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THE RELATIONSHIP BETWEEN FAMILIES AND STAFF IN NURSING HOMES AND ITS IMPLICATION FOR STAFF'S CARE APPROACHES

by

MARGRÉT GÚSTAFSDOTTIR

DISSERTATION

Submitted in partial satisfaction of the requirements for the degree of

DOCTOR OF PHILOSOPHY

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THE RELATIONSHIP BETWEEN FAMILIES AND STAFF IN NURSING HOMES AND ITS IMPLICATION FOR STAFF'S CARE APPROACHES

ACKNOWLEDGEMENTS

I decided to contact my old school in San Francisco during the fall of 1991 when I was preparing to travel to the West Coast to attend a conference in Los Angeles. I had been teaching in the Department of Nursing at the University of Iceland for seven years and had a sabbatical year coming up to concentrate on research work. The problem was that I did not feel very confident with regard to conducting research. Some of my colleagues were at the time working on doctoral dissertations and there was a growing concern among us, the teachers, that we needed to some degree to shift emphasis from teaching to research in our work. Otherwise, the department would be no more than a nominal entity within the university structure. I myself really felt more at home in the clinical site than in the academic setting, and was rather ambivalent when I considered doctoral studies. However, I thought I could explore the possibilities, so I wrote to Betty Furuta, former academic administrator and asked her if I could meet with Dr. Patricia Benner and Dr. Jeanie Kayser-Jones when I visited the school while I traveled through. Nonetheless, I was thinking at the same time that if I decided to apply for doctoral studies it should be at a school nearer to home, or on the East Coast. After all it only takes half the time to travel that distance from Iceland compared to San Francisco and I was concerned that it might be better to have a shorter distance to travel, as my mother was aging and not in good health.

But my destiny was determined as I walked into Dr. Benner's office when I came on my visit to the School of Nursing. I had asked to see her because I had become exhilarated when I first started to read her work and felt that her vision of nursing was true. Dr. Benner received me graciously in her appreciative manner and I felt surprisingly at ease as I faced my guru. I told her that I was interested in families visiting in nursing homes and how their visits influenced the nurses' knowledge of their patients, and I mentioned my hunch that such knowledge might be very important for nursing. Dr. Benner then told me that she was working on an article on this subject with

two colleagues, one of whom was Dr. Chesla, and that she might actually be just the right person for me to meet as she was a family specialist. Dr. Benner made a quick phone call, and before I knew it, I sat opposite my advisor-to-be in the doctoral program, Dr. Catherine A. Chesla.

I started my studies under Dr. Catherine A Chesla's guidance in the fall of 1992. I stayed continuously in San Francisco for two years while I undertook the required course work in the school, but I have since been a long-distance student while resuming my teaching responsibilities back home. However, I have visited twice for shorter periods and the third time I stayed for almost half a year while I started to work on the interpretation of my data. Dr. Chesla has been very understanding and patient with regard to my circumstances which have, needless to say, been demanding for her as a teacher. She actually proposed to my dissertation committee that I might defend my proposal during a phone meeting to save me a trip to San Francisco. This was agreed and it made a lot of difference for me. Our means of communication have, however, changed in a revolutionary way, as time has gone by, with the new net technology. Dr. Chesla's high standards of conducting interpretive studies in a systematic and rigorous manner have been directive, as I have been learning to bring forth my work in a disciplined and structured manner. I have deeply appreciated her thorough and succinct feedback and comments upon my evolving work, both during our meetings in her office in San Francisco and through our conversation on the e-mail.

I attended all courses that Dr. Benner offered while I stayed in San Francisco and found it a precious opportunity to be a part of her class. I was very grateful when Dr. Benner was willing to be the chair of the committee for my qualifying exam and it was amazing how she managed to coach me through the last preparation of the papers during a hectic three-week stay in San Francisco. But she did so with her special insight and elaborate refinement, while keeping up my spirit and belief in my purpose. And during that time I certainly appreciated Jim Grout's help in the Learning

Resources as he put his finishing touch on my qualifying papers as on many other papers through the years.

I initially approached Dr. Margaret Wallhagen to ask her to be part of my committee for the qualifying exam and though she had not known me previously, she was very generous and encouraging as she agreed to do so, later she agreed to continue on my dissertation committee. I have certainly appreciated her support.

I did an independent study with Dr. Sharon Kaufman during the summer of 1994 when my permanent stay in San Francisco was nearing its end and she advised me which ethnographic studies to read on nursing home life. These readings turned out to be eye-opening and helped me much in preparing the qualifying papers. Furthermore Dr. Kaufman agreed to be on my qualifying committee, which I really appreciated.

Many trips to UC Berkeley to attend Dr. Jane Rubin's, and later two of Dr. Hubert Dreyfus courses, were certainly worthwhile and simply wonderful. Dr. Dreyfus' voice has actually sustained me through my long-distance learning as I have much enjoyed pursuing the subject of the late Heidegger and Foucault while spending hours listening to audiotapes of Dr. Dreyfus' lectures' on this subject. Dr. Dreyfus' voice has brought me back to California and in a way reminded that my student days are still there during my everyday life in Iceland.

My everyday life in Iceland has however changed considerably since my mother died in 1996. My mother, Kristín, supported every step of mine in going to America as she always did whatever the endeavour was and in a way still does. My sister Kristín has been of great support all the way through and put my practical files in order while I have been away, as only a librarian can do. My little nieces Hrefna, Berglind Sunna and Birna, daughters of my younger sister Helga, have been a source of joy during this time as they always are and I treasure all the beautiful paintings they sent me while I stayed in San Francisco. Gudrún, my friend from childhood, and her family have been very solicitous as always. My eighty-year-old neighbor Jóhanna and her daughter

Droplaug have looked after my apartment while I have been away and have been my saviours during difficult times. A mother and daughter in San Francisco, Helen and Reid Dorwing, have been family in San Francisco since my master studies, and not least the late William Dorwing. In the distance, I have leaned on María Gudmundsdóttir my friend and fellow student to handle practical affairs on the spot on Parnassus Avenue and another colleague Karel Koenig has also helped me out during crucial times.

Gudlaug Vilbogadóttir, office manager in the Department of Nursing, has kindly contributed to this research with very exact and careful transcriptions of the interviews and so has Ingibjörg Ingadóttir, administrative secretary in the Department of Nursing, who has edited endless pages of my English writing with patience and kindness. Gunnhildur Jóhannsdóttir, medical secretary also provided valuable transcription service. Anna H. Yates, a certified translator, did the second editing in an efficient and thoughtful manner. I am very appreciative of their help and support.

The process of my doctoral studies at the School of Nursing, University of California, San Francisco has been discontinuous, as I have been granted leaves of absence for shorter or longer periods, i.e. for data collection in Iceland. The University of California, San Francisco has, however, during many periods of my enrolment in the School of Nursing supported me with non-resident tuition waiver which I have been very grateful for. I am indeed deeply appreciative of the generosity of the School of Nursing, University of California, San Francisco in supporting my education.

Finally, but not least, I am deeply appreciative of the contribution of the participants in this study. Everyone who participated in this study did so willingly with a positive and open stance. The experience of working with the participants during the data collection was invaluable for me and in fact very pleasant and good.

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THE RELATIONSHIP BETWEEN FAMILIES AND STAFF IN NURSING HOMES AND ITS IMPLICATION FOR STAFF'S CARE APPROACHES

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ABSTRACT

This interpretive phenomenological study was conducted in Iceland. The purpose of the study was to shed light on families' experience of visiting in a nursing home and their relations with the staff. The sample encompassed family members of 15 nursing home residents and 16 groups of staff with 4-5 staff members in each group. The data collection entailed interviews with family members and staff as well as participant observation.

The findings depict that these families attempt to come to terms with institutionalization of their member by continuing involvement in the elder's life. The family visits are regular and their structure constitutes the ground of being with the elder while visiting, and gives content and meaning to the visiting time. These families have learned "to handle visiting" in a world that is to a degree designated by the inevitable decline of the inhabitants.

The family ties, the family member's circumstances and the family's perception of the situation influence the family's involvement in care. The family's involvement in the care of a loved one is exemplified by six paradigm cases which explicate the family's perception of care and its relationship with the staff, the family's engagement in the care of the elder, and the staff's response to such input. Each family has its characteristic style of engagement in the care. The main distinctive feature of the different styles is the extent to which the care of the body is compartmentalized and ascribed to the realm of staff's concern as opposed to the family's care of the self. There is an inclination on both the family's and the staff's part to perceive that there are boundaries between each party's territory of care. The staff addresses to a limited extent issues of care with the family, but shows a certain receptiveness to any initiative on the family's behalf to establish exchange.

The findings of this study show that the visiting family is the guardian of the elder's wellbeing and watches over the loved one's condition and responses to the situation. Thus, it is important for the staff to acknowledge the ramifications of such guardianship.

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Chapter One

NURSING APPROACHES TO CARE IN THE CONTEXT OF A NURSING HOME

Introduction

In recent decades, there has been a phenomenal growth in the nursing home industry. A 1954 Public Health Service inventory found a total of only 260,000 beds in 9,000 nursing homes in America that provided some degree of health services over and above room and board. By 1985 that number had increased to 1.5 million beds in about 15.000 certified nursing homes (Foner, 1994).

The aim of this chapter is to shed light on nursing approaches to care within this expanding area of health care. It delineates institutional features with regard to characteristics of nursing homes and the meaning of placement in such settings for the aging person. The attributes of nursing care in this context are discussed and I will clarify how the work is organized, valued and defined. The discussion focuses on the interpretation of what constitutes nursing care of the elderly in nursing homes. This part addresses especially the meaning of bedside care, which is frequently referred to as "bed and body work," i.e., custodial care or routine work. It attempts to explore how the care of the body has been devalued and somewhat separated from the care of the person and put in the hands of aides or assistants of nursing. Finally the notion of complexity of care is addressed with regard to the importance placed on medical technology on one hand compared to meaningful relationships between the patient and the nurse on the other hand. The chapter closes with concluding remark about registered nurses' participation in bedside care and what it entails in this context.

Historical Links Between Almshouses and Nursing Homes

Schell (1993) states that the birth of gerontological nursing was foreshadowed by nurses' concern for the elderly poor of the almshouse, "a speciality conceived in the womb of the almshouse, a marginalized, stigmatized institution" (p. 203).

In America ever since colonial times almhouses provided shelter for the poor of all ages and conditions, sick and well alike. From their conception, they sheltered substantial numbers of elderly. According to census data, the proportion of elderly in the almshouses increased to reach majority in the first decade of the twentieth century (Schell, 1993). Many of the elderly residents were sick, dependent and vulnerable, suffering from chronic conditions such as rheumatism, stroke, and senility (Schell, 1993). Schell (1993) maintains that nursing homes, as the institutions that arose to carry on the charge of these earlier institutions, inherited the stigma attached to the almshouse.

Schell (1993) delineates the futile attempt of one of nursing's pioneers, Lavinia Dock, at the beginning of this century, to establish almshouse nursing in cooperation with women's charity organizations. Almshouse conditions remained appalling until the houses began to wither away in the late 1930s. The Social Security Act of 1935, although aimed at deinstitutionalization, "inadvertently fostered the transfer of the chronically ill elderly to private and voluntary nursing homes" (Schell, 1993, p. 210). In spite of the name, few of these facilities employed professional nurses to administer or supervise care (Schell, 1993).

Presently, in the last decade of the twentieth century, care of the elderly in nursing homes is provided by nursing aides or nursing assistants with apparently limited guidance of recognized nursing knowledge (Diamond, 1992; Foner, 1994). "Nursing aides and orderlies constituted over 40 percent of all full-time employees in nursing and related care homes in 1985 and 71 percent of all nursing staff"(Strahan cited in Foner, 1994, p. 163). Indeed, Schell (1993) claims that: "The difficulties that beset Dock and others in their attempt to improve care for the institutionalized elderly continue to plague us today. Nursing has failed to seize the opportunity to take control of the institutional care of the aged" (p. 214).

Institutionalization in a Nursing Home

The terms "institution" and "institutionalization" bear with them negative connotation. Kleemeier (1959) in his discussion about the living arrangements of the aged, states that "in the broadest community sense the essential problems of living are those of living in the group [thought of as institutional or quasi-institutional group living]" (p. 446). Lawton (1977) has extrapolated Kleemeier's delineation of three dominant institutional characteristics. Kleemeier posited the segregate, the congregate and the control dimensions as the three dominant characteristics of institutionalization. The extent to which members of an institution are separated from, or integrated with, the larger society indicates the segregate dimension. The degree to which members tend to perform the same activities at the same time in the same place refers to the congregate dimension. The control dimension represents the extent to which individual behavior is standardized by staff and organizational rules and procedures (Lawton, 1977).

Goffman (1961) used the term "total institution" to describe the context of jails, mental hospitals and nursing homes in which the self of the people guarded was degraded in the interactional processes. He describes a total institution as a social hybrid; part residential community, part formal organization. His (1961) description of total institution captures to a degree, the underlying structure of the situation facing a person leaving her or his own home and entering a nursing home:

> A basic social arrangement in modern society is that the individual tends to sleep, play, and work in different places, with different co-participants, under different authorities, and without an over-all rational plan. The central feature of total institutions can be described as a breakdown of the barriers ordinarily separating these three spheres of life. First, all aspects of life are conducted in the same place and under the same single authority. Second, each phase of the member's daily activity is carried on in the immediate company of a large batch of others, all of whom are treated alike and required to do the same thing together. Third, all phases

> of the day's activities are tightly scheduled, with one activity leading at a prearranged time into the next, the whole sequence of activities being imposed from above by a system of explicit formal rulings and a body of officials. Finally, the various enforced activities are brought together into a single rational plan purportedly designed to fulfill the official aims of the institution (Goffman, 1961, p. 6).

Shield (1988) points out that Goffman did not provide illustrations of old-age homes, although he included them in his scheme. However, Shield (1988) found that Goffman's description of these structural characteristics of total institution, apply in the case of Franklin, the nursing home in focus of her study of nursing home residents. While acknowledging the usefulness of Goffman's understanding of total institutions, Shield critiques the model because it is too simple and does not capture the competing ideologies and stake holders in the everyday life of the institution:

> Hierarchies that operate within the bureaucracy, each with its own territorialities, worldviews, and modi operandi, create undulating tensions that prevent unity - prevent the totality of total institutions. Administrators contend with the need for budget cuts at the same time that they want to show their contributors in the community how up-to-date and complete their services to the elderly are. The home-hospital dichotomy pits staff member against staff member, and frequent life versus quality-of-life decisions challenge staff members to cooperate in the residents' interests. The rehabilitation philosophy struggles against that of maintenance and surfaces in treatment routines and pursuit of daily activities (Shield, 1988, p. 102).

Shield (1988) points towards the myriad of responses created by a heterogeneous population in a nursing home, contrary to the more uniform responses of the inmates portrayed by Goffman. Shield posits three different residents group in the nursing home that are "not necessarily the same as the level-of-care-designations that the state makes for each resident" (p. 102). Extremely ill or debilitated individuals who are unable to fulfill any of their physical needs represent one group; they may, however, be capable of understanding and communicating. Residents who are considered demented represent the largest group in the nursing home. Individuals belonging to this second group of patients may or may not be physically capable of certain activities. The third group is composed of individuals who are heterogeneous in their needs for support, medication, and so forth. They are considered the most capable, both physically and mentally. Shields (1988) puts forward that " these groups, fairly distinct and with quite separate needs, are contained in the same institution. Nursing-home personnel at times try to treat people individually, but they also treat them as if their needs were similar" (p.102).

In discussing caregiving in primary groups, on the one hand, and formal organizations on the other, Bowers and Becker (1992) point out, that in formal organizations, tasks must be carried out in a routine and predictable way in the interest of efficiency. In formal organizations, breakdown of a single activity into several component parts is often the result of the division of labor according to skill. Bowers and Becker (1992) maintain that "different individuals perform different tasks or different parts of a single task, according to their expertise and the organization of the work. This results in fragmented care provided by several individuals rather than one" (p. 361). In their study of the work of nurses' aide, Bowers and Becker (1992) illuminate the multiple and simultaneous demands shouldered by nurses' aides in nursing homes. Nurses' aides participating in their study had to develop their own organizational style to be successful in meeting those demands. Bowers and Becker (1992) note that

> More experienced aides were likely to integrate several tasks for several residents at once. For example, an experienced aide explained how she decided which women to get up first in the morning based on a plan to put three "slow feeders" together in one place. In this way she could feed three residents, literally, in the time it would otherwise take to feed one. This activity turned three consecutive 1/2-hour tasks (11/2 hours) into one 1/2- hour task. This strategy of coordinating the residents' location and timing or sequencing the work to eliminate wasted time was carried out

> in a variety of inventive and clever ways by the more experienced NAs. The work was conceptually and practically broken into its components parts and carried out efficiently, according to a plan (p. 363).

Foner (1994) points out that to prevent patient abuse and ensure decent care, explicit organizational rules are necessary. However, extensive demands of the working situation in nursing homes may force the nurses's aides to break the rules in the process of cutting corners to get the work done (Bowers & Becker, 1992).

Efficiency in nursing homes rests primarily upon the work force of women, in which nurses' aides or nursing assistants constitute the majority (Bowers & Becker, 1992; Diamond, 1992; Foner, 1994). According to Laird's (1979) experience: "The aides were all 'girls,' in institutional usage, no matter what their age" (p. 61). And Laird found out that "the most important persons in our lives, the real arbiters of our daily destinies, were the nurses' aides, the 'girls'" (p. 82). Indeed, the daily destinies of a nursing home resident may more or less depend upon the "girls" as well as upon the meaning ascribed to institutionalization in a nursing home.

The Meaning of an Institutionalization in a Nursing Home

The notion of an institutionalization in a nursing home reflects a wide spectrum of meaning. On one side of the spectrum, nursing home placement may be seen as a relief from a battle of "keeping oneself going" in the face of decreasing capacity to cope with the tasks of every day life. On the other side of the spectrum, nursing home placement may be seen as a fall from grace -- that is, an institutionalization is looked upon as the last resort in the face of failing health.

Savishinsky (1991) describes the experience of a number of residents at Elmwood, the nursing home in focus of his study, where "being in a nursing facility meant freedom *from* worry about the day-to-day details of food, security, shelter, and care, as well as freedom from being a burden on family or friends. Life in an institution had liberated them from having to live as dependents in other people's homes" (Savishinsky, 1991, p.

236). Conversely, Laird (1979) dedicates her memoir about life in a nursing home to the family that rescued her from it this book is “for the Michelsons, who saved my life.” In her experience, the world of a nursing home, was one that held “age and mental aberration and preoccupation with dreary physical routines" (p. 144).

In Gubrium’s (1975) terms hopelessness accompanies move to a nursing home, as he describes in his account of the Murray Manor nursing home:

> Making peace with hopelessness is a difficult task, and it is the one people encounter in breaking up a home to take up life at the Manor. What does breaking up a home mean? It may mean near total loss of a familiar way of living. Although some describe it mostly in terms of losing others and their familiar possessions at home, it is their selves that are still clearly at stake (Gubrium, 1975, p. 85).

Carboni (1990) describes a home from a phenomenological perspective as a lived experience that possesses deep existential meaning for the individual. She defines homelessness as “the experience of the negation of home, where the relationship between the individual and the environment loses its intimacy and becomes severely damaged” (p. 33). Furthermore, she proposes that “the experience of home and homelessness can be conceptualized as existing on a continuum with varying degrees of home and homelessness” (p. 33). Entry into the nursing home may move the elderly person to the furthest end of the continuum -- homelessness -- as the relationship between self and the environment becomes weakened, distorted, or broken. The institutionalized person does not experience home in a nursing home, either phenomenologically, existentially, or physically, as he or she might in "house" (Carboni, 1990).

Both Gubrium (1975) and Carboni (1990) emphasize how the breaking up of one's home and the loss of a familiar way of living undermines the self. Shield (1988) also emphasizes how the continuity of the self may be affected. She defines “entrance to the nursing home as a rite of passage with few if any rituals. The entrance is lonely, accomplished primarily by a series of leave-takings from a past life. The resident makes the adjustment alone; it is accomplished without institutional, community, or ritual assistance" (p. 215).

In spite of discouraging circumstances, people have ways of sustaining self by taking a stance on themselves in their new situation in one way or other. Chenitz (1983) puts forward that "for an elder to accept a nursing home admission, *legitimation* must occur. Legitimation is the finding of a plausible reason for the admission that allows elders to see themselves as other than a 'typical nursing home patient'"(p. 94). The reasons for admission whether it be physical, social, familial, medical, financial, or usually a combination give legitimation to this experience. Legitimation provides an incentive. "Once the reason for the admission was explained and accepted by the elder, entry into the nursing home was legitimated. The move could be made voluntarily because the elder had accounted for it in his or her self-perception " (Chenitz, 1983, p. 94). Elders, to varying degrees, accept nursing home admission "if they believe it is necessary, legitimate, desirable, the result of their own decision and for a short time. Elders who see admission as undesirable, involuntary, and permanent usually resist "(Chenitz, 1983, p. 95).

Brooke (1989) describes four phases in the process of adjusting to living in a nursing home: disorganization, reorganization, relationship building, and stabilization. The disorganization phase which pertains to the experience of past and present losses, Brooke describes as follows:

> Individuals who saw themselves as being there voluntarily usually related loss to disease or disability and were able to consider choices within range of their remaining physical or cognitive possibilities. "My relatives made the decision for me to come here, but I realized I needed help and my sister could not help me."
> By contrast, those who perceived themselves as involuntarily admitted often blamed losses on institutionalization and were less cognitively competent. "They put me down here, when I've no reason to be here just because I have pneumonia. There is

nothing wrong with me, I can't see it any other way" (Brooke, 1989, p. 67).

In the phase of reorganization, the challenge is to find meaning in the experience of living in the nursing home. This generally happens in the second or third month. Older adults are involved in problem-solving during reorganization, "identifying preferred care and directing others in that care and resolving or justifying why they live in a nursing home" (Brooke, 1989, p. 67). Residents' self-confidence comes partly with experience -- experience of the way in which the institution provides care as well as finding out who the good and poor providers of that care are (Brooke, 1989). Brooke's description shows that people's interpretation of why they moved to or live in nursing homes gives way to the meaning of the situation and paves the way for how they settle in.

Kaufman (1986) has shown how old people draw upon themes in their life stories to create meaning and continuity. Themes, the building blocks of identity, integrate personal experience, particular structural factors, and a constellation of value orientations as sources of meaning. In her interpretation of Millie's move into a nursing home, Kaufman (1986) illuminates, how "the sources of meaning which themes integrate are continually reinterpreted in light of new circumstances" (p. 149). Kaufman identified affective ties as the essential theme in Millie's life story. In the nursing home "her current self-image is in keeping with this theme that is woven through her life story" (p. 152). This theme is reflected in Millie's account of why she moved to the nursing home:

> Before I came here I was so lonely, I was afraid of going out of my mind. I'm not the type to sit around and watch TV and read magazines. That's why I came here. I like to mingle, to be around people, to have a roommate, to have company. It's what my disposition needs (Kaufman, 1986, p. 153).

Kaufman points out that Millie does not account for the experience of a mild stroke and declining ability to provide for her physical needs in explaining why she came to the nursing home. Indeed, Kaufman only heard Millie refer to herself as a patient on one occasion. On this occasion Millie felt she had been abused. She perceived herself, however, as weak and ill only in instances when she was treated otherwise than she would have liked. Millie used the identity of being weak and ill as the reason why she should not be abused. Kaufman (1986) talks of this self-perception as a survival tactic, stating "it is only called into play when needed to gain respect or take control of a situation" (p.153).

It is, indeed, remarkable that Millie's perception of herself as a patient serves as means "to gain respect or take control of a situation". Actually, inherent in the concept of an individual living in a nursing home as a resident on the one hand and as a patient on the other hand is an ambiguity about the degree of control of the situation. This ambiguity is interwoven with a stance towards a nursing home either as a home or a hospital.

Shield (1988) emphasizes how the home-versus-hospital dichotomy in nursing homes undermines continuity and connectedness of the residents. In her study of the Franklin Nursing Home she addresses how the concepts of a nursing home as a home and a hospital both complement and oppose each other in some way. She points out that staff members who believed the Franklin should be a home also believed the nursing home should have limited amount of control over the residents. A stance towards the nursing home as a hospital is inclined to assert control over more aspects of the residents' lives. Shield puts forward that the Franklin Nursing Home "is a home where comforts, companionship, continuity, and individuality are inhibited. It is a hospital, but no one is cured of the ailments that brought him to it, frail old age" (p. 104).

In Diamond's (1992) experience working as a nursing assistant, the nursing home seemed more a hospital than a home: "This institution was organized around rules appropriate for a hospital. Even though there was very little curing going on, the organization seemed to draw legitimacy by demonstrating that it was a place where medical personnel, practices, and terminology were the repository of authority" (p. 128). Diamond (1992) further maintains:

> To be sick, frail, confused, disabled, or old is not the same as to be a patient. In becoming a patient in a nursing home one enters a social organization; patient emerges in the meeting of person and institution. Day and night as boxes got checked and records reviewed, these people were entered into the administrative language and codes of what services were rendered to them. In turn, these terms and categories and codes came to be viewed by many staff and outsiders as the ultimate reality itself, rather than small part of it. The status of patient begins only in sickness. There in the nighttime was a glimpse of another facet of the production process of this industry. As they lay in their beds, another blanket was being folded over their lives, a blanket of paper that defined them as patients (p. 126).

From Diamond's stance, to be defined as a patient undermines the identity of the people involved. However, it may be argued that to be sick, to be a patient, gives a meaning to the situation of being institutionalized in a nursing home and a bearable kind of identity. It may in some ways be sounder to admit to failing health rather than one's own failure as a person to cope with the "golden" years and age gracefully. However, it is debatable to what extent a person in a nursing home is cared for as a patient. The extent to which one is cared for appropriately as a patient depends upon the understanding by the caring personnel of the conditions that bring about this label and its consequences for each individual.

Shield (1988) refers repeatedly to ailments of "frail old age" as being the constitutive factor of nursing home placement. The risk of chronic diseases certainly increases with age, old age may bear with it some ailments, but old age per se does not yield debilitation (Fries & Crapo, 1981). However, diseases of neurological and circulatory origins among other serious, chronic debilitating ones, rather than ailments, bring people to nursing homes (Kayser-Jones, 1992). In Diamond's (1992) terms there may be "little curing going on" in nursing homes. Nevertheless, the presence of multifaceted chronic illnesses rather than old age may imply the need for more comprehensive caring practices than are currently understood or employed.

Organization of Nursing Care Approaches

Kayser-Jones (1981, 1990) has argued for professional leadership in providing a high quality of care in nursing homes. Different obstacles towards that goal have been attributed to many factors, such as negative attitudes towards the elderly, especially towards the care of the debilitated ones in nursing homes, as well as multifaceted unattractiveness of the working conditions. The impact of professional nursing on quality of care in nursing homes is certainly affected by the limited number of registered nurses on the staff. In contrast with a ratio of 1 full-time equivalent (FTE) registered nurse (RN) for 4.5 patients in hospitals, there are only 5.1 RNs per 100 patients in nursing homes (Harrington, 1991; Kayser-Jones, 1990). Registered nurses' numerous coworkers, the nursing aides or assistants, because of their educational or training background, address care approaches from different premises. However, a large proportion of the care needs to be put into the hands of those coworkers. The ways in which this may be done are complex and depends upon the nurses' conception of what constitutes quality of care within the institutional conceptual framework of care and their individual approaches to administering the available resources to accomplish the desired quality.

Care of the body or bedside-care is the overarching activity in nursing homes. This activity is planned more or less by professional or registered nurses, but guided or supervised by them to a very limited degree. The way in which nursing aides or assistants incorporate nursing care plans or go about the care they give is more often than not their own business (Bowers & Becker, 1992; Diamond, 1992; Foner, 1994; Gubrium, 1975; Laird, 1979). The extent to which the bedside-care of nursing aides or assistants is independent or an integrated part of professional nursing varies. The nursing care in nursing homes appears to be segmented or fractionated into patient care performed by the nursing assistants and instrumental and administrative care performed by registered nurses (RNs) or licensed practical nurses (LPNs) (Bowers & Becker, 1992; Diamond, 1992; Foner, 1994; Gubrium, 1975; Laird, 1979). Jung (1991) points out that most nurses who direct nursing assistants have little knowledge or experience in personnel management. Accounts of nurses' administrative input show it to be limited to and consolidated in some kind of documentation or charting (Diamond, 1992; Gubrium, 1975) or to be a matter of scrutinizing how institutional rules or regulations are upheld (Foner, 1994). Foner (1994) proposes in her study in Crescent Nursing Home that:

> Crescent nurses have much in common with Weber's ideal bureaucratic officials who carry out their duties with an impersonal spirit. Floor nurses devote large amounts of time to clerical tasks required by government regulations and internal organizational demands. Because they are responsible for what happens on their floors and blamed when problems are discovered they are pressed to attend to supervisory details and infractions of rules (p. 77).

After eight months of having immersed herself in the life of the Crescent Nursing Home, Foner maintains: "I never heard nurses talk about how [the aides] should behave toward patients. Emotional abuse is ignored" (p. 86). Actually Foner noticed that nurses call in social workers at the aides' request "when for example, patients refuse to be washed, will not have their rooms cleaned, or are physically violent" (p. 29).

In Bowers' and Becker's study (1992), nurse's aides' accounts of their work did not refer to the quality of care they provided, the supervision they received, or the special knowledge and skills necessary to do their work. Rather they focused upon breaking activities into their components parts, and responding to discrete pieces of larger tasks in the most efficient manner.

Diamond (1992) offers a different perspective on the work of nursing assistants. He talks of the shock of finding out how hard the work as a nursing assistant was: "Each of the four nursing assistants on the floor was charged with waking and preparing fifteen to twenty people, each with her or his distinct circumstances, moods, stories, and needs" (p.

79). He discusses how the work of nursing is looked upon as menial or as a series of tasks, but he soon found out "it took continual mental work to balance the tasks from above with the contingency of the moment" (p. 143) and to fulfill the charge to " 'assist as needed' would take up the bulk of the day and constitute the most complex part of the work" (p. 131).

Diamond (1992) and Foner (1994) bring forward how nurses' aides or assistants draw upon their skills and understanding as mothers and family keepers in their caregiving work in nursing homes. Diamond's teacher in the vocational school where he trained to be a nursing assistant referred several times to "mother's wit". "A certain kind of just being there" (p. 18) was how his nursing teacher Mrs. Bonderoid defined this term. Her phrase stayed with him all the time he was working in the homes. Diamond (1992) does, indeed, emphasize "the relational narrative of mother's wit" (p. 239) in making the situation livable for residents in nursing homes in the following comment:

> Mother's wit requires a host of unwritten emotional, physical, and interpersonal skills. But it also involves working with residents under a specific set of rules and regulations and trying to make sense of them and make them livable, trying to bridge everyday needs and external control. Take away mother's wit and the industry is left without the women and the work that hold the building up, mediating between its base in everyday caretaking and the superstructure of ownership that has been built over it (p. 237).

Valuing and Defining the Work

Historically bedside care does not belong to the domain of nursing practice in nursing homes. On one hand nursing homes substituted as almshouses wherein neither bedside nor other care was in the hands of professional nurses (Schell, 1993). On the other hand, as work division of bedside nursing evolved in hospitals, care of the convalescent or chronically ill patients was delegated to nursing aides. To be chronically ill meant to be disposed to routinized delegate care. The editorial in the March issue1947 of the American Journal of Nursing reiterates the importance of expert nursing care:

> Although professional nurses consider the skills involved in expert nursing care their special prerogative, far too few nurses have, are given, or make the opportunity to give expert bedside care. The ability to give expert care is highly variable. But in the attainment of this ability lies the greatest satisfaction in professional nursing ("Expert Nursing", p. 142).

However, later in this issue the editorial draws attention to a pamphlet, “Practical Nurses and Auxiliary Workers for the Care of the Sick”:

> In the early years of the [nursing] organization, efforts were directed toward attaining this end through the licensure of professional nurses only. More recently they have recognized the contribution which less highly but adequately prepared nurse can make to the care of non-acutely and chronically ill patients. They are now promoting a program of licensure for all *who nurse for hire.* The context of the pamphlet is devoted principally to an analysis of the "nursing situation" -- with respect to the various personnel concerned. These include the patient, physician, nurse, other professional workers, and members of the service staff ("Practical Nurse", p. 143).

“Analysis of the nursing situation with respect to the various personnel concerned” characterized the process of developing teamwork within nursing services by the end of the fifth decade of this century. Indeed, Struve and Lindblad (1949) begin their article on teamwork by saying "It is not the purpose of this article to discuss the desirability of utilizing the services of nonprofessional workers, nor the many problems which arise in the use of aides” (p. 5). The problem of the use of aides in the care of elderly in nursing homes has hardly been addressed within the realm of nursing discourse and is today far from being resolved by any means. The model of Red Cross voluntary nurse's aides developed during the second World War guided the endeavor to extend nursing care by using the services of trained nursing aides (Wilson, 1945). Struve and Lindblad (1949) point out that in the first experiments in teamwork it became soon apparent, especially in the larger units, that certain activities that the aides performed were more efficiently done on a functional basis than as an individulized patient-care assignments. This functional basis bears upon task orientation of nursing on a continuum from simple or menial tasks to even more complex or prestigious tasks.

Hughes (1951), in an article called "Studying the Nurse's Work," points out that tasks in a bundle are not equally pleasant nor are they equally prestigious. In his words: "Some tasks are unpleasant. Some are considered menial, and beneath one's dignity as a nurse" (p. 295). He classifies some tasks as those that everyone would proudly agree is nursing and others as generally considered drudgery that require no skill. The drudgery task have low prestige and are part of the 'dirty work' of nursing. He suggests that as medical technology and hospital organization change, new things (perhaps new tests, new techniques requiring scientific knowledge or high skill; new levels of supervision, planning, coordinating, teaching, et cetera) may have more prestige than the best of the old tasks. Although these new tasks often lift the ceiling of the profession, and hence offer new career lines, there may also be some rated lower than any of the old tasks. Thus, there is an increased differentiation of tasks with "a greater difference in the prestige and desirability of the topmost and the bottom tasks"(p. 295). Hughes further states: "The process of turning an art and an occupation into a profession often includes the attempt to drop certain tasks to some other kind of worker. And this is exactly what is happening to the nursing profession. One of the aims of the study of the nurse's job is to discover ways in which various tasks, old and new, have been regrouped and with what resulting difficulties and successes"(p. 295).

Attempts towards professionalization of nursing were, in a way, interwoven with increased differentiation of nursing tasks and more distinctive categorization of patients with regard to the seriousness of the illness or the acute state of the patient.

In Brown's account (1947) of the future professional nurse

> ...the functions of the professional nurse of the future are likely to be so numerous and so important that no energy can be wasted, as energy has been prodigiously wasted in the past and is still wasted to a lesser degree, in the doing of routine and repetitive tasks that can be performed satisfactorily by trained attendants or trained practical nurses. The Professional Advisory Committee agrees with the director that for the bedside care of the chronically or subacutely ill and of the convalescent, the practical nurse with a high school education and a year of sound training in nursing technics and in understanding human personality can well replace the graduate nurse (p. 822).

The care of the chronically or subacutely ill came to be graded as second class and termed "routine care" as nursing strived for professionalization. It is debatable whether or not the notion of routine care within the realm of nursing has undermined the work of nursing and the development of nursing knowledge. In a way the definition of routine care has adversely affected the chronically ill elderly in nursing homes as has the stigmatizing legacy of the almshouses. Diamond (1992) however, shed new light on the ill defined aspects of the so-called routine work of nursing. He gives a fine portrayal of the delicate skills displayed by some of his fellow workers performing so called "routine task" in following phrase: "It often seemed one of the most refined nursing skills of the day as I watched a seasoned nursing assistant sensitive to the slow pace of an old person's eating, knowing how to vary portions and tastes, how to reinforce nonverbally while feeding - a refined and complicated skill, but unnamed and suppressed when forced into a forty-minute task" (p. 134).

Care and Resocialization of the Institutionalized Body

Steinbach (1992) cites the most common risk factors for institutionalization among elderly people as being age, functional status, marital status, living arrangements, income, race, sex and medical status. She identified in her study five variables which affected the likelihood of institutionalization: age, self-perceived health status, limitations of number of activities of daily living, ‘social activities’ and living arrangements (Steinbach, 1992). Old age, functional status or ability to perform activities of daily living are the overriding terms used to define the profile of the nursing home patient upon which the nature of care approaches bears.

Foner (1994) delineates a full range of patient care in the nursing home by referring to Johnson and Grant (cited in Foner) as they sum up: Aides “lift patients out of bed, wash them, brush their teeth, bathe them, groom them, make their beds, change their soiled linen, clean up after them, dress them, escort them to the dining room, help feed them”(p. 25). Foner further points out:

> Toileting patients involves taking them to the bathroom, offering a bedpan, or, most often, changing their incontinence briefs; when necessary, aides give enemas and collect specimens for the laboratory. Bedridden patients must be turned and positioned every two hours and the appropriate bedside chart filled out each time. Other regular paperwork includes recording bowel movements (daily) and vital signs (monthly); filling out an accountability sheet on a daily basis on the care given each patient; and completing an Intake/Output form (on fluids taken in and ejected) when, for example, a patient has temperature or is on antibiotics (Foner, 1994, p. 25).

In some instances, as reflected in Foner's delineation, the nursing care of the elderly in a nursing home is interpreted in simplistic terms. In those instances the interpretation bears upon definition of a "straightforward manual labor" or "simple" assistance or help in activities of daily living connoted as routine work.

Gubrium (1975) describes how normal work routine at Murrey Manor is primarily a matter of bed-and-body work:

> Regardless of work shift, the content of bed-and-body routine is the same. What varies is its sequencing and the proportion of its components. On one shift, bed work occurs early; on another shift it occurs later. The same is true of body work.

> On one shift, the amount of body work may be about the same as bed work; on another, work is mostly a matter of attending to the bodily needs of patients and residents (p. 124).

Bedside care in nursing homes is in the hands of nursing aides or assistants as Foner (1994) points out: "Nursing homes are bottom heavy, with enormous numbers of low-skilled workers and a small percentage of professionals" (p. 27). Gubrium's and Foner's interpretation of nursing activity in nursing homes bears upon the staffing pattern and staff´s activity rather than the condition of the patients. Nursing aides or assistants have only to a limited extent the premises to assess or appreciate the condition of the patients, therefore their work, connoted as nursing, becomes instead routine work according to Johns and Pfefferkorn's conclusion in their Activity Analysis of Nursing in 1934: "Whether bedside care should be regarded as routine activity or as skilled professional service depends, then not upon the nature of the activity itself, but upon the condition of the patient "(p. 40).

The complex way in which disease processes and their treatment affect bodily or physical needs and the appropriate means to sustain them is hardly taken into account in addressing care approaches in nursing homes. Foner, (1994) maintains:

> Caring for nursing home patients is difficult, demanding, and frustrating. Many are suffering from severe dementia; most are confused to some degree. Their physical ailments are severe, and they do not get better. Some are completely unresponsive, while others are bitter and hostile. In short, residents' physical and mental condition and their need for enormous attention and assistance are a never-ending source of pressure for nursing aides (Foner,1994, p. 31).

Foner neither considers to what extent the pressure for nursing aides pertains to limited understanding of the residents' physical and mental condition nor does she question to what extent the aides' caring approaches are patterned to alleviate these conditions. Caring approaches in nursing homes pertaining to direct patient care encompass "helping frail elderly residents dress and eat and keeping them clean" (Foner, 1994, p. 1).

For example the means to accomplish efficient and humanitarian nursing care for patients with Parkinson's disease on the one hand and Alzheimer's patients on the other hand are different. Indeed, Tappen (1994) conducted a remarkable study, the purpose of which was "to test the effectiveness of group-based skill training in improving the demented older adult's ability to perform the basic activities of daily living (ADLs) and progress towards meeting individual ADL-related goals compared with a more commonly used group stimulation approach and with the regular care received by nursing home residents with dementia" (p. 159). The results of the study showed significant improvement in function in the skill training group in comparison with the control group. There was not a significant difference between the stimulation group and the two other groups. However, there was a modest improvement in the stimulation group and a decline in the control group. The author points to the need for further refinement and testing of the skill training approach. Further, she proposes that "it may also be possible to train ancillary staff and family members to conduct practice sessions under professional supervision" (p. 164). This kind of a study shows promising research avenues to improve caring approaches towards demented elderly. At the same time, it points towards the importance of the role of professional supervision and the need to explore means to achieve it in an effective and efficient manner. However, the role of registered nurses in nursing homes carries with it conflicting demands and ill-defined aspects of their work, particularly with regard to their participation in and supervision of bedside care.

There is, indeed, some kind of contradiction inherent in the interpretation of what constitutes nursing care of the elderly in a nursing home. Gubrium's (1975) delineation, as well as Foner's (1994) reflects a tendency towards belittlement in accounts of attendance and help with sustenance of bodily or physical needs. The latter is objectified as manual labor pertaining to performance of a range of tasks. Bodily needs are also to a limited extent contextulized in the complex range of human experience as associated with being a helpless recipient of care. The concept of care with regard to so called "people work" places emphasizes aspects like warmth , compassion and attentiveness aimed at sustaining the humanity of the individual recipient of care. On the one hand, accounts of care of the elderly in nursing homes frequently take issue with the lack of those caring aspects. On the other hand, an overly narrow perspective defines as merely mechanical the kind of tasks required to substitute for decreased ability to perform activities of daily living.

The way in which the necessities of the self grounded in physical or bodily needs pervade the experience of humanity is, however, often overlooked. Indeed, to feel oneself or to be oneself in the role of a recipient of nursing care in a nursing home may first and foremost bear upon how physical or bodily needs are sustained. In his account of life in a nursing home Savishinsky (1991) points out:

> Volunteers, often equating age with wisdom, were shocked to learn how concerned the elderly were with the physical rather than the philosophical, with the state of their stomachs rather than the condition of their souls. But Louise Santorine, as a nurse, was more accustomed to seeing residents attend "to what others wear as a given - teeth of your own that naturally fit, a varied diet that the palate can taste, the freedom and self-respect of controlling your bowels and your other movements" (p. 119).

Gadow (1980) discusses "the patient's dichotomy - between the body as private, lived reality and a public object open to inspection" (p. 92). The object body belongs to "the dimensions of quantified space and time and to the realm of the general, the category" (p. 93). It does not have emotional, esthetic, or spiritual value but only functional value. "The lived body is existentially opposed to the object body, but it *is not its opposite* " (Gadow, 1980, p. 94). Gadow further proposes: "The lived body is not a thing at all ... Instead, it is a mode of orientation: the immediate, prereflective consciousness of the self *as capable of affecting its world*, as well as the consciousness of being vulnerable to the world's impact" (p. 94).

The lived body orientation of being vulnerable to the world's impact is hardly taken into consideration in caring for the elderly in nursing homes. Neither is the object body. Kayser-Jones (1981) maintains that: "In many long-term facilities in the United States, there is little emphasis on diagnosis, treatment, and rehabilitation; the focus of care is custodial, and the daily routine revolves around getting patients up in the morning, bathing them, and overseeing visiting hours"(p. 32). She delineates how staff-patient interaction in the American nursing home is characterized by the staff's indifference and authoritarian way of dealing with patients. Kayser-Jones (1981) reasons that this pattern of interaction infantilizes, dehumanizes, and victimizes the patient, undermining the dignity and rights of the individual. Indeed, Kayser-Jones shows how this pattern of interaction is reflected in provision of personal care. This mode of providing physical care does not bear upon consideration of the self as it is experienced in the lived body; rather it objectifies the patient's body. Gadow (1980) proposes that:

> The lived body, unlike the object body, is not in objective space and time. On the contrary, it forms its own space through its actions, drawing the world's space toward it, so to speak, centripetally. Nearness and distance are a function of relevance, not measure. In the same way the lived body shapes its own time, with retension and protension interwoven and overlapping according to one's purposes, unconstrained by linearity (Gadow, 1980, p. 94).

Gadow maintains that the unity of self and body is prerequisite for true self-determination. She maintains that unique possibilities exist in nursing for reconciliation of the discrepancy between the lived body and the object body "generated for the patient, first by the experience of incapacity and, second, by the perspective of sciences" (p. 95).

Gadow (1980) points out that "nursing can make possible for the patient an enrichment of the lived body by the object body, and an enlivening of the object body by the lived body. The nurse can assist the patient to recover the objectified body at a new level at which it is neither mute immediacy nor pure otherness, but an otherness-made-one's-own, a lived objectness"(p. 96).

This stance asks for meaningful relationship between the patient and the nurse. However, from Foner's (1994) perspective nurses in general, registered nurses as well as licensed practical nurses, show little concern for interpersonal relationship, rather they place emphases on physical care and the mechanics of care:

> Nurses tend to have a bureaucratic view and aides a more personalistic view to patient care. As enforces of the institution's rules, the nurses' first priority is that regulations are followed - that aides show up on time, adhere to care plans, complete tasks of schedule, and keep rooms and patients neat and clean. When nurses, on the floors and in the administration, check on aides, they are concerned with the physical aspects and mechanics of care. Is the bath on schedule and the whirlpool cleaned? Are patients' nails cut? are patients positioned properly when fed? (p. 83).

Foner (1994) criticizes how "patients' physical needs and meeting state regulations are given priority over the emotional components of care"(p. 153). She recommends that "nursing homes, in particular, nursing departments, should make conscious efforts to stress emotional, as well as the physical, aspects of caring" (p. 157). Foner (1994) points out that this means more of a psychosocial model of organization, in terms used in the nursing home literature. In this model, according to Foner, there is less emphasis on a medical model and its stress on health problems that need diagnosis and treatment than there is on the social and psychological needs of patients. Foner's discussion of caregiving dilemmas overlooks the inherent difficulties in emphasizing the dichotomy between physical and psychosocial needs of the individual. Compassionate, supportive care is glamorized as an entity in itself while physical care is "dirty", simple and rule regulated.

Nurses themselves are inclined to devalue the care of the body or physical care, as Shield (1988) points out:

> Some nurses expressed to me their preference for residents for whom they could perform "real nursing." They liked the skilled-nursing floors better than the intermediate-care floors because there are more procedures to perform. When specific nursing tasks are not called for, many nurses say their skills are not being utilized, and they are bored. Chart work and staffing take priority over talking to the residents when specific nursing tasks are not pressing (p. 101).

However, there is a growing opportunity for nurses to perform "real nursing" since the acuity level of nursing home residents has increased in recent years.

Medical Technology and Relations of Care

The scene of the nursing home is changing as "the complexity of care" has been increasing. Harrington observes (1991):

> As the acuity level of nursing home residents increases, medical technology formerly used only in hospitals is now being used in nursing homes. Thus, the "performance of duties" has become an even more complex task for personnel. The use of intravenous feedings and medications, ventilators, oxygen, special prosthetic equipment and devices, and other technologies has made patient care management more difficult and challenging (p. 154).

Harrington's perspective highlights the importance of medical technology in conception of patient care as "difficult and challenging". The importance of medical technology easily overshadows the challenge of the helping role as one of nursing domains proposed by Benner (1984) and the aspect of existential advocacy as proposed by Gadow (1980) in sustaining personhood of the elderly institutionalized in a nursing home.

The challenge of the helping role as well as the display of existential advocacy is reflected in Savishinsky's (1991) portrayal of Louise Santorini -- nurse that "gave until she almost gave out" (p. 156) in the nursing home in which he carried out his study. She was driven from her job by being "a pivot person" in her terms: "caring for the patients, supporting the families, being accountable to the administrators above, and responsible for the staff below" (p. 166). For Louise the bureaucracy of the state regulation was overwhelming and replaced patient work. Freedom from the hub of the paper work, would enable her as she put it:

> ... to give patients the time to explain their real needs. You can't walk in and give somebody a medicine, spend three or four minutes with them, and expect them to tell you all their problems. And I think that finding out what patients want and feel is the hardest part of my job. Without that, I get reduced to a technician, and competency can't take the place of compassion (p. 160).

This account emphasizes the relational process inherent in the helping role, particularly what Benner (1984) delineates as "finding an acceptable interpretation or understanding of the illness, pain, fear, anxiety, or other stressful emotion" (p. 49). It also points towards Gadow's (1980) proposal that: "the essence of nursing is the nurse's participation with the patient in determining the unique meaning which the experience of health, illness, suffering, or dying is to have for that individual" (p. 81). Turning back to Savishinsky 's (1991) portrayal of Louise Santorini, Louise maintains:

> It's a hard job and people don't know the amount of work, not just paperwork, that it demands. You carry a lot around in your mind and on your mind. Most nurses don't simply sit at their desks and write things. If residents were only charts and notes and medicines, then all you'd be aware of is what you put into or took out of their bodies. Then you've reduced them - and yourself - to being a machine. If you looked at my med sheets you'd see we don't "snow" [oversedate] people here: we rarely use drugs to control patients ... which means that staff have to be even *more* attentive to people.
>
> I'm not claiming every nurse is good, but good nurses are more than technicians.

> They're out on the floor, talking to patients, trying to understand their whole situation. Because you don't know your patients unless you spend time with them. And if you don't know them, you can't care for them the way you should (Savishinsky, 1991, p. 165).

Lousie claims that knowing the patient is a prerequisite for caring for the patient. This stance suggests an accordance with the stance of critical care nurses elicited in an interpretive phenomenological study of development of expertise in their field (Tanner, Benner, Chesla & Gordon, 1993) which put forward the following assertions:

> Knowing the patient is central to skilled clinical judgement and is broader than what is captured in formal assessments of physical systems.
>
> Knowing a patient is a practical nursing discourse that points to specific nursing skills of seeing and involvement.
>
> Knowing the patient creates the possibility of advocacy.
>
> Knowing individual patients sets up learning about patient populations (p. 277).

In Diamond's (1992) report of his ethnographic study in nursing homes, he describes vividly the fundamental aspect of knowing the patient in caring for her or him in a nursing home. Diamond states that "when nursing assistants described their work, they often referred to gaining experience or skills in terms of getting to know people. In getting to know someone, the knowledge of anticipating their needs and desires took shape" (p. 144). He later points out that: "While the tasks formally named the job -- vitals, weights, showers, beds, feeding, toileting -- the subtle human interaction provided the matrix within which those tasks got accomplished (p. 205). On his entry into the working world of nursing assistants, one of his heroines -- Laina Martinez, a nursing assistant -- tells him "once you get to know the people, it's not that hard" (p. 38), another one, Vera, states: "I hate changing strangers" (p. 144). He finds out himself: "It was something of a turning point in learning this work when one day I left Bill's room and realized that while cleaning him I had not even noticed the assault on my senses that had so dominated the encounter when he was a stranger" (p. 137). Diamond (1992) points out how bits of information about personal histories scattered among definitions of physical and mental problems served as jumping-off points for conversations while the assigned tasks proceeded. This information was especially helpful during the intimate contact on the agenda. "As I quickly learned from the other nursing assistants, the trick was to engage each person in some kind of conversation, something personal if possible, to execute the task and minimize the conflict" (p. 78).

Concluding Remark

The role of registered nurses in nursing homes carries with it conflicting demands and ill-defined aspects of their work, particularly with regard to their participation in and supervision of bedside care. Expansive administrative load, increased medical technology and the number of patients for whom an individual nurse is accountable in a nursing home may not give her much leeway to get to know her patients. However, the long-term nature of the patients' stay in a nursing home carries with it the potential to develop a growing knowledge of the patients, in so far as the nurse can establish a rapport with the patients and spend time with them. Time specifically allocated for bedside care allows for comprehensive assessment of a particular patient and gives the nurse opportunity to learn to know the individual and to mediate the lived/object body duality with and for her or him. Gadow (1980) proposes :

> Nursing is uniquely able to mediate the lived/object body duality, inasmuch as it addresses both aspects of the person as one. It affirms the value of the lived body through the intimacy of physical care and comforting. At the same time, it affirms the reality of the object body by interpreting to patients their experience in terms of an objective framework - usually science, in Western cultures - which enables them to relate an otherwise hopelessly unique and solitary experience to a wider, general understanding (Gadow, 1980, p. 96).

The experience of giving bedside care, particularly to the most vulnerable patient gives the nurse unique opportunity not only to establish a healing relationship with the patient, but to communicate with and guide the nursing assistants and possibly the patient's family in caring for the individual. Knowledge of the patient acquired through bedside care allows for the possibility of care of the embodied person and paves the way for a conversation about caring approaches with nurses' aides or assistants as well as the patient's family. Conversation empasizing caring practices that sustain the self of the inhabitants while giving appropriate care with regard to the condition of the patient.

Chapter Two

FAMILY PARTICIPATION IN NURSING HOME CARE

Introduction

This chapter discusses the role of the family in the care of aging kin. Expectations towards the supportive role of the family may seem to fail when a nursing home placement of its member takes place. Such an event may evoke issues of kinship reciprocity and family obligations for the involved family members. The continuing discussion, however, shows that families remain supportive to their relatives once placed in the nursing home and participate in the nursing home care.

Limited research has been conducted on family involvement in nursing homes, nevertheless, some studies have shed light on the role expectation and the subdivision of tasks between nursing home staff and families. Others have looked at family perception of care, in particular with regard to quality of care. The latter studies point to the importance of person-oriented focus rather than task-oriented focus, when attempting to bring forth some aspects of the respective contribution of family and staff to the care of elders in nursing homes. Studies of nursing home life tend to show that communication problems occur between nursing home staff and family members. Programs aimed at promoting communication between these parties have been developed and they are briefly described. Included in this description is a delineation of a program intended to improve interaction between family members and patients with dementia.

The chapter closes with clarifying features of preservative care and discusses the prospect of developing the informal discourse of knowing the patient in the nursing home.

The Supportive Role of the Family

Allen (1993) puts forward that the vast majority of elder care is provided by women, who make up 90 percent of paid caregivers and about three out of four unpaid family caregivers. She finds that many family caregivers to the elderly reduce their hours of paid work or quit their jobs altogether to provide such care. Women may sacrifice job earnings, health insurance, and pension coverage when they take on the job of caring for disabled elderly relatives. In the process, they become more vulnerable to impoverishment as they age, which is part of the reason women constitute three-quarters of the elderly poor. Furthermore, elderly women are currently twice as likely to be institutionalized as elderly men. In many cases, Allen (1993) states, the caregivers of young children one year will be elder care providers at a later date; they are the same women at different points in their lives. Guberman, Maheu and Maillé (1992) asked why women as family caregivers do care. They found that anti-institutional feelings played a part as well as feelings of closeness and interconnectedness with family, gender-role conditioning, and life situation. Availability of family, community or institutional resources as well as factors associated with the person being cared for affected women's decisions to assume caregiving responsibilities.

Expectation towards the supportive role of the family in a person's life tend to presume that nursing home placement is the last resort. Laird (1979) tells about her own isolation during her stay in a nursing home and gives an account of her efforts "to hold onto sanity and identity in an atmosphere which was, by its very nature, dehumanizing" (p. 1). She says that it was impossible for her at the time to appeal to any of her seven living children for a home, because of either her long-standing estrangement from the children or their own then-present difficulties. It appears that these reasons as well as the geographical location of the nursing home contributed to Laird's experience of very few visits during her stay in the nursing home.

In spite of that or because of that, Laird highly appreciated family visits in Golden Mesa, the nursing home where she stayed for a few months. She describes how Florence Kramer, her roommate, was able to assert her individual preferences rather more than most of the patients because she had a family who kept careful watch over her. Florence's husband came in every day and her daughter spent an afternoon with her every week. In her account, Laird (1979) furthermore gives tribute to two women visitors that came every day and did not confine their care to a husband and a mother respectively, but paid attention to other residents and gave them a helping hand, like wheeling patients who could not easily propel themselves or doing errands for some of them outside the nursing home. Laird also tells of Miss May Anderson, "... who was one of the fortunate ones whose relatives had not abandoned her" (p. 101). Laird's (1979) description of family involvement in the nursing home appears to bear upon her expectation towards the supportive role of the family in a person's life. These expectations are fundamental to her view of nursing home placement, and she speaks of her own prejudices regarding matters of nursing home placement. She describes the anxious seekers who came to Golden Mesa in the process of searching out a suitable place for a parent or grandparent, and how the relatives would eventually be convinced, "... heave sighs of relief, or helplessness; stifle the last qualms of conscience, or make a bad and uneasy bargain with it; and go into the office to complete the financial arrangements" (p. 124). However, she could not fault the three devoted daughters of Mrs. Chancellor in any way for placing their mother in a nursing home, as Laird reasoned that wherever she was she would be ". . . just as restless and unhappy, requiring ceaseless watching and unresponsive to any efforts made on her behalf" (p. 152).

There is an inclination to interpret a nursing home placement as somebody's fault, either the fault of the person being placed or of the relatives bringing the placement about. Shield (1988) tells of an aloof president of a civic organization who was "reduced" to entering the Franklin Nursing Home; the entry into nursing home could mean to the other residents that "he may not have been the model parent that he maintained himself to be" (p. 53). Shield addresses the conflicts in kinship reciprocity in Franklin Nursing Home:

> This group of aged Jews endured great sacrifice so that their children could succeed. The reciprocal obligations of children toward their parents remained unspecified and

> murky. There are tangled emotions about the responsibility that should or should not be directed by children to their aged parents. These intensely difficult problems are created by American and Jewish ideals of maintaining independence along with that of extending or accepting help. There seem to be many factors involved in the quandaries produced (p. 160).

Shield (1988) maintains that easy reconciliation is not at hand as family members of the residents at Franklin are torn by competing cultural norms about individualism and relatedness. A staff member at Franklin, where stories about one's obligations to family circulate among the staff, resolved her anguish in the following way:

> When her father was told he had terminal cancer and would only live six months, she knew that if she cared for her father at home family life would suffer terribly. She'd be up at all hours; she would be exhausted; she'd be unavailable to her family. Where did her obligation lie? She was aware of what happens in nursing homes, and she did not want her father to have to be in one. Finally, she decided: she searched out the best nursing home that she could find, knowing full well that it wouldn't be as good as it was supposed to be. And then she made sure that she would go each and every day and supervise what was being done to her father. She wanted them to know that she was watching them carefully. She would make her requests and complaints loud and clear, and she made sure that her father received good care. It was difficult and exhausting. But she was satisfied that when he died she would have done the very best for him that she could, balancing carefully her obligation to her husband and children and her obligation to her needy father (p. 163).

This account highlights what Brody (1985) calls successful resolution of the filial crisis. According to Brody (1985), successful resolution of the filial crisis, may "involve acceptance by adult children of what they cannot do as well as acceptance of what they can and should do" (p. 24). Brody points out that parent care does not cause interpersonal problems to occur. Rather the conflict may be in decisions regarding the allocation of time and attention between the old person and the caregiver's spouse or children. The pressure may be such that family relationship problems are reactivated or exacerbated. Old rivalries between siblings revive. However, daughters continue to outnumber sons in shouldering parent care after nursing home placement, just as when their parents lived in the community (Brody, Dempsey, & Pruchno, 1990). Gilligan (1982) has amply demonstrated how central to women's moral domain responsibility and care is.

Finley, Roberts and Banahan (1988) investigated motivators and inhibitors of attitudes of filial obligation. They found that obligation is not simply a product of affection but that the degree of obligation is also explained by such structural and demographic factors as distance and role conflict. However, their findings indicated that for women greater affection for their mothers was related to greater feelings of filial obligation, but that this was not necessarily so for men. Pohl, Boyd, Liang and Given's (1995) analysis of the impact of mother-daughter relationships on the commitment to caregiving showed that these relationships were powerful predictors of commitment, especially affective commitment to caregiving during the first three months of this experience. Horowitz (1985) found that sons tended to become caregivers only in the absence of an available female sibling; they were more likely to rely on the support of their own spouses; and they provided less overall assistance to their parents, especially 'hands-on' services. However, fulfilling the family's affective function emerged as the most common caregiving role, for both sons and daughters, with over ninety percent reporting that they provided their parents with emotional support (Horowitz, 1985).

The expectations inherent in the supportive role of the family towards its aging kin draw upon different sources. On one hand there may be an emphasis on affective ties, feelings of closeness and interconnectedness; on the other hand there may be emphasis on family members' duty or filial obligation or some kind of contractual arrangement. However, structural and demographic factors such as distance and role conflict may mediate these expectations. Baier (1986) defies the idea of contractual arrangement in addressing the care of one's aging parents. In her discussion of trust and antitrust, Baier puts forward: "Trust, the phenomenon we are so familiar with that we scarcely notice its presence and its variety, is shown by us and responded to by us not only with intimates but with strangers, and even with declared enemies" (p. 234). Baier furthermore illuminates trust in parental and filial relationship in the following lines:

> As the child approaches adulthood, and as the parents draw nearer to the likely dependency of old age, the trust may approximate much more closely to mutual trust and mutual vulnerability between equals, and they may then make explicit or even formal agreements about what is to be done in return for what. But no such contractual or quasicontractual agreement can convert the young child's trust and the parent's trustworthiness retrospectively into part of a contractual mutual exchange. At most it can transform what was a continuing relation of mutual trust into a contractual obligation to render some sort of service to one's parents. The previous parental care could become a moral *reason* for making a contract with parents, but not what one received as 'consideration' in such a contract. At best that could be a virtual 'consideration,' perhaps symbolized by the parents' formal cancelling of any until then outstanding 'debt' of gratitude, in return for the rights the contract gives them. But normally whatever grateful return one makes to another is not made in exchange for a 'receipt' which is proof against any outstanding 'debt' (Baier, 1986, p. 243).

Rather than contractual mutual exchange, according to Baier, the supportive role of the family towards its aging kin draws upon a continuing relationship of mutual trust that may be rooted in the family's stance towards solidarity and solicitude within the family.

Katina Glover did not consider matters of exchange or contractual arrangement in caring for and about her father, Stavros Costa. Furthermore, she could not conceive at the outset of his being in the nursing home for any length of time (Savishinsky, 1991).

The progressive decline of his health and ultimate death was unforeseen at the time of his placement. Indeed, before this event, the idea of nursing home placement of her father had been a possibility not thought of, not even remotely. "... she felt she had crossed into a moral no-man's land when her father actually moved to a nursing home"(Savishinsky, 1991). Katina described how this event came about with the following words:

> We had hired a series of women to come in and help care for my father at home. Some turned out not to be well trained, or not very sensitive, and the good ones moved on. So it was not just expensive, it was so unreliable. There was the constant aggravation of looking and interviewing, and the hiring, the firing, and the quitting. I didn't know whether I was running an employment agency or a drop-in centre. Moving Dad here was something that was against all our principles. It was a very difficult decision for me, for Alan [her husband], and for my children -- even though the children were grown and not living at home by the time. I had never dreamt of either side of the family putting a parent in a nursing home, much less having someone *want* to go into one. But Dad wanted to go. It wasn't even a case of our making the decision. This was my father's choice. Once he got the catheter, and once he realized that there was no way he would be able to walk on his own, it became an ordeal for him as well as for us. So he said, when he was in the hospital, "Look, you can't handle this. Nor can I. It's out of the question. I want to go to a nursing home."
>
> Maybe the fact that he said it made it easier for us. I don't know. But it was still the last possible decision we could have come to. When we went to look at nursing homes, I cried through the whole thing. I didn't want it, but there it was: there was no alternative (Savishinsky, 1991, p. 77).

It took a long, long time for Katina to eventually accept the nursing home placement of her father. And the pain would come back to her:

> Even now sometimes I dream about it. I'm back there in time, arguing -- in the

> dream-with my mother. "Can I do this to Dad?" I cry to her. But my face is down in her lap and I can't see her expression. I can smell her perfume the way I used to, but she's not saying anything. I'm afraid to look up. I'm afraid of how she'll judge me and I start shaking . . . and then I wake up (Savishinsky, 1991, p. 79).

Katina Glover did not abandon her father when he moved to a nursing home; rather she attempted in every way to make the situation as bearable as possible for her father. She visited him almost every day and she visited as well other residents who had no relatives. She established rapport with the residents and showed regard for the staff. Her involvement created a fruitful ground for her advocacy on behalf of her father. As time went by she found herself at home in the nursing home where her father stayed. Indeed, she said:

> I don't feel so guilty about it, and it's not so alien to me now. Maybe that's because I'm quite involved with many of the others here, the residents as well as the staff. We've become friends. What it amounts to is that I don't feel like a stranger. When I go down to visit Dad and kid around with people, for me it's the nucleus of having a kind of family with him again (Savishinsky, 1991, p. 77).

Savishinsky (1991) points out that because Katina socialized with staff on her daily visits and was well liked by them, workers were more aware of her father Stavros: "... they stopped to talk to him whether his daughter was there or not. Katina's presence thus gave her father both greater visibility and more attentive care" (p. 73).

Brody et al. (1990) maintain that daughters appear to go beyond the call of duty to a greater extent than do sons for their institutionalized parents. Katina Glover certainly appears to have gone beyond duty in her care for and about her father. Her relationship with her father resembles what Kierkegaard (1843/1985) proposed as unconditional commitment. According, to Kierkegaard (1849/1989) relation of body and soul that relates to itself or a synthesis of the self bears upon unconditional commitment or defining relationship. By unconditional commitment the self understands itself and grounds its being in relation to the past, present and the future. The self is grounded in a finite cause that bears with it infinite compassion; the cause gives concrete concerns and opens up avenues of possibilities that set the person free to be vulnerable in a devoted relationship. Vulnerability can hardly be escaped when a beloved person is put into the hands of others in a nursing home. However, air of freedom is reflected in Katina Glover's comportment in the nursing home. She appears to have accepted her vulnerability, and her relations with residents and staff alike testified to her infinite compassion for her father and made his world as livable for him as possible. Indeed, her concern and attentiveness increased the staff's awareness of her father's well-being.

Family Participation in Nursing Home Care

Kellett (1999) explored families' experience of nursing home placements. She points out that "placement of a relative into a nursing home was not an act of rejection, rather it was often the final desperate step after previous efforts to maintain a relative at home had broken down" (p.1478). Family members visiting in a nursing home bear witness to the debilitated elderly living in a nursing home as a person with a past and a place in others lives. Family members invoke a remembering of the past and the recognition of the relative's uniqueness. Mannheimer (1992) speaks of his old friend Hildegard living in a group home as "the person persisting over time, and as the person whose time is almost over" (p. 330). He further notes:

> Hildegard's situation calls out to me to maintain recognition of her dignity as the person I have known, now grown frail in old age. Where her willful ability seems reduced, I am called upon to compensate for and supply support to her process of being a person through my own personhood. At the same time, I must allow Hildegard to move toward death (p. 331).

York and Calsyn propose that the patient's family in a nursing home could be a potentially powerful and inexpensive resource, however, this resource "lies fallow or, worse, works against the patient's well-being" (p. 500). York and Calsyn (1977) put forward that "contrary to the common belief that families abandon or 'dump' their relatives once placed in the nursing home, the families in this study stayed involved with their older relatives after placement" (p. 503). Physical or mental deterioration of the resident did not affect family visiting; rather the number of visits after placement were related to the amount of family involvement with the patient prior to placement. However, self-care disability, impaired cognitive functioning, and poor personal appearance did affect visits. Visits with people who were disheveled and /or confused seemed to be less enjoyable. Physical or sensory disabilities did, however, not affect enjoyment of visits. In light of families' continuing involvement with their older relatives after placement in a nursing home York and Calsyn (1977) point out that an experience of frustration, resentment, and guilt accompanies families' visits in nursing homes, and this experience is related to families' lack of knowledge concerning their relatives' situations and lack of skill in visiting. They discuss different means to develop a therapeutic and constructive role for the family while visiting in a nursing home as well as the need for supportive help for the families themselves. Their study showed that families relied on nursing home personnel for emotional support, both nurses and nurses' aides.

Rubin and Shuttlesworth (1983) address the ambiguity in the subdivision of tasks between nursing home staff and families. Rubin and Shuttlesworth (1983) highlight "those tasks that clearly appear to be most problematic, particularly in regard to the extent of ambiguity within groups" (p. 635). They posit as the most problematic the following five broad categories of tasks:

> 1) Personalizing care: provide special foods (extras); make sure the resident's room is attractive; give birthday party for resident. 2) Monitoring and ensuring the provision of care: report any abuse or neglect to the authorities; ensure that drugs/medication not covered by medicare-medicaid are ordered; make a telephone accessible to resident; file claims for resident benefits; transport resident to doctor; provide

> adequate supplies (facial tissues, etc.). 3) Clothing needs: launder resident's personal clothing; mark resident's personal clothing; keep resident's clothing inventory up to date. 4) Grooming: clip finger- and toenails; arrange for hair grooming. 5) Providing reading materials: make current newspaper available; keep books, magazines available (p. 636).

Schwartz and Vogel (1990) used Rubin and Shuttlesworth's (1983) inventory of 100 nursing home tasks to investigate nursing home staff and the role expectations of residents' families; however, they modified the scoring procedure. Contrary to Rubin and Shuttlesworth's findings they found overall the level of agreement to be remarkable between staff and relatives as to the assignment of responsibilities. Both staff and relatives tended to rate safety and security and physical health as primarily the staff's responsibility and special or extra services as principally the relatives' responsibility.

Bowers (1988) applied a grounded theory approach to investigate family perception of care in a nursing home. Overriding issues in her findings were dimensional aspects of quality of care. Instrumental (technical) and preservative (emotional or psychosocial care) evolved as significant subdimensions of quality of care. Preservative care is used by Bowers, "to refer to care which is engaged in to maintain the older person's self, or more accurately, the adult offspring's perceptions of that self. This concept more accurately corresponds to the purpose of the caregiving work" (p. 362). Bowers' findings suggested much more discrepancy between staff and family in the matter of attribution of responsibility for the elderly residents' care than had been described in Rubin and Shuttlesworth's study (1983). Bowers (1988) points out that "family caregiving responsibilities in nursing homes are much more complex and extensive than is indicated by the visible tasks they perform" (p. 363). Bowers further puts forward:

> Family members attributed responsibility for the performance of most tasks to the nursing home staff but held themselves responsible for monitoring and evaluating the effectiveness and quality of caring tasks (technical and nontechnical). This

> included teaching the staff how to deliver high quality care, picking up where the staff failed (filling gaps), and providing direct care to their relative (p.363). ... It was suggested by the findings that the ability of families to provide preservative care is largely dependent on staff cooperation. Conversely, families perceive good quality care by the staff as largely dependent on family participation and input. The provision of good quality care is perceived to require a collaborative process between family and staff rather than a division of tasks between them (p. 364).

Furthermore, Bowers (1988) puts forward that "... family members described their continual efforts to personalize the staff's care of their elderly relative, believing that the staff viewed old people as 'all pretty much alike'"(p. 365). The quality of care was, however, undermined by staff's lack of appreciation for biographical expertise and preservative care. The family members in Bowers' study were overwhelmingly distressed over the staff's failure to provide preservative care and referred, repeatedly, to the staff's unwillingness or inability to collaborate. The lack of communication among the staff members was also thought of as a contributing factor to this failure. Hertzberg and Ekman (1996) study of family perception of the staff in institutional care in Sweden showed that their findings corresponded extremely well to those reported by Bowers (1988) in matters of psychological care.

According to Wiener and Kayser-Jones (1990) their research also suggested a picture consistent with the findings of Bowers with regard to kin perception and kin work in nursing homes. It showed that a clear demarcation between formal and informal tasks in long-term care was not possible. Wiener and Kayser-Jones (1990) found that most families are ill-prepared for the conditions in nursing homes, which conditions only become evident to them after their relatives have been admitted. Family grievances focused on (1) the quality of nursing care (2) the quality of food and feeding of residents (3) loss of property (4) the depressing environment (5) poor communication with physicians and (6) poor communication with staff. Relatives still found themselves engaged in care after admission of their aging kin to a nursing home and developed strategies to control to some extent their care (Wiener & Kayser-Jones, 1990).

Duncan and Morgan (1994) point out that it is a shift of caregiving rather than termination of it when family members no longer have the capacity to meet the demands of caregiving at home. Duncan and Morgan (1994) noted that specific technical tasks and the matter of which task should be done by staff and which by the family were addressed to a very limited extent in focus group interviews. However "... one clear theme that emerged centered on caregivers' reactions to how staff related to their resident. Caregivers voiced a strong desire for staff to treat the resident as a person rather than as an object of care. The fact that these residents had Alzheimer's disease made it especially important to convey a sense of their cognitively impaired resident as a person who was worth caring for. This was the key staff behavior in their view that constituted high quality care" (p. 239). Indeed, the families monitored staff behavior to determine whether the staff was in fact sensitive to the needs of patients as persons. They monitored the staff's treatment of other patients during their visits to get insights into what things might be like when they were not present. Ongoing family-staff relationships bore upon recognizing the caregivers by name and sharing information about the resident's activities, appearance and behaviors. When staff validated caregiver's past experience, a powerful sharing occurred. A way of having an active influence on the staff was implicit to the family's felt need to form relationships with staff members. As one caregiver put it, "We've come to the conclusion now that the purpose of the visit is to show the staff that you care" (p. 240).

Shield (1988) addresses only briefly family participation in care in her study of the Franklin Nursing Home. She proposes that a resident who has visible support from family members gains in status. Visits and phone calls create contact with the outside world and contact with family also structures and varies time. Regular evening visits with a son or a daughter can be anchoring for the resident, both emotionally reassuring and temporally orienting. Family members "can do valuable services. They can do errands, help furnish the resident's room, and ensure that the resident's clothing is cleaned and mended properly, either by the housekeeping staff or by themselves" (p. 59). The family can protect the resident and can and does intercede on the resident's behalf. As pointed out by Shield (1988) "... family members who are nearby and willing to help can thus be effective arbiters, promulgators, and nurturers" (p. 60). Greene and Monahan's (1982) study indicated, indeed, that visitation had a significant therapeutic influence on patient well-being. A noteworthy aspect of their study showed that families appeared to maintain contact with elderly institutionalized relatives with relatively little long-run drop-off over time.

Foner (1994) found during her research at the Crescent Nursing Home (in which there were two hundred beds), there were about 20 regular family visitors on the day shift and about the same number in the early evening. She points out that many families had sought out the Crescent Nursing Home precisely because it was near their homes and they could visit often. Most of the regulars lived in the neighborhood, a few traveled long distances every day (in several cases, more than an hour and a half each way) to see their parent or spouse. A sizeable number came almost every day, some for a few hours and some for even longer; many came once a week or less often.

It was a common view among aides in the Crescent Nursing Home that patients' relatives interfered and made life more difficult for them. An aide with many ever-present relatives in her section was considered unlucky. A couple of aides during Foner's (1994) research even mentioned patients' families as the biggest problem they had in doing their job. Foner (1994) found in her conversations with family visitors that they were concerned about aides' failure to provide competent technical care and their lack of responsiveness to relatives' own requests and difficulties. Family members pointed repeatedly to failings in care. They complained, too, about aides' unsympathetic attitudes to them and unhelpful, sometimes antagonistic, behavior. Foner (1994) found family members often overwhelmed, sometimes to the point of tears, by the helplessness entailed in asking staff busy with other priorities to attend to a relative's needs. Foner puts forward that this experience drives home the fact that their relative's care is no longer in their hands.

Nevertheless, Foner found out that, usually, family members and aides became accustomed to each other, and a level of cordiality was maintained. Family members did not want to antagonize aides, which might have resulted in worse treatment for relatives and more uncomfortable visits for themselves. Thus, a tolerable working relationship was usually developed between the family members and their relative's aides at the Crescent Nursing Home. At the same time, aides have come to expect that certain regulars will do specific jobs, like helping with meals, and they build such assistance into their own schedules. And in spite of all, Foner (1994) observed that "... some aides get along with family members and go out of their way to keep them up to date about the patients' condition and to try to cheer them up despite the unhappy circumstances" (p. 112).

Programs aimed at promoting communication between nursing home staff and family members of residents have been developed (Campbell & Linc, 1996; Pillemer, Hegeman, Albright & Henderson, 1998). Campbell and Linc (1996) describe a planned program to create support groups for visitors. The program entailed six evening one-hour session and was very well attended, indeed it had to be run twice a week to accommodate interested individuals. The family members shared experience and feelings during time intended for socializing, however, each of the sessions were structured and included information about the aging process. During the sessions the nurse facilitators realized that families wanted to assist with resident care needs including ways to promote comfort. Furthermore, the facilitator of these groups identified topics for in-service programs which were found to be important to address with staff to improve their communication with the family members. Pillemer, Hegeman, Albright and Henderson

(1998) created the *Partners in Caregiving* program to train staff and family members in communication techniques and conflict resolution skills. The *Partners in Caregiving* program has been detailed in comprehensive training manual and consists of two parallel workshop series. The staff workshop for nurses and nursing assistants in a long-term care facility is structured as a full-in-service day. The workshop for family members of residents in the same facility includes three 2-hour sessions to be conducted weekly. However, the authors point out that alternative scheduling options are also provided in the manual, as this schedule may not be appropriate for all facilities. The training methods include minilectures, case discussions, brainstorming sessions and role plays all aimed at improving mutual understanding and communication techniques. The authors have evaluated the program in six facilities and maintained that "evaluation data indicated that satisfaction with the program was extremely high, and that positive changes in staff-family interactions occurred"(p. 499).

McCallion, Toseland and Freeman (1999) have examined the impact of the Family Visit Education Program (FVEP) on family members, nursing staff, and nursing home residents with dementia. The program aimed at improving family members skills in communicating and interacting more effectively with the nursing home residents with moderate or severe dementia. To this end the program proved to be effective, with beneficial effects on residents. However, the program did not have impact upon nursing staff's management of residents' behavior problems. Furthermore, only a limited amount of data indicated benefits, like reduction in self-reported stress in caregiving, for the family members. Nevertheless, the program appeared to be well received by family members, social workers and nursing staff. The authors conclude their article by suggesting that the program may not only involve the family visiting members but the direct staff who have 24-hour contact with residents. By these means the staff may be able to supplement the family members' effort to sustain and enhance communication with residents. The authors also point that the staff could possibly deliver the FVEP interventions to residents without visiting families.

Preservative Care and Medical Technology

Bowers (1988) identified four types of preservative caregiving in her previously discussed study of family perception of care in nursing home. Four types of preservative caregiving were undertaken to preserve the elderly relative's self and prevent depression in the elderly relative. Families perceived only one type of caregiving, pertaining to maintaining family connectedness, as primarily their responsibility. The other three types, maintaining their relative's dignity, maintaining their relative's hopes (generally for recovery), and helping their relative maintain control of the environment were seen to require collaboration between staff and family. Purpose rather than associated tasks distinguished the four types of preservative caregiving. However, a variety of tasks was used to carry out each type of caregiving. In Bowers (1988) study, families distinguished between technical expertise as a prerequisite for physical care and medical supervision, and biographical expertise as necessary to provide preservative care. Technical expertise is acquired through prolonged experience caring for the sick, formal training, and education, but biographical expertise requires an intimate knowledge about the life of the older person and what makes that person unique. Simultaneous use of both types of expertise is needed to provide good quality technical care. Thus, from the family perspective, the prerequisite for quality of care is a mutual education process in which the staff shares their technical expertise with the family and the family shares their biographical expertise with staff.

Duncan and Morgan's (1994) study of the relationship between family caregivers and staff, discussed above, showed that families referred the most to nurses's aides in addressing the care of their relative. Families emphasized their consistent contact with aides and brought forward that aides were the ones who really knew the resident's needs in both technical and personal terms. Family members shared with the aides understanding of the kind of tasks performed for the residents. In a way, the families in

Duncan and Morgan's study can be seen as sharing what Harvath et al. (1994) term "local knowledge" in their discussion about establishing partnership with family caregivers. According to Harvath et al. :

> Local knowledge is knowledge that is unique to the inhabitants of a particular culture. The term refers to the skills and understanding that the family brings to the caregiving situation. It includes the beliefs families have about the nature of the caregiving problems they are managing, the perceptions they have about what factors influence the problems, and the strategies they use to manage problems and/or their consequences. The family's local knowledge is derived from experience in managing the older person's chronic illness and is embedded in the context of the family culture and relationship (p. 30).

Local knowledge and what Bowers terms (1988) biographical expertise may be looked upon as intertwined aspect of knowing the patient in a particular situation in a nursing home. Apparently, the family members in Duncan and Morgan's study found nurses' aides more appreciative of this kind of knowing than the nurses. Harvath et al. (1994) refer to nurses' knowledge and skills as "cosmopolitan knowledge" which appears to be identical with Bowers' (1988) definition of technical expertise. The extent to which cosmopolitan knowledge or technical expertise acknowledges and appreciates biographical expertise and local knowledge differs. Tanner, Benner, Chesla and Gordon (1993) have illuminated how knowing the patient is the nurses' basis for particularizing care. At the same time they assert "that despite its centrality, the informal discourse on knowing patients is underdeveloped without the legitimacy and status of technical-procedural discourse" (p. 278).

An increase in advanced technology may give more of a legitimacy and enhance the status of technical-procedural discourse in addressing the care of the patients in nursing homes. Certainly an enhancement of this kind of discourse is critical to ensure the appropriate treatment of the more acutely ill inhabitants. Nevertheless, the prospect of developing the informal discourse on knowing the patient may also be crucial to sustaining the elder's personhood and helping the respective inhabitant to be more at home in this final place of her or his settlement. Nurses' conversation with families which appreciates the family's biographical or local knowledge, can facilitate the development of an informal discourse on knowing the patients and enhance a feeling of partnership between the staff and the family in caring for the elder. Such partnership may be of support to the family and sustain the family's participation in the elder's care.

Chapter Three

METHODOLOGY

Introduction

My encounters with families participating in the care of their aging kin in nursing homes brought about my research interest reflected in this project. The disclosedness of these encounters evoked questions pertaining to possibilities of nursing practice to illuminate the significance of family and staff relationship in nursing homes. In the previous chapters, addressing nursing care approaches in the context of a nursing home and family participation in care, I have attempted to delineate my clues for guiding my move towards inquiry into these phenomena. My inquiry pertains to the way in which the family and staff understand how the elderly debilitated person constitutes and is constituted by the nursing home world. Furthermore, it will attempt to articulate how the family and staff perceive of and understand their encounter and how the possibility of the family's engagement is projected in such an encounter. Thirdly, my inquiry will strive towards understanding what meaning and value is ascribed to the different aspects of caring for the person in a nursing home and the family's impact upon the care.

My inquiry will be grounded in the interpretive phenomenological approach or "a hermeneutical phenomenology, a practice of interpretation and understanding of human concerns and practices. This approach attempts to capture everyday skills, habits, and practices by eliciting narratives about the everyday and by observing action in meaningful contexts" (Benner, Tanner & Chesla, 1996, p. 351).

Interpretive Phenomenological Inquiry

Interpretive phenomenology is built upon a philosophical stance that maintains that studying phenomena within the human sciences requires different premises from studying phenomenon within the natural sciences (Dreyfus, 1991). From this perspective the phenomena of the lived human world can not be fixed in time and space, isolated and unitized into some measurable quantities to bring forward some "true" aspects or proof of lived experience. In contrast, it is the phenomenon and its context that "frame the interpretive project of understanding the world of participants or events" (Benner, 1994, p. 99) in which "the goal is to study the phenomenon in its own terms" (Husserl cited in Benner, 1994, p. 99).

Bohman, Hiley and Shusterman (1991) point out that "Taylor and Dreyfus have remained staunch defenders of fundamental distinction between the natural and human sciences" (p. 4). They point out that Taylor for his part

> ... has argued that there is something about human agency, bound up with the fact that we are self-interpreting beings, that would be lost in the reduction of the human to the natural sciences. Because humans are self-interpreting beings, the meaning of human actions are always for an agent - the beings-for-whom they are meaningful. As such, the goal of the human sciences, according to Taylor, is not to achieve objectivity as in the natural sciences, but to grasp what these meanings are for the agents (p. 6).

We give sense to the disclosure of entities within the world and their involvement by ascribing meaning to them. The structure of meaning draws upon interpretation which in turn bears upon development of understanding. "In interpretation, understanding does not become something different. It becomes itself" (Heidegger, 1927/1962, p. 188). Interpretation is a way of "working-out of possibilities projected in understanding" (Heidegger, 1927/1962, p. 189). Meaning emerges on the basis of a projection "in terms of which something becomes intelligible as something; it gets its structure from a fore-having, a fore-sight, and a fore-conception" (Heidegger, 1927/1962, p. 193). Fore-having, fore-sight, and fore-conception are the foundations on the basis of which something is interpreted as something.

What we have in advance - our "fore-having" is the degree to which our background practices illuminate the situation with regard to our familiarity with equipment and people in these circumstances. In light of this illumination we see "a point of view".

Something is in sight that calls for unveiling by an act of appropriation. The different dimensions of an entity may not be fully clear - something is still veiled, as if only the outlines have been disclosed. A point of view focuses the dimension to be unveiled so what is understood can be interpreted.

> Anything understood which is held in our forehaving and towards which we set our sights 'foresightedly', becomes conceptualizable through the interpretation. In such an interpretation, the way in which the entity we are interpreting is to be conceived can be drawn from the entity itself, or the interpretation can force the entity into concepts to which it is opposed in its manner of Being. In either case, the interpretation has already decided for a definite way of conceiving it, either with finality or with reservations; it is grounded in *something we grasp in advance* - in a *fore-conception* (Heidegger, 1927/1962, p. 191).

We get some clues about what is veiled, as an illumination of our fore-having enlightens some outlines of an entity. The sight gets clearer, when we grasp a delineation of its emerging dimensions. The way in which anything understood becomes conceptualizable through the interpretation will in turn clarify our fore-having and fore-sight. Thus, a clearing of our moving center of pragmatic activity in the midst of a shared world unfolds in an ongoing circular mode of interpretation (Dreyfus, 1991).

This study is brought forward by phenomenology as an understanding of world, personhood and being. It does not attempt to ascertain any relationship among presumably measurable, objective facts about the phenomenon of interest. Consequently, it does not aim at any generalization to allow for predictions about the implication of the relationship between the family and staff in a nursing home given some specific conditions. Neither does it attempt to achieve conceptual specification of the phenomenon as in theory-building research. Rather, this understanding defies the idea of an objective lived human world which one can step outside of, and evaluate from a detached perspective; a detached perspective of everyday activities is "a deficient mode of being-in-the-world" in Heideggerian terms as said by Dreyfus (1991):

> Heidegger's analysis of the natural situation of everyday activities is meant to show that the traditional epistemic situation of a mind distinct from objects, *whether observing or acting upon them*, is a deficient mode of being-in-the-world and cannot, therefore, have the broad philosophical implications modern philosophers of mind have supposed (p. 54).

Contrary to what modern philosophers of mind have supposed, "interpretive phenomenology seeks to preserve the participant's engaged action in the world and to understand human actions in everyday skillful comportment and in breakdown"(Benner, 1994, p. xxv). Families visiting and staff working in nursing homes comport themselves each in their own way. They each see from their particular vantage points the ways in which elderly people in the nursing home are affected, and the ways in which everyone involved in the situation contributes to the care and well-being of a particular resident. Each person's perspective is evident in the ways in which family members and staff members encounter each other in action, and the ways they describe the relationship between themselves. However, this form of inquiry does not expect the participants to give an explicit description of the relationship between themselves. Rather, they will be encouraged to use a natural, narrative form to describe their experience and engaged action. Benner (1994) has pointed out that "when people structure their own narrative accounts, they can tap into their more immediate experiences, and the problem of generating false generalities or ideologies is diminished" (p. 108). She further cites Rubin when she puts forward:

> Narrative accounts of actual situations differ from questions about opinions, ideology, or even what one does in general because the speaker is engaged in remembering what occurred in the situation. Spoken accounts allow the speaker to give more details and include concerns and considerations that shape the person's experience and perception of the event. A story of an event is remembered in terms

of the participant's concerns and understanding of the situation. Therefore, narrative accounts are meaningful accounts that point to what is perceived, what is worth noticing, and what concerned the storyteller (Benner, 1994, p. 110).

The Goal of the Inquiry

The goal of interpretive phenomenology is to uncover commonalities and differences in the perspectives that persons have on their situation and how they act. Interpretive phenomenologists look for commonalities in culturally grounded meanings and the way in which commonalities make distinctions and differences possible (Benner, 1994). Benner (1994) points out that phenomenology draws upon five sources of commonality: Situation; embodiment; temporality; concerns; and common meanings.

The elder experiences transition in her or his life patterns and everyday activities on entry into a nursing home. However, the past is not left behind, but creates a ground to find one's footing, upon which a horizon arises and towards which the person heads. The way in which the elders embody their situation is to a degree reflected in their comportment and perceptual and emotional responses. However, various multifaceted diseases, especially of circulatory or neurological origin, may affect their embodied understanding of the situation. Elderly people have come a long way when they enter a nursing home. Everyone brings with them their particular concerns about being there. Furthermore, the conditions contributing to institutionalization influence the meaning of the situation for the self.

The way in which family members perceive and act in this situation may rest upon the expectations inherent in the supportive role of the family towards aging kin. As discussed more fully in the previous chapter, the expectations inherent in the supportive role of the family towards aging kin draw upon different sources. On one hand there may be an emphasis on affective ties, feelings of closeness and interconnectedness; on the other hand there may be emphasis on family member's duty or filial obligation, or some kind of contractual arrangement. However, structural and demographic factors such as distance and role conflict may mediate these expectations (Brody, 1985; Finley, Roberts & Banahan, 1988; Guberman, Maheu & Maillé, 1992).

The impact of the family on the inhabitant's situation may to some degree be influenced by the nursing personnel stance. Nursing care approaches may also be affected by the family stance. Families and staff respectively influence the meaning of the situation for the self of a nursing home inhabitant in the way they go about their caring activities. The relational quality of their encounter, and its effect upon the elderly person's care, certainly has many facets which could only to a limited degree be illuminated by sophisticated measurement tools and statistical methods. As Benner (1985) points out:

> The analysis of variance model of interaction will not be sufficient to capture the relational quality of the person in the situation. That is, separating person variables and situational variables and then calculating their independent contribution to a singular main effect does not capture the configurational relationships inherent in the situation (p. 3).

Indeed, the interpretive phenomenological approach assumes that a phenomenon of the lived human world can not be captured beforehand in an effort to apply a yardstick to its different dimensions to find out what constitutes its being. Rather, phenomenology is the method of bringing what is hidden out (Dreyfus, 1994). It is my premise that there are many aspects of family and staff's relationship in the nursing homes that lie hidden in spite of the family's obvious presence in the facility.

Heidegger (1927/1962) asks:

> What is it that phenomenology is to 'let us see'? What is it that must be called a 'phenomenon' in a distinctive sense? What is it that by its very essence is *necessarily* the theme whenever we exhibit something *explicitly*? Manifestly, it is something that proximally and for the most part does *not* show itself at all: it is something that lies ***hidden***, in contrast to that which proximally and for the most part does show

> itself; but at the same time it is something that belongs to what thus shows itself, and it belongs to it so essentially as to constitute its meaning and its ground (p. 59).

The project of my study is to illuminate the ways in which the families are present in nursing homes, to describe some aspects of what constitutes the meaning and the ground of family participation in care in the nursing home and its implication for care approaches. The premises of my following research questions indicate my preconceived notion of what comprises the family's presence in nursing homes, as I saw it at the outset of my study. This outlook derived from my experience of working in nursing home, having been a visiting daughter in a nursing home, as well as clues described by other investigators in nursing homes. However, I have been ready to have my questions and premises challenged. As Benner (1994) says:

> The participants' own practical worlds and concerns must challenge the initial questions. The researcher makes explicit as many assumptions as possible prior to beginning the study and establishes boundaries to the lines of inquiry for the study, but these must be held tentatively and allowed to be challenged, altered, extended, and transformed by what is learned in the field (p. 105).

I shared practical knowledge with participants in my study because of my own personal experience of having been a visiting family member in a nursing home. Indeed, the issues I myself tackled showed me precisely the way concerns and meanings are implicit to one's own background and practical world. This experience facilitated my conversation with the participants, but at the same time I was on guard against allowing my own experience to overshadow emerging aspects of comparisons among the practical lived worlds of the participants in the study.

Research Questions and Assumptions

My inquiry pertains to the way in which the family and staff understand how the elderly debilitated person constitutes and is constituted by the nursing home world. Furthermore, the project will attempt to understand and articulate how the family and staff understand their inter-relationships and the different ways in which families are engaged in relations with staff. Thirdly, my inquiry will strive to understand the meaning and value that is ascribed to the different aspects of caring for the person in a nursing home and the family's impact upon the care. I shall address the following questions in my research project:

1. Do family relations with the old person affect the staff's caring approaches in a nursing home, enhancing or diminishing the quality of her or his life?
2. How do family and staff relations manifest themselves ?
3. How does the family understand these relations?
4. How does the staff understand these relations?
5. What meaning and value does the family on one hand, and the staff on the other hand, ascribe to the different aspects of caring for the person in a nursing home?

The premises inherent in my research questions or problem statement can be outlined in following way:

(1) Regular visiting in nursing home for an extended period can be wearing or stressful for family members, particularly if the person visited shows little recognition or response. This stress is to some extent regulated by understanding of the plight of the nursing home resident, the purpose, meaning or value ascribed to the visit by the visitor and by the visitor's relations with the staff in a nursing home.

(2) The demand of visiting and caring for a relative in a nursing home can affect the health and well-being of visiting kin.

(3) The care of the aging person is demanding and often stressful. One way that staff deals with the stress is to attend to people like 'processing packages on an assembly line.' The result of the staff's efforts may often be obscure, as the aging person may not be able to express how she or he experiences the care given. However, regularly visiting kin may express their views on the staff's efforts, and give positive or negative feedback. Furthermore, regularly visiting kin may change staff's view from that of an old person

'wrapped up in a package on an assembly line' to that of a person with bearings of a lifetime.

The Icelandic Context of the Study

I conducted my study in my home country, Iceland, whose population is about 275,000 (275,712)). In 1980, 9.9% of the population was 65 years old or older; this percentage had increased to 11.6% in 1998 (Statistics Iceland, 1999). In 1983, legislation on services for the elderly came into force in Iceland and this legislation was amended and reissued in 1989. The main objective of the statute is the provision of the appropriate health and social services to enable the elderly to live independently for as long as possible, but also to provide the necessary institutional care when appropriate (Act on Services for the Elderly, 1989). A year later, in 1990, a special regulation on institutional services for the elderly, as well as a regulation setting fundamental criteria to evaluate the need for nursing home placement, was enacted by the Ministry of Health and Social Security.

Institutional services for the elderly are, according to legislation:

1. Service Housing for the elderly, either flats or old-age homes, both especially designed with regard to the needs of the elderly and meant for those elderly people who are incapable of house-keeping even with home-help services. Assistance should be available on a 24-hour basis, and there should be a security system in each flat. The homes offer a complete range of services, including all meals, all personal services, physician's services and nursing, rehabilitation and facilities for socialization. Individual services depend upon individual need assessment and should be based on help towards self-care.
2. Nursing placements in a geriatric institution or nursing home are meant for those elderly who are too disabled to dwell in Service Housing. The facilities of nursing placements in a geriatric institution or nursing home should allow for nursing and physician's service. The design should aim towards making the institution homelike

> and warm. There should be facilities for elderly patients with dementia. If possible nursing placements in a geriatric institution or nursing home should be associated with departments of geriatrics, departments of internal medicine or hospitals, depending on the circumstances in each case. Individual services depend upon individual need assessment and should be based on help towards self-care (Act on Services for the Elderly, 1989, p. 386).

The financing of nursing placements in a geriatric institution or nursing home is paid by National Health Insurance. The elderly themselves are expected to pay a proportion of their income, whether it be a social security income, national pension income or retirement income, towards the cost of their care in these institutions. However, the amount the elderly keep for themselves shall never be less than a certain amount which is stipulated in the legislation (Regulation on Institutional Services for the Elderly, 1990).

The Ministry of Health and Social Security's web site (1999) shows that there are 3.694 institutional placements for the elderly in the country. Those are divided into day care placements (400), placements in service housing (1.065), nursing home placements (1.631), nursing placements in hospitals (439) and placements in geriatric units (159). That is, 5.1% of the population 65 years old and older live in a nursing home, but 6.5% when nursing placements in hospitals are counted as well. The latter type of placement is common in the rural areas. There has been a considerable increase in available placements since 1981, when the total number of available placements was 1.982: 992 nursing home and long-term ward placements and 990 old-age home placements (service housing). However, the rather large increase in nursing home placements compared to old-age home placements can partly be ascribed to transition of old-age home placements to nursing home placements; also more accurate reports of placements as well as categories of placements had been made to the Ministry of Health and Social Security since 1981 (Ingibjörg R. Magnúsdóttir, 1992).

There is a persistent lack of available nursing home placements in the larger urban area of the capital, Reykjavík. Thus there is a long waiting list for placements in most nursing homes, especially the newer ones. One rather small nursing home is expected to open this year in the area, and a second, larger one is being planned under the aegis of the Ministry of Health and Social Security. However, at the same time some of the older available facilities are becoming outdated and sub-standard and in need of remodelling, which will consequently decrease the number of places available. There is a dispute regarding the projection of "needed" nursing home placements in Iceland, a dispute which is too complex to address within the scope of this work.

However, the legislation on services for the elderly that was evaluated and reissued in 1989 has indeed, by improving community services, made it easier for the elderly to live independently, to some extent, as long as possible. Furthermore, the special regulation on institutional services for the elderly, as well as the regulation setting fundamental criteria to evaluate the need for nursing home placement, has contributed to more appropriate nursing home placements. There are some signs that point to an impetus towards improved care for the institutionalized elderly in Iceland as this century runs its course. On one hand, the staffing pattern of nursing homes shows an increasing ratio of registered nurses employed, and on the other hand there have been a number of geriatricians entering in the field. The care of the elderly in nursing homes in Iceland is however largely provided by nursing aides or assistants guided by nursing knowledge.

Design of the Study

Sites

As over half of the population in Iceland lives in the capital, Reykjavík, or its neighborhood, more than half of the available nursing home placements are located in this area. I had a fairly good sense of the practical world of these nursing homes at the time of my prospective data collection, as I had planned and overseen clinical teaching in the nursing homes in the Reykjavík area for over a decade, and conducted the teaching myself in some of them. Thus I had open avenues to all nursing homes in the Reykjavík area at the outset of my data collection, and I decided to pursue access in three of them. My method of access consisted of writing identical letters to the Director of Nursing and the Administrator in each home asking for written permission to conduct the proposed study. I submitted with the letters a description of the project, consent forms and guidelines for the interviews.

The three nursing homes to which I pursued access to carry out data collection are relatively new but well established nursing homes, which have good reputations and are, according to waiting lists, much sought after. One of these nursing homes has mostly single rooms (90), the other two have over two-thirds single rooms (100 and 70 placements respectively) and they all have a fairly high staff-to-residents ratio. Furthermore, the caring practices of these nursing homes appeared to be quite person-oriented, and placed emphasis on the autonomy and privacy of the people "who were living at home". One of these three nursing homes is owned by a private association, the other two are public, but they are all financed by National Health Insurance. I have conducted clinical teaching in all of these nursing homes throughout the years, so I felt well grounded in these places.

The Directors of Nursing and the Administrators in these three nursing homes were very positive towards my research project and gave me permission for access, with a kind offer of any assistance to ease the process. I prepared the way for my access into each nursing home by attending a meeting with the director of nursing and the head nurses, where I was given the opportunity to give an account of my project. We came to an agreement during these meetings on the unit where I would begin my data collection, and when would be the best time to introduce my project and presence in each unit. I was lucky enough to be able to attend staff meetings in some units for this purpose, but in others units I visited during midday report, to tell the respective staff working that day about my study, and to answer any questions that were evoked. I had the opportunity to follow up on this account of my project during my participant observations.

The Sample

The sample encompasses family members of 15 nursing home residents (six spouses and nine children) and 16 groups of staff (4-5 staff members in each group/ mixed groups of registered nurses, practical nurses and nursing assistants, in total 75 staff members).

The family members of nursing home residents

Originally the sample encompassed 16 family members, seven spouses and nine children, but one spouse, a wife, dropped out of the study. The family members participating in this study were asked to do so because of their regular visiting. Their pattern of visiting met the prerequisite for participation in the study, which was regular visiting every day, every other day or at least two or three times a week. All the six spouses visited daily, except one wife who visited five days a week. One daughter, her mother's only child, would visit daily, the other seven daughters and the one son would visit at least three times a week. More women than men gave voice to this study, in accordance with the major part they play in shouldering the care of the elderly, as discussed in previous chapter.

Table 1 gives an overview over the residents' gender, age, a route of entry, length of stay in the respective nursing home at the time of my first interview with a family member, and the respective family member participating in the study. The table displays a route of entry to show that various alternatives to nursing home placements such as day care services, service housing and respite placements had been pursued beforehand in most cases. And others wait for some time in a hospital's geriatric unit for an available placement, or stay in a temporary nursing home placement. Thus table 1 reflects the often extended route to an entry to a nursing home, as well as some other features of the sample. Table 2 summarizes the number of female and male residents participating in the study and the age distribution.

Table 1

Overview of Sample

Resident Subject	Age	Gender	Route of Entry	Approximate Length of Stay	Interviewee
1	81	Female	Geriatric unit	2 years	Husband
2	68	Female	Home/Day Care	3 years	Daughter
3	78	Female	Geriatric unit Temp. n.h. placement	10 months	Daughter
4	92	Female	Home/Respite placement	3 years	Daughter
5	71	Male	Home/Respite placement	7 months	Wife
6	86	Male	Home/Respite placement	3 years	Wife (Dropped)
7	74	Female	Hospital	1 year	Husband
8	85	Female	Service Housing	3 years	Daughter
9	77	Male	Geriatric unit	1 year	Wife
10	73	Male	Home/Day-care	1 year	Wife
11	87	Female	Geriatric unit/Temp. n.h. placement	2 years	Son
12	88	Female	Home	2 years	Daughter
13	72	Male	Home/Day Care	1 1/2 years	Wife and Daughter
14	93	Male	Service Housing	2 1/2 years	Daughter
15	94	Female	Hospital/Geriatric unit	2 years	Daughter
16	75	Male	Geriatric unit	3 years	Daughter

Table 2

Age Distribution of the Sample

Age range	Number	Number of Females	Number of Males
60 - 70	1	1	
70 - 80	7	2	5
80 - 90	4	4	
90 - 100	3	2	1

Residents who had been in a nursing home for at least a year were chosen for participation in the study. However, two exceptions were made; in one case this exception was made for a resident in a temporary placement in one unit, expecting a move to another unit in the home. This was done in order to get a better grasp of how the atmosphere of a unit affects the resident's experience of institutionalization and the family's relationship with the staff. In the other case the resident had stayed in a temporary nursing home for few months before her move to the present one, so the resident had actually stayed in a nursing home for more than a year. But in the latter case it was particularly the family's troublesome relationship with the staff that suggested a distinct perspective of the relationship between the family and staff in nursing homes, which I felt should be closely examined to inform the study.

I kept the criteria flexible with regard to specific physical and mental impairments and the age of the residents, in selecting family members of residents. I had planned to include in my sample at least 7 family members of residents with dementing illnesses with regard to the proportion of demented residents in Icelandic nursing homes, in which about half of the population have extensive cognitive impairments (Anna Birna Jensdóttir, Hlíf Gudmundsdóttir, Hrafn Pálsson, Ingibjörg Hjaltadóttir, Pálmi Jónsson, &

Sigurbjörg Sigurgeirsdóttir, 1995). And seven of the residents participating in the study had been diagnosed with dementia; however some of the others also had mental impairments following another illness such as a stroke or Parkinson's disease. I did not invite into the study family members of residents who were terminally ill. However, one man became acutely ill after the first interview with his daughter, and died rather suddenly. I phoned the daughter about a month after his death to express my condolences and asked her how she would feel about telling me about her father's last days in the nursing home. She was prepared to do so, and told me her story of saying goodbye to her father at his deathbed in our second interview.

One person, a wife, dropped out of the study after our first interview. Actually the staff was rather surprised that this wife was willing to participate when she consented to the first interview, as they found her very anxious about her husband's condition as well as about other personal affairs. Our first interview went well, or so I thought, but she told me at that time about her plans about selling her apartment and moving to a new one, and how worried she was about the whole prospect. I was informed in the unit that these proceedings came about shortly after our first interview. I waited to contact her until I heard that she had apparently settled into the new apartment to some extent. However, she told me when I contacted her that she was still overwhelmed by the move, and did not feel inclined to continue participating in my study.

I started my selection of participants in the study by arranging for a meeting with each of the head nurses in the respective wards of the nursing homes to which I had been permitted access to conduct my data collection. I asked her to tell me about the regular visitors in the ward and discussed with her how they went about their visiting and their encounters with the staff. Then I continued with observations in each unit and looked through prospective participants' file while I tried to figure out which ones would inform my study the best. This was rather a puzzling process, especially at the beginning, as there were many visitors in the units that met the prerequisite for participation in the study. Nevertheless, I tried to achieve a balance in the numbers of visiting family members who were wives, husbands, daughters and sons. But on the whole I chose to invite family members who showed some distinctive visiting pattern and manner of involvement in the life of their family member residing in a nursing home.

I talked initially to the respective residents about the study and asked if I might contact this particular person in the family for the purpose of my project. One resident agreed formally by signing a consent (Appendix E), some agreed verbally, others were not able to take a stance because of their disease condition. I then approached prospective family participants through a letter I had written for recruitment of the sample (Appendix F). I asked the head nurse or a registered nurse to give the recruitment letter to the respective family member. And I asked her to point out that other nursing homes were participating, so that the final information would be presented from multiple facilities, ensuring confidentiality of informants and institutions.

Many of the residents participating in this study have since died, before its results finally come to light, but their story while dwelling in a nursing home is told as it unfolded during the data collection.

Staff participants

A group interview with staff was matched with each family member's interviews. The selection of staff members took into account the strategies employed in the respective nursing home or ward to assign to staff members the care of individual patients or group of patients. A group of nursing staff included 4-5 staff members, with a mix of registered nurses, licensed practical nurses and nursing aides. Staff members were asked to participate with regard to work percentage and length of employment in the facility. Consideration was paid to the length of time each staff member had been engaged in the care of the respective resident. From the clues in the literature and my pilot study, I concluded that it was important to include nursing staff from all levels in the group discussion. It was apparent that the nurses' aides or assistants might have more frequent and closer relationship with the family members visiting than the registered nurses (Duncan & Morgan, 1994). I had planned to interview individual staff members, optionally, and I did so in the case of two unit managers and one registered nurse. I also relied on the help of the head nurse to choose individual nursing staff to participate. I wrote a letter to prospective staff participants (Appendix G), which I had intended to ask the head nurse to give to the chosen individuals. However, I decided to do this personally in order to have the opportunity to follow up on the content of the letter and discuss a convenient time for the interview. Furthermore I could point out at that time that other nursing homes were participating, so that the final information would be presented from multiple facilities, ensuring confidentiality of informants and institutions.

Data Collection

A potential risk of recognizing a subject or site is inherent in the small population of Iceland. Data was collected in three nursing homes so that the final information will be presented from multiple facilities, ensuring confidentiality of informants and institutions. The consent process and documentation were twofold in the project (Appendix C, D, E): On one hand the family member, and on the other hand the participating staff members. If the family or staff member agreed to participate, she or he was given the relevant consent form to read and sign. The individual resident's agreement was sought, if the person was able to give consent for her/himself. Consent was obtained according to the protocol established through the Committee on Human Research, University of California, San Francisco. Furthermore, the Data Protection Commission of the Icelandic Ministry of Justice approved my protocol for this project.

Family participants

Each family participant was individually interviewed in two interviews at a few months' interval. This was done according to Benner's (1994) emphasis on the importance of multiple interviews and observation to enhance one's understanding and clarify the initial interpretations. Each interview lasted from 1 to 2 hours, generally just over one hour. They were audiotaped and transcribed to generate text for interpretive analysis. The transcription was done in Icelandic from which the interpretive work continued in English; however, a sample of interviews (2) was translated into English, as necessary to ensure guidance by my mentor along the interpretive process. The participants had choice of a site of the interview. Eight chose to meet me in their homes, five participants came to my office, and two found it most convenient to meet me in the respective nursing home. In families where there was a sharing of visiting or participation of care, I turned to the key visiting family members, or the one who was instrumental in handling the elder's affairs in the home. In one case I interviewed a wife and one of her daughters together. I made records of all the family participants and their family member living in the nursing home during the interviewing process. I delineated the resident's profile and her or his circumstances in these records, as well as the family's pattern of visiting. This information proved to be very helpful as I started to analyze the data. An interview guideline had been developed (Appendix A) for the family interviews, but I did not follow it strictly from one question to the next, as each interview unfolded in a conversational style with questions generated to follow the participants narrative. I had the opportunity to fill in any gaps or unclear aspects in the second interview.

I often mentioned very briefly at the beginning of the first interview that I had myself gone through this experience of visiting a beloved family member in a nursing home. Such a remark appeared to ease the way for people to address their experience, and not least the issue of institutionalization of a family member. I had not intended to explore the issue of institutionalization of a family member in the interviews. However, this aspect was mentioned in all the interviews, even if the institutionalization had taken place some time ago. It was often a painful aspect to remember, but people seemed to find comfort in talking about it. And it grounded the continuing conversation about an important "way of being" or pattern of daily conduct or comportment of their debilitated aged kin, and the person's response to institutionalization and the caring practices in the respective home. Intertwined into this conversation were questions about their family relationship, and the place of the elder in the family member's history. In the course of the conversation I inquired about the family's involvement in its member's life in the nursing home, as well as the family's relations with the staff. I also asked the participants to tell me about special encounters with the staff and to elaborate on their context or to address particular incidents. In the beginning I used the word "story" when I asked the participants to tell me about occasions when they were involved with staff regarding the care of their elder that worked really well, or was on the other hand rather difficult. But this term appeared to perplex the participants, so I put my questions differently and just said "can you tell me about ...". However, quite a few stories turned up in the line of the conversation as the participants reflected upon their experience.

Staff participants

Group interviews with a designated group of the staff were conducted, in which relationships with family members of a particular patient were talked about. Each group usually consisted of one registered nurse, two practical nurses and two nursing assistants, so as to mirror the general composition of staff on duty in the units. I also talked informally with many of the staff at the bedside during my participant observations. The group interviews were conducted in the nursing homes. Each interview lasted about one hour. They were audiotaped and transcribed to generate text for interpretive analysis. The transcription was done in Icelandic from which the interpretive work continued in English; however, a sample of interviews (2) was translated into English, as necessary to ensure guidance by my mentor along the interpretive process.

I discussed with the head nurses when would be the best time to conduct the group interview, and came to the conclusion that it would best to combine staff members from the early and late shift during the hour of shifts' changeover. An early shift in most of the units lasts from 8 am to 4 pm and the late shift from 3:30 p.m. to 11.30 p.m., so I conducted the interviews between 3 and 4 pm. I figured out from the work schedule which day all the participants in a prospective group of participants would be working either on an early or a late shift, to set a date for an interview. Then I delivered a recruitment letter (Appendix G), most often personally, or asked the head nurse to do so, asking at the same time if the date was convenient. I had to ask the late shift staff to arrive half an hour earlier for the interview but all those of whom I made the request did so without hesitation. I arranged with the head nurse that the participants on the late shift would receive a postponed report. The head nurses did this willingly, and also said that they would try to make the half hour up for the respective staff members, when there happened to be a relatively easy workload in the unit.

Another guideline was developed for the group interview with the staff (Appendix B). Benner (1994) has pointed out that a small group interview is "an effective way to set up a familiar communicative context and dialogue" (p. 108). Staff members were encouraged to tell about how a particular family was involved in the care of its member living in the unit, and how they themselves were involved with the family. I asked the participants to tell me about special encounters with the family and to elaborate on the impact of these encounters upon the care of the respective resident. Then I inquired especially about the context of such encounters or particular incidents. The flow of the conversation was smooth in all the interviews, and I managed for the most part to ensure that the voice of all participants was heard and considered in the group. My previous participant observations in the unit, and my personal contact with each of the participants in every group, somehow made it easier to include everybody in the conversation. It was helpful that I knew all the faces and all the names in each group. Certainly, the voice of the registered nurse or the unit manager became at times quite dominant, but I strived to have the others in the group comment upon their input. And the nursing assistants and practical nurses had a strong voice describing the respective resident's comportment and response to care.

Participant observation

I spent considerable time making participant observations, particularly in the two first nursing homes where I did my data collection. I knew the third one best beforehand, so I spent less time there. Nevertheless I spent some time in that nursing home for the purpose of choosing participants, and I found it helpful to compare some aspects of its world to those of the two others. I had initially planned to visit the units to compare prospective participants, look through the residents' files, consider different aspects of their conditions and situations, especially their family relations, and consider which ones to choose for possible participation. Then I planned to make observations of care approaches to the participating nursing home resident.

However, I soon found out that there was much to learn about the nursing home world, of which I had caught no more than a glimpse before. And I realized that I needed a better sense of this context in which the relationship between the visiting families and staff evolves. So I visited each unit at least six to eight times at different hours of the day, and stayed for 2 - 5 hours at a time in the first two nursing homes. I collected samples of activities and relations at various periods in the units. I came in, for example, around breakfast time and stayed until the midday report at one o'clock was over, or I came before lunch time and stayed until the late shift had taken over at about four p.m. Then I came after the rest period about two o'clock, and stayed until supper had been served, or I came after the late shift had taken over and stayed until the staff began to help the patients to bed. I was mostly just "hanging around" in the units; I would often sit down next to one or more patients, chat a little and look around, or I would sit down with a morning paper "pretending" that I was reading, watching things go on around me or I would tell the patient sitting next to me what I was reading in the paper. Actually, one resident said to me during my observations in the unit where she lived "I think this is really a good idea, to hire somebody to be with the patients and talk to them". However, I had told her before the purpose of my being in the unit, and I told her again, but she did not pay much attention and just said “it is nice that somebody has the time to sit there with the people”. Finally, I observed care at the bedside of all the participants in the study on one or more occasion towards the end of my stay in each unit. On this occasion I asked the resident and the respective staff if I could do so, to observe the way in which the participant received a helping hand. And the resident and the staff always responded in a relaxed manner and allowed me to do so without hesitation, probably because by that time I was a familiar face in the unit. These bedside observations were made to gain a closer sight of the person, how she or he embodied the situation and responded to caring approaches.

During the participant observations care was neither interfered with, nor reported to nursing supervisors. The observation of care focused on how the staff differentiates care approaches between patients, and how care was individualized with regard to the person’s ways of being and how the atmosphere of the unit affected the caring practices. I found it especially illuminating to attend “midday reports” where the staff reported to the registered nurse in charge and discussed specific problems. I typed my observational notes as soon as possible after observational periods, and also delineated in my notes the decisional process while I was considering which families I should invite to participate. I also scanned as well a sample of written reports or notes with regard to a pattern of written documentation of family relationship; however, I found that these data would not be informative for my study.

Approach to Data Analysis

According to Benner (1994) “three narrative strategies provide the basis for entering practical worlds and understanding socially embedded knowledge: (a) paradigm cases, (b) thematic analysis, and (c) exemplars” (p. 112). Strong instances of concerns or ways of being in the world, doing a practice, or taking up a project indicate paradigm cases. “The practical world of one paradigm case creates a basis for comparison of similarities and differences with other paradigm cases”(Benner, 1994, p. 114). In a thematic analysis meaningful patterns, stances, or concerns are considered to clarify distinctions and similarities. Benner, Tanner and Chesla (1996) explain that:

> Thematic analysis is made possible by the accretion of understanding of the phenomena that occurs via the engagement of the interpreter with the text, and the working out of understanding that occurs via reading and writing about portions of that text. Thematic analysis is the attempt to articulate the broader understandings that arise from constant comparison and reading side by side of different paradigm cases and exemplars (p. 364).

Central to the interpretive task is the collection and aggregation of exemplars which may be extracted from the text to demonstrate the similarity or contrast. Meanings and intents become illuminated and disclosed as one exemplar is compared with another to give way to qualitative distinctions (Benner, 1994). Exemplars convey aspects of a paradigm case or thematic analysis as the researcher is developing her or his practical reasoning and understanding (Benner, 1994).

In analyzing my data I paired the family members' and staff's interviews into a set of data concerning the care of each of the involved residents. First I reviewed each set of data by listening to the tapes, and corrected errors in the transcribed text, furthermore I identified speakers in the group interviews. Along with repeated readings of the interviews, I started writing an account of the family member's experience of visiting, and translating excerpts from the text. The translation of excerpts from Icelandic to English proved to be cumbersome but it nevertheless enhanced my dialogue with the text. My translation was, however, later corrected and verified by a certified translator. Individual accounts unfolded in light of the family member's storyline as she or he described the experience of visiting and being involved in the nursing home world. And the staff's side of the story further illuminated the case, as the staff's response to a particular family's caregiving activities was examined. During this process I presented and discussed individual accounts with my mentor. I analyzed more than half of the data sets (8) as separate examples of family members' involvement in the nursing home world and the staff's response to that involvement, before beginning any real comparison between cases. However, recurrent patterns like "the way in which the visit is structured", issues like "coming to terms with institutionalization" and "learning to handle visiting" or concerns like "safeguarding the resident's wellbeing" had certainly emerged in the accumulating accounts. And paradigmatic narratives became evident. I attempted to study these paradigmatic narratives in line with Benner, Tanner and Chesla's (1996) delineation of the aim of such effort:

> In studying a paradigmatic narrative, the aim is to understand the situation within the practical lived world of the participant, with all of its constraints, realities, and possibilities. The aim is not to identify abstract structures within action or basic social processes that underlie the action. Rather than making a theoretical move away from the action-in-context described in the narrative, the interpreter tries to enter into a dialogue with the narrative, and to understand it through the concerns of the interpreter, but also to grasp the concerns and action of the narrator (p. 363).

As I have compared one paradigm case with other paradigm cases I have aimed "to understand the situation within the practical lived world of the participant, with all of its constraints, realities, and possibilities". And my concerns have been the concerns and actions of the family member caring for her or his loved one within the nursing home world and the way in which the staff responds to such particular caring. I realized as I continued my data analysis that it was necessary to clarify the context of the family and staff's relationship in more detail and a thorough examination of the observational notes was called for. The observational notes and exemplars, based not least on individual interviews with two unit managers, disclosed the context more fully and filled in the story of the relationship between the families and staff in nursing homes. A thematic story that attempts to give insight into the phenomena of inquiry, but "the insight into the essence of a phenomenon involves a process of reflectively appropriating, of clarifying, and of making explicit the structure of meaning of the lived experience" (Van Manen, 1990, p. 77).

Evaluating the Interpretive Account

Guignon (1983) addresses certain difficulties characteristic of textual interpretation. He discusses on the one hand, the problem of determining the closure for the interpretation since the interpretations may always uncover deeper levels of meaning and the question arises as to when the deepest or final interpretation has been reached. On the other hand, he maintains: "there is the problem of a *criterion* for the correctness or adequacy of our interpretation" (p.72). As Packer and Addison (1989) point out:

> ...a true interpretation is one that uncovers an answer to the concern motivating the inquiry. If an answer has been uncovered by an interpretive account we should find it plausible, it should fit other material that we are aware of, other people should find it convincing, and it should have the power to change practice. These are the four approaches to evaluation. But it will not necessarily be all of these at once. Nor may the account be any of these immediately. An interpretation that brings a solution to a practical concern may seem implausible and unconnected at first. Evaluation will never be straightforward and procedural; a choice among perspectives will be risky and sometimes incorrect (p. 289).

Riessman (1993) addresses validation of an interpretation in a similar vein as she discusses persuasiveness, correspondence, coherence and pragmatic use as the four ways of approaching validation in narrative work. She points out that:

> Validation, the process through which we make claims for the trustworthiness of our interpretation, is the critical issue. "Trustworthiness" not "truth" is a key semantic difference: The latter assumes an objective reality, whereas the former moves the process into the social world (p. 65).

Dreyfus (1994) suggests that Taylor says that one can't make an interpretation that is absolutely right in talking about human beings. "The best move you can make is to make as much sense as you can of all the elements and how they are interrelated - and then you say this is the best interpretation I have got - if you think this one is wrong you have to come up with a better one". Dreyfus claims that Heidegger would agree upon Taylor's delineation of the interpretive approach in itself. However, Heidegger's method of interpretation is intertwined with the phenomenological approach. The phenomenological approach lets things show themselves as they are in themselves; it brings what is hidden, but not necessarily hidden out of hiding; when it is there you just see it (Dreyfus, 1994).

According to Packer and Addison (1989) "a good interpretive account is one that advances the practical concerns with which we undertake an interpretive inquiry, and one that works well with the other activities we are engaged in" (p. 291). My practical concern is the circumstances of an elder living in a nursing home and the manner in which her or his well-being may be enhanced or diminished by nursing care approaches. The premises of this study were that increased understanding of the relationship between family and staff in nursing homes might disclose the significance of these relationships for the elder's well-being. And the study is designed and conducted in a manner which attempts to bring this disclosedness forth in a systematic and rigorous way, while staying receptive to and respectful of the participants' voices.

Chapter Four

THE WAY IN WHICH THE VISITING ACT IS INSTITUTIONALIZED

Introduction

The aim of this chapter is to describe the visiting families' experience of institutionalization and their comings and goings in the nursing home. The chapter is divided into two sections; in the first section the reality of coming to terms with institutionalization is discussed, and the meaning of this transition in the family. Then various factors are clarified that affect the degree to which the elder accepts this lot and the family's effort to facilitate her or his acceptance of it. A success story of such effort is told in a paradigm case about Kristín's story of acceptance of institutionalization. The first section is closed with concluding remark that leads into the second section which addresses the structure of family visiting. This structure reflects the visiting families manner of organizing their visits as they continue their involvement in the elder's life, while attempting to come to terms with institutionalization of their loved one. Finally, the staff stance towards family visiting and the impact of visits upon their work is briefly addressed.

For the residents participating in this study the need for extensive care did not come on abruptly preceding institutionalization, with the exception of two people. Rather there had been a gradual process of deterioration with accompanying dependency leading to a nursing home placement. A special standardized assessment tool is used to evaluate the state of dependency and social circumstances of elders applying for nursing home placement in Iceland. Elders' ratings according to this tool qualify them for nursing home placement and determine their position on the waiting list of the home to which they have applied. There is a waiting list in all nursing homes in the urban area of Reykjavík, the capital and its neighboring towns. However, some of them are more sought after and have longer waiting lists than others. The elders themselves, or their relatives, can express a preference for two or three homes, but they might be offered a placement in another one if there is a possible placement and there has been an extensive wait for the home or the homes of their choice.

In fact, all the relatives participating in my study were pleased with the placement lot of their own family member. Indeed, almost all of them were allotted a placement in a home of their first choice among other homes. Some of the elders themselves had definite ideas about what particular nursing home would be preferable, or their relatives would take a determined stance towards a preferable home. And other relatives had inspected a number of homes before making a choice. People would go by different indicators in considering which nursing homes would be most preferable. The location of a nursing home often counted as important, on the one hand with regard to the closeness to the relative's home or working place, as people were thinking about a convenient route for visiting. On the other hand a familiar neighborhood of the nursing home itself mattered to people, especially to the elders themselves. The building itself, its size and the interior design and its decor, certainly counted as important, and not least the atmosphere. The relatives who had been inspecting homes would refer to a certain home as "bright and inviting" or "warm and not too big". In some ways people sounded as if they had been seeking some indication of the quality of life in the relevant nursing home. However, the relatives would not really know which attributes of the nursing home would indicate quality of life within its wall other than some outward signs of the place.

Many would go by some word of mouth with regard to "good care" or the inhabitants' satisfaction with dwelling in a particular nursing home. True enough, some nursing homes have a better reputation than others or are talked about as preferable to others. Some of the participants in my study had turned down a placement offer in a home other than that of their choice and would rather wait for an opening in the preferred home, while others were relieved to accept a placement offer in "a good home" although it was not the one of their choice. Indeed, all of the relatives were relieved when an acceptable placement offer arose. Nevertheless, it often turned out to be hard to come to terms with institutionalization of their family member.

Coming to Terms with Institutionalization

A number of themes pertaining to the visiting family member's experience of coming to terms with institutionalization emerged, as the participants talked about their visits to the nursing home and their concern for their loved one's condition and wellbeing in these circumstances. Three themes in particular will be delineated in the following discussion: (a) The Transition to a Final Dwelling, (b) Justification of Institutionalization, and (c) The Elder's Acceptance of the Placement.

The Transition to a Final Dwelling

Implicit to elders move to a nursing home is a transition to the final dwelling of their lifetime. The entry into this dwelling is marked by "a one way ticket" as Jón's wife would say. Jón is a 77-year-old man who has lived in a nursing home for just a year at the time of my investigation. He has a history of diabetes and was admitted to a geriatric unit because of gangrene in his left foot, which was amputated later during his stay in the unit. However, he had been living at home for four years with considerable disability following repeated strokes before his admission to the geriatric unit where he stayed for ten months before the move to the nursing home. His wife took care of him during these years and those were " quite good years" as she says:

> I actually had him at home for over four years and then he was actually up and about and I could leave him, I went to the shop, I went to the hair salon, I was never gone for long, I never went in the evening. Those were quite good years, I thought. We were never bored, neither of us, and he could make use of the TV. However, you see his hands gave way almost immediately after the blow so he could not button up and not fasten a loop. And if he was trying to go to the bathroom when I was not at home, then everything was ... it worked out but it was not nicely done.

Jón's wife says that it was as if he had got wings when he was offered to move from the geriatric unit to the nursing home. The two of them, with one of Jón's two daughters, went to inspect the home "and he was not even tired though he was much more ill then. He was not at all used to sitting in the chair for so long. He just got wings, as I say".

So Jón was just very pleased to move out of the hospital and into the home. However, Jón's wife was not quite as happy. On one hand she had inspected and chosen two other nursing homes nearer to their home which were more accessible by a car and in particular by busses. And then when the placement offer turned up, it was a shock for Jón's wife to face the end of all their years living together and see her husband go into a place of no return as she says: "... if I had been asked and I had thought it out for myself then I knew that he would not come back home. But this was in a way the final point. He was just gone," and little later on in the interview Jón's wife speaks again of the finality of this move as she points out "then this label, people are discharged from hospitals but never from places like that".

Jón's wife emphasizes that this kind of an event is more significant than you think when you see it happen to others:

> .... although this is always a much bigger thing than you think, you see it happen among others, yes, someone gets sick and goes away. But when this happens to you yourself then it's really a big thing. This is an enormous transition. It is this - what should I say - one way ticket for people. I actually think that people do not understand this before it happens to themselves. But it makes a difference to have somewhere. Think about it, that it happens that there is nowhere available for these people according to what you hear. But to be contented with a place and have trust in it, that is invaluable.

Jón's wife is grateful for having a place, she has come to accept the place and has trust in it. Furthermore, Jón himself is favorably disposed to his new dwelling. All the same Jón's wife addresses the issue of no return and admits to the pain of such a thought. Now the two of them will live in separate worlds after having shared a world for decades. Jón has entered a new world, while his wife has to redefine their old one and find a way of bringing these two worlds together during her visits to the nursing home. Jón's wife regrets that they have reached some final point of living together, but at the same time she sees her husband's move to the nursing home as inevitable as his disability has increased to a degree beyond her capacity to care for him. The meaning of the situation draws upon this perspective and is in a sense verified by the extensive limits of Jón's functional ability, and the means by which he is assisted by two helpers and moved in and out of bed with special lifting equipment.

Justification of Institutionalization

In fact, all the relatives participating in my study would place major emphasis on how the disability of their respective family members had increased to a degree beyond their capacity to care for her or him at the time of institutionalization. However, the nature of the disability on one hand, and on the other hand the complexity of care required to compensate for the elder's helplessness, differs and determines in some ways the extent to which the family can justify the need for placement or interpret it as a reasonable decision. The demarcation between the type and magnitude of care that can be provided at home and conversely in the nursing home may be somewhat unclear, so it may be hard for the family to counteract the thought of having failed the elder or abandoned her or him in some way.

Anna's daughter has been facing her mother's ever-increasing helplessness in almost all aspects of daily activities for number of years due to mobility problems and dementia. In coming to terms with the placement Anna's daughter has been tackling the thought of her 68-year-old mother having moved, or rather being moved, into a place of no return which she finds degrading. Actually the thought is so overwhelming and painful that she tries to shield herself from it.

> Of course one wasn't happy that she needed to go in there, you see. One found it awful of course, but of course there was nothing else to do. Then one often felt really terrible, because maybe I had this feeling that this was also something that I felt she

> was blaming me for, you see ... No, then it is useless to be upset about it. You may actually be like that if you are somehow down, tired and just not right or something, you know, then you may make a big deal out of it, but so I try not to. I did it a bit in the beginning, you see. I have tried to take care, in a way, lately to do as little as possible of that.

The thought of institutionalization is overwhelming and painful for the daughter, as it pertains on one hand to her mother's deterioration and helplessness which shows itself in almost all aspects of daily living, and on the other hand to the very kind of help her mother needs to compensate for this helplessness. The assistance Anna needs to compensate for her helplessness might not appear particularly "complex" or beyond the usual domestic caregiving tasks, so it may be somewhat difficult to justify her being placed in an institution in order to receive this help, instead of having it provided in her own home. Anna's daughter has to debate the situation with herself to come to the conclusion that there is nowhere else her mother could be. However, Anna's daughter does not define in what sense this is "the best place" for her mother - it is possible that the very issue of addressing this aspect might in some way undermine her mother's dignity because she would have to speak of her inability to meet her basic needs and make public or explicit the way in which they are met with the staff's help.

Anna's daughter remarks upon how badly she has felt as she believes that her mother is in some ways blaming her for her lot of institutionalization, as if it is the daughter's fault. Indeed it is very hard on the family when the elder does not grasp her or his circumstances and has not quite settled in the nursing home or accepted a placement. As Anna's daughter points out "you sense that there is, of course, restlessness about her, and she is on her way home, you see".

The Elder's Acceptance of the Placement.

Dementia or other neurological impairment in the brain may certainly affect the elder's grasp of the situation and her or his ability to deal with it. However, the elder may to a degree understand her or his disability and be aware of the impediment against living at home. Nevertheless, they may simply desperately want to get out of the nursing home, like Soffía who just does not think she belongs in such a place.

Soffía is 74 years old and has been confined to a wheelchair since she suffered cerebral insult with left hemipareses. She has lived in a nursing home for fourteen months at the time of my investigation. Her illness experience, as well as the institutionalization, has been hard on her and she wants very much to get out of the place. Unfortunately, the family home in an old house with steep steps and narrow door openings is not particularly well suited for a wheelchair, and she also needs considerable help to get up and about every day. Her 77-year-old husband acknowledges that his wife has not accepted the situation at all and really wants to be back home.

> No, naturally she does not accept this at all. It is altogether-- She wants to come home. I said, well, I can't help her to go to bathroom and - or anything else. Even though you could re-fit just here on this floor. Then it is actually..., yes I think that the wheelchair would not make it - does not make it into this room which is here in... because the doors [are so narrow] it is like, yes the bathroom door, it is not possible to change it. I had thought about that - it is possible that she could make it through the other door (pointing towards a second door opening into the room).

Soffía's husband refers to the circumstances in the nursing home as monotonous and boring as there is hardly anybody around to talk to. "She is very bored. Sure you can say that. There is no doubt about that".

However, he does not seem to see his wife living with him at home. He refers to their impractical house on one hand, but it is implicit, on the other hand, that he can't imagine the extensive way in which his wife is being helped in the unit as being manageable at home. He can see that she needs considerable help, as there are generally two helpers who come along to assist his wife to go the bathroom while he is visiting, or to help her to go to bed when he leaves in the evening, after his second visit to the home during the day. Soffía's husband holds on to some hope that his wife might become more self-sufficient, if her condition improved. But for the time being he has to deal with Soffía's discontentment with institutionalization and her unhappiness with her lot.

There are many aspects of Soffía's situation that contribute to the couple's difficulties in coming to terms with institutionalization. They are both relatively young, only in their seventies, and her disability came on abruptly following a stroke. There has been a sudden closure to their sharing of everyday activities and leisure time spent in various sport and travelling projects. From the husband's point of view Soffía's disability, and the extensive help she needs to compensate for her helplessness, justifies to a degree her institutionalization. But Soffía has limited insight into her own dependency, which undermines the husband's justification and makes the experience of institutionalization hard for both of them. Young age and abrupt closure of shared involvement in everyday activities with her husband and other family members certainly make it more difficult for Soffía to accept a permanent placement in a nursing home. It was actually a common view among both relatives and staff that the younger age group, that is people in their seventies, did not really belong in such a place. One of the relatives, a daughter of an 85-year-old severely demented woman declared:

> ... you see I speak for myself, I would not want have this kind of fate, to need to get into a unit like this, unless I were like my mom. I find this a terrible fate. For example, there is a young woman, just little more than seventy, confined to a wheelchair. The quality of life is so little there. You hang on to the prospect that your relatives will come for a visit and there are the meals and there is what they read for you in the morning. I do not see that the people there are all that active. They are just somehow waiting. That is the way I see things. I find this a good place for my mom, but I do not think this is a good place for many others. But there is nowhere better.

Soffía is the "young woman" to whom the visiting daughter is referring and, true enough, the young patients in their seventies stand apart in the nursing home units, where the average age is in the range of 83-86 years. Nevertheless, the resident's understanding of the extent of help she or he needs to sustain bodily needs and everyday activities, rather than the age in and of itself, appeared to determine her or his acceptance of or discontentment with institutionalization. And the transition to nursing home living is easier on all concerned if the elder herself or himself is able to justify her or his destiny in light of the necessary help supplied in these circumstances. Conversely, it can be a severe strain on the resident and the relatives if the elder has only limited understanding of the extent to which she or he needs help in sustaining herself or himself. The transition to nursing home living was not easy for 94-year-old Kristín and her family, but her story exemplifies how family members can, with thoughtfulness and a lot of work, facilitate the elder's adjustment to this transition while simultaneously they themselves come to terms with institutionalization with a positive outlook.

Paradigm Case: Kristín's Story of Acceptance of Institutionalization

> I actually admit that we have tried in a way to do this in such a way that she will be as content as possible and will accept this as much as possible, because this is of course very difficult for many, to have to admit that they can't live at home any more. (Kristín's daughter)

Kristín is a very attractive 94-year-old woman with warm, cheery, brown eyes; her white hair is cut short and nicely set and her whole composure bears with it a sort of kindness, and there is a brightness about her. Kristín sits in a wheelchair when she is up; she is of average height, a little on the heavy side and always very nicely dressed and groomed, indeed she goes to the hair salon once a week. Kristín responds warmly to greetings and talk. She may ask you repeatedly about something or tell you something repeatedly, but she does so graciously.

Kristín has stayed in the nursing home for almost two years at the time of my investigation. She moved to the home after a three-month stay in a geriatric hospital to which she had been transferred for a placement evaluation from an acute care hospital. She was admitted to the acute care hospital after she broke her leg, and stayed there for almost four months, waiting for a move to the geriatric hospital, as she was not regarded as capable of resuming her former household tasks because of problems of mobility and symptoms of dementia. The accident happened in her home in service housing for the elderly, where she had lived for a number of years.

Kristín has three daughters, and she and her daughters seem to be very close. It is possible that the loss of husband and father in an accident when the girls were quite young has led them to bond very closely. In every way it is obvious that Kristín's daughters are very concerned about their mother's wellbeing. One of Kristín's daughters lives abroad, but the other two rotate their respective visits according to a fixed schedule throughout the week to ensure that the mother has a visit every day. The daughter who is my storyteller, actually a RN, points out that this visiting arrangement came about while they were helping their mother when she lived at home. The daughter abroad visits her mother every year and regularly talks with her on the telephone. She often buys clothes for her mother and sends them to her, as Kristín likes her choice of clothes. There is indeed something of a task division among the daughters, as the RN daughter takes more responsibility for the health-related matters on her mother's behalf and is her advocate within the nursing home, while her sister takes care of her mother's finances and buys supplies of snacks to keep in stock.

Kristín was not keen on the idea of moving to a nursing home at the time of the move. My storyteller had brought up the subject of nursing home living before her mother broke her leg, as it was becoming increasingly difficult for Kristín to look after herself. But she refused to consider it, even though her daughter pointed to Kristín's sister who has lived quite happily in a nursing home for some years, suggesting to her mother the possibility of applying to the same nursing home. This suggestion came about as Kristín's two daughters spent more and more time daily in assisting their mother with her personal care and household tasks. However, considerable services were available in the service housing, but Kristín did not think she needed them as she had her daughters' help. Actually the daughter maintains that:

> There would indeed have been a need for [nursing home placement], but we were trying to postpone it as long as possible because she did not want to go into a home. She always said stop. ... Well, when she went to the geriatric unit, then it was supposed to be temporary, but then just ... She did not protest, but she felt all the same that she could go home. She did not grasp that she could not take care of herself and really she thought so for quite a long time. It is just recently that she stopped talking as if she did everything for herself. She is not quite oriented in that regard.

As Kristín moved into a two-bed room in the nursing home, she did not want a single item of her personal belongings to be brought in, not even her cherished old chest of drawers. Kristín has usually got on well with other people but she could hardly associate with her confused roommate and often slept badly at night due to some disturbance when her roommate was up and about during the night. So her daughter asked if her mother could be moved to a private room if one became available. And things changed considerably towards the end of Kristín's first year in the nursing room as she moved into "her own room". Kristín was quite pleased with this move and thought it was fine when her daughters suggested that they would bring in few of her things to make the room more comfortable. The daughters have managed to make the room very nice and personal in a way in which glimpses of Kristín's person and her story are brought forward: As you walk into the room there is a small old table with a thick green velvet tablecloth standing by the wall sideways to the bed; placed on the table is a photograph of her husband when young and her youngest daughter at her christening. Above the table is a small decorative mirror and two dainty antique chairs standing on each side of the table. Along the wall opposite the bed are two easy chairs and a small table between them. There are many photographs on the window sill and on the walls. On the window sill there is also a box with some food supplies and candies and there are also candies in a glass bowl on the table. So the room certainly makes the impression of a home, but it has taken quite a time for Kristín to feel at home as her daughter describes:

> It is not all that long since she started to feel she lived there. It is not all that long ago. ... Yes, she has begun to say: "It is very good to be here". She has begun to say so. I found this actually changing when she got her private room.

Actually, Kristín intended to leave the nursing home, if only somebody could help her to find an apartment. Apparently the regret at having been institutionalized, and the feeling of having no home anymore, was always present, so Kristín was trying to seek some means to find a way out and have a home of her own again. As her daughter says:

> She never meant to go into an institution like this. She was very unhappy about going. As I was telling you, when people were visiting her, until quite recently she would ask people to find her an apartment. She was going to go home. But now she has accepted it. She said to us not long ago: "I find it so good to be here that I am really thinking of not getting an apartment for myself". I was so pleased to hear this, and although she has not been very sad, then all the same this was always there. We were actually saying that this was such a good room, whether she did not think so. "Yes this is just fine" she says. But all the same she is still talking about not being able to make coffee. Then I go out and get some coffee - you are always welcome to have a cup of coffee in the hall, there is always coffee in the thermos. Then everything is just fine.

Indeed, the daughters have made a great effort to help their mother to settle in the nursing home and facilitate her acceptance of this lot. It has been difficult, as Kristín's judgement of her own capability is rather distorted because of her dementia. But, all the same, the daughters' strategy has been aimed at reestablishing her practices of relating to people. Actually, Kristín has always tended to relate to people by offering them something to eat or drink when they have come to visit her, so of course she finds it difficult not to be able to make them some coffee. But, as her daughter says "everything is fine" if she just goes and fetches some coffee for them. And the other daughter shops for her mother and ensures that she has in stock some soft drinks and biscuits, as well as candies in her room. As her daughter points out:

> Mother was always a hostess when she was in her home, always offering something. ... When you visited her, then she always started by offering: "What would you like to have? Shall we have a cup of coffee together? She really enjoyed having a time to drink coffee with somebody.

"Her own room" sustains Kristín's practices of relating to people; now she can receive people visiting in her usual fashion. She has the authority to invite her guests to make themselves comfortable and she has her supplies to treat them as she used to do. Kristín used to be very good at keeping in touch with people she knew and when she stopped going out much she simply turned to the telephone and talked to people on the phone. So her daughter came to think that her mother could probably still enjoy keeping in touch with people through the telephone. Some people in the daughter's family thought this idea was altogether out of the question, but she decided to give it a try. And Kristín really enjoys having her own telephone. Indeed, the daughter wanted to reestablish her mother's practice of reaching out to people through the telephone as she says:

> With regard to the telephone I talked to Jóna [the unit manager] and actually asked more people in the unit what they thought about it, because some people back home thought that this was just some nonsense of mine to be thinking about letting her have a telephone. But I did not think so. I really wanted her to be able to, because she used the phone so much before she came here and it would be nice if she could carry this on somehow like it used to be. They thought it was a good idea, the girls I talked to there. She does not phone herself, she does not have the initiative to phone.

> But when we visit her, then we help her to phone and then she phones her granddaughter who lives up north. She has another granddaughter who lives out in the country. She really enjoys phoning them and they enjoy talking to her. They are not able to visit her that often. Then she might even phone her daughter who lives abroad so she does not have to spend her money phoning all the time. Mom can easily afford to phone. It is also good that she can then use her money in doing something for herself.

Kristín can actually answer the phone and she gets quite a few calls "when we know she is in bed before she gets up in the morning and after she gets into bed in the evening" as the phone is "ready to hand" where it is placed on the bedside table. The daughter actually points out that her mother's helpers always make sure that the phone is in a position where she can reach it:.

> When I brought it, then I put it on the bedside table and I think that they make sure to place it so that she can reach it when she is bed. [Although] I have not mentioned it.

And Kristín's daughter abroad feels that it makes a great difference that she can now phone her mother directly instead of going through the nursing station.

It becomes apparent as the daughter tells the story that Kristín's sense of self is to a large extent grounded in her relationship with her family and friends. And the daughters certainly sustain their mother's sense of self as she is indeed an important person within their families. She participates in all celebrations in the families and quite often goes for visits to her daughters' homes and can definitely count on being visited. And Kristín will certainly be all dressed up for these encounters; she has always enjoyed dressing nicely and still does and she has a good selection of quite "modern" clothes. She has always liked her clothes to be "modern" and that is the way her daughters will keep it.

As stated above, two of Kristín's daughters rotate their visits to their mother every other day and every other weekend, or someone in each respective family may go "on their behalf". One of them visits Tuesday and Thursday and the other one Monday and

Friday each week, then the one who is not responsible for the upcoming weekend visits Wednesdays. As the daughter says:

> We do actually not keep it quite so rigid. But we keep it organized. We find it very good. ... Yes. Then we are not always thinking: "Well, now I have to go". We just keep these days and go if we are able to. We always know that the other takes care of the following day. ... But if we need to swop, or my sister knows of somebody who is going to visit mom that day, then she lets me know. Two of her children live out in the country and if they are in the city and are going to go to her on my day, then she lets me know. I let her know just the same if I know about somebody who is going during her day.

Kristín in fact has quite a number of visitors. Her daughter says that she has always cultivated her relationships with her grandchildren, so they like to visit their grandmother and their mothers also remind them. Then Kristín still has quite a few "younger" friends who stay faithful to her and visit regularly. Kristín likes to take her visitors to her room where she can treat them and act as a hostess. The daughter thinks that they can "have a nice time together" when she visits and actually finds the visits in the nursing home quite enjoyable, compared to the time when she had to do some chores while visiting, towards the last days of her mother's stay in her home. As she says:

> Back then one unfortunately did not have enough time to sit with her and talk to her. One did it, of course, perhaps while one was doing odd tasks, but there we have a nice time together when we come. I don't always stay equally long. I feel like I can visit her anytime, I have never been told that there was any fixed visiting time. I think there are open visiting hours.

So the daughters come whenever it is convenient for them during the day, and quite often the daughters, as well as other visitors, have a nice time singing. Kristín likes to sing with her guests and the family has brought her texts of "good old" songs in large print. And Kristín keeps a visitor's book in which people write their names and often also a little account of their visit. And she thoroughly enjoys looking at her book, as it helps her to remember and talk about her visits. Kristín's daughter actually thinks that her mother's life has become more pleasant since her move into the nursing home because she is not "so much alone"

> I think of course that this is really comfortable for her there, and much more pleasant than when she was alone at home. ... We certainly felt it the two of us, my sister and I, when we came to mom, that she was so much alone. "Oh how nice of you to come" she would say and she was sorry when we left. Actually it was harder when we were leaving her when she was at home towards her last days there. "Do you need to be going". I think that I hear this rarely when I leave her now. I assume that it is just because she is feeling better, she is not alone. Although she would not admit to it and did not want to go.

The daughter does not think that she or her sisters do have much to do with the staff. But it made a great difference for her to get a very positive response from the staff when she brought up the issue of a private room for her mother, as she says:

> They were very receptive to the matter of her getting another room. I was hesitant at first, because you do not want to be..., everybody wants to be in a private room. It is easy for mom to be among other people, so she does not necessarily need to be in a private room in that sense, but it was just because it did not go together, the two of them who were together there. But then they were very receptive and said they would consider it if a room became available.

Actually, a feeling of trust was established between the family and the staff on Kristín's very first day in the unit. And the daughter recalls, in both of my interviews with her, how much she appreciated the way in which the staff responded to her mother's reaction to being moved to the home:

> I remember actually when mom first went there from the geriatric unit and we both went with her, my sister and I. We stayed with her for quite a long while to arrange

> her things and help her to settle. Then we went, after having been there for most of the day, and we had just come back to my sister's home, we went there together afterwards, then there was a phone call to say that mom was so sad. She did not realize that she was supposed to stay there. I found it very good that they phoned us immediately to let us know. I went down there at once and stayed with her and talked to her and then she came round. Then she did not understand that she was supposed to stay. I found this very good.

It was very important for the daughters to realize on their mother's first day in the unit that the staff paid particular attention to their mother and showed sensitivity to her feelings. They appreciated that the staff understood that Kristín was lost in these strange surroundings and needed her family around to make sense of the situation. And they thought that the staff responded appropriately in light of their understanding of their mother's experience of moving, by contacting them immediately. And this feeling of trust has prevailed between the family and the staff. The daughter who is a RN has not had any say in her mother's care, as she says:

> I have not done so. I felt they do well and I have been pleased with it, I think she looks good. She is content and I have not thought that I have had any reason to, you see. Except that, perhaps I should have done it with regard to walking, but that was the way it was, I don't really know why I didn't do it.

The daughter is having some kind of afterthought in our interview that she might have taken up the issues of physiotherapy or walking exercises with the staff, and she says she does not really know why she did not do so. It is possible that the nursing home placement of her mother meant in a way to the daughter that the time had come to relinquish her care into others' hands, as she actually says later: "I just put this altogether into their hands. I just see that she is feeling good and she is well taken care of". However, the daughter certainly observes her mother's condition and the manner in which the staff relates to her mother and her mother's response. And the daughter refers to her mother's words. "She says 'they are actually nice to me'. She thinks so. I know that they are". The daughter knows and she can see how the relationship between her mother and the staff has become closer as the staff gets to know her mother better, as the daughter maintains:

> I think they are all very kind towards her and they are fond of her. This I think is changing more as they get to know her. They have always been very kind to her. But the longer you are there with the people then the relationship becomes closer.

The daughter really does not find it necessary to interfere with the way in which the staff takes care of her mother. She and her sister have themselves placed more emphasis on helping their mother to settle in the home by sustaining her practices of relating to people. It is indeed highlighted in Kristín's story how the family's concern and sustenance has helped her to accept this final dwelling during her lifetime. But Kristín's story also shows how the staff in this unit facilitated her settling by being sensitive to her response to this new dwelling and receptive to the family's concerns about the mother's wellbeing. And it is important for the daughter that the staff has learnt to know her mother and is fond of her. Nevertheless it took a long time to help Kristín to feel "as if it was her home" and the family has put in much work and genuine effort to make this happen with the staff's collaboration.

Concluding Remarks

Similar patterns of devoted effort to ease the elder's transition to a final dwelling emerged in all the families participating in the study. The family members deal with the transition by the means of continuing their involvement in the elder's life in the nursing home, while attempting to bring their own world and that of the family to the nursing home. However, the family's continuing involvement and concerns did not always suffice to reconcile the elder with the destiny of nursing home living. It certainly was more difficult for younger patients like 68-year-old Anna and other patients in their early seventies, and their families, to accept a placement in a nursing home. Older residents like Kristín and their families had quite a different background, as it makes a difference when the older resident and her or his family have had the opportunity to have some "good years together" before institutionalization, as Jón's wife pointed out. Furthermore it may make a difference if the family members have become reconciled with what they have done or could do to support the elder before the institutionalization. Actually, one of the unit managers proposed that family members who know that "they could not do anymore or try any longer" to keep the elder at home may find it easier to come to terms with institutionalization. But all but two of the participants in this study had certainly done as much as they could do, and tried longer than could really be expected, like Kristín's daughters, to help their family member to stay at home as long as possible. However, Soffía's husband, and a daughter of a male resident of Soffía's age, never had the opportunity to offer them the option of living at home. On one hand both Soffía and the other resident had suffered strokes resulting in extensive physical impairments, and on the other hand Soffía's husband was not in good health himself, and the circumstances of the other resident's family did not really allow for such an option. But Soffía and the other resident were the two residents in this study who had the hardest time in accepting institutionalization for good, and this position put a considerably strain on their nearest and dearest.

Jón's wife "knew that he would not come back home" while he was in a hospital, and she had inspected nursing homes before the family applied for one, but the nursing home placement was nevertheless hard to go through for her, as she said: "But this was in a way the final point. He was just gone". Jón's wife spoke explicitly of the nursing home placement as Jón's final dwelling and so did the family members of the very old residents, but others did it implicitly and with regret, like the family members of the younger residents. And few, like Soffía's husband, would contemplate whether her condition would improve so she could return home. Nevertheless, it was a big thing for all the family members to face this transition and part with their loved one as she or he entered a different world of living. And Marta's husband found it almost unbelievable that this was the way their fifty years of marriage had come to an end, when he said as he looked around in the sitting room in their home "she is probably not going to be able to return back home". Marta, with her advanced dementia and very limited mobility after a fracture of her leg, was hardly going to come back home after staying two years in the nursing home. And her husband knew this in a way, but he was still, all the same, trying to get used to the thought that his wife's entry into the nursing home had been destined by "a one way ticket".

But Marta's husband, like the other family members participating in the study, attempts to come to terms with institutionalization by continuing involvement in her life, and concern for her wellbeing in the nursing home. Each family develops its own pattern of visiting and caregiving in the nursing home, but a similar structure became evident in the manner in which the participants organized their visits to their loved one. And this structure will be discussed in the following section.

The Structure of Family Visiting[1]

The family members' visits to a nursing home may appear easy enough to see, but there are implications to these comings and goings of the visitors that are not entirely obvious at first sight. The visiting family member structures her or his visit in a particular way as she or he settles for the visit with the elder in their "usual spot" to go about the regular agenda of the often rather extended visit. The agenda helps the visiting family member to find her or his footing within the respective unit and is the matrix for her or his relationship with the elder. And it is not least important for the visiting family member to structure the leave-taking in some kind of ritualistic manner, to counteract the feeling of having abandoned her or his relative.

The following discussion will further delineate how the organization and structure of

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[1] An earlier version of this section was presented at the conference Omvårdnad Nu 6e komferensen The State of the Art in Nursing, September 24-25 1998 in Stockholm, Sweden and published in the proceedings of the conference under the same title in Omvårdnad 8 published by Svensk sjuksköterskeförening (The Swedish Society of Nursing) and Spri 1999.

family visiting is disclosed and will attempt to bring into focus these four themes: (a) The Way in which the Visit is Set, (b) The Visiting Act, (c) The Agenda of the Visit and (d) The Meaning of Family Visiting.

The Way in which the Visit is Set

The 15 family members in three nursing homes participating in this study were asked to do so because of their regular visiting. All six spouses would visit daily, except one wife who visited five days a week. One daughter, her mother's only child, would visit daily, while the other seven daughters and the one son would visit at least three times during the week. The visiting hours of most of the participants were quite fixed and they would visit during the same hours every day or the same days every week. It was noteworthy that few families had worked out a rotation of visits during the week so as to ensure a daily visit to their relative. Kristín's two daughters exemplify a way of rotating visits according to a fixed schedule throughout the week to ensure that the mother has a visit every day. All of the participants had incorporated their visits into their everyday activities. However, there was a distinctive difference between the spouses and the daughters and the son. The spouses' everyday activities would be carried out around their visits to the nursing home - for them the nursing home visit was the major agenda of the day - but the children would plan their visits in order to fit into their daily schedule of household duties, work, leisure and other things. Nevertheless visiting was a definite routine for all of the participants.

Two husbands had actually visited their wives daily in a hospital before the placement and simply carried on with the same visiting hours to which they had grown accustomed during the hospitalization. Other visiting family members would figure out the relative's schedule or routine in the home and work out the best time to visit according to this schedule, also taking into account how the visiting hours fitted into their everyday activities. One of the visiting wives was still working full time at the time of her husband's placement, and made a habit of visiting her husband after work every day.

She maintains that she will simply carry on with the same visiting hours now on her retirement a year after her husband moved into the nursing home. She has found it good to come about an hour before supper and assist her husband with his meal, and she may occasionally bring in a meal she has made herself. Then she will leave as her husband has settled in front of the TV in his room to watch the evening news.

The Visiting Act

Some common features of the structure of family visiting in nursing homes are highlighted in Katrín's son's approach to his visiting. He reflected on his ritual of visiting his mother on his days off from his shift work when he said: "I suppose that one would feel strange or awkward, finding something lacking in the chain of life on your day off when you do not need to come by here anymore".

Katrín's son used to drop in at his parents' house on his days off while Katrín and her husband lived together in their home. Katrín was hospitalized at the time when her husband died and was not able to return to her old home. So the son, who is Katrín's only child, points out "this has just continued". For him it is a part of "the chain of life" to see his mother through during this last passage of her life.

The son usually comes by late in the morning, as Katrín does not get up before eleven o'clock; he finds it convenient to visit in the morning so "the day is not going to be interrupted". He does not stay long, and finds it good to leave as his mother is getting ready to go for her lunch into the dining room. This timing allows him not only to go "smoothly" through the rest of the day, but also makes it easier for him to come and go without feeling bad about his rather brief visit. However, he will visit with his wife in the afternoon during his weekends off, and then they may stay for a little longer. Katrín's son finds it increasinly difficult to keep up conversation with his mother, as her horizon is shrinking and she might not quite remember who of her life companions are gone and who are still around. But he will certainly come and his mother takes his visits for granted, as he says:

> She wants you to come. That is actually just something old. She just thinks that you should come, she says sometimes "what a long time it is since I have seen you". Even if it was yesterday or the day before yesterday. Of course it affects all these old people, it must be, even though you have become disoriented, that their closest ones visit. Actually, I come, I do not stay long but she accepts it altogether, she accepts it because it is, of course, getting more difficult to talk, there is nothing to talk about and she always asks the same questions "have you not heard from so-and-so". Then you know, you see, that in her mind it is like this one is still here, this person is still here and the other one is still here and something like that, but they are not with us anymore. Then it is always the answer: "No I have actually not heard anything at all". So that the conversation always revolves about the same thing. But she accepts it altogether that you just drop by. [She has] altogether stopped saying "are you going" or "you have only stayed for such a short while". She used to do that sometimes. [Talking of] what kind of hurry you were in. Now she is just happy to see me. Yes, yes I think also that she perhaps does not realize how long I have been staying. And just accepts it. That is the way it is.

And he adds:

> ... it is, of course, more difficult to [get the conversation going], there are only a few things you can bring up, which you can be sure that she will grasp. The best thing is to tell her something about the children - ... something like that. Other than that she does not follow...

So the visits during the week are not long, as it becomes increasingly difficult for Katrín's son to relate to his mother through conversation. And the son finds it better to leave when his mother is getting ready for lunch. She is occupied by her daily schedule so her son's leave-taking is just sequential to the matters at hand and the shortness of his stay becomes less noticeable.

Marta's husband, in contrast to Katrín's son, does not attempt to keep the conversation going, but shares his presence in and of itself with his wife. He usually arrives just after two o'clock when she has just been helped out of bed and made comfortable in her wheelchair. Actually, the staff always makes sure that Marta is up by the time her husband will be there. They usually sit in the dining room as the afternoon coffee is served and Marta's husband helps her with the refreshment and has some coffee and a cake himself. The couple then moves over to the sitting area after the coffee hour and the husband places the wheelchair at the end of a semicircle of chairs and takes a seat next to his wife. The semicircle of chairs frames the sitting area in front of the TV. There are often quite a few inhabitants around, and opposite Marta and her husband there would be another couple sitting. Both of the husbands would just sit there holding their wife's hand, and occasionally Marta's husband pats her cheek. Neither Marta nor the other woman show much response and Marta hardly speaks at all. As Marta's husband says:

> She welcomes me when I come and even though we can't talk together, however, she does answer often in a rather clever way, just like a well person, but we can't talk together because if she is going to say something she just begins and then it falls apart - so I just sit by her and hold her hand and so on - whether she has maybe ... I don't have any sense that she misses me particularly if I don't come one day.

However, there is a tangible sharing between Marta and her husband as they sit there together and there is a togetherness among the small group of people sitting, although there may not be all that much talk, but occasional comment. Marta's husband, as well as the other husband, bring the group together in some way as they address each other as well as other people around. Sometime the TV might be turned on and there might be a small talk about the program, especially if there is a soccer game on. The late shift comes along just after four o'clock with a trolley offering everyone a glass of water or juice. Marta's husband gives her a glass of juice and may have one himself, then shortly after, about half past four, he kisses her goodbye and takes his leave. Marta's husband emphasizes that he "owes her this time" after more than fifty years of marriage and that she certainly "deserves" his solicitude.

And Marta certainly brightens up when her husband arrives and in a way there is a glow about her while he sits by her side. Indeed her husband maintains that the visiting family members are the light of their relatives' life in the nursing home and he himself finds that this time with his wife constitutes "the bright spots" of his life. It is noticeable when Marta's husband talks about his visits, how important it is for him to assist his wife with the drinks, first the coffee and later the juice. It has by now become a ritual to open his visit, in a sense, and establish closeness by helping his wife with the coffee and then to prepare for his leave-taking and close his visit by giving her the juice. By the same time it is a symbolic gesture of the way in which he looks upon mutual sustenance as part of their longstanding togetherness, "we have been together all these years" he says and adds a little later:

> ... and there I assist - I know that they assist her with drinking and things like that if I am not here, but I think as I am saying that she just deserves this.

The Agenda of the Visit

The presence of every visitor had its more or less obvious hallmarks such as where they prefer to spend their time and how they would share their time while visiting, to bring about togetherness. Some would go into the resident's room or would find a quiet corner in the communal area or the sitting area of the unit, but each and every one would find their spot which would remain the same from one day to another. The visiting family member structures her or his visit in a particular way as she or he settles for the visit with the elder in their "usual spot" to go about the regular agenda of the often rather extended visit. The agenda helps the visiting family member to find her or his footing within the respective unit and is the matrix for her or his relationship with the elder. The agenda is characterized by the way in which the visitor shares his presence with the elder to bring about togetherness often without much talk. It is certainly not easy to keep the conversation going when you visit in nursing home, as Katrín's son pointed out. On the one hand there might not be much to talk about, as the respective worlds of the visitor and the resident have to some extent grown apart and on the other hand there might be a greater or lesser breakdown in conversation because of the elder's debility or handicap.

Actually, all the participants had redefined their pattern of relating to their relative living in the nursing home; some of them would just share their presence in and of itself as Marta's husband does. Others would share their presence with some kind of activity by means of which they got in touch with and would fill in the presence with some kind of diversion, like Kristín's family that would often share a while during their visits just singing along with the ninety-four year old mother and grandmother. Her family had, as described above, made a booklet with old song texts printed with rather large letters for this purpose. Some had brought playing cards along and would play cards or assist the elder in playing patience or a solitaire card game. Anna's daughter and her sisters play patience or solitaire card games with Anna by means of which all of them relate to the mother or the sister. At the same time they find it stimulating for Anna to tackle the game. But Anna's daughter is often also quite busy attending to her mother's appearance during her visits, her hair and her nails, checking her laundry and making sure that there is nothing lacking which might undermine her mother's grooming and dressing and the way she looks and appears to others. The daughter places a lot of emphasis on this aspect of caring for her mother, both because it has always been important for her mother's sense of self and still is, and also her mother appreciates this kind of attendance and enjoys it. This kind of attendance brings about a special kind of matrix to the relationship with the loved one in a way which gives meaning to the situation. It was common among the participants to pay a lot of attention to their relatives' appearance and some would attend to the grooming and dressing of the elder while visiting. However, the extent to which the family members would attend to direct bodily care was limited. In fact there was only one participant, Magnús' wife, who shared her presence by active caregiving as she participated directly in her husband's care during her visits. The wife looks upon bodily care as very important for Magnús' wellbeing and she also thinks that she gets best in touch with him by touching him while feeding him and giving him bodily care. The manner of Magnús' wife of getting in touch with her husband by touching him through bodily care is her way of dealing with the difference in the way in which she can relate to him now. In one way this difference bears upon his diminishing response to conversation, and also the context of their relationship has changed along his institutionalization.

Female visiting family members who brought some knitting along often appeared to have some advantage of passing time while they were sharing their presence. Actually, one wife just kept her "special set of knitting" in her husband's room instead of carrying it back and forth. Others would bring the daily newspaper along to read aloud for their relative, or they would listen to some special program on the radio or watch a program on the TV. Still others would regularly go for a walk outside with their relative or just along the corridor and indeed all of the residents confined to a wheelchair were very appreciative of being taken on a short "trip". The residents confined to a wheelchair seemed to find it soothing to be wheeled about and in some way it may be seen as a temporary relief from a static situation which by its very lack of motion is hard to bear.

Wheelchair excursions were for example very important for Soffía. Soffía's husband visits her twice every day, first in the afternoon for at least an hour and then in the evening for one and a half hours. Soffía and her husband have developed a special manner of being together during the visits. They are almost continuously on the move, particularly in the afternoon, as the husband wheels his wife around in her wheelchair back and forth down the corridors in the unit and about the building. The husband says that Soffía finds it soothing to be wheeled in her chair, and the main agenda for the husband during his visit in the afternoon is to get his wife "moving". However, they often have a quiet time together in the evening sitting in Soffía's room watching the evening news. Soffía's husband has found out that timing of his leavetaking in the evening makes all the difference, so he does not leave until Soffía is getting ready to go bed, sitting by the washbasin about to brush her teeth and he says:

> ... then it is all right for me to leave. It was more difficult when I left while she was having ... the water or the coffee [the refreshment before bedtime]. It is like half past eight or something instead of fifteen to twenty minutes past eight. That was all the difference, and she is feeling somehow a whole lot differently when I stay until she goes into her room. It is maybe 10 minutes' difference, if that".

It is not least important for the visiting family member to structure the leave-taking in a ritualistic manner to counteract the feeling of having abandoned their relative. The family members may easily be struck by their loved one's vulnerability in these rather foreign surroundings among people who are more or less strangers, looking back, as they go. Somehow, it appeared to be easier to leave your loved one behind occupied or engaged in some activity or resting in bed rather than empty-handed on his or her own. Any kind of activity, even just having a nap or going to sleep, is in some way purposeful, and gives the impression that the person has a say in her or his destiny along the passage of nursing home life or is in some way settled in this dwelling.

Magnús' wife, for example, visits late in the afternoon and gets him ready for bed after supper. However, she does not like to leave until her husband is comfortably settled in bed and "resting" rather than "left behind" or "left alone" as the wife sees it, so she will just stay a little longer if there is no staff available to give Magnús a hand, as she says:

> If I miss them for supper you see, then I just wait until they have finished their break, then it is perhaps seven thirty ... Then I just sit by him or take him out to see the TV or something in the meanwhile. ... I never leave before he is in bed.

> Of course this pays off somewhere, I think, to nurture your people so well and care for them so well. It must pay off somewhere, even though they are not jubilant and waving [when you come], this is just a kind of energy which will show up somewhere, I am just altogether convinced in that regard, though you do this naturally perhaps first and foremost for yourself. I'm just drawn to it, I have to know how he is and things like that. And with regard to for example when people are talking about that ... well, I do not know whether my dad even knows me, I can not see it. I do not understand this stance. It just has nothing to do with this person whether he recognizes him [the visitor] or not. Yes that is the way I see it that [the visitor] first and foremost does not know it. Though there's not much response, then [the visitor] does not know, and then naturally he himself, the visitor himself, it is for he himself [the visits] you could imagine. This person is so close to you.
>
> (Jón's wife)

The visiting families organize and structure their comings and goings in the nursing home in a manner which constitutes the ground of being with the elder while visiting, and gives meaning to their time together. A number of the family members would articulate the meaning of their visits in an explicit way, like Marta's husband, who emphasized that he owed his wife this time. However, it was actually rather more often implicit in the participants' account that the elder deserved their concerns. The elder had earned this deserving status for being solicitous to the family and concerned about its members' wellbeing, but first and foremost for being the person she or he was. However this stance was not a matter of "paying back" the time and devotion that the elder had dedicated to the family through the years. Rather, the visiting family member had taken over or adopted this manner of solicitous comportment in the family. And it is a matter of this solicitous comportment to find ways to counteract any ill effects of institutionalization and possible feelings of abandonment on the elder's behalf. It was common among the participants to refer to the special situation of nursing home living and their way of structuring the visits was precisely their means of making the situation more bearable.

But, aside from a deserving status, the family member's solicitous comportment appeared for the most to be brought forth by long-standing relations with the elder situated in a world of shared meanings and concerns. The visiting family member's role as a wife or a husband, a daughter or a son, and her or his self-interpretation, is situated in these longstanding relations and is reflected in the words of Jón's wife, "I'm just drawn to it" when she speaks of her visiting. She is indeed drawn by her relations with her husband which sustain her way of being in the world. And it is important for Jón's wife as well as for him, to have their time together to affirm these relations in each other's presence. Thus, people visit for themselves as much as for their relative. It was indeed a recurrent remark in the participants' account to point out that "I have to see her" or "I have to see him".

And they would do so whatever the pain felt in facing the deterioration of their loved one, like Sigrún's husband. Sigrún and her husband had lived in service housing adjoining the nursing home for few years, when she moved to the nursing home following her advancing symptoms of Alzheimer disease. Her husband was quite exhausted at the time of the move as he had been watching over her day or night; nevertheless he found the transition difficult to face. And he continued to spend considerable time with his wife in the nursing home unit after the move. However, he only visited for a short while in the afternoon at the time of my data collection, three years after her move. He would join his wife in the sitting area around the coffee hour and sit by her side for about a quarter of an hour, holding her hand and occasionally patting her cheek, with a painstricken face. Then their daughter would come in swiftly and cheerfully and take her father's seat as he took his leave, having kissed his wife goodbye. Later on the daughter told me that their visiting pattern had developed this way as it got harder and harder for her father to visit his wife. And his stamina was limited, as he had a long history of cardiac disease. So he would visit at this hour of the day just before the daughter finished work and she would come to the nursing home and relieve him. The daughter then visited for about a quarter of an hour with her mother, but would then continue her visit in the service housing with her father.

The father and the daughter feel they have to see Sigrún, the wife and the mother, every day of the week; they come for a brief visit and the daughter says "this is just a routine, it just belongs to our life". It is very hard for the husband to see his wife deteriorate, and the daughter points out that he is still very distressed in his relationship with his wife after the conflicts that arose between them earlier in Sigrún's disease process. The daughter herself maintains that looking after her mother is something she has just intended to do, and she certainly has done so for a very long time. And it makes a difference that her mother still enjoys holding her hand, so she does actually get in touch with her mother.

The husband's and daughter's pattern of visiting have changed as Sigrún's disease has advanced and in fact this change of pattern was common among the visiting family members of the oldest patients with advanced dementia. These patients had stayed for quite a long time in the respective units and the family members had changed their pattern of visiting as their disease advanced, especially after their loved recognized them only occasionally or vaguely. Sigrún's husband and her daughter would, like the other daughters of the very old demented residents, shorten their visits but nevertheless visit as frequently and structure their visits in a definite manner. They would come every day, or four or five times during the week, to reassure themselves how their relative was doing and to get in touch by touching their loved one. As the daughter of 93-year-old Pétur, who usually visited just after lunch, when her father was in bed during the rest hour described:

> ... this is a good hour, then he is resting after the lunch and I am so pleased to see that he is feeling well, then I see quite well how good he is feeling you see ... I go just for

> myself - first and foremost - just this to see him, touch him, embrace him a bit and sense in a way that there is such a warmth also on the staff's behalf, which is so important, you see I can feel it, their warmth towards him.

Pétur's daughter finds it good to visit her father when he is resting after lunch, then she can just come by and hug him and leave him peacefully to continue his nap. She emphasizes that there have always been strong emotional bonds between her and her parents, and how important it is for her to confirm these ties as she visits with her father by touching him and embracing him. She confirms at the same time that her father is in good hands and embraced by the staff's warmth, but she also attests to the staff that Pétur's care and wellbeing matter to his family.

These daughters of the very old demented residents were watching over their parents, and the visiting family member is indeed first and foremost the guardian of the elder's wellbeing, watching over her or his condition and responses to the situation. All the participants are very much aware of their relative's vulnerability and want to see them through this last passage of life in a reasonably good way and with as little suffering as possible. The visiting family members and the elders have certainly shared quite a long story of their life, and it was apparent from the way in which the family members participating in this study looked after their relatives that they saw it as an inherent part of their own story to sustain this close relative all the way through.

The staff looked upon the families participating in this study as either exceptional or exemplary because of their concern for the wellbeing of their family member. However, some found it rather peculiar to study the experience of these families caring for their relative living in a nursing home. They actually thought that it would have been more important to investigate the families that did not visit or show particular concern for their relative in these circumstances. The staff had problems with the latter families, not the former. And they would bring up stories of large families who had hardly been seen for years of a resident's stay, who suddenly turned up on the person's deathbed, much to their surprise. The staff certainly pointed out that there were a number of residents who did not have a close family alive. nevertheless there were others who had a family. that did not visit

The staff's tales about their forgotten patients bring to light a dilemma which they face at work. A dilemma that pertains to the kind of messages society conveys about the existence of a nursing home patient and the extent to which it is accounted for. The care and wellbeing of a person written off by society may not seem very important. But a family's concern for a nursing home resident attests to the staff that the respective resident is still rooted in society through the family attachment and a mutual influential impact. So the visiting families do indeed verify to the staff that the particular resident's care still counts as important in society.

The above discussion has addressed the way in which the visiting act is institutionalized. The visiting act evolves as the families attempt to come to terms with institutionalization while continuing their involvement in the elder's life in the nursing home with regular visits and care. But the nursing home world is a foreign one and the family has to learn about its many features and way of life. The nursing home world is the context of the relationship between the families and staff and this context will be described in the following chapter.

Chapter Five

THE NURSING HOME WORLD: THE CONTEXT OF FAMILIES AND STAFF RELATIONSHIPS

Introduction

> You see it by the flag here - when it is at half-mast, people naturally leave this place. You take it for granted. This is the last dwelling place. ... no, it does not really upset me. No. Although this is a very good place, at my age today, you think to yourself that you would actually prefer to be gone before ending up in a place like this. It's not that it isn't good to be here, as I say, people are well cared for, but of course it is a kind of an old people's asylum and people are more or less perhaps out of it, and sit there and mumble. I think to myself, well, she's getting worse, and then she'll be able to rest and won't need to be here anymore. This is of course no place of entertainment. But the people who are here, I think that they feel fine and undoubtedly the way of thinking changes so that they accept it well, or you see they do not know anything else by now. I have seen women with whom I have been familiar and who have died, as expected, as one may say. (Katrín's son)

The nursing home where Katrín resided was the only one of the sites of this study where it was a custom to fly the flag at half-mast when somebody died. It was said in the other homes that there was no need to constantly remind the residents of the kind of "leave-taking" which is assumed in the place they inhabit. However, it becomes clear to the families as they encounter the world of a nursing home, that this world is to a degree designated by the inevitable decline of the inhabitants. It was actually common among the family members to say that "you get used to it" or "you learn to handle visiting" as they spoke of their experience of visiting in a nursing home. The visiting family member may find it especially hard and distressing to enter the unit and see all the helpless people about, not least if they are not quite oriented. It can certainly put the visitors off "to meet somebody in the corridor mumbling and not knowing which way to go" as Katrín's son points out as he speaks of his children's experience of visiting their grandmother but he adds "you get used to it":

> You get used to [seeing so many people perhaps not oriented]. That's the thing with the children, it puts them off as they enter and meet somebody in the corridor mumbling and not knowing which way to go and so on. But you just get used to it, like you nurses do. I actually took it to heart in the beginning, then you would just think, these poor people, having to stay here, really, in a place in which they do not know where they are. Yes actually, yes, yes ... like the other day some man was sitting there crying you see and said that he was supposed to be at work a long time ago, and nobody had come to fetch him. I had not seen this man before, he must have been new and had not [yet] found his footing, thinking that he should be at work. You think to yourself, yes, well, hopefully that won't happen to you. Hopefully you will be six feet under before that. But you get used to it. You get used to it.

Katrín' son felt downhearted in the beginning of his visiting in a nursing home to see people around being lost, but maintains that "you get used to it". And one daughter who had been visiting her mother-in-law in a geriatric unit referred to this experience when she said "I had some idea of what I was getting into" as she spoke of her visits to her own mother. However, geriatric units may differ from nursing home units, and different units in the same nursing home certainly have their distinctive atmosphere. Indeed, the wife of a husband who had to move from one unit to another in the same nursing home was struck by the difference between these two units and how long it took for the family to find its footing in the new unit, which nevertheless had exactly the same design. And she pointed out "it is just the people, you have got to start it all over again while you learn to know them".

Indeed, when the family members start coming and going in the nursing home where their relative lives, they realize quite soon that the building itself does little to constitute the world they are learning to know. It is the other patients and staff who make up this world, and the way in which the care approaches structure the everyday life. The following discussion will attempt to shed light on this world and will be guided by the themes that arose through close observations carried out in the units. These themes will be illuminated by exemplars that emerged in the participants' delineation of their impression of this world and their experience of going about it. The themes are (a) The Scene, (b) The Notion of Home, (c) Everyday Care and (d) Quality of Life. The discussion attempts to delineate how the surroundings and the people inhabiting them come across when a visitor enters this world. In the continuing description I am trying to depict common features designated as basic characteristics of a home within this world, and the strategies employed to enhance the elder's feeling of being at home. Then attributes of everyday care are brought forward, considering how the nursing agency's view of the person determines the manner in which the residents' impairments is evaluated. Furthermore, the discussion addresses how the meaning ascribed to the demand of everyday care is reflected in the organization of care and the care approaches in the units. The last part of this chapter attempts to bring forth how the meaning of a quality of life shows up in a nursing home and clarifies the families' and the staff's expectations of what constitutes quality of life in a nursing home.

The Scene

All the eight units in the three nursing homes included in this project have a pleasant outward appearance. The sight of the interior design and decor catching the eye of the visitor is either light or colorful, but generally inviting, with light furniture and there are generally pot-plants around and pictures on the walls. It is a common feature of the design of the units in these nursing homes, as in many others, that there is a large communal area lying open upon entry into the units, divided with some kind of partition into a dining area and a sitting area. The number of patients who are around in the communal area depends upon the time of the day. There are few if any about during the rest hours after lunch but then it becomes quite crowded during mealtimes or if there is some special activity going on. The atmosphere in the communal area varies according to the time of the day, and differs between units during the same time of the day, and actually is to a degree marked by the tone of each shift in each unit.

At times there is a striking silence and a certain air of remoteness among the patients scattered around or gathered together in a group, perhaps around a table. At other times there appears to be more of a coherence, even a togetherness, among the inhabitants and there might be a feeling of tranquillity. Actually, the atmosphere, or the ground for togetherness, is for the most part brought about by the staff or perhaps a relative or relatives, as it is an exception if the patients establish any kind of companionship with each other or even talk together on their own initiative. The impression of institutional life arises primarily from the appearance of the residents as the visitor enters the respective unit or sits in the communal area and looks around, noticing the immediate surroundings. The appearance of a patient may more often than not indicate a poor condition, if the person for example is confined to a wheelchair or going about with a walker, or needs the assistance of one or two staff members to get around. Jón's wife describes the scene as she sees it and points out:

> I find it, to say the least, not encouraging, the picture as a whole, one is brought out for coffee, led by two, and then they put the chair beneath her. Then another one is brought out, with only one person leading her, and then the wheelchairs are brought out and things like that, this is not encouraging, but that's just the way it is.

All of the patients are to some degree debilitated and may have a limited ability to reach out and establish contact with others and also they may not have very much in common with the other inhabitants but their multiple losses. Jón's wife addresses precisely these multiple losses as she ponders the lack of cheerfulness in the nursing home.

> But I think that the people are not all that cheerful in places like this. Whether this

> comes about to a degree from having, of course, lost something, otherwise they would not be there, and having to accept leaving home and not being sufficient to yourself, and perhaps just not having the energy for cheerfulness, it is quite possible, I do not know. I think that if you spent perhaps one or two days during this time while I am there [you will see] that there is nobody laughing there, and there is nobody joking. ... It is actually their health, it just puts these limits on people.

Jón's wife is actually extraordinarily perceptive of the surroundings, and it is obvious that she has thought much about her husband's situation which she finds so lacking in cheerfulness. She appears to attempt to make sense of the circumstances by focusing on the declining health and the helplessness of the inhabitants, which in and of itself may make the lack of cheerfulness understandable. The inhabitants have certainly "lost something" and it is actually the characteristics of these multiple losses that they share and bring them together in this place. First and foremost the people have lost their health in such a way that they are not sufficient to themselves, and to such a degree that living in their own homes is not possible anymore. And they have had to be reconciled with leaving home and finding a way to accept "a new home" in the nursing home. Van Manen (1990) points out that "the home reserves a very special space which has something to do with the fundamental sense of our being" (p. 102). He further clarifies that secure inner sanctity is rooted in the meaning of home as it is a place where we can feel protected and be ourselves. And Van Manen (1990) adds: "Home is where we can *be* what *we are*". Perhaps the tone of sadness in the nursing home also arises from the residents' loss of their home, as a protected and private place. Augmenting this loss may be the additional loss of the self that one experiences solely in one's home. If, as Van Manen says, the home is where we can be who we are, the residents may be feeling a profound loss of a comfortable familiar self, once introduced to the nursing home world. Grieving these multiple losses is insufficiently acknowledged in the nursing home. Expression of grief by residents may be misinterpreted, for instance behaviors that are labelled “acting out“ and thus mismanaged by the staff.

It may be quite a shock for a family member visiting in a nursing home to face this scene of multiple losses, and see her or his loved one among so many debilitated, old people. Like Anna’s daughter said “I think that I have found it awfully hard to see, in a way, how the people were, you see ... I found it actually most difficult to see, in a way, how many were really in a poor condition, you see”. It certainly may be hard and distressing to enter a unit and see all the helpless people about, not least if they are not quite “with it” or confused.

Smith (1992) discusses dementia’s ability to trigger fear and shame and he refers to Carl Schneider when he denotes shame as a central part of our humanity and says:

> Shame refers to our reaction to the exposure of what should have been concealed. I am ashamed when my privacy has been violated, when certain aspects of myself are made visible to the public. Schneider distinguished what he call shame as *discretion* - which *anticipates* the possibility of disclosure - from shame as *disgrace* - which *follows* the disclosure. He notes that shame is closely tied to the body and that it is an aesthetic category. We are ashamed of the unattractive, the ugly, that which calls attention to itself. Schneider suggests close connection between shame and death, noting that one of our words for shame is “mortification” (Smith, 1992, p. 53).

An anticipation of the possibility of disclosure of the unattractive was a fundamental aspect of the nursing care in the units participating in this study, as it was in fact customary to pay a great deal of attention to the grooming and dressing dimensions of caring. And it was very important for almost all of the family members to enhance their loved one’s dignity and sense of self by soliciting the staff’s keeping up a presentable appearance of the person, not least if she or he had some mental impairments. It was important for Marta’s husband, for example, that his wife would go to the hair salon every week. As he said

> She has very beautiful hair ... she probably feels better to have it washed every week

> and go down and have beautiful hair and I prefer to see her with beautiful hair rather than, you see, otherwise ... Then I remember her the way she was.

Indeed, Smith further discusses the shame that leads to discretion.

> Sometimes people are able empathetically to recognize what would shame someone and to help them to "cover". Sensitive care for the demented may entail a great deal of covering, neither futile nor a waste of time. Rather, it is the deepest form of respect for dignity (Smith, 1992, p. 53).

The family members certainly appreciated the way in which the staff helped their relative to cover any deficit or impairments by "putting on" a presentable appearance. A presentable appearance may to some degree help the family members to look beyond the deterioration of their loved one and remember them the way they used to be, as Marta's husband found important. And the scene becomes less offensive, anyway the regular visitor learns to face the scene of the nursing home world as time goes by, as Anna's daughter pointed out when she talked about her visits and said "this is something you learn, in a way, the more frequently you come".

The Notion of Home

> It is a bit difficult to make a home out of an institution. That is the way it is. But I think that by respecting their needs, and accommodating them as much as possible, they can continue to be themselves. It is possible to do so even though they have entered a different environment and receive assistance. We can help them and take care of them, offer support, and can support their self-image rather than undermine it. We can let them feel that this is something that they are entitled to, and can choose as individuals. ... But I do not know [if the people themselves think of themselves as patients or inhabitants]. I have sometimes wondered, how the people think of their position. Do they always think of themselves in the position of a guest or a stranger? Somehow I think that most of them, or many think so. This is that kind of situation. It is perhaps not all that easy to perceive yourself as being at home

here, in the sense that we feel in our homes. (Unit manager)

This unit manager acknowledges that it may not be easy to give the residents a sense of a home, but she clarifies by what strategies it may be possible to enhance such a feeling. However, in the nursing homes where I conducted my study, it was unusual to encounter any reservations on the staff's part with regard to the notion of home. The staff was indeed quite adamant when they addressed the dichotomy between a hospital and a nursing home. It was a general view that a nursing home should be looked upon as "a home" rather than a hospital, and the staff emphasized that the residents in this kind of an institution are inhabitants but not patients. Nevertheless, the degree to which the notion of a home or an inhabitant was defined and specified differed among the units. However some common features were designated as basic characteristics of a home in all the units. It was important in this regard that the surroundings were not as bare and sterile as in hospital, and furthermore the staff tended to emphasize that the shared mealtimes in the home's dining room resembled customs in people's homes.

The residents themselves or their relatives were encouraged to bring some personal belongings to facilitate each one's settlement and help the person "to feel at home". The extent to which the family members manage to personalize their relative's room is often astonishing. However, there was distinctive difference between the ones who lived in private rooms and the others who shared rooms. It was actually remarkable that there were a number of people, like Kristín, as exemplified in the previous chapter, who did not want any of their belongings around while they shared a room, but were quite pleased to do so as soon as they got a private room. Jón's wife indeed points out that it should be "a basic human right" to have a room of your own when you move into a nursing home. There were some double rooms in all the units, although the proportion of single rooms to double rooms varies. And there were often a few people sharing a room with another person, waiting for a private one to become available, either on their own request or their family's request.

A resident on the waiting list, who is assumed to benefit from the advantage of a private room, is usually offered an opportunity to move when one becomes available, while a new resident is likely to share a room at the beginning of her or his stay. Nevertheless, it was seen as preferable policy to assign a new resident a permanent room on her or his entry, but this did not always work out. Room assignment may be up for debate among the staff in the units on these occasions, but the unit manager usually has the last word. However, the unit manager confers with the staff to address the impact of a room assignment upon care approaches. For example it may be almost impossible to apply some bulky equipment to care in a double room. The extent to which a person may be able to enjoy a private room is also addressed. Certainly the more capable residents, both physically and mentally, are seen as having better potential of enjoying a room of their own. Also, the staff as well as the unit managers usually find it important that the residents whose family members visit regularly can share their time with their visitor in some privacy.

The residents themselves and their relatives ascribe different importance to the way in which one's room is set up. Some, like Pétur's daughter, had carefully chosen furniture and various decor that would reflect important aspects of his personhood and life story, and which also solicit her father's former habits of being at home. Pétur's room is very tasteful and beautiful with dark but pretty curtains and nice light bedspread on the bed. On the walls and on the shelf are paintings and photographs of Pétur himself as well as of people and places that have in some way or other constituted his life, giving glimpses of his life story. The main piece of furniture in Pétur's room is a rather large old dining table with chairs around, where Pétur indeed liked to sit paging through his photo albums or playing with cards while he was relatively well. However, Pétur's dementia had progressed to a quite advanced stage at the time of my data collection, so the degree to which he may have been aware of his surroundings was at least questionable. Nevertheless, the staff emphasized that his room should definitely be his place in the home until the very end. The staff saw the room in a sense as conveying a sense of Pétur's lifelong personhood and embracing his fading self.

Marta's room was, in contrast, very bare; somehow the two chairs in her private room did not really seem to belong, nor the lamp on the window sill. And the three family photographs hanging on the wall were placed haphazardly. The husband said that he had brought these things according to the unit manager's suggestions of bringing some personal things, to make the room more of a home. But it appeared as if Marta's husband did not really look upon the room or the nursing home as "her home". Rather, he referred to the old home where he still lived as theirs, although Marta had not returned there since her placement more than two years ago. Marta's husband would spend his time with her in communal area when he visited, and hardly ever entered his wife's room. Nevertheless he became very upset when the unit manager discussed with him her tentative plan of moving Marta into a double room. In the unit manager's view, neither Marta nor her family seemed to enjoy any advantage from the private room, so she did not think that the move would make much difference for any of them. The husband all the same saw the proposed move as an assault upon his wife's territory, undermining her dignity, and he was deeply insulted when the move was brought about. His reaction may be seen as rather debatable, as the move did not really have any impact upon the way in which he was spending his time with Marta while visiting, and she was not really losing "a home". But the husband felt that his wife was discounted as a person when she was "chucked out of her" room, as he said:

> I was happy that Marta was allowed to be in that room - I thought the room, even though it was not all that homelike - but there were nevertheless two chairs and a table from our home ... She had been there for 2 years and 2 months, there in this room, and I did not think there was any reason to chuck her out.

From the husband's perspective, Marta's room was clearly her place since for more than two years it had belonged to her. But not so from the point of view of unit manager, who said according to the husband "nobody owns anything here, neither a room nor a seat". But what really upset and hurt the husband was the manager's manner of speaking about his wife when she brought up the imminent move according to the husband: "... it does not matter, Marta does not make any sense of it - she does not perceive that" and the husband says "I was very upset by this, to let my wife move into this room with somebody else, because she would not understand it. You see, that she was really out of it and would not understand it. It is actually quite true, but the nurse did not necessarily need to put it that way". The husband felt that the unit manager's explicit labeling of Marta as an incompetent resident implied her non-significant status, as a human being who could be placed anywhere instead of living in her own room. Thus, by the move Marta had not only lost her place in the unit, but her status had been diminished. Now she had definitely been grouped with the other incompetent residents in the unit and was in fact sharing a room with another one in that group.

Apparently, the unit manager in the unit where Marta was staying ascribed quite a different meaning to the notion of a private room, compared to the staff in the unit where Pétur lived. It is, from the unit's manager's perspective, as if a private room should necessarily be of particular use to the person living there, in some sense or other. In the latter unit, in contrast, the staff saw Pétur's room as his place, where he belonged and was rooted as a person, whether he himself made sense of his room or not anymore. The deep sense of regret that Marta's husband felt because of his wife's move was not least because his wife had been uprooted while her personhood was being disregarded. And somehow the husband sounded as if Marta did not really have a place anywhere, anymore, even though she still was located in exactly the same nursing home.

It matters to the residents to have some sense of territory where they can take root and have some refuge, even just a nook. Owning a definable territory with a private room allows people sanctuary in the nursing home, and a place where they can be themselves. This is certainly a positive aspect of a private room. Indeed, the more competent residents seem to prefer to spend more of their time in their own rooms rather than in the communal area which they may even avoid although they go to the dining area during mealtimes. As one of the unit managers pointed out:

> It is very rare that the people who are more independent [sit in the sitting room]. They stay in their rooms except when there is something special going on, like the reading, the church service, the meals or something like that. Yes, it is the people of whom we take total care, you see, who come into the sitting room and whom we actually place in the sitting room to keep them more under surveillance, and also because you perceive these people as being so alone in their rooms, you see, there are both good and bad aspects to the private rooms.

This unit manager points out that mentally impaired people may feel lost left or alone in a room of their own, become frightened and wander away, looking for somebody. It is in fact customary for the staff in all units to guide or move the less competent residents into the communal area during waking hours as to prevent their isolation, as well as to keep them in sight to ensure their safety.

But everybody is usually gathered together during mealtimes in the communal area or the dining room. Mealtimes are presumably supposed to resemble practices of a home and create a homelike atmosphere. They are the main events of the day, but their characteristics differ considerably between units, and even between shifts in each unit. The quality of the mealtime certainly depends upon the food, but actually there was a general contentment with the food, especially in two of the three nursing homes. However, the way in which the meals were organized, and the whole atmosphere, varied. The seating, the way in which the table is set, whether napkins are or special type of bibs are normally used, and how the food is served, affects the atmosphere and so does the pace, and not least the amount of small talk.

The inhabitants are usually seated in small groups, apparently with regard to what they have in common, and their ability to handle customary table manners is also considered in this respect. The less able ones, especially those who need help in feeding themselves, or must be fed, are often grouped together at the outskirts of the dining area or in a special niche where the assisting staff joins them. The tables may be set with cutlery and glasses in some units and the plates are then served with the food on. It was noteworthy that there was usually a jug with water placed on the tables in the units in one of the nursing homes, so people could help themselves to a drink, pour the water for others at the table, or pass it around. It was indeed remarkable how the water jug appeared to connect the people a little, as it would go around. Actually, sandwich plates were placed on the table in this manner during supper time, as well as coffee jars in this same nursing home. In other units the food was mostly arranged and served on trays with a glass of water or milk on. There is a tendency for the staff to put the plates or the trays or the dishes mechanically in front of the elders, and they rarely comment on the food, or ask the people how they have liked the food when the plates or the trays are removed, or simply chat a little about things. However, it was a custom in some units, particularly during lunch hours, to have the radio for the news, as has been practiced in many homes in Iceland since radio was first introduced in the country.

The units often have different means of controlling the sequence and the pace of the meal. On one hand it is important to organize the way in which assistance is provided with feeding, especially if there are many who need total help in feeding themselves. On the other hand it is very important to avoid hassle regarding the way in which the staff's breaks for their own meals are organized, otherwise there may be quite some "small talk" about who is on a break, who is going for a break, and so on. Small talk with the inhabitants did not appear to be common during meals in these nursing homes, but there were "kitchen ladies" in the units in one of the homes participating in my study, and all of them simply seemed to master small talk with the inhabitants, as their way of being around while setting the tables and preparing for the meal ahead. Perhaps the task at hand for the nursing staff is simply too demanding for small talk and they certainly have their hands full during meals. However, small talk somehow connects the inhabitants and brings some degree of coherence to the group, as they sit together, and brings about something of a homelike atmosphere during the meal.

There appeared to be at times a more homelike atmosphere or a spirit of belonging and togetherness, when the inhabitants were gathered together in the communal area during the evening news on TV around seven o'clock. At this time some refreshment is usually served, such as fruit or hot chocolate with biscuit, in all the units. Most often some or all of the staff would join in for a cup of coffee or chocolate themselves, watching the news and sharing a while with the inhabitants, perhaps commenting on some news item. I sometimes joined the various groups while carrying out my participant observation, and felt particularly comfortable in one of the units when an older RN was on duty. I came to realize as I was sitting there that the relaxed atmosphere was not really accidental, but thoughtfully created by the nurse. The dining area and the sitting area are split with a partition, and people move or were moved from the dining area to the sitting area or the corner in front of the TV around seven o'clock. The RN guided this move smoothly, addressing each and every one - saying like "here is your chair, Jens, just in front of the TV", then directing Ásta, who is suffering from memory deficit, to sit next to Jens asking "Ásta, wouldn't you like to sit next to Jens and discuss what is on? - you used to - please come and sit here" and on she went, placing each and everyone, making sure that everybody was comfortable and everybody could see the TV. Then she sat down herself and, when the news came on, perhaps made some comment or drew attention to something on the news, or asked for the opinion of someone in the group about the news. Then, as eight o'clock approached, she fetched the trolley and served refreshments without any hassle. And the people had their coffee and seemed quite at home.

Everyday Care

The structure of everyday care in a nursing home aims at establishing patterns of daily rhythm that mirror people's usual way of life. The majority of residents get up in the morning and go about their day as it unfolds, with its routine, diversions and possible upheavals until bedtime arrives. Most people need considerable assistance to get up, and it usually takes some time; actually it may be the major task of the day to receive a helping hand to get up and about, and to endure the day.

Everyday care may be demanding both for the residents and the staff. A large proportion of residents have extensive limitations in performing basic self-care activities in all units participating in this study. In fact people do not enter nursing homes in Iceland unless they are quite impaired either physically or mentally. However, the characteristics of the care requirement depend on one hand on the impairments of the resident, and on the other hand on the meaning ascribed to this demand of everyday care on the staff's behalf, and the way in which they manage it.

The manner of evaluating the resident's impairments is determined by the nursing agency's view of the person. The nursing agency view of the person may range from a rather mechanical one that emphasizes assessment of the resident's limitations according to some standardized forms, and the extent to which she or he needs help to maintain cleanliness, nutrition, elimination and getting up and about. At the other end of the spectrum, the nursing agency may focus on the way in which the person comports herself or himself and moves and acts in the situation, while appreciating life-long habits of going about bodily practices and everyday activities. This latter view was especially evident in one of the units, where the unit manager talks of the special needs of each individual, as she says when she speaks of an excessively fastidious resident:

> This way of keeping everything in strict order, and exactly the same as he wants the things to be - it just matters regarding his condition, the everyday condition. ... [The girls] attend to him on that basis. Some of them find him rather picky and with his

> special needs, but they know him and respect him as such. These are special needs but not demands. I think there is a whole lot of difference between those two [things]. ... These are just his needs. ...

The distinction between special needs and demands bears upon the unit manager's outlook towards the elderly inhabitants in her unit as she further delineates her stance:

> It quite annoys me when people are saying that this one or the other one is pampered, too pampered. I don't deny that I hear this sometimes. Some people have this opinion that it's indulgence ... like this, meeting all these special needs, which perhaps differ in number and degree among people. We have had many here with particularly many special needs. These are needs, not something they are pretending to have, rather something which they bring along. This is their home, so I find it reasonable for them to have such things, to the extent that it is possible to do so, and within acceptable limits.

This unit manager apparently interprets the inhabitants' lifelong habits as "special needs" and finds it reasonable for the inhabitants to bring their "special needs" along, as they constitute their way of being and as "this is their home". And implicit to the meaning of home in her view, is that people can keep their way of being or their lifelong habits. It is remarkable that she points out that "we have had many here with particularly many special needs" as there have been more residents with physical impairments than mental impairments in her unit. Certainly the more alert of the residents can claim or make a case for their "special needs". Some habits, however, are conveyed in people's embodiment as they go about their everyday activities. This unit manager points out that it is possible to observe the demented residents, and discern their habits and diurnal rhythm. That is, she recognizes needs that are expressed nonverbally or through embodiment as making an equal claim to those expressed in a verbal or coherent manner. In the following, she considers the definition of "needs":

> But what are special needs and what are needs? Aren't they all simply needs? These

> are all individuals whose needs we try to accommodate, from what we can see, in the whole range from demented individuals, from whom we can perhaps observe that they enjoy sleeping in the morning. Others are early risers and want to wake up early, these are needs. It suits us as well, perhaps accommodates the unit's needs, it suits us to serve some of the residents [breakfast] in bed.

The unit manager sees it as an advantage to incorporate individual habits into the care approaches, as it allows for flexibility in the organization of care. The unit managers' and staff's stance towards the degree to which flexibility can be allowed, without impeding efficient and safe care, varies among units; as does the extent to which it is seen as an advantage to incorporate individual habits into care approaches or not.

The organization of care and care approaches in the various units is indeed determined by the staff's stance, and in particular the unit manager's and the RNs' stance towards the meaning ascribed to the demands of everyday care. The nursing administrator in the nursing home may have proposed a definite conceptual framework of care, but nevertheless each unit to a greater or lesser extent values and defines the work in its own way. However, there is a difference between homes, and the nursing administration's impact upon the units certainly depends upon its concern for the everyday care, and the staff's resources to carry it out.

The meaning ascribed to the demands of everyday care is reflected in the qualitative difference in the manner in which the staff attends to the residents. The staff's assignment influences this qualitative difference and so does the extent to which care planning informs everyday care, and not least the extent to which the work of the RNs and the other nurses or nursing assistants is divided into two separate components of care. Each unit is usually divided into two or three sections, to which a certain number of workers are assigned to take care of the residents within that section. Usually two workers are assigned to work together and it is common for them to handle the care of about 8-10 residents during morning shifts. In some units there may be an emphasis on consistent staff assignment to each section for a period a time, for example, one or two weeks. However, there tends to be a dispute over such assignment between the staff and the unit manager. It is common for the practical nurses and the nursing assistants, who carry the main load of bedside care or the direct attendance to the residents, to maintain that it is too demanding and possibly boring to attend to same residents from one day to another. At the same time they may point out that there is quite a lot of rotation of staff anyway, because of the number of part-time staff working in the relevant unit. They may also add that in their opinion things stay pretty much the same in each section most of the time. Nevertheless, the same staff may admit that things usually go more smoothly if they attend to same group of residents two days in a row. Indeed, when I asked the staff in one unit, if they had some definite sequence of attending to the residents in this particular section, the practical nurse told me that it depended on the residents' schedule and habits. It would of course determine the sequence if the resident was scheduled for physio, a bath or had a D-day (the resident is given a suppository to assist with elimination). But then she added that there were always one or two residents who wanted to be the first to get up, and two or more others who wanted to sleep in and "and you can shift 'the favors' a bit if you attend to the same group of residents two days in row". And in units in which there was a consistency of staff assignment, it was apparent that the staff would actually refer more to how things had being going, and what had happened in the preceding days, while attending to the elder.

The qualitative difference in the manner in which the staff attended to the residents was striking when I observed the various staff help the residents to get up in the morning. The manner of attendance ranged from a quick, rather indifferent, way of getting the resident cleaned and dressed, to a sensitive skilful manner of helping the resident to sustain her or his cleanliness and to get dressed in a personalized way. The former manner of attendance was exemplified when I observed two nursing assistants get an old, very demented, woman up in the morning. They hardly seemed to notice her as they gave her perineal care, changed her diaper and put her into clean knickers, pantyhose and trousers rather quickly, as one was doing the work while the other held the old woman's hands. Then she was moved out of bed and escorted to the bathroom where she was put on the toilet to void. One of the assistants carried on with the work, while she was sitting there, washed her face and upper body and put clothes on as the other held her hands. And they told me that the old woman tended to be rather aggressive during her attendance, so they were on their guard. When all this was done the old woman was taken off the toilet and it seemed to be irrelevant whether the woman had been able to void. I asked if she was usually able to void when she was helped to the toilet and the assistants answered that it was rather random, and that anyway she had a diaper on. But the little lady seemed to be more lost than ever before, when she was led into the communal area.

In fact the staff appeared at times to be at a loss in relating to the demented residents, especially residents with advanced dementia. And there was a noteworthy lack of consensus in the group conversation about the best way to relate to a particular demented patient, especially if the patient tended to be agitated or even aggressive. Actually, there would always be one or two staff members in a group, discussing the approaches to a particular demented person, who would suggest that it was much more successful to be on your own as you attended to this very person. This approach is reflected in the following excerpt, as a practical nurse tells about her way of dealing with a quite demented woman in the following way:

> This has worked out very well lately - I do think that the best thing is to be alone with her - - it is worse if there are more - two people talking to her at the same time, and then I think as well, you see, you need to be quite tremendously diplomatic and talk about how elegant she is and how nice her hair looks and ... She likes it when you praise her, how good-looking she is and how presentable - tell her that she is elegant " yes, you are actually very good-looking yourself" she may say - it is, you

> see, perhaps the best way you can manage her, in this way - to be ever so persistent ... and never to contradict her [sayings]... and if she says "you are such a fool" - then you say "yes, I'm a bit stupid" - then she says "yes" - then you just do not talk any more about that ... it is far the best to be on your own with her.

It seems logical to spare a demented person the effort of grasping too many stimuli as she or he receives a helping hand, but the other staff seems often rather reluctant to agree upon this view. The may argue that the patient might hit them or harm them in some way, so it is better to have somebody accompanying you to keep the patient's responses in check or hold the person. However, some staff may be very receptive to the cognitively impaired elder's composure and her or his manner of relating to herself or himself and others. This staff appears to know well the particular person's responses to the matter at hand in everyday care and is able to coach the elder's activities by various means; for example, by sequencing the activities predictably, and structuring them, so as to be straightforward to tackle or ready-to-hand, and by using purposeful cues to direct the action at hand while keeping the tempo slow and the surroundings calm.

Approaches to the alert residents tend, on the other hand, to be somewhat different as it is tacitly assumed by both parties that the respective resident has some say in how she or he is cared for. The collaboration between the staff and the resident may actually be quite amicable, as when I observed a practical nurse and a nursing assistant assist a large man paralysed on his left side to get up one morning. This man usually gets up before breakfast, except two days of the week when he gets a suppository to promote defecation. This was one of these days and when the two helpers came into the room they asked how he was doing and if was ready to go to the toilet. Yes, he was, so they got him into the lift and moved him to the toilet, placed him, making sure he was sitting comfortably and then left him alone. One helper then left to see how another resident was doing while the other stayed behind getting things ready for continuing the attendance, but keeping in touch with the elder through the half-closed door, asking "how are you doing" and "are you done, love". The other helper turned up when the man had finished and they moved him back to bed in the lift to clean his perineal area properly and dress his lower body. While doing this they asked about his chest and whether he was still short of breath and coughing, and if it had disturbed his sleep and so on. Then the RN came in to see how things were going, how the bowels had been, then inquired also about his chest, suggesting that the physician should see him in the afternoon. The RN referred to his daughter, and said that she had been a bit worried about his coughing when she had spoken to her yesterday, and the conversation continued as the man was helped into his wheelchair. And while talking he was wheeled into the bathroom, where he was placed at the washbasin and helped to wash his face and upper body, but then he was able to brush his teeth and shave himself. Now the RN and the other one of the helpers had left, when the bed was made. The other assistant who stayed behind looked in the closet for a sweater or a shirt, chose two shirts from the man's closet, went into the bathroom and asked which one he preferred, he chose one quickly and then the assistants helped him to dress his upper body in a relaxed manner. Now they were talking together about a tattoo, as the nursing assistant's son wanted to have one done. She asked the man if it was painful to have a tattoo done, obviously referring to the tattoo on his right upper arm. The man talked a little about the tattoo, but discounted the pain and they turned to the matter at hand of getting ready for the physio. The rather lengthy process of attending to this large, quite physically impaired man and helping him to get ready for the day actually went amazingly smoothly, in an easygoing and pleasant mood that seemed to suit him very well and be comforting to him. Indeed, the man appeared strong and lively, ready to face the demands of the day, as I accompanied him to the physio department. The care of his body this morning, while sustaining his spirit, certainly seemed to have given him strength.

The timing of events, the sequence and tempo of the activities, and not least the helpers' skills in attending to the elder and relating to her or him, which entails receptiveness to the resident's composure and bearings, is crucial to the person's experience of receiving a helping hand. However, all these factors may be unpredictable, depending on the staff's skills and the consistency of their assignment, and the way in which care plans inform everyday care and are carried out.

The extent to which care plans informed everyday care differed between units, and indeed between the nursing homes participating in this study. But the difference was particularly distinctive with regard to the strategies used to apply relevant components of the care plans to guide how the care was carried out on the floor or at the bedside. One home, in particular, had developed special sheets or a comprehensive one-page summary of the "the nursing needs" of individual patients which was kept "out on the floor" in a folder on the linen trolley while the staff attended to the patients. The practical nurses or the nursing assistants would then go through these summaries during the midday report as the registered nurse paged through the resident's records while each resident's condition and care that day was addressed. And during the reports some of the overviews might be updated according to the group's discussion concerning necessary change regarding the respective resident's needs. The units in the two other nursing homes had actually some kind of a directive "out on the floor", delineated by the registered nurses regarding individual resident's needs, to guide the attendance of the everyday care. However, these directives were neither as comprehensive in the way in which the care was particularized with regard to the individual resident, nor kept as well updated, as in the aforementioned nursing home.

This nursing home actually had a considerable advantage compared to the two other homes, such as low turn-over rate of both professional and auxiliary nursing staff. Furthermore, the competent and ambitious registered nurses working in the various units in this home had collaborated actively among themselves, and were very concerned about the care delivered in their respective units, as well as in the home as a whole. And they all had a way of working with the practical nurses and the nursing assistants that promoted the importance of attendance to bodily needs and flexibility of care approaches. The registered nurses in this home are certainly visible "out on the floor" as they participate in the care to a greater or lesser extent depending on the situation in the unit. The collaboration between the RNs and the other nurses or assistants was indeed noteworthy in this home. The division between the registered nurses' work and the attending staff was far more distinctive in all but one unit in the other two nursing homes. The practical nurses and nursing assistants would shoulder the attendance more or less within their own realm of work in these units, but under the surveillance of the registered nurses who would keep check on the work done.

However, a common characteristic of care approaches in all the units in these three nursing homes is the emphasis which the staff places on the residents' grooming and dressing. And a presentable appearance is considered important for all residents alike. It is also a common policy in all units to respect the resident's habitual way of dressing before a placement in a nursing home, whether it is a formal suit or a dress. In this context consideration is given to whether the resident herself or himself prefers to dress that way or the relatives of this particular resident, if she or he is not able to speak up for herself or himself. There is nevertheless a tendency to favor "easy to wear" clothes, like some kind of exercise suit or jogging suit, not least for the very dependent residents, but it is by no means enforced. The staff actually sees the resident's selection of clothes as an important token of the person's place in society and the family's stance towards the nursing home world. A person that is of account in society is assumed to keep up a presentable appearance in so far that the world she or he belongs to is seen as measuring up to common standards of a mutual one. Actually, the staff appreciates it if a resident has an adequate stock of clothes, as it makes it easier for them to assist the resident to look neat and composed. One nursing assistant pointed out that an adequate stock of clothes makes a difference "so you do not have to run around to find something to wear". The tasks at hand certainly go more smoothly if you do not need to run around to get things done. Furthermore, the attendance to bodily needs may take on a different dimension, and a more personal one, when the staff can address the issue of what would be becoming the resident to wear that day. The staff often said that they found it much more enjoyable to dress people that have nice clothes. And this stance is reflected in the words of a practical nurse when she says:

> I find it much more enjoyable, for example, when the people have enough clothes and nice clothes, it is much more enjoyable to dress people like that rather than people who have ... nothing at all ... yes, I think so, just with everybody, I think it matters a lot if people are nicely dressed, you see, and have nice clothes.

Another practical nurse agrees as she continues the conversation and says "this matters ever so much - it matters a lot that the people can look all right and nicely dressed, I think it is a very important". The difference between people who have "nothing at all" to wear and the ones who have "nice clothes" may certainly reflect the respective person's financial status, and the staff realizes that. But, they know at the same time that all the residents have at least some Social Security allowance that should suffice for adequate clothing, if there is somebody to take care of such tasks as buying clothes. Actually, there are always a few residents that do not have anybody at all close to them, and in such cases the staff may go out shopping, or they will find some "left over" clothes that fit the resident. There are always some families who leave quite good clothes when their family member dies, and the staff usually makes good use of these. They will discuss which of their patients needs clothes and whether the available outfit would suit that person.

The subject of what to wear is a matter of sharing between the staff and the resident, as the staff goes about the care. The staff like to have something to talk about as they go about their care, as things then go more smoothly. Actually, the subject of the family and the patient's connection to the family may often be a relevant matter of a conversation as the staff attends to the patient. Furthermore, the staff refers a lot to a patient's sense of humor, and finds it very helpful to banter a little as they go about their care, if the patient is responsive and ready for a bit of joking or teasing. Bantering actually allows for a special kind of sharing between the staff and patient, which both parties appear to appreciate. It is indeed remarkable that the staff does not rate a patient as difficult to care for, even if she or he needs extensive assistance of two staff members to get up and about, as long as the person is easy to relate to. This perception of care is reflected in the words of a nursing assistant, as she speaks of the care of a very dependent resident:

> It is good to attend to her, she is positive ... Yes, I think it is good to attend to her. She is religious and always prays for us when we leave her in the evening. ... She has her prayer book there in the bed, she actually always asks God to bless us ... When you have finished putting her to bed.

The staff will also refer to another valuable kind of sharing, which comes about when a patient shows interest in the staff member's background and everyday activities or some special events like a vacation. As a young part-time nursing assistant puts it as she describes her relationship with one of the residents: "I just find it good to talk to her and she actually knows that I am studying and I am doing this, and she asks me how my life is going, and I ask her. I just think she is a very pleasant personality". The staff gets to know the resident and finds out what she or he is like through different dimensions of sharing, as they attend to the particular person in their hands and go about their care. But while performing the care and chatting the staff notices to more or less extent the resident's mood and composure from one day to another. And such recognition sees the resident's way of embodying her or his illness and responding to the situation as the person's expression of self.

However, the staff's conversation about their caring work during report time reflects that the importance of this kind of recognition differs between units. It was noteworthy that treatments aimed at maintaining optimal physical condition, not at least with regard to skin integrity and bowel elimination, were a central issue during reports in all units.

Doubtless to say that it is essential to pay attention to the physical needs of the inhabitants or to safeguard the necessities of the self. However, the units differ in the extent to which the effect of this safeguarding upon the person's sense of self, and her or his response to it, is addressed. In some of the units the conversation among staff, especially during reports, was focused on how the various inhabitants were disposed or were feeling this particular day, while their responses to treatments were discussed. These accounts were often highlighted by an anecdote or two of the respective resident in question, perhaps colored by a humorous raillery which gave way to a good-natured laughter. Comments like "he is not his usual self today" or "her bearing is somehow fragile today" or "she was quite frustrated and cranky as I got her up" would spur discussion about this person's condition and what could possibly have upset it and so on.

In other units the characteristics of the conversation were more concentrated on the work done and how the behavior of the inhabitants had influenced the smooth performing of the tasks at hand. In these units there was a tendency to look upon a problematic behavior as an obstacle to the performance of a task, like when the staff would point "there have to be two of us to manage her". The issue then in the staff's conversation often appeared to be the degree to which the patient had been easy or difficult to deal with to ensure proper treatment, rather than addressing a better or worse way of approaching the care of this respective person with regard to her or his responses.

In Doris Lessing's novel, "The Diary of a Good Neighbour", Jane Somer depicts how "the tone of the ward" is set, as she describes her experience of visiting her over ninety-year-old friend Maudie in the "Old Hospital":

> The sister is that person in this cast of people, all of whom seem to be admirable, who represents "the one" that Joyce and I used to talk about. It is she who sets the tone of the ward. She is middle-aged, rather tired, has thick legs that seem to ache, and a broad sensible pleasant face that gives confidence. She is always on the watch for the slightest sign of unkindness or impatience by her nurses. She does not mind

> that they are slapdash, casual, and–apparently–sometimes inefficient, forgetting to do this or that, recovering the situation with a laugh and an apology. On the contrary, I have understood she encourages this atmosphere. But when I saw one of the more brisk quick nurses using a sharp edge on her voice to old Maggie, Sister White called her over and said to her, 'This place is her home. It's all the home she's got. She is entitled to be silly if she wants. Don't hurry her and harry her. I won't have it, Nurse!' (Lessing, 1983, p. 239).

Jane Somers points out that "if you want to make things work, you have to look for *The One Person* in a department or an office who is fact running it, or who knows about it, or is in some way or another real" (Lessing, 1983, p. 45). Each unit manager is certainly "the one" of her unit and "sets the tone of the ward", but each shift may improvise their own version of this tone, strongly influenced by the RN supervising the shift. The tone of the unit appears in fact to be expressed particularly in the staff's comportment towards the inhabitants. The tone arises from the ethics of care in the unit, and reflects the staff's outlook towards the elderly inhabitants, and directs the way in which they approach the care. The care approaches may range from strongly emphasized individualized care to rather mechanistic routine care, depending on the degree to which particular personal characteristics, habits and practices are acknowledged.

Quality of Life

> You see, considering the circumstances, the quality of life is as good as it can be. I would not want - would not wish myself to get into these kind of circumstances. ... These people, here in this institution, they have everything, they go to the hair salon and to exercises and listen to readings and watch the television and everything, you see. The quality of life for the people as they have become is as good as it gets. But of course a person who is out there in society you see, he just thinks differently. He thinks to himself, I hope I will never need to get into this kind of a situation. But I am sure that when people have been here for some time and have adapted [to the

> situation], then they do not think about anything else, then they are just you see - this is the world - this is the world and then you might perhaps say, although you think like this today, so if it happened, then you will be just be like the others, you will just become - then this has just become your world. You are not speculating any more about what is happening in the Mall or the Pearl [a rotating restaurant with a panoramic view] or something like that, which these [people] do not of course do. ... But I think that the quality of life for these people who are here is good, I think so. I'm sure they're content. (Katrín's son)

The words of Katrín's son reflect the assumption that expectations of quality of life have different premises for the nursing home residents, compared to someone out in society regarding "the way in which they have become". And certainly the notion of quality of life has multifaceted dimensions, depending on the person's background and where and how she or he is situated in life. The families' and the staff's expectations of what constitutes quality of life in a nursing home draw upon the place itself, its organization and structure and not least on their perception of how the resident is situated in the place.

Actually, Katrín herself says that she is quite content with her life in the nursing home. Katrín was, after all, 85 years old when she moved into the nursing home and had been repeatedly hospitalized during the couple of years before her placement. She emphasizes, when she speaks of her life in the nursing home, that at the time of her placement she had thought of nursing home living as a better arrangement than living with her son and his family. Katrín tells the staff that she did not consider such a living arrangement an option in light of her experience of having her own mother-in-law share her family life for a number of years. It is obvious that she did not consider living on her own, after her husband died, when she was in hospital. She lives in a large, comfortable and tasteful room decorated with pictures, photographs and other personal items. She directs her own care to a degree and it is in fact remarkable that she decided herself upon full treatment after a bad accident about a year ago, at the time of my data collection, in which she suffered serious fractures. The staff remembers her vigor in getting herself up and about after the accident, and indeed they refer to her stamina, and her disciplined manner of keeping herself going. Katrín insists on walking to the dining room three times a day, using a tall walker with wheels, and with the assistance of one person, for the sake of the exercise and to meet her dining companions. The walk takes quite a while, as Katrín moves slowly with her cautious movements and bent back, compressed by repeated fractures, with a big shawl wrapped around her shoulders.

Katrín's routine of activities and rest every day is scheduled according to her habits and preferences. She likes to sleep in and gets up rather late, just to get ready for lunch, however she must rise a little earlier those days of the week when she goes to physiotherapy or to the hair salon. Then she sits in her "special" chair at the window in her room, when she has rested after lunch and had her coffee, and reads her paper and enjoys the view. She only comes into the communal area during meals and for the evening refreshments when she watches the evening news on TV with the other residents and the staff. She retires early, as her body aches least in bed, as she says, and either listens to radio or watches the TV at her bedside until late in the evening. Katrín gets on well with the staff and her tablemates in the dining room, and enjoys the support of her son and his family. There was a general agreement among the staff that "she lives a rather good life in a way" as one of the nursing assistants pointed out:

> But Katrín rather likes to be comfortable, as I said, and she always asks you to put the radio on if it happens to be turned off, and move it closer, and things like that. You see, she does have something of a life, I think ... in spite of all the handicaps she suffers from, I think that she lives a rather good life in a way ... she keeps a bit up to date and knows what she wants, and things like that.

Katrín exemplifies what Golander (1987) calls "old survivors" as she points out that "the aged succeed in reaching old age because of their strengths and their ability to cope with stressors and changes throughout their long lives" (p. 27). It has not been Katrín's way of being in the world to give way except in the last resort, and she has her own strategic manner of keeping herself going and holding her aches at bay in the current circumstances. Katrín makes the situation meaningful by the means of these strategies and apparently lives "a rather good life".

The resident's condition, and her or his stance towards the circumstances, are of importance when the issue of the quality of life in a nursing home is addressed. Furthermore, both families and staff were inclined to see the person's ability to respond appropriately to her or his world, and engage in purposeful activity and meaningful relationships, as a major determinant of the residents' potential for any quality of life. However, the extent to which both parties considered the activities and relationships of the daily routine, with regard to their impact upon a quality of life, varied. Rather, people would look upon some structured activity, or any diversion, as means to add to the quality of life in nursing homes. And structured activity obviously made a difference. For example during the morning hours in two of the three nursing homes participating in this study, one staff member was assigned to gather the residents, so inclined, together in the communal area after breakfast for some activity and diversion. The structure and content of these morning periods differed somewhat between units, depending on the creativity and relational skills of the respective worker. However, most of them had actually been assigned to this work because of their skills in this regard, and they appeared to manage to make this hour really pleasurable for the participating residents. The hour would often start with paging through the morning papers together, or a reading from a novel that continued from one day to another, then coffee would be served with a chat. Some "good old music" might be played on the CD player, and during the winter a candle or candles would be lit. Some of the "activity ladies" were simply very warm and cheerful, and a few were ingenious in helping some of the female residents to master knitting or some needlework. However, I hardly ever saw so much togetherness, joy and even excitement as during a morning hour in one of the units when a nursing assistant, relieving the usual activity lady that day, was giving the female residents a manicure and painting their nails with pale pink nail polish. It was in fact amazing to watch even very disoriented and restless residents sit there peacefully waiting for the polish to dry, while watching the activity going on around them. Needless to say that the person "setting the tone" of this hour made all the difference. But it was, nevertheless, noteworthy that there appeared to be a somewhat closer relationship in the group during this hour in the home, where one of the nursing assistants participating in the bedside care was assigned to conduct this quality time, rather than somebody hired just for this purpose, as was the case in the other home. The nursing assistants may be expected to know the residents quite well through their relations and sharing during bedside care, and it is possible that this kind of connection is reflected in the way in which they bring the group closer together.

These morning hours of togetherness and activity certainly brighten up the day in the nursing home, as do all diversions like some special festivity, or occasions where there is a performance by some artists for example, playing instruments or a choir singing. And so do the family's visits. The aim of improving the loved one's quality of life in the nursing home was in fact more or less explicit in the families' account of their visits. And the visiting hours appeared to be the highlight of the day for many residents, even the only quality time which the younger residents enjoyed during the day in the nursing home. These residents often did not want to participate in shared activities in the unit, and might spend much of their time in solitude between visiting hours. Outings were also very important for this group of residents, and a day out certainly breaks up the everyday routine, as do the preparations. The staff actually cherish all connections with society which bridge the gap between the nursing home world and the outer community, like patients' outings. It was a general consensus among the families participating in this study that messages regarding the timing of an outing are normally attended to. And the way in which the staff prepares a resident for an outing with her or his family is indeed remarkable. It is a priority, as daily routine goes on in the unit, to make sure that the resident is ready and all dressed up when the family arrives to pick the resident up to go out. And the staff by no means looks upon it as an extra burden to prepare a resident for an outing. An outing brings about a formal contact between the family and the staff, and a planning of an outing and a discussion about its success is an aspect of the relationship between these two parties that is taken-for-granted.

There is a consensus among the staff that almost all patients who are up and about enjoy an outing and cherish a visit, and are enlivened by it. However, the staff is rather hesitant as they address the family's contribution to the quality of life of their demented patient, while they certainly believe that the family does so as far as other patients go. But the staff feels that there is often an air of contentment and calmness about people after a visit, even though they may not remember it. There is no doubt in the staff's account of the family's contribution to the quality of life of Kristín, whose story is told in the previous chapter. The staff's voice is unanimous as they speak of the family contribution to her wellbeing. The staff perceives Kristín's family as an exemplary family, and in many ways exceptional, while they regret that there are not more families like this, visiting and caring for their relatives. Indeed the RN participating in the group conversation maintains that Kristín's quality of life is certainly better than the life of an average person her age, and she adds:

> I would say, because of this good relationship with the family, this concern which they show for her, and actually from the staff as well, that comes about because she is so positive herself and calls forth [such] good responses. She really charms us, she has that kind of eyes which simply get to you ... and I think she wins everybody over, so her quality of life, considering that she is confined to a wheelchair, is actually just as good as it gets, considering her condition and being in a nursing home. She is active, she has her knitting going and... the tasks of the day, and enjoys

everything which is on offer.

The unit manager adds that Kristín has many good days, especially since she got a room on her own. She appears to feel well, the unit manager says, and does not suffer any pain or discomfort. Furthermore, the staff thinks that it is important that Kristín does not show any signs of depression, even though she needs so much help, as a nursing assistant puts it "she does not seem to take it hard even though she needs so much help. She is just grateful for that and she does not wallow in it or become sad or anything like that". So the staff maintains, all things considered, that Kristín has a good quality of life. As a practical nurse points out "she has a very nice room and a lovely family", and nursing assistant adds "I think she enjoys a very good life, she can participate in various things and go out, and does so sometimes, and can enjoy what is there. Actually, I think she can enjoy many things, considering her age, and that she is in a nursing home and confined in a wheelchair". Indeed, one of the staff members says as she talks of Kristín and her family "I would actually like to have more of this recipe for the whole unit".

It is noteworthy how the staff interprets Kristín's quality of life, as it summarizes in a sense the kind of wellbeing they envision as possible for a person living in a nursing home, all things considered, as they say. And certainly, the staff has to consider the inevitable slow deterioration and helplessness of their patients. Patients are living into very old age, often with multiple diseases or impairments, and the staff is not going to see progress in that sense, but possibly some kind of wellbeing which may nonetheless be hard to define. Indeed, both the staff, and often the families of the mentally impaired residents, found it hard to address a notion of quality of life with regard to their condition and a family member may say with regret "this is no kind of life". The staff may also contemplate whether "there is any life at all" when a resident responds to a limited degree to the care they give. This stance is reflected in the words of a nursing assistant when she addresses the quality of Pétur's life, considering his advanced stage of dementia:

But this has of course become in a way like a closed circle. He, of course, does not

> know anything himself, there are just some outside persons who attempt to make him comfortable and he does not ask for anything, we just have to see to it that this is all right and suits him as far as it is possible. But he has of course lost everything himself, so it is somehow not possible to talk about any quality of life or anything else in that regard, I think so, he is just here until he falls asleep, and he is just there, he is really half dead you see, that is the way it is. We are just here to take care of his physical needs, you see. And I think that it's as good as it gets. (Nursing Assistant)

However, Pétur's daughter takes a different stance and looks upon the accommodation of the unit as she speaks of his quality of his life and points out:

> I think this is quite a luxury - the quality, just this elegant, fine food, there is you see, plenty of it, and it is good and really fine food too. And the environment is good there, chairs have been bought, armchairs with a footstool ... two new chairs at least have been bought and I know that he always sits in one of them, and he feels good there, he can recline the back, and things like that, so that the furniture is good and there are handicrafts and there is reading and there is music. There was a man playing the piano yesterday or the day before yesterday, when I arrived, a man playing the piano for the residents, old Icelandic songs, and that's what I call quality. ... I must say it's super to live like that in your old age, being helpless like that.

The daughter has always placed emphasis on her father's accommodation because this has mattered to him throughout his life. She still finds it very important for his father's quality of life to be in a pleasant surroundings "dad is used to it, you see, to have nice things around him". Pétur's daughter takes his helplessness, and possibly his more than ninety years of age, into account as she interprets his quality of life and finds it "super to live like that in your old age", given his condition.

The visiting family members may indeed establish their definition of quality of life with regard to the resident's condition, as the daughter speaking of her 85-year-old mother suffering from advanced dementia put it: "The people there are at very different stages. It is like that with mom, I think that her quality of life is for somebody to be kind towards her, give her something to eat, dress her and that she does not feel any pain". Actually the daughter's interpretation of Sigrún's quality of life reflects the stance of the families of the very old demented residents towards the notion of quality of life. For them it is very important that their loved ones' bodily needs are taken care of, and that any signs that could possibly be indicative of some discomfort or pain are attended to. Furthermore, the staff's comportment towards their relative matters a good deal, an attentive comportment that evokes security and a feeling of ease, while acknowledging the person's being.

A daughter of a 92-year-old demented woman was grateful if the staff had remembered to light a lamp above her mother's bed when she arrived in the afternoon, during the dark hours of the winter. The daughter had actually asked the staff always to leave the light on, as her mother had always been very frightened of losing her sight, but her sight had in fact diminished very much. And the daughter was trying to compensate for the ever-increasing darkness of her mother's blindness by keeping the lamp lit. A lit lamp on her arrival was an acknowledgement of her mother's being, as she had addressed her concern with the staff and told them about her mother's fear of darkness. The staff's attentiveness to "little things" like that is in fact an issue of great concern for the family members of the mentally impaired residents, because such attentiveness, or lack of it, conveys to them whether their loved one's being is counted as "any life at all" or not.

Implicit to the meaning of "no life at all" is a notion of an exhausted and helpless life, but a life nonetheless, and it is imperative for the families concerned to honour that life while it lasts, and the person living it. The person living it may be fading away, and the quality of that person's life may be questionable. However, a quality nonetheless may draw upon the inherent possibilities of the care given to the person "while waiting" for the ultimate rest at the end of a long life. It is necessary, when such possibilities are pursued, to recognize that the premises for quality of life have a distinctive meaning for the particular person who is there in the nursing home world. To this end a collaboration with the visiting family may prove valuable.

The above discussion has attempted to shed light on the constituents of the nursing home world. It has described the scene and common features designated as basic characteristics of a home within this world. The discussion has emphasized how the organization of care, and a qualitative distinction of care approaches, have an impact upon the elder's sense of self and wellbeing. Furthermore it has addressed the issue of quality of life in nursing homes. The aim of this articulation was to delineate the ground upon which collaboration between families and the staff may be established.

Chapter Six

THE RELATIONSHIP BETWEEN FAMILIES AND STAFF IN NURSING HOMES

Introduction

This chapter will address the pattern of family involvement in the life of their loved ones living in a nursing home and the staff's response to this involvement. The interpretation will attempt to bring to light how the relationships between the nursing home staff and families evolves and establishes itself through the mutual engagement of these two parties in the care of the elder. The families' involvement is exemplified by six paradigm cases. Each case explicates the family's perception of care and its relationship with the staff, then the family's engagement in the care of the elder is delineated, and the staff's response to such input. The discussion of each case is concluded by depicting the distinctive pattern of a family's style of engagement. The chapter closes with a discussion of the various factors that influence the way in which family's engagement evolves and establishes itself within the nursing home world.

There was a positive stance towards family visiting in all the units participating in this study and it was usually looked upon as a particular asset for the resident to have a regular visit from a family member. However, only one of the nursing homes employed a special strategy to encourage family visits. On entry into this nursing home a new resident or her or his relative is given a small pamphlet with information about the home and its services, in which there is a section on cooperation with relatives. In this section it is emphasized how important it is for the relatives and the staff to cooperate together and to have a good relationship. The relatives are encouraged to turn to the unit manager or the RN on duty to address any matters at hand and to inform staff of any problems or special wishes. Special family duties are also pointed out, such as ensuring certain supplies and the pamphlet tells families that all diversion that they can provide are highly favorable for the residents.

Furthermore, this nursing home attempts to invite the family for a meeting with the resident's physician and the unit manager in the first few months of the resident's stay to discuss her or his condition and adjustment in the home. Possibly the idea of advance directives may be brought up. However, this latter strategy to encourage the family's input in the resident's care is not necessarily followed up in all cases. Nonetheless the nursing home's effort to encourage family visiting appeared to work to a degree, as widespread family presence in this home seemed to be more obvious in this home than in the other two. However, some demographic factors, like marital status, do affect the extent of visits in all units from time to time as does age, particularly with regard to visits from siblings and friends, as many may be gone as the resident grows older.

So only one of the three nursing homes had directly stated its position towards family visiting in the small pamphlet discussed above. However this stance which is announced in few sentences is indeed reflected in the two other nursing homes by the staff's attitude to cooperation with visiting families. It is common in all the units to appreciate family visiting and the family's concern about their relative staying in the unit, and the staff is prepared and willing to deal with questions and requests from family members. But the family is mostly expected to take the initiative or to turn to some of the staff to address any matters at hand. The staff tends to be very respectful of the privacy of the family gathering and it is tacitly assumed that each family has its own mode of being together and relating to others.

The staff expects each family to set the tone in its relationship with the members of the staff, as they see the evolution of a pattern in a particular family's involvement in the care of their member. The characteristics of the family's involvement are expressed in different types or styles of engagement in the care of their relative which can be described in the following terms: a) parallel care; b) supervisory care; c) complementary care; d) participatory care and e) antagonistic care. The family's style of engagement in the care of the family member determines the nature of the family's cooperation with the staff and the way in which these two parties relate to each other. However, these styles are not mutually exclusive, as they may overlap, and the family may as well shift their emphasis of involvement with regard to the condition of their relative. All the styles bear upon guardianship of the family member's self and her or his condition and wellbeing.

The main distinctive feature of the different styles is the extent to which the care of the body is compartmentalized and ascribed to the realm of staff's concern as opposed to the family's care of the self. However, the visiting family certainly looks upon the staff's manner of comportment towards the inhabitants as a measure of a relational care of the self. Nevertheless, the degree to which the relational component in the staff's and family's care of the body is accounted for differs both among both the families and the staff members themselves.

Parallel care appeared to be the most common way of caring for a loved one living in a nursing home. In this style the caring activities of the family and the staff in fact run parallel to each other most of the time, without much apparent overlapping. The family places the main emphasis on companionship with their relative so as to manifest their concern for her or him, while bringing about some diversion or relief from everyday routine.

Supervisory care resembles parallel care in many ways. However, it differs from parallel care in the way in which the family member's guardianship shows up as a more direct inspection of their relative's condition and the staff's approach to care. The family members take a more overt stance to the care of their relative, and have an outspoken way of making inquiries and stating their concerns. And their directives about care may arise from their experience as a caregiver for quite a long time, and their knowledge of the respective person's response to a treatment.

Complementary care shows up in the way in which the family complements the staff's care of the body. Bodily care sustains the self from the family's point of view. And the family may give the staff subtle cues about the importance of bodily care, which is seen as manifested in a presentable appearance of their relative, for example by a thoughtful supply of clothes and cosmetics. And the staff take these cues as their lead in their bodily care and appreciate this acknowledgement of this demanding part of their work, which is often taken for granted. The family contributes in various ways to the care of the body, but direct sharing of activities and concerns between the family and staff is limited in this type of engagement.

In participatory care both parties, family and staff, participate in the everyday care of the person, and supplement each other's contribution and there is a mutual acknowledgement and respect for the other's input into care. The care of the person is not compartmentalized into care of the body and care of the self. The relational aspect of the care of the body may matter the most, and is integrated with the care of the self as the person's wellbeing is being sustained. And the family and staff address issues of bodily care with each other and share their activities and concern about the condition and wellbeing of the resident.

Antagonistic care resembles participatory care in the way in which the family may contribute to the everyday care of the person, and the family's care of the body is integrated with the care of the self. However, staff and family have differing expectations of each other's contribution to care. This divergence may create suspicion and conflicts, and undermines the care and wellbeing of the person. The family may give directives and tends to monitor the staff's care approaches, and is critical of any deviation from their expectation of acceptable standards of care. The staff feels intimidated by this kind of supervision, and tend to become defensive towards the family.

I will now clarify these different types or styles of family engagement in the care of their family member in a nursing home and the staff's mode of responding to the different styles. I will do so, as pointed out above, by delineating a paradigm case or cases which highlight the particular characteristics of each style.

Parallel Care

Óskar's Family Style of Engagement in his Care

Óskar is a poised man of benevolent appearance. He is rather thin, of average height and almost bald-headed, mostly sitting in a wheelchair if he is up. He smiles in a gentle manner when he is addressed and usually tries to say something but his speech is often hard to understand, although this varies. At times he has been able to walk a short distance with a support and his cane, but his mobility varies due to his Parkinson's disease, and is actually declining rather fast. He stays for the most of the time in his private room where there are rather few personal belongings other than a leather armchair and a television set. He watches the TV in his room, especially in the afternoon, and this is also where he receives his visitors. Óskar is visited quite frequently, both by his family and old friends and workmates. His wife visits every day and his three children take turns to make evening visits.

Óskar himself says that it was good to get into a place where help was available. He needs indeed extensive help in almost every aspect of everyday activities, and did so for many months before his admission to the nursing home. Actually the staff points out that Óskar's wife had been totally exhausted by that time, "no wonder" they add.

However, Óskar's wife states that the institutionalization was "terribly difficult step to take" even though she realized that she had no choice as she says:

> But one had, of course, realized that this could not go on. You see I could not get him about when he could not do anything at all himself, get him to the toilet and other things you see, and it happened that I dropped him on the floor here, you see, and to get him up again, it was more than you really can do. So he could not get to his feet [from a chair] on his own or anything like that. It becomes a great struggle. ... It is of course a terribly difficult step to take. But it is just when you have realized that there is no alternative. And he agreed ... he realized that I could not manage this, and it was bound to happen. But actually people are, of course, never

> ready for this, that's not the way it is, you see.

Óskar's wife remembers the time leading up to his institutionalization as a hard struggle and she subsequently fell ill and was hospitalized for a while shortly after her husband's admission to the nursing home. And she did not feel strong enough to visit her husband during the first few months of his stay in the nursing home. However, he was visited every day by one of his three children who alternated their visits between days.

The Family's Perception of Óskar's Care

Óskar's wife finds her husband's care very good and emphasizes that "they are ever so good towards him" and that "she could not do it better". But she does not see herself participating in his care as she says "actually I can't really manage to participate in his care, because he just needs so much help and I am just not strong enough to do it".

Óskar's wife has totally relinquished his "hands-on care" into the staff's realm and does not take a definite stance towards the way it is done, while she finds it good. She refers to his cleanliness and his neat way of dressing, while he was still working in a rather messy job but would always shower and change clothes before he came home. Now he is normally wears some kind of a jogging suit and she maintains that "they prefer to dress them like that, of course when people can't dress themselves anymore then it has got to be something like this, even though I find this, of course, horribly ugly clothing ... there is just no question of anything else". Óskar's wife does not think there is a question of anything else as it is "such a hard job and much more difficult for them" to keep the people better dressed. She points out that her husband's selection of clothes has just turned out this way, but she remembers having talked about it with somebody in the unit and "she said that it was quite good when people were dressed like that and I see that most of them are dressed like that ... the ones who can't help themselves at all". The wife knows the heavy demand of caring for a helpless person and she sees the staff's care approaches in light of that knowledge, as she says:

> It is difficult to take care of patients like that, very hard, the ones who can't even turn

> over in bed themselves. It is obvious. And who are not able even to reach for a drink or anything else, you see. It is obvious that it is more difficult to take care of people like that. Because you actually have to guess about things just as if you were caring for a baby.

She repeatedly refers to the staff's warm and good conduct as the most important aspect of her husband's care and she is also very appreciative of the staff's cheerfulness. She says that her husband enjoys the cheerfulness, and on his good days likes bantering with the staff, which the staff usually responds to. She notices that the staff always make sure that he has the call bell within reach and has a proper way of getting him in and out of bed and so on. She emphasizes that she is familiar with the different ways in which people may suffer from Parkinson's disease, as the disease runs in her husband's family; her sister-in-law also had the disease, and she and her husband Óskar used to visit her every other day in the nursing home where she eventually died. Her knowledge of the disease, and her experience of caring for her husband, appears to have given way to a form of acceptance or resignation which is reflected in her words when talking of her husband's condition "but this is just the way it is, you see".

The Relationship with the Staff

Óskar moved between units in the home during the data collection; he had lived for about six-and-a- half months in the former unit at the time of the first interview, and just about four months in the other unit at the time of the second interview. He himself and the family were actually expecting a possible move between units as they knew that the room available at his admission was designated for temporary respite admission. So the move to a permanent placement was looked upon as a positive event, without anticipation of much change. Nevertheless, the move turned out to be quite demanding for Óskar and the whole family. It is noteworthy that Óskar's wife points out that it has been the process of getting to know the staff or "to start anew " that has been the most difficult part of her husband's move.

It emerged in the former interview that Óskar's wife had become acquainted with many of the staff in the first unit as she said: "It varies, of course, a bit how close you get to people, but you do chat to most of the people". She emphasized the staff's warm and welcoming comportment as she said "they are just always lovely towards you, it does not matter who it is" and little later on she added "they are always cheerful" and she remembered how enjoyable it was to see one of the nursing assistants dance with one of the inhabitants when the radio played some dance music, and how this rather stiff and silent man tuned in and danced along. She does not refer to any staff member by her name, except the unit manager. However only a few of the staff members wear name tags and the relatives rarely learn the names of individual members, except perhaps a few. But Óskar's wife says that she does not turn especially to the unit manager or any particular person of the staff to address any issue of concern, just the one who is working at the time and adds "it does not matter, you see. They are all equally nice".

Actually it comes across that Óskar's wife does not think there are all that many issues to address, as things are just running their course and she knows what this disease is like, "this disease is just like that, I know that, this disease is nothing new to me" as she says referring to a meeting with the unit doctor. She says that she often talks with the staff about his husband's condition if he has been very bad, but she adds "this is just the way it is".

The staff has mentioned how nice it is for Óskar to get so many visits, so his wife believes that her visits are in agreement with the staff. And she feels that the way in which she is greeted when she enters the unit is affirmative of the staff's positive stance towards her visits. She does not think that her visits have any influence upon Óskar's care, as she answers a question on this subject by saying:

> No , I do not think so. I believe this is just the way it is. It seems to me it's the same with the others, they are just this way towards the people, that is the only thing I can see. ... I think it does not matter who it is, so to speak.

There is a rather different tone in our second interview, as Óskar's wife is more reserved is some ways as she addresses her experience in the new unit. It is obvious that the change has been hard for Óskar and his family, but his wife is very cautious not to discuss any aspect of the care approaches, or the staff in the new unit, in a critical way. She speaks courteously and respectfully of the way things are in the new unit and hints vaguely at some negative aspects as compared to the former unit, but cuts herself off by saying "I do not know what it is, but as I say they are all very good". She ascribes the difficulties to the process of growing accustomed to everything new as she points out:

> It is harder than I anticipated ... you see I've nothing against the people, but to learn to know everything anew, start again anew, it's more than I actually realized ... it is a big thing to get used to new people. ... You see I find it tremendously hard, but just think about him ... he does not usually say all that much, and has never been inclined to complain, but it was difficult for him to start with.

Certainly there is a different tone in these two units and the staff's mode of care approaches is somewhat different, but it may be difficult to pinpoint what the difference is, as Óskar's wife put it " it is not a direct difference". But there is a different staff, who by their means of involvement with their patients and their families make up the world of each unit.

The Family's Engagement in Óskar's Care

Óskar's wife found it miserable when she first started visiting the nursing home to see her husband among the other inhabitants because "he is not old enough really to be in a place like that, as a matter of fact" but she says "you get used to it". She has been visiting daily since her recovery, and the children have continued to alternate their visits during the week, as one of them usually visits each day in the evening. All of his grandchildren visit regularly and the two great-grandchildren may come along, although the younger grandchildren prefer to come with their parents rather than on their own. The wife finds it lovely to enter the home and points out that the staff is very special and she emphasizes their warm manner towards her and the family. She does not think that the nursing home gives "all that much impression of an institution", the surroundings are warm, relatively modern and well maintained and there are flowers about. She comes just before coffee time, about half past two, drinks coffee with her husband in the dining room, then they go into his room where they sit together until she leaves about four-thirty or five o'clock in the afternoon. She keeps a special set of knitting with her husband which she is doing while she visits as her husband watches the TV.

> I come around coffee time, and usually I drink coffee with him, then we go into the room - he has a television set there and watches it sometimes. I sit there by him, and talk to him depending on his ability. It differs how much he can communicate and things like that. Just sit there knitting, just as I would at home.

However she takes quite a few breaks from her knitting while she takes her husband out in his wheelchair. They may just go around the unit or down into the hall or outside the house if the weather permits. Óskar's wife points out that he really enjoys being wheeled around as it gives him "some relief"; she can't really tell in what sense it gives him relief, but suggests it may be a matter of getting in touch with the surroundings, especially if they go outside. The structure of the wife's visiting is more-or-less set in the same way from one day to another. However, the experience of visiting depends upon Óskar's condition on the day of each visit. His condition due to the Parkinson's disease fluctuates and so does the experience of visiting like his wife puts forward:

> It is actually hard when he is very bad. He was, for a period of time, he was actually tremendously bad and he always seemed sleepy and tired somehow, but now he has been better for probably about three weeks, and then is it, of course, not as hard.

Óskar's suffering is hard to bear on his bad days, not only for him, but for his visitors as well, not least his wife. She knows the very minute she sees his face how he is and what kind of day it is for him. However, the visit may ease his condition somewhat as "he is always enormously relieved when there is somebody visiting".

Óskar's institutionalization was a hard step to take, and it is justified in the family by emphasizing that his care had become too demanding to manage at home. So it is a part of the justification process to relinquish Óskar's care into the hands of the nursing home staff, as if to confirm that this is something that has to be carried out by special workers in a special setting. However, Óskar's family, his wife and children, are extensively involved in his life in the nursing home. They are very concerned about his wellbeing and they engage in his care. The way in which this engagement is defined as a part of his care is a matter of interpretation. It may be termed indirect, informal or socio-psychological care, as opposite to the staff's more direct, formal or physical care. The family's involvement in Óskar's life in the nursing home is confirmed by their presence in the unit every day. This presence has a quietness about it because, as his wife says "it has become so difficult for him to communicate. It is not possible, except when he is at his very best, for him to do it to any extent". And his wife understands his plight and just tunes into their silent togetherness as she says:

> Of course you do perhaps unconsciously [talk less together], and I think actually that he finds it just best that I sit by him and that he is aware of me there, that one is not forcing him to answer. ... I think so actually. It is hard for him to do it, and he finds it just better to know I'm there, even though I sit silently knitting. And when there are more people around visiting him you see, then he just enjoys listening to the people talking together, rather than being spoken to directly in a way in which he is forced to answer.

Then every now and again she breaks up their quietness and takes him out in the wheelchair. The wheelchair excursions are the most obvious performing aspect of her care, besides her assistance as she gives Óskar his coffee and cake during the coffee hour, while she has some herself. And later on she will give him a banana which she always brings along. However, inherent in the family's presence are multiple aspects of care. The family watches over Óskar, his wife knows his condition and his way of responding to his circumstances. She can tell how he is the very minute she sees his face. She notices how he is cared for and how the staff goes about their care, not only so far as Óskar is concerned, but with regard to the other patients as well. And she draws her conclusions about the nature of the care and its quality from these observations. She keeps up to date about how things are going by her observations and by bringing up different aspects of Óskar's condition as she talks with the staff. Her conversation with the staff is easy-going and casual, and questions about Óskar's condition are brought up in her chat with any of the staff who might be around assisting her husband in some way. She finds this piecemeal, informal information good and satisfying, and does not think there is any need for a more formal kind. The wife gets the picture of how her husband is doing when she arrives and she knows quite well the state of affairs. However, she finds it good to clarify the picture from one day to another in light of her husband's shifting condition and any events of the day, by means of this informal conversation with the staff. And she has no complaints and does not interfere with the staff's care or make any special requests. She knows the demands of caring for a very helpless person and sets her expectations of care relative to those demands.

> ... you see of course that there are periods of heavy demand on the staff, you are aware of that. And when you yourself have taken care of a patient you see, then you know just exactly how much work this is, and it becomes a tremendous amount of work when there are many patients in the same place ... yes, really heavy work.

So it does not even occur to her to bring up any special request with regard to Óskar's physical care, even though she thinks it would be favorable for example for her husband to have a bath twice a week. It is just too much to ask. And she does not comment on her husband's unshaven face until his growing beard is becoming really obvious. But it is of vital concern to be with Óskar every day. And his wife will be there each and every day. He expects her and looks out for her as half past two approaches. She lets him know if she can not visit as usual, for instance if she must attend a funeral, but then she ensures that somebody will go instead of her.

The presence of the family brings about togetherness, not least the time the couple shares together in his room while Óskar's wife sits there knitting, resembling the familiarity of countless hours spent together in their home. This togetherness sustains Óskar's sense of self in his roles as a husband and father in his family. His time with his family stands apart from the everyday experience of being a helpless, more-or-less passive, recipient of care, as the presence of the family brings about a diversion from Óskar's plight as a patient and may in some way give him a feeling of being at home. Óskar is actually quite active in his silent quietness during his visits as he shares togetherness with his family or friends. In a sense his family's care may be seen as recreational while embracing his self.

The Staff's Response to the Family's Visiting

The staff in the unit where Óskar was placed initially finds his family just lovely and exceptionally caring towards him. Actually the staff repeatedly refers to the family's concern for Óskar as exemplary. The staff sees the family's concern reflected in their consistent, extended visits to Óskar every day. They find all the family members courteous and friendly, they greet everybody as they enter the unit and move about and just have a nice manner of being around. However, they think that the wife is rather reserved, as if she is hesitant to interfere with the staff's work, but they find her very responsive as soon as something is brought up in conversation, and actually she appears to appreciate a little talk. So the staff may have an easy-going conversation with the wife as they attend to Óskar while she is visiting. His wife may ask how he has been doing or the staff may ask her about some aspect of her very artistic knitting as things go on. However, issues of Óskar's care are just touched upon. Sure enough Óskar's sleeping patterns, his declining mobility, problems with nutrition and elimination are addressed as the wife or his children bring up how he is doing. But it is not really talked over as "everything is just going so smoothly" as the RN puts it. One of his daughters once brought in some special vitamins and asked if they could be given to him, and his medication for the Parkinson's disease has occasionally been discussed. Furthermore, the staff has suggested some means of diversions to the family, such as having a cassette player in his room to play stories from tapes. And the family has been very positive towards any suggestions; this family always is, according to staff.

The staff nevertheless has some scruples considering suggesting to the wife that she might give a little hand in Óskar's care, like giving him a shave in case it has been delayed or missed or cutting his fingernails, or just adding some finishing touch like putting on aftershave or something like that. The staff finds it rather strange as Óskar's wife has attended to him in all aspects of care at home that she does not do such minor things for him herself. But she will call the staff to ask something like "does he only have a shave every other day" or she mentions that he has enough clean clothes in his closet so his shirt can be changed as the staff is attending to him. The staff does not find such comments in any way offensive, because of the manner in which Óskar's wife makes them. Actually they think that one of their co-workers may be to blame for not doing her work properly. Indeed, the staff's scruples considering suggesting that the wife lend a hand in Óskar's care seem to be rooted in their sense of their realm of responsibility for taking full care of their patients. And they hesitate to give any impression that might suggest that they would want to shift some of their duties from their shoulders to the wife's.

However the RN ponders about the wife's stance as she says: "...anyway she was absolutely exhausted by the time he entered ...but it just is not her business since he came to us - she does not do anything at all. ... I would like to see her do something more, I am not talking about any heavy work or something unpleasant". And the exchange on this matters continues as the two practical nurses join in:

PN/E: Yes, but how do you talk about things like that?

RN/A: Yes the question is whether she thinks that ...

PN/E: You see, if it is a sensitive issue, or how she would respond

PN/D: Perhaps she just thinks that she is intruding into our realm

RN/A: We think in a different way, you see. I find it so obvious to do things, like if she sees that we have not managed to get the shaving done, she would just do it, and make sure that the table is clean, this is just one little nightstand and that she would see to that things are like he wants them at home - no, it is nothing like that, hopefully she is just pleased with the way it is. ... perhaps it is just a question of respecting her stance...

In this conversation one of the staff members suggests that the wife might not find it appropriate to invade the staff's territory within which her husband's body is situated and cared for by the staff. Actually, the staff members themselves may necessarily look upon bodily care as the core of their domain of perpetual demands, as one of the practical nurses points out that "I tend to feel that we do not have the time to attend to the social and psychological aspects of care, neither of the patients nor the relatives" and a little later she says "when you know that people [like Óskar] get such good visits and then he is feeling good and you know that - you see - then you do not worry at all about him, do you understand". It is indeed reflected in this practical nurse's perspective that Óskar's family compensates for the staff's perceived lack of time to attend to the social and psychological aspects of his care. And the staff appreciates this contribution to Óskar's care and they point out that his family may influence their own care because of the family members' attention and pleasant presence. The staff certainly thinks that Óskar's family makes all the difference in his life, as the family members are the ones who bring about the quality of his life, which they all find quite good considering his situation of being in a nursing home at his age.

Patterns of Parallel Care

Óskar's care in the nursing home is characterized to a degree by a compartmentalization into bodily care, ascribed to the staff's realm, and care of the spirit or the self taken up by the family. And these two aspects of his care appear to run more or less parallel to each other. There is a mutual respect for each party's role in safeguarding Óskar's wellbeing, but the two parties do not interfere with each other's way of going about its care.

Óskar's wife had to surrender, as the load of caring for her husband's body overwhelmed her, and she had to relinquish its care into the hands of the nursing home staff. And she appears to have distanced herself to an extent from this stiff almost immobile helpless body of her husband, with its growing unfamiliarity. It seems to be better from her point of view to let the staff be in charge of this failing body as the disease process runs it course. There seems to be almost no point in making too much fuss about the body's appearance, or making much attempt to keep up her husband's habits of cleanliness and grooming. At least, she could no longer do it at home and from her perspective there are limits to what you can ask of the staff as they go about their demanding work of caring for helpless bodies. So it comes across as if it is up to the staff how they attend to the necessities of the Óskar's body, while she herself and the whole family concentrates on the sustenance of his spirit and his self.

The care of Óskar's body is indeed very demanding, as he needs extensive care in every aspect of everyday activities, as his body is mostly very stiff and almost immobile, or has some involuntary movements. There have been some attempts to control his body by timing his medication according to the hours when he gets up and other helping activities, but the staff does not think that the timing makes much difference. Even more importantly from the staff's perspective, attempts have been made to make the care of his body more manageable by "getting some hold" of his elimination habits like the RN points out:

> But it is a bit of a pity you see, he is rather, or was in the beginning particularly rather demanding, you see he had always gone to the toilet as many as ten times really, or something like that, at home, and the dear wife had always accompanied

> him - then he comes here and then it just - does not work out - you see a case like this, neither for him nor anybody and then a change was needed, you see, and it was of course a great shock for the poor man - then he realized himself - and we were trying all kinds of solutions like putting on him a uridome or wrapping him in a diaper, you see, so he would also get his rest, because of course he needed a rest during the night; this has actually improved a bit.

Actually "going to the toilet" is almost the only thing Óskar asks for, but it is certainly time-consuming and hard work to help him to go, so it appears to the staff to be unrealistic to expect them to meet his frequent requests at all times. So Óskar's habits of elimination have to be brought under some control or other. Óskar attempts some resistance, but he does it in his gentle, courteous manner. And his resistance is fading as he realizes the constraints of his situation.

Óskar's response to the caring approaches in fact makes a great difference. He is gentle, humorous and very grateful when he is being helped, and it makes the care a lot easier as they can have some fun as he always laughs at "our stupid jokes" as one of practical nurses puts it and "even tells some himself". This sharing of a joke highlights the social and psychological aspects of care which is grounded in the relationship that constitutes the bodily care. The relationship that constitutes Óskar's bodily care rests upon the staff's understanding of his manner of relating to others, and sustains his way of being in the world. The staff appears to go automatically about Óskar's care with cheerfulness and a little small talk, possibly integrated with some bantering. But the staff has learnt to know that it makes their approaches to his care easier to tune into his way of responding to his failing body and receiving a helping hand. The staff has not acquired their knowledge of Óskar's manner of relating by any formal means but by their sensitive observation of his response to his situation. They say themselves that they do not really know his background and "the way he used to be" though some have picked up some comments made in passing in their conversation with the family like when the wife said "he often shaved himself twice a day" or when the daughter said "he was never one for recreation but just liked to rest". And the staff has concluded that he must have been " a good man" in light of one of the daughter's comments as she said "he certainly deserves it" when a nursing assistant brought up the family's frequent visits when she met the daughter at a swimming pool.

Certainly the staff's relationship with her husband stands out as the most important part of Óskar's care as the wife talks about his wellbeing in the unit. And it is quite possible that all the difficulties accompanying the move to another unit can be ascribed to the difference in the staff's knowledge of Óskar's manner of relating. So the compartmentalization of Óskar's care into bodily care, ascribed to the staff's realm, and care of the spirit or the self taken up the family, is a matter of the emphasis that each party puts on its contribution to Óskar's wellbeing that are established upon visible aspects of care. But the family certainly watches over Óskar's physical condition and the way he is cared for and the staff cares for his spirit as they go about his bodily care in a way which sustains his self. But the parties do not interfere with the other's way of carrying out the care they give, or consult with each other, possibly because they themselves are more aware of the visible aspects of their care, and count it as the most important and somehow appropriate for their domain.

Indeed, there appears to be unnecessary reserve on both sides, as each party has the potential of supplementing each other's input into care. The wife could certainly contribute to the staff's practice of caring for her husband with her knowledge of his habits and concerns, with regard to bodily needs and grooming and dressing. Such provision of information could be encouraged in so far as the staff appreciates such kind of information. Furthermore, the staff could probe whether the wife feels she would like to add some "finishing touch" to her husband's care or not. Such potential bridging between the two lanes carries with it the possibilities of enhancing each party's contribution to Óskar's care in a way in which that may make it more wholesome. But such bridging needs to be done in a sensitive manner, as Óskar's wife has actually resigned from his bodily care and does not feel strong enough to participate in this aspect of his care. However, contributing a little " finishing touch" to her husband's care, and providing information on his customary manner of being, may nevertheless help Óskar's wife to acknowledge his failing body and help her to get further in touch with her husband the way he is now.

Parallel Care

Soffía's Family Style of Engagement in her Care

The way in which Soffía's family is engaged in her care has some similar features to the engagement of Óskar's family in his care, as the family's contribution to Soffía's care appears to run more or less parallel to the staff's care. However, the family's experience of visiting and involvement in Soffía's life in the nursing home is quite different, due to Soffía´s resentment of her institutionalization and upheavals in her relationship with the staff.

Soffía is 74 years old, a serious looking woman who seems to be somewhat on her guard, even distrustful. She does not smile very often, but she completely changes when she does and there is a quick glimpse of warmth and sincerity. She is rather slim, of average height, mostly dressed in rather sporty outfits, trousers and a sweater. Soffía has a short haircut, the hair is grayish with white streaks in it and it is mostly simply combed in the way in which it is cut, and she hardly wears any make-up. Soffía has lived in the nursing home for fourteen months at the time of my investigation. The institutionalization has been hard on her and she longs to get out of the place. Soffía sits in her wheelchair all day, sitting for most of the time slightly reclined outside her room in a niche in the hall facing the elevators. She is confined to a wheelchair since she suffered cerebral insult with left hemipareses.

It is the passivity that gets on her nerves, she says, just sitting there all day. Soffía has been physically very active throughout her life and engaged in various sports with her husband and they have also traveled extensively together. Actually the staff maintains that Soffía's negative stance towards everything within the institution prevents her from making her life more bearable within the place, and hinders her in enjoying the things which she could enjoy, as this practical nurse points out:

> There are various things. As I once said to her "you have a lovely family, plenty of children and grandchildren and you have lots of friends here, and there are various things going on, if only, my dear Soffía, you would allow yourself to participate a little". But you see it is this negative attitude which always turns up, and hinders her in participating in certain things. This I think is a bit of a problem and is certainly the main problem. ... she naturally does not see this light.

The light to which the practical nurse is referring is the realm of possibilities which might make the situation more bearable for Soffía. However, Soffía's sense of possibilities appears to have been, throughout her life, very much tied up with physical strength and movement, consequently any notion of participation in a world in which she can only move to a limited extent is foreign. Physiotherapy is in fact the only thing she sees as enjoyable and therapeutic in the home.

Her 77-year-old husband visits her twice a day every day, first in the afternoon for at least an hour and then in the evening for one-and-a half hours. Maybe it is somehow symbolic for their "mobile" life together that they are almost continuously on the move during his visits, particularly in the afternoon as the husband wheels his wife around in her wheelchair back and forth down the corridors in the unit and about the house. The husband says that Soffía finds it soothing to be wheeled around and in some ways it may be seen as a temporary relief from a static situation, which by its very lack of motion is so hard for her to bear.

The Family's Perception of Soffía's Care

Soffía's husband seems quite perplexed about her helplessness and the extensive helps she needs to ambulate and get dressed. And her problems with toiletting and perineal care are in particular hard to face. But the husband stands by his wife as she receives help and he realizes the difference in the way in which the care is given. He says that Soffía makes a distinction between the staff, actually she has always discriminated a bit between people and now she definitely ranks the staff. Highly ranked staff are characterized by their tactful conduct as they address and speak to her in the right manner, but the husband says it is hard to explain "the right way of speaking to her", that is to his wife. As he says when he is asked about what helpful conduct implies:

> It is just you see, being obliging, in a way. There is one who is in the top category with her. I mean, you see, she can talk to her and then everything is ... in the right manner. I don't know how to explain it.

Then he says that the staff has different manners of working, of course, and points out "that it is no small thing to have a diaper put on you and let it fit well. It matters how it is done, as with other work it matters how it is done".

The husband says that his wife tends to bear a grudge for a long time if she feels that she has been offended in some way. She still feels the resentment evoked by an incident a while ago when she rang the bell and heard a staff member announce outside the door "it's just Soffía" and the husband refers to this incident in both of our interviews. He says when he is asked about what may determine Soffía's ranking of the staff:

> It is to some extent, you see, there are some who are irritable towards her if she is, if she is, if she is ...she has a very large urinary output, like that, and if they are yes, suggesting that she is, always doing this, always calling for help and everything like that ... or in a way not acted enough... once she heard it outside in the corridor: "it is only Soffía calling". And it annoyed her tremendously, I mean such a tiny thing, I was actually telling her that there is no point in taking this to heart, or something like that. But you know, of course, when something regards yourself.

The husband actually says that his wife maintains that the staff responds more swiftly to her calls when he is there with her, but he admits at the same time that his wife is impatient, as her sense of time has suffered some damage since the insult. And he points out that, due to his wife's impaired sense of time, her perception of a period of waiting might be inaccurate:

> They are not always quick enough, you see, because sometimes she has waited for half an hour, but it is actually only about five minutes. Time like this, time like this is a bit abstract with her. If she needs to wait a bit then it gets exaggerated.

Actually, the husband has come to realize that his wife's account of an incident might be a little distorted, especially with regard to any time aspect of the event, so it might be that the staff's response to his wife's calls is not always slow.

Soffía's husband speaks also of his wife's long-standing tendency to discriminate between people, which may not be easy to deal with, and which may affect Soffía's relationship with some staff more than others. But he thinks, at the same time, that some of the staff have a better way than others of relating to Soffía while going about her care. The husband, like Soffía herself, places a considerable importance on physiotherapy. He even ponders Soffía's possibilities of getting around with a walker, which is something she hopes to do. The future prospect of Soffía's rehabilitation has certainly been addressed while she was still in the hospital and the issue of institutionalization had to be brought up. But Soffía and her family were probably too engrossed in their difficult experience at the time to get any clear message of these future prospects. And the way in which Soffía, and in particular her husband, talk about her hope for restoration, suggests that this prospect has only been discussed to a limited extent in the nursing home. The couple has altogether rather unclear ideas about Soffía's rehabilitation potential, but both of them hope for some progress.

The husband finds it however, rather contradictory that Soffía is on one hand very enthusiastic about physiotherapy and ready to work hard during the physio hours. But then she is not all that interested in participating in her own care or doing any work in the unit. Nevertheless, Soffía has indeed shown quite some progress, as she can lately keep her balance with support, and stand on her right leg when she is transferred. And she is very pleased if she can manage to go the toilet with the help of one person instead of two. Actually it sounds like as if this achievement gives Soffía a tiny hope of being able to return home one day. And that is what she is longing for. However, the staff does not regard Soffía's thoughts about returning home as realistic. They do not expect such progress, but reason that they do not want to discourage Soffía, so they do not say much or talk it over.

The Relationship with the Staff

Soffía's husband only turns to the staff if there is an outing on the agenda, as his wife's impaired sense of time may lead to conflicting messages and make her anxious. It is difficult for Soffía to keep track of dates and timing of any planned outings, so she may actually get quite agitated if something of that kind is coming up. It is mainly on such occasions that the husband's lane of care intersects with the staff's.

Soffía's husband is indeed his wife's ally, he stands by her and it is possible that he finds it best not to mingle too much with Soffía's attendants. Indeed, both the husband and the staff point out that it would do Soffía good to have a rest during the day, as she stays continuously in her wheelchair for eleven to twelve hours during the day. However, Soffía firmly refuses to have a rest during the day. She says that she gave it a try and she felt she was under restraint, as she could not get out of bed with the bedrails up and the staff was not very willing to help her to get out of bed. Soffía actually, according to the staff, wanted to get up just minutes after she got into bed and grew very offended and annoyed when they tried to persuade her to stay in bed and have a nap. But that was it for Soffía, as far as naps go, and she says she has never been used to taking a nap in the middle of the day during her life, so she can do without it. The husband has not tried to persuade his wife to take a nap during the day because "then she says I am simply nagging like the girls" and he is first and foremost determined to stand by her, whatever her attitude may be, even though it may not at times be quite beneficial for Soffía.

The staff point out that they find it hard to discuss Soffía's condition with her husband as he tends to consider things from his wife's perspective, whether it seems to be realistic or not. And it appears that he distances himself from the staff's realm of care with this firm stance on his wife's side. He keeps to a degree his distance from her bodily care, and it is possible that he finds it in some way disrespectful and disloyal to his wife to discuss her condition with the staff.

Soffía's children, especially the daughter, are more friendly towards the staff when they visit, and readier than the husband to enjoy a casual chat with the staff. Soffía is proud of her family and often refers to the family in conversation with staff, as if her family is a testament to her self and her life. And indeed the family's concern, and the way in which the family members act towards Soffía and go about in the unit, brings about recognition of Soffía's person and her impact upon the family. The staff does not think that the family makes any particular request about the way in which they care for Soffía, but there is this unspoken expectation in the air that the staff should attend swiftly and well to Soffía.

The Family's Engagement in Soffía's Care

Soffía appears to make it through the day only with her husband's support and the other family members' visits. She is very proud of her many visitors, all of whom write their name in a visitors' book. She enjoys showing her visitors' book and referring to her guests, not least her three children who visit frequently, often with Soffía's grandchildren. Soffía also enjoys inviting guests into her room, which is very pleasantly arranged with a few pieces of tasteful furniture and many beautiful paintings. Actually, Soffía shared a room with another patient for a short while at the beginning of her stay in this home, during which time she definitely did not want any personal belongings around, not even a single painting. But she could in a sense "declare" a place of her own as soon as she moved into her own room where she could convey some sense of her self by the way in which she arranged her personal belongings with the help of her family.

The husband looks upon the visits as a part of his everyday activities and it has become part of his daily habits to spend this time with his wife in the nursing home. They just have their kind of calm time together as the husband puts it; however, he says that the way in which he leaves his wife is critical to the outcome of their time together, and how Soffía feels. It is important that Soffía is engaged in an activity when he leaves, rather than left somehow empty-handed and abandoned, in this place which is not to her liking. Other visitors, like their children, often come in the afternoon towards the end of their father's visit, making it easier for him to slip away. Conversely he is often the only visitor in the evening, and he has found out that timing of his leave-taking makes all the difference, so he does not leave until Soffía is getting ready to go bed, sitting by the washbasin about to brush her teeth and he says:

> ... it was like, when she was going to be helped to bed, then it is all right for me to leave. It was more difficult when I left while she was having ... water or coffee [refreshment before bedtime]. It is about half past eight or something like that, instead of fifteen to twenty minutes past eight. That was all the difference, and she feels somehow entirely different when I stay until she goes into her room. It is maybe 10 minutes' difference, if that ... after I started doing it that way, I would not consider doing it otherwise.

Then he goes, and leaves the care of his wife in the staff's hands; his part of the care is over. However, he does not interpret his visits as care in that sense, but simply time spent with his wife. He is his wife's ally in her struggle with a helpless body, and gives vent to her frustration and grief. At the same time he supports her hope for restoration of some of her former strength through physiotherapy. Soffía's husband keeps in his own track as he wheels his wife about and has his own way of minding Soffía's spirit and sustaining her self. He is not going to interfere with the staff's work in any way, but stands by Soffía and the way in which she attempts to direct her own care, which she certainly does to a degree.

The Staff's Response to the Family's Visiting

The staff find it hard to figure out Soffía's mental status or clarity of thought; they find that her long-term memory is apparently more-or-less intact, but think that she may at times confuse recent events. However, her thoughts come across as very lucid on other occasions. Simultaneously the staff finds it hard to figure out how her husband perceives her condition and how literally he accepts his wife's side of the story going on in the unit. As the unit manager says:

> ... yes, chiefly if Soffía is in rather a bad mood or something, and you might know the reason, and then I have gone to him and explained to him why things are like that, and then he appears to understand it altogether, he seems to understand it you see, but then on other occasions you may perhaps think that he takes it rather seriously, somehow, what she says... even though it is something which does not have its place in reality.

And a nursing assistant adds:

> ... you see, when Soffía is in a sullen mood, then she complains to him about us and if he actually begins to contradict her or something, then I think you see that he will suffer for it also, so that I think he tries just to stay silent.

Soffía's problem of urinary incontinence, and her frequent requests for help to go to the bathroom, is definitely a source of conflict with the staff. Her husband has at times discussed the swiftness of response to her calls when the staff has come along. One nursing assistant actually addressed the issue, as she overheard some rather negative comment about the staff as she entered and she said something like "even though we are like that, we are doing our best. I was occupied with another person" and the husband did not say much at all, according the practical nurse telling the story.

The staff points out that the husband took quite a critical stance towards them at the beginning of his wife's stay, however it has been becoming less so, as a practical nurse says: "yes, it is getting better. I think he is, in a way, understanding her condition better and getting to know us as well" Then the staff is learning to deal with Soffía's emotional swings and her way of conducting herself in a very headstrong manner. The staff thinks that it is of paramount importance in Soffía's care to maintain her routine and that she receives positive responses. As the "highest-ranked staff member", a practical nurse, describes with regard to a positive response:

> Yes, somebody to talk to, attend to her, show her ... - you see, when you come on duty "how are you Soffía", that you greet her when you are arriving on your shift. She notices that. ... Yes, that you say "how do you do, love, here I am" and then she perhaps says "what do you say" and, in a way, like talking just a little together, it matters enormously to her. That she is noticed. That she is just like every other person who matters. ... Yes, that she is not passed by without saying anything, you see.

However, it is the fluctuation of Soffía's mood and to some extent her clarity of thought that the staff finds difficult to deal with when they are caring for her, not only from one day to another but from one hour to another. The unit manager says "she is like two personalities" and a nursing assistant says " you see, she can be very difficult for an hour, say like in the evening, and then just fine the following hour, and then she may ring the bell and need something; then, you see, she kisses you and pats you and says "sorry, I was nasty to you before, and things like that.

The staff finds it hard to discuss Soffía's condition with her husband and the unit manager says "you see, I think he is not keen at all on discussing [her condition] himself, that is the way I see it. He says little. Personally, I find it rather hard to talk him except about something casual".

The staff recognize that Soffía's life in the nursing home revolves around her family's, and particularly her husband's, visits. She waits for him to come, and might actually be afraid of leaving her spot in case her husband might miss her when he arrives, as she once said to a staff member. But her husband can hardly miss her because she sits in her niche opposite the elevators, where she can observe what is going on in the unit and notice every person that enters. The staff knows by now that Soffía gets upset if her husband is delayed or his routine is changed at all, then she may complain to the staff, when her husband has left, maintaining that he did not say good bye or said that he would only be gone for a little while. So the staff will assure her that her husband will definitely return as "he always leaves during this hour and then he will return". And the staff has overheard the husband when he returns by seven o'clock explaining to his wife "my dear Soffía, you know that I always come back, I always go during this hour and I always come back around this time". There is a difference between days depending on the stability of the routine, and depending also on Soffía's condition.

The staff finds Soffía's children very nice and pleasant. Soffía has a way of introducing her visitors and any staff member who may enter the room to give her a helping hand while she has a visit. The staff member's presence in the room is personified by this gesture and the staff appreciates being treated as persons rather than a mere commodity of helping hands. Indeed Soffía and her family acknowledge the staff by the way in which they pay attention to individual staff members and show their appreciation. The staff points out that Soffía knows each and everyone of them, and most by name. In this context they refer to the time when Soffía was giving out handmade Christmas cards done by one of her family members and she would know who had already got one and who had not. The staff looked upon this gesture as a symbol of acknowledgement of their work, and received with gratitude their own cards, which each one was invited to pick out from a larger selection. The staff noticed that Soffía appeared to feel good about being able to acknowledge the help she receives from the staff, by giving an individual staff member a gift as a token of her appreciation apparently "without any discrimination".

The staff also remember quite a few occasions when Soffía's children have paid particular attention to, and given recognition, to the part they play in their mother's life.

For instance one Sunday, shortly after Soffía's entry, the daughter brought some photo albums with pictures of important events in the family and sat down with her mother and some staff members in the sitting room to look through the photos and give the staff some idea of the mother's story and former status. And another time when the daughter wanted to show the staff Soffía's great-granddaughter while visiting, or when one of her sons gave them a helping hand while decorating before Christmas. Soffía's husband and her family are the source of the only light in her life, but she may nonetheless become quite anxious if there is special family occasion coming up, as one of the practical nurses says: "if she is going to go somewhere, something is coming up, then she might turn around against it, find everything impossible and everybody impossible, and both herself and others".

But this practical nurse points out that she finds it helpful to pamper Soffía in a way, to call forth a positive outlook towards the respective agenda of the day, as she further clarifies with an example:

PN/A: Then I think you also sometimes need you see to pamper her a bit - if she is going somewhere, then you need to build up with her a kind of positive outlook towards... towards actually this, going, that it is going to be fun, and it's all right and she is not going to stay too long and things like that, so that she can ... - I don't know quite why this is. This has happened to me.

INT: Yes, yes. Can you tell me an example of this?

PN/A: There was some Sunday, it began right at breakfast, that she was not going to go, she did not feel up to it and everything was impossible.

NA/D: Something which had been coming up for while, wasn't it?

UM/F: There was some birthday party, I think or something. It is unfortunate to tell her about [such things] long time in advance you see.

PN/A: Yes, she actually knew about this the evening before and I had plenty to do naturally also on the corridor, but I allowed myself plenty of time to do things for her, and in the end then it went very well. But she was ... I talked a lot with her, and we began to look for the clothes and things like that, but she was always very negative, that she could not go, and would not enjoy it, and they would not enjoy having her, because she was not what she used to be.

INT: Yes

PN/A: I don't know, there are some associations with regard to the relatives then

INT: Yes, yes indeed

PN/A: But then it worked out, and she looked fine, and was positive by the end you see

INT: So did it begin right in the morning or was it ...?

PN/A: She rushed from the breakfast table, that was it

INT: Yes she rushed from the breakfast table

PN/A: Yes and I was taking care of her this morning and I noticed this and I say "Shouldn't we start getting you ready soon for this event" and then she says "no, I am not going" and this actually begins like that

INT: Yes. And how did you think it was best to work on this with her, did you then ...

PN/A: I just began with small details, in a way, like what would suit her and what would be comfortable to wear, and what would really be enjoyable with regard to the outing, I stressed the pleasurable points.

INT: Yes, yes

PN/A: The little kids, and that it was a long time since she had seen this one, and things like that, these were in a way just details, to let her forget the main [thing], perhaps... really that she was going to go, but began kind of talking around it in a way. Began to speculate about the clothes - she had got something new and kind of various points in a way, details by which I could let her forget a little, perhaps what she had decided

INT: Yes, distracted her thoughts away from it

PN/A: Yes, and somehow it worked, you see, because I allowed myself plenty of time

INT: Yes

PN/A: But it really needs to be done with her

INT.: To allow her extended time.

PN/A: Yes, so she will be happy. Or don't you think so?

UM/F: Yes, yes

PN/A: Yes, when there is something different, whether it is something with herself or then ... like on this occasion, if she is going to go somewhere, something is coming up, then she might turn around against it, find everything impossible, and everybody impossible, both herself and others.

This example reflects the way in which the staff is able to relate to Soffía, which helps her to redefine her situation and enhances her sense of belonging in her family in spite of her handicaps.

Patterns of Parallel Care

Soffía has never been very preoccupied with the way she dresses or uses cosmetics, and it matters even less now according to her husband. Actually Soffía always looks very clean, but not decorative or stylishly dressed. It appears that Soffía feels that her body has failed her, as it is lacking in strength in sustaining her bodily practices. She herself in a way compartmentalizes the care of her disabled body from her self. The body appears to give her some sense of self when she works in physiotherapy, but she tends to objectify it when it receives help. It does not work properly, so it is somehow useless to make any feeble effort just to manage a tiny part of the activity while the staff more-or-less gets the work done. However, she may try to control the staff's attendance to its necessities. Actually, Soffía's refusal to rest during the day may be looked upon as an attempt to control the way in which her body is taken care of. She is not going to let the staff put her to bed in the middle of the day, contrary to her lifelong habit of being up and around all day.

The staff finds it not all that easy to attend to Soffía and relate to her, especially when she is posited in a negative stance. However, some members of the staff have been able to develop a helping relationship with Soffía, that bears upon recognition of her personhood. This recognition acknowledges the importance of a feeling of strength for Soffía's sense of self. It is indeed possible that the way in which the staff relates to Soffía while attending to her physical care may determine to a degree the extent to which a feeling of strength may give her some hope of enjoying the light of the day, or conversely aggravates her experience of a helplessness and a sense of a profound loss.

Soffía's husband witnesses or attests to her account of the way in which she is cared for by the staff. And he realizes also, as he listens to Soffía's account and watches the staff help her to the toilet, that the crucial point is whether the staff relates to her in a way in which that sustains her self while they attend to her bodily practices. However, he stands off from her bodily care, as it is up to Soffía to act upon the situation. He is not going to demean his wife by speaking on her behalf of the experience of receiving help. After all it is her body, and Soffía's husband will respect her attempt to control the staff's attendance to its necessities. So the husband actually keeps himself on the periphery of this territory of his wife's bodily care, although he is observant of the situation and thoughtful with regard to his wife's response to it. And this is the way in which the staff perceives his presence.

Soffía and her husband appear to prefer to keep to themselves during the husband's visits, and the husband tends to be reserved towards the staff. And the staff has reasoned that Soffía's husband wants to keep rather apart from them, so they find it important to respect the couple's privacy while the husband is there with his wife. The staff thinks that the husband does not quite know "how things are with" Soffía and thus he may be inclined to draw "wrong" inferences about the appropriateness of their responses to

Soffía's requests for help. But the staff is not defensive towards the husband's occasionally critical stance, as they recognize his dilemma in the role of Soffía's ally. The staff acknowledges that Soffía's life revolves around her husband's visits and respects their time together as very valuable for Soffía. The visiting hours in fact provide Soffía with a refuge, and this time enhances her limited sense of territory in the nursing home. And this sense of territory is reflected in her manner of allowing the staff to step inside "the family lane "as she introduces them to her visitors.

The staff recognizes the family's impact upon Soffía's wellbeing as a supplementary aspect to their care, which runs in a sense parallel with the family's. Apparently the staff attends to the physical aspect of Soffía's care and the family to the psychosocial aspect of her care. However, it is obvious as both parties tell the story, that it is the relational aspect of the caring for Soffía's that is fundamental to her wellbeing.

Supervisory Care

Jón's Family Style of Engagement in his Care

> He has been here for more than a year now since November - November the year before last. It has happened that I have asked about whether he has had any sleep medication because then I have thought that he was perhaps sleeping in the chair and that [he] was unusually drowsy. And that is because all drugs of this sort affect him badly, this is almost like giving [a drug] to a baby. Perhaps also because this happened in the geriatric unit that he was given an antidepressant drug which was no good for him. And so I happen sometimes to think about this, if he is somewhat different, but it has not turned out to be the case, there is just some difference between days which you do not understand. I realize that I do not understand this difference between days, neither with regard to him nor the people around. I have indeed such a lot of time to look around there, perhaps the people become somewhat - do look bad and become quite drowsy and in a way somehow different, and then it occurs to me that this is the beginning of the end. (Jón's wife)

Jón is a 77-year-old man who has lived in the nursing home for just a year at the time of my investigation. Jón is a tall, good-looking, strongly built man with rather thick, dark nice-looking hair. He sits quite erect in his wheelchair, apparently very stoic, he does not seem to pay much attention to his surroundings as if he is just dwelling in his own world, often facing the window. He usually gets up rather late, perhaps at eleven o'clock, and stays up in his chair until three o'clock or three-thirty in the afternoon; then he rests until five o'clock when he gets up before supper and stays up until nine or ten o'clock in the evening, often watching the TV. Jón has a history of diabetes and his mobility is severely limited due to repeated strokes with extensive left side paralysis and decreased strength on the right hand side. Jón moved to the nursing home after ten months' stay in a geriatric unit in a hospital, where his left leg was amputated above the knee following a gangrene in the foot.

Jón's wife says that it was as if he had grown wings when he was invited to move from the geriatric unit to this nursing home. The two of them went, with one of Jón's two daughters as well, to inspect the home "and he was not even tired though he was much more ill then. He was not at all used to sitting that long in the chair. He just grew wings, like I say". So Jón was very pleased to move out of the hospital and into the home. However, Jón's wife was not quite as happy. On one hand she had inspected and made a priority choice of two other nursing homes nearer to their home, which were more accessible by car and in particular by busses. Jón's wife drives their car, but she only drives some limited routes she is familiar with, and she does not drive if the roads are icy or the sun so low that it dazzles her.

And when the placement offer turned up, it was a shock for Jón's wife to face the end of all their years of living together, and see her husband go into a place of no return. But she sees her husband's move to the nursing home as inevitable, because his disability has increased to a degree beyond her capacity to care for him. Now Jón's wife accepts it as a matter of fact that he is cared for by the nursing home staff. However, she is certainly going to monitor his condition and make sure that her husband feels as well as possible. She points out that "he is certainly my business" and follows up on this stance with close observation of how Jón is feeling and how things are going during her frequent visits. And she is certainly sensitive to his feelings as she says:

> But I have naturally felt bad when he has been feeling bad. It's as if it goes straight into my blood stream, when he is downhearted then I am downhearted. It was actually in particular when he - he was so much in pain while the wound in the foot was at its worst, it was just so hard, because he is a man who does not know how to complain.

The Family's Perception of Jón's Care

Jón's wife points out that "he is a man who does not know how to complain", but she is actually monitoring his condition to detect whether he shows any signs of discomfort and has something to complain about. And she has given the staff's care approaches close inspection, and she has come to the conclusion that she can trust the staff with the care of her husband as she points out:

> I trust them with it - I do so here. I am not worried when I am back home that he will not be attended to in any way. I do not have worries. And this matters a lot for me. I do not worry about that.

And Jón's wife has noticed the way in which the staff talks to the inhabitants:

> And then the people are always friendly, I never hear anything else. I never hear anything else, you see for example "Don't behave like that" or something like that, I never hear things like that, even though there are people perhaps calling out rather more than they need to.

Jón's wife does not really address or talk of particular aspects of her husband's care or how the staff goes about it, but she certainly will assess how her husband is feeling. But she will not interfere or make any fuss as long as she finds her husband in a good condition and in a pretty good mood. She has accepted that she can no longer handle her husband's care requirements; she has put his care into others' hands and she has found out that the staff does it right. She can not quite delineate what she finds most important in his husband's care, but she emphasizes the importance of watching over him and then she really appreciates any diversion, as she points out:

> ... just this, to make the effort of moving him, taking him outside, taking him downstairs, buying one piece of chocolate yourself for him, even though it is forbidden because he is not allowed it, just in a way to make some fun and like take him out for an outing, I think that this matters, naturally, altogether tremendously.

Jón's wife thinks all variation works wonders, as it may mobilize whatever energy is left for gladness, and she recalls:

> But it is so strange, that it is as if any variety of whatever sort works a bit of a miracle in some way. Once I went with him downstairs and there was a choir singing, but he was actually then rather worn out and did not want to go, but then we stayed for an hour and he was feeling much better when we went upstairs. This is just like you know with yourself.

Furthermore she remembers with joy how exhilarated Jón was when he returned from a trip into the countryside with a group from the nursing home and she says: "when he was wheeled out of the elevator then he was just like a young man, I just do not forget it ... ruddy-faced and happy-looking and it was ever so pleasant to see him like that".

The Relationship with the Staff

The staff's effort to break up the routine of everyday activities matters a whole lot to Jón's wife. Actually she is fortunate enough to have been superficially acquainted, a long time ago, with the nursing assistant who is responsible for the unit's pastimes for residents. When they had reestablished their acquaintance, from when they both lived in a small village years ago, Jón's wife actually asked this member of staff if she could turn to her with her concerns for Jón's wellbeing. Indeed, Jón's wife points out that her husband misses this particular nursing assistant when she is on holidays and adds "she is quite animated when she is looking after the people, takes them for a little turn down here in the corridor, just [takes them] out to the balcony or just something. I think it matters a whole lot to the people". The wife acknowledges the importance of having a particular contact person in the unit to whom she can turn to air her concern, and when asked how she finds it supportive, she says:

> I do not know in which way, because then this gets into a kind of comparison with the other people and that is perhaps not fair, because I think actually that everybody does her duty. But she is very watchful, first and foremost, and is on the alert if somebody needs something or something is wrong with somebody then it is just done right away, however things may differ. ... But on the whole I think that this is very good care. In my mind I am very grateful for that. You cannot do it yourself and you do not have any worries, I just do not have any worries. I do not think that you can have a better deal.

Indeed Jón's wife emphasizes that she would not have any problem with turning to any staff in the unit, anticipating appropriate response from all of the staff. Nevertheless all the staff refers to this nursing assistant as "the one who knows" Jón's wife and has the most relationship with his family.

Jón's wife does not do much instrumental work as his care goes, but she certainly is very instrumental in communicating how he is, according to her measures of his wellbeing. This input into Jón's care could be seen as informative to the staff considering his passivity and limited communication. Indeed it was his wife who realized that he was becoming hard of hearing and made sure that he was seen by a specialist who cleared his clogged ears, with beneficial effect to his whole composure. The wife is very sensitive to Jón's composure, and brings it to the staff's attention, if only to remind them of how cute he is and good-looking, but such a stance certainly manifests the personhood of Jón.

However, Jón's wife does not really interfere with his physical care or personal appearance. She says herself that she enjoys it very much when she finds him nicely dressed when she arrives, but the staff emphasizes that she is very tolerant about the way in which he is dressed and does not make much fuss at all if something gets lost, or things like that happen. Her "contact" nursing assistant finds it rather amazing that Jón's wife does not take any stance at all on his dressing, as the nursing assistant remembers Jón's wife as having always been rather stylish and it is obvious that appearance matters to the wife herself, as she is always nicely dressed when she visits her husband, and she will actually comment if she finds him particularly smartly dressed that day.

But Jón's wife makes it clear that Jón does not pay much attention to his clothes anymore, and it does not seem to matter to him how he is dressed. So his wife is not going to make an issue of that aspect of his care, even though she certainly makes sure that he has a nice selection of clothes and indeed enjoys seeing him nicely dressed as she states:

> I enjoy it when he is dressed up. However it was certainly very difficult to dress him for a time. He has for example never had a jacket on. I am going to bring a jacket now just for fun. He always had such trouble with the arm, he was in so much pain, but this is all much better now. He had an operation done on two fingers, in which they were straightened and now this is a whole new life. They dealt with it here, the operation was done after he came in here. I know it was very hard to dress him. He was then often dressed in loose jumpers with a zip or a vest and a shirt.

The staff agrees with the wife that this hand operation made a great difference, as Jón suffered such pain because of the left hand's contraction and accompanying skin problems. But this operation, which turned out to be relatively simple, not only eliminated to a degree Jón's suffering but made his care much easier on him. And there has been less for Jón's wife to worry about regarding his well-being as he has needed less medication since the operation. The wife maintains "that it was certainly very difficult to dress him for a time" and has found the staff's way of dealing with this difficulty agreeable. But she watches the way the staff goes about Jón's bodily care with the help of lifting equipment at a distance, as if this mechanism of care is just beyond her business.

Jón's wife does indeed not think that she has much of a relationship with the staff, as her husband has not been really "sick" since he entered the nursing home. Jón's wife finds things more-or-less straightforward; she does not think there is all that much to talk about with regard to the attending care compared to active medical treatment. Indeed she says that the context of the relationship with the staff in the nursing home is very different from the one she learned to know in the geriatric unit where her husband was sick. And she points out that "when you are sick, then you are always asking and they try various things and do this and that. Nursing homes are different". Jón's wife actually maintains that she does not have much of a relationship with the staff as her husband's condition is indeed pretty good considering the circumstances, as the following excerpt reflects:

> INT: Is there anything with regard to the relationship with the staff which matters the most for you?
>
> W: No this is simply not much of a relationship, this is just this way, you see, because he has not been sick at all, so to speak. If he had been being treated by a doctor and you would have needed to discuss that or [had] anything been out of the ordinary - these diseases, as such, they leave him alone, they are at rest, so there is naturally just the disability and the foot and the whole thing, but his condition is pretty good considering the circumstances, I think.
>
> INT: You do not think that you need to relate to the staff regarding the everyday activities?
>
> W: No I do not think so. That's the way it goes. There is no reason to interfere with that at all.

Jón's wife does not think that her relationship with the staff is all that much. But she communicates for the most part with "her" nursing assistant, and both Jón's wife and the nursing assistant define their relationship more like a matter of acquaintance rather than a formal relationship between a staff member and a relative as such. So the kind of relationship Jón's wife actually has with "her" nursing assistant may explain to a degree that she does not think she talks much with the staff. Nevertheless, this nursing assistant is in a sense the wife's ally, the wife knows that she will keep a special eye on her husband. And this nursing assistant may actually act as spokeswoman for the couple within the unit.

The Family's Engagement in Jón's Care

The wife visits five days during the week - she says that she takes Monday and Wednesday off to do some errands and take a break as well. Jón's wife finds it "very good to enter the home" and she thinks it makes a lot of difference that Jón's private room has a beautiful view. She comes about one-thirty or two o'clock and stays for one-and-a-half or two hours, or until her husband is helped into bed to take a rest. They usually drink coffee together just before she leaves. The couple spend their time together in various places; sometimes they stay in his room listening to the day's novel reading on the radio, or watching the parliament session or a ball game on the TV. Other times they may sit in the sitting area or the wife may take her husband downstairs in his wheelchair and go outside with him, especially if the weather is good. However, the wife emphasizes the importance of a private room which she thinks is very nice, and actually she maintains that it is "a basic human right" to have a room of your own in these circumstances. The room is indeed very pleasant, even though there is limited personal furniture within the room, due to the space required by the wheelchair and the lifting equipment, but on the walls there are attractive paintings and pictures recalling Jón's past.

Jón and his wife have five children, and four of them and their families visit frequently particularly during weekends, while one of their daughters lives in a small village out in the country. However, the wife sees it as "her task" to look after Jón. Jón's

wife feels drawn by her husband to visit - "I'm drawn to him, I want to know how he is and things like that" and she is certain that it does good "to nurture your people":

> Of course this pays off somewhere, I think, to nurture your people that well and care for them so well. It must pay off somewhere, even though they are not jubilant and waving [when you come], it's just a form of energy which will show up somewhere, I am just altogether convinced in that regard, though you do this, naturally, perhaps primarily for yourself. I'm drawn to it, I have to know how he is and things like that...

The wife points out that people might discount Jón's attention and awareness because of his passivity. She talks of his passivity as a handicap consequential to his strokes, but maintains that he may be and is more aware than you would often think. And it is very important to her to keep him to some extent in touch with her, she may gloss over the moments when he loses touch, but emphasizes at the same time what a gift it is when he can share with her their story together:

> But he is amazingly oriented, it is not all that often that he is confused, perhaps sometimes, like for example just now, he asked me to help him to get to his feet, when he felt somewhat bad, this happens now and again. But then he begins to tell me about a man we have known for a long time who had visited him. I knew that he went to see him, and everything was correct, he knows exactly who has arrived, but the days blend together. You see, we are not for example talking about Friday, instead he says that Karl came this morning, but then Karl may have been here the day before yesterday. But I do not pay all that much attention to this, I feel quite pleased that he is not more confused than he is. ... Yes I find it rather a pity when he loses touch. I hold on to it somewhat, you see, that he is himself, you see. But this I think has not got all that much worse.

Jón's wife finds it at times hard to keep the conversation going while visiting, but she refers to the family or a particular family member and keeps him a bit up to date regarding the daily news. As she says:

> I am sometimes at a loss what I should say to him. I try it actually, you see, I try to tell him about the kids and the youngest boy you see, he is rather witty and funny and a bit particular in his way and it happens that he says to me: "Has Frikki said something lately? Has he been doing anything lately?" I tell him some news from the village, and that his daughter has phoned. And [I tell him] something about what is in the news. I just told him that the teachers and the committee have been closeted inside until Monday morning. I have noticed that when somebody comes who comes rarely, and just starts right ahead to talk about something really old, then it suits him very well. Then he is really lucid. All the same I see that he deteriorates a bit.

Jón's wife makes a conscious attempt to keep her husband abreast of what is going on in his family and in the news. By these means she is holding on to Jón's awareness of a world they share and affirming his social identity. She will not let him slip away into a no man's land without a struggle. So she watches over his condition and inspects everything that affects his awareness of his world. To that end she will supervise his care. It is probable that her emphasis on all diversion serves this end. And so does her concern with Jón's medication, which becomes evident in the staff's account of their relationship with his wife.

The Staff's Response to the Family's Visiting

> What I think with regard to this couple you see, I think they do tremendously well in coping with this, and I think there is just one thing I can say about Jón, that I find him altogether enormously diligent, you see. I see this as diligence, to be able to deal with it - to feel this helplessness - I am sure that he senses his helplessness, not to have the initiative to do this or that ... then just this, you see, to be able to have fun with us, I think that is so lovely - to be able to smile. (Nursing Assistant)

The staff thinks that, even though Jón may have his days of bad mood, it is his humor that makes the difference in caring for him. Just a good joke at the beginning of the ordeal of getting him up may change the whole scene into an amicable process, not least if the staff person can get Jón to work with her, by constantly reminding him of the part he can play in it.

Then the staff thinks that Jón's wife is very loving and warm towards her husband, no matter how he might be feeling or what mood he might be in. Indeed, they sense a lot of warmth between the couple, and some of the staff find it fascinating that Jón's wife is still quite infatuated with her husband. She finds her husband very good-looking and may call the staff's attention to this and ask "don't you find Jón handsome" - and then she adds " he has always been such a cute guy".

The staff realizes that Jón's wife very much appreciates any effort to break up the routine of the everyday activities. And a nursing assistant remembers how exhilarated Jón's wife was when the staff made waffles in the unit, and how grateful she was when the staff offered to serve to the couple the treat with coffee in Jón's room. The nursing assistant recalls this incident because she realized at the time that the wife's exhilaration was due to the staff's effort to break up the routine, and do something out of the ordinary. The staff recognizes that Jón's wife watches over him and is certainly going to monitor his care, and points out that the wife keeps herself very well up to date about his condition and actively seeks whatever information she thinks is important. Jón's wife does not hesitate do make comments if she finds anything out of order, and may be quite adamant with regard to the matter at hand. Actually, the unit manager points out that the staff even found the wife meddlesome at the beginning of Jón's stay in the unit, particularly with regard to the wife's inquiries into his medication.

> ... you see, she is always afraid - she is always a bit afraid that we are giving him some unnecessary drugs ... Well, in a way she had - she thought that it had once been proved true that he did not tolerate sleep medication ... She is always, if she comes and thinks he is somewhat sleepy or in some way different from the way he is used

> to be - then - then she always wants to know exactly, you see, whether he has received something - she prefers that he is not given anything at all or as little as possible.

At the beginning of Jón's stay the whole issue of medication lead to repeated inquiries, as Jón's wife was not really convinced by the RNs' arguments about the necessity and benefits of the medication, as they were trying to alleviate some of Jón's suffering and sleep difficulties step by step. And the unit manager continues the story of this debate:

> But I mean, this is naturally just one side of the story - and naturally just - I think you do actually perceive it as a positive thing - but in a way, you see, this was sometimes a bit, one might say some work for us, that she somehow - she did not understand things - I thought - I often found it difficult to explain to her, and help her to understand the reason for the medication, particularly at the beginning, you see; his condition has become much more stabilized lately, so he has needed less - she, in way - I thought, in a way, that she closed her eyes against reality [or that was what] we sometimes thought, you see.

The RNs did indeed consider the wife's inquiry as "a positive thing", and were actually caught in an ambivalent position, as they felt that Jón was not feeling well, sleeping very badly during the first months and having pain, but they simultaneously wanted to pay due respect to his wife's stance. And the unit manager describes how the RNs had to juggle with the medication as they were trying to find the suitable dose of pain and sleep medication to make Jón feel better:

> We thought this was within acceptable limits, and it was just fine to go on step by step with this... but she was very much against it, so perhaps he got less than we thought he needed during that period - but this has in a way become stabilized lately and he needs - he does not need much ... he gets very little before he goes to sleep, you see, he sleeps better now.

The unit manager says that she thought that the wife's stance was caused by lack of knowledge, as she was not willing at least to give a try to this step-by-step process, of finding a suitable medication dose. The unit manager adds that she found this situation rather uncomfortable, as she felt that the wife did not really trust them, but she points out that "she was naturally quite within her rights [not] to do so, and one doesn't know, of course, what she has experienced in the past or whatever, which justified this suspicion on her part".

The RNs appear to have acted in a very respectful manner towards Jón's wife's resistance towards any "drugging" medication. It is possible that the RNs' stance has come about because of their understanding of the wife's experience of coming to terms with institutionalization. The unit manager actually delineates this understanding as she says:

> I thought also that one realized with regard to her when he came in, you see, how hard it really is for the relatives to - like to see your relative gone, entering an institution like that, and let others take over caring for them and let others do something which you yourself have been doing for a long period of time.

However, the staff seems only to a limited extent to draw upon the wife's experience of caring for her husband. Jón needs extensive help; he is able to feed himself, the only thing he can do of the so-called activities of daily living. The staff sees his wife help him with his coffee, but otherwise they do not see his wife as taking active part in his care, but the unit manager points out that she contributes to his psychosocial care. Nevertheless, the wife's "particular" nursing assistant was little disappointed when the wife turned down the offer to meet her husband in the Pearl [a rotating restaurant with panoramic view], when the nursing assistant was planning this outing for a small group of residents. But Jón's wife seems to prefer to stay in "her lane" as she monitors her husband's care. But she will be waiting in the nursing home when he returns from an outing like this, just to make sure that her husband is in a safe condition. The staff is certainly aware that Jón's wife looks after her husband, and believes that the family contributes to his quality of life, as is evident in the following excerpt:

> NA/F: Quality of life, well, I think like [it is] with Jón today, I do not think of him as an unhappy man, there are lots of things about which it is possible to smile and enjoy life, he does not just lie there and ... There are at least many things which can make Jón glad, that is for sure.
>
> INT: And what do you think is most outstanding?
>
> NA/F: Well, there is, I think, in many respects, like these visits in particular, if his youngest son visits - he seems to suit him very well
>
> INT: So do you think that these visits contribute to his quality of life?
>
> NA/F: Well, just think if he didn't get them, it's important, I think.

Patterns of Supervisory Care

Jón's wife has a decisive bearing and was quite adamant about her inquiries at the beginning of her husband's stay in the unit. And she has been lucky enough to be able to establish her special line of connection with the staff through her "own agent" in the unit, who is actually an acquaintance from a long time ago. Jón's wife watches over his wakefulness, making inferences about his response to sedative medication and inquires about its place in his treatment. It is important for Jón's wife to prevent him from falling into any drug-induced drowsiness, so as to be able to relate to him or keep him "with her". She supervises the staff's receptiveness to his condition by bringing his wakefulness to their attention, as she addresses the extent to which he responds to communication. It is precisely the wife's manner of taking an overt stance to his care, and her outspoken way of making inquiries and stating her concerns, that distinguishes this type of engagement from parallel care.

The staff is aware of Jón's wife's monitoring of his condition and his response to their care. And they accept it without being defensive, as they see it as her manner of coping with his institutionalization. But they really find it rather odd that the wife thinks that she knows better then they do how Jón is, and what may serve his wellbeing best, such as the type and dose of medication. It amazes the staff somewhat that Jón's wife finds it necessary to be there when he comes back from an outing, just to make sure that he has returned in good shape. The staff sees it as an inherent part of their care to watch over the patients' condition, as they sustain their wellbeing, and to that end they do not think that they need a family member's supervision. But the staff is not going to confront Jón's wife, even though they may think that her guardianship of her husband's care is not entirely necessary. Indeed they respect her love and concern for Jón, so they pay her inquiries and any directives due attention.

And it is obvious in Jón's wife's account that she does not worry about his care in the nursing home, and she has in fact told her "contact" nursing assistant that she and the whole family are quite happy with Jón's placement and the way in which he is cared for in this unit. Perhaps the most important factor is that Jón's wife perceives that she has a hand in her husband's care; she will definitely watch over him and ensure his comfort until the very end. But she would probably not regard her care for her husband as supervising. Her overt, monitoring stance towards her husband's care, nevertheless, makes the staff more aware of the family's evaluation of their care and the extent to which its quality measures up to the wife's expectations.

Complementary Care

Anna's Family Style of Engagement in her Care:

Anna is among the youngest residents in the nursing home in which she is living. She is in her late sixties and has lived in the home for almost three years. Memory deficit and failing functional ability accompanying Alzheimer disease added up to a mobility handicap of many years and led to difficulties in managing at home with her husband, so eventually she moved into this nursing home. She lives in quite a large private room which is pleasantly arranged with pictures on the wall, some photographs and also it is decorated with the woman's own needlework which she has made in recreational or occupational therapy. There are two very fine chairs in a rococo style in the room, and a television set.

Anna is a rather heavy woman of an average height who sits in a wheelchair which she pushes herself around, if she is not resting in her bed, but she can stand with a support. She gets around a lot in her chair. She has short thick grayish hair, wears glasses and is always very nicely dressed and groomed and it is noteworthy how well her hands and nails are usually manicured. She looks composed, has rather a decisive manner and is observant of her surroundings and the people within. Anna enjoys a very solicitous family; she has a husband, three sisters and one brother and two friends who visit regularly as well as a son, but her daughter is the key visiting family member as she oversees her mother's care, both the institutional and the family's.

The Family's Perception of Anna's Care

Anna's daughter thinks that the staff's takes good care of her mother, she appreciates particularly their thoughtful attendance to her grooming and dressing. Anna herself has always placed an emphasis on her appearance, so the daughter finds it very important to solicit this lifelong concern of her mother like she says: "she has always wanted to have elegant nails and elegant hair and things like that you know, this was always ..."

The daughter finds her mother's appearance usually quite good when she comes visiting, her clothes are nicely coordinated, she usually has a scarf on and some jewellery. Indeed the daughter says "she really likes to wear scarves you see, and she has a lot of nice scarves and fine suits and dresses". The daughter ascribes this pleasant appearance to the staff's way of handling her mother's care as she knows that her mother is not able to cope with things like choosing what clothes to wear or to dress herself, except with the staff's extensive help. The daughter is aware that the staff appreciates Anna's nice selection of clothes as she says:

> ... and I have heard them speaking ... - or my aunts actually - that they have indeed talked about it that she has really very nice clothes, you see. They have been very pleased with this, I believe, and then it is easier for them to dress her, you see...

So Anna's daughter realizes that it is easier for the staff, and more enjoyable, to take care of people who have enough clothes. And it matters to her that the staff sustains Anna's concern about how she looks, and that they enable her to keep up a presentable appearance. By this means Anna's handicap is to a degree covered up and her dignity safeguarded.

The daughter's hunch with regard to the importance of providing her mother with a nice selection of clothes was actually confirmed by one of her aunts. She told Anna's daughter about an incident in the unit when "they were quite certainly just giving one of the men a hint" in the following way:

> One of mom's sisters just said that, you see, it was once, then they were certainly...- she said "they were quite certainly just giving one of the men a hint", then they were talking about how nicely mom was dressed, and then she said you see "I am quite sure - that they were just giving him a hint", because they did not think, you see, that his wife was well enough dressed, you see.

Anna's daughter pities for the husband and wonders if he does not get any help from his daughter in these important matters. However, she does not assume that the staff could possibly address this issue with the husband in a more direct manner. For her it is essential respect for the personhood of her mother to pay attention to this aspect of her care, as she says:

> I would feel badly if she was not nicely dressed, if she was a bit shabby or something like that. As I say, it is not like her. And her sisters would not be pleased with that. Her oldest sister is actually a seamstress, incredibly capable you see, so that she would not accept it if mom was not nicely dressed, you see. ... So that anything else is just not possible.

From the daughter's point of view the two things are intertwined, to mind Anna's spirit while attending to her bodily care, to enhance her dignity. And she and the family appreciates the emphasis that the staff places on enabling Anna to keep up a presentable appearance. Nevertheless, the daughter finds the staff's mode of dealing with her mother's urinary incontinence at times unsatisfactory. The pile of wet laundry differs depending on the respective shifts and the daughter suspects that its quantity is determined by the way in which her mother's toilet regime is upheld. She has tried to address the issue with individual staff members as well as the unit manager, but without much success.

Furthermore, Anna's daughter is disappointed or slightly puzzled about the staff's slack vigilance in watching over Anna's condition, as she says:

> And I think, if there is something wrong with mom, then I generally need to tell them so, they may not altogether keep an eye on her well enough, if there is something. I think naturally that they should know it, you see, and should keep an eye on her.

Anna has limited ability to express herself and to tell the staff how she is, or complain about any discomfort. It is possible that the staff may not think that there is much need to make too much of a deal about things as long as Anna is able to go along with the daily rhythm of the care. At least the daughter thought that they were rather easygoing when Anna did not show much response to an allergy treatment, so she decided to intervene herself as she describes:

> ...you see, then during last winter then ...- she had such a bad allergy, she was just about breaking out all over, just altogether - and I could not accept it at all, I did not think that anything was done about it. She was given some creams and then I felt that this was not applied enough on her, and she was given some allergy pills all the time, but nevertheless she always flared, up you see, and I wanted to know, of course, why this was and things like that. Then finally one day then I said to the RN "tell me, doesn't mom's doctor come here tomorrow?" And she says "yes". "Yes, I'm going to come here tomorrow morning and just meet him", I said. And I went and met him. ... Yes, I just went up there and was on the spot by nine o'clock, then I just waited until the doctor showed up. ... And I spoke to him. He was quite pleasant and it was no problem and we talked for quite a while, and things like that. But he actually said very little with regard to mom, of course, so to speak but just what I naturally knew and realized and things like that. But however, I found this better anyhow, you see, that I had gone and spoken to him you see. ... I had actually phoned there a few times and just spoken to them on the phone, but then I decided just to go there that morning and speak to him, because she had such a bad allergy, you see.

The daughter decided to intervene after she had made repeated attempts to address the issue of her mother's condition and her discomfort with the nursing staff. The staff apparently did not think there was much more to do than had already been done; after all Anna was being treated for her allergy. The daughter mentions that the doctor has addressed her mother's condition, but he did apparently not bring up any aspects of her mother's chronic illnesses with which she was not intimately familiar. But the doctor took notice of the daughter's concern for the mother's more acute condition and her intervention brought about a specialist's consultation and finally Anna's condition improved considerably.

Anna's daughter certainly knows that her mother has chronic irreversible diseases, but she is not going to let her mother's "irreversible condition" overshadow all feelings of discomfort and episodes of acute illnesses. And she thinks that she must be on her guard, as the staff might disregard her mother's ill feelings in light of her inevitable decline. She does not hesitate to address issues with regard to the care of her mother because "she has to do something about it" and she adds

> These are naturally patients, who are there, and I think that you must treat them just like proper human beings, not as if they were some poor wretches you see. That is not right. So I don't know... I think that I just have to do it, if there is something. Then I naturally talk to them if I find something wrong and things like that, you see, but for the most I have not needed to do that, you see.

The Relationship with the Staff

Anna's daughter tends to speak of her relationship with the staff in this nursing home in comparative terms. She used to visit her mother-in-law in a geriatric unit for a number of years, and later on her mother for a few weeks, where she found the staff's comportment towards her and the family very supportive. And she addresses her experience in her mother's nursing home in the following way:

> They could be somehow more in good spirits and cheerful and things like that. Actually, there are some very lively women in that way, and always chatting with you and maybe giving you a cup of coffee and things like that. Then there are others who never do that. I found it quite an advantage when I was in the geriatric unit because I always went to my mother-in-law after work, and then you started to give her, you see, her supper and then as you had begun to feed her, then they would always offer you a cup of coffee. I found that very pleasant.

The daughter finds it an important gesture of acknowledgement to be offered a cup of coffee, as she points out:

> I think it is really important when you are coming into a place like that that you are at least shown that [much recognition] that you are offered a cup of coffee. You are

> not asking for anything to go with it, or anything like that, just to have a cup of coffee perhaps. I really like that.

Such invitation bears upon a mode of recognizing the visitor, from the daughter's standpoint, and conveys a welcoming stance on the staff's behalf. Actually one might say that the inhabitant may share this welcoming stance, as the guest is being received as one does at home. Or the offer may bring about togetherness, as the inhabitant shares a cup of coffee with her or his guest. Anna's daughter finds this quite comforting and important. Then Anna's daughter remembers the way in which the staff in the geriatric unit used to come into the room and talk to her about how her mother-in-law had been doing that particular day. Her mother-in-law was not able to communicate about her condition, or how things had been, so the staff tried to give her some insight into her day, as the daughter refers to:

> For example I found when mother-in-law was there in the geriatric unit, and then when mom was there, always when you went there, then they actually often came, somebody who was on duty, into the room and talked to you and perhaps told you how she had been during the day and things like that. But I think perhaps that they could do more of that here. Maybe come to you and talk to you, and tell what mom has been doing today or something like that. You often think perhaps...it could be done.

The daughter thinks that it would make a difference, if somebody came along while she is visiting, to fill in for the memory gaps in her mother's very limited tale of the day, just as the staff did in the geriatric unit. It matters to her to have some idea about how the events of the day have unfolded for her mother. It is possible that the staff finds the days pretty much alike, so there may not be all that much to tell. But the little events of the day count for the daughter, and after all Anna might respond differently from one day to another to the routine events of the day. And then there might have been a special event, such as the day when the daughter came on a visit and Anna was all dressed up and looked as if she was returning from some special festivity. But Anna could not tell, and the daughter could not find anybody around to ask if there had been some special event going on.

Anna's daughter is not certain if she influences the way in which her mother is cared for, as she answers a question about her influence upon her mother's care:

> I don't know. Yes, perhaps it has some effect, they know, naturally, and sense that you are looking after her, isn't it so. It may well be that it has some effect, you see. I don't know.

The daughter says that she does not know "because they never talk to you about these things". Actually the staff has not shown much initiative in addressing issues in Anna's care, it is usually the daughter that brings things up. She has discussed the stressful aspects of her father's visits with the unit manager and she does not hesitate to turn to the staff if there is something to inquire about. On one such occasion Anna's daughter said to the RN "I really want you to let me know if there is something lacking, or something that needs to be done or something". So Anna's daughter has certainly attempted to voice her concern for her mother's wellbeing. Consequently, she felt really let down on an occasion when she came visiting and found her mother quite sick. And it is with regret that she tells about the following incident:

> I was however a bit disappointed last winter - or actually it was during the spring - then I came to mom on Saturday after I had finished work and I was extremely shocked when I came to her, I just ...yes, I had first gone home from work, hadn't gone straight to her - I did not come to her until about just after three o'clock, half past three - and then she was lying in bed and she was so terribly sick you see, that I just... I just thought - I'll be damned, that she was dying there - I felt so shocked when I saw her. And then I sat down by her side and started talking to her and then she had actually been feeling somehow so bad and was really ill. Then one of the assistants came into the room and started telling me that the doctor had been called

> to see her, and they were actually not quite certain what this was, if this was some embolism or whatever it was, or if she just had something in her lungs, and then I actually said to her "I am absolutely hundred percent sure that she is running a very high temperature". "No, what do you say", she got somewhat startled and started touching her and discovered that she has high temperature. And they took her temperature, then she actually had a very high temperature, and then they got really startled, you see and they called again ... - the doctor had been there and then they phoned him again . And I was actually a bit surprised that they had not phoned me and let me know, I had actually you see... - I was both surprised because I had asked them to phone me if there were something wrong, and they know that and then I was also quite angry that they had not let me know. Because they could easily have reached me, first I was at work, then I just went straight home and then straight there. So it would have been no problem to reach me, you see.

Anna's daughter feels very let down by this indifference towards her concern for her mother. The staff does not meet the daughter's expectations regarding monitoring of her mother's condition. And it bothers and actually hurts the daughter, as it raises a question regarding her mother being worthy of thoughtful attention as a deteriorating demented person. But the staff appears only to a limited extent to recognize the kind of messages conveyed, by the way in which they watch over Anna's condition in a rather easygoing manner, without paying much attention to the daughter's concerns for her mother's wellbeing.

The Family's Engagement in Anna's Care

Anna's daughter finds it miserable for her mother to stay "somewhere" like that. And she makes every effort to create a more tolerable situation for her mother. It is essential in that respect that somebody visits her mother each and every day - three of her mother's sisters rotate their visits three days of the week and it takes a lot of weight off the daughter's shoulders that she can count on this "it is a great weight off my shoulders, it does not depend as much on me and you are thinking all the time, ‘oh God, nobody has gone to her today, I have to go’. Then I always know that there are these days and then I do not need to worry about that”.

However, the daughter very often drops by daily, but she does not count it as a proper visit when she does not “really” sit down - but is there for picking up laundry and generally making sure that things are all right. The daughter finds it important for Anna to have a visit every day to attest to her mother, as well as to herself and the family itself, that Anna has not been abandoned and still belongs in the family. At the same time the family is attempting to make the situation more bearable for Anna by breaking up the routine activities of the nursing home with their visits, or by arranging for an outing. It has been hard for the daughter, and the sisters as well, to learn how to go about the visiting, as the daughter says:

> They find this a bit hard, yes. They actually find it hardest, I believe, that mom should be like this. You see, actually, how unwell she has become, you see. They take it a bit to heart, I know that. Because they are all ... - you see, mom is the youngest of them and I know that they think about it a lot and take it rather seriously how unwell she is. ... I found, you see, when I first came into a place like that, then it is naturally hard for you, but you have got to learn it, and this is something you learn, in a way, the more frequently you come, I think.

On one hand it is hard for all of the family members to witness how unwell and debilitated she - the wife, mother or sister - has become. And furthermore to deal with the difference in the way in which they can relate to her now, often she does not say much, and at the same time she may be curt or annoyed when her family visits, especially her husband. On the other hand it is hard to be comfortable in these new surroundings, especially to face the condition of the patients around, and then to recognize their family member as a member of this group and in this place.

The husband still has difficulties in grasping how his wife’s disease condition affects her conduct and he has not been able to repattern his way of relating to his wife despite the fact that his wife has been suffering from Alzheimer disease for some years now. The daughter and the sisters have learned to deal with the situation by "taking it as it is" and trying to look a little the other way while they visit. For example they may go into Anna's room with her or find a quiet corner to spend their time together. One of Anna's sisters often brings her knitting with her, and the others quite often play patience or a solitaire card game with their sister. The daughter thought of bringing the cards as a source of relating to the mother or the sister in the current situation. Also they find that the card game is stimulating for Anna. The daughter might have the TV on while visiting during weekends, because then there is something to talk about as the TV program goes on. The husband apparently is the only one of the regular visitors who does not have any "agenda" during his visit other than talking to his wife in her room, maybe watching some TV, possibly bringing her some sweets "contrary" to her recommended dietary regime. And the staff tends look the other way, as "that is his only way to please his wife".

On her visits the daughter is often quite busy attending to her mother's appearance, checking her laundry and making sure that there is nothing lacking which might undermine her mother's grooming and dressing, and the way she looks and appears to others. The daughter attends to special "beauty" aspects of her mother's appearance, such as setting her hair and giving her manicure. The mother appreciates this kind of attention and enjoys it. It has always been important to her mother to have long and polished nails, and she is herself still very attentive to the way they look. Anna's daughter also always makes sure that her mother has enough supplies of beauty products like shampoo, body lotion and so on. She solicits the staff's bodily care by having everything available so they can attend to her mother with a special touch. At the same time she conveys a message to the staff about the importance of paying attention to her mother's appearance with the aim of maintaining her poise and sustaining her sense of self. A RN said to her "you actually always look after your mom so well and we have actually talked about it, you see" and the daughter was pleased to hear that her effort had been noticed by the staff and talked of. But she adds:

> Actually, I have naturally never thought anything of it, I just naturally make sure that she does not lack anything and things like that, but then Hrefna said so, then they have naturally been discussing it, but they never mention anything to me. Naturally they might quite well say to you, you see, the things they find positive as well ... then they can naturally quite well let you know that they are pleased that you look after these things and take care of this you see. Because they have generally not needed to tell me that something is lacking or something like that, because I have always tried to take care of that, you see. It is naturally certainly not like that everywhere you see. So they could perhaps really show you in a way, a bit, you see.

Anna's daughter maintains that she has tried to look after things and she appears to do it in a mode that complements the staff's care. However, the staff seems to take her contribution to her mother's care more or less for granted, without any acknowledgement at all. And it is actually up to the daughter to air her concerns and lay the ground for the staff's care as the staff only addresses to a limited degree issues with regard to her mother's care with her.

The Staff's Response to the Family's Visiting

> I think she is [extremely lucky] - when you look at all the others who are in the hall - every single day the daughter is here and picking up ... "oh, are you coming" - " I am picking up trousers" - she is saying - like her clothes and her nails and everything, she is well catered for - she gets everything - I think she is very well ... yes, in the way she is treated as somebody else ... (Nursing Assistant)

The staff finds Anna's family, and particularly her daughter, exceptionally attentive to her wellbeing and thoughtful with regard to her care. Actually, the staff maintains that "they never need to talk to them" as the daughter thinks of everything Anna might be wanting. The family has been more than willing to accompany Anna on the rare occasions when she has had an appointment outside the institution, such as going for an X-ray or something similar.

The staff is very respectful to the respective family member's conduct and the way in which she or he may visit and relate to Anna. They see that the family keeps somewhat to itself, and most often the visiting family member goes into the room with Anna or stays a bit apart with her in a quiet corner. And the staff does not find it appropriate to interrupt her time with her guests. They think that the visits are very important to Anna, even though she does not remember the guest who has just left. Nevertheless, the staff agrees that Anna gets uneasy and somewhat upset on the exceptional days when she does not receive any visit.

Neither the staff nor Anna's family really bring up many expectations towards the other, or makes many inquiries or requests. However, there are some legitimate inquiries or requests each party can make, for example the staff can ask Anna's family to accompany her to appointments outside the institution, and the family can make inquiries about her medical condition and outcome of any medical investigations or interventions. The staff tends to discount it when Anna's daughter brings up her mother toilet regime. The staff considers that aspect of care to be within the staff's territory, and they do it their way. And the extent to which it is considered, how the incontinence management in this unit affects the daughter's job of doing the laundry, is more or less dependent upon the individual staff member on each respective shift.

However, there is a consensus among the staff that they need to ease this job while Anna's daughter recovers after surgery. This stance indicates an understanding of the daughter's workload, but this is not done by following the toilet regime in a more stringent way, instead the staff does the washing themselves in the unit. The staff normally have to change the diaper when they guide Anna to the toilet, so it might not seem to make all that much difference to delay the scheduled toilet trip a little or skip it all together until next time. Anyway Anna often makes a fuss when accompanied to the toilet, maintaining that she can manage herself, and the diaper is just going to be a bit more wet and perhaps accidentally also the clothes. Some staff might also ask, what is the issue here, the clothes can be changed and even be washed in the unit. Other staff may consider "such accidents" as degrading and will stick to the protocol to sustain Anna's dignity and wellbeing. However, irrespective of the staff's stance towards Anna's toilet regime, none pays all that much attention to the daughter's concern in these regards or thinks it is necessary to talk it over with her. They just tend to assume that "she knows how things are with her mom" in this regard, as one of the staff members said. The staff actually often appears to assume that Anna's daughter just "knows how things are with her mom". And they do not really consider when she comes by more or less daily to check her mother's condition and wellbeing, that it is important for the daughter "to know how mom is" from one day to the next.

The staff does imply in their talk about Anna's condition that she has, because of her disease, difficulties in conveying messages about feeling bad, but the daughter might be more likely to understand the mother's messages. It evokes the question whether Anna might complain to her daughter rather than to the staff or simply that her daughter might be more receptive to her way of being and thus be able to recognize any deviation from her usual conduct. Because of Anna's communicative problems it would seem the more important for the staff to "fill in" for her the memory gap and tell the daughter about how things have been going, what the day has been like for Anna and how she perceives her mother to be. They might directly ask whether Anna has complained of anything or conveyed any messages about how she is feeling to her daughter. But the staff does not really initiate any conversation about Anna's condition or her care. Somehow it seems as if there is not very much to talk about, things are seen as more or less the same from one day from another, with no need to make an issue of it, though there are some small incidents or minor upheavals. After all "this is a home, not a hospital". But, any kind of incident or upheaval matters to Anna's daughter, and she perceives this "easygoing" stance towards some deviation from her usual way of being as an indifference towards Anna's condition, as well as towards her own guardianship of her mother's wellbeing.

Patterns of Complementary Care

Anna's daughter sees her mother's appearance as an important expression of her self. It has always been an integral part of her personhood to cherish a presentable look. Anna herself can still relate to herself and others by presenting a neat appearance, even though it is put together by others. So the daughter ingeniously sustains her mother's self by cultivating the mother's lifelong habits of tending to her hairdo and manicure, as well as dressing in a way that becomes her. By these means the daughter can herself still relate to her mother in something like her customary manner and make their time together meaningful. Furthermore, Anna's daughter is trying to enhance the quality of her mother's care by complementing or adding to the staff's input into care, to make it more wholesome and dignified. Anna's daughter is guarding her mother's position as "a proper human being" in a both an indirect and direct manner; indirectly she gives the staff various cues to direct their "routine" daily care, by which she also shows respect for the way the staff cares for her mother. On the other hand, Anna's daughter turns directly to the unit manager or the physician if there are any issues to be addressed, like her mother's medical condition or some structural changes in her mother's surroundings. Nevertheless, the staff members' inconsistent stance towards Anna's toilet regime indicates that the extent to which some staff grasp the meaning of the daughter's effort may be somewhat limited. After all, the staff does not talk much about Anna's condition and wellbeing with the daughter.

The daughter does not seem to look upon herself as directly participating in her mother's bodily care, even though she ensures that her mother has enough supplies of clothes and cosmetics, sets her hair and gives her mother a manicure. She realizes that her participation is only to a limited degree incorporated into the daily routine of attending to her mother's body, but she attempts to prepare the ground for the staff's care approaches. And she shows the staff the way, and complements their everyday care and attentiveness to the mother's appearance by adding a special touch to it. Anna's daughter appreciates the extent to which the staff attends to her mother's bodily practices and takes up the family's leads with regard to the importance of this aspect of Anna's care. The daughter's input into her mother's care is certainly appreciated by the staff, but as a complementary part of their care rather than participatory. However, Anna's daughter's style of engagement may indeed rather be complementary than participatory, because the staff does not address issues of her mother's care with her, share activities with her or talk with her about her concerns for her mother's wellbeing.

Participatory Care

Magnús' Family's Style of Engagement in his Care

Magnús is a 72-year-old man who has lived in the nursing home for more than one-and-a-half year at the time of my investigation.

He stays in bed much of the time, but sits in his wheelchair for a while during mealtimes. He is a good-looking man with gentle features, and he looks rather small as he lies in bed or sits in his chair. He tends to lean to his left side with his head bent forward when he sits in the chair and appears rather distant. He hardly says a word but appears to notice his surroundings and responds to attention. Magnús has strange sleeping spells, when he sleeps or is very drowsy for some time - for a part of a day or even for the whole day. He is totally dependent upon help in every aspect of activities of daily living, but can walk a small distance with much effort and the support of two helpers. Magnús has been a cardiac patient and he had gone through an extended period of illness because of his cardiac condition when he suffered cerebral insult five years ago. It is his wife and one of his two daughters who tell the family's story of looking after Magnús in his nursing home.

The Family's Perception of Magnús' Care

The wife and the daughter find Magnús' care quite good even though they may have some misgivings about the quality of some aspects of his physical care. As the wife says:

> These are altogether lovely girls who are there you see, quite remarkably, and they are so kind towards him and somehow considerate. That matters a lot as well, you see.

They emphasize the manner in which the staff relates to Magnús in just "a normal way", as they address him and talk to him as if he understands all they may be saying as they go about his care. Indeed, the wife has noticed that Magnús actually appears to respond quite appropriately to the staff's leads, such as when they ask him to lift himself or turn on his side and things like that. As Magnús' wife points out:

> Their manner is kind and that matters, naturally, an enormous amount, although one may think that those people don't understand much, I think nevertheless that it must matter a whole lot that they are treated kindly and well, the atmosphere actually, you know, for them.

However, she and the family certainly monitor Magnús' condition and look after him. It is obvious that the wife finds it necessary to be around every day, to ensure that some "minor things" are done for her husband which she thinks are important. As the wife and the daughter say:

> W: There is an awful lot of mucus in his mouth often when we arrive, you see, we just get some paper and clean his mouth. Then it sometimes needs to be moistened inside. Like yesterday, you see, she brought some ... because we began to talk about it. He sleeps with his mouth so open and he gets so dry inside the mouth and on the tongue.
>
> D: He had slept there for many hours with his mouth open like that
>
> W: And it is impossible to give him something to drink or anything
>
> INT: Yes

W: And then she went and got some kind of q-tips with which to wipe, with a kind of lemon taste

INT: Yes, yes

W: Yes. I mean if we were not there, it wouldn't be done. It is ....kind of minor things you see, which make him feel better if they are done

INT: Yes, indeed

W: And that's why we're there

So Magnús' wife makes sure that she is there to look after "the minor things" while there are others she has not been able to have any impact upon. She is quite upset at the time of my first interview with her and the other one of their daughters because there has recently been a change of her husband's frequency of bathing. He used to have a bath twice a week, but then this was changed to once a week because of excessive demand on the staff's labor in the unit. The wife has taken this up with the unit manager, but apparently not much could be done about the issue, as there just is not enough staff to bathe any patient twice a week. Magnús' wife finds the situation rather upsetting as her husband may perspire a good deal and his hair gets greasy and becomes smelly as the days of the week pass, since this change in his bathing schedule. Some of the staff has suggested to the wife that it would only be fair to make an exception and bathe Magnús twice a week, considering all the help they receive from her with his care, but these suggestions have not worked their way through, so there has been no change. The involvement of Magnús' wife in his physical care is indeed substantial and sustained. For example, she helps him by feeding him dinner every night, she prepares him for bed, including giving detailed skin care, and she and her daughters provide primary care of his teeth, oral care. It becomes clear in the second interview that the wife rather expects that she will simply have to accept the state of affairs of her husband's personal care. But she finds it hard to accept how "lightly" the staff treats Magnús' sleeping spells.

She potters around if Magnús is having a sleeping spell when she arrives, maybe massaging his feet. But then she will phone later in the evening to find out if he has woken up, and if so whether he has eaten something, or she phones again the next morning if he is still sleeping in the evening to find out how things are. The wife actually finds it somewhat disturbing that the RNs do not seem all that well informed at all times about how long a respective sleeping spell has lasted or how long Magnús has been awake after a sleeping spell. As the wife delineates:

> The late shift says, no they did not bring it up today, they did not mention it. "Has he slept like that ever since noon", I will say, "or the whole day". "Well, I don't know, it has not been mentioned". Like this, you see, they should of course know this, because it is not normal for the man to sleep like that. They should be able to say that Magnús has slept like that since that time. They know actually that we always ask a lot about this. ... But it is like this ... - they take it very lightly.

The wife finds it "not normal for the man to sleep like that", but the staff does not seem to find it necessary to pay particular attention to Magnús' sleeping spells. However, it is possible that they do, but without making much out of them, as the sleeping spells are just the way things are with Magnús.

The Relationship with the Staff

Actually the wife puts a lot of effort into finding avenues so that the staff will pay some particular attention to her husband. It becomes apparent in both of our interviews that she has tried to figure out how she can ensure that her special messages are heard and taken notice of when the staff goes about Magnús' care. And she does not really know whether it is best to talk to "girls" at the bedside, the RN on duty or the unit manager, so her messages will be heard.

All the same Magnús' wife thinks that the staff is very accommodating to her going about in the unit, as they always tell her that she can do as she wishes and get the things she needs, for example in the kitchen when she is giving her husband his meal. And the daughter says: "They are awfully nice with regard to that, we are just allowed to get whatever we need from the refrigerator and everything, and just get what we want there" and the wife adds "I feel quite at home when I go in there, you see" and a little later in the interview she says "I have been sitting there for such a long time, one feels quite at ease there, so to speak, you see."

Also Magnús' wife and the whole family finds the staff very friendly and the wife says that she has appreciated their concern in times of stress, such as when she was selling the house and moving, as well as during times of enjoyment, such as when she has gone on a short trip. Her daughter appreciates this concern also, and recalls that the staff usually asks about her mother if she is away, and likes to know how she is doing. Indeed, both Magnús' wife and his daughter emphasize that they feel really comfortable in the unit and very much at ease.

The Family's Engagement in Magnús' Care

The family finds the circumstances in the nursing home rather miserable as the inhabitants and Magnús himself are in such a poor condition, as the wife says:

> Oh, it is naturally quite miserable to enter the unit and see all these people. ... I find it quite terrible, they have become so muddled and confused, you see, they hardly know their names you see. Sure it is very sad to look upon it.

But Magnús' family has long since grown accustomed to his vulnerable health condition, and his wife had actually cared for him at home for more than three years at the time of his institutionalization. Nevertheless, his poor condition is even augmented in this group of fragile and often disoriented people, and this makes it even harder to face. The wife visited twice a day at the beginning of her husband's stay in the nursing home, when she came to help him with his lunch as well as dinner. Now she visits once a day; she arrives about five o'clock in the afternoon and stays until seven or seven-thirty. She sits by him, either by his bed or his chair, before the dinner arrives, and often she reads the newspaper to him. Just before dinner arrives she wheels him to the sitting room, where she feeds him, it takes a long time, at least half an hour, to give him his meal.

Actually the wife and the daughter think it is better for him if they feed him, rather than the staff:

D: We actually feel it is better that we do it, rather than they [do it], sometimes

W: It takes him a long time to eat, I think we give him more time

D: We have the time, they do not have as much time perhaps

INT: Yes

W: It takes him so long to chew, and one can't really expect them to have the time for this.

Then shortly after dinner the wife takes her husband to the bathroom where she helps him to brush his teeth, washes his face and upper body and puts some cream on his skin. The staff comes along and helps Magnús into bed when his wife has got him ready for it. The wife does not like to leave until her husband is comfortably settled in bed and "resting" rather than "left behind" or "left alone" as the wife and the daughter see it as they talk about leaving after visiting:

W: Oh, I always find it very hard to leave him behind

D: Yes, and that's why, you see, I would rather not go before he is in bed, and things like that, and he is just going to go to sleep. ...I always find it a bit miserable to leave him out front

W: Yes, I never do that

D. No, neither do I myself. ...Yes, I feel somehow that I'm just leaving him alone there

W: Yes, I can't do it

D: No, me neither, I always have to go

W: I do not go before...

D: Not before he is in bed, you see. Then I wash him and brush his teeth and put him to bed, you see, or they put him to bed.

INT: Indeed, yes

W: Yes. If I miss them and they've gone to supper, you see, then I just wait until they have finished their break, then the time is maybe seven-thirty

INT: Yes, yes

W: Then I just sit by him or take him out to watch the TV or something in the meanwhile.

INT: Yes, yes, you do not go before

W: I don't go at all before he is in bed.

Magnús' wife says that she is simply attending to him the way she used to back home, so she is just continuing what she has done for a long time and knows very well. She says "it has just somehow got this way" and her daughter further explains: "It is also that he had been at home for three years, and she had naturally looked after him for years at home. So of course this somehow just turned out to continue this way ..."

The wife looks upon bodily care as very important for Magnús' wellbeing and she also thinks that she makes the best contact with him by touching him while feeding him and giving him bodily care. Magnús' daughters also help him in the same way during times when the wife has gone away on holiday. And his sister may help with his meals. Actually, the wife and the daughter find it better do something while they are there, as they say:

D: This is actually the only thing you can do for him

INT: Yes, indeed

D: One always wants to do something for him

W: There is nothing else you can do for him, but just something like this

D: You get [something out of it] in a way yourself, perhaps, you know, that you are doing something for him

INT: Indeed

W: Yes that he may feel better you see, there is actually nothing else you can do for him but something like this

INT: Indeed, yes

W: And I buy some cream, like Aloe Vera, to put on his back, and I put it on

INT: Yes

D: Massage his feet and .. things like that

INT: Yes

W: Yes, yes, you are actually doing this just for yourself, you see, somehow

D: But you really know that he likes it, you can see it when you look at him

W: Yes, yes

Magnús' wife is particularly concerned about her husband's mouth care and skin condition. Magnús often has mucus in his mouth and there may also be food residue sticking to his teeth or his gum. It is quite hard to help Magnús to brush his teeth and clean them properly, but mouth hygiene has always been very important for Magnús, as his daughter says: " it's important, like this, to clean his mouth. He was actually always so careful about that".

The wife and the daughter think that the mouth care is more or less in their hands, as they think that this aspect of care might sometimes be left out during morning hygiene, as the wife often notices that the toothbrush is exactly in the same position as she left it in the evening before, when she finished helping her husband brush his teeth. Magnús' wife watches also over his skin condition as he may perspire a good deal and he may have abrasions because he scratches himself when he is itches. The wife points out that he is so vulnerable to skin breakdown because he is on anticoagulation medication, so there is bleeding if he scratches himself. So she washes his upper body before he goes to bed every night and applies some cream. She has been experimenting with different kinds of creams and she keeps a selection of these on the sill above her husband's bed, and addresses with the staff the issue of what cream to use at each time, as she says: "So I make sure that they put cream on him properly and things like that". But then she adds: "I don't distrust them, you see, not at all, this has just somehow got this way". Then

Magnús' wife finds it important that he does not lie in bed swathed in clothes so she has asked the staff to take his sweater off when they put him to bed during the day to prevent him from sweating.

Magnús' wife and daughter think that he is slipping more and more away from them and find him becoming quite distant, as the wife expresses it: "He shows very little, in a way ... - little response, so to speak. ... He speaks very little ... A whole lot has gone, you see ... He says yes and no, really, so to speak". However, the daughter maintains that he knows all of the family when they are around.

> It's as if he has now become, you see, a bit more distant. ... But he does really know us and ... Yes, he does, and knows everybody you see. ... But actually you know, he never asks about anybody, and never shows any reaction when we come. ... But nevertheless, you know, I think that he does, naturally, appreciate it and he likes it.

The wife is not certain if her husband is aware of it when she goes away for a while, for instance when she went abroad for two weeks during the fall, as she says: "For example like when I went away, I went away twice this fall, I do not know – I might say that he smiles, in a way, more when I come back ... He never asked for me - he never asked for me".

But she keeps him up to date about what is going on in the family, and reads aloud from the newspapers for him or "we read the newspaper for ourselves and then we have him listening to something a bit at the same time. I think he enjoys it a little, depending upon what it is", she says. However she points out that he follows her reading less and less; he no longer grasps the meaning, for instance, if she reads a notice of the death of someone they have known. Anyway she says that time passes while reading the newspaper and actually it strikes you as you walk into the room where the wife sits by Magnús' side and reads from the papers, that the reading appears in a sense to bring them closer to each other and connect them.

At times, more or less the whole family is gathered around Magnús, as his son with his wife and two children might be visiting, as well as one or both of his two daughters and their families. And it is as if they are trying to involve Magnús with the life going on in the respective families, as they talk among themselves about how things are, they talk and he is there listening, even though it might go "into one [ear] and out of the other" as his daughter says. The family have regularly brought Magnús back home for the day, weekly at the beginning of his stay in the nursing home but now less frequently. Magnús seemed to like it and the wife recalls that the staff used to say that he had always been very cheerful when he returned from his outing. But his daughter however points out that "he is nevertheless always relieved to go back. Then I think it's just that he wants to get to bed".

And although Magnús can no longer participate in family parties, he will often get a taste of some of the food served in the party, so that he does not miss out altogether. Actually the wife or the daughters may bring in some food, specially sweets, any day - just something that they know he likes.

The Staff's Response to the Family Visiting

The staff finds Magnús' wife and his whole family very nice and see their presence and caregiving in the unit as very important for him. Actually, the staff sees Magnús' family as the core of his whole "poor" life. The staff maintains that he brightens up while his wife or the family is around, as they find him hard to reach and "terribly indifferent, except somehow while she is there". However, the wife does not think Magnús shows much response while she is around, but it is possible that her warm and pleasant presence casts a glow upon Magnús' composure, in and of itself, in the eyes of the staff. Indeed, a practical nurse points out that Magnús' wife is able to give a lot of herself to her husband as she attends to him, and another one agrees in the following exchange:

> PN/B: And this, you see, must be precious for a relative, to be able to give in this way off herself like Vera does. Both that she massages him with the creams, and she feeds him [his meal]. It is perhaps really a question of what is possible to do for a

patient like Magnús.

INT: Yes, indeed

PN/A: You can't keep up conversation with him, but you can have this relationship with him, which involves this, and talk to him by the same time.

INT: Yes, indeed.

PN/B: This must give them a whole lot

INT: Indeed, yes. So you find that this, attending to him, that it is in a way an avenue to...

PN/A: Yes, I mean, you can't get into any conversation with him, or anything like that, so this is in a way an avenue. I think it is really a pity to see how few relatives there are who have discovered this, this avenue.

The staff finds the wife's input into his care very helpful, and think actually that she is often more successful than themselves in helping Magnús with consuming his meals and brushing his teeth. They have simply allowed her pattern of caregiving to evolve, and see it very much as a continuation of her care of her husband at home, and have not tried to influence or interfere with her activities in any way. However, they are always ready to back up her caregiving activities and step in when Magnús needs to go the toilet or is helped into bed. So it seems that each party contributes to the other's caregiving activities in a participatory manner.

Nevertheless, it turns out that one of the wife's particular messages has not reached the ears of all the staff, as the group discusses the wife's input into Magnús' care:

PN/B: She has her own opinions, like in connection with his clothes, and she gets quite tenacious.

RN/D: She has for example asked us in particular for his sweater to be taken off when he has his nap after the lunch hour and, you see... - actually it is not always done

PN/F: No, and the temperature in the room varies a bit. You see, he is so close to

> the window. I did not take it off him this time, for example, because we just thought it was...
>
> RN/D: She can't accept something like that, she wants us to do what she asks
>
> PN/B: Yes, like when his radio is tuned to some rock and roll station, she wants it to be left on station one
>
> RN/D: Yes, she doesn't like it being fiddled with it and tuned to some different stations.

The issue of "taking off the sweater" is actually addressed again in this interview, as the staff discusses whether things have gone wrong at any time in their relationship with the wife and a practical nurse recalls:

> It has once happened to me, then she was bit... - I thought she was more hurt somehow, because of the sweater, having asked often that he would not be put into bed with the sweater on when he is having a nap, when I was on duty once, then she came, and he was dripping with perspiration, and she says "Oh, I have asked so often for his sweater to be taken off..". I did not think ... - she was not unpleasant or unfair, she was just somehow hurt: "oh, I have asked so often for this". Of course it's different how people complain, I did not respond negatively at all you see, just said: "yes we need to do a better job and write it down in the book and...".

This practical nurse emphasizes that Magnús' wife was not "unpleasant or unfair" and adds "Of course it's different how people complain". And it is very clear in the way in which that staff talks about the wife's comportment in the unit that they find her manner of watching over her Magnús' care very polite and fair. It comes through also that it is fair enough for her to ask or make some request on her husband's behalf, as after all, she relieves the staff of some considerable work.

Some of the staff regrets that Magnús has not been offered a private room, when one has become available, simply for the family's sake. And they find it rather unpleasant for the wife to be around in the bathroom, where the floor may be quite sticky from urine, as the bathroom is used by two other men as well. But the family has not asked for a move and in fact they just talked about the double room as the way in which things were, without expressing any kind of opinion, in my interviews with them.

The staff recalls that there had been "some pressure" on the family's behalf to get a placement before Magnús' entry into the home, and at the time the family had simply accepted a double room. So the wife might just be sticking to that agreement, or possibly she might prefer to know that her husband has somebody in the room with him.

Patterns of Participatory Care

The wife and the daughter feel at ease and comfortable in the unit, as the staff accommodates their presence with their friendly and flexible stance. Furthermore they find the manners in which the staff relates to Magnús considerate and gentle. They appreciate the staff's manner of comportment, but find it simultaneously disturbing how easygoing they are with regard to their mode of observing and reporting of Magnús' sleeping spells. This easygoing mode touches upon the family's struggle between their strong concern for his wellbeing on one hand, and the aimlessness of his life on the other hand. This struggle is disclosed as the wife and the daughter address the issue of the quality of his life in which "There it is just eating and sleeping. ... And just lying there" and as the exchange continues:

W: I think that this isn't any life at all

INT: You don't think this is any life at all?

W: No

INT: No

D: Of course it's no kind of life, just lying there

W: Staring up at the ceiling like that. ... No, I don't think this is any kind of life, really

In a way, the staff's manner of observing and reporting Magnús' sleeping spells conveys to the family some kind of disregard for his wellbeing and aggravates the family members' dilemma of tackling the meaning or meaningless of the situation. However, this family appears to be determined to give meaning to the situation:

> INT: ... it happens also that there are people who perhaps say indeed that this is no life at all, then some perhaps think... - sometimes you hear that people do not think it matters to come
>
> D: ... although people are like that, then you never know what kind of feelings they have inside
>
> W: Dear me, no
>
> INT: Absolutely
>
> W: Of course
>
> D: I mean, people must find it good to have their closest relatives visit and have various things done for them ... and that is, of course, also the only thing which you can do for them
>
> INT: Yes, indeed
>
> D: Yes, dear me, it is of course ... - it is impossible to say that this is no life and not to pay attention to him anymore
>
> W: No, absolutely not.

The staff is very much aware that Magnús' wife is very concerned about him, and that "she takes pride in his being well taken care of". They know that she watches over him and makes inquiries about his condition. But they respect her stance and make an effort to solicit her concern in most regards. The staff acknowledge the importance of the contribution of Magnús' family to his care and wellbeing and give the family members leeway to have their own manner of attending to him. The staff thinks that the wife certainly has opinions about the way in which her husband should be cared for, but they do not perceive her as demanding, but simply fair in her requests. They point out that usually she is not being fastidious or critical about their work, as a practical nurse says:

> She is not criticizing our work, perhaps just now and again we have to do a bit more.

> She is grateful for what we do, she doesn't talk about things being not done well enough, but perhaps she wants a bit more sometimes, and that is no problem at all.

Magnús' wife indeed wants the staff at times to add a bit more thoughtfulness to their work, so they will pay more attention to "the little things" which contribute to his physical wellbeing and make him feel more comfortable. And her own way of participating in her husband's care, the attention she herself pays to "the little things" of bodily care, manifest to the staff the importance of these aspects of Magnús' care. She shows them that it matters to relate to Magnús through bodily care and, after all, these little things give meaning to the situation as this "no life at all" runs its course. But while it lasts Magnús' family will be there and pay attention to his wellbeing.

Antagonistic Care

Dóra's Family Style of Engagement in her Care

Dóra has stayed in the present nursing home for nearly a year at the time of my investigation. She has bright and lively features, but does not seem to notice all that much that goes on around her, although she usually responds when she is addressed with one or two words or short sentences. She is a short, rather plump, woman particularly around her middle, and she has short beautifully white hair, usually with a perm and nicely set. She is always nicely dressed, often in bright colors, and very well groomed. She walks around with the support of one person, but lies in her bed or sits at a table for most of the time.

The Family's Perception of Dóra's Care

Dóra's family of six children was quite happy when she got placement in this particular nursing home at the beginning of a new year. At the time Dóra was in her late seventies and her disease of dementia of Alzheimer type was quite advanced, though she had been living alone just few months before her placement, managing with close supervision of her children, especially one of her daughters living nearby. However, close supervision did not suffice, and one evening Dóra got lost, and was not found until late that night. She was consequently hospitalized with pneumonia and later on transferred to a temporary nursing home placement. This approximately two-month temporary nursing home placement turned out to be a very satisfying experience for Dóra and her family, and became the standard by which the placement in the present nursing home is being evaluated. Dóra moved from a cramped, dilapidated space in the old temporary nursing home into a rather large private room in a special wing for Alzheimer patients, for a permanent stay in this relatively new and quite tasteful home.

So the evaluation of the permanent nursing home placement was favorable at the very beginning with regard to the physical environment. However, from the perspective of one of Dóra's daughters, this promising physical environment has not shown itself to be all that inviting or supportive as time has gone by, but rather a closed-off, isolated storage space as the daughter describes it:

> Then she had actually got a placement in ..., and we were of course very pleased with that, in a new home, and we went and took a look. It was a big room which she got and things like that, we were very pleased. I'm not as pleased today, I miss the ... just incredibly much and I see that she feels ... - you see, there is just a total change, she is so lonely, I feel. She is on this closed corridor, and so often when I come then the corridor is closed, and no personnel inside. And then the people are just closed in there, and some are tied to their chairs and are of course shouting, naturally. And she is afraid, and things like that. I often feel very badly when I leave her again ...

The daughter's concern pertains first and foremost to the way in which the staff relates to patients and in particular the extent to which they do not relate to them and just leave them on their own "tied down and closed in" in the closed wing where Dóra is staying with other eleven patients. The special characteristics of the wing are aimed towards the creation of a safe and stable environment. The door can be closed with a special feature to prevent the residents from straying, and the same group of staff works continuously in the wing to establish stability, presumably to provide a sense of security and consistency for the patients. Precautions are certainly taken to prevent patients from getting lost, as the door is generally closed, especially in the afternoon when Dóra's daughter comes for a visit. However she rarely sees a staff person within the wing, with whom the distraught patients could possibly feel more secure, as she says:

> There is so much more loneliness there, and it was ... – one would often come and the people were there quite alone, there was nobody with them and the corridor was even closed, actually more often if you came after three in the afternoon. It is all right until then, but then the door is very often closed between [the wings of the unit]

Dóra's daughter misses with deep regret the way in which the continuous presence of staff or a staff member among the patients in the temporary nursing home brought about calmness, but at same time togetherness, of the staff and the patients as well as the relatives. And she continues her comparison:

> On the contrary when she was in the... then I felt it was so reassuring for us, the relatives, we knew it was so small and there was always somebody around - she was so contented. And they would sit among the people and listen to music and sing and things like that. She was so contented. In this place I think ... everything is lacking.

Dóra's daughter had some definite expectations towards the manner in which the mother's care should be organized and approached in her new home, in light of her experience of her care in the temporary nursing home, which is actually designated for care of demented patients. It took some time for her to realize that her mother was cared for in an altogether different manner, a manner by which her mother's condition deteriorated more than could be expected from the disease process per se, as she sees it.

What the daughter saw as the most prominent sign or symptom of different care was her mother's diminishing mobility. Indeed the daughter came to believe that her mother was being immobilised by medication and inactivity and that this condition was in a way augmented by isolation and the staff's indifferent manner toward the patients. Or, on the contrary, as the daughter pondered, it could also be the case that the isolation and indifference had lead to feelings of fear and loneliness; and that these feelings would actually have been conducive to the behavioral problems that had led to an increase in medication. The daughter found the whole situation distressing and first brought up the medication aspect, but then many more issues emerged in the wake of the upheaval of this inquiry.

The Relationship with the Staff

The daughter asked if her mother's medication could be evaluated and reduced, because she was beginning "to be over-drugged in a way which was really not acceptable". But her exchange with the staff because of this inquiry turned out to undermine her relationship with the staff, as she delineates:

> And I complained then about this medication matters because I thought she had become so drugged, she could not stand up from a chair. She had been quite...- gone with me for a long walk or something like that yes, twenty minutes walking outside. And I complained about that and then I got this explanation that she had become so aggressive that it was necessary to drug her like that. And I could not accept that. I said you see that she was an Alzheimer patient within an Alzheimer unit and my feeling was that she was aggressive because she was alone so much. ... It was fear, too, and I said " So why is the corridor closed if she is so aggressive that you are afraid that she will be violent towards other patients, why do you close the corridor off with no member of the staff inside?" But then I somehow got everybody up against me. Then, you know, they stopped saying hello to me.

However, an attempt was made to amend the situation by planning a meeting with family and the unit physician, as well as the unit manager. But the meeting had to be postponed and the problems were actually aggravated when an RN spoke to the daughter on the phone with regard to this postponement, as their conversation turned out in the following way according to the daughter:

> And then she actually said that she didn't agree upon that her medication ought to be

changed, because she was so aggressive. And I ask her "how is she aggressive, what does she do?" because I felt that I had to know. I did not know this side of her; of course I was quite aware that she has a short fuse and gets angry quickly, ... but I could not see that she could be violent to anyone ... And then she said "yes, she bites and scratches and tears and hits and kicks and pinches and squeezes" and gave a very unfavorable picture of her. I was very upset and said "how can it be that we have not been told this, since we spend a lot of time in there and we haven't been told this" I said to her. Then she said "well, I don't know" she said ... then I started to protest against these medications, because, the way things were, she would soon be in a wheelchair. Then she said to me "it's of no importance, because she will end up in a wheelchair anyway". And I said "no, that's not true", because I don't think that Alzheimer patients necessarily end up in a wheelchair; they often do, but not always. And I do think that it is just so important to keep up the mobility of all people. And then she tells me about this, and she said "it was only yesterday that she hurt a patient here". And I was, of course, very upset and I said "then of course you do what you have to do, because you of course can't have her like that" and I said "dear God, what happened?". Then she said "there was a mark on the patient". And I just got somehow so upset that I simply could not talk to her anymore, and I just broke totally down over it. So I phoned my brother and asked him to go down there and find out what had happened, and if she had harmed another person, and I was just awfully upset, because I had been objecting to the medication, and she had been having ... four times daily and I had got it down to ... because I found that she was always so sleepy because of it, and drowsy and weak. And so I blamed it on myself. ... So I phoned my brother and asked him to go down there and find out what had happened and get to know if she had harmed another person. ... So he went down and got to talk to the RN who was on duty that evening, and she was actually quite upset about it, and said that things had not at all been like that at all, it was just exaggeration ...

Nevertheless the daughter believes that the RN with whom she spoke on the phone had alerted the physician, as he called her the very same day and promised to evaluate her mother's medication and even ask a geriatrician for a consultation. And this was successfully done according to the daughter, as she found her mother slowly achieving a better balance. But Dóra got a thrombus in one of her legs before she really got back on her feet, and her daughter was not entirely surprised, because "you know, she hardly moved at all and was always lying in the same way, in the same position". But it shocked the daughter all the same when she found out herself what was happening to her mother:

> Then one day when we came, I and my son came along as well, and she just held her leg like this and just whimpered and we checked her and the foot was twice its size and dark blue. She had got this bad thrombus, from the knee and up to the groin. And my car had just then been out of order for 3 days and I had not been able to go to her, and of course I felt awfully guilty, because this must have been happening already ... - this does not come on acutely, not like that, she must have been in pain because of it. She was very dehydrated and she had a bad urinary infection, and I had mentioned it to them twice that I thought that there was a very strong smell from her urine, whether they did not think that she might have an urinary infection. But then I do think now that a situation had arisen where it did not matter at all what I say, everything is just you know ... - I do think so. You know, that they had thought that I make too much of it all.

The daughter maintains that with regard to the way in which her relationship with staff had developed in the unit "that they had thought that I make too much of it all". She suspects that the staff will respond in a defensive mode to any inquiries on her behalf, as they see her as overprotective towards her mother and very critical towards their manner of attending to Dóra. And actually the daughter's relationship with the staff broke totally down after this incident, as she points out herself:

> But when I took her to the hospital, then I thought that she was in a very bad condition. She had an nasty-looking rift here, beneath "the apron" (abdominal fold of fat), which had just developed in three days, because she was with me the Friday before and then there was no mark on her. She has just been lying down all that time. And then it came to light that the previous Sunday she had fallen on the floor twice, and I had already asked that I should always be notified if something like that happened, because you want to know, but they did not let me know and I was of course hurt because of that and annoyed and discouraged with this, and discouraged with feeling... - I felt she was in a bad condition when I took her to the emergency room, I just thought, you see. ... And since then, then in a way ... - yes, I can just say so, I think you know, that there is no relationship with the staff.

And Dóra's daughter has been overwhelmed with anger because of the way in which her mother is cared for.

> ... particularly first afterwards. I was really, you see ... - I was just quite overwhelmed with anger. But, you see, I often feel it that my stomach is in knots, I'm anxious about... I'm anxious about finding her in some condition like that again and because I thought this was so terrible, those were difficult examinations and hard on Alzheimer patients to be moved like that, I was really distressed because of that.

She has to some extent expressed her anger, with fierce criticism towards the manner in which the care is organized and approached in this special wing of the unit. She says herself that she has not been all that diplomatic, but "you say things accidentally" when you get overly tired with the way things are going as she expresses it herself:

> Yes, yes. I told them really my opinion you see, and I didn't try to be tactful; I told them that I found it unacceptable that people were shut up within the corridor like prisoners, and nobody there who looked after them even if they were shouting and calling and things like that, and maybe I said things I should have said in a different manner, but I simply did it, I was just ...- I was so tired out with it.

The staff evidently did not find the daughter's manner of addressing the issue of their attendance to the patients in the Alzheimer wing "diplomatic", because she is aware that the staff keeps her at a distance and "there is a kind of wall" between her and the staff, as she expresses it:

> And since then, because I said that I thought this was unacceptable, what with this closed door and just how the people were not feeling well enough, and things like that, then I'm just really aware that there is a kind of wall.

The daughter actually says that the staff often appears to be invisible when she is there, and her son has suggested that the staff does not like her presence in the unit at all. However, the daughter repeatedly mentions that there are some very different staff members in the unit who she sees as going about the care in a more constructive manner than others, however they do not "set the tone" for the care approaches in the unit. She can tell the difference between shifts when she enters the unit and "the constructive staff" is on duty, there is a different atmosphere in the unit and the door into the Alzheimer wing is open and some staff members inside. And she is really appreciative of a particular RN who always comes into the room while she visits, just to talk to the two of them and tell her how her mom has been during the day.

> There is particularly one, she is a lovely person, she knocks on the door, enters and talks with us, an RN, a young woman, and, you know, talks with us and is warm and in a way. ... I find it good, we find a way to chat a bit together. I say "do you know, has this been a good day for her, how has she been and things like that, how are things going, and so on". I find it good.

The Family's Engagement in Dóra's Care

This daughter is the one of the six sisters and brothers who oversees her mother's care and does all the instrumental work that needs to be done, and is the mother's advocate in affairs within the nursing home. She visits five days a week, often in the afternoon after working on morning shift as a practical nurse in a nearby hospital; she usually stays for one or two hours, even longer. Then she quite often invites her mother to her house or takes her out for a ride in her car. She is single but has one grown-up son who lives in a separate household, but he visits his grandmother frequently with his mother. Another daughter relieves her sister for two days during the week. The other siblings, who live in the country and relatively nearby, visit occasionally.

The daughter is not only devastated by anger, but also burdened by a multifaceted ambivalence regarding her guardianship of her mother's condition. She finds it necessary to address issues like the medication matters when she thinks her mother is over-sedated. But then she gets very upset and asks if her interference might consequently have caused harm to another patient, when the RN tells her that her mother has hurt somebody and suggests that this has happened because she has not been sedated enough. At the same time she feels that she has failed her mother when she does not come to see her for a few days when her car breaks down, and her mother's development of a thrombus goes unnoticed in the meantime. A nagging conscience caught the daughter in a vicious circle after this incidence and consequent hospitalization, driving her to spend more and more time with her mother to safeguard her condition.

So Dóra's daughter monitors her mother's condition, she tries to give her enough fluid and mobilize her to prevent a formation of a new thrombus. The daughter had before the incident always taken her mother for a walk, often outside, but now this is even more important. Indeed, for at least a couple of weeks after the incident the daughter did not leave Dóra before she had helped her to go to bed. Actually, Dóra's daughter has always attended her mother in various ways, tending to her appearance, her nails and her hairdo, giving her foot massage and so on. Sometimes they have watched TV together or played cards or patience and the daughter has taken up reminiscing as her mother has got "more lost", bringing her somewhat back by remembering "the good old days".

Dóra's daughter recognizes how the disease process is engulfing her mother and that it has been a steep downhill ride since she got lost from her home. She has read a considerable amount about Alzheimer disease, and she shares her experience with a group of peers, so she is knowledgeable about the disease and possible ways to go about it in manner which sustains her mother's dignity. As she says: "the disease has become worse. It has done so, you see. But all the same I do think, you see, of course, that people are entitled to keep their dignity as much as possible".

And she describes her way of caring for her mother in the following manner:

> You see I'm helping her, giving her something to drink and cutting her nails and massaging her feet and doing various things so she will feel better. And now lately I have taken up talking about the old days to her. You see, she was so sad the other day and just looked into space and was chewing somehow and I began to talk to her about it, and she just changed completely and I reminded her that she had always bought bird fodder and fed the birds outside, and then things just followed, with all the kids, and she had a cat and I reminded her of the cat and things like that, and when we had talked about this – it must have been over an hour - she glowed and said "and I who thought that I had lost all of this, and yet it's all here" and sweeps her arms towards her. Then she was meaning those memories. "I thought I had lost all this", she said, "yet it's all here". And I have been doing that a bit now, reminiscing with her in a way about what have been pleasant events, but which she doesn't remember. You see she might say to me "did I do that, was I so nice?" and you see I find that she is feeling better to know for certain that she has been good and proven herself a true friend to her folks and been willing to help everybody and things like that, this gives her a lot. So that I find it very good, when I'm minding her in some ways, to talk about this.

The Staff's Response to the Family's Visiting

> Her mother was getting sicker - this began really after I came back from the summer holidays then her medication had been totally changed - change of medication for

> her - she had been prescribed much more sedatives – isn't it right what I'm saying - and she became very dull - part of it was the medication - part of it was the progressing disease condition and the daughter was told that this was a progressing condition of the disease and then she said like "well, there is one thing that I find very wrong here, that there is always something being done for mom and something happening with mom and I'm not told anything and we are not told" - she often speaks in the plural - "we are not told what is happening and I just want people to speak to me in frank terms", and so I got that said frankly to me and I began to tell her about various things that were happening... (A RN)

The RN points out that she totally misunderstood the daughter when she said "I just want people to speak to me in frank terms" and really spoke out about her mother's "unmanageable " behavior. And the RN was caught with surprise and regret when it came to light in the unit that the daughter had interpreted her outspoken mode of describing her mother's conduct as derogatory. But by this incident an emerging conflict between the staff and the family came to the surface.

The staff is in a defensive position when they talk about Dóra and her daughter in a rather aloof manner. Dóra has Alzheimer disease and they know the progress of the disease, and can tell how to categorize the patients within its course. They talk about her disease condition in generalizing terms when they refer to the way in which Alzheimer disease is exhibited in Dóra's case. However, they think that the disease has been advancing quite rapidly since her entry into the home. The staff's maintains that Dóra's behavior had become "unmanageable" subsequent to her rapid deterioration calling for an increase in sedative medication. But they admit to Dóra's dulled condition at the time of the daughter's inquiry, and beneficial change of her medication.

Nevertheless the staff agrees with the RN when she maintains that the daughter is not able to face her mother's deteriorating condition, and talks of the daughter as being in a state of denial, as she does not admit to her mother's advancing signs and symptoms of the disease. The daughter's unrealistic expectations regarding the mother's care bear upon this denial from the staff's point of view. The staff talks with righteous indignation about the daughter's criticism of the way in which the care is organized and approached in the unit, though the RN says "we must be able to handle criticism and hopefully we do so". However, the staff has not handled the critique by evaluating the way in which they go about their care, but by organizing "specific" interventions for Dóra, so as to hold any criticism at bay. In fact there is a notable lack in the staff's account of any notion that there might have been a better way of handling Dóra's care, or a different manner of responding to the daughter's objections.

The RN says with a hint of irony "I actually think that she is in a bit of crisis now", as she speaks of the daughter's attempts at monitoring her mother's condition, referring briefly to the mother's development of a thrombus and a fungal infection at the same time. As she says:

> I actually think that she is in a bit of crisis now you see - that the daughter does have a rather hard time now - I think so you see - I have got a report about it from the evening shift that, it is very common and I have indeed seen it myself you see - she searches - she examines her mom very thoroughly - she looks beneath the clothes - she examines under the breasts - she examines the groin and she checks how we are doing ... it had actually once happened - it was also - was associated with this - let me see - she got thrombus in her leg and it was totally our fault - she got thrombus in the leg and it was because we of course don't take care of her ... and when we were examining the leg then I noticed and I'm sorry to admit it, even though I hinted at it to her that we knew about this - I did not know it - there was a fungal infection beneath the apron (abdominal fold of fat) and at that time she had been so difficult and it had been hard to clean her.

It comes through in the group discussion that these incidents of thrombus formation and fungal infection were "unavoidable" as the mother was simply unmanageable at the time and difficult to care for. And the staff has to watch out to avoid confrontation with the daughter, as they feel that she does not trust them anymore. So they try, to a degree, to live up to the daughter's expectations of care whether it might seem reasonable to do so or not. The staff perceives the daughter as being rather unrealistic about the possible outcome of care, for instance when she is persuading her mother to move out of bed so she will not be bedridden, as the staff sees the mother as declining inevitably.

Nevertheless the staff talks sincerely about the daughter's feelings of enormous responsibility for her mother, and the way in which she cares in an exemplary manner for her mother, and other staff echoes this as a staff member says: "she takes awfully good care of her mom ... nothing is too good for her". But the daughter's care is looked upon as her own business, though rather bothersome for the staff as her presence in the unit implies a critical stance. Some staff thinks that the daughter wants to keep at some distance, a few steps apart, which they think is conveyed to them by the way in which the daughter closes the two doors (into the small corridor in front of the room and into the room) when she is visiting; other staff says that the doors are sometimes open. It is possible that the daughter closes the doors in a protest against "the closed storage space", or she may be shielding her mother and herself from the shouting of the other patients, which she attributes to the closed door into the wing.

Actually it is the daughter who talks about the necessity of resolving this conflict in one way or another, possibly by setting up a meeting where the family could talk things over with the physician and the RNs. There have been two previous unsuccessful attempts to have a meeting with the family and staff; one did not work out as the physician could not make it to the meeting, and the family had to ask for postponement of second planned meeting. Conversely, the staff does not seem to think there is much to talk about as the daughter's "unwarranted criticism" reflects her denial of her mother's condition and unreasonable expectations. So there is generally a gap between the daughter and the staff, as each party carries out care, in a rather mutually antagonistic manner.

Patterns of Antagonistic Care

Dóra is living in an "isolated storage place" in an atmosphere of antagonism between her daughter and the staff, as her first year in this nursing home comes towards its end. The antagonism has been growing, along with fulminating disagreement about the way the mother is cared for, between the daughter and the nursing staff. Quarrels have arisen about various aspects of the mother's care, medication in particular, both sedative and pain-relieving drugs. And shortly after Dóra's return from the hospital after her treatment for the thrombus, the same RN made a mistake when she addressed Dóra's elimination, like she says:

> I often go if I see the door ajar and greet people, and say 'good day' and things like that - but this time I actually had a reason to speak to her and intended to ask her if she had been aware of her mother having a bowel movement, because there were a few days when nothing had been recorded and she is with her so much that she could really have had bowel movement in her presence and she might not have said - and then the tirade began " you do not even take care of this here" - you see - "there are not even regular days" - then it just went on.

But by this time it was inevitable that things would go wrong, whatever the subject of the staff's inquiry, as the daughter's distrust had mounted subsequently to her mother's hospitalization. However, the major dilemma bears on different views of the Alzheimer patient and the possibility of constructive intervention to halt the demented person's decline. The daughter emphasizes the relational aspects of care of the demented patient, in light of her reading about Alzheimer disease, and she finds this helpful as she goes about her mother's care, not least if her mother is agitated, as she points out.

> Of course there are hard times. She feels bad, and especially as things have been. She felt really terribly bad and was just foul-mouthed and things like that, but she you see... - she did not know me, but she did not use personal violence towards me.

> Therefore I think it is so… - I never believed that she did this. But she could say many things, just “”revolting”, and “terrible” and “ugly” and” just go away”, and “I don’t want to see you here” and so on. ... it was hard in the beginning perhaps, then just ... - I have read a lot about this disease and often it sufficed for me to just go outside the room, and then come back in and say ”hi, nice to see you” and then she had forgotten it ... I just started over with her. I just went outside and then started over and then things worked out. ... It is the same, you know, when I’m maybe helping her to eat, if she does not want this and becomes angry and something like that, then I just take it away and then I come back with it maybe two minutes later and say “look how nice this is”. Then she just changes completely.

The daughter says that she has read the book The 36-Hour Day, “again and again”. And she adds “I always think there is some, some section which fits her accurately and I find I can make use of. I think it is very good”. She has actually tried to tell the staff how to relate to her mother, and she remembers when she said to a staff member “you always need to tell her before you are going to do things, otherwise she will respond in an angry way”, but then the respective helper “responded in an angry way that I should be teaching her how to relate to her”.

The staff has got into a position of a defensive stance by what they see as the daughter’s unwarranted criticism. They are not ready to either listen to daughter’s advice or to address issues of her mother’s care with her. And the daughter knows as she says:

> I’m aware, that it would not matter at all what I would say today, you know it would just be ”oh, there she goes again” - you know, just somebody who is absolutely crazy and does not have an understanding of the disease. I do have an understanding of the disease and I know that mom’s condition is not going to get any better, but on the other hand it is quite unnecessary you see, not to try to maintain what can be maintained.

But the possibility of any constructive intervention to halt Dóra’s decline seems to be remote in this atmosphere of antagonism between the family and the staff. In fact it emerged in our first interview that the daughter had considered terminating her mother's placement and caring for her in her home. However, she had come to the conclusion that this would probably not be feasible and was at a loss as to how she could handle the situation. There had been a huge tragedy in Dóra's family when I met the daughter for our second interview, and consequently the mother's situation had moved somewhat into the background. But a few months later Dóra was moved to another nursing home, after one more incident in the unit, which overextended the family's tolerance towards the way in which the mother was cared for in this nursing home.

The breakdown of trust and the growing antagonism between Dóra's family and the staff in the unit brings to light the importance of the way in which each party comports itself towards the other in the relationship between families and staff in nursing homes. Furthermore, it illuminates the role that the family's expectations of quality of care play in these relationships, and the manner in which the staff meets those expectations. However, Dóra's daughter expectations of safe and adequate care should indeed be the minimum requirement that a family can request in these circumstances. But these minimum requirements did not seem to be met in this situation. Dóra's condition when her daughter took her to the emergency room evidences that the mother's care was lacking during this period of time.

Discussion

The above interpretation of the different styles of families engaging in the care of a loved one living in a nursing home has attempted to amplify distinctive aspects of the family's involvement. Various factors influence the way in which family's engagement evolves and establishes itself within the nursing home world. On one hand the family has different premises for involvement and on the other hand the context of the nursing home is to differing degrees conducive to the family's engagement in care of the residents. I will now address these factors and try to clarify their meaning .

The Family Ties

The family members participating in this study managed to develop ingenious strategies to create closeness and togetherness with the elder in these circumstances. Even the daughters of the very old demented residents managed to "get in touch" with their parents and give them a sense of belonging in their embrace. And it was certainly crucial for the visiting family members to be able to attest to their ties to the respective resident, while looking after and sustaining their loved one's personhood and wellbeing. All the visiting family members had a long story of apparently close and fond relationships with their loved one residing in a nursing home. Obviously the visiting spouses had been living with their respective husband or wife for decades, and the communication between the daughters and the son with their respective parents had been frequent and extensive before the nursing home placement. So visiting in the nursing home was taken for granted as a continuation of these long-standing relationships. It became apparent, as the visiting family member talked of her or his involvement in the loved one's life in the nursing home, that this kind of concern was inherent to her or his family bond to the elder. Løgstrup (1971) has argued that the radical demand is implicit to all relationship "demanding in every instance that a man care for the other person" (p. 111). He further states:

> ... the demand is, as it were, refracted through a prism in a variety of ways. In the first place, we might mention our various unique relationships with one another - as husband and wife, parents and children, employer and employee, teacher and student. The demand is refracted through the psychic content of these relationships, and since the content of these relationships differs from one nation to another, from one time to another, the refraction takes place in a great variety of ways. ... It is important that these various relationships not oppose the demand but point in the same direction that it does. Through each one of them - each one in its own way - the individual holds something of the other person's life in his hands (p. 113).

The demand was indeed refracted through all of the participants' understanding of the relationships in which they found themselves with the elder. Nonetheless, the demand is invisible, and actually none of the participants would refer to their sense of duty, or directly declare their responsibility for the elder's wellbeing; their concerns were assumed to be taken for granted. As Anna's daughter said " I do not think it is strange that you want to see your mum and find out how she is". It came across as the participants talked about their ties with the elder, that they had over the years been grounded in mutual concern for each other's wellbeing. It was actually common among the daughters to recall that the mother had been a great support as they were rearing their own children, and even acted as "a surrogate mother" during some particular periods of the upbringing of their children. And a spouse would refer to the time she or he had shared with the resident as couple, and often the closeness of their togetherness. Indeed, the deeply rooted "psychic content" of the relationship between the visiting family member and the elder was reflected in the family's various efforts to sustain these ties and connectedness.

The Family's Circumstances

The family member's circumstances allowed for different kinds of involvement in the life of the elder and amounts of time spent for that purpose. The spouses considered it natural to spend a designated time in the nursing home, although some of them, like Óskar's wife, were not in very good health themselves. Thus, the personal health of the visiting spouse may place some constraints on the type and amount of involvement in the life of their husband or wife. And indeed, the time spent in the nursing home may be taxing for their health.

The children, generally daughters had competing obligations, as all except one had full-time or part-time jobs, and several children, and some of them had grandchildren as well. One of the participants was in fact faced with a growing demand on her time when I first spoke with her and was tackling a perceived need to cut down her visits and reduce the time she was accustomed to share with her father. This daughter was by far the youngest of four siblings and said that she had probably been closest to her parents, and that her closeness to her father grew even stronger after her mother died at a rather young age. The father appeared to have become a part of the youngest daughter's family life after the loss of his wife, and got along well with her husband and two children. And the daughter and her family had sustained the father's sense of belonging to the family after his placement in a nursing home, with frequent visits and shared outings. Actually they had done so for three years at the time of our first interview.

But the daughter's family had expanded at this time, after she had given birth to her third child, and now she was seeing her maternity leave coming towards an end, and getting prepared to return to work. The daughter was realizing that there were simply going to be too many demands on her resources. And she had come to the conclusion that she had to cut down the frequency and length of her visits to her father for the sake of her primary family. But this was not an easy decision to make, and the daughter was in fact worried about the future prospect of handling her close connection with her father, while forced to cut down the time spent with him.

I met the daughter again for our second interview a few weeks after she returned to work. Then the daughter told me that she was just too exhausted to worry much about her father's response to her change of visiting pattern. And she added "this has got to work out this way", and in fact she had not much choice, but simultaneously she appeared to assume that her father would understand. Somehow it was implicit to her stance that after all, there had always been a mutual understanding of each other's situation between the two of them. In some ways it made things easier for the daughter that she was not the sole child, and her father was fortunate enough to receive many visits from his other children and his many friends as well. However, these companionships may not have the same kind of togetherness as characterized his daughter's company. It was in fact apparent, when I met the daughter and her three children while they visited their father and grandfather that they belonged in each other's company in a relaxed manner. Actually the daughter said "we do not do anything special while we visit - we are just together like we used to be". The involvement of the daughter and her family in the father's life in the nursing home appeared to resemble their pattern of being together as companions before his placement. The situation of their relationship had completely changed, but the daughter and her family had nevertheless been able to establish a continuation of companionship. And this feeling of companionship will probably prevail in spite of the changing circumstances in the daughter's life, because of their deep-rooted manner of relating to each other, while the extent of her involvement in her father's life will lessen.

This example shows how particular circumstances of the visiting family member may affect the extent and manner of family's involvement in the nursing home. The family members' style of engagement is indeed predicated on family's ties, their circumstances, and not least the family's perception of the situation in which the elder find herself or himself.

The Family's Perception of the Situation

The visiting family watches over how the elder is doing within the nursing home world. They are very receptive to their relative's comportment and the manner in which the elder embodies her or his illness and responds to the situation. They are quite aware of the elder's helplessness, and very sensitive to her or his vulnerability while receiving a helping hand in maintaining bodily practices and everyday living. Indeed the family member monitors her or his relative's condition and responses to the situation in the nursing home, and evaluates how he or she is doing and being cared for. And the visiting family members do so because they are concerned about how the elder fares in her or his last dwelling place. However the extent to which the families give voice to the matter of their concerns differs.

The institutionalization has made a shift in the family's perception of their role in their loved one's life. And the family members may not know what say they may have in this situation, as the staff in the nursing home has taken charge of the person and in particular her or his body. It is indeed the family's perception of "who is in charge" which determines the way in which they envisage possible ways of guarding the personhood and wellbeing of their loved one. The family's sense of the staff's command of the situation tends to be augmented by the degree of the resident's helplessness, and the extent to which she or he receives help in attending to bodily needs. However, command of the situation may be shifted somewhat if the resident can speak up for herself or himself in matters of importance in her or his care. And the family member may certainly support the resident's effort to have a say in her or his own care, or may speak up on behalf of those not able to do so. But, as in parallel care, the family may not address the necessities of the body directly; somehow these aspects of care may seem too complicated or too intimate to speak of, and perhaps humiliating to the family member. It is also possible that the family may find it too painful to address the way in which their beloved member is rendered helpless in going about the necessities of the body. On the other hand, the way in which a disease or diseases show up in the body, and the person's response to them, is a matter of discourse. In such discourse the experience of a disease or diseases can be objectified and addressed in terms of strategies that are more amenable to control than the family member's experience of their loved one's helplessness.

However, in spite of the family's close circumspection of the state of affairs in the nursing home, matters of their concern in the care of the elder tend to be addressed in a very diplomatic manner. This diplomacy comes about since the family does not really know what expectations to have regarding their relative's care. Indeed, the family may have rather unclear ideas of what measures of quality of care can be applied in this context of health care services. And the family may be much aware of the constraints of the situation, as they see so many very helpless patients about, and not many staff, a limited number of them trained or professional. Thus the families pattern their expectations to the situation at hand, and try rather to develop their own strategies to improve their relative's circumstances. A family member may in fact hesitate to question any aspect of their loved one's care and circumstances, as they fear that it might offend the staff. Marta's husband, for example, openly admitted that he would not want to evoke any antagonism on the staff's behalf, as he was afraid that his wife might suffer if this would happen. But Dóra's daughter was not as cautious in airing her concerns and putting forward her expectations towards the care of her mother. It is indeed possible that the daughter's experience of working as a practical nurse in a acute-care hospital may have influenced her standards of quality of care. And from the nursing home staff's point of view, a hospital's standards of quality of care may not be at all appropriate in this context of care.

Apart from diplomacy, the families found it very hard to tolerate it when their expectations of surveillance were not met. Due attention to signs and symptoms of changing condition matters to the family, as does the way in which it is responded to. An easygoing manner on the staff's behalf about signs of discomfort or suffering disturbs the family most, not least if the staff does not regard it as important to notify the family. The families appreciated due attention to particular problems, and found it important when the staff intervened in a appropriate manner.

Pétur's daughter, for example, emphasized the importance of the staff's intervention when a dermatologist had been asked to see her ninety-two-year-old father, when he was very bothered by bad itching all over. And she also referred to other instances of the staff's close surveillance and appropriate interventions in our first interview. And she found great comfort in remembering the way in which the staff responded to her father's worsening condition and impending death when I met her again about a month after her father's funeral. Her father's worsening condition came on rather suddenly. He had had long history of digestive problems, but a physician was called to see him on a Sunday afternoon when he was vomiting and growing very weak. The daughter was notified, and she immediately came to see her father. She was told that the physician on call had decided to have him moved to hospital the following day for further examinations. However, her father was very weak the next morning, and the unit manager decided to contact the nursing-home physician to address the state of affairs. The unit manager found it necessary to reevaluate the benefit of a taxing examination for the old man, in his weak condition, and the examination was cancelled after this consultation. Then the unit manager talked on the phone to the daughter, who fully agreed with this decision and new directives in her father's treatment. Pétur's daughter came to the nursing home during the morning, shortly after this phone call, and stayed by her father's bedside until his death in the afternoon. The daughter found it very important to have been able to be with her father until the very end, and remembered this time with her father with great gratitude. Her father had a peaceful death, and the daughter appreciated that the staff had taken a respectful stance with regard to the intensity of interventions at this critical point of time during her father's stay in the nursing home. Pétur's daughter talked indeed with warmth and gratitude about her father's stay in the nursing home in both of our interviews, as she thought that her father had been well looked after and cared for with kindness.

Surveillance is multifaceted, and it was common among the visiting family members to notice subtle signs of the staff's manner of watching over their loved ones. Family members found it, for example, very disturbing if no staff turned up while they were staying, particularly if they had come in the late afternoon and found their relative lying in the dark, during wintertime. Conversely, people found it very reassuring if a staff member "checked on" their relative without particularly knowing that the elder had a visit. Such "checking" not only conveyed to the visiting family member that the staff looked after the residents but that they were considerate and concerned about how the elder was doing.

Consideration towards the elder was of great importance for the family, and in fact all the participants in this study would place major emphasis on the staff's conduct and comportment towards the residents. The visiting families noticed how the staff talked to and about their respective relative, and other residents as well. They appreciated the presence of the staff among the residents, and all gestures of attention to a particular person. And the staff's receptiveness to their loved one's response to the situation at hand and her or his feelings and mood, was very important for the visiting family. The family greatly valued all signs of the staff's comportment and care that indicated recognition of the personhood of their relative, such as an acknowledgement of the elder's concerns and customary habits of everyday living. And any effort on the staff's behalf that enhanced the elder's sense of self and dignity mattered to the family. This effort may be reflected in the staff's attention to the grooming and dressing aspects of care as was exemplified in Anna's case. Indeed all attention to physical comfort conveyed a message about the importance of the elder's being, whether or not the family ascribed this aspect of care to the staff's realm or actively contributed to bodily care as Magnús' family did.

However, the families did not really know how they might influence the staff's comportment towards the elder. But towards this end most families certainly attempted to hold any criticism at bay, and conduct themselves in a polite and respectful manner towards the staff. The families were usually very responsive to any directives on the staff's part and responded quickly if the staff simply mentioned that the elder might lack something, or might benefit from some special supplies. But the extent to which the families addressed issues of care with the staff, made inquiries about their relative's condition and wellbeing, and stated their concerns differed. And this became evident in the distinctive styles of each family's engagement in their loved one's care, as I have explicated in the preceding text. But it was precisely up to the family to establish sharing with the staff, and indicate concern for their relative's wellbeing, by opening up the boundaries between the family's and the staff's realm of care.

The Staff's Stance towards Family Visiting

The staff welcomes the family presence and appreciates the impact of the family member's companionship upon the wellbeing of the residents. But the staff appears to be rather reluctant to overstep what they see as the boundaries of the family's caregiving in the nursing home. The way they observe the boundaries of the family's caregiving is shaped by the staff's respect for the privacy of deep rooted family connections, and the manner in which its members relate to each other and especially to the resident. This stance of respect is characteristic for all staff members alike, in all the units, as they talk about their relationship with the family, whether there is a RN, practical nurse or nursing assistant speaking. The staff members do not find it appropriate to invade the family's territory, or interfere with the way in which the family engage in the care of their member. Nevertheless, there is a certain receptiveness to any initiative on the family's behalf to establish exchange, and usually the staff is quite responsive to the family's wishes or requests, such as preparing a resident for an outing. Such request pertains to the family's territory of care, and the staff is ready to support the family members as they go about their care.

Complaints or inquiries into the staff's care approaches may on the other hand be perceived to a varying degree as legitimate or fair. Actually, the staff finds it more legitimate for regular visitors to comment on their care, rather than the ones who rarely show up. Nevertheless the line of the staff's conversation as they speak of family complaints tends to minimize any criticism of their work because the family "does not really know how 'she is' or 'he is'". The staff often seems to think that the family does not have a realistic view of the incapacity of its member, and the way to deal with it. So the staff is inclined to dismiss a complaint or special concern of the family's behalf as irrelevant to their care approaches. The real care is within their area of responsibility and this has its boundaries as well. After all they are there all the time, take care of the body, and deal with the elder's response to her or his helplessness and the situation at hand.

I spoke to two groups of staff in each unit participating in the study and there was a noteworthy congruence between these two groups in the way in which they conversed about and referred to the visiting families. But there is a difference between units when the two groups' conversations in one unit is compared to the two groups' conversations in another unit considering the staff's regard for the family's concern for the wellbeing and care of the elder. However, this distinction is far from clear-cut.

It becomes apparent in the group conversation in some units that the staff regards the family as peripheral to their domain of care. It is certainly fine if the family comes on visits, or takes the resident for an outing, and even better if the family sees to that its member does not lack anything, like clothes. However, the staff may not pay much attention to the family, neither to the family member's relationship with the patient nor the family feelings about the situation. And the staff knows rather little about the family's history of connections. The group's conversation about a particular family in these units tends to be rather superficial, as the main emphases are on the family's comportment towards the staff. The staff appreciates if the family is polite and grateful for the help that its member receives. But these groups only vaguely address any special concern of the family with regard to the elder response to her or his situation. Nevertheless they think it matters a lot for the resident to get regular visits, not least as providing some diversion.

It is more evident in the group conversation in other units that the staff knows the patient's family quite well, and the family's concern is more central to their care. The staff in these latter units will refer to the events leading to the nursing home placement, or the family's experience of caring for its member prior to the institutionalization. They converse about the family way of coping with the institutionalization and the demand of redefining its pattern of relationship with the resident. The staff notices and discusses the family's respond to the situation, and the way in which its members relate to the resident.

The staff in these latter units may not move much closer into the family's territory, but they accommodate the family visiting in various ways. Furthermore they are very flexible in the way in which they give the family leeway to cultivate it in its own way. They may stop by when the family is there, or pause as they go about some errands in the resident's room, to listen to the family's voice or just to establish a line of connection with a little chat. The staff in these units talks about the family's concern as a matter of handling the care of the respective patient, and they give deliberation to the family's expectations. It is common for the RN in these group conversations to give voice to the family's concern and expectations as the other staff members tune in to bring forward their side of the story. However, the extent to which this understanding of the family's concern and expectations is articulated in a nursing care plans differs, but mostly it appears to be known by the word of mouth. This understanding evolves as the resident settles in and the staff learns to know her or his response to the situation, and in particular to their attendance. At the same time the staff comes to realize the degree to which and in what way the family is concerned about the condition and wellbeing of its member.

These latter groups' conversation may actually reflect the staff's attempt to understand among themselves and in their work, how the self of a particular family member residing in a nursing home is constituted by the family, and how she or he is part of the family constitution. However, the staff's understanding of the resident's self and the family's concern is incorporated into their work in a manner that is taken for granted in a nonreflective way. This taken-for-granted nonreflective understanding emerges as the staff may actually deny, in a quiet determined manner any influence of the family upon the care they give. This does indeed sound rather strange in a group conversation reflecting a very thoughtful regard to the family's concern. But the staff in such a group is actually very eager to point out that they do not discriminate among their patients in terms of paying extra attention to a patient because of her or his family's concern, rather they maintain that they treat everybody equally. The nurses already feel that the residents who receive few or no visits are in a disadvantaged position, and they feel sorry for them.

So it seems unfair to even suggest that they would augment such a disadvantage of any of their patients. It is also ingrained into their practice ethics that all patients should be treated equally, and it is unthinkable for them that they would do otherwise. However the visiting family concern for their loved one may bring to the staff's awareness the importance of the personhood and wellbeing, not only of that respective resident, but others as well. It is also quiet possible that staff's receptiveness to the concern of families engaged in care of their member in these unit reflects a particular stance towards their care approaches; a stance that bears upon a regard for the expression of the self of their patients that is indeed amplified by the presence of the family, but taken for granted in a nonreflective manner.

The Boundaries of Family's and Staff's Caregiving

There is an inclination on both the family's and the staff's part to perceive that there are boundaries between each party's territory or realm of concern or care. On the one hand these boundaries are constituted by the staff's respect for the family's privacy while visiting, and on the other hand on the family's perception of the staff's command of the situation. It is hard to discern on what ground staff's respect for the family's privacy is based, as it is at odds with most families appreciation of at least some contact with the staff. However, it is possible that this emphasis on respect for the family's privacy may partly disguise the staff's insecurity in contacting and relating to the family. They simply may not know what subject to address with the family when there is nothing "special" going on. And from the staff's point of view things may be much the same from one day to another. The unit managers or the RNs may in fact address issues like a change of medication or any prospective examinations, and they, and other staff as well, may take up with the family the subject of resident's supplies or clothing, or something like that. But the staff will only to a limited degree bring up just how the resident has being doing during the day, or recently, or address aspects of their care approaches and the resident's responses to these. Neither will the staff ask much about the family's perception of how the elder is doing, or inquire about their expectations or concerns.

It is especially important for the families of the mentally impaired residents to establish lines of connections with the staff, but they often have to do so on their own initiative. However, these families are facing tremendous loss and decline, and some of them may find it hard to address issues of care and give voice to their concerns. But other families are able to, as exemplified by Jón's wife and Anna's daughter, who focus on their loved ones' embodiment of their illnesses and responses to the situation, by watching their composure and comportment as they move and act. Such families bring their observations to the staff's awareness and address issues of concerns in their care. Furthermore, a family like Magnús' manages to convey to the staff the importance of bodily care, and show the staff how "the little things" of physical comfort can bring solace.

These families may in fact be particularly receptive to the elder's embodiment of her or his condition and wellbeing because of their long-standing ties to that person. But this receptiveness also reflects a wholesome view of the person, which regards the body as inherent part of the self. The extent to which the staff shares such view, or is inclined to see the body as an assemblage of the person's self, differs. This latter view reflects Cartesian dualism "which views the body as a collection of biochemical and physiological mechanism, the mind as a set of cognition, and emotions as a source of disruption of cognition" (Benner, 1996, p. 31). The prevailing features of parallel care apparently arise from an outlook that tends to regard the person's self as a separate entity from the body. However, the actuality of Óskar's and Soffía's caregiving shows that this outlook may be rather illusory as the relational aspect of both family and staff care nullifies any compartmentalization. Nevertheless, both parties manner of addressing their engagement in care shows an ingrained view that regards the care of the self and care of the body as separate components of care.

The degree to which the family's and staff's view of the person diverge or converge influences the demarcation of the boundaries between these two parties. A very clear demarcation of boundaries emerges when the family's and staff's view of the person diverge as is evident in the case of Dóra's family. Nevertheless, the boundaries are rather clear-cut between the care of Soffía's family and the staff's, as both parties' view of the person tend to converge. But from this shared point of view Soffía's self is seen as a separate entity form her body. Such convergence of both parties' view of the person has, on the contrary, to some degree phased out the boundaries between the care of Magnús' family and the staff's. The shared outlook sees Magnús' body as an inherent part of his self.

This chapter has attempted to show the characteristics of family's involvement in the life of a loved one residing in a nursing home, and its collaboration with the staff to ensure the elder's condition and wellbeing. The family ties, the family member's circumstances and perception of the situation influence the way in which the family engagement evolves and establishes itself within the nursing home world. As does the staff's stance towards family visiting. There is, as delineated above, an inclination on both family's and staff's behalf to perceive boundaries between each party's territory or realm of concern or care. However, such demarcation of boundaries between the family's and staff's care of the elder tends to be phased out when both parties regard the person's body as an inherent part of the self.

Chapter Seven

IMPLICATION FOR STAFF'S CARE APPROACHES

> ...she did not return from there, and died after eight years of continuous suffering in the spring of 1996, at the age of 87. This was all very hard on Stefán, he himself had been in frail health since his childhood. Such was Stefán's care for his mother that he visited her sickbed daily for five years. During her last three years, he became so distressed by visiting these institutions, seeing old people in ill health and watching his mother deteriorate slowly but progressively, that he did not feel up to going more than once or twice a week and he always felt badly the days he felt compelled to go. I tell this to show the kind of loyalty which Stefán always showed his parents ... (In Memoria, The Morning Paper, 1999).

It is a custom for family and friends in Iceland to write an "In Memoria" article or often a number of articles in the newspaper in the memory of a person on the day of her or his funeral. This citation is from such an article written in memory of a 53-year-old friend, who was the only son of his parents and apparently a loving one. The author remembers how hard it was on his friend when his mother was institutionalized shortly after the father's death, and the consequent strain of caring for her in a nursing home.

This citation brings to light the ramifications of a nursing home placement of a close relative for the family. However, these ramifications for the institutionalized person and her or his family are not fully recognized by the nursing home staff. Institutionalization is a major transition in the life of the individual and those with whom the person has shared her or his world. This shared world of a family grows to some extent apart as the transition of its member to a nursing home world comes about.

However, the findings of this study show that there are families who are able to bridge the gap between the world of the family and the nursing home world. And this ability makes a difference for the wellbeing of the residents and indeed for the atmosphere of the nursing home world. But, the findings show as well that it is the family who paves the way for cooperation between the family and staff in nursing homes, as the staff shows limited initiative in establishing this kind of connection. Thus the findings suggest that the staff in nursing homes has something to learn from the families participating in this study; not only with regard to the way they care for their own loved one, but by considering how family care affects the residents' wellbeing. Indeed, the nursing staff may need to pay particular attention to the residents who have no family, in order to sustain their wellbeing in a manner similar to the families' way of keeping watch over their loved one. I will now attempt to explicate what possible lessons may be learned from these findings.

To Settle in the Right Way

The new inhabitant and her or his family are usually quite lost and bewildered at the move into the nursing home, so all support and guidance are important. The new inhabitant and the family certainly need leads to follow. Information about the daily rhythm of the unit, such as mealtimes, needs to be given clearly; it may be helpful to provide the resident with a schedule in which some routine activities like mealtimes are written, as well as special ones like the day of a weekly bath or physio hours. It would certainly help if there were one or two key contact persons, who could be distinguished among all the new faces of "endless" number of staff, on whom a resident could rely and to whom the family could turn.

It is important for the new inhabitant to be able to claim a demarcated space as her or his own from the very beginning, and to have at determined spot of reference in going about the new place. A private room to set up as one's own is an asset for many residents. But the person herself or himself and the family may need advice or discussion about the preferable way to do so, in considering what may help the person to feel at home. It may be a special chair rather than a fine rococo chair; any item that the person especially cherishes and looks upon as a part of herself or himself, like a compass for an old seacaptain. Pictures of the family, such as children and grandchildren, or of the little village where the person grew up, certainly reflect upon the resident's background and seem to give the person a sense of herself or himself; at the same time the staff may capture an insight into the resident's background. A memory album and a visitor's book may be valuable, especially for the mentally impaired residents. A big clock on the wall and a calendar help the resident to keep track of the passing days. To this end, it may be important for the resident to continue to subscribe to a daily newspaper in so far she or he has done so before the placement. A radio and a television set, even a CD player, make some diversion possible on the person's own terms. It may also be important for some people to have their own telephone, and even a small refrigerator to keep some supplies in. One's own territory appears to give the resident a sense of self and allows for a refuge, while facilitating her or his settlement in this last dwelling place in life.

Inviting the Family upon a Collaboration

The visiting family needs to be acknowledged and information sought about the family members' premises for involvement in the life of the elder. Families' concern for their member living in a nursing home certainly differs and so does their willingness to be involved in that world. So it is indeed necessary to address the family ties and connections with the closest kin at the time of institutionalization, to reveal the family's stance towards any engagement in care. It is also necessary to consider the extent to which a continuous relationship with the resident may need sustenance, in so far as the family ties and the family's circumstances indicate a ground for it. The impact of family visiting upon the wellbeing of its member has to be emphasized, and also the staff's appreciation of any effort on the family's behalf to improve the care of the resident.

It is important to give the family an opportunity to express its feelings about the institutionalization of its member and the family's expectations towards her or his care. It is also important to address the family's concern about the quality of life of its member, and what they think is most important in safeguarding her or his wellbeing. The way in which the family attempts to sustain the self of its member needs to be recognized, especially the family's emphasis on the elder's practices and habits. The family could also be asked to prepare a brief biographical summary of the resident's life to inform the staff about the resident's background.

The possibility of rotating visits, dividing special responsibilities between siblings or members of the family, and means of sharing the care of the elder may be addressed. Furthermore, the staff may discuss with the family the best way to structure visits, considering convenient times for the family, and the resident and how the family member envisions involvement in the loved one's life. In this regard the possible agenda of the visit should be talked over and it may be possible to propose to the visiting family member ways to spend time with the elder, if only by simply being there. The staff could suggest possible avenues to be with the elder, or reach a patient to whom it is hard to relate.

Sustenance of the Resident's Self

A view of the person which focuses on the way in which the person carries herself or himself and moves and acts in the situation, while appreciating life-long habits of going about bodily practices and everyday activities, facilitates care that sustains the self. Such recognition may be known by word of mouth in the staff's everyday care, but the degree to which it is understood as important in nursing discourse in the unit is to a large extent determined by stance of the unit manager or RNs. It is indeed very much the unit manager and the RNs who affect the understanding in unit of the particular resident's expression of self. It should be the hallmark of nursing to facilitate such an expression of the self. Indeed, consideration of the person's embodiment of her or his condition and the way in which the person relates to herself or himself and others and responds to her or his situation makes a difference in the manner in which staff approaches the care.

However, the resident's profile is usually constituted by her or his medical records, the placement evaluation and more or less comprehensive nursing assessment. This profile may only to a limited degree reflect the person's experience of a failing body and increasing helplessness, or her or his response to the situation. A circumscribed view of the person tends to focus on the person's impairments within a scope of some measuring strategy which aims at evaluating the resident's limitation, especially in performing activities of daily living. Application of some kind of standardized assessment tool is an accepted mode of categorizing nursing home residents for the purpose of evaluating a resident's care requirements within geriatric care and its cost. The Icelandic government actually requires and regulates the application of a special kind of assessment instrument in the country's nursing homes. This mode of assessment in fact takes up a lot of the RNs' time and some of them would indeed like to pose questions regarding its relevance to the nursing care approaches in the respective unit. The issue of applying standardized assessment instruments to evaluate nursing care requirements in nursing homes is beyond the scope of this discussion, but nevertheless it needs to be taken into consideration.

It needs to be considered in as much as this mode of assessment undermines the nursing agency's view of the way in which the person expresses a particular sense of self in her or his relationship with the staff. It is within a view that focuses on the person's expression of self, that the family is seen as an integral part of the person's sense of self. Such scope prepares the ground for the staff's receptiveness to the family's influence upon the resident's wellbeing. Continuous staff development is called for to develop the nursing agency's view of the person and its discourse on the dialogical self, in line with Taylor's stance (1991) which asserts:

> We cannot understand human life merely in terms of individual subjects, who frame representations about and respond to others, because a great deal of human action happens only insofar as the agent understands and constitutes himself or herself as integrally part of a 'we' (p. 311).

One's understanding of himself or herself as integrally part of a 'we' is not least obvious in family relationships, in which shared meanings and concerns shape the family members' self-interpretation and sense of togetherness and belonging. The elder's sense

of belonging to her or his family is grounded in such understanding, and it is important for the nursing agency to acknowledge and enhance the resident's feelings of being an integral part of the family.

The Staff's Receptiveness to the Family's Influence upon its Member's Wellbeing

The staff's receptiveness to the family's influence upon its member's wellbeing rests upon the way in which the staff sees the resident's self constituted by the family, and her or his part in the family's constitution. However, in some units this understanding may be mostly a taken-for-granted understanding that needs to be made more explicit. The staff in other units may regard the family as peripheral to their domain of care and such a view limits the staff's awareness of the family's concern for its member.

The staff may not fully realize how the family's feelings about its member's institutionalization and stay in a nursing home affect the closest kin and indeed the life of most of the family members. Allowing the closest kin to give voice to this experience may possibly be of help and support the family member in coming to terms with institutionalization. It is important in this context to discuss the elder's attitude towards and response to this transition, and possible ways to facilitate her or his acceptance of this lot.

Furthermore, the staff may actually disregard the family's perception of its role in safeguarding the patient's self and wellbeing, while appreciating its attempts to break up the everyday routine by some diversion. The family's ability to monitor the resident's condition in view of its knowledge of the resident is often overlooked, and so is the family's perception and evaluation of the resident's response to her or his situation. Consequently, this potential valuable input into the staff's care is not utilized. The staff also vary in their receptiveness to the family's opinion of the most important factors in the care of its member and to any cues that the family provides in that regard. However, the family may not necessarily be outspoken about its stance, and its cues may be given less than directly. The family may indeed be hesitant to make any special request of the staff, as its members recognize the multifaceted demands of the caring situation. Thus, it would seem even more important to seek the family's opinion about care, which is, however, not done much, at least not in a strategic manner.

What disturbs the family most is an easy-going manner on the staff's behalf about any signs of discomfort or suffering, not least if the staff does not count it as important to notify the family. It should indeed be imperative to evaluate any sign of discomfort, and consider whether it is necessary to contact the family. Nevertheless, the staff appears at times to be lacking in knowledge to distinguish between the inevitable deterioration and eventual death of their patients, and on the other hand the available means to alleviate any suffering as each life runs its course. Furthermore, the staff may not be sufficiently aware of the ethical issues involved in such a situation. The main issue is that any human life whether it is seen as "not being any life at all" is a life nonetheless and needs to be honored as such as part of our shared humanity. A humanity that recognizes that each human life is rooted in a community of relations and implicit to all relationship is the radical demand "demanding in every instance that a man care for the other person" (Løgstrup, 1971, p. 111).

The Vigilance of Care Approaches

The staff's stance towards the degree to which care approaches in nursing home should be vigilant, or simply follow the course of the resident's progressive decline, is a central issue in nursing home care. It is indeed a difficult ethical issue, but hardly tackled in the discourse of everyday care. On one hand because the staff may not be appreciative of the ethical issues of everyday care, and on other hand because the staff lacks the language and does not know how to address such matters. It is common for all staff alike to say "but this a home not a hospital" to justify what could be seen as slack vigilance on their part to the signs and symptoms of the residents' changing conditions. This remarks presumably clarify that there is less emphasis on watching over or monitoring special signs and symptoms of nursing home patients and responding to them, compared to the way it is in a hospital.

However, it is certainly possible that there is not enough professional competence in some units to distinguish unclear symptoms of a changing condition from the accepted impairments of a particular patient. Symptoms may indeed be quite vague and unclear in this very frail population of patients. Furthermore, there may not only be lack of competence in evaluating a deteriorating condition, but insecurity in taking a stance on the matters at hand. The staff may find themselves in a rather ambivalent situation, in which deterioration and death is in one way or another an accepted aspect of the patient's progress.

Nevertheless, suffering should not be. It is imperative for staff in nursing homes to have the knowledge and directives to respond to deterioration in the conditions of their patients and have the means to alleviate their suffering. Some units actually manage to do so. There has been an incipient interest in introducing a hospice approach in nursing homes in Iceland. Such incentive evokes hope for better management of suffering in nursing homes, which is certainly called for. It matters enormously to the families to prevent their members suffering. However, any family, whether engaged or not in its member's care, is at a loss in face of a deteriorating condition. So it is up to the staff to take the initiative of distinguishing suffering from general decline and taking measures to alleviate it.

But the staff needs to be knowledgeable to handle this kind of situation. To this end it is necessary for nursing home administrations to recognize the importance of well-educated and competent nursing staff. Furthermore, ongoing, in-service education needs to be acknowledged and sustained. Ethical issues in the care of the elderly should be addressed in such education, furthermore discourse in the units about a particular resident's caring situation needs to highlight ethical considerations in the everyday care.

Measures of Quality

The lack of competent professional guidance is a problem in Icelandic nursing homes, just as in most other countries. There is actually a current shortage of registered nurses in the country, and there is and has always been a shortage within the nursing home practice arena. However, there has been a great expansion of geriatric services in the country during the last decade or so, with increasing demand for professional workers, and many registered nurses have actually joined forces within these services. There is a slight increase in interest in work in nursing homes among registered nurses. It is imperative to sustain this interest, as this practice field certainly calls for a development that is predicated on professional input.

However, professional discourse about this practice field tends to downplay its importance by defining either safe care or adequate care as a measure of the quality of care in this arena of care. It is indeed ironical that quality indicators of nursing home care focus on the prevalence of residents' conditions, like the prevalence of pressure sores or use of restraints, that arise from deficient or negligent care (Zimmerman et al., 1995; Rantz er al., 1996). Research on care in nursing homes, especially in the United States has amply demonstrated that deficient or negligent care is indeed far too common within this arena. Thus, safe care or adequate care is certainly required as a minimum standard of care. But minimum standards of care should not be indicators of quality of care. Minimum standards of care for the elderly population residing in nursing homes reflect ageism which is rooted in images of the aged body. Laws (1995) points out that ageism is a form of prejudice, a form of oppression and "ageism is something that we will all encounter, should we live long enough" (p. 113). Indeed, Laws states that "ageism as a set of social practices, and its embodiment in the aged body, are central concepts for understanding the way we treat people of different ages" (p.112). Laws (1995) maintains that images of embodiment, which connote negative images such as frailty, disease, and death, tend to overshadow other representations of the process of aging. Such representations of the process of aging become especially evident when embodiment of aging is viewed within the nursing home world. The frail aging body located in this context is too often regarded as not being entitled to other measures of quality than safe or adequate care.

Researchers within gerontology and gerontological nursing in particular are pursuing promising treatment options for many of the common health-related problems encountered in nursing home care. However, these options are not well enough known or made use of. This is especially evident in the care of the demented residents. The main obstacle to research findings filtering through to nursing practice in nursing homes is the lack of a sufficient number of well qualified competent nursing personnel, not least registered nurses. But a practice field within which it suffices to ensure only minimum standards of care does not represent a challenge to ambitious and competent nurses. A different scope of quality criteria within this area is necessary; a scope that acknowledges the aging body as expression of a self who has come a long way, a scope that focuses on the assessment and relational skills required of professional nurses to plan and carry out appropriate nursing care for individual residents in nursing homes. The organization of care and care approaches should be informed by comprehensive care planning, based on a knowledgeable assessment of the resident's condition and evaluation of possible treatment options. However, much of the direct care or bedside care is performed by practical nurses or nursing assistants. A high proportion of practical nurses is certainly an asset for a unit, but skilful nursing assistants also promote quality of care in the unit in a very valuable manner. Nevertheless, thoughtful, organized collaboration between all levels of staff is called for to enhance the contribution of individual workers. The organization of care and care approaches is determined especially by the managerial skills of the unit manager, but also by the registered nurse leading each shift. However, the education of registered nurses may not prepare them for working with assistant personnel with limited training in relational skills and attendance to bodily needs. It is up to nursing administration in each nursing home to help nurses to learn new skills to handle supervision in this context, to make them more competent in guiding the care approaches of their coworkers with lesser skills. The importance of in-service education as pointed out above, needs to be recognized, to promote the staff's knowledge and skills in everyday care. What is called for is not least enhancement of the staff's understanding of the meaning of home for the residents, and the way in which the nursing home world is constituted and their part in that constitution.

Finally, the visiting families may not know what measures of quality of care may be applied in this context of health care services, but they nevertheless consider what in their eyes counts as quality of care of their loved one. Indeed, the voice of the visiting family may be looked upon as an indicator of quality of care, in as much it is listened to in appreciative way .

Recognizing the Significance of Working with Families

Implicit to the family visit in a nursing home is an attestation of the importance of the care provided in this setting. However, the nursing staff neither explicitly recognizes the impact of such attestation, nor fully acknowledges the meaning of families' concern for the wellbeing of the elder residing in a nursing home. It is important to learn and know the family's concern. This concern reflects the family's stance towards engagement in care and whether there are grounds to encourage the family's input into care. Furthermore the family's concerns may bring to light invaluable dimensions of care in this context that may not have been clearly visible or recognized, such as the means to sustain the person's sense of self, not least by sustaining her or his bodily practices and habits of everyday life. However, the staff may discount these aspects of the person's self, or they may become transparent in their everyday care. Thus, they may not realize the importance of addressing such aspects of care with the family or they may not find it necessary. The staff may also ascribe care of the body totally to their realm of concern, and not regard it as an appropriate matter of discussion with family.

The staff may indeed not know how to talk about the care of the body with the family, even when the family shows obvious concerns about this aspect of care. However, this is not a subject which anyone and everyone should be discussing haphazardly with the family, unless the family brings something special up while the staff attends to elder. Rather, a particular contact person or an agent or two, for example a team of registered nurse and practical nurse, should be assigned to the family, with whom aspects of the resident's care may be addressed. These staff members need to give deliberation to the family's expectations and address how they can inform and guide the care of the particular resident. Nevertheless, all staff needs to be able to inform the visiting family, not least the families of the mentally impaired residents, about their daily disposition and responses to everyday care.

Furthermore the staff needs to recognize the extent to which the family is comfortable in going about the unit, and having a say and even a hand in its member's care. However, it may be preferable to give the families leeway to find their footing in the unit at the beginning of the residents' stay and let their style of engagement evolve on their own terms. The family's style of engagement needs to be respected, and the family's contribution to the wellbeing of the elder acknowledged as a supplementary input into the staff's care. It is especially the less visible or instrumental aspects of the family's care that need to be recognized and addressed with the visiting family and talked of as important. Recognition of the less visible or instrumental aspects of the family's care may indeed give way to a new interpretation of care in this context, that might benefit those inhabitants who do not enjoy family visiting.

Nevertheless, the staff may also need to confirm to the family that the presumed demarcation of the staff's domain of bodily or instrumental care is not by any means definite, but flexible in accordance with the family's inclination to participate. The staff may actually suggest to the visiting family members that they can provide some finishing touch to their loved one's care. However, it may be advisable to stress, both with the family and staff, that such participation in care does not entail any "family duties" which would be neglected if the family member is not present. The family needs to be reassured that the staff will take care of the family's part in any instrumental or bodily care, and pay attention to any finishing touch and special details, if the family is absent. But to this end staff needs to know what is important to the family in the elder's care, not least in the care of the mentally impaired. Elderly visiting spouses certainly need special consideration, and a constant mutual consultation about care may be called for with very involved family members, such as Magnús' wife. But first and foremost, the staff must know how much it matters to the family that the elder is looked after in a thoughtful and knowledgeable way.

Making Life in Nursing Homes Easier to Bear

The findings of this study show that families who are involved in their member's life in a nursing home make their life easier to bear. The possibilities of working with families in nursing homes need to be addressed with the staff, and their understanding of the meaning of family visiting enhanced. It is important to listen to the family's voice and learn to know the family's concern and expectations with regard to care, to improve the quality of life in this setting. Care approaches in nursing home need to aim at sustaining the person's self in coping with particular condition of health and illness, while soliciting the person's relations, her or his bodily practices and everyday habits. A home in a nursing home should make room for and embrace the self, in such a way that the person has a sense of belonging and feels at ease with herself or himself.

The ramification of staff's work in a nursing home for the wellbeing of elders in this last dwelling place of their life needs to be recognized. But such recognition may indeed reveal the importance of their work as the following citation from an "in memoria" article reflects. This "in memoria" is written by a niece, remembering her frail 95-year-old aunt at her death, and she closes her article with the following words:

I want to express special thanks to the staff in ... from all of us who were so fond of

> María. We owe it to these people, that her life became easy to bear and pleasant during these last years of her life (The Morning Paper, 1999).

This citation acknowledges the part that the staff played in constituting a world that made it possible to experience life as easy to bear and pleasant for a frail elder in a particular nursing home. And it is such a possibility that should be envisioned in all nursing homes.

References

Act on Services for the Elderly, 1989. [Lög um málefni aldradra nr. 82/1989].

Allen, J. (1993). Caring work and gender equity in aging society. In J. Allen and A. Pifer (Eds.), *Women on the front lines: Meeting the challenge of an aging America* (pp. 221-239). Washington, DC: Urban Institute.

Anna Birna Jensdóttir, Hlíf Gudmundsdóttir, Hrafn Pálsson, Ingibjörg Hjaltadóttir, Pálmi Jónsson, & Sigurbjörg Sigurgeirsdóttir. (1995). *Daglegt líf á hjúkrunarheimili. Heilsufar og hjúkrunarthörf.* [Daily life in a nursing home. Health and nursing care needs]. Reykjavík: Heilbrigdis- og tryggingamálaráduneytid [Ministry of Health and Social Security].

Baier, A. (1986). Trust and antitrust. *Ethics*, 96, 231-260.

Benner, P. (1984). *From novice to expert: Excellence and power in clinical nursing practice.* Menlo Park, Ca: Addison-Wesley.

Benner, P. (1985). Quality of life: a phenomenological perspective on explanation, prediction, and understanding in nursing science. *Advances in Nursing Science*, *8* (1), 1-14.

Benner, P. (1994). The tradition and skill of interpretive phenomenology in studying health, illness, and caring practices. In P. Benner (Ed.), *Interpretive phenomenology: Embodiment, caring, and ethics in health and illness* (pp. 99-127). Thousand Oaks, CA: Sage.

Benner, P. (1996). Embodiment, caring and ethics: A nursing perspective. *The Science of Caring, 8* (2), 30-36.

Benner, P., Tanner, C.A., & Chesla, C.A. (1996). *Expertise in nursing practice: Caring, clinical judgement and ethics.* New York, NY: Springer.

Bohman, J. F., Hiley, D. R., & Shusterman, R. (1991). Introduction: The interpretive turn. In D. R. Hiley, J. F. Bohman, and R. Shusterman (Eds.), *The Interpretive turn: Philosophy, science, culture.* (pp. 1-14). Ithaca and London: Cornell University

Press.

Bowers, B. J. (1988). Family perception of care in a nursing home. *The Gerontologist, 28*, 361- 368.

Bowers, B. J., & Becker, M. (1992). Nurse's aides in nursing homes: The relationship between organization and quality. *The Gerontologist, 32*, 360-366.

Brody, E. M. (1985). Parent care as a normative family stress. *The Gerontologist, 25*, 19-29.

Brody, E. M., Dempsey, N. P., & Pruchno, R. A. (1990). Mental health of sons and daughters of the institutionalized aged. *The Gerontologist, 30*, 212-219.

Brooke, V. (1989). How elders adjust: Through what phases do newly admitted residents pass. *Geriatric Nursing, 10*(2), 66-68.

Brown, E. L. (1947). Professional education for the nursing of the future: A progress report on the national nursing council's study of schools of nursing. *The American Journal of Nursing, 47*, 820-825.

Campbell, J. M., & Linc, L. G. (1996). Support groups for visitors of residents in nursing homes. *Journal of Gerontological Nursing, 22*(2), 30-35.

Carboni, J. T. (1990) Homelessness among the institutionalized elderly. *Journal of Gerontological Nursing, 16*(7), 32-37.

Chenitz, W. C. (1983). Entry into a nursing home as status passage: A theory to guide nursing practice. *Geriatric Nursing, 4*(2), 92- 97.

Diamond, T. (1992). *Making gray gold: Narratives of nursing home care*. Chicago: University of Chicago Press.

Dreyfus, H. L. (1991). *Being-in-the-world: A commentary on Heidegger's Being and Time, Division I*. Cambridge, Massachusetts: The MIT Press.

Dreyfus, H. L. (1994). *Philosophy 187: Heidegger's Being and Time*. University of California, Berkeley. [Lecture notes/ "transcripts"].

Duncan, M. T., & Morgan, D. L. (1994). Sharing the caring: Family caregivers' views of their relationships with nursing home staff. *The Gerontologist, 34*, 235-244.

Expert nursing care. [Editorial]. (1947). *The American Journal of Nursing, 47*, 142-143.

Finley, N. J., Roberts, D., & Banahan, B. F. (1988). Motivators and inhibitors of attitudes of filial obligation toward aging parents. *The Gerontologist, 28*, 73-78.

Foner, N. (1994). *The caregiving dilemma: Work in an American nursing home.* Berkeley, CA: University of California Press.

Fries, J. F., & Crapo, L. M. (1981). *Vitality and aging: Implications of the rectangular curve.* San Francisco: W.H. Freeman and Company.

Gadow, S. (1980). Existential advocacy: Philosophical foundation of nursing. In S. F. Spicker, and S. Gadow (Eds.), *Nursing: images and ideals: Opening dialogue with the humanities* (pp. 79-101). New York: Springer.

Goffman, E. (1961). *Asylums: Essays on the social situation of mental patients and other inmates.* Garden City, NY: Anchor Books, Doubleday.

Gilligan, C. (1982*). In a different voice: Psychological theory and women's development.* Cambridge, MA: Harvard University Press.

Golander, H. (1987). Under the guise of passivity. *Journal of Gerontological Nursing, 13* (2), 26-31.

Greene, V. L., & Monahan, D. J. (1982). The impact of visitation on patient well-being in nursing homes. *The Gerontologist, 22*, 418-423.

Guberman, N., Maheu, P., & Maillé, C. (1992). Women as family caregivers: Why do they care? *The Gerontologist, 32*, 607-617.

Gubrium, J. (1975). *Living and dying at Murray Manor.* New York: St. Martin's Press.

Guignon, C. B. (1983). *Heidegger and the problem of knowledge.* Indianapolis, Indiana: Hackett.

Harrington, C. (1991). The nursing home industry: A structural analysis. In M. Minkler and C. L. Estes (Eds.), *Critical perspectives on aging: The political and moral economy of growing old* (pp.153-164). Amityville, New York: Baywood.

Harvath, T. A., Archbold, P. G., Stewart, B. J., Gadow, S., Kirschling, J. M., Miller, L., Hagan, J., Brody, K., & Schook, J. (1994). Establishing partnerships with family caregivers: Local and cosmopolitan knowledge. *Journal of Gerontological Nursing, 20*(2), 29-35.

Heidegger, M. (1927/1962). (J. Macquarrie & E. Robinson, Trans.). *Being and time.* New York, N. Y.: Harper & Row.

Hertzberg, A., & Ekman, S. L. (1996). How the relatives of elderly patients in institutional care perceive the staff. *Scandinavian Journal of Caring Science, 10,* 205-211.

Horowitz, A. (1985). Sons and daughters as caregivers to older parents: Differences in role performance and consequences. *The Gerontologist, 25,* 612-617.

Hughes, E. C. (1951). Studying the nurse's work. *The American Journal of Nursing, 51,* 294-295.

Ingibjörg R. Magnúsdóttir (1992). Vistrymi fyrir aldrada. [Residential placements for the eldely]. *Tímarit Fhh,* [The Journal of the Association of University Educated Nurses], *9*(1), 22-25.

Johns, E. & Pfefferkorn, B. (1934). *An activity analysis of nursing.* New York City: Committee on the grading of nursing schools.

Jung, F. D. (1991). Teaching registered nurses how to supervise nursing assistants. *Journal of Nursing Administration, 21*(4), 32-36.

Kaufman, S. R. (1986). *The ageless self: Sources of meaning in late life.* Madison, Wis: University of Wisconsin Press.

Kayser-Jones, J. S. (1981). *Old, alone and neglected: Care of the aged in the United States and Scotland.* Berkeley: University of California Press.

Kayser-Jones, J. S. (1990). *Old, alone and neglected: Care of the aged in the United States and Scotland. Paper edition with Epilogue.* Berkeley: University of California Press.

Kayser-Jones, J. S. (1992). Culture, environment, and restraints: A conceptual model for research and practice. *Journal of Gerontological Nursing, 18*(11), 13-20.

Kellett, U. M. (1999). Transition in care: family carers' experience of nursing home placement. *Journal of Advanced Nursing, 29*, 1474-1481.

Kierkegaard, S. (1985). *Fear and trembling: Dialectical lyric by Johannes de silentio.* (A. Hannay, Trans.) London: Penguin Books.

Kierkegaard, S. (1989). *The sickness unto death: A christian psychological exposition for edification and awakening by Anti-Climacus.* (A. Hannay, Trans.) London: Penguin Books.

Kleemeier, R. W. (1959). Behavior and the organization of the bodily and the external environment. In J. E. Birren (Ed.), *Handbook of aging and the individual* (pp. 400-451). Chicago: University of Chicago Press..

Laird, C. (1979). *Limbo: A memoir about life in a nursing home by a survivor.* Novato, Ca: Chandler & Sharp Publishers, Inc.

Laws, G. (1995). Understanding ageism: Lessons from feminism and postmodernism. *The Gerontologist, 35*, 112-118.

Lawton, M. P. (1977). The impact of the environment on aging and behavior. In J. E. Birren and K. W. Schaie (Eds.), *Handbook of the psychology of aging* (pp. 276-301). New York: Van Norstrand Reinhold.

Lessing, D. (1984). *The diaries of Jane Somers.* New York: Vintage Books.

Løgstrup, K. E. (1971). *The Ethical demand.* (T. I. Jensen, Trans.) Philadelphia: Fortress Press.

Manheimer, R. J. (1992). In search of the gerontological self. *Journal of Aging Studies, 6*, 319-332.

McCallion, P., Toseland, R. W., & Freeman, K. (1999). An evaluation of a family visit education program. *Journal of the American Geriatrics Society, 47*, 203-214.

Ministry of Health and Social Security's web site (1999). *Institutions with placements* *for elders* [Stofnanir med vistrymi fyrir aldrada].

Packer, M. J., & Addison, R. B. (1989). Evaluating an interpretive account. In A. J. Packer and R. B. Addison (Eds.), *Entering the circle: Hermeneutic investigation in psychology* (pp. 275-292). New York, NY: State University of New York Press.

Pillemer, K., Hegeman, C. R., Albright, B., & Henderson, C. (1998). Building bridges between families and nursing home staff: The partners in caregiving program. *The Gerontologist, 38*, 499-503.

Pohl, J. M., Boyd, C., Liang, J., Given, C. W. (1995). Analysis of the impact of mother-daughter relationships on the commitment to caregiving. *Nursing Research, 44*(2), 68-75.

Practical nurses. [Editorial]. (1947). *The American Journal of Nursing, 47*, 143.

Rantz, M. J., Mehr, D. R., Conn, V. S., Hicks, L. L., Porter, R., Madsen, R. W., Petrowski, G. F., & Maas, M. (1996). Assessing quality of nursing home care: The foundation for improving resident outcomes. *Journal of Nursing Care Quality, 10*(4), 1-9.

Regulation on Institutional Services for the Elderly, 1990. [Reglugerd um stofnunathjónustu fyrir aldrada]. Ministry of Health and Social Security [Heilbrigdis- og tryggingarmálaráduneytid].

Riessman, C. K. (1993). *Narrative analysis.* Newsbury Park, CA: Sage Publication.

Rubin, A., & Shuttlesworth, G. E. (1983). Engaging families as support resources in nursing home care: Ambiguity in the subdivision of tasks. *The Gerontologist, 23*, 632-636.

Savishinsky, J. S. (1991). *The ends of time: Life and work in a nursing home.* New York: Bergin and Garvey.

Schell, E. (1993). The origins of geriatric nursing: The chronically ill elderly in almshouses and nursing homes, 1900-1950. *Nursing History Review, 1*, 203-216.

Schwartz, A. N., & Vogel, M. E. (1990). Nursing home staff and residents' families role expectations. *The Gerontologist, 30,* 49-53.

Shield, R. (1988). *Uneasy endings: Daily life in an American nursing home.* Ithaca, NY: Cornell University Press.

Smith, D. H. (1992). Seeing and knowing dementia. In R. H. Binstock, S. G. Post and P. J. Whitehouse (Eds.), *Dementia and aging: Ethics, values, and policy choices.* (pp. 44-54). Baltimore: The Johns Hopkins University Press.

Statistics Iceland (1999). *Statistical Yearbook of Iceland.* Reykjavík: Statistics Iceland.

Struve, M. & Lindbland, A. H. (1949). The nursing team in the hospital. *The American Journal of Nursing, 49,* 5-11.

Tanner, C. A., Benner, P., Chesla, C., & Gordon, D. R. (1993). The phenomenology of knowing the patient. *IMAGE. Journal of Nursing Scholarship, 25,* 273-280.

Tappen, R. M. (1994). The effect of skill training on functional abilities of nursing home residents with dementia. *Research in Nursing & Health, 17,* 159-165.

Taylor, C. (1991). The dialogical self. In D. R. Hiley, J. F. Bohman, and R. Shusterman (Eds.), *The Interpretive turn: Philosophy, science, culture.* (pp. 304-314). Ithaca and London: Cornell University Press.

Van Manen, M. (1990). *Researching lived experience: Human science for an action sensitive pedagogy.* London, Ontario, Canada: State University of New York Press.

Wiener, C.L., & Kayser-Jones, J. (1990). The uneasy fate of nursing home residents: an organizational-interaction perspective. *Sociology of Health & Illness, 12*(1), 83-104.

Wilson, E. R. (1945). Alleviate your nursing shortages with aides. *The American Journal of Nursing,, 45,* 184-188.

York, J. L., & Calsyn, R. J. (1977). Family involvement in nursing homes. *The Gerontologist, 17,* 500-505.

Zimmerman, D. R., Karon, S. L., Arling, G., Clark, B. R., Collins, T., Ross, R., & Sainfort, F. (1995). Development and testing of nursing home quality indicators. *Health Care Financing Review, 16*(4), 107-128.

APPENDIX A

INTERVIEW WITH FAMILY MEMBER

1. You often come to visit your relative in the nursing home. Can you tell me what the visiting experience is like for you?
   Probes: What leads you to visit?
   What is important about the visit?
   Do other family members visit as well?

2. How do your visits fit into your daily schedule? What is it like for you before you come to visit your family member? How do you anticipate it?

3. What is it like for you after you have visited? Do you feel more or less anxious, happy?

4. What do you think is the same about your elder family member considering the present in comparison with a time before he or she needed to be in the Nursing Home? What do you think is different?

5. Is there a particular story that describes your relative well? Get full narrative.

6. Are there particular details about his/her person that I should know if I am to understand him/her?

Now I would like you to switch gears and have you talk about the care that your elder family member receives.

7. Can you describe the kinds of involvement you have with NH staff when you visit your elder family member?
   Probes:-
   Do you think that you have different kinds of relations/ involvement with different staff?
   What are the important differences that you notice?

7a. What kinds of care do you think the staff provide for your family member and for you? Are there important gaps in the care that your family member and you receive?

8. Can you tell me a story about a time when you were involved with staff regarding the care of your elder that worked really well?
   a) Tell me what happened.
   b) What led up to this situation?
   c) What were your thoughts, feelings and reactions to the situation? What were your priorities in this situation?
   d) What did you do?
   e) How did you feel afterwards?
   f) How did your action change the situation?
   g) What else did you consider doing?

h) Who was most helpful to you in this situation?
i) Looking back on it now, is there anything you would do differently?
j) Did you learn anything new from the situation?

9. Can you tell me a story about a time that your involvement with staff regarding the care of your elder was difficult or frustrating?
Repeat probes as above.

10. In what ways do you think you influence, through staff, the care your family

11. What do you think of your relative's quality of life since she/ he has been living here?

APPENDIX B

GROUP INTERVIEW WITH STAFF

1. Can you describe how the family is involved with the care of this particular resident?
   Probes: How do they relate to the elder during visits?
   How frequently do they visit?
   What is the nature of their involvement with the elder between visits?

2. How are you involved with this family around the care of the elder? How do they relate to you as staff during visits?
   Do you notice any differences in how they relate to different staff?
   Can you describe the nature of your contact with this family between visits?

3. Is there a particular story that describes this respective resident well?

4. Can you tell me a story about a time that you were involved with the family regarding the care of this particular elder that worked really well?
   a) Tell me what happened
   b) What led up to this situation?
   c) What were your thoughts, feelings and reactions to the situation? What were your priorities in this situation?
   d) What did you do?
   e) How did you feel afterwards?
   f) How did your action change the situation?
   g) What else did you consider doing?
   h) Who was most helpful to you in this situation?
   i) Looking back on it now, is there anything you would do differently?
   j) Did you learn anything new from the situation?
   k) Is there anything about this situation that my questions haven't covered?

5. Can you tell me a story about a time that you were involved with this family, regarding the care of the elder, that was difficult or frustrating?
   Repeat probes as above.

6. In what ways do you think the family influences the care you provide to this elder?

7. In what ways do you think the staff influences the care the family provides to this elder?

8. What do you think of this resident's quality of life since she/ he has been living here?

APPENDIX C

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

CONSENT TO PARTICIPATE IN A RESEARCH STUDY

Family member or Relative

A. PURPOSE AND BACKGROUND:

Margrét Gústafsdóttir RN, MS and Catherine A. Chesla RN, DNSc, in the School of Nursing, University of California, San Francisco are conducting a research study that explores the relationship between family members of nursing home residents and staff in nursing homes. I am being asked to participate in this study because I have a relative in a nursing home.

B. PROCEDURES:

If I agree to be in this study, the following will occur:

1. I will be interviewed by the investigator at a time and place convenient to me.

The interview will include questions such as:

a) Would you tell me about your relative or any particular story that describes your relative well ?
b) How would you describe your visits in the nursing home and times when you talked with staff about your family member ?

The interview will take about one to one and a half hour. There will be at least one follow-up interview to clarify the initial interpretation from the first interview. My relative may be asked to participate in one of these interviews.

2. If I agree, the interviews will be taped and transcribed. I will have the opportunity to check the transcription for accuracy.

C. RISKS AND/OR DISCOMFORTS:

1. Some of the interview questions may make me upset. I am free to decline to answer any questions I do not wish to answer or to stop the interview at any time.
2. Confidentiality: Participation in research may mean a loss of privacy; however, my records will be handled as confidentially as possible. Special precautions will be made to maintain anonymity of the particular nursing home where my relative resides.

Only Margrét Gústafsdóttir will have access to the master list of participants, identification codes and audio tapes. Audio tapes will be destroyed after transcription. No individual or site identities will be used in any reports or publications that may result from this study.

D. BENEFITS:

There will be no direct benefit to me from participating in this study. However, the information that I provide may help nursing staff to provide better care to nursing home residents.

E. COSTS:

There will be no cost to me as a result of taking part in this study.

F. PAYMENT

I will not be paid for my participation in this study.

G. QUESTIONS:

I have talked with Margrét Gústafsdóttir about this study and have had my questions answered. If I have further questions, I may call her at (354) 5524797 (home), 5254977 (office) or Dr. Chesla at (415) 476-4439. If I have any comments or concerns about participation in this study, I should first talk with the investigators. If for some reason I do not wish to do this, I may contact the Committee on Human Research, which is concerned with the protection of volunteers in research projects. I may reach the committee office between 8:00 and 5:00, Monday through Friday, by calling (415) 476-1814, or by writing:

Committee on Human Research, Box 0962, University of California, San Francisco,
San Francisco, CA 94143.

H. CONSENT:

I have been given a copy of this consent form to keep.

PARTICIPATION IN THIS RESEARCH IS VOLUNTARY. I am free to decline to be in this study or to withdraw from it at any point. My decision as to whether or not to participate in this study will have no influence on my present or future position or my relative's care in the nursing home.

DATE	SIGNATURE OF STUDY PARTICIPANT
DATE	SIGNATURE OF PERSON OBTAINING CONSENT

APPENDIX D

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO
CONSENT TO PARTICIPATE IN A RESEARCH STUDY

Staff member

A. PURPOSE AND BACKGROUND:
Margrét Gústafsdóttir RN, MS and Catherine A. Chesla RN, DNSc in the School of Nursing, University of California, San Francisco are conducting a research study that explores the relationship between family members of nursing home residents and staff in nursing homes. I am being asked to participate in this study because I am a staff member in a nursing home.

B. PROCEDURES:
If I agree to be in this study, the following will occur:

1. I will be interviewed with a group of 3-4 other staff members by the investigator. The interview will occur at a time and place convenient to the group. The group will be asked about care of individual patients and relationships with respective family members. Each member of the group will be asked to talk about encounters with family members.
2. If the group agrees, the interview will be taped and transcribed. I will have the opportunity to check the transcription for accuracy. The interview will take about one to one and a half hour.
3. I may be asked to be interviewed individually. If I agree, the individual interview will last about one hour and will occur at a time and place convenient to me. In this follow up interview, I will be asked to further discuss topics from the group interview. And, if I agree, this interview will be tape recorded.

C. RISKS AND/OR DISCOMFORTS:

1. Some of the interview questions may make me upset. I am free to decline to answer any questions I do not wish to answer, leave the group interview, or stop an individual interview at any time.

2. Confidentiality: Participation in research may mean a loss of privacy; however, my records will be handled as confidentially as possible. Only Margrét Gústafsdóttir will have access to the master list of participants, identification codes and audio tapes. Audio tapes will be destroyed after transcription. No individual or site identities will be used in any reports or publications that may result from this study.

D. BENEFITS:

There will be no direct benefit to me from participating in this study. However, the information that I provide may help nursing home staff in providing care to the residents.

E. COSTS:

There will be no cost to me as a result of taking part in this study.

F. PAYMENT

I will not be paid for my participation in this study.

G. QUESTIONS:

I have talked with Margrét Gústafsdóttir about this study and have had my questions answered. If I have further questions, I may call her at (354) 5524797 (home), 5254977 (office) or Dr. Chesla at (415) 476-4439 If I have any comments or concerns about participation in this study, I should first talk with the investigators. If for some reason I do not wish to do this, I may contact the Committee on Human Research, which is concerned with the protection of volunteers in research projects. I may reach the committee office between 8:00 and 5:00, Monday through Friday, by calling (415) 476-1814, or by writing:

Committee on Human Research, Box 0962, University of California, San Francisco,
San Francisco, CA 94143.

H. CONSENT:

I consent to tape recording of an individual interview: [ ]
I have been given a copy of this consent form to keep.

PARTICIPATION IN THIS RESEARCH IS VOLUNTARY. I am free to decline to be in this study or to withdraw from it at any point. My decision as to whether or not to participate in this study will not influence my present or future employment status in the nursing home.

DATE SIGNATURE OF STUDY PARTICIPANT

DATE SIGNATURE OF PERSON OBTAINING CONSENT

APPENDIX E

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

CONSENT TO PARTICIPATE IN A RESEARCH STUDY

Resident

A. PURPOSE AND BACKGROUND:

Margrét Gústafsdóttir RN, MS and Catherine A. Chesla RN, DNSc in the School of Nursing, University of California, San Francisco are conducting a research study that explores the relationship between family members of nursing home residents and staff in nursing homes. I am being asked to participate in this study because I am a resident in a nursing home.

B. PROCEDURES:

If I agree to be in this study, the following will occur:

1. A member of my family will be interviewed by the investigator. My relative will be asked to describe me and my care. She or he will be asked to tell about my family's visits with me and their relationships with the nursing home staff. I may be asked to participate in an interview.
2. A group of 4-5 staff members will be interviewed by the investigator. The group will be asked about my care and their relationships with my family. A staff member may be asked to be interviewed individually.
3. The investigator will observe when I am assisted in my daily care and I may be asked about my well-being and the care I receive.

C. RISKS AND/OR DISCOMFORTS:

1. Confidentiality: Participation in research may mean a loss of privacy; however, my records will be handled as confidentially as possible. Special precautions will be made to maintain anonymity of the particular nursing home where I reside. Only Margrét Gústafsdóttir will have access to the master list of participants, identification codes and audio tapes. Audio tapes will be destroyed after transcription. No individual or site identities will be used in any reports or publications that may result from this study.

D. BENEFITS:

There will be no direct benefit to me from participating in this study. However, the information that my family member or relative and the staff provide may help nursing staff to provide better care to nursing home residents.

E. COSTS:

There will be no cost to me as a result of taking part in this study.

F. PAYMENT

I will not be paid for my participation in this study.

G. QUESTIONS:

I have talked with Margrét Gústafsdóttir about this study and have had my questions answered. If I have further questions, I may call her at (354) 5524797 (home), 5254977 (office) or Dr. Chesla at (415) 476-4439. If I have any comments or concerns about participation in this study, I should first talk with the investigators. If for some reason I do not wish to do this, I may contact the Committee on Human Research, which is concerned with the protection of volunteers in research projects. I may reach the committee office between 8:00 and 5:00, Monday through Friday, by calling (415) 476-1814, or by writing: Committee on Human Research, Box 0962, University of California, San Francisco, San Francisco, CA 94143.

H. CONSENT:

I have been given a copy of this consent form to keep.

PARTICIPATION IN THIS RESEARCH IS VOLUNTARY. I am free to decline to be in this study or to withdraw from it at any point. My decision as to whether or not to participate in this study will not have influence on my present or future care in the nursing home.

__________ ______________________________

DATE SIGNATURE OF STUDY PARTICIPANT

__________ ______________________________

DATE SIGNATURE OF PERSON OBTAINING CONSENT

APPENDIX F

RECRUITMENT LETTER FOR FAMILY

Date

To:

I am interested in learning what it is like to be a relative of a resident in a nursing home and to have contact with nursing home staff. I am conducting a nursing study and would like to ask you to participate. The study involves a conversation or interview about your relative and your experiences visiting in the nursing home. We would set up a time and place to talk that would be convenient to you. The interview usually lasts about one to one and half hour.

I would ask you questions like: Is there any particular story that describes your relative well? What do you consider most important in your relatives' care? What do you think is the importance of visiting? How would describe the meaning of your relationship with the staff? There will be at least one follow-up interview to clarify the initial interpretation from the first interview and your relative may be asked to participate in one of these interviews.

Participation in the study is voluntary and confidential. I hope the information that the study may give will help nurses to provide better care of nursing home residents.

Please call me if you would like to learn more about the study or have questions. My telephone number is 5524797 at home and 5254977 at work. If you are interested in participating, please notify me by mailing the self-addressed postcard or let N.N. the Head Nurse, know. Otherwise, I assume that you are not going to be a participant in the study. If you agree to participate, I will contact you to set up an appointment. Thank you.

Margrét Gústafsdóttir, RN, MS

APPENDIX G

RECRUITMENT LETTER FOR STAFF

Date

To:

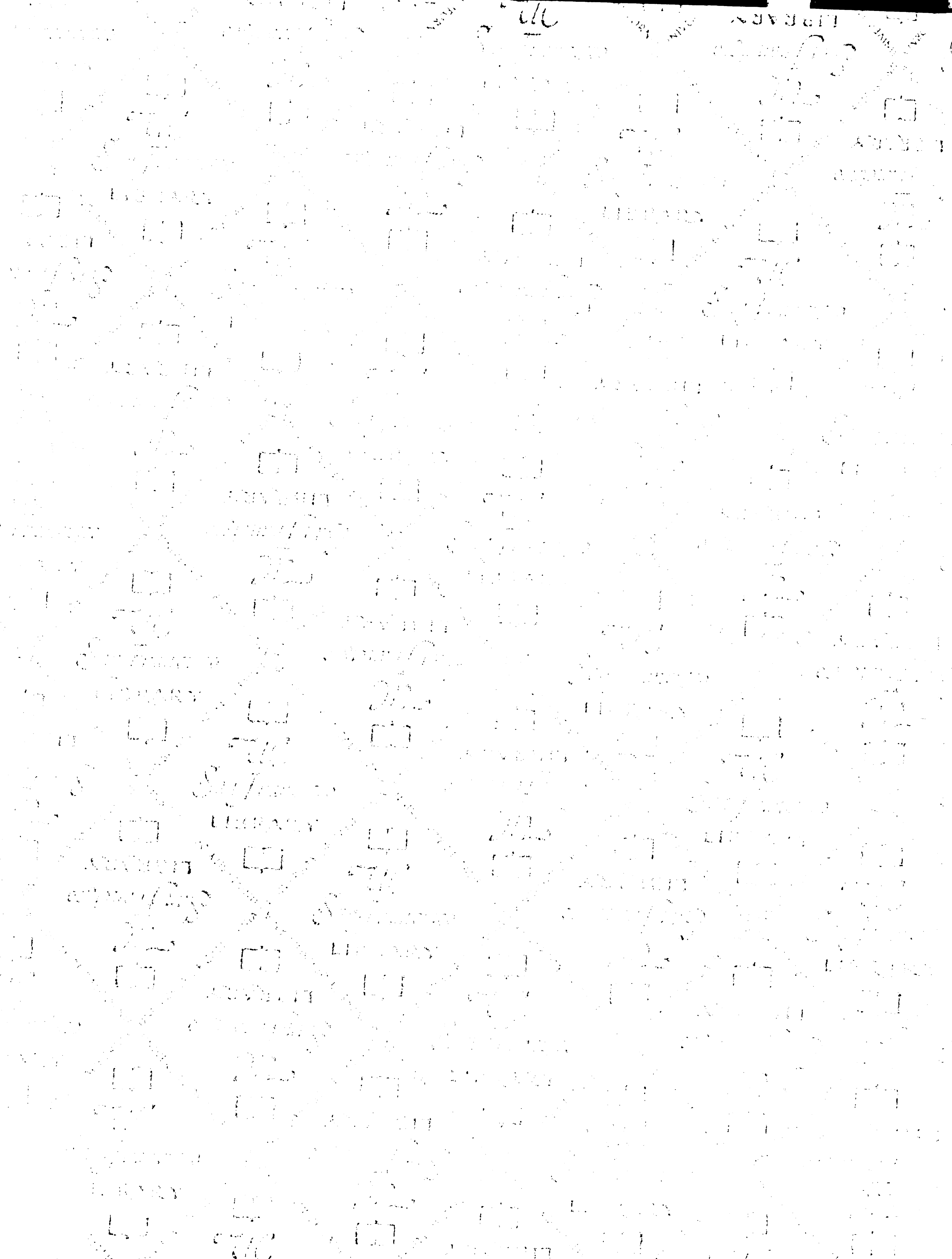
I am interested in learning what it is like to be a staff member in a nursing home and to have contact with relatives of nursing home's resident. I am conducting a nursing study and would like to ask you to participate.

The study involves participation in a discussion with 3-4 other staff. Each member of the group will be asked to tell about dealing with families of residents. I would ask you questions like: How would you describe the visiting patterns of the family of this particular resident ? How would you describe the contacts the family has with the staff? How would you describe participation of the family in care of this resident. You may also be asked if you would like to be interviewed individually after the group meeting. We would set up a time and place to meet for the group discussion when it would be convenient for the participants in that group. The group discussion will last about one hour.

Participation in the study is voluntary and confidential. I hope the information that the study may give will help nurses in providing care of nursing home residents.

Please call me if you would like to learn more about the study or have questions. My telephone number is 5524797 at home and 5254977 at work. If you are interested in participating, please notify me by mailing the self addressed postcard or let N.N. the Head Nurse, know. Otherwise, I assume that you are not going to be a participant in the study. If you send me the card I will contact you to set up an appointment. Thank you

Margrét Gústafsdóttir, RN, MS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