me. The main thing is that you are doing well.
>
> Und ich bin gut aufgehoben, mir fehlt gar nichts, Du musst gar keine Angst haben meinetwegen. Die Hauptsache ist, dass es Dir gut geht. (2a, 2b 570-573)

Even when family members felt some reluctance to comply with a patient's wish, they still did so. Mrs. Alder agreed on the installation of a stair elevator, although she at first did not like the idea, because she thought it would not fit well into their house. She changed her mind when she realized how relevant the elevator was for her husband, stating: "Now he is motivated and pleased. That is the main thing." („Jetzt ist er motiviert und freut sich. Das ist die Hauptsache." 1b 183-184) Mr. Dolder's parents disagreed with his wish for assisted suicide, but when he repeatedly asked for the information brochures, they procured them for him (4b 37-47).

Mr. Dolder had basic health insurance only. His parents thought he would be charged for the single room, and they were willing to pay for him in order to ensure the privacy he needed during the last weeks of his life. Due to the room allocation policy on the in-patient units, they did not have to do so, however. Nevertheless, they were willing to take on a considerable financial burden for the sake of their terminally ill son's well-being.

The latter example points to another relevant aspect: The families' living situation influences the possibilities of members to prioritize the patient's needs; it may both limit or promote them. Mr. Dolder's parents were retired and living comfortably; they had the time to visit as often as they wished and could have afforded to pay for their son. This was very different for another family member who lived in restricted circumstances and could neither afford to take a leave of absence nor to lose his job. This man's perspective was the same as that of other family members: The patient came first, and he wanted to spend as much time as possible with her. However, he had no choice other than go on working, and even though he adjusted his schedule as much as possible, work clearly restricted his time with the patient.

> At work they also already grouse, because I just changed shifts now in order to have more time for her. Yeah... "You can't do that repeatedly..." Why not? Well, work doesn't interest me at all at the moment. I don't know how long she can live on, you know. (...) I said: "I'm not interested anymore in what's going on all round." I comply with the duty I have, and that's it, you know. The rest of the time I am here.

> Am Arbeitsplatz motzen sie auch schon, weil ich jetzt gerade Dienste abgetauscht habe, damit ich mehr Zeit habe für sie. Ja… „Das kannst Du nicht immer machen…“ Wieso nicht? Also, die Arbeit interessiert mich zurzeit gar nicht. Ich weiss nicht, wie lange sie noch leben kann, oder. (…) Ich habe gesagt: „Mich interessiert alles zusammen nicht mehr, das rundum läuft.“ Die Pflicht, die ich habe, mache ich, und dann ist fertig, oder. Den Rest der Zeit bin ich hier. (6b 169-179)

This partner had to cope with additional burdens: On the one hand, he had to explain to the patient that his work obligations constricted visiting time. For instance, when he was on night shift, the patient, under heavy doses of opioids, thought he had a day off and expected him to stay, while he still needed some sleep during the day in order to work at night (6b 456-460). On the other hand, he had to negotiate with his employer in order to adapt his schedule to his current needs as much as possible without putting his job at risk.

Patients' Experiences Shaping Family Members' Experiences

Since the patients' well-being had priority for family members, they often experienced the situation through the patients' eyes, so to speak. The patients' experiences decisively shaped the family members' experiences. The following quote from a family member illustrates this:

> When I remember, how she chatted on Sunday. I was really delighted. I couldn't say a word. With colleagues. These are the moments I like, when she is feeling so well.
>
> Wenn ich denke, am Samstag hat sie geschwatzt. Ich hatte richtig Freude. Ich kam gar nicht zu Wort. Mit Kolleginnen. Das sind die Momente, die mir dann gefallen, wenn sie so gut drauf ist. (6b 361-364)

Another family member stated that the patient was in good hands in the hospital. Asked how she came to this conclusion, she explained that her view was based on how she experienced the patient in the hospital, on the latter's mood and behavior, and mainly on the feedback she got from the patient about her care (5a, 5b 259-268).

The patients' good experiences with care made their hospital stay much more bearable for the family members. Knowing that the patient was well cared for greatly relieved their concerns, as one husband explained:

> She feels in good hands. If this wouldn't be so, she would call me, if she is anxious or so. For instance, today she didn't feel so well. It is a relief for me to know that the nurses look well.
>
> Sie fühlt sich gut aufgehoben. Wenn dies nicht so wäre, würde sie mich anrufen, wenn sie Angst hat oder so. Zum Beispiel heute ging es ihr nicht so gut. Das ist eine Erleichterung für mich, zu wissen, dass die Pflegenden gut schauen. (3b 181-185)

Comprehensibility Versus Incomprehensibility

In addition to the influence of the patients' experiences, the families' experiences in the hospital depended on how well they understood the patients' situation and could comprehend care interventions. Their observations, the information they got, and whether or not they agreed with it, shaped their perception. For instance, Mrs. Dolder observed that the nurses provided excellent body care, that they knew how to position the patient in the chair or bed, or that he was not left alone for long periods. This was very reassuring for her; she concluded that the nurses knew exactly what was best for the patient in this respect and that she could trust them (4b 4. 330-342; 4b 5. 105-118).

However, some care interventions were incomprehensible for Mrs. Dolder. For instance, the parents together with the care providers had decided upon the patient's medication: He should have to take as few as possible, but should get those contributing to his well-being, mainly cortisone and anti-epileptics. Then, one day Mrs. Dolder was not allowed to give the pills, the nurse wanted to do it herself to make sure the patient got them all. Later, she was told several times that the patient had not gotten medication, because he refused to take them. However, she felt that he should get at least the few

relevant pills, and she doubted his ability to make informed decisions at this time. With her, he always took the pills. She wrapped them with food and fed them carefully one by one, while some of the nurses just stuffed the pills into the patient's mouth without any supporting measures. Mrs. Dolder felt disappointed and confused about this situation and wondered: "Is there a clear line or not?" („Ist eine Linie da, oder keine Linie?" 4b 2. 137-167).

At times, Mrs. Dolder also questioned the information or explanations given to her. When the patient had a crisis, for example, she considered it to be an epileptic attack, but was told that it was a consequence of strain.

> He had a crisis on Saturday evening. I thought it was an epileptic attack, but one said, no, it wasn't. He trembled and had difficulties with breathing, and it lasted quite a while… Then they called the physician, and he said that it was from strain. (…) For me it had been one of the nicest days, when he was really very calm… (…) It was in fact no strain. He talked little and laughed a lot, and was happy. And he had never been as relaxed as on Saturday. It is probably from the tumor, in relation to the tumor, but he had not had the medication, and perhaps it would have been better with… I don't know it.
>
> Er hat am Samstagabend eine Krise gehabt. Ich habe gemeint, es sei ein epileptischer Anfall, aber man hat gesagt, nein, es sei keiner. Er hat einfach gezittert und konnte nicht mehr atmen, und es ging also eine Weile… Nachher haben sie dem Arzt telefoniert, und er hat gesagt, es sei die Anstrengung. (…) Es war für mich einer der schönsten Tage, wo er wirklich sehr gelassen … (…) Es war effektiv keine Anstrengung. Er hat wenig geredet und viel gelacht, und war glücklich. Und er war noch nie so entspannt wie am Samstag. Das ist wahrscheinlich eben von dem Tumor, in Zusammenhang mit dem Tumor, aber er hat die Medikamente nicht gehabt, und vielleicht wäre es besser gewesen mit … ich weiss es nicht. (4b 2. 175-212)

From Mrs. Dolder's statement it becomes obvious that she disagreed with the physician's judgment and could hardly believe his explanation. Mrs. Dolder spent much time with her son and observed him carefully. She was, however, aware of her lay perspective, ready to accept professional information, and grateful for clarifications. But some explanations given by care providers did not make sense to her. The mismatch between her interpretation and that of the professionals was not solved and she was left with insecurity and confusion.

Patients' Caring for Family Members

While families were concerned about the terminally ill patients' well-being and committed to caring for them, the patients for their part were concerned about the family members' well-being. Their ability to express concerns and care for family members was limited by their illness, that is, by physical and cognitive disabilities, which hampered their activities and their perception of reality at times. However, within the boundaries imposed by the illness and the hospital stay, patients manifested their concern and commitment. For instance, one patient said:

> I just want that, if something new shows up, she hears it from me, not from anyone else.
>
> Ich will einfach, wenn irgendetwas Neues zum Vorschein kommt, dass sie dies von mir vernimmt, nicht von anderen Leuten. (7a, 7b 181-183)

This patient wanted to save his partner any negative experiences and insecurity from rumors about his health status. Although his concern was somewhat unfounded, because the care providers recognized his partner as a significant other and she felt well informed, the statement still stands for his commitment towards the partner. This patient also had his son buy a birthday gift for the partner, which she greatly appreciated as a sign of his esteem for her (7b 438-442).

Mr. Blum, shortly before his discharge, stayed up after an unexpectedly tiring physiotherapy session, because he was afraid of scaring his wife when she found him in bed again at her arrival. He then prepared her for the next day, explaining that exercising was strenuous and that she should not be afraid in case he was sleeping when she visited

(2a 2. 607-611). The patient, concerned about his wife and anticipating her reaction, did without a nap to save her the fright of immediately assuming a sudden deterioration in his health status.

Telling or Not Telling Each Other

Their concern for each other's well-being let patients and family members carefully consider what they were or were not telling the other and which themes they were or were not talking about. Patients and family members tried to avoid topics that might hurt the other. For instance, Mr. Blum never told his wife how disappointed he was, when he heard that his son, on their way home from the hospital, went for dinner with his mother, but had her pay for the meal herself (2a 2. 40-105). Mrs. Blum never let her husband know how hurtful she found the son's statement that the patient could not return home because she had not searched for another flat (2a, 2b 1014-1026). In these two cases, not telling probably saved Mr. and Mrs. Blum additional sadness about their son's behavior. They agreed that their son differed from them in some respects, but both liked him and got along well with him and his family. It seems unlikely that a discussion of what they experienced as an occasional slipping from the expected behavior would have had any positive effect, but much more likely that both would have been affected negatively. Thus, not telling may be the preferable option at times.

However, not telling could also cause problems for patients and family members. Since the terminal illness per se was a painful topic, talking about it was not easy. Some patients and family members, fearing to burden the other too much, avoided talking about their experiences with the illness, their concerns for the other, their relationship, and themselves. One patient explained her problem:

> Just that I have at times some trouble to know how much I must spare my partner, should spare, and how much she is sparing me. We actually know it. Just that we are not honest with each other anyway.
>
> Einfach manchmal habe ich noch etwas Mühe, wie weit ich die Partnerin schonen muss, schonen sollte, und wie weit sie mich schont. Eigentlich wissen wir es ja. Einfach dass wir dann trotzdem nicht ehrlich sind zueinander. (5a 536-540)

When the partner suspected that the patient was hiding information, her anxiety increased. The lack of openness threatened to undermine their relationship at a time when they needed each other most (5a 541-549; 5a, 5b 407-415, 523-527). Thus, not talking may add trouble instead of avoiding burden. Not talking together about the terminal illness and all the related concerns seems to have a high potential for negative consequences for either patients or family members or both. For instance, what seemed to work well as a coping strategy for Mr. Alder, that is, refusing to take note of his illness, was problematic for Mrs. Alder.

When the conversation between patient and family member was blocked, an intervention from a care provider was at times experienced as helpful. The couple, whose problem was described above, related that they recognized their difficulties and were able to open up when talking with a counsellor together. In fact, this couple seemed to use the research interviews in a similar way. They frequently talked to each other rather than to me, and at the end of the first interview, they stated that talking had been helpful and suggested a second interview (5a, 5b 859-861).

For Mr. and Mrs. Blum, talking openly about his cancer was at first an insurmountable task. Mr. Blum was not sure if his wife knew his diagnosis and assumed she might deny that he had metastatic cancer. Prior to his hospitalization, they had never talked openly about his prostate cancer. Mrs. Blum, however, was fully aware of her

husband's terminal illness, very concerned and disappointed that he seemed to exclude her. While Mr. and Mrs. Blum did not talk together first, they both talked to the nurse about their concerns. The nurse then told Mr. Blum that his wife seemed to be well informed about the diagnosis. He was relieved, thought things through once more, and then successfully started up the conversation with his wife (2a 2. 332-342; 2 PD 138-142).

The two examples outlined above show that care providers can successfully smooth the way for patients and family members who experience difficulties in talking about the terminal illness and struggle to overcome the hurdles. While the counsellor intervened directly by participating in the couple's conversation, the nurse did so indirectly when she reassured the patient that the family member knew his diagnosis. However, any intervention has to be tailored to the individual situation. With persons who refuse any conversation about the illness, like Mr. Alder, an inadequate intervention may only increase the distress of the other person involved.

Even when patients and family members are talking openly about the terminal illness, with or without the support of a care provider, they may still decide to keep silent about certain issues. One patient assumed that her terminal illness made her husband feel guilty, because he had focused on his interests and disregarded hers after their retirement.

> My husband certainly has a bad conscience now, what we could have done and didn't do. And I only say this to you and confidentially, I would never tell him or someone from the family. He just always allowed himself his hobby, and this hobby had priority. (…) And I believe his conscience is now nagging a bit on him. I don't have to reproach him with it, he is clever enough to think about it. And it doesn't help him in any way, and I now don't want to poison the remaining short time with reproaches. I mean, that would be totally inadequate. He is now always coming, when he leaves, he comes back one more time and says: "You know, if we still have some time together, we want to enjoy every day, every day." But well, who regrets nothing he did? And would do it differently, if one could start all over again?

> Mein Mann hat jetzt sicher ein schlechtes Gewissen, was wir alles hätten tun können und nicht taten. Und ich sage dies jetzt nur zu Ihnen und im Vertrauen, zu ihm würde ich das nie sagen, auch nicht zu Leuten der Familie. Er hat sich schon einfach immer sein Hobby geleistet, und es musste erstens nach diesem Hobby gehen. (…) Und ich glaube, da nagt jetzt das Gewissen etwas an ihm. Ich muss es ihm nicht vorhalten, er ist selber schlau genug, daran zu denken. Und es nützt ihm ja nichts, und ich will nicht die letzte kurze Zeit jetzt noch vergiften mit Vorwürfen. Ich meine, das wäre ja total daneben. Er kommt jetzt auch immer, wenn er geht, kommt er nochmals zurück und sagt: „Aber gell, wenn wir noch etwas Zeit zusammen haben, wollen wir dann jeden Tag geniessen, jeden Tag." (…) Aber eben, wer bereut nichts, das er gemacht hat? Und würde es anders machen, wenn man von vorne anfangen könnte? (3a 2. 486-528)

This couple talked openly about the illness. The husband stated explicitly that they had no secrets. It seemed somewhat disturbing, however, that the patient explained exactly what had been done and why, whenever she talked to me, and repeatedly praised the supportive and informative conversations they had with the specialist, while the husband complained about a lack of information and suspected that they were not told the truth. In fact, the husband appeared extremely distressed. It is easy to assume that feelings of guilt contributed to his distress. However, this is pure speculation, because the issue was never disclosed in the hospital; the patient decided to keep silent.

Palliative care practitioners who advocate fostering growth actively in patients and family members during the dying process might feel compelled to intervene in this situation. By talking it through, the couple might be able to settle this matter and experience this as relieving. However, talking about such sensible aspects may never have been part of their relationship. Disclosure might end in reproaches and despair. Care providers should be aware that they may never know all the issues that influence a patient's and family member's situation. They must respect the boundaries set by patients and family members and realize that they will always remain outsiders to some extent. Care providers are required to avoid intruding in patients' and family members' privacy.

They are, nevertheless, challenged to skillfully intervene if a patient or family member provides a clue to do so.

Family Members as Caregivers

Most family members felt welcomed and integrated in the hospital. Flexible visiting hours, the options of eating or sleeping on the unit, and the nurses' readiness to let family members participate enabled the latter to get involved in the patient's care as much as the patient and they themselves wished and were able to. Family members became co-caregivers; they cared for the patients in different ways and the depth of their involvement varied. Caregiving was not always easy, but was mostly experienced as rewarding by family members.

Various Ways of Caregiving

Most frequently, family members provided company to the patients by visiting regularly and for, at times, quite extended periods. The days could be very long in the hospital, as one patient explained, and the company of a family member was highly welcomed (2a 2. 286-290). Keeping company could mean just sitting with the patient, talking, eating or enjoying a drink together. Frequently, family members took patients outside their room, to one of the hospital restaurants, and even outside the building to the hospital garden.

Family members acted as patient advocates who either supported the patient in ensuring the best possible care or made decisions on the patient's behalf if necessary. For instance, one wife strongly encouraged her husband to ask for sufficient pain medication, and when he became more and more tired and sleepy, he used to say: "Ask my wife, she

knows everything, I'm too tired now." (Fragen Sie meine Frau, die weiss alles, ich mag jetzt nicht." 8b 339-341). This couple had discussed issues around death and palliative care repeatedly in the past, and the wife was well prepared to speak for her husband. The parents of Mr. Dolder had to make decisions for him when his cognitive abilities decreased with the progression of the brain tumor.

Family members took over all the tasks of daily life that the patients could not take care of while in the hospital. They ran errands, took care of the flat, went shopping for the patient, and so on. For some family members, the challenge was huge. For instance, one family had to vacate the patient's flat, take care of all his administrative issues, and fill out applications for nursing homes and his disability pension.

Family members made sure that the patients had the personal belongings they needed and liked to have in the hospital. Some contributed to the atmosphere of the hospital room. Mrs. Dolder, for instance, always decorated her son's room with nice flowers, and when Mr. Dolder was no longer able to listen to music with the ear phones, his parents bought another CD-player, so that they could still play music for him (4b 5. 6-13). One daughter called her father every morning to check the phone line. His phone had once been broken for a day, and this cut off from his family had distressed him (2c 30-35).

Finally, some family members were involved in the hands-on care for patients, mainly by supporting them in their activities of daily living. One patient related such an episode. She looked forward to eating dinner, but was then unable to sit up for the meal, because of pain.

> Happily, the daughter just visited, and when I said: „Uh, I must lie down again," she said: „You know what, I will sit on your bed and feed you bite by bite." Like that, I ate dinner pretty well.

> Zum Glück war die Tochter gerade zu Besuch, und dann habe ich gesagt: „Uh, ich muss wieder liegen," und dann sagte sie: „Weisst Du was, ich sitze da auf Deinen Bettrand und gebe Dir Mundvoll für Mundvoll ein." So habe ich recht gut z'Nacht gegessen. (3a 2. 64-74)

Mrs. Dolder also supported her son by feeding him. In addition, sometimes she brought meals from home, and shortly before his death, when he could hardly swallow anymore, she prepared special apple sauce for him.

Thus, family members provided care in different ways. While all kept company, made sure the patients had what they needed in the hospital, and took over upcoming tasks at home, some also acted as patient advocates, took care of the patient's room, and helped patients with activities of daily living.

Different Levels of Involvement

Family members were involved at different levels, depending on the patients' needs and wishes, but also depending on their own possibilities. For instance, for working family members, the visiting time was limited; and keeping company was the only option for Mrs. Blum, given her physical disability. The depth of family members' involvement seemed also associated with the kind of relationship they had with the patient. Family members who were more involved in caregiving were also more involved with the care providers on the unit.

The brother and sister-in-law, who had not maintained a very close relationship with the patient before he got sick, visited him about three times per week. The brother dealt with all the upcoming issues for the patient and discussed those as much as possible with him, the sister-in-law took the patient to the restaurant for a drink, and both were working to vacate his flat. They did not know the patient's care providers on the unit and did not consider this to be necessary. They valued information, however, and assumed that they would be informed should something relevant come up (9b 420-441).

Other family members, more intimately related with the patient as spouse, partner or parent, visited almost daily. Some provided occasional assistance as needed; others supported the patient on a regular basis. One man actually spent six days in the hospital, not only staying at the bedside of his dying partner, but in fact nursing her day and night. The following care episode was observed one day prior to the patient's death.

> The patient sits on the toilet chair and should transfer to the bed. The nurse and the partner help her put her hands around the partner's neck, he embraces her waist and helps her get up. Together they move to the bed and turn around, so that the patient can sit on the bed. The nurse and the partner want to help her go to bed. She prefers to remain sitting on the bed. The partner sits next to her, supports her, caresses her, and talks to her at a low voice.
> Eventually, the patient wants to go to bed. She slips back herself, the partner helps with her legs, he positions her feet on small cushions and covers her. He does this very carefully and proficiently and explains that the heels should not touch the bed to prevent pressure sores.
> Later, the nurse returns. She discusses body care with the partner. He had helped yesterday? How it would look like today, how they should proceed today, and what should they do? The partner states that they should do what the patient wanted them to do.
>
> Die Patientin sitzt auf dem Nachtstuhl und soll aufs Bett transferieren. Die Pflegende und der Partner helfen ihr, die Hände um den Nacken des Partners zu legen, er umfasst ihre Taille und hilft ihr so beim Aufstehen. Zusammen bewegen sie sich dann zum Bett und drehen, so dass die Patientin sich auf den Bettrand setzen kann. Die Pflegende und der Partner wollen der Patientin ins Bett helfen. Sie zieht es vor, am Bettrand sitzen zu bleiben. Der Partner setzt sich neben sie, stützt sie, liebkost sie, und redet leise mit ihr.
> Schliesslich will sich die Patientin dann hinlegen. Sie rutscht selber nach hinten, der Partner hilft ihr mit den Beinen, er lagert ihr die Fersen frei und deckt sie zu. Er tut dies sehr sorgfältig und profimässig und erklärt, die Fersen sollten nicht aufliegen, damit sie nicht wundliege.
> Später kommt die Pflegende zurück. Sie bespricht sich mit dem Partner wegen der Körperpflege der Patientin. Er habe gestern geholfen? Wie es heute sei, wie sie vorgehen und was sie machen sollten? Der Partner sagt, es komme auf die Patientin an. (6c 2. 76-92, 163-169, 187-191)

Observing this man caring for the patient was remarkable: He in fact acted like a professional. The nurse, a student who had not often cared for the patient before, got support from an experienced nurse, but she clearly relied as much on the patient's partner. It was striking to hear *him* say that, regarding body care, they should do what the patient wanted. He mentioned that he had learned what he did from observation. He felt integrated on the unit and stated: "Somehow one becomes a part of it." („Irgendwie gehört man dann hier dazu." 6 po 716-717).

The partner later commented on his caregiving, explaining how he supported the patient in transfers from bed to chair, that he considered pain relief to be his major task, and that it was important for him to be present, because he was aware of the patient's reluctance to ask for help from others.

> I always said, to get her up: "Come on, embrace me," you know. And then she tightly held me, and I could then lift her. Or well, to turn to the chair or so: "Come on, let's dance tango a bit." Then she turned around with small steps, and I could help her sit down. That's how I did it.
> (...)
> I could only make sure that she was not in pain. When she said her leg would hurt, I just rang the bell.
> (...)
> You know, when I did it for her, it was okay for her. Then she did not depend on an outsider. She didn't like that, depending on outsiders. But when I did it, it didn't matter. Then it didn't matter. But she never wanted to depend on outsiders. (...) She would have waited ten times longer to get an injection, would have waited ten times longer to get some tea. (...) That's why I was glad to be able to stay. Because I knew exactly how she reacts... thinks, you know.
>
> Ich habe immer gesagt, zum Aufnehmen: „Komm umarme mich," oder. Und dann hielt sie mich ganz fest, und so konnte ich sie gut raufnehmen. Oder eben, beim Rumgehen auf den Stuhl oder so: „Komm, wir tanzen ein bisschen Tango." Dann hat sie sich mit kleinen Schritten gedreht, dann konnte ich sie hinsetzen. So habe ich das einfach gemacht.
> (...)
> Ich konnte einfach noch schauen, dass sie keine Schmerzen hat. Wenn sie gesagt hat, sie habe im Bein Schmerzen, habe ich halt geläutet.
> (...)

> Oder, wenn ich es für sie gemacht habe, dann war es ihr egal. Dann war sie nicht auf jemand Fremden angewiesen. Das hatte sie nicht gerne, auf jemand Fremden angewiesen sein. Aber wenn ich es mache, spielt es keine Rolle. Dann spielt es keine Rolle. Aber auf jemand Fremden angewiesen wollte sie nie sein. (…) Sie hätte zehnmal länger gewartet, bis sie eine Spritze erhalten hätte, zehnmal länger gewartet, bis sie einen Schluck Tee hätte trinken können. (…) Deshalb war ich auch froh, dass ich hier bleiben konnte. Weil ich genau wusste, wie sie reagiert… denkt, oder. (6 po 359-361, 720-747, 822-828)

This family member, who, by chance, had a holiday during the last week of his partner's life, threw himself fully into caring for her. His commitment was absolute; living meant caring for her during these last days. When the patient died, life lost its meaning completely for him. His suffering from the loss was tremendous, and it was extremely hard for him to discover a new horizon and begin leading a new life.

Although this family member suffered incredibly from his whole life situation, he still experienced caregiving as rewarding. The next section focuses on family members' experiences from their caregiving activities, while their experiences with leading a life together with a hospitalized patient suffering from a terminal illness has already been addressed in chapter four.

Experiences From Caregiving

Family members usually enjoyed spending time with the patients. One of them explained that she liked to visit the patient in the hospital; they could be together, and she might even be able to help him with something. This was more preferable than sitting at home alone (7b 233-237). But visiting could also be quite challenging. Spending whole days with her sleeping or non-responsive son was not possible for Mrs. Dolder, for instance. She used to stay with him when he was awake, but left his room for a walk or for a cup of coffee when he was sleeping. Occasionally, she went to his flat or met a friend during the day (4b 5. 514-541). She experienced massaging his arms and holding his hand as a good way to get into contact with her son when conversations were no longer possible.

The family member who spent many days caring for his dying partner, stated regarding his experience with caregiving: "I was glad that I could still help her a bit." („Ich hatte Freude, dass ich ihr noch etwas helfen konnte." 6 po 718-719). In the middle of his misery, this family member still experienced the rewards of being able to support the patient. She was dying, but thanks to his care, she suffered less pain and less embarrassment – a consoling thought. As witnesses of the patients' suffering, family members feel compelled to react. Actually being able to alleviate suffering is a relieving experience for them.

Summary

This final result chapter addressed patients' and family members' experiences with the care that the professionals in the hospital provided. Although care can never fully alleviate the existential suffering that a terminal illness brings along, the quality of the care they receive decisively influences patients' and families' perceptions of their hospital stay.

Patients and families value the care providers' steadfast endeavors to improve their quality of life and their advocacy. The care providers balance advantages and disadvantages of medical procedures – not always an easy task. The professionals tend to err on the side of intervening, and failures in this respect call for reflection. For some patients, the care providers readily achieve good symptom control, while they struggle unsuccessfully for others. Nagging symptoms can wear down patients to a point where living means suffering and seems worthless. A comprehensive and continuing approach to

symptom management is required to alleviate symptoms and open up patients' worlds again. The consideration of details, flexibility and good coordination allow most patients and families to experience the care they received as adequate. Inadequate care results from providers' lack of expertise, disregard of details, or carrying on routines regardless. The care providers more or less successfully strive for individual care, which requires them to do the right thing at the right time in the right way, to constantly adapt the support they give to the patient's fluctuating needs, and to share responsibility regarding decisions on care interventions with patients. Knowing patients and family members, recognizing them as persons, and phronesis – practical knowledge about how to act well – are prerequisites to attune care to individual patients' and families' felt needs. Patients and family members welcome understandable, honest, and timely information by a knowledgeable provider, and counselling that meets their particular situation. Advice is easily misguided, if it does not take into consideration how closely intertwined family members' and patients' lives are. At times, care providers intervened with great social competence, preventing negative developments for patients and families. Such actions are easily overlooked, but essential in the context of a distressing hospital stay. Unfortunately, some care providers also act inappropriately, even unethically, causing tremendous distress and avoidable suffering to patients and families. The care providers' skills are decisive regarding the quality of care, however, the latter does not solely depend on them. The patients' and family members' ability and willingness to articulate needs and concerns, their expectations, and the structure and organizational system of the hospital are other influential aspects.

The care providers mostly consider patient and family as the unit of care, living up to the goal of palliative care in this respect. For family members and patients, each others

well-being is paramount; the patients' needs clearly have priority for family members. The welcoming atmosphere on the units allows family members to care for patients as much and in the way that is appropriate to them, from keeping company for a limited time to nursing around the clock. Being able to contribute to the patients' well-being is a rewarding and relieving experience for family members. Their presence and caring enables patients to maintain connections with their homes and everyday life; patients and family members are going on with their lives together.

In conclusion, this chapter demonstrates how the hospital, where the terminally ill patients and their family members as guests of necessity have to live – and where some patients die – is constituted as a social space by the professional care providers. Several examples illustrate the negative consequences of sub-optimal care. Care providers, who lack a caring stance towards patients and families, are inattentive, or do not have the needed skills and expertise, are unable to recognize patients and family members as persons, to act adequately and attune care interventions to particular patients. Inappropriate actions, such as the use of cost-and-effect language or expressing mistrust towards a family member, are profoundly painful for patients and family members, and they experience being disregarded and devalued as dehumanizing. Inadequate care adds avoidable suffering to patients' and families' burden of living with a terminal illness and being in the hospital.

However, this chapter also demonstrates the power of adequate and finely tuned care interventions to greatly improve patients' and their families' well-being. Committed and caring providers who give individualized care enable patients and families to accept this care and feel well cared for; the hospital stay becomes more bearable. Effective care interventions, which ensure patients' and families' best possible quality of life, contribute to keeping their horizons open, to preventing a premature closing down of their worlds from suffering. Care interventions that are frequently considered mundane and uninteresting, such as support in activities of daily living, appear as complex and challenging tasks and become powerful recognition practices in the context of illness and disability. Skillful emotional engagement and expertise in providing effective and attuned care hold many possibilities for humanizing the hospital setting for patients and families and help them move on together.

CHAPTER EIGHT: CHALLENGES AND POSSIBILITIES IN PROVIDING HOSPITAL END-OF-LIFE CARE

This study aimed at exploring terminally ill patients' and families' experiences with hospital end-of-life care. From conversations with patients, interviews with family members and observations, it soon became clear that to focus only on care experiences was too narrow. The patients' and families' experiences of living with a terminal illness and being in the hospital had to be considered as well.

Patients and family members do not experience the care they receive in the hospital as isolated events that can be described independently. Rather, their experiences with receiving care are deeply embedded in the experience of being in the hospital. A hospital stay encompasses more than the care by professional providers; it means being in this at first alien place away from home for 24 hours a day for the patient, and visiting this place regularly for the family member. Care episodes are parts of the hospital stay and shape patients' and family members' experiences of being in the hospital, whereas their experience of the whole hospital stay shapes experiences of the care they receive. Furthermore, every hospital stay is only an episode, although at times a very decisive one, in the life of patients and family members. They are leading their unique life and, when facing a terminal illness and during hospital stays, they are still continuing to live this life. Therefore, the experience of being in the hospital cannot be related or understood independently from patients' and family members' life stories.

The presentation of the results takes into consideration that a focus on care experiences of patients and family members would provide an incomplete picture, it

accounts for a broader approach. The findings show how patients' and family members' way of leading their life influences and is influenced by their experiences of being in the hospital and of receiving professional care.

Findings Revisited

The study participants' stories illustrate how their lifeworlds are disrupted when a terminal illness intrudes. The everyday life can no longer be taken for granted. The terminal illness causes suffering to patients and families, suffering from the loss of life plans and a common future, from physical and mental disabilities, from caring for patients and being witnesses to their suffering, and finally, from facing death. In the midst of suffering, nevertheless, some patients and family members still experience some good and meaningful times along with the bad times. The patients' and family members' accounts also show how they hold on to familiar background meanings, practices and language, while moving in the new worlds of illness, hospital and professional caregiving. Their stories render their situation in the hospital more understandable and open up possibilities for the providers to individualize their care.

Patients and family members experience the hospital in different ways at different points, for instance, as prison, heaven, or necessary sojourn. Their perceptions may alter or fade away over time, but are decisively influenced by the illness and the care they receive. Retaining connections to their home supports patients' and family members' dwelling in the hospital.

Patients and family members greatly appreciate care providers who show commitment and concern, while they experience a lack of this caring stance in providers as problematic and disruptive. Family members feel integrated in the hospital if they are

welcomed, well informed, and have free access to the patient. Patients and family members are aware of the reciprocal nature of their relationships with care providers and try to contribute to good relations. The perceived continuity of care and the units' atmosphere also influences patients' and family members' care experiences. The care providers' commitment and caring enables them to be alert to the felt needs of patients and family members and subsequently enables the latter to receive support, whereas a lack of concern leads to inattentiveness and to feelings of being disregarded in patients and family members.

Professional care in the hospital cannot alleviate patients' and families' existential suffering from a terminal illness. However, the quality of care decisively influences patients' and families' experiences. Most care providers take great efforts to improve patients' quality of life, to prescribe adequate medical procedures, to control symptoms optimally, and to attune their care to patients' and family members' individual needs. Thus, patients and family members mostly experience the care in the hospital positively. However, some experience sub-optimal care. When providers lack the needed skills, act inappropriately, do not know the patient and the family member, or do not recognize them as persons, patients and family members suffer unduly and care is experienced as devaluing and dehumanizing. In addition, patients' and families' care experiences are also influenced by the latter's expectations and by the hospital structure and organizational design. For family members and patients, each other's well-being is paramount. The care providers mostly consider patient and family as the unit of care, which allows family members to contribute to the patients' care in the hospital. Through family members' presence and caring, patients can maintain connections with their

homes and everyday life; patients and family members can continue to lead their lives together.

The Findings in the Light of the Literature

The literature review shows that descriptions of patients' experiences with hospital end-of-life care are rather scarce, while the body of literature related to families' experiences is more extended. These publications provide a fractured and incomplete picture of patients' and families' experiences with hospital end-of-life care.

In contrast to the publications focusing on specific aspects of care, this study provides a local and particular, but more comprehensive picture of patients' and family members' experiences with actual hospital end-of-life care. The study shows that care experiences cannot be considered in isolation, because they are intertwined with patients' and family members' feelings about being in the hospital and with their way of living their particular lives. The examples of Mr. Dolder (p. 254) and Ms. Egger (p. 265), who saw the hospital as prison and as heaven respectively, point out two very different and specific ways of experiencing the hospital, while the stories of the Blum (p. 191) and Alder (p. 204) families illustrate particular ways of leading a life and of going on with this life when a terminal illness intrudes.

Nevertheless, publications point to an array of issues that influence patients' and families' experiences either positively or negatively. A comparison of findings in the literature to results of this study reveals correspondence in many areas. Three themes, namely the relevance of good communication, the need for excellent basic care, and the high satisfaction levels in spite of insufficient symptom control, are taken up in the following paragraphs.

The Relevance of Good Communication

Early studies investigating family members' needs as well as more recent publications on patients' and families' experiences pointed out communication among patients, families and care providers as an important aspect of hospital end-of-life care (Addington-Hall et al., 1991; Andershed & Ternestedt, 1998; 1999; Berns & Colvin, 1998; Hampe, 1975; McCormick & Conley, 1995; O'Brien Abt, 1983; Irwin & Meier, 1973; Pierce, 1999; Rogers et al., 2000; Ryan, 2003; Sykes et al., 1992; Wenrich et al., 2001; Wright & Dyck, 1984). Patients and family members valued professionals who listened to them, provided ongoing and honest information, and gave this information, especially bad news, in a sensitive way and in an adequate place. However, many patients and families experienced a lack of information and problems with communication that overshadowed the whole experience of care.

Similarly, patients and family members in this study experienced adequate information, that is, understandable, honest and timely information provided by knowledgeable professionals, as very helpful. The couple, who faced the recurrence of the woman's lung cancer and several diagnostic tests that would enable the physicians to suggest an adequate palliative chemotherapy, serves as an example (p. 376). However, the same couple was left in limbo regarding the next steps, because further treatment decisions depended on the effect of the current radiotherapy (p. 230). This highlights an aspect, which has hardly been addressed in the literature, namely that the trajectory of the terminal illness is often unpredictable and, therefore, the much desired information may not always be available. Thus, a lack of information is related to insufficient communication, but even with excellent interactions, professionals may be limited to

explaining which factors will influence future decisions and that questions cannot be answered at the moment due to the ever variable and unpredictable illness trajectory.

The study participants did not always experience communication with professionals as adequate. While most providers were described as very kind, empathic and considerate, some were experienced as rather cold and distanced or even insensitive and harsh; accordingly, communications with these providers were problematic. The Dolder family, for instance, experienced a resident's conversation with the patient after his fall off the wheelchair as inappropriate (p. 302). And although the patients and families in this study did not complain about conversations in public places, the context of communications with care providers was not always experienced as adequate, for instance, when the Dolders experienced the round table conversation as a tribunal (p. 383).

Counselling that met and took into account patients' and families' individual situations was highly valued. For instance, talking about death was comforting for Mr. Dolder (p. 376). However, family members, who had fully committed themselves to caring for a patient, experienced professionals' suggestions to take a break and go on with their own life as inadequate and misunderstanding their relationship with the family member (p. 379). This is another finding of the study that has barely been described in the literature. Professionals, who take seriously the call to not only care for patients, but for family members as well, may easily feel compelled to suggest a rest from caregiving when they meet exhausted family members. Hence, such advice disregards the family members' perspective; it overlooks that caring for the patient is their current world-defining concern. The advice is, therefore, experienced as inappropriate.

The Need for Excellent Basic Care

Across studies, the patients' well-being had priority for family members, and in several publications the relevance of basic care was mentioned (Atwood, 1977; Dyck & Wright, 1985; Freihofer & Felton, 1976; Hampe, 1975; Petit de Mange, 1998; Rogers et al., 2000; Teno et al., 2001). A lack of assistance with activities of daily living, such as feeding or maintaining personal hygiene, was experienced very negatively and seen as compromising the patient's dignity. While family members may not always know what to expect regarding medical treatments, they are certainly able to judge if the patient looks well groomed. Family members, as patient advocates, felt burdened when they perceived the care as insufficient (Rogers et al., 2000; Teno et al., 2001).

For the participants in this study, adequate basic care for patients was also essential for positive care experiences. But while the literature occasionally mentioned positive or negative examples, this study provides numerous concrete narratives. These care episodes illustrate, on the one hand, how a lack of experience, compassion, and attentiveness led to inadequate care, for instance, when the nursing student was feeding Mr. Dolder (p. 367) or when the nursing assistant missed to deal properly with the patient's urinary bag (p. 329). On the other hand, these stories show that caring and experienced providers could skillfully attune their care activities to particular patients' needs, so that, for instance, receiving body care was experienced as natural or even enjoyable, rather than embarrassing (p. 331). The narratives highlight that mundane care activities, such as feeding or bathing, become challenging and complex nursing interventions in the presence of illness, suffering and disability. The examples also point out how fine tuned care interventions work as powerful recognition practices.

High Satisfaction Levels in Spite of Insufficient Symptom Control

Repeatedly, publications described the prevalence of many symptoms in terminally ill patients and a lack of symptom control, while family members as study participants still reported rather high overall satisfaction with care (Addington-Hall et al., 1995; Addington-Hall et al., 1991; Lynn et al., 1997; McCarthy et al., 1996; Rogers et al., 2000; Sykes et al., 1992; Tolle et al., 2000; 2000). This discrepancy also appears in the current study; for instance, the patient who highly praised the professionals for their caring and concern (p. 324) did never have her vomiting and constipation relieved (p. 352).

This study illustrates that patients' and family members' expectations may differ greatly. The immigrant patient, for example, did not even expect to be cared for in the hospital (p. 394). Patients and family members who do not know what they can expect regarding symptom management, but feel that the professionals try hard, will likely be satisfied with their care and assume that a better symptom control is impossible. Patients may in fact expect to suffer from symptoms with a terminal illness, as Mr. Blum explained (p. 197). In addition, patients' willingness to acknowledge symptoms and their ability to express their needs varied (p. 391). Thus, achieving the best possible symptom control for terminally ill patients requires professionals who adequately engage with patients and help them articulate their needs, and who take on the responsibility to provide optimal treatments according to palliative care standards. Like Masterson (1996) and O'Neill (1999), I consider a lack of knowledge and expertise in palliative care as the main reason for insufficient symptom control.

Leading a Life – Taken for Granted and Overlooked

Persons and families lead their unique, biographical and historical life, while they share with others the world of their society and culture. Thus, it seems obvious that people continue to live their life when a terminal illness intrudes. Persons and families are leading a life; that is just what human beings do, and it is, therefore, a taken-for-granted fact. It seems at first banal to mention this fact and elaborate on it. However, because it is so much taken for granted, it resides in the background and gets overlooked. When a terminal illness breaks into patients' and family members' lives and shakes up their everyday lifeworlds, they become aware of aspects of their life that they do not usually take into consideration consciously; issues that have resided in the background are brought to the foreground through the illness. But even when living with a terminal illness, patients and families still cling as much as possible to their own unique ways of leading their life without becoming fully aware of all its aspects. That is, the terminal illness brings certain issues to the foreground, but not all of them; many parts of patients' and families' lives still remain in the background, while nevertheless influencing their actions, behavior, and perceptions. The fact that patients and family members continue living their life is still taken for granted and overlooked.

Taking their way of living for granted and overlooking it works well for patients and families as long as they live in their familiar worlds of home, work, and so on, and meet people who usually belong to these worlds. As long as people move in their everyday worlds, they are recognized as individual persons with their particular identity and social roles as family member, employee, colleague, and so on.

Taking their way of living for granted and overlooking it may become problematic, however, when patients and family members are moving in the new worlds of illness, hospital, and professional caregiving, where they may meet health care providers with whom they share a cultural background, but whose lifeworlds may be different in many aspects. The illness, the alien hospital environment, and the need for professional care render patients and family members vulnerable. In the midst of extreme illness, their well-being heavily depends on the care providers. Patients may become one patient among others, family members may be seen as just another visitor; their particular identity is unknown in this new world, and patients are thrown out of their social roles. The non-recognition as an individual person may create a sense of loss of identity and even self-worth for patients and family members; the hospital may appear as an impersonal bureaucratic institution (Coyle, 1999; Pierce, 1999; Rogers et al., 2000). Taken to its extreme, patients and families may experience the hospital as a total institution, where blocks of human needs or people, not individual persons, are handled by an organization (Goffman, 1961).

Being recognized as a person requires a dialogue with others (Taylor, 1991). Such a dialogue is influenced by the way people relate to each other; the care providers as the more powerful partners may either foster this dialogue and enable patients and family members, who depend upon them, to open up, or their way of meeting patients and families may preclude a dialogue (Van Manen, 1999). With care providers who relate to patients and family members in a detached, or even authoritarian or intimidating way, this dialogue is not taken up, and patients and family members do not feel recognized. Professionals who do not recognize patients and families as persons, overlook their

particular ways of living, and take for granted the hospital world, which is so familiar to them, will provide routinized care and likely focus on the obvious physical needs; patients' and family members' individual needs will not be met and identity-conferring concerns will be further disrupted rather than supported.

For instance, the care providers did not take up this dialogue successfully with Mr. and Mrs. Alder. Without knowing Mr. Alder's story, they did not recognize that, for many years, he had best coped with his illness by going on with life and work, and that he had no intention to change his approach in the hospital. Similarly, the professionals did not realize Mrs. Alder's very different perspective, but just labelled the couple as being in denial. In accordance with the routine approach, they then unsuccessfully tried to promote awareness of the patient's impending death in the couple (p. 204).

In contrast, patients and family members feel recognized as persons when professionals take up the dialogue with them and skillfully relate to them in a way that allows them to tell their stories and trustfully talk about their concerns. These care providers elicit and listen to patients' and family members' life stories, to their joys and concerns, as well as to their illness experiences, and take into consideration that the hospital world looks very differently from the latter's perspective than for themselves. They will be able to recognize specific physical as well as psychological, social and spiritual needs, adapt interventions and provide more individual and comprehensive care. Patients and family members will feel well cared for.

Furthermore, providing excellent and individual comfort care works as a profound recognition practice, and adjusting care to accommodate patients' and families' identity-conferring concerns helps them to continue living their life while in the hospital and even

when approaching death. When patients and families were met in their lifeworlds, the professionals were able to open up the needed space and create possibilities that allowed patients and families to go on with their life until death – to complete their common life in their own unique way. The dying patient and her partner, who was fully integrated in her care and allowed to stay 24 hours per day at the unit, can serve as an example (p. 413).

Most patients and family members in this study wished to go on with their usual life as much as possible given the consequences of the terminal illness and the constraints of a hospital stay. They felt best cared for when the professionals supported them in this endeavor through excellent palliative care. That is, they seemed to prefer what has been described as generic approach (p. 53). This perspective offered by the patients and families stands in contrast with expert literature on hospice care that points to developmental tasks and "work" to be done by those dying and those letting go. These patients and families, despite being aware of impending death, did what they knew how to do – they continued living their life with familiar concerns, goals, and relationships.

End-of-life care in the hospital tends to have a bad reputation. Death in the hospital is often seen as a lonely, anonymous death, where the dying is surrounded by technology rather than by a committed family and caring providers. Through the recognition of the patient and the family members as unique persons, death is acknowledged as the ending of a particular patient's biographical identity and life. Death can be experienced as a human passage instead of being seen as a clinical event (Benner, 2001a), as the story of Mr. Dolder's death illustrates (p. 250).

Abstract and generalizable scientific theories provide valuable explanations and guidelines for interventions. However, if their application is taken too far, theories can become deterministic and prescriptive. Patients' and families' particular lives and illness experiences are always far more complex than any theory. Knowing patients' and family members' life stories and illness experiences and meeting them as persons can be seen as a bridge from theory to practice; it enables professionals to appropriately adapt and use general scientific knowledge when caring for particular patients and family members. Knowing patients and family members as persons is also a central notion of good, the expression of a relational ethic that respects how human beings, who are socially constituted, want to be known and recognized as the person they are and have been in their life.

The conclusions that this study led up to are not novel, although, to my knowledge, no other study has described the interrelationship of patients' and families' way of leading their life and care experiences, the importance of caring, recognition, and excellent care, and the problems of non-recognition and sub-optimal care in relation to terminally ill patients' and family members' experiences with care in a particular hospital. However, the interaction of lived experiences and theory was a central theme in writings about phenomenology from Heidegger (1927/1962) to, among others, Gadamer (1960/1995), Taylor (1985a; 1985b), and Dreyfus (1991). The discussion was also taken up in medicine and nursing (Benner & Wrubel, 1989; Toombs, 2001b). Several nursing studies illustrated the relevance for care providers of taking patients' and families' lived experiences into account in other areas of the field (Benner, 1994d; Boller, 2001; Cho, 2001; Drought & Koenig, 2002; Habermann-Little, 1993; Kesselring, 1990; Kinavey,

2002; Koenig, 1999; Ryan, 2003; Weiss, 1996). The relations of caring relationships between providers and patients and families, of knowing patients and families and of positive patient and family experiences and preferable outcomes have been shown repeatedly (Benner et al., 1999; Benner et al., 1996; Luker, Austin, Caress, & Hallett, 2000; Radwin, 1996; Whittemore, 2000).

A Call for Phronesis and Techne

Terminally ill patients have to undergo medical procedures and nursing interventions during their hospital stay. Therefore, knowledgeable professionals are called for who can carry out requested tasks and achieve excellent results without unduly burdening patients. These professionals are able, for instance, to easily insert an intravenous line or produce well readable X-rays. Patients value expert professionals who act effectively and prevent unnecessary suffering; stated otherwise, Aristotle's productive knowledge or techne is welcomed (Dunne, 1997).

However, techne is not sufficient; patients' and families' good or bad experiences with hospital care do not depend on outcomes only. Rather, their lived experiences are strongly related to the process of caregiving, to their relationships with professionals, to the latter's caring and way of acting. Phronesis, embodied practical knowledge about how to act well, is also required (Dunne, 1997). Phronesis calls for care providers, who engage in their actions and with patients and families, can apply universal knowledge in a particular context to individual patients and families, and strive for excellence while continually learning from their experiences.

Patients and family members are not always aware of the best possible outcomes, whereas they are constantly being cared for. Accordingly, their experiences of the care

they receive are mainly shaped by the process of caregiving. When providers are caring, patients and family members may experience their care as excellent, even though achievable positive outcomes, for instance pain control, are missed. The responsibility to acquire the needed scientific knowledge and technical skills and to transfer them appropriately into practice rests with the care providers.

Phronesis is relevant for such a complex area as end-of-life care, where unspecific situations and rapid changes are common and the nature of the illness trajectory is often undetermined. At each point, care providers have to provide attuned care interventions. Often means and ends are joined or even trade places. Clinical judgment, caring practices and technical skilled know-how must be intertwined in order to respond to the patients' and family members' changing needs. If patients and family members are consulted, care can be tailored to their particular needs over time, and the best possible quality of life can be achieved for them.

Hospital End-of-Life Care as a Caring Practice

In chapter one, the notion of a caring practice was outlined, based on Benner and Wrubel's (1989) description of caring and on definitions of practice by Taylor (1989), MacIntyre (1984), and Whitbeck (1984). Thus, a caring practice refers to a culturally based, shared activity with a tradition, which attends to persons and may be performed in the private or public area. Its practitioners are genuinely committed to these persons; they strive to achieve the practice's standards of excellence and, thereby, realize goods internal to the practice and extend their capacities to achieve excellence as well as their standards of excellence. Palliative care has been described as the gold standard in end-of-life care, and I claimed that it constitutes a caring practice. The literature review shows

that terminally ill patients' and their families' perceptions of what constitutes satisfactory end-of-life care in the hospital are in agreement with the goals of palliative care, that is, excellent symptom control and adequate psychological, social, and spiritual support in order to achieve the best possible quality of life for patients and families. The question arises if the hospital end-of-life care that the study participants experienced represents a caring practice and to what extent palliative care was actualized.

Patients and family members who participated in this study mostly experienced the care they received in the hospital positively. Many care providers were greatly committed to the patients and their family members; they showed empathy, consideration, patience and respect, and were experienced as caring and very attentive. Ms. Egger's story about how the nurses recognized and solved her problem with a roommate (p. 326) illustrates, for instance, these positive attitudes. Continuity of care and a pleasant atmosphere on the units were welcomed. The patient who praised good documentation and communication and another's illuminating analogy on how nicely he experienced the unit's atmosphere may serve as examples (pp. 318, 321). Patients and family members asserted that many of their felt needs were met, and they related that they got all the support they needed. They experienced the care as being adequate and finely tuned to the individual patient's and family's particular needs and concerns, and as comprehensive, that is, as extending beyond physical needs to the patient's and family's whole living situation. The immigrant patient's and her partner's experiences underline this (p. 326). Patients and family members especially valued the care providers' endeavors to achieve the best possible quality of life for them. For instance, Ms. Egger and her partner greatly appreciated the rosemary compresses that the nurses offered as a complementary measure to relieve symptoms from constipation (p. 340). For some patients, a good symptom control was achieved, their health status was stabilized or even improved so that they could return home once more, a much hoped for goal for many, including Mr. Blum (p. 201). Most family members felt welcomed and integrated by the care providers. This gave them the possibility to be with and care as much as wished for the patient, and to feel some rewards of their caregiving. The experience of the partner who could continually care for the dying patient serves as an example (p. 413).

Thus, in many situations, the care providers' caring stance, their attentiveness, their endeavors to achieve the best possible quality of life, to control symptoms, to provide adequate and attuned care, and to integrate the family members, yielded positive results for patients and families. In these respects, the professionals were able to actualize palliative care standards; they successfully took up the challenges of the caring practice of palliative care.

However, patients and family members also experienced sub-optimal care, and these negative experiences partly cloud the positive picture. At times, care providers did not live up to the above positive aspects. They were not always experienced as caring and attentive; for instance, one wife felt disrespected by certain providers (p. 307), and a patient experienced the nurse on night shift as unfriendly and uncaring (p. 296). Some care interventions seemed inadequate; the care providers lacked the needed skills to attune their actions to patients' and families' particular needs. An example is a nurse's unsuccessful attempt to plan Mr. Alder's discharge with the patient and his wife (p. 359), another one the nursing student who provided inadequate assistance when feeding Mr. Dolder (p. 367). The balancing of advantages and disadvantages of medical procedures and the struggle for symptom control did not always yield satisfactory results. One wife's story of the likely futile tube insertion (p. 344) and the unrelieved nausea, vomiting and constipation of a patient (p. 352) illustrate this. Finally, some inappropriate actions of providers caused unnecessary suffering to patients and families, for instance, a physician's slide into economic language during a conversation with a patient and his family (p. 385).

Most palliative care institutions offer occupational therapy that allows patients to still be creative and find a way to express themselves. Most specialized institutions also provide bereavement counselling for family members. While a few patients profited from occupational therapy sessions, and one counsellor continued to support a bereaved partner (p. 377), these services were not officially available for most patients and family members in the hospital.

Thus, the standards of excellence in palliative care were not always actualized for the patients and family members who participated in this study. This does not seem surprising in a hospital without any form of a specialized palliative care service, where few care providers have special knowledge in palliative care at their disposal. Consequently, the great compassion and the endeavors of most professionals to provide excellent end-of-life care to terminally ill patients and their family members were at times jeopardized by a lack of scientific knowledge and expertise in palliative care.

In summary, the analysis of patients' and family members' experiences confirm the conclusions of the literature review. The study results demonstrate that what participants consider as good end-of-life care corresponds well with the description of palliative care as a caring practice. That is, professionals in the hospital are called by the patients' and

family members' vulnerability and suffering to provide more than routine care. Patients and families must be met in their lifeworld and in response to their particular concerns. Caring providers must skillfully intervene by adhering to the standards of excellence in palliative care.

Allocation of Resources

According to MacIntyre (1984), institutions are involved in acquiring and distributing material goods such as money and power. They have to do so to sustain themselves and the practices they bear. Without institutional support, practices cannot survive. Thus, practices and institutions – in this case the hospital and end-of-life or palliative care as a caring practice – are closely related. The goods internal to a practice are always vulnerable to the acquisitiveness and the competitiveness of the institution. That is, the goods that excellent end-of-life care can bring about – caring relations to providers, the best possible quality of life for patients and families, completion of a unique life, a peaceful death for the patient, bearable memories for the family – clash with the hospital's financial interests that call for efficient procedures, measurable outcomes, and reducing length of stays. For instance, allocating a single room to a patient with basic insurance coverage only ensures privacy for the dying patient and the family, gives the latter undisturbed access 24 hours per day, and saves other patients from witnessing the death of a roommate. But what seems the right thing to do from a human and ethical perspective means of course a monetary disadvantage for the hospital.

Caring cannot be mandated, it can only be facilitated. A caring practice cannot survive on its own; it needs the support and nurturance of the institution bearing it. What looks strikingly easy when it works at its best requires skilled and experienced professionals who are able to build up and maintain a well coordinated interdisciplinary team, to create a pleasant atmosphere on the unit, and to ensure care continuity. A caring practice calls for professionals who let patients and families matter to them and engage in a meaningful dialogue. These professionals also constantly strive for improving their practice. Thus, staffing levels are required that prevent high turnover rates and burnout from constant work overload, but allow team building and learning from experience, for instance by providing time for team meetings. Stated otherwise, the caring practice of palliative care can greatly improve the quality of life for terminally ill patients' and their families' and open up the possibility for them to complete their common life in their own way. The practice also has the potential to contribute to a positive reputation of the hospital. Building up and maintaining the practice over time, hence, depends on the allocation of adequate resources.

However, the caring practices that patients and families highly value are easily overlooked and often taken-for-granted unless a breakdown occurs. For instance, the nurse's decision not to send the patient to the X-ray department without giving pain medication first ensured the patient's comfort during the procedure (p. 341). But this advocacy becomes barely visible; it is likely that only a breakdown, such as the painful mammography (p. 312), gets recognized. Thus, caring practices tend to be marginalized.

Furthermore, publications (Czerwiec, 1996; Hampe, 1975; Rogers et al., 2000) showed that patients and families frequently excused shortcomings in caregiving with heavy workloads, staff shortages, and a lack of resources. This study demonstrates the same tendency and alludes to a potential reason for patients' and family members'

unwillingness to complain: They may not want to risk jeopardizing their relationship with care providers (p. 313).

In addition, two large studies revealed only minor differences between hospitals and hospices regarding care outcomes, such as symptom control (Greer et al., 1986; Kane et al., 1985). Devery et al. (1999) concluded that, by focusing on quantifiable outcomes, the researchers missed the unique contribution of palliative care services. These two and additional studies (Dawson, 1991; Higginson, 1990; Seale & Kelly, 1997; Seamark et al., 1998; Teno et al., 2004; Wakefield & Ashby, 1993) comparing hospital and hospice showed that hospice care was mostly perceived as better due to a greater presence and involvement of families, better communication with staff, and more psychosocial support for families before and after death – aspects that relate to the process of care and are not easily quantified and measured. The findings of this study reinforce the conclusions from the literature by underlining that process-related aspects of professional care, such as caring and being recognized as persons, decisively influenced patients' and families' experiences.

Thus, while caring practices markedly influence patient and family care, these practices are easily taken-for-granted and marginalized. Means and ends are often intertwined, so that, while patients and families can relate positive or negative experiences, outcomes are not easily transferred into measurable quantities. Furthermore, patients' and families' tend to excuse shortcomings, rather than standing up and calling for appropriate care. Given this situation, it is all but easy to demonstrate the need and argue for the allocation of adequate resources to the caring practice of palliative care. On the health care policy level, this is problematic for all institutions that care for terminally ill patients and aim at providing palliative care. Resource allocation may be a less prominent problem on the institutional level for a hospice, when the provision of palliative care is the central purpose of the whole institution. In a hospital, however, where multiple purposes compete and resource allocation is mostly based on the effectiveness of measures and demonstrable outcomes, caring practices like palliative care are easily marginalized further, and urgently needed resources are not allocated. Researching patients' and family members' experiences of hospital end-of-life care, that is, articulating caregiving that does or does not live up to the challenges of palliative care as a caring practice, is one way to highlight the relevance of excellent end-of-life care; through articulation, the practice is moved from the margins to the foreground. This study may, thus, provide arguments for adequate resource allocation within the hospital as well as on the health care policy level.

Interpretive Phenomenology as an Appropriate Method

Svenaeus (2001) said that Husserl's "back to the things themselves" taken to the area of health care means going beyond theories of diseases to the experiences of the ill persons who suffer from these diseases. Thus, phenomenology provides an explication of the distinction between the immediate experiencing of everyday life with an illness and the scientific account of these experiences (Toombs, 2001a). In this study, interpretive phenomenology was used to explore patients' and their families' experiences with hospital end-of-life care, with being in the hospital, and with leading their life with a terminal illness. Interviews, conversations and observations provided numerous examples of concrete lived experiences, which then allowed reflecting upon and articulating their meanings (Van Manen, 2002). Interpretive phenomenology has proven to be a very appropriate method for this study.

This interpretive phenomenological account highlights a variety of patients' and families' experiences, including common and distinct, positive and problematic aspects of hospital end-of-life care, being in the hospital, and leading a life with a terminal illness. The account can support terminally ill patients' and family members' voices (Benner, 1994c). These voices are often not recognized in the current debates about health care and health care costs. Patients' and family members' stories can also increase health care professionals' awareness and positively affect their caring practices as well as the deleterious effects of the absence or diminution of caring practices.

Limitations

This study explored experiences of ten terminally ill patients and their family members in one university hospital in Switzerland. All patients suffered from cancer, their mean age was 62.7 years (range 38 – 85), and most family members were the spouse or partner. Patients who were too sick or tired, as well as patients and family members who were for other reasons unwilling to relate their experiences, did not participate. Thus, the results provide a particular and local picture of patients' and family members' experiences of living with a terminal illness, being in the hospital and receiving professional care. However, I claim that the basic structure of care experiences as being embedded in the experiences of being in an institution away from home and of leading a life with a terminal illness apply as well for patients and families in other settings, be it in another hospital, in a nursing home, or in a hospice. The same holds for the positive

effects of caring providers. Readers must decide if and which particular aspects of the findings described in this study are transferable to different settings.

From the findings of this study it may well be concluded that they do not solely apply for terminally ill patients and their families. In fact, many aspects of care experiences, of being in the hospital, and of leading a life described in this study may also be relevant for acute or chronically ill patients and their families. Due to the difficulty to prognosticate which patients would die in the hospital, this study sample included a few patients whose health status improved more than expected at the moment of their recruitment, and some others who recovered just enough to be discharged. With these patients' recovery, they and their families no longer faced the patient's imminent death in the hospital; the patient could return home once more. Such patients' and family members' experiences may be comparable to other seriously ill patients' and their families' experiences of being cared for in the hospital.

What remains different, however, is the context, namely the fact that the patients and families in this study were confronted with a terminal illness. With no cure available, sooner or later, the patients faced the ultimate collapse of their world and family members the definite loss of a loved one. When cure is no option, the goals of care need to be shifted to improving comfort and well-being, along with attending to and supporting patients' and family members' central life concerns. The extent to which care providers are able to achieve these goals in cooperation with patients and families determines the quality of the common lifespan left to patients and family members.

Finally, when death approaches, a peaceful death for the patient becomes the ultimate goal. The care providers are challenged to continue providing excellent comfort care to the patient and adequate support to the family. In addition, they are also challenged to go beyond nursing, to acknowledge the patient's death as the end of a particular person's life, and to open up a space that allows the patient and the family to live their common life until the end in their unique way, whatever this may mean regarding the family's presence, involvement, closing relationships, religious or other rituals, and so on. The patients' experiences during the final days and hours in the hospital depend to a great extent on the care they receive as well as on the illness trajectory, and their suffering ends with death. The family members, however, continue living and for them, witnessing a beloved person's terminal illness and death causes lasting memories, memories that are decisively shaped by how well or poorly their loved one was cared for in the hospital (Berns & Colvin, 1998; Saunders, 1984a). With patients who are discharged once more, the care providers may get a chance to "remedy" bad experiences to some extent or at least cover them over with better ones during a subsequent hospital admission. When patients die, there is no second chance to improve their situation, and the family members will have to live and come to terms with their memories of the death – extremely painful lasting memories with bad care experiences, or bearable, sometimes even consoling, memories with optimal care and a peaceful death.

Eventually, a methodological limitation has to be mentioned, namely that there is no clear end-point to interpretations in phenomenology. The option of a deeper, more comprehensive or more convincing interpretation always remains available (Leonard, 1994). In this study, not all the themes that appear in the data were explored further, for instance, patients' and family members' experiences with roommates and other visitors were not described. Furthermore, the participants' world can never be articulated

completely (Benner, 1994c). The findings in fact reveal situations where the articulation of specific experiences could not be taken further in the participant – researcher dialogue. Thus, these findings represent one account of patients' and families' experiences that is neither exhaustive nor the only possible.

Implications for Practice

The fact that no cure is available, never means that "nothing can be done" for terminally ill patients and their families. This has been proven in the palliative care literature, and this study underlines it again. The professional health care providers in the hospital can make a decisive difference. Their commitment, a caring relationship, getting to know and recognizing patients and family members as persons, opening up the space to let patients and families go on and complete their unique life, and applying the available knowledge in palliative care optimally to individual situations greatly contribute to patients' and families' well-being and humanize the hospital setting.

Even with the best possible care, however, patients' and families' existential suffering from the losses that a terminal illness brings about cannot be prevented. Still, the professionals can acknowledge this suffering and take care not to add unnecessary burden, not to put stumbling blocks, but rather to remove them from patients' and families' paths. In addition, the care providers should keep in mind that, even when they know patients and families well, they never get to know all aspects of their lives, and they should remain careful to respect boundaries set by patients and families.

In order to provide excellent palliative care, the professionals in the hospital need to acquire a solid, scientific knowledge base and to keep themselves updated regarding new developments. Thus, further education specializing in palliative care should be made

available, and access to the relevant literature should be ensured. Since professionals who work on acute care units can barely focus on palliative care only, a consulting specialist team might be a valuable resource. A palliative care unit within the hospital could provide optimal care for the most complex cases and serve as a learning centre.

Patients and family members experienced many providers as committed and caring. The atmosphere of several units was perceived as comforting. These positive aspects must be maintained and nourished, while lapses should be taken up as learning possibilities. Excellent practice should be recognized and rewarded. Individual professionals as well as teams can learn from reflecting upon good and bad practice examples. An ongoing dialogue contributes to the development of expertise and of a shared vision of what constitutes excellent practice on a unit. Less experienced team members can learn from the more experienced ones, and all can be challenged to live up to the unit's expectations. Better articulations of what is experienced as good and poor care, such as described in this study, are needed to make the centrality of good caregiving more visible and more valued. Supervisors can promote end-of-life care in the hospital by supporting team building and continuity, fostering a climate for clinical learning, and take into account team members' different levels of expertise (Benner et al., 1996).

The provision of hospital end-of-life care that will ensure the best possible quality of life for patients and families will be experienced positively by them. Such care, however, does not solely depend on caring, knowledgeable, and experienced individual professionals and teams, but also on the design and allocation of resources within the hospital and within the health care system. Professionals, as advocates of terminally ill patients' and their families' needs, must get involved in health care policy and make sure that end-of-life care is not overlooked.

Implications for Education

End-of-life care has not been a priority in health care education programs in the past (Carron et al., 1999; B. Ferrell et al., 1999; M. J. Field & Cassel, 1997). To improve performance, the basics of palliative care have to become an integral part of basic education in health care. In addition, post basic educational programs are needed that allow the acquisition of further know-how as well as a specialization in palliative care. The endeavors of the Swiss Association for Palliative Care to coordinate education in palliative care in Switzerland can be seen as a first step in the right direction (Schweizerische Gesellschaft für Palliative Medizin Pflege und Begleitung, 2001).

Education in palliative care should comprehend acquiring a sound scientific knowledge base and learning through experience to apply it optimally to particular patients and families. The Dreyfus model of skill acquisition applied to nursing by Benner (1984) and Benner et al. (1996) provides an excellent framework upon which clinical education programs could be built.

This study highlights that caring relationships between providers and patients and their families, knowing patients and family members, and supporting them in leading and completing their particular life are cornerstones of good end-of-life care. To achieve this, mastery in engaging with patients and families is required from professionals. Educators should not advocate detached concern, disengaged reasoning and judgment, instead they must find ways to teach skillful emotional engagement (Benner et al., 1996; Halpern, 2001). Halpern (2001) suggested cultivating genuine curiosity about patients' views in care providers. This curiosity will prevent early judgments and quick treatment decisions and allow care providers to first explore and then take into consideration patients' perspectives. Narratives from clinical practice can give examples of skilled emotional engagement as well as over-involvement and disengagement, and thereby transmit boundaries of good practice (Benner et al., 1996). Studying literature, that is fiction and poetry, on patients' lives or health care professionals' work can support care providers' understanding of particular patient and family experiences. Drama, film, and narrative studies, such as this one, can serve the same goal (Charon et al., 1995; Charon et al., 1996).

Implications for Research

The literature provides a sketchy picture of hospital end-of-life care from the patients' and families' perspectives. This study is a small contribution to make this picture more complete. However, more qualitative research is needed. Future research projects should involve other patient groups, especially patients dying from non-malignant illnesses. It would also be worthwhile to further explore commonalities and distinctions in the experiences of different age groups, family members with various relationships to the patient (e. g. spouses, adult children, parents), and chronically as well as terminally ill patients and their families. For the latter groups, it would be helpful to investigate if and how they experience a transition from chronic to terminal illness and to explore the related changes in their experiences. With shorter hospital stays, more patients die in other settings, mainly in nursing homes or at home. Several aspects of these patients' and their families' experiences certainly differ from experiences in the hospital; for instance, the possibilities to continue living their life may radically differ at home or in a nursing home, while experiences of relationships to professionals and actual care interventions may be comparable. Thus, these experiences should also be researched and articulated. In addition, this study shows that aspects of the Swiss culture may influence patients' and families' experiences. Consequently, care experiences likely differ in various contexts and should be explored in different cultures. Finally, future projects could add the perspectives of the members of the interdisciplinary care team to the view of patients and families.

This study shows that research with hospitalized, terminally ill patients and their family members is feasible. But the project also demonstrates the problems with recruiting seriously ill and exhausted patients and concerned family members and with carrying out such a study in the context of a busy acute care clinic. My experiences may alert other researchers to aspects that need to be considered carefully during the planning phase of a project.

This research project revealed strengths and weaknesses in the provision of end-of-life care, for instance, insufficient symptom management. Further research could contribute to improving end-of-life care in specific settings. Observational studies of symptom prevalence, for instance, might show areas of symptom management that need improvement of the current practice. Action research seems a valuable option to implement, support and evaluate changes in clinical practice.

Finally, research could serve to enhance teaching methods. For instance, methods to teach skilled emotional engagement could be explored and the effectiveness of the suggested approaches could be evaluated.

Recommendations for the Study Site

In this final section, I want to draw on the implications for practice, education, and research outlined above to suggest an action plan that could help maintain positive aspects and improve sub-optimal components of end-of-life care in the clinic where this study was conducted. Reporting the findings of the study to the staff and the clinic management team could be a first step to increase their awareness of the relevance of optimal end-of-life care. Such a report should especially point out the aspects that were experienced positively by patients and families, for instance, the caring stance of most providers or the integration of family members, to underline the importance of carrying on these practices and to ensure the necessary resources.

On the inpatient units, when caring for terminally ill patients and their families, the team could meet regularly and reflect on the situation and the care they provide. After a death, they could look back and consider how their care influenced the patient's dying and the families' experiences. Palliative care standards as well as findings of this study could serve as a guideline. Such team discussions could help recognize excellent caring practices of experienced providers, who could serve as role models. During these meetings, the importance of knowing and recognizing patients and family members as persons, and letting them go on living their unique life, rather than imposing any expectations of a certain dying trajectory, could be pointed out. Care plans could be reviewed for gaps and sub-optimal interventions, and be adapted cooperatively. The team, when hearing what different members learned from the patient and the family, would get to know the patient and the family better, and would be better able to recognize them as persons. Relevant aspects of the patient's and the family's life story, their

experiences with the illness, their goals, concerns, and points of enchantment should be described in the written records, so that these issues could be supported and would get transferred to professionals who subsequently care for the patient and the family. These team reflections would support a learning atmosphere on the units, enhance the expertise, and create shared expectations regarding good end-of-life care.

A consulting specialist team, with a physician and a clinical nurse specialized in palliative care, could increase endeavors to improve end-of-life care. They could advise the staff, or even care for the patients and family members for a limited time, thereby following in the footsteps of the clinical nurse specialists who already work on the units. They could guide reflective team discussions. As specialists in palliative care, they would have the required scientific knowledge and be able to keep themselves updated with new developments by critically reading the relevant literature and attending palliative care conferences.

A consulting team could also be responsible for education in palliative care within the clinic. The team could teach on the job when involved in the care of a particular patient and family, as well as offer lectures. In addition, the clinic management team should support interested staff members in getting post basic education in palliative care outside the hospital.

A small palliative care unit within the clinic could become a resource centre. Such a unit could provide optimal care for the most complex cases. Rotations would offer great learning opportunities for staff members, who could subsequently apply their newly acquired know-how on the regular units.

Finally, the endeavors to improve end-of-life care could be embedded in an action research project. This approach would allow establishing a baseline and determining areas in need of improvement; for instance, the prevalence of symptoms and the effectiveness of symptom management could be investigated. Changes could then be implemented and evaluated.

In summary, good end-of-life care in the hospital is challenging but not impossible. Enough knowledge and experience has been gained from palliative care institutions to adapt and design the integration of palliative care as a practice into the hospital setting. Some patients, supported by their families, may prefer to die at home, but this may be logistically impossible due to the frailty of the family caregiver or the extremity of the patient's symptoms and the need for highly technical care. The health care system and hospitals must allocate adequate resources to make the hospital a humane place to die. This will call for further research, enhanced inservice education, and, in addition to the curative care, the development and support of a care-oriented approach to accommodate the demanding human challenges of end-of-life care.

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APPENDIX A

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO
INSELSPITAL, BERN
INFORMATION FOR HOSPITAL EMPLOYEES
Seriously Ill Patients' and Their Families' Experiences of Hospital Care

A. PURPOSE AND BACKGROUND OF THE STUDY

Patricia Benner, RN, PhD, University of California San Francisco, Annemarie Kesselring, RN, PhD, University of Basel, and Elisabeth Spichiger, RN, MS, PhDcand, employee at the Inselspital are conducting a research study to help understand how seriously ill patients and their families experience hospital care. The Inselspital and the management team of your clinic have approved this study. You may care for a patient and family member who have agreed to participate in the study.

B. PROCEDURES

Throughout a participating patient's hospital stay, Elisabeth Spichiger will repeatedly spend some time with the patient and observe the care he/she receives. She will talk to the patient about his/her hospital experiences. She will also repeatedly interview the closest family member and review the medical records.

The needs and the well-being of the patient and family member will always have priority. Elisabeth Spichiger will make arrangements in collaboration with the charge nurse or the nurse responsible for the patient's care. Frequency, timing and duration of observations, conversations with the patient and family member interviews will first be adapted to each patient's and family member's situation and the illness trajectory, and second depend on the researcher's need for data collection.

If you care for a patient who participates in the study, the following may occur:

1. Elisabeth Spichiger may observe the care that you provide to the patient.

2. Elisabeth Spichiger may ask you some questions in order to better understand the patient's situation. With your permission, she will tape-record these short conversations.

C. RISKS/DISCOMFORTS

1. To be observed when providing care may be uncomfortable.

2. You may feel uncomfortable to answer questions.

3. Confidentiality: Participation in research will involve a loss of privacy; however, records will be handled as confidentially as possible. After study completion, the tapes will be destroyed. Codes will be used instead of names on all records. No observations will be disclosed to other hospital employees. Exception: Should Elisabeth Spichiger perceive that one of your actions puts the patient at risk, she will notify you and, if necessary, your supervisor.

D. QUESTIONS

If you have any questions, comments or concerns about this study, you may call Elisabeth Spichiger at 031 371 42 88 or you may call Dr. Annemarie Kesselring at 061 267 09 52.

Elisabeth Spichiger is a student at the University of California San Francisco. The Committee on Human Research of the University is concerned with the protection of volunteers in research projects. You may reach the committee office between 8.00 am and 5.00 pm (5.00 pm and 2.00 am Swiss time), Monday through Friday, by calling 001 415 476 1814, or by writing: Committee on Human Research, Box 0962, University of California, San Francisco/ San Francisco, CA 94143.

E. CONSENT

PARTICIPATION IN RESEARCH IS VOLUNTARY. Please notify Elisabeth Spichiger if you prefer not to be observed or to be asked any questions. You are free to decline to be observed at any time, not to answer any questions or to have conversations tape-recorded.

APPENDIX B

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO
INSELSPITAL, BERN
INFORMATION FOR RECRUITMENT OF PARTICIPANTS

Seriously Ill Patients' and Their Families' Experiences of Hospital Care

Dear nurse manager,

The management team of your clinic has been informed of my dissertation research and has agreed to the potential participation of your patients. You have agreed to find eligible participants and to make the first contact with patients.

Patients who fulfill the following criteria can be asked to participate in the study:

1. The patient is terminally ill and expected to die within the next weeks or few months.
2. The patient is 18 years or older.
3. The patient can designate a close family member who visits regularly.
4. The patient and the family member speak German.
5. The patient and the family member are able to give informed consent.

Please meet eligible patients for the following:

1. Tell the patient that a nurse of the Inselspital, Elisabeth Spichiger, is studying seriously ill patients' and their families' experiences of the care they receive in this hospital. This nurse would like to observe the patient's care and talk to him/her and his/her closest family member.
2. Inform the patient that the management of the Inselspital and your clinic have approved this study.
3. Ask the patient if he/she is willing to meet this nurse and to learn more about the study. Inform the patient that meeting the nurse does not obligate him/her to participate in the study, that participation is voluntary, and that a refusal will not influence his/her care in any way.
4. If a patient agrees to meet the nurse, tell him/her that you will forward his/her name and room number to Elisabeth Spichiger, and that she will contact him/her soon.

Please forward the following information to me as soon as possible:

1. The name and room number of a patient who has agreed to be contacted.
2. The fact that you asked a patient who then refused to be contacted and his/her *spontaneously* given reason to do so.

My phone number: 031 371 42 88 My e-mail address: espichi@itsa.ucsf.edu

I greatly appreciate your support in finding eligible participants for my study. Thank you!

Elisabeth Spichiger

APPENDIX C

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO
INSELSPITAL, BERN
CONSENT TO BE A RESEARCH PARTICIPANT
Seriously Ill Patients' and Their Families' Experiences of Hospital Care

Consent form for the patient

A. PURPOSE AND BACKGROUND

Patricia Benner, RN, PhD, University of California San Francisco, Annemarie Kesselring, RN, PhD, University of Basel, and Elisabeth Spichiger, RN, MS, PhDcand, employee at the Inselspital are conducting a research study to help understand how seriously ill patients and their families experience hospital care. You are being asked to participate in this study because you currently experience such care.

B. PROCEDURES

If you agree to be in the study, the following will occur:

1. Throughout your hospital stay, Elisabeth Spichiger will repeatedly spend some time with you and observe the care you receive.

2. She will ask you questions regarding how you and your family experience your illness and the care at the hospital. With your permission, these conversations will be tape-recorded. Elisabeth Spichiger will talk to you in your room or in a separate room, according to your wishes.

3. Your needs and well-being will always come first. Elisabeth Spichiger will arrange times with you for observations. However, these times will be flexible according to your needs. The length of conversations will be adapted according to your comfort.

4. Throughout your hospital stay, Elisabeth Spichiger will repeatedly interview your … (add appropriate relationship term). Your … (add appropriate relationship term) will be asked how he/she experiences your illness, how he/she perceives the care, and how the family experiences your hospital stay. The interviews will be tape-recorded.

5. Your medical records will be reviewed.

6. Elisabeth Spichiger will talk to the persons who care for you at the hospital. She will ask questions about your care or the hospital unit, if this is necessary to better understand your situation. She will tape-record these short conversations.

7. Elisabeth Spichiger may contact you again post discharge to ask if you would answer some additional questions. You will be free to agree to or decline this further conversation.

C. RISKS/DISCOMFORTS

1. The observation of your care may disturb your privacy. You are free to stop it at any time.

2. Talking about your experiences may be unpleasant. You may feel at times uncomfortable to share your thoughts. Some questions may make you feel sad. You are free not to answer a question or to stop the conversation at any time.

3. To know that your … (add appropriate relationship term) or a hospital employee is talking with the researcher about your care may be unpleasant for you. You can ask the researcher at any time not to do so.

4. Confidentiality: Participation in research will involve a loss of privacy; however, your records will be handled as confidentially as possible. Only Dr. Annemarie Kesselring and Elisabeth Spichiger will have access to the tapes. After study completion, the tapes will be destroyed. Codes will be used instead of names on all records. Individual identities of participants will be disguised in any published reports, so that your personal identity will not be recognized.

D. BENEFITS

There will be no direct benefit to you from participating in this study. However, the information that you provide may help nurses better understand how seriously ill patients and their families experience hospital care and it may help nurses to make appropriate improvements.

E. COSTS

There will be no costs to you as a result of taking part in this study. Costs associated with your stay on this unit will remain the same.

F. PAYMENT

There will be no reimbursement for study participation.

G. QUESTIONS

You have talked to Elisabeth Spichiger about this study and have had your questions answered. If you have further questions or any comments or concerns about participation in this study, you may call her at 031 371 42 88 or you may call Dr. Annemarie Kesselring at 061 267 09 52.

Elisabeth Spichiger is a student at the University of California San Francisco. The Committee on Human Research of the University is concerned with the protection of volunteers in research projects. You may reach the committee office between 8.00 am and 5.00 pm (5.00 pm and 2.00 am Swiss time), Monday through Friday, by calling 001 415 476 1814, or by writing: Committee on Human Research, Box 0962, University of California, San Francisco/San Francisco, CA 94143.

H. CONSENT

You will be given a copy of this consent form to keep.

PARTICIPATION IN RESEARCH IS VOLUNTARY. You are free to decline to be in this study, or to withdraw from it at any point. Your decision as to whether or not to participate in this study will have no influence on your present or future status as a patient.

If you agree to participate you should sign below.

_____________________ _____________________________________

Date Signature of Study Participant

Your ... (add appropriate relationship term) is physically unable to sign this form. He/she has been informed about the study. In your presence, he/she has verbally agreed to participate and has asked you to sign the form for him/her.

_____________________ _____________________________________

Date Signature of Family Member

_____________________ _____________________________________

Date Signature of Person Obtaining Consent

APPENDIX D

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO
INSELSPITAL, BERN
CONSENT TO BE A RESEARCH PARTICIPANT
Seriously Ill Patients' and Their Families' Experiences of Hospital Care

Consent form for the family member

A. PURPOSE AND BACKGROUND

Patricia Benner, RN, PhD, University of California San Francisco, Annemarie Kesselring, RN, PhD, University of Basel, and Elisabeth Spichiger, RN, MS, PhDcand, employee at the Inselspital are conducting a research study to help understand how seriously ill patients and their families experience hospital care. You are being asked to participate in this study because your ... (add appropriate relationship term) is currently hospitalized. The patient has agreed to participate in the study and that the researcher talks to you.

B. PROCEDURES

If you agree to be in the study, the following will occur:

1. Throughout your ... (add appropriate relationship term) hospital stay, Elisabeth Spichiger will repeatedly interview you about how you experience the patient's illness, how you and your family perceive the care and the patient's hospital stay. With your permission, the interviews will be tape-recorded. The interviews will usually take place outside the patient's room, at the hospital. If you prefer not to leave the patient, the interview can be done in his/her room.

2. During the first interview, Elisabeth Spichiger will also ask you about your age, occupation, religious affiliation, and the duration of your relationship with the patient.

3. Your and the patient's needs and well-being will always come first. Elisabeth Spichiger will arrange times with you for the interviews. However, these times and the duration of the interviews will be flexible according to your needs.

4. Elisabeth Spichiger may contact you again post discharge to ask for an additional interview. You will be free to agree to or decline this further interview.

C. RISKS/DISCOMFORTS

1. Talking about your experiences may be unpleasant. You may feel at times uncomfortable to share your thoughts. Some questions may make you feel sad. You are free not to answer a question or to stop the interview at any time.

2. You may feel uncomfortable after a while to have left the patient. You are free to stop the interview at any time and return.

3. Confidentiality: Participation in research will involve a loss of privacy; however, your records will be handled as confidentially as possible. Only Dr. Annemarie Kesselring and Elisabeth Spichiger will have access to the tapes. After study completion, the tapes will be destroyed. Codes will be used instead of names on all records. Individual identities of participants will be disguised in any published reports, so that your personal identity will not be recognized.

D. BENEFITS

There will be no direct benefit to you from participating in this study. However, the information that you provide may help nurses better understand how seriously ill patients and their families experience hospital care and it may help nurses to make appropriate improvements.

E. COSTS

There will be no costs to you as a result of taking part in this study.

F. PAYMENT

There will be no reimbursement for study participation.

G. QUESTIONS

You have talked to Elisabeth Spichiger about this study and have had your questions answered. If you have further questions or any comments or concerns about participation in this study, you may call her at 031 371 42 88 or you may call Dr. Annemarie Kesselring at 061 267 09 52.

Elisabeth Spichiger is a student at the University of California San Francisco. The Committee on Human Research of the University is concerned with the protection of volunteers in research projects. You may reach the committee office between 8.00 am and 5.00 pm (5.00 pm and 2.00 am Swiss time), Monday through Friday, by calling 001 415 476 1814, or by writing: Committee on Human Research, Box 0962, University of California, San Francisco/ San Francisco, CA 94143.

H. CONSENT

You will be given a copy of this consent form to keep.

PARTICIPATION IN RESEARCH IS VOLUNTARY. You are free to decline to be in this study, or to withdraw from it at any point. Your decision as to whether or not to participate in this study will have no influence on your present or future status as a family member of an inpatient.

If you agree to participate you should sign below.

____________________ ____
Date Signature of Study Participant

____________________ ____
Date Signature of Person Obtaining Consent

APPENDIX E

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO
INSELSPITAL, BERN
CONSENT TO BE A RESEARCH PARTICIPANT
Seriously Ill Patients' and Their Families' Experiences of Hospital Care

Consent form for the family member post bereavement

A. PURPOSE AND BACKGROUND

Patricia Benner, RN, PhD, University of California San Francisco, Annemarie Kesselring, RN, PhD, University of Basel, and Elisabeth Spichiger, RN, MS, PhDcand, employee at the Inselspital are conducting a research study to help understand how seriously ill patients and their families experience hospital care. You and your deceased … (add appropriate relationship term) already contributed greatly to this study. You met Elisabeth Spichiger during your … (add appropriate relationship term) hospital stay and talked to her several times about your experiences. During one of the interviews, you gave her permission to contact you again later. You are now being asked to participate in a follow-up interview because the researchers want to learn how you experienced hospital care during the days prior to the death of your … (add appropriate relationship term).

B. PROCEDURES

If you agree to participate in this follow-up interview, the following will occur:

1. Elisabeth Spichiger will make an appointment and meet with you at a time and place convenient to you.

2. Elisabeth Spichiger will interview you about how you and your family experienced the care that your deceased … (add appropriate relationship term) received during the last days and how you think now about his/her whole hospital stay. With your permission, the interview will be tape-recorded.

C. RISKS/DISCOMFORTS

1. Talking about your experiences may be unpleasant. You may feel at times uncomfortable to share your thoughts. Some questions may make you feel sad. You are free not to answer a question or to stop the interview at any time.

2. Confidentiality: Participation in research will involve a loss of privacy; however, your records will be handled as confidentially as possible. Only Dr. Annemarie Kesselring and Elisabeth Spichiger will have access to the tapes. After

study completion, the tapes will be destroyed. Codes will be used instead of names on all records. Individual identities of participants will be disguised in any published reports, so that your personal identity will not be recognized.

D. BENEFITS

There will be no direct benefit to you from participating in this study. However, the information that you provide may help nurses better understand how seriously ill and dying patients and their families experience hospital care and it may help nurses to make appropriate improvements.

E. COSTS

There will be no costs to you as a result of taking part in this study.

F. PAYMENT

There will be no reimbursement for study participation.

G. QUESTIONS

You have talked to Elisabeth Spichiger about this study and have had your questions answered. If you have further questions or any comments or concerns about participation in this study, you may call her at 031 371 42 88 or you may call Dr. Annemarie Kesselring at 061 267 09 52.

Elisabeth Spichiger is a student at the University of California San Francisco. The Committee on Human Research of the University is concerned with the protection of volunteers in research projects. You may reach the committee office between 8.00 am and 5.00 pm (5.00 pm and 2.00 am Swiss time), Monday through Friday, by calling 001 415 476 1814, or by writing: Committee on Human Research, Box 0962, University of California, San Francisco/ San Francisco, CA 94143.

H. CONSENT

You will be given a copy of this consent form to keep.

PARTICIPATION IN RESEARCH IS VOLUNTARY. You are free to decline to participate in this follow-up interview, or to withdraw from it at any point.
If you agree to participate you should sign below.

______________________ ______________________________
Date Signature of Study Participant

______________________ ______________________________
Date Signature of Person Obtaining Consent

APPENDIX F

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO
INSELSPITAL, BERN
CONSENT TO BE A RESEARCH PARTICIPANT
Seriously Ill Patients' and Their Families' Experiences of Hospital Care

Consent form for the patient post discharge

A. PURPOSE AND BACKGROUND

Patricia Benner, RN, PhD, University of California San Francisco, Annemarie Kesselring, RN, PhD, University of Basel, and Elisabeth Spichiger, RN, MS, PhDcand, employee at the Inselspital are conducting a research study to help understand how seriously ill patients and their families experience hospital care. You and your ... (add appropriate relationship term) already contributed greatly to this study. You met Elisabeth Spichiger during your hospital stay and talked to her several times about your experiences. During one of the interviews, you gave her permission to contact you again later. You are now being asked to participate in a follow-up interview because the researchers want to learn how you experienced the discharge process and how you think in retrospect about the hospital care.

B. PROCEDURES

If you agree to participate in this follow-up interview, the following will occur:

1. Elisabeth Spichiger will make an appointment and meet with you at a time and place convenient to you. The length of the conversation will be adapted to your comfort.

2. Elisabeth Spichiger will interview you about how you and your family experienced the discharge process and how you think now about your whole hospital stay. With your permission, the interview will be tape-recorded.

3. Elisabeth Spichiger will interview your ... (add appropriate relationship term). He/she will be asked how he/she and the family experienced the discharge process and how they think in retrospect about the whole hospital stay. The interview will be tape-recorded.

C. RISKS/DISCOMFORTS

1. Talking about your experiences may be unpleasant. You may feel at times uncomfortable to share your thoughts. Some questions may make you feel sad. You are free not to answer a question or to stop the conversation at any time.

2. To know that your … (add appropriate relationship term is talking with the researcher about your care may be unpleasant for you. You can ask the researcher at any time not to do so.

3. Confidentiality: Participation in research will involve a loss of privacy; however, your records will be handled as confidentially as possible. Only Dr. Annemarie Kesselring and Elisabeth Spichiger will have access to the tapes. After study completion, the tapes will be destroyed. Codes will be used instead of names on all records. Individual identities of participants will be disguised in any published reports, so that your personal identity will not be recognized.

D. BENEFITS

There will be no direct benefit to you from participating in this study. However, the information that you provide may help nurses better understand how seriously ill patients and their families experience hospital care and it may help nurses to make appropriate improvements.

E. COSTS

There will be no costs to you as a result of taking part in this study.

F. PAYMENT

There will be no reimbursement for study participation.

G. QUESTIONS

You have talked to Elisabeth Spichiger about this study and have had your questions answered. If you have further questions or any comments or concerns about participation in this study, you may call her at 031 371 42 88 or you may call Dr. Annemarie Kesselring at 061 267 09 52.

Elisabeth Spichiger is a student at the University of California San Francisco. The Committee on Human Research of the University is concerned with the protection of volunteers in research projects. You may reach the committee office between 8.00 am and 5.00 pm (5.00 pm and 2.00 am Swiss time), Monday through Friday, by calling 001 415 476 1814, or by writing: Committee on Human Research, Box 0962, University of California, San Francisco/San Francisco, CA 94143.

H. CONSENT

You will be given a copy of this consent form to keep.

PARTICIPATION IN RESEARCH IS VOLUNTARY. You are free to decline to participate in this follow-up interview, or to withdraw from it at any point.

If you agree to participate you should sign below.

Date Signature of Study Participant

Your ... (add appropriate relationship term) is physically unable to sign this form. He/she has been informed about the interview. In your presence, he/she has verbally agreed to participate and has asked you to sign the form for him/her.

Date Signature of Family Member

Date Signature of Person Obtaining Consent

APPENDIX G

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO
INSELSPITAL, BERN
CONSENT TO BE A RESEARCH PARTICIPANT
Seriously Ill Patients' and Their Families' Experiences of Hospital Care

Consent form for the family member post discharge

A. PURPOSE AND BACKGROUND

Patricia Benner, RN, PhD, University of California San Francisco, Annemarie Kesselring, RN, PhD, University of Basel, and Elisabeth Spichiger, RN, MS, PhDcand, employee at the Inselspital are conducting a research study to help understand how seriously ill patients and their families experience hospital care. You and your ... (add appropriate relationship term) already contributed greatly to this study. You met Elisabeth Spichiger during your ... (add appropriate relationship term) hospital stay and talked to her several times about your experiences. During one of the interviews, you gave her permission to contact you again later. You are now being asked to participate in a follow-up interview because the researchers want to learn how you experienced the discharge process and how you think in retrospect about the hospital care of your ... (add appropriate relationship term).

B. PROCEDURES

If you agree to participate in this follow-up interview, the following will occur:

1. Elisabeth Spichiger will make an appointment and meet with you at a time and place convenient to you.

2. Elisabeth Spichiger will interview you about how you and your family experienced the discharge process of your ... (add appropriate relationship term) and how you think now about his/her whole hospital stay. With your permission, the interview will be tape-recorded.

C. RISKS/DISCOMFORTS

1. Talking about your experiences may be unpleasant. You may feel at times uncomfortable to share your thoughts. Some questions may make you feel sad. You are free not to answer a question or to stop the interview at any time.

2. Confidentiality: Participation in research will involve a loss of privacy; however, your records will be handled as confidentially as possible. Only Dr.

Annemarie Kesselring and Elisabeth Spichiger will have access to the tapes. After study completion, the tapes will be destroyed. Codes will be used instead of names on all records. Individual identities of participants will be disguised in any published reports, so that your personal identity will not be recognized.

D. BENEFITS

There will be no direct benefit to you from participating in this study. However, the information that you provide may help nurses better understand how seriously ill patients and their families experience hospital care and it may help nurses to make appropriate improvements.

E. COSTS

There will be no costs to you as a result of taking part in this study.

F. PAYMENT

There will be no reimbursement for study participation.

G. QUESTIONS

You have talked to Elisabeth Spichiger about this study and have had your questions answered. If you have further questions or any comments or concerns about participation in this study, you may call her at 031 371 42 88 or you may call Dr. Annemarie Kesselring at 061 267 09 52.
Elisabeth Spichiger is a student at the University of California San Francisco. The Committee on Human Research of the University is concerned with the protection of volunteers in research projects. You may reach the committee office between 8.00 am and 5.00 pm (5.00 pm and 2.00 am Swiss time), Monday through Friday, by calling 001 415 476 1814, or by writing: Committee on Human Research, Box 0962, University of California, San Francisco/ San Francisco, CA 94143.

H. CONSENT

You will be given a copy of this consent form to keep.

PARTICIPATION IN RESEARCH IS VOLUNTARY. You are free to decline to participate in this follow-up interview, or to withdraw from it at any point.
If you agree to participate you should sign below.

Date	Signature of Study Participant
Date	Signature of Person Obtaining Consent

APPENDIX H

Questions for Conversations with the Patient

Note: The conversations with the patient will follow his/her lead as much as possible, and the timing and duration will depend on the patient's health status and well-being. The goal is to cover over time as many of the questions as the patient's situation allows and to follow up with topics if feasible.

1. How you are doing today? Can you tell me how you are feeling?
2. And how have you been feeling in general since you are at the hospital?
3. Could you tell me how you felt before your admission and what brought you to the hospital?
4. Could you tell me about your illness? When and how did it start, how did it proceed?
5. Please tell me a bit about yourself, about who you are, about your life prior to the illness.
6. What is it like for you now at the hospital? Has that changed since you first came?

   Probe: Follow up with appropriate questions about the patient's daily life at the hospital and how this has changed since admission.
7. The … (use appropriate term, e.g., nurse) does … (mention appropriate action). How is this for you?

   Probe: Follow up with appropriate questions about the patient's experiences of his/her care.
8. I observed … How was this for you?
9. Can you tell me what kind of problems and symptoms you experience?

   Probe: Follow up with appropriate questions about what bothers the patient and how interventions work.
10. You met different staff members: physicians, nurses, and may be others. Can you tell me about your experiences with them?

    Probe: Follow up with appropriate questions about the patient's experiences of interactions with staff members.
11. Do you have any issues that you would like to discuss with someone or get help from someone at the hospital?
12. Can you think of anything that anyone at the hospital could do to make things better for you now?
13. How is your … (add correct relationship term here and whenever appropriate) doing with the illness? How is the family doing?

14. Was your … involved in your care at home? Was the family involved?
15. Is your … involved in your care now? Is your family involved?
16. Have your … or other family members had contact with staff members at the hospital? Have they gotten any support?
17. Is there anything else you would like to tell me?

Potential Follow-up Questions

1. Please tell me how things were going since we met? How did you feel?

   Probe: Follow up with appropriate questions about how the patient's daily life at the hospital has changed.
2. Do you remember any specific event with your care that happened since we met? Do you remember an especially good / bad experience with your care that you may share?
3. I observed … How was this for you?
4. Last time, you told me about … (problems / symptoms). How is this going now?

   Probe: Follow up with appropriate questions about how these problems / symptoms developed and how interventions worked.
5. How is it going with you now? Has anything changed for you since we met?

   Probe: Follow up with appropriate questions about new problems / symptoms and related interventions.
6. Have you met any new staff members since we met? Can you tell me about your experiences with them?

   Probe: Follow up with appropriate questions about the patient's experiences of interactions with staff members.
7. Did any issues come up since we met that you would like to discuss with someone or get help from someone at the hospital?
8. Can you think of anything that anyone at the hospital could do to make things better for you now?
9. How is your … doing? How is the family doing?
10. Last time you told me … (closest family member / family involvement in care). Has anything changed?
11. Last time you told me … (closest family member / family contact with and support from staff members). Has anything changed?
12. Last time you mentioned … I have been thinking about this and wondered … (Fill in gaps from previous interview.)
13. Is there anything else you would like to tell me?

APPENDIX J

Questions for Family Member Interviews

Note: The interview will be conversational and follow the family member's lead as much as possible. The questions serve as a guide of topics to be covered if feasible.

First Interview

1. Let me first ask you how your … (add correct relationship term here and whenever appropriate) is doing. Could you tell me how he/she is feeling today?
2. And how has he/she been feeling in general since he/she is at the hospital?
3. Could you tell me how your … felt before his/her admission and what brought him/her to the hospital?
4. Could you tell me about your … illness? When and how did it start, how did it proceed?
5. Can you tell me a bit about your … life before his/her illness?
6. What is it like for your … now at the hospital? Has that changed since he/she first came?

   Probe: Follow up with appropriate questions about the patient's daily life at the hospital and how this has changed since admission.
7. The … (use appropriate term, e.g., nurse) does … (mention appropriate action). Can you tell me how this is for him/her? What do you think about the care he/she gets?

   Probe: Follow up with appropriate questions about the patient's and the family member's experiences of the care.
8. I observed … How do you think about this?
9. Can you tell me what kind of problems / symptoms your … experiences?

   Probe: Follow up with appropriate questions about what bothers the patient and how interventions work, and to get the family member's view.
10. Your … met different staff members: physicians, nurses, and may be others. Can you tell me anything about your … experiences with these staff members?

    Probe: Follow up with appropriate questions about the patient's experiences of interactions with staff members and the family member's view.
11. Do you think it would be helpful for your … to talk to or get support from someone else at the hospital?

12. Can you think of anything that anyone at the hospital could do to make things better for your … now?
13. Let us talk about your family. So far, we talked about … (state family members mentioned before). Do you have other family members?
14. How are you doing with your … illness?
15. How is the family doing with your … illness?
16. Can you tell me a bit about yourself, about who you are, about your life prior to your … illness?
17. Can you tell me a bit about your family, about your family life prior to your … illness?
18. Were you involved in the care of your … at home? Was the family involved?
19. Are you involved in the care now? Is the family involved?

    Probe: Follow up with appropriate questions about how the closest or other family members are involved in the patient's care at the hospital.
20. Have you had contact with staff members at the hospital?

    Probe: Follow up with appropriate questions to understand if and how the staff members interact with and support the closest or other family members.
21. Do you have any issues that you would like to discuss with someone or get help from someone at the hospital?
22. Can you think of anything that anyone at the hospital could do to make things better for you now?
23. Let me ask you a few questions about yourself: What is your age? Your occupation? Your religious affiliation? If adequate: How long have you been married to/living with your spouse/partner?
24. Is there anything else you would like to tell me?

Subsequent Interviews

1. How is your … feeling today?
2. Please tell me how things were going since we met? How has your … been feeling?

   Probe: Follow up with appropriate questions about how the patient's daily life at the hospital has changed.
3. Do you remember any specific event with your … care that happened since we met? Do you remember an especially good / bad experience with your … care that you may share? What do you think about your … care?
4. I observed … How do you think about this?

5. Last time, you told me about your … … (problems / symptoms). Can you tell me how this is going now?

   Probe: Follow up with appropriate questions about how these problems / symptoms developed and how interventions worked, and to get the family member's view.

6. How is it going with your … now? Has anything changed since we met?

   Probe: Follow up with appropriate questions about new problems / symptoms and related interventions, and to get the family member's view.

7. Has your … met any new staff members since we met? Can you tell me anything about your … experiences with them?

   Probe: Follow up with appropriate questions about the patient's experiences of interactions with staff members and the family member's view.

8. Do you think it would be helpful for your … to talk to or get support from someone else at the hospital?
9. Can you think of anything that anyone at the hospital could do to make things better for your … now?
10. Let us talk about you and your family. How are you doing? How is the family doing?
11. Last time you told me … (involvement in care). Has anything changed?

    Probe: Follow up with appropriate questions about how the closest or other family members are involved in the care at the hospital now.

12. Last time you told me … (contact with and support from staff members). Has anything changed?

    Probe: Follow up with appropriate questions to understand if and how the staff members interact with or support the closest or other family members now.

13. Did any issues come up since we met that you would like to discuss with someone or get help from someone at the hospital?
14. Can you think of anything that anyone at the hospital could do to make things better for you now?
15. Last time you mentioned … I have been thinking about this and wondered … (Fill in gaps from previous interview.)
16. Is there anything else you would like to tell me?

APPENDIX K

Questions for Post Bereavement Interview

Note: The interview will be conversational and follow the participant's lead as much as possible. The questions serve as a guide of topics to be covered if feasible.

1. How are you doing? How have you been doing over the last 2 months?
2. We last met on ... and your ... (add correct relationship term here and whenever appropriate) died ... days later. Can you tell me about his/her final time at the hospital? How did he/she feel? How were things going?

   Probe: Follow up with appropriate questions about the patient's daily life at the hospital and how this changed over the final days.
3. Can you tell me what kind of care your ... received?

   Probe: Follow up with appropriate questions about the patient's and the family member's experiences of the care.
4. Last time, you told me about your ... ... (problems / symptoms). Can you tell me how these developed over the final days?

   Probe: Follow up with appropriate questions about how these problems / symptoms developed over the final days and how interventions worked, and to get the family member's view.
5. How was it going with your ... over the final days? Did anything change?

   Probe: Follow up with appropriate questions about new problems / symptoms and related interventions, and to get the family member's view.
6. Did your ... meet any new staff members over the final days? Can you tell me anything about your ... experiences with them?

   Probe: Follow up with appropriate questions about the patient's experiences of interactions with staff members and the family member's view.
7. Do you think it would have been helpful for your ... to talk to or get support from someone else at the hospital?
8. Can you think of anything that anyone at the hospital could have done to make things better for your ... during his/her final days?
9. Let us talk about you and your family. How were you doing during your ... final days? How was the family doing?
10. Last time you told me ... (involvement in care). Did anything change?

Probe: Follow up with appropriate questions about how the closest or other family members were involved in the care at the hospital over the patient's final days.

11. Last time you told me ... (contact with and support from staff members). Did anything change?

    Probe: Follow up with appropriate questions to understand if and how the staff members interacted with or supported the closest or other family members over the patient's final days.

12. Did any issues come up over the final days that you would have liked to discuss with someone or get help from someone at the hospital?
13. Can you think of anything that anyone at the hospital could have done to make things better for you over the final days?
14. Can you tell me how your ... died? Were you present? What happened after the death? How did you experience the situation?
15. Lets talk about the whole hospitalization of your ... in retrospect. How do you feel about it now?
16. What were your experiences with the care your ... got in general? Does any special event come to your mind? Do you remember an especially good / bad experience?
17. Do you think that your ... missed something? What could staff members have done in addition to make things better for your ... ?
18. How did you / your family feel treated at the hospital? Does any special event come to your mind? Do you remember an especially good / bad experience?
19. Do you feel that you or your family missed something? What could staff members have done for you in addition to make things better before or after your ... death?
20. Is there anything else you would like to tell me?

2. Elisabeth Spichiger stellt Ihnen einige Fragen, um die Situation des Patienten besser zu verstehen. Falls Sie zustimmen, nimmt sie diese kurzen Gespräche auf Tonband auf.

C. RISIKEN UND UNANNEHMLICHKEITEN

1. Es kann unangenehm sein für Sie, bei der Arbeit beobachtet zu werden.

2. Es kann Ihnen unangenehm sein, Fragen zu beantworten.

3. Vertraulichkeit: Die Teilnahme an einer Studie führt zu einem gewissen Verlust der Privatsphäre. Alle Unterlagen werden jedoch so vertraulich wie möglich gehandhabt. Nach Abschluss der Studie werden die Tonbänder gelöscht. In allen Unterlagen werden Codes anstelle von Namen benutzt. Informationen über Beobachtungen werden nicht an andere Spitalmitarbeiterinnen weitergegeben. Ausnahme: Sollte Elisabeth Spichiger den Eindruck haben, eine Ihrer Handlungen schade dem Patienten, macht sie Sie darauf aufmerksam und informiert nötigenfalls Ihre Vorgesetzte.

D. FRAGEN

Falls Sie Fragen haben bezüglich dieser Studie, einen Kommentar dazu abgeben oder Bedenken äussern möchten, rufen Sie bitte Elisabeth Spichiger an. Ihre Telefonnummer lautet: 031 371 42 88. Sie können auch Frau Prof. Annemarie Kesselring anrufen. Ihre Telefonnummer lautet: 061 267 09 52

Elisabeth Spichiger ist Studentin an der Universität von Kalifornien, San Francisco. Das Ethikkomitee der Universität befasst sich mit dem Schutz von Studienteilnehmern und –teilnehmerinnen. Sie können das Büro des Komitees zwischen 8.00 und 17.00 Uhr (Schweizerzeit zwischen 17.00 und 02.00 Uhr), Montag bis Freitag, telefonisch unter der Nummer 001 415 476 1814 oder unter folgender Adresse schriftlich erreichen: Committee on Human Research, Box 0962, University of California, San Francisco/San Francisco, CA 94143.

E. EINWILLIGUNG

DIE TEILNAHME AN STUDIEN IST FREIWILLIG. Falls Sie nicht beobachtet werden oder keine Fragen beantworten möchten, teilen Sie dies bitte Elisabeth Spichiger mit. Sie können die Beobachtung jederzeit stoppen. Es steht Ihnen frei, Fragen nicht zu beantworten oder Tonbandaufnahmen abzulehnen.

APPENDIX M

UNIVERSITÄT VON KALIFORNIEN, SAN FRANCISCO
INSELSPITAL, BERN
INFORMATIONEN ZUM REKRUTIEREN VON STUDIENTEILNEHMERN/-TEILNEHMERINNEN

Spitalbetreuung: Erfahrungen schwerkranker Patienten und Patientinnen und ihrer Angehörigen

Liebe Oberschwester

Die Leitung Ihrer Klinik ist über das Forschungsprojekt für meine Dissertation informiert worden und hat einer möglichen Teilnahme Ihrer Patienten/Patientinnen zugestimmt. Sie haben sich bereit erklärt, geeignete Studienteilnehmer/-teilnehmerinnen zu finden und zuerst Kontakt mit diesen Patienten/Patientinnen aufzunehmen.

Patienten/Patientinnen welche die folgenden Bedingungen erfüllen, können zur Teilnahme in der Studie angefragt werden:

1. Der Patient/die Patientin erhält palliative Betreuung und wird voraussichtlich innert einiger Wochen oder weniger Monate sterben.
2. Der Patient/die Patientin ist 18 Jahre alt oder älter.
3. Der Patient/die Patientin kann einen sehr nahen Angehörigen/eine sehr nahe Angehörige benennen, der/die regelmässig zu Besuch kommt.
4. Der Patient/die Patientin und der/die Angehörige sprechen deutsch.
5. Der Patient/die Patientin und der/die Angehörige sind fähig, eine aufgeklärte Einwilligung zu geben.

Bitte besuchen Sie in Frage kommende Patienten/Patientinnen und tun Sie Folgendes:

1. Teilen Sie dem Patienten/der Patientin mit, dass eine Krankenschwester, Elisabeth Spichiger, untersucht, wie schwerkranke Patienten und Ihre Angehörigen die Betreuung im Inselspital erleben. Diese Krankenschwester möchte gerne die Betreuung beobachten und mit dem Patienten/der Patientin und dem/der nächsten Angehörigen reden.
2. Sagen Sie dem Patienten/der Patientin, dass die Leitung des Inselspitals und der Klinik dieser Untersuchung zugestimmt haben.
3. Fragen Sie den Patienten/die Patientin, ob er/sie bereit ist, diese Krankenschwester zu treffen und Näheres über die Untersuchung zu erfahren. Sagen Sie dem Patienten/der Patientin, dass ein Treffen mit dieser Krankenschwester ihn/sie noch nicht zur Teilnahme verpflichtet, dass eine Teilnahme freiwillig ist und ein Verzicht keinen Einfluss auf seine/ihre Betreuung haben wird.

4. Wenn ein Patient/eine Patientin zustimmt, sagen Sie ihm/ihr, dass Sie seinen/ihren Namen und die Zimmernummer an Elisabeth Spichiger weiterleiten werden und dass diese ihn/sie bald aufsuchen wird.

Bitte leiten Sie die folgenden Informationen sobald wie möglich an mich weiter:

1. Den Namen und die Zimmernummer eines Patienten/einer Patientin, der/die einem Treffen mit mir zugestimmt hat.
2. Die Tatsache, dass Sie einen Patienten/eine Patientin angefragt haben, dieser/diese jedoch ein Treffen mit mir abgelehnt hat, und allfällige, spontan geäusserte Gründe für die Ablehnung.

Meine Telephonnummer: 031 371 42 88
Meine e-mail Adresse: espichi@itsa.ucsf.edu

Ich schätzte Ihre Unterstützung beim Finden von geeigneten Studienteilnehmern/-teilnehmerinnen sehr und bedanke mich herzlich für Ihre Mitarbeit!

Elisabeth Spichiger

APPENDIX N

UNIVERSITÄT VON KALIFORNIEN, SAN FRANCISCO
INSELSPITAL, BERN
EINWILLIGUNG ZUR STUDIENTEILNAHME

Spitalbetreuung: Erfahrungen schwerkranker Patienten und Patientinnen und ihrer Angehörigen

Einwilligungsformular für den Patienten/die Patientin

A. ZIEL UND HINTERGRUND DER STUDIE

Prof. Patricia Benner, RN, PhD, Universität von Kalifornien, San Francisco, Prof. Annemarie Kesselring, RN, PhD, Universität Basel sowie Elisabeth Spichiger, RN, MS, PhDcand und Mitarbeiterin am Inselspital führen eine Studie durch mit dem Ziel, besser zu verstehen, wie schwerkranke Patienten und Patientinnen und ihre Angehörigen die Betreuung im Spital erfahren. Sie werden angefragt, ob Sie an der Studie teilnehmen würden, weil Sie im Moment Spitalbetreuung erleben.

B. MASSNAHMEN

Falls Sie einwilligen, an der Studie teilzunehmen, geschieht Folgendes:

1. Mit Ihrer Zustimmung verbringt Elisabeth Spichiger während Ihrem Spitalaufenthalt wiederholt Zeit in Ihrem Zimmer und beobachtet Ihre Betreuung.

2. Sie redet mit Ihnen darüber, wie Sie und Ihre Familie Ihre Krankheit und die Betreuung im Spital erfahren. Falls Sie zustimmen, nimmt sie diese Gespräche auf Tonband auf. Die Gespräche finden je nach Ihrem Wunsch in Ihrem Zimmer oder in einem anderen Raum statt.

3. Ihre Bedürfnisse und Ihr Wohlbefinden haben immer Vorrang. Elisabeth Spichiger spricht Termine zum Beobachten mit Ihnen ab. Diese werden jedoch jederzeit Ihren Bedürfnissen angepasst. Die Dauer der Gespräche richtet sich nach Ihrem Befinden.

4. Während Ihres Spitalaufenthaltes spricht Elisabeth Spichiger wiederholt mit Ihrem/Ihrer ... (Bezeichnung der Beziehung). In diesen Gesprächen geht es darum, wie Ihr/Ihre ... (Bezeichnung der Beziehung) und die Familie Ihre Krankheit, Ihren Spitalaufenthalt und die Betreuung, die Sie erhalten, erfahren. Die Gespräche werden auf Tonband aufgenommen.

5. Elisabeth Spichiger liest Ihre Krankengeschichte und die Pflegedokumentation.

6. Elisabeth Spichiger spricht mit den Mitarbeitern und Mitarbeiterinnen, die Sie betreuen. Sie stellt ihnen Fragen über Ihre Betreuung und die Abteilung, um Ihre Situation besser zu verstehen. Sie nimmt diese kurzen Gespräche auf Tonband auf.

7. Elisabeth Spichiger wird Sie möglicherweise nach dem Spitalaufenthalt nochmals kontaktieren und fragen, ob Sie zu einem weiteren Gespräch bereit wären. Es wird Ihnen freistehen, einem zusätzlichen Gespräch zuzustimmen oder dieses abzulehnen.

C. RISIKEN UND UNANNEHMLICHKEITEN

1. Das Beobachten Ihrer Betreuung kann Ihre Privatsphäre beeinträchtigen. Sie können die Beobachtung jederzeit stoppen.

2. Es kann Ihnen unangenehm sein, über Ihre Erfahrungen zu sprechen. Es mag Ihnen schwerfallen, Ihre Gedanken weiterzugeben. Einige Fragen werden Sie vielleicht traurig stimmen. Es steht Ihnen frei, eine Frage nicht zu beantworten oder das Gespräch jederzeit abzubrechen.

3. Der Gedanke, dass Ihr/Ihre ... (Bezeichnung der Beziehung) oder Spitalmitarbeiter und -mitarbeiterinnen mit Elisabeth Spichiger über Ihre Betreuung sprechen, mag Ihnen unangenehm sein. Sie können Elisabeth Spichiger jederzeit bitten, dies nicht zu tun.

4. Vertraulichkeit: Die Teilnahme an einer Studie führt zu einem gewissen Verlust der Privatsphäre. Alle Unterlagen werden jedoch so vertraulich wie möglich gehandhabt. Nur Prof. Annemarie Kesselring und Elisabeth Spichiger hören die Tonbänder ab. Nach Abschluss der Studie werden diese gelöscht. In allen Unterlagen werden Codes anstelle von Namen benutzt. In Publikationen wird die Identität der Studienteilnehmer und -teilnehmerinnen so verändert, dass Sie nicht wiedererkannt werden können.

D. NUTZEN

Sie werden keinen direkten Nutzen aus der Teilnahme an der Studie ziehen können. Dank Ihrem Beitrag werden aber Pflegende besser verstehen, wie schwerkranke Patienten und Patientinnen und ihre Angehörigen die Betreuung im Spital erleben, und sie werden entsprechende Verbesserungen planen können.

E. KOSTEN

Mit der Teilnahme an der Studie sind keine Kosten verbunden. Die Kosten für den Spitalaufenthalt werden unverändert sein.

F. BEZAHLUNG

Sie werden für die Teilnahme an der Studie nicht bezahlt.

G. FRAGEN

Elisabeth Spichiger hat mit Ihnen über diese Studie gesprochen und Ihre Fragen beantwortet. Falls Sie weitere Fragen zu einer Teilnahme an der Studie haben, einen Kommentar dazu abgeben oder Bedenken äussern möchten, rufen Sie bitte Elisabeth Spichiger an. Ihre Telefonnummer lautet: 031 371 42 88. Sie können auch Frau Prof. Annemarie Kesselring anrufen. Ihre Telefonnummer lautet: 061 267 09 52

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E. EINWILLIGUNG

Sie werden eine Kopie dieses Einwilligungsformulars erhalten.

DIE TEILNAHME AN STUDIEN IST FREIWILLIG. Es steht Ihnen frei, eine Teilnahme abzulehnen oder Ihre Einwilligung jederzeit zurückzuziehen. Ihr Entscheid, an der Studie teilzunehmen oder eine Teilnahme abzulehnen, wird keinen Einfluss auf Ihre jetzige oder zukünftige Betreuung im Spital haben.

Falls Sie bereit sind, an der Studie teilzunehmen, unterschreiben Sie bitte hier:

Datum Unterschrift des Teilnehmers/der Teilnehmerin

Ihrem/Ihrer ... (Bezeichnung der Beziehung) ist es aus körperlichen Gründen nicht möglich, dieses Formular zu unterschreiben. Er/sie ist über die Studie informiert worden. Er/sie hat in Ihrer Gegenwart mündlich einer Teilnahme an der Studie zugestimmt und Sie gebeten, für ihn/sie zu unterschreiben.

Datum Unterschrift des/der Angehörigen

Datum Unterschrift der Person, welche die Einwilligung einholt

APPENDIX O

UNIVERSITÄT VON KALIFORNIEN, SAN FRANCISCO
INSELSPITAL, BERN
EINWILLIGUNG ZUR STUDIENTEILNAHME

Spitalbetreuung: Erfahrungen schwerkranker Patienten und Patientinnen und ihrer Angehörigen

Einwilligungsformular für den Angehörigen/die Angehörige

A. ZIEL UND HINTERGRUND DER STUDIE

Prof. Patricia Benner, RN, PhD, Universität von Kalifornien, San Francisco, Prof. Annemarie Kesselring, RN, PhD, Universität Basel sowie Elisabeth Spichiger, RN, MS, PhDcand und Mitarbeiterin am Inselspital führen eine Studie durch mit dem Ziel, besser zu verstehen, wie schwerkranke Patienten und Patientinnen und ihre Angehörigen die Betreuung im Spital erfahren. Sie werden angefragt, ob Sie an der Studie teilnehmen würden, weil Ihr/Ihre ... (Bezeichnung der Beziehung) im Moment hospitalisiert ist. Der Patient/die Patientin hat eingewilligt, an der Studie teilzunehmen und Elisabeth Spichiger erlaubt, mit Ihnen Kontakt aufzunehmen.

B. MASSNAHMEN

Falls Sie einwilligen, an der Studie teilzunehmen, geschieht Folgendes:

1. Während dem Spitalaufenthalt Ihres/Ihrer ... (Bezeichnung der Beziehung) spricht Elisabeth Spichiger wiederholt mit Ihnen darüber, wie Sie die Krankheit Ihres/Ihrer ... (Bezeichnung der Beziehung) erfahren, und wie Sie und Ihre Familie den Spitalaufenthalt und seine/ihre Betreuung erleben. Falls Sie zustimmen, nimmt sie diese Gespräche auf Tonband auf. Die Gespräche finden normalerweise im Spital, ausserhalb des Zimmers des Patienten/der Patientin statt. Wenn Sie es vorziehen, bei ihm/ihr zu bleiben, kann das Gespräch in seinem/ihrem Zimmer stattfinden.

2. Während dem ersten Gespräch bittet Elisabeth Spichiger Sie auch um folgende Angaben zu Ihrer Person: Alter, Beruf, Religionszugehörigkeit, und Dauer der Beziehung zum Patienten/zur Patientin.

3. Ihre Bedürfnisse und Ihr Wohlbefinden sowie diejenigen der Patientin/des Patienten haben immer Vorrang. Elisabeth Spichiger vereinbart Termine für Gespräche mit Ihnen. Der Zeitpunkt und die Dauer der Gespräche werden jedoch jederzeit Ihren Bedürfnissen angepasst.

4. Elisabeth Spichiger wird Sie möglicherweise nach dem Spitalaufenthalt nochmals kontaktieren und fragen, ob Sie zu einem weiteren Gespräch bereit wären. Es wird Ihnen freistehen, einem zusätzlichen Gespräch zuzustimmen oder dieses abzulehnen.

C. RISIKEN UND UNANNEHMLICHKEITEN

1. Es kann Ihnen unangenehm sein, über Ihre Erfahrungen zu sprechen. Es mag Ihnen schwerfallen, Ihre Gedanken weiterzugeben. Einige Fragen werden Sie vielleicht traurig stimmen. Es steht Ihnen frei, eine Frage nicht zu beantworten oder das Gespräch jederzeit abzubrechen.

2. Vielleicht wird Sie nach einer Weile der Gedanke, dass Sie die Patientin/den Patienten allein gelassen haben, beunruhigen. Sie können das Gespräch jederzeit abbrechen und zurückkehren.

3. Vertraulichkeit: Die Teilnahme an einer Studie führt zu einem gewissen Verlust der Privatsphäre. Alle Unterlagen werden jedoch so vertraulich wie möglich gehandhabt. Nur Prof. Annemarie Kesselring und Elisabeth Spichiger hören die Tonbänder ab. Nach Abschluss der Studie werden diese gelöscht. In allen Unterlagen werden Codes anstelle von Namen benutzt. In Publikationen wird die Identität der Studienteilnehmer und -teilnehmerinnen so verändert, dass Sie nicht wiedererkannt werden können.

D. NUTZEN

Sie werden keinen direkten Nutzen aus der Teilnahme an der Studie ziehen können. Dank Ihrem Beitrag werden aber Pflegende besser verstehen, wie schwerkranke Patienten und Patientinnen und ihre Angehörigen die Betreuung im Spital erleben, und sie werden entsprechende Verbesserungen planen können.

E. KOSTEN

Mit der Teilnahme an der Studie sind keine Kosten verbunden.

F. BEZAHLUNG

Sie werden für die Teilnahme an der Studie nicht bezahlt.

G. FRAGEN

Elisabeth Spichiger hat mit Ihnen über diese Studie gesprochen und Ihre Fragen beantwortet. Falls Sie weitere Fragen zu einer Teilnahme an der Studie haben, einen Kommentar dazu abgeben oder Bedenken äussern möchten, rufen Sie bitte Elisabeth Spichiger an. Ihre Telefonnummer lautet: 031 371 42 88. Sie können auch Frau Prof. Annemarie Kesselring anrufen. Ihre Telefonnummer lautet: 061 267 09 52

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E. EINWILLIGUNG

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DIE TEILNAHME AN STUDIEN IST FREIWILLIG. Es steht Ihnen frei, eine Teilnahme abzulehnen oder Ihre Einwilligung jederzeit zurückzuziehen. Ihr Entscheid, an der Studie teilzunehmen oder eine Teilnahme abzulehnen, wird keinen Einfluss auf Ihren Status als Angehöriger/Angehörige des Patienten/der Patientin haben.

Falls Sie bereit sind, an der Studie teilzunehmen, unterschreiben Sie bitte hier:

Datum	Unterschrift des Teilnehmers/der Teilnehmerin
Datum	Unterschrift der Person, welche die Einwilligung einholt

APPENDIX P

UNIVERSITÄT VON KALIFORNIEN, SAN FRANCISCO
INSELSPITAL, BERN
EINWILLIGUNG ZUR STUDIENTEILNAHME

Spitalbetreuung: Erfahrungen schwerkranker Patienten und Patientinnen und ihrer Angehörigen

Abschliessendes Gespräch: Einwilligungsformular für den Angehörigen/die Angehörige

A. ZIEL UND HINTERGRUND DER STUDIE

Prof. Patricia Benner, RN, PhD, Universität von Kalifornien, San Francisco, Prof. Annemarie Kesselring, RN, PhD, Universität Basel sowie Elisabeth Spichiger, RN, MS, PhDcand und Mitarbeiterin am Inselspital führen eine Studie durch mit dem Ziel, besser zu verstehen, wie schwerkranke Patienten und Patientinnen und ihre Angehörigen die Betreuung im Spital erfahren. Sie und Ihr verstorbener/Ihre verstorbene ... (Bezeichnung der Beziehung) haben bereits viel zu dieser Studie beigetragen. Sie haben Elisabeth Spichiger während dem Spitalaufenthalt Ihres/Ihrer ... (Bezeichnung der Beziehung) kennengelernt und mehrmals mit ihr über Ihre Erfahrungen gesprochen. Im Verlauf eines dieser Gespräche haben Sie ihr erlaubt, Sie später nochmals zu kontaktieren. Deshalb werden Sie jetzt angefragt, ob Sie an einem weiteren Gespräch teilnehmen würden. Die Untersuchenden möchten erfahren, wie Sie die Betreuung im Spital während der letzten Lebenstage Ihres/Ihrer ... (Bezeichnung der Beziehung) erlebt haben.

B. MASSNAHMEN

Falls Sie einwilligen, an einem weiteren Gespräch teilzunehmen, geschieht Folgendes:

1. Elisabeth Spichiger trifft sich mit Ihnen zu einem abschliessenden Gespräch. Sie können Zeitpunkt und Ort des Gesprächs wählen.

2. Elisabeth Spichiger spricht mit Ihnen darüber, wie Sie und Ihre Familie die Betreuung Ihres verstorbenen/Ihrer verstorbenen ... (Bezeichnung der Beziehung) während der letzten Tage erlebt haben, und wie Sie rückblickend über ihren/seinen ganzen Spitalaufenthalt denken. Falls Sie zustimmen, wird das Gespräch auf Tonband aufgenommen.

C. RISIKEN UND UNANNEHMLICHKEITEN

1. Es kann Ihnen unangenehm sein, über Ihre Erfahrungen zu sprechen. Es mag Ihnen schwerfallen, Ihre Gedanken weiterzugeben. Einige Fragen werden Sie vielleicht traurig stimmen. Es steht Ihnen frei, eine Frage nicht zu beantworten oder das Gespräch jederzeit abzubrechen.

2. Vertraulichkeit: Die Teilnahme an einer Studie führt zu einem gewissen Verlust der Privatsphäre. Alle Unterlagen werden jedoch so vertraulich wie möglich gehandhabt. Nur Prof. Annemarie Kesselring und Elisabeth Spichiger hören die Tonbänder ab. Nach Abschluss der Studie werden diese gelöscht. In allen Unterlagen werden Codes anstelle von Namen benutzt. In Publikationen wird die Identität der Studienteilnehmer und -teilnehmerinnen so verändert, dass Sie nicht wiedererkannt werden können.

D. NUTZEN

Sie werden keinen direkten Nutzen aus der Teilnahme an der Studie ziehen können. Dank Ihrem Beitrag werden aber Pflegende besser verstehen, wie schwerkranke und sterbende Patienten und Patientinnen und ihre Angehörigen die Betreuung im Spital erleben, und sie werden entsprechende Verbesserungen planen können.

E. KOSTEN

Mit der Teilnahme an der Studie sind keine Kosten verbunden.

F. BEZAHLUNG

Sie werden für die Teilnahme an der Studie nicht bezahlt.

G. FRAGEN

Elisabeth Spichiger hat mit Ihnen über diese Studie gesprochen und Ihre Fragen beantwortet. Falls Sie weitere Fragen zu einer Teilnahme an der Studie haben, einen Kommentar dazu abgeben oder Bedenken äussern möchten, rufen Sie bitte Elisabeth Spichiger an. Ihre Telefonnummer lautet: 031 371 42 88. Sie können auch Frau Prof. Annemarie Kesselring anrufen. Ihre Telefonnummer lautet: 061 267 09 52

Elisabeth Spichiger ist Studentin an der Universität von Kalifornien, San Francisco. Das Ethikkomitee der Universität befasst sich mit dem Schutz von Studienteilnehmern und -teilnehmerinnen. Sie können das Büro des Komitees zwischen 8.00 und 17.00 Uhr (Schweizerzeit zwischen 17.00 und 02.00 Uhr), Montag bis Freitag, telefonisch unter der Nummer 001 415 476 1814 oder unter folgender Adresse schriftlich erreichen: Committee on Human Research, Box 0962, University of California, San Francisco/San Francisco, CA 94143.

E. EINWILLIGUNG

Sie werden eine Kopie dieses Einwilligungsformulars erhalten.

DIE TEILNAHME AN STUDIEN IST FREIWILLIG. Es steht Ihnen frei, eine Teilnahme an diesem abschliessenden Gespräch abzulehnen oder Ihre Einwilligung jederzeit zurückzuziehen.

Falls Sie bereit sind, am Gespräch teilzunehmen, unterschreiben Sie bitte hier:

______________________	____
Datum	Unterschrift des Teilnehmers/der Teilnehmerin
______________________	____
Datum	Unterschrift der Person, welche die Einwilligung einholt

APPENDIX Q

UNIVERSITÄT VON KALIFORNIEN, SAN FRANCISCO
INSELSPITAL, BERN
EINWILLIGUNG ZUR STUDIENTEILNAHME

Spitalbetreuung: Erfahrungen schwerkranker Patienten und Patientinnen und ihrer Angehörigen

Gespräch nach Spitalaustritt: Einwilligungsformular für den Patienten/die Patientin

A. ZIEL UND HINTERGRUND DER STUDIE

Prof. Patricia Benner, RN, PhD, Universität von Kalifornien, San Francisco, Prof. Annemarie Kesselring, RN, PhD, Universität Basel sowie Elisabeth Spichiger, RN, MS, PhDcand und Mitarbeiterin am Inselspital führen eine Studie durch mit dem Ziel, besser zu verstehen, wie schwerkranke Patienten und Patientinnen und ihre Angehörigen die Betreuung im Spital erfahren. Sie und Ihr/Ihre ... (Bezeichnung der Beziehung) haben bereits viel zu dieser Studie beigetragen. Sie haben Elisabeth Spichiger während ihrem Spitalaufenthalt kennengelernt und mehrmals mit ihr über Ihre Erfahrungen gesprochen. Im Verlauf eines dieser Gespräche haben Sie ihr erlaubt, Sie später nochmals zu kontaktieren. Deshalb werden Sie jetzt angefragt, ob Sie an einem weiteren Gespräch teilnehmen würden. Die Untersuchenden möchten erfahren, wie Sie den Spitalaustritt erlebt haben und wie sie ihre Spitalbetreuung rückblickend sehen.

B. MASSNAHMEN

Falls Sie einwilligen, an einem weiteren Gespräch teilzunehmen, geschieht Folgendes:

1. Elisabeth Spichiger trifft sich mit Ihnen zu einem weiteren Gespräch. Sie können Zeitpunkt und Ort des Gesprächs wählen. Die Dauer des Gesprächs richtet sich nach Ihrem Befinden.

2. Elisabeth Spichiger spricht mit Ihnen darüber, wie Sie und Ihre Familie den Spitalaustritt erlebt haben, und wie Sie rückblickend über Ihren ganzen Spitalaufenthalt denken. Falls Sie zustimmen, wird das Gespräch auf Tonband aufgenommen.

3. Elisabeth Spichiger spricht mit Ihrem/Ihrer ... (Bezeichnung der Beziehung) darüber, wie er/sie und die Familie den Spitalaustritt erlebt haben und wie sie rückblickend über den ganzen Spitalaufenthalt denken. Das Gespräch wird auf Tonband aufgenommen.

C. RISIKEN UND UNANNEHMLICHKEITEN

1. Es kann Ihnen unangenehm sein, über Ihre Erfahrungen zu sprechen. Es mag Ihnen schwerfallen, Ihre Gedanken weiterzugeben. Einige Fragen werden Sie vielleicht traurig stimmen. Es steht Ihnen frei, eine Frage nicht zu beantworten oder das Gespräch jederzeit abzubrechen.

2. Der Gedanke, dass Ihr/Ihre ... (Bezeichnung der Beziehung) mit Elisabeth Spichiger über Ihre Betreuung spricht, mag Ihnen unangenehm sein. Sie können Elisabeth Spichiger jederzeit bitten, dies nicht zu tun.

3. Vertraulichkeit: Die Teilnahme an einer Studie führt zu einem gewissen Verlust der Privatsphäre. Alle Unterlagen werden jedoch so vertraulich wie möglich gehandhabt. Nur Prof. Annemarie Kesselring und Elisabeth Spichiger hören die Tonbänder ab. Nach Abschluss der Studie werden diese gelöscht. In allen Unterlagen werden Codes anstelle von Namen benutzt. In Publikationen wird die Identität der Studienteilnehmer und –teilnehmerinnen so verändert, dass Sie nicht wiedererkannt werden können.

D. NUTZEN

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E. KOSTEN

Mit der Teilnahme an der Studie sind keine Kosten verbunden.

F. BEZAHLUNG

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G. FRAGEN

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Falls Sie bereit sind, an der Studie teilzunehmen, unterschreiben Sie bitte hier:

________________	________________________________
Datum	Unterschrift des Teilnehmers/der Teilnehmerin

Ihrem/Ihrer ... (Bezeichnung der Beziehung) ist es aus körperlichen Gründen nicht möglich, dieses Formular zu unterschreiben. Er/sie ist über das Gespräch informiert worden. Er/sie hat in Ihrer Gegenwart mündlich einer Teilnahme am Gespräch zugestimmt und Sie gebeten, für ihn/sie zu unterschreiben.

________________	________________________________
Datum	Unterschrift des/der Angehörigen

________________	________________________________
Datum	Unterschrift der Person, welche die Einwilligung einholt

APPENDIX R

UNIVERSITÄT VON KALIFORNIEN, SAN FRANCISCO
INSELSPITAL, BERN
EINWILLIGUNG ZUR STUDIENTEILNAHME
Spitalbetreuung: Erfahrungen schwerkranker Patienten und Patientinnen und ihrer Angehörigen

Gespräch nach Spitalaustritt: Einwilligungsformular für den Angehörigen/die Angehörige

A. ZIEL UND HINTERGRUND DER STUDIE

Prof. Patricia Benner, RN, PhD, Universität von Kalifornien, San Francisco, Prof. Annemarie Kesselring, RN, PhD, Universität Basel sowie Elisabeth Spichiger, RN, MS, PhDcand und Mitarbeiterin am Inselspital führen eine Studie durch mit dem Ziel, besser zu verstehen, wie schwerkranke Patienten und Patientinnen und ihre Angehörigen die Betreuung im Spital erfahren. Sie und Ihr/Ihre ... (Bezeichnung der Beziehung) haben bereits viel zu dieser Studie beigetragen. Sie haben Elisabeth Spichiger während dem Spitalaufenthalt Ihres/Ihrer ... (Bezeichnung der Beziehung) kennengelernt und mehrmals mit ihr über Ihre Erfahrungen gesprochen. Im Verlauf eines dieser Gespräche haben Sie ihr erlaubt, Sie später nochmals zu kontaktieren. Deshalb werden Sie jetzt angefragt, ob Sie an einem weiteren Gespräch teilnehmen würden. Die Untersuchenden möchten erfahren, wie Sie den Spitalaustritt erlebt haben und wie sie im Rückblick die Spitalbetreuung Ihres/Ihrer ... (Bezeichnung der Beziehung) sehen.

B. MASSNAHMEN

Falls Sie einwilligen, an einem weiteren Gespräch teilzunehmen, geschieht Folgendes:

1. Elisabeth Spichiger trifft sich mit Ihnen zu einem abschliessenden Gespräch. Sie können Zeitpunkt und Ort des Gesprächs wählen.

2. Elisabeth Spichiger spricht mit Ihnen darüber, wie Sie und Ihre Familie den Spitalaustritt Ihres/Ihrer ... (Bezeichnung der Beziehung) erlebt haben, und wie Sie rückblickend über ihren/seinen ganzen Spitalaufenthalt denken. Falls Sie zustimmen, wird das Gespräch auf Tonband aufgenommen.

C. RISIKEN UND UNANNEHMLICHKEITEN

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D. NUTZEN

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E. KOSTEN

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F. BEZAHLUNG

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G. FRAGEN

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E. EINWILLIGUNG

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DIE TEILNAHME AN STUDIEN IST FREIWILLIG. Es steht Ihnen frei, eine Teilnahme an diesem weiteren Gespräch abzulehnen oder Ihre Einwilligung jederzeit zurückzuziehen.

Falls Sie bereit sind, am Gespräch teilzunehmen, unterschreiben Sie bitte hier:

____________________ Datum	______________________________________ Unterschrift des Teilnehmers/der Teilnehmerin
____________________ Datum	______________________________________ Unterschrift der Person, welche die Einwilligung einholt

APPENDIX S

Fragen für Gespräche mit Patienten und Patientinnen

Anmerkung: Die Untersuchende folgt im Gespräch inhaltlich der Initiative des Patienten/der Patientin. Häufigkeit, Zeitpunkt und Dauer der Gespräche hängen vom Befinden des Patienten/der Patientin ab. Das Ziel ist, in den Gesprächen nach und nach soviele dieser Fragen zu klären, wie das Befinden des Patienten/der Patientin erlaubt.

1. Können Sie mir sagen, wie es Ihnen heute geht? Wie fühlen Sie sich?
2. Und wie haben Sie sich im allgemeinen gefühlt, seit Sie im Spital sind?
3. Können Sie mir erzählen, wie es Ihnen vor dem Spitalaufenthalt gegangen ist, und was zum Spitaleintritt geführt hat?
4. Können Sie mir etwas über ihre Krankheit sagen? Wann und wie hat diese angefangen? Wie war der Verlauf bisher?
5. Bitte erzählen Sie mir etwas über sich selber, wer Sie sind, was Sie so gemacht haben bevor Sie krank wurden.
6. Wie ist es für Sie jetzt im Spital? Hat sich etwas verändert seit Ihrem Spitaleintritt?

   Nachfragen um zu erfahren, wie der Alltag des Patienten/der Patientin im Spital aussieht und wie sich dieser seit dem Spitaleintritt verändert hat.
7. Die ... (richtige Bezeichnung, z.B. Krankenschwester, benutzen) macht ... (richtige Massnahme ergänzen). Wie ist das für Sie?

   Nachfragen um zu erfahren, wie der Patient/die Patientin Pflegemassnahmen erlebt.
8. Ich habe beobachtet ... Wie war das für Sie?
9. Können Sie mir sagen, welche Probleme und Symptome Ihnen zu schaffen machen?

   Nachfragen um zu erfahren, welche Beschwerden das Befinden des Patienten/der Patientin beeinträchtigen, wie diese behandelt werden und wie erfolgreich die Behandlung ist.
10. Sie haben hier im Spital sicher mit verschiedenen Mitarbeitern und Mitarbeiterinnen zu tun gehabt, z.B. mit Aerzten und Krankenschwestern, vielleicht auch noch mit anderen. Können Sie mir etwas über Ihre Erfahrungen im Umgang mit Mitarbeitern und Mitarbeiterinnen erzählen?

    Nachfragen um zu erfahren, wie der Patient/die Patientin seine/ihre Interaktionen mit Mitarbeitern und Mitarbeiterinnen erlebt.
11. Gibt es etwas, das Sie gerne mit jemandem vom Spital besprechen möchten? Möchten Sie für etwas Unterstützung von jemandem?

12. Könnte jemand im Spital irgend etwas tun, um die Situation für Sie zu verbessern?
13. Wie geht es Ihrem/Ihrer ...(hier und in den folgenden Fragen richtige Bezeichnung ergänzen)? Wie kommt er/sie damit zurecht, dass Sie krank sind? Wie kommt Ihre Familie damit zurecht?
14. Hat Ihr/Ihre ... Ihnen zu Hause mit etwas geholfen (z.B. Körperpflege, Medikamenteneinnahme)? Hat Ihre Familie sie irgendwie unterstützt?
15. Beteiligt sich Ihr/Ihre ... hier an der Pflege? Beteiligt sich Ihre Familie?
16. Hat Ihr/Ihre ... oder haben andere Familienmitglieder Kontakt gehabt mit Mitarbeitern und Mitarbeiterinnen im Spital? Haben sie in irgendeiner Form Unterstützung erhalten?
17. Gibt es noch etwas, das Sie mir erzählen möchten?

Fragen für weitere Gespräche

1. Bitte erzählen Sie mir, wie Ihre Tage verliefen seit wir uns gesehen haben. Wie haben Sie sich gefühlt?

   Nachfragen um zu erfahren, ob und wie sich der Spitalalltag für den Patienten/die Patientin verändert hat.

2. Geschah irgend etwas Besonderes seit wir uns gesehen haben? Können Sie sich an eine besonders gute / schlechte Erfahrung erinnern und mir davon erzählen?
3. Ich habe beobachtet ... Wie war das für Sie?
4. Letztes Mal haben Sie mir gesagt, dass Sie ... (Probleme / Symptome) haben. Wie sieht es jetzt damit aus?

   Nachfragen um zu erfahren, wie sich die Beschwerden des Patienten/der Patientin entwickelt haben, wie diese behandelt wurden und wie erfolgreich die Behandlung war.

5. Wie geht es Ihnen jetzt? Hat sich etwas verändert seit wir uns gesehen haben?

   Nachfragen um zu erfahren, ob der Patient/die Patientin unter neu aufgetretenen Beschwerden leidet, wie diese behandelt werden und wie erfolgreich die Behandlung ist.

6. Sind Ihnen neue Mitarbeiter und Mitarbeiterinnen begegnet? Können Sie mir etwas über Ihre Erfahrungen im Umgang mit diesen erzählen?

   Nachfragen um zu erfahren, wie der Patient/die Patientin seine/ihre Interaktionen mit neuen Mitarbeitern und Mitarbeiterinnen erlebt hat.

7. Gab es etwas, das Sie gerne mit jemandem vom Spital besprochen hätten? Hätten Sie sich für etwas Unterstützung von jemandem gewünscht?
8. Könnte jemand im Spital irgend etwas tun, um die Situation für Sie zu verbessern?

9. Wie geht es Ihrem/Ihrer ... ? Wie kommt er/sie zurecht? Wie kommt die Familie zurecht?
10. Letztes Mal haben Sie mir erzählt, dass Ihr/Ihre ... (Beteiligung des/der Angehörigen / der Familie an der Pflege). Hat sich etwas verändert?
11. Letztes Mal haben Sie mir gesagt, dass Ihr/Ihre ... (Kontakt des/der Angehörigen / der Familie mit Mitarbeitern und Mitarbeiterinnen). Hat sich etwas verändert?
12. Letztes Mal haben Sie gesagt ... Ich habe darüber nachgedacht und mich gefragt ... (Fragen klären, die sich aus dem vorhergehenden Interview ergaben.)
13. Gibt es noch etwas, das Sie mir erzählen möchten?

APPENDIX T

Fragen für Interviews mit Angehörigen

Anmerkung: Die Untersuchende folgt im Gespräch inhaltlich der Initiative des Angehörigen/der Angehörigen. Die Liste enthält Fragen, die im Verlauf des Gesprächs beantwortet werden sollen, wenn die Situation dies erlaubt.

Erstes Interview

1. Zuerst möchte ich Sie fragen, wie es Ihrem/Ihrer ... (hier und in den folgenden Fragen richtige Bezeichnung ergänzen) heute geht. Können Sie mir sagen, wie er/sie sich heute fühlt?
2. Und wie hat er/sie sich im allgemeinen gefühlt, seit er/sie im Spital ist?
3. Können Sie mir sagen, wie es Ihrem/Ihrer ... vor dem Spitalaufenthalt gegangen ist und was zum Spitaleintritt geführt hat?
4. Können Sie mir etwas über die Krankheit Ihres/Ihrer ... sagen? Wann und wie hat diese angefangen? Wie war der Verlauf bisher?
5. Können Sie mir etwas erzählen über Ihren/Ihre ... , wer er/sie ist, was er/sie so getan hat bevor er/sie krank wurde?
6. Wie ist es jetzt für Ihren/Ihre ... im Spital? Hat sich etwas verändert seit dem Spitaleintritt?

   Nachfragen um zu erfahren, wie der Alltag des Patienten/der Patientin im Spital aussieht und wie sich dieser seit dem Spitaleintritt verändert hat.
7. Die ...(richtige Bezeichnung, z.B. Krankenschwester, benutzen) macht ... (richtige Massnahme ergänzen). Wie ist das für Ihren/Ihre ... ?

   Nachfragen um zu erfahren, wie der Patient/die Patientin und der/die Angehörige Pflegemassnahmen erleben.
8. Ich habe beobachtet ... Wie denken Sie darüber?
9. Können Sie mir sagen, welche Probleme und Symptome Ihrem/Ihrer ... zu schaffen machen?

   Nachfragen um zu erfahren, welche Beschwerden das Befinden des Patienten/der Patientin beeinträchtigen, wie diese behandelt werden, wie erfolgreich die Behandlung ist und wie der/die Angehörige die Situation sieht.
10. Ihr/Ihre ... hat hier im Spital mit verschiedenen Mitarbeitern und Mitarbeiterinnen zu tun, z.B. mit Aerzten und Krankenschwestern, vielleicht auch noch mit anderen. Können Sie mir etwas sagen über die Erfahrungen, die Ihr/Ihre ... im Umgang mit Mitarbeitern und Mitarbeiterinnen macht?

Nachfragen um zu erfahren, wie der Patient/die Patientin seine/ihre Interaktionen mit Mitarbeitern und Mitarbeiterinnen erlebt und wie der/die Angehörige ... diese sieht.

11. Haben Sie den Eindruck, dass es gut wäre für Ihren/Ihre ... , noch mit jemand anderem zu sprechen oder zusätzlich Unterstützung zu erhalten für irgend etwas?
12. Haben Sie den Eindruck, dass jemand im Spital irgend etwas tun könnte, um die Situation für Ihren/Ihre ... zu verbessern?
13. Jetzt möchte ich noch auf Ihre Familie zu sprechen kommen. Bisher haben wir über ... (Familienmitglieder nennen, die bisher erwähnt wurden) gesprochen. Haben Sie noch andere Familienmitglieder?
14. Wie geht es Ihnen? Wie kommen Sie mit der Krankheit Ihres/Ihrer ... zurecht?
15. Wie kommt die Familie mit der Krankheit Ihres/Ihrer ... zurecht?
16. Bitte erzählen Sie mir etwas über sich selber, wer Sie sind, wie Ihr Leben ausgesehen hat bevor Ihr/Ihre ... krank wurde.
17. Können Sie mir etwas über Ihre Familie erzählen, wie Ihr Familienleben ausgesehen hat vor der Erkrankung Ihres/Ihrer ... ?
18. Haben Sie Ihrem/Ihrer ... zu Hause mit etwas geholfen (z.B. Körperpflege, Medikamenteneinnahme)? Hat die Familie ihn/sie irgendwie unterstützt?
19. Beteiligen Sie sich hier im Spital an der Betreuung Ihres/Ihrer ... ? Beteiligt sich die Familie?

    Nachfragen um zu erfahren, wie der/die Angehörige / die Familie in die Betreuung im Spital involviert sind.
20. Haben Sie Kontakt gehabt mit Mitarbeitern und Mitarbeiterinnen im Spital?

    Nachfragen um zu erfahren, ob und wie Mitarbeiter und Mitarbeiterinnen den Angehörigen/die Angehörige / die Familie einbeziehen und unterstützen.
21. Gibt es etwas, das Sie gerne besprechen möchten mit jemandem vom Spital? Möchten Sie für etwas Unterstützung von jemandem?
22. Könnte jemand im Spital irgend etwas tun, um die Situation für Sie zu verbessern?
23. Nun möchte ich Sie noch um einige Angaben zu Ihrer Person bitten: Wie alt sind Sie? Ihr Beruf? Ihre Religionszugehörigkeit? Falls zutreffend: Wie lange sind Sie verheiratet/leben Sie mit Ihrem/Ihrer ... ?
24. Gibt es noch etwas, das Sie mir erzählen möchten?

Nachfolgende Interviews

1. Wie geht es Ihrem/Ihrer ... heute?
2. Bitte erzählen Sie mir, wie seine/ihre Tage verliefen seit wir uns gesehen haben. Wie hat sich Ihr/Ihre ... gefühlt?

Nachfragen um zu erfahren, ob und wie sich der Spitalalltag für den Patienten/die Patientin verändert hat.

3. Geschah irgend etwas Besonderes seit wir uns gesehen haben? Können Sie sich an eine besonders gute / schlechte Erfahrung Ihres/Ihrer ... erinnern und mir davon erzählen? Welchen Eindruck haben Sie von der Betreuung Ihres/Ihrer ... ?
4. Ich habe beobachtet ... Wie denken Sie darüber?
5. Letztes Mal haben Sie mir gesagt, dass Ihr/Ihre ... ... (Probleme / Symptome) hat. Wie sieht es jetzt damit aus?

   Nachfragen um zu erfahren, wie sich die Beschwerden des Patienten/der Patientin entwickelt haben, wie diese behandelt wurden, wie erfolgreich die Behandlung war und wie der/die Angehörige die Situation sah.

5. Wie geht es Ihrem/Ihrer ... jetzt? Hat sich etwas verändert seit letzter Woche?

   Nachfragen um zu erfahren, ob der Patient/die Patientin unter neu aufgetretenen Beschwerden leidet, wie diese behandelt werden, wie erfolgreich die Behandlung ist und wie der/die Angehörige die Situation sieht.

6. Sind Ihrem/Ihrer ... neue Mitarbeiter und Mitarbeiterinnen begegnet? Können Sie mir etwas über die Erfahrungen sagen, die Ihr/Ihre ... im Umgang mit diesen gemacht hat?

   Nachfragen um zu erfahren, wie der Patient/die Patientin seine/ihre Interaktionen mit neuen Mitarbeitern und Mitarbeiterinnen erlebt hat und wie der/die Angehörige diese sieht.

7. Haben Sie den Eindruck, dass es gut wäre für Ihren/Ihre ... , noch mit jemand anderem zu sprechen oder zusätzlich Unterstützung zu erhalten für irgend etwas?
8. Haben Sie den Eindruck, dass jemand im Spital irgend etwas tun könnte, um die Situation für Ihren/Ihre ... zu verbessern?
9. Jetzt möchte ich noch auf Sie und Ihre Familie zu sprechen kommen. Wie geht es Ihnen? Wie geht es der Familie?
10. Letztes Mal haben Sie mir erzählt, dass ... (Beteiligung des/der Angehörigen / der Familie an der Betreuung). Hat sich etwas verändert?

    Nachfragen um zu erfahren, wie der/die Angehörige / die Familie jetzt in die Betreuung im Spital involviert sind.

11. Letztes Mal haben Sie mir erzählt, dass ... (Kontakt des/der Angehörigen / der Familie mit Mitarbeitern und Mitarbeiterinnen). Hat sich etwas verändert?

    Nachfragen um zu erfahren, ob und wie Mitarbeiter und Mitarbeiterinnen den Angehörigen/die Angehörige / die Familie jetzt einbeziehen und unterstützen.

12. Hat sich etwas ergeben seit dem letzten Mal, das Sie gerne besprechen möchten mit jemandem vom Spital? Möchten Sie für etwas Unterstützung von jemandem?
13. Könnte jemand im Spital irgend etwas tun, um die Situation für Sie zu verbessern?

14. Letztes Mal haben Sie gesagt … Ich habe darüber nachgedacht und mich gefragt … (Fragen klären, die sich aus dem vorhergehenden Interview ergaben.)
15. Gibt es noch etwas, das Sie mir erzählen möchten?

APPENDIX U

Fragen für das abschliessende Interview mit Angehörigen

Anmerkung: Die Untersuchende folgt im Gespräch inhaltlich der Initiative des Angehörigen/der Angehörigen. Die Liste enthält Fragen, die im Verlauf des Gesprächs beantwortet werden sollen, wenn die Situation dies erlaubt.

1. Wie geht es Ihnen? Wie ist es Ihnen während der letzten 2 Monate gegangen?
2. Wir haben uns zuletzt am ... getroffen, und Ihr/Ihre ... (hier und in den folgenden Fragen richtige Bezeichnung ergänzen) starb ... Tage später. Können Sie mir etwas sagen über seine/ihre letzten Tage im Spital? Wie verliefen diese? Wie hat sich Ihr/Ihre ... gefühlt?

   Nachfragen um zu erfahren, wie der Spitalalltag für den Patienten/die Patientin ausgesehen hat und wie sich dieser während seiner/ihrer letzten Lebenstage verändert hat.
3. Können Sie mir erzählen, welche Betreuung Ihr/Ihre ... benötigte?

   Nachfragen um zu erfahren, wie der Patient/die Patientin und der/die Angehörige die Betreuung erlebt haben.
4. Letztes Mal haben Sie mir gesagt, dass Ihr/Ihre ... ... (Probleme / Symptome) hatte. Wie haben sich diese entwickelt während der letzten Tage?

   Nachfragen um zu erfahren, wie sich die Beschwerden des Patienten/der Patientin entwickelten während der letzten Tage, wie diese behandelt wurden, wie erfolgreich die Behandlung war und wie der/die Angehörige die Situation sah.
5. Wie ging es Ihrem/Ihrer ... zuletzt? Hat sich etwas verändert?

   Nachfragen um zu erfahren, ob der Patient/die Patientin unter neu aufgetretenen Beschwerden litt, wie diese behandelt wurden, wie erfolgreich die Behandlung war und wie der/die Angehörige die Situation wahrnahm.
6. Sind Ihrem/Ihrer ... neue Mitarbeiter und Mitarbeiterinnen begegnet im Verlauf der letzten Tage? Können Sie mir etwas über die Erfahrungen sagen, die Ihr/Ihre ... im Umgang mit diesen gemacht hat?

   Nachfragen um zu erfahren, wie der Patient/die Patientin seine/ihre Interaktionen mit neuen Mitarbeitern und Mitarbeiterinnen erlebt hat und wie der/die Angehörige diese wahrnahm.
7. Haben Sie den Eindruck, dass es gut gewesen wäre für Ihren/Ihre ... , noch mit jemand anderem zu sprechen oder zusätzlich Unterstützung zu erhalten für irgend etwas?

8. Haben Sie den Eindruck, dass jemand im Spital irgend etwas hätte tun können, um die Situation für Ihren/Ihre ... zu verbessern?
9. Jetzt möchte ich auf Sie und die Familie zu sprechen kommen. Wie waren die letzten Tage für Sie? Wie waren diese für die Familie?
10. Letztes Mal haben Sie mir erzählt, dass ... (Beteiligung des/der Angehörigen / der Familie an der Betreuung). Hat sich während der letzten Tage etwas verändert?

    Nachfragen um zu erfahren, wie der/die Angehörige / die Familie während der letzten Tage in die Betreuung im Spital involviert waren.
11. Letztes Mal haben Sie mir erzählt, dass ... (Kontakt des/der Angehörigen / der Familie mit Mitarbeitern und Mitarbeiterinnen). Hat sich während der letzten Tage etwas verändert?

    Nachfragen um zu erfahren, ob und wie Mitarbeiter und Mitarbeiterinnen den Angehörigen/die Angehörige / die Familie während der letzten Tage einbezogen und unterstützt haben.
12. Hat sich etwas ergeben im Verlauf der letzten Tage, das Sie gerne besprochen hätten mit jemandem vom Spital? Hätten Sie sich für etwas Unterstützung von jemandem gewünscht?
13. Hätte jemand im Spital irgend etwas tun können, um die Situation für Sie zu verbessern?
14. Können Sie mir erzählen, wie Ihr/Ihre ... starb? Waren Sie anwesend? Was geschah nach seinem/ihrem Tod? Wie haben Sie die Situation erlebt?
15. Jetzt möchte ich noch auf den ganzen Spitalaufenthalt Ihres/Ihrer ... zu sprechen kommen. Wenn Sie zurückschauen, wie denken Sie jetzt darüber?
16. Wie haben Sie im allgemeinen die Betreuung Ihres/Ihrer ... erlebt? Erinnern Sie sich an etwas Besonderes? Können Sie sich an eine speziell gute / schlechte Erfahrung erinnern?
17. Haben Sie den Eindruck, dass etwas fehlte in der Betreuung Ihres/Ihrer ... ? Was hätten Mitarbeiter und Mitarbeiterinnen zusätzlich tun können, um die Situation für Ihren/Ihre ... zu verbessern?
18. Wie fühlten Sie / Ihre Familie sich behandelt im Spital? Erinnern Sie sich an etwas Besonderes? Können Sie sich an eine speziell gute / schlechte Erfahrung erinnern?
19. Haben Sie den Eindruck, dass Sie / Ihre Familie im Spital etwas vermissten? Was hätten Mitarbeiter und Mitarbeiterinnen zusätzlich tun können, um die Situation vor oder nach dem Tod Ihres/Ihrer ... für Sie zu verbessern?
20. Gibt es noch etwas, das Sie mir erzählen möchten?