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Reclaiming the House: An Interpretive Study of Nurse-Family Interactions and Activities in Critical Care

This work is dedicated to my mother, Katherine Stannard,
and to my husband, Beau Simon.

In memory of my father, Jerry Willmert Stannard.

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ABSTRACT

While many studies have examined the need for nursing interventions and others have tested specific formal family interventions, few have investigated the practical or everyday family interventions of intensive care unit (ICU) nurses. The purpose of this interpretive study was to articulate the everyday activities and interventions that nurses commonly employed with families around patients' bedsides. Primary data sources included repeated interviews with six families of critically ill patients, multiple nurse-family observations, and repeated small group interviews with 24 ICU nurses.

Findings included three relational stances which characterized how nurses typically related to patients' families, namely: standing apart from the patient's family; standing at a distance from the patient's family; and standing alongside the patient and family. The degree to which a nurse was emotionally available to care for a suffering family was inextricably intertwined with how the nurse was in the situation, which can be thought of as the nurse's relational stance.

The habits, practices, concerns, and skills which a nurse brings to the situation are all aspects of her/his stance. A nurse's stance made certain

activities and interventions possible and determined, in part, how successful the nurse-family interaction would be. Relational stances can be understood as the "why" behind the "how," the "how" being the ways in which nurses cared for critically ill patients' families.

A nurse's and family's situational understanding also made certain activities and interventions possible while prohibiting others. Situational understandings or reasoning in transitions can be thought of as individual and collective experiential transitions characterized by changes in understanding as the clinical situation unfolded. The three situational understandings which most practitioners and families of dying patients experienced were: fighting for the patient's life; shifting focus based on changing clinical relevance; and facing death.

By their nature, nurse-family interactions and family care interventions and activities are constituted by what is accessible to nurses and family members. This study demonstrated that it was through the context-dependent nurse-family relationship that nurses and families understood the possibilities and options for care. If we are to realize more enlightened ways of caring for families of critically ill patients, educational and healthcare arenas need to ensure that relational work between nurses and families remains a possibility.

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TABLE OF CONTENTS

Chapter 7 Reclaiming the House: Implications for Practice, Education, Healthcare Administration, and Research (294)

Chapter 1

Nursing Care of Critically Ill Adult Patients' Families: Review of the Literature

In 1991-1992, there were approximately 33 million hospital admissions in the United States, with more than 25,000 patients in intensive care units (ICUs) (American Hospital Association, 1993-94; Groeger et al., 1992). Of those in ICUs, 17% were considered "chronic" patients (greater than 14 days in an ICU) (Groeger et al., 1993). These are particularly notable statistics given the reciprocal relationship between a family member's health problems and family functioning (Gilliss & Davis, 1993). Since a family member's hospitalization affects the entire family, the impact of the 33 million hospital admissions is far greater than the number implies.

In spite of these figures, families during serious illness have been the least studied domain of the family health and illness cycle (Doherty & Campbell, 1988). While many studies have examined the need for nursing interventions and others have tested formal family interventions, few have investigated the practical family interventions of ICU nurses. The purpose of this chapter is to critically review the nursing intervention literature pertaining to families of adult critically ill patients.

Background

Nursing interventions are bounded by history. How we understand ourselves as nurses and the patients and families for whom we care sets up what is understood as an "intervention." Before turning to the review of the literature, a brief examination of the historical context and scope of the review is in order.

Historical Context

All human beings are historically situated, and families and healthcare providers are no exception. To understand how and why family interventions developed, one needs to understand the history of caring for families in the most restricted of acute care areas, the ICU. In order to situate the development of critical care areas, however, a brief detour examining the rise of the modern hospital is necessary.

In 1800, the hospital was still an insignificant aspect of American medical care. In fact, at that time, there were only two hospitals in the United States dedicated exclusively to inpatient care of the sick (Rosenberg, 1987). Nearly 100 years later, however, much had changed. The hospital had become far more central, both in the provision of medical care and in the careers of ambitious "house" (or hospital) physicians. By 1909, there were 4,359 American hospitals (Rosenberg, 1987).

The modern hospital came of age in the early part of the twentieth century. The premature station at the Sarah Morris Hospital in Chicago opened in 1922 and is often heralded as the first permanent neonatal ICU in the United States (O'Donnell, 1990). One year later, a three-bed adult ICU was opened to care for postoperative neurosurgical patients at Johns Hopkins (Hilberman, 1975). Nearly 40 years later, virtually all hospitals in the United States had an ICU (Groeger et al., 1992). Once organized, ICUs became official medical spaces under medical control, in spite of the fact that they were architecturally discrete areas designed for watchful vigilance by specially trained nurses (Fairman, 1992).

From the outset, "patients were separated from families and the outside world in the interest of facilitating their therapy" (Hilberman, 1975, p. 159). Concerns regarding infection, space limitations, and patient rest were the most commonly cited rationales to limit family visitation and participation (Beck, 1965; Bell, 1969; Hard, 1948; Hardgrove & Roberts, 1989; Heater, 1985; O'Donnell, 1990). In 1965, the International Council of Nursing (ICN) surveyed 58 national nurses' associations to determine the level and amount of family involvement in hospitalized settings (Beck, 1965). Twenty countries responded, displaying a wide range of family visitation and involvement. For adult units, family visitation ranged from daily visitation (amount of time unspecified) for private patients to two hours twice a day for all patients. Most of the responding countries limited the amount of visitors and restricted children. For pediatric units, there was unrestricted visitation in many countries. Family involvement was strongly encouraged in pediatric units, but was only allowed in adult units in countries with labor shortages (Beck, 1965). The bias in healthcare institutions favoring and recognizing the importance of families for pediatric and neonatal patients (in contrast to adult patients) becomes obvious.

As the 1970s approached, dramatic changes in attitude toward parents and families were noted in neonatal and pediatric units in the United States, but it was not until the 1980s that entry of siblings into neonatal units was advocated (Heater, 1985; O'Donnell, 1990). These changes were happening in adult ICUs as well, as reflected by the increasing number of articles in adult critical care journals addressing family concerns. Many of these changes in adult ICUs, however, would prove to take much longer than in pediatric and neonatal areas. Part of the explanation lies in the larger societal interpretation of adult, role of family in relationship to adults, and nursing care of families consisting of adults. These are difficult issues to analyze fully, as they are no longer historical notions, but societal views we currently hold. It is important to realize that our collective understanding directly affects how the family, nurse, and patient understand themselves, as well as the range of possible family interventions available to the nurse.

Terminology and Scope of Review

Drawing from Heidegger (1927/1962) and family systems theory, a family both constitutes and is constituted by the individual. Family precedes and shapes the individual through socialization, which enables the individual to interpret the familial and larger societal interpretation. As Coontz notes, "The family mediates between people's definitions of themselves as individuals and as members of society" (1988, p. 13). Likewise, the family's interpretive account is based on, among other things, the individuals in the family (Taylor, 1985a). As such, the family consists of the individuals comprising it and the patterns of relationships connecting these individuals (McWhinney & Patterson, 1992).

Not all family researchers share this definition of family. Some researchers study the individual in order to understand the family, thereby studying the family as context. Other researchers study the family in order to understand the individual, thereby studying the family as a unit. These distinctions are arbitrary, however, if one believes that the family constitutes and is constituted by the individual. From this perspective, one would not make sense of the individual without first taking the family into account, nor would one think of the family as an entity while disregarding the importance of individual family members (Ramos, 1992; Stein, 1992). Therefore, all adult critical care nursing research related to family interventions was considered for this literature review.

Review Of The Literature

Because interventions are historically situated, some descriptive studies will be reviewed alongside the intervention research to historically locate the interventions and to situate the reader. This section will be organized as follows: summary and critique of the ICU “needs” research, followed by a review of the family intervention literature in adult ICUs.

ICU “Need” Studies

The largest research cluster studying families of critically ill adults has focused on the needs of family members while in the ICU. This cluster of research, aptly termed the “need” studies, began with Molter's work in 1979. While these studies have shed light on family needs and have certainly propelled and legitimized the study of families in the ICU, the most important impact these studies has had is on the subsequent development of formal family intervention studies.

With regard to instrumentation, Molter (1979) developed 45 need statements through a review of literature and a survey of 23 graduate students. Validity and reliability were not established prior to Molter's use of the instrument. Leske (1986) randomly assigned order to the statements, added an open-ended item to identify new needs, and named the resulting instrument the Critical Care Family Needs Inventory (CCFNI). Internal psychometric properties of the CCFNI based on 677 subjects, collected by 21 nurse investigators in 14 states over a period of nine years, have been reported (Leske, 1991a). Additionally, content validity, test-retest reliability (ranging from 64.71% to 96.08%), and readability (Gunning Fox 8.6) of the CCFNI have been established (Macey & Bouman, 1991).

Research projects examining family members' needs have ranged from studies conducted in general adult ICUs or combined medical-surgical adult units (Chartier & Coutu-Wakulczyk, 1989; Daley, 1984; Koller, 1991; Leske, 1986; Molter, 1979), to family members of adult specialty patient populations (Bernstein, 1990; Blackmore, 1996; Kleinpell & Powers, 1992; Mathis, 1984; Norheim, 1989).

Based on eight research projects that reported the needs of families of adult critically ill patients, the ten most important needs (followed by frequency percentage of the ten) are as follows: to have questions answered honestly (100%); to know specific facts regarding what is wrong with the patient and her/his progress (100%); to know prognosis/outcome/chance for recovery (90%); to be called at home about changes (90%); to receive information once a day (80%); to receive information in understandable explanations (80%); to believe that hospital personnel care about the patient (80%); to have hope (70%); to know exactly what/why things are being done to the patient (70%); and to have reassurance that the best possible care is being given to the patient (70%) (Hickey, 1990).

Leske (1991b) examined 27 studies which had investigated family members' needs of adult ICU patients using the CCFNI within the first 72 hours of the patient's ICU admission. Her empirical analysis of results indicated that families have three primary categories of needs: assurance, proximity, and information.

Other variations on the need studies include: modifying the CCFNI to specifically examine visitation and informational needs (Boykoff, 1986; Freismuth, 1986; Halm & Titler, 1990; Spatt, Ganas, Hying, Kirsch & Koch, 1986; Stillwell, 1984), studying the relationship between needs and unmet needs (Dorn, 1989; Warren, 1993), examining needs over time (Freichels, 1991), comparing the needs of families in the ICU to the needs of families on the ward

(Foss & Tenholder, 1993), studying needs with other survey instruments (Dyer, 1991; Liddle, 1988; Zawatski, Katz & Krekeler, 1979), and studying needs from a qualitative approach (Coulter, 1989; Wilkinson, 1995). The reported needs from all of these studies roughly agree with Hickey's (1990) and Leske's (1991b) analyses and do not differ with regard to clinical significance.

The degree of congruency between ICU nurses' perceptions of family needs and family members' perceptions have also been studied, with nurse responses differing from family members in all three categories of needs as identified by Leske (1991b) (namely, assurance, proximity, and information). In particular, the need to be perceived as an integral part of the patient's caring team was rated more important by family members than by nurses in three studies (Forrester, Murphy, Price & Monaghan, 1990; Jacono, Hicks, Antonioni, O'Brien & Rasi, 1990; Norris & Grove, 1986). Three other studies found that nurses ranked families' cognitive needs higher than psychologic or personal and physical needs (Dockter et al., 1988; Lynn-McHale & Bellinger, 1988; O'Malley et al., 1991). Additionally, Murphy, Forrester, Price, and Monaghan (1992) found that the more empathic ICU nurses were (as measured by La Monica's Empathy Construct Rating Scale), the greater their ability to accurately assess ICU family members' needs.

It is evident that much work has been done in this area, and replication has aided in building a family needs knowledge base (Whall & Loveland-Cherry, 1993). Doyal and Gough (1991) have suggested that "need" implies something universal. It is commendable to prove empirically that, indeed, there are needs common to family members' of ICU patients across patient populations, settings, and time. The needs studies have also drawn attention to families of critically ill patients and have served as the cornerstone for many of the family intervention studies which will be reviewed next.

The needs studies, however, have also limited our inquiry into families of ICU patients by focusing exclusively on nurses' and family members' needs as opposed to investigating family-level meanings, family members' resources and strengths, and the nature of the nurse-family relationship. Attempting to understand the family's ICU experience has also been overlooked. Re-framing research questions and employing different research methodologies in the study of families and family members is sorely needed, and would provide clinicians and family scientists with new understandings and possibilities for family care.

Intervention Studies with Families of Critically Ill Adult Patients

Nursing interventions with families of ICU patients can be understood on a continuum of proximity to the bedside (see Figure 1). Interventions made at the patient's bedside are at one end of the continuum, while specialized programs undertaken away from the bedside are at the opposite end of the continuum. Because interventions at both ends of the continuum have been demonstrated to assist families of ICU patients to varying degrees, interventions across the continuum were considered for this review. Formal interventions for families of ICU patients have four identifiable forms, and will be reviewed in the following order: visitation, information, family involvement in caregiving activities, and education and counseling.

Visitation

Younger, Coulton, Welton, Juknialis, and Jackson (1984) examined visitation policies from 78 ICUs in 37 Midwestern hospitals. Data were collected by telephone interviews with head nurses. Although tremendous variation existed, 25% of the ICUs allowed only two visits per day, and 42% restricted visits to less than 20 minutes. Most units rarely or never allowed children less than 12 years of age to visit, and 58% of the units allowed visitation by immediate family members only.

More recently, another study which examined visitation policies in five midwestern ICUs found that while 70% of the units had official policies restricting family visitation, only 22% of the nurses reported actually adhering to unit policies in their daily practice (Simon, Phillips, Badalamenti, Ohlert & Krumberger, 1997). Variables that affected nurses' practices regarding visiting hours were the patient's need for rest, the nurse's workload, and the beneficial effects of visitation on patients.

Since the immediate concern for most ICU nurses is the physiologic stability of the patient, the logical starting place for visitation research is the examination of the physiological effects of family visitation on the patient. The three main clusters of research examining the physiological effects of family visitation focus on patient changes with regard to cardiovascular indicators, intracranial pressure (ICP) changes, and changes in mental status.

While two studies conducted in the 1970s found statistically significant increases in systolic blood pressure (BP) and heart rate (HR) and an increased frequency of ventricular arrhythmias in coronary care patients during family visitation (Brown, 1976; Theorell & Webster, 1973), no significant cardiovascular changes were found in two more recent studies that examined a total of 72 coronary care patients' BP, HR, rate of premature ventricular contractions (PVCs), ST segment, and oxygen saturation before, during, and after visitation by family or friends (Kleman et al., 1993; Simpson & Shaver, 1990). Both studies found some patients that demonstrated more cardiovascular reactivity to visits than others, suggesting to nurses that they carefully monitor patients' conditions during visitation.

Schulte et al. (1993) compared HR and rate of PVCs in 25 coronary care patients who were divided into restricted and unrestricted visitation groups. There were no significant differences in rates of PVCs or premature atrial contractions between the two groups, although patients with unrestricted visitation had a significantly lower HR than those in the restricted group (F(2,46)=3.75, p=.030). These findings suggest that unrestricted visiting may contribute to decreased anxiety levels in coronary care patients.

In another study, Fuller and Foster (1982) examined changes in BP, HR, and vocal stress before, during, and at the end of family/friend visits with 28 surgical ICU patients who served as their own controls, and compared those changes to changes occurring with nurse interactions with a task focus and nurse interactions with an interpersonal focus. No significant differences were found in the physiological parameters during family or nurse interactions, which is to say that family interactions were no more stressful on patients than were the interactions with nurses.

Lazure and Baun (1995) compared HR, rate of PVC's, BP, and indicators of the stress response (salivary cortisol and finger temperature) in 60 randomly assigned coronary care patients who were divided into a visitor control device (VCD) group and a group receiving visitors in the traditional manner. The VCD indicated when the patient desired visitors. No adverse cardiovascular effects were noted in either group during family visitation, but HR and diastolic BP were significantly lower in patients in the VCD group, demonstrating a physiological benefit from patients' perceived control over visiting.

Studies examining ICP have shown a clinically significant decrease in 18 of 24 ICU patients during family visits (Hendrickson, 1987), and no statistically significant increase in pre-, during, and post-visit ICP ($F(1,40)=2.60$, $p=.086$) in 15 ICU patients (Prins, 1989). Finally, mental status in 74 ICU patients was assessed before and after a family visit. The researchers found that family had little effect on patients' mental status (Bay, Kupferschmidt, Opperwall & Speer, 1988).

In summary, no overarching physiological reasons have been identified which should exclude or limit family visitation. In fact, nurses' attitudes and beliefs about family visitation appear to drive many of the limiting and exclusionary practices surrounding family visitation in ICUs. Studies examining patient, family, and staff preferences for visitation in ICUs have shown conflicting results.

Two studies examining visitation preferences in a total of 199 coronary and surgical ICU patients demonstrated that older patients preferred longer family visitation times (as opposed to shorter, but more frequent visitation) (Simpson, 1991; Simpson, 1993). In contrast, another study examining visitation in several adult ICUs with restricted visiting policies found that 65% of the 77 ICU patients surveyed after ICU discharge preferred shorter but more frequent visitation than did the 58 (unrelated) family members (Halm & Titler, 1990). In that same study, 23% of the nurses reported unlimited visitation length as a preference, but 52% desired limiting family visits to 15 to 30 minutes. Finally, two studies examining a total of 138 nurses' beliefs and perceptions about family visitation found that nurses believed the consequence of visiting was more positive for the patient from a psychological than a physiological perspective. Additionally, nurses believed that visiting was disruptive for nursing care delivery (Kirchhoff, Pugh, Calame & Reynolds, 1993; Simpson et al., 1996).

Given these oppositional results, how should ICUs address family visitation? At the risk of creating even more inconsistency for patients and families, visiting regulations should be recast as guidelines, which would allow nurses to take into account the uniqueness of each patient and family and the demands and possibilities of each nurse-patient-family situation.

Information

Informational interventions can often share a blurry border with educational activities. For the purposes of this chapter, informational interventions are broadly defined as short-term and "quick contact" interventions with families, as opposed to longer-term and "extended contact" associated with the education and counseling interventions. Additionally, information interventions are characterized by their unidirectional explanatory nature.

Information interventions in the ICU setting have ranged from informational booklets for family members of critically ill adult patients (Williams, 1978) to visiting information checklists for the ICU nursing staff to fill out each time a family visits (Ward, Constancia & Kern, 1990). Doerr and Jones (1979) studied the effect of family information on 12 coronary care patients' anxiety levels. Using a quasi-experimental, pretest-posttest control group design with random assignment, patients who were visited by family members who were prepared ahead of time by way of an informational booklet experienced a statistically significant decrease in their state anxiety score, while patients who were visited by family members receiving routine care experienced an increase in their state anxiety score ($t = 2.23$, $df = 10$, $p < 0.05$). The researchers concluded that family preparation reduced the amount of anxiety transferred from family members to patients.

In a similar study, 40 family members were randomly assigned to receive either routine care (control group) or an informational handout and a ten-minute pre-visitation tour of the ICU (experimental group). Using a quasi-experimental, pretest-posttest control group design, family members receiving the informational intervention had a statistically significant decrease in their mean HR after the informational intervention and again after visiting ($t = -2.65$, $p = 0.016$; $t = -2.73$, $p = 0.13$, respectively). Family members' BP and subjective stress scores, however, remained unchanged (Chavez & Faber, 1987). This study adds to the research literature by testing information that was provided to family members in an alternative form, namely the pre-visitation tour.

Testing the effects of information and visitation, Henneman, McKenzie and Dewa (1992) compared the effectiveness of an information booklet coupled with open visitation, no booklet and open visitation, and no booklet and restricted visitation on a total of 147 family members of critically ill adult patients hospitalized in a medical ICU. Using a one-way, between-subjects design, family satisfaction and knowledge were measured in all three groups. Open visitation, as a singular intervention, significantly improved family satisfaction scores ($p<.05$). Additionally, the information intervention achieved statistical significance ($p<.05$), as families who received the booklet were able to recall discrete pieces of information concerning the ICU environment. Family visitation enables family members to be physically close to their critically ill loved ones, but may also permit families to glean firsthand important clinical information.

Finally, Johnson and Frank (1995) studied the effectiveness of a telephone informational intervention on a total of 40 family members divided into experimental and control groups. Using a quasi-experimental, pretest-posttest control group design, family members who received twice-daily telephone calls from their ill family member's nurse experienced a statistically significant decrease in their mean anxiety scores when compared to family members receiving routine care ($t = -4.98$, $p<0.05$). While family members in the control group also experienced a decrease in anxiety over time, families receiving the informational intervention had a greater decrease in their anxiety scores. This finding suggests that providing families with information over the telephone may serve, in some cases, as a substitute for family visitation ("virtual visitation") when families are unable to travel extended distances to visit their critically ill family member.

Although information as an intervention has been shown to decrease family and patient anxiety and increase family satisfaction and knowledge, little is known about the content and kind of information that families find most helpful during different points in their ill family members' critical illness trajectories. While nurses commonly provide information to patients' families both formally and informally, innovative research strategies are needed to test and describe these common informational interventions.

Family Involvement in Caregiving

Few interventional studies have examined the effect of family involvement on adult critically ill patients and their families. Chatham (1978) studied the effect of family interaction and involvement in care during the first four days following open-heart surgery and the development of postcardiotomy psychosis in 20 ICU patients. Family members were assigned to experimental and control groups, with the experimental group receiving systematic instruction regarding the significance of eye contact, frequent touch, and verbal orientation to time, person, and place. Family members in the control group received routine care, which is to say that they received no systematic instruction. A two-way ANOVA revealed that patients in the experimental group were more oriented ($F = 23.84$, $df = 1$, $p<0.05$), less confused ($F = 5.99$, $df =1$, $p<0.05$), had fewer delusions ($F = 6.68$, $df = 1$, $p<0.05$), and had longer periods of sleep ($F = 2.29$, $df = 1$, $p<0.05$) as compared to patients in the control group. Unfortunately, the effects of participation and interaction on the families were not studied. One can speculate that engaging in activities thought to reduce patient complications would be a positive experience for family members. This area, however, needs additional study.

Hickey and Lewandowski (1988) surveyed 226 ICU nurses from four hospitals about their perceptions of family involvement in care. In their sample, there was a consensus among nurses that family members should play a supportive, although nonparticipative, role in their loved ones' provision of care.

Among the factors that most influenced nurses' involvement with families were situations relating to the patient's actual or impending death and the nurses' likes and dislikes for the patient and family. This finding suggests that the patient's disposition and the nurse-family relationship greatly influence nurses' care delivery. These areas warrant additional investigation.

In another study, Hammond (1995) surveyed 27 nurses' and 20 family members' attitudes concerning family involvement in caregiving activities. While a high proportion of nurses and family members agreed with the concept of family involvement (96.3 and 85%, respectively), some nurses reported that family involvement in care would be too time consuming for the nurses. Other nurses indicated that family involvement would aid in building the nurse-family relationship.

The extant research literature provides few insights into how family involvement in patient care influences the patient or the family. Nurses' facilitation of family involvement in their ill family members' care is a practical family intervention commonly employed which should be further described and tested.

Education and Counseling

Education and counseling interventions imply longer-term and "extended contact" with families. Perhaps it is for that reason that few education and counseling interventions have been tested on family members of adult ICU patients, as ICUs have typically been conceptualized as short-term units. While several educational family interventions in the form of educational support groups have been described in the literature, none, to my knowledge, has been tested (Boettcher & Schiller, 1990; Brown, Glazer & Higgins, 1984).

In terms of counseling interventions[1], two studies examined the effects of support groups on family members. Support groups differ from educational support groups in that the primary purpose of family support groups is to enable families to express their feelings. The principal purpose of the educational support group, on the other hand, is to provide education, with secondary support occasionally provided to participants because of the group format.

Sabo et al. (1989) examined support groups and their effectiveness on ICU family members' appraisals of stress, social support, and hope. The quasi-experimental study employed a convenience sample of 67 family members from three ICUs. Thirty-one family members in the treatment group attended a support group and received routine care, while the 36 family members in the control group received routine care only. A non-standardized questionnaire with face validity, but no established reliability, was used to assess effectiveness of the intervention. No significant difference was found between family members'

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[1] My use of the term "counseling" refers to psychosocial counseling performed by nurses and differs from the counseling performed by trained therapists. For more on this topic, refer to McDaniel, S. H., Hepworth, J., & Doherty, W. J. (1992). Medical family therapy: A biopsychosocial approach to families with health problems. New York: Basic.

mean stress (t = 0.31, p =0.76), social support (t = 1.01, p = 0.31), or hope (t = 0.53, p = 0.60) scores.

In another study, Halm (1990) compared the effectiveness of conventional bedside support to the use of support groups in reducing anxiety of family members in the ICU. The quasi-experimental study randomly assigned 25 family members to the treatment group (who attended a support group and received routine care) and 30 family members to the control group (who received routine care only). Family members' state anxiety was measured at the beginning of the study and 12 to 18 hours after either routine care or attendance at a support group. No significant differences were found in prestate or poststate anxiety scores between the two groups, but family members in the treatment group had a significant reduction in anxiety from pretreatment to posttreatment measurements (t = 2.69, p<0.01). Thus, attendance at a family support group was more beneficial in decreasing family members' anxiety levels than was conventional bedside support. Describing what constituted conventional bedside support (including the unit's family visitation policy) would have strengthened the study's findings.

Although neither study provided decisive proof that family support groups are effective interventions, both studies quantified what is probably better captured using qualitative methods. Educational and counseling interventions beg for further research, especially in light of the fact that 17% of ICU patients are considered "chronic" (Groeger et al., 1993). Assuming a "chronic" patient's family stays at the ICU for some period of time during that two-week period, there is ample opportunity to test some of the family interventions requiring "extended-contact" with families.

Conclusion

This review has demonstrated the impact which family-focused interventions--such as visitation, information, family involvement in caregiving activities, and education and counseling--can have on patients' families. But everyday or practical family interventions that nurses routinely employ are arguably just as important as, if not more important than, formal family interventions. However, only one study examining everyday nursing activities and interventions directed toward families of adult critically ill patients has been reported (Chesla, 1996). As Curley writes, "Family-centered care implies more than just unrestricted visiting hours, but...describes a constellation of philosophies, attitudes, and approaches" (1993, p. S386). These approaches cannot be formally tested or taught until initially chronicled.

Figure 1.

Family Interventions Along a Continuum

Interventions At The Bedside
- visitation
- bedside information
- involvement in caregiving activities
- bedside education and counseling

- telephone information or "virtual visitation"
- unit information
- involvement in careplanning activities
- unit education and counseling

- information in waiting areas
- family conferences

- in house education and counseling
- in house support groups

Interventions Away From The Bedside
- post-discharge education and counseling
- post-discharge support groups

Chapter 2

Family Research and Theory in a Postmodern Age

In the United States, 15% to 20% of patients admitted to hospitals spend at least some portion of their hospital stay in an ICU (Dragsted & Qvist, 1992). Additionally, it is estimated that 80% of all Americans will experience critical care firsthand, either as a patient or as a family member of a patient (Foundation for Critical Care, 1990). Given the sheer number of those affected by the ICU, coupled with the fact that families during serious illness have been the least studied domain of the family health and illness cycle, there is little doubt that research focusing on families in the ICU would help shed light on this important, yet understudied, phenomenon (Doherty & Campbell, 1988).

What is open for debate, however, is how a family's experience should be conceptualized and studied, and even what "family" means. Because of shifting societal and individual understandings and expectations, the debate becomes even more complex. The purposes of this chapter are twofold: to discuss theory and the social sciences from modernity to postmodernity, and to examine modern and postmodern family forms.

Theory: More Than a Systematic Abstraction of Reality

According to Heidegger (1927/1962, p. 236), human beings are "thrown" into an already meaningful world. This world holds meaning because society preceded the individual, and, in so doing, established a shared, public understanding of what it is to be a human being (Dreyfus, 1991a). Additionally, Heidegger believes that epochs or historically situated societal understandings are fundamental to any historical culture. A given epoch comes from, and is reflected in, the shared practices into which the people of a culture are socialized (Heidegger, 1954/1977).

While an epoch is not itself a societal understanding, it is the ontological condition necessary for the emergence of a shared societal understanding. A shared societal understanding of being or societally held paradigm is a filter through which the world is understood. It is not a theory or a set of rules, as much as an orientation (Kohl, 1992). When dwelling with a shared societal understanding of being, language, behavior, and practices (such as research and theorizing) are shaped by the ways in which things and people manifest themselves (Zimmerman, 1990). Theoretical perspectives in our culture's intellectual history, therefore, mirror the central societal understanding of being at the time (Benner & Wrubel, 1989; Taylor, 1985a).

Many cultural theorists and scholars believe that postmodernism is our current societal understanding (Best & Kellner, 1991). In order to better understand theory in the postmodern age, a brief examination of the previous societal understanding--modernism--is in order.

Out of the chaos and insecurity of the Middle Ages (spanning roughly from the fifth century to the 15th century) dawned the Age of Reason or Enlightenment in the West. The Enlightenment, as an epoch, developed during the 18th century, and was characterized by three central beliefs. The first was that reason could solve all of humanity's problems. Second, progress--achieved through reason and science--was dependent on the person, rather than God. Finally, nature could be discovered and understood rationally (Shils, 1981).

The steady secularization of society and the rise of scientific and philosophical rationalism during this epoch laid the foundation for the development of a new societal understanding of being, namely modernism. Modernism (dating from the 19th century through much of the 20th century) is known for three major influences still felt today: domination of nature for the scientific accumulation of knowledge; the dualistic view of mind and world; and the sovereignty of the individual (Foucault, 1970; Sandel, 1982; Taylor, 1989).

Because reason was the watchword of the time, empiricism and rationalism as scientific methods of inquiry prevailed for much of modernity (see Table 1). Both of these scientific methods were well suited for the examination of physical objects, however, as we will see, application becomes more complicated when studying human beings.

Theorizing: An Overview

Coupled with the modern scientific program came renewed efforts to theorize, which is a special form of intellectual activity initially recognized by Socrates and refined by the philosophical tradition (Dreyfus, 1991b). The ideal formal theory has six essential characteristics: explicitness, universality, abstractness, discreteness, systematicity, and prediction (Dreyfus, 1991b).

Because formal theories strive to present a systematic abstraction of reality, complete theories must formalize *all* aspects of reality, including those which are not readily formalizable, such as everyday, common-sense background knowledge and skilled know-how (Benner & Wrubel, 1989; Chinn & Jacobs, 1987; Dreyfus, 1992). While no formal theory can ever fully achieve all of these characteristics, many of the characteristics are approached to varying degrees.

Formal theories can approach the ideal of theory by making as little reference as possible to the shared understanding of a particular epoch (Dreyfus, 1991b). This is achieved by decontextualizing objects and entities in what Heidegger (1927/1962) refers to as the present-at-hand mode (which will be more fully discussed in the next chapter). It is in this mode that formal theorizing leading to explanation and prediction can occur. Yet, without the shared understandings, prediction in the human sciences would be impossible.

Practical or interpretive theory, on the other hand, aims at explicating common-sense understanding using the phenomenological method (Benner, 1994a; Taylor, 1985b). Mechanistic and reductionistic viewpoints have enabled natural scientists to make huge strides in theory and research. However, when used as the basis for studying people, these traditional accounts do not allow for meanings and everyday, practical understandings to be revealed (Benner & Wrubel, 1989). Both the ready and unready-to-hand levels of involvement are the bases for practical theorizing (see Table 1).

While many social scientists can and do engage in formal theorizing, the degree of control needed for explanation and prediction never approaches that found in the natural sciences. Because human beings are self-defining and understand themselves in relation to the prevailing societal understanding, individual and group understandings and meanings can change. This applies to the subjects being studied as well as to the researcher and theorist. When the societal and self-understandings are stable, the explanations and predictions based on those understandings will hold constant. When the understandings shift, however, the explanatory power of the formal theory is diminished. The social sciences, therefore, do not progress through "scientific revolutions" like the natural sciences, but instead go through historical shifts in which certain issues and questions drawn from our background understanding dominate theory and research (Dreyfus, 1991b; Kuhn, 1970).

Family theory and research, as a social science, is no exception. As will be discussed shortly, societal, familial, and individual understandings and expectations of "family," as an institution, are shifting. While much of the family research and theory has not readily responded to the changing demographics and compositions of families, the human being engaged in the scientific effort is, nonetheless, influenced. As Osmond (1987, p. 114) writes, "Family theory cannot 'accumulate' (in the manner of, say, biochemical theory) because such theory does not transcend its historical boundaries." As such, in the social sciences, historical accounts capturing societal and self-understandings take the place of timeless explanatory and predictive "truths." This is not to be perceived as a deficit of the social sciences, but rather as an ontological condition unique to human beings engaged in scientific inquiry concerned with individual or group understandings, meanings, and beliefs (Benner & Wrubel, 1989; Heidegger, 1927/1962).

Theorizing in Postmodernity: Pluralism Happens

"An epoch approaches its end when its fundamental convictions weaken and no longer inspire enthusiasm among its advocates" (Borgmann, 1992, p. 48). Borgmann maintains that this holds true in our culture for each of the three principal tenets of modernism. Many argue that postmodernism has grown out of disillusionment with modernity (Readings & Schaber, 1993). While there is no unified postmodern theory, systemic thinking has been influential in shaping many of the postmodern positions, as demonstrated by the "modern" trends and postmodern hybrid shifts presented in Table 2. Although many cultural theorists and scholars are divided as to whether postmodernity is the transition before the next epoch or is, in fact, the next epoch, most agree that postmodernity embraces and blends some modern aspects while refuting others. Thus, postmodernity can be characterized by hybrid shifts and pluralism (Best & Kellner, 1991; Doherty, 1991; Fox, 1994; Jencks, 1992).

While pluralism is associated with postmodernism as a societal understanding, many familial and individual understandings are still situated in modernism. Heidegger (1954/1977, p. 44) believes that, while the ontological condition necessary for a new societal understanding of being can change in a "lightening-flash," the everyday human practices and understandings may take longer to be transformed. Sweeping and radical transformative changes in one's culturally constituted ways of being, however, do not occur very often. When societal understandings do shift, they rarely occur in a "lightening-flash," and are often ambiguous, redundant, and overlapping with the previous societal understanding.

When a societal understanding shifts, it occurs, in large part, due to a "critical mass" of marginal concerns becoming central concerns. Marginal concerns are anomalous understandings held by individuals and communities that fall "outside" the essence of any particular epoch (Dreyfus, 1993; Kuhn, 1970). Once concentrated, marginal concerns can shape a cultural movement or even become a central societal understanding of being.

Family: More Than One Universal Form

According to the 1990 census data, only 51% of children lived in intact, two-parent families where both parents were married only once and the children were all born after the marriage. This figure is sharply down from the 66% reported in 1970 (Shogren, 1994). It is possible that the "modern" and monolithic nuclear family, favored by law and ingrained by family theory and research, is becoming a cultural artifact (Allen, 1985; Doherty, Boss, LaRossa, Schumm & Steinmetz, 1993; Thorne, 1992; Walsh, 1993). As Stacey (1990, p. 258) writes, "The modern family system has lost the cultural and statistical dominance it long enjoyed, and no new family order has arisen to supplant it."

Historically, the premodern family existed, in large part, for dynastic, political, and economic reasons (Luepnitz, 1988). Gottlieb (1993) notes that the word family (from the Latin *famulus*) means "servant," and originally referred to the live-in staff as opposed to blood or marital relations. Social historians believe the conjugal family (consisting of husband, wife, four or five children, servants, lodgers, and apprentices where appropriate) had been the common family form since the 16th century (Gottlieb, 1993; Harriss, 1991).

Starting in the 17th century and converging with modernism, economic life became separated from the household, creating two distinct spheres of "private" domesticity and "public" production (Coontz, 1988; Gottlieb, 1993; Thorne, 1992; Tronto, 1993). Taylor describes the advent of the "modern" nuclear family:

> From the seventeenth century on, in the higher classes of Anglo-Saxon societies, and spreading outward and downward from these, we find a new outlook in which the companionate marriage and the life of the nuclear family come more and more to be seen as one of the central fulfillments of human life (1981, p. 113).

The distinctive characteristic of the "modern" family was the emphasis on emotional sustenance: the private sphere of the family (typically the "moral" woman) provided the nurturance, support, and commitment to family members (most importantly, the man and children) in an attempt to buffer the individualistic tendencies characterizing the "modern" public sphere (Bellah, Madsen, Sullivan, Swidler & Tipton, 1985; Coontz, 1992; Hareven, 1987; Tronto, 1993).

Individuals and families began to understand themselves in relation to, and often aspired realization of, this new, self-contained, “modern” understanding of family (Laslett, 1977; Stacey, 1992). While the nuclear form became a central societal understanding of family characterizing modernism, Tronto (1993) observes that it was an ideological construction which took the white family as normative, and moreover, assumed that white experience was universal. While the nuclear family has been a common family form throughout Western history, there have always been a variety of other successful family arrangements.

If, in fact, there has been a decline of the “modern” nuclear family, it can be blamed on societal changes. The rise of postmodernism (and its watchword, pluralism) and the individual, familial, and general social challenge of the “modern” family should not be construed as separate developments. As families both facilitate and respond to the changing societal interpretation of what constitutes family, there legitimately exists now a multiplicity of family and household arrangements. As Stacey writes, "Like postmodern culture, contemporary family arrangements are diverse, fluid, and unresolved" (1990, p. 17).

Given the societal shift from modernism to postmodernism, there exists the potential for mismatch on the part of the individuals and families who understand themselves in relation to the “modern” family. This mismatch forms the basis of the perceived "family crisis," and can lead to feelings of moral outrage, despair, and romanticized notions of the past. As Stacey observes:

> No longer is there a single culturally dominant family pattern, like the modern one, to which the majority of Americans conform and most of the rest aspire. Instead, Americans today have crafted a multiplicity of family and household arrangements, which we inhabit uneasily and reconstitute frequently in response to changing personal and occupational circumstances (1992, p. 93).

It should be obvious from history that no family form existed in a vacuum. It is no different today, as many of the alternative living arrangements found in society are reactions to larger social, economic, and political changes. As Coontz notes, "the family is always as much a political institution as a personal one" (1988, p. 13). Although discussing family policy is beyond the scope of this chapter, in an attempt to solve whatever family "crisis" exists, society must, first and foremost, pay attention to the larger social and economic changes that impinge upon families of all configurations (Bellah, Madsen, Sullivan, Swidler & Tipton, 1991).

Given the highly politicized "family crisis," any given definition of family becomes a "conceptual and linguistic mine field" (Bernardes, 1993, p. 37). There is general agreement among many family researchers, theorists, and clinicians, however, that a broader definition of family is needed in order to better reflect and express the diverse family forms found in current society (Beutler, Burr, Bahr & Herrin, 1989; Dilworth-Anderson, Burton & Johnson, 1993; Sprenkle & Piercy, 1992; Sussman, 1987). Because "family" can mean very different things from one person to another and is dependent on the situation, the definition I use is that family is a locus of meaning and connection.

While nuclear families may become a minority family form, there is little doubt that they will continue to exist as a viable family option. This family living arrangement may come to be known as the "classical" family--a form surviving through the ages. Despite the continuation of the "classical" family, there is still a great need on behalf of family theory and research to recognize what is quickly becoming the majority of living arrangements. Bernardes (1993) calls for family theorists and researchers to take seriously the responsibility they have to better reflect the varied and diverse complexities of family life. Finally, the import of a plurality of family forms to nursing is clear: the patients and families with whom nurses routinely interact are increasingly of the "postmodern" variety.

While this may sound like an academic point, a nurse's perception of the family can influence care delivery and the kind of family interventions initiated. In one study, 68 nursing students' perceptions of a child were examined (Siebert, Ganong, Hagemann & Coleman, 1986). The participants were split into two groups, with both groups viewing a videotape of a four-year-old child; the two groups were given different information about the child's family structure. The researchers found that a child believed to be from a two-parent family tended to be perceived more positively than a child believed to be from a single-parent family structure. As the "landscape of the postmodern surrounds us," the way in which nurses interact and care for varying family forms warrants further research (Huyssen, 1992, p. 69).

Conclusion

Many family researchers have called for increased research on nontraditional family forms and family populations seldom studied, including racial and ethnic variations. This chapter has demonstrated that understanding the family, in its many forms, can add to our understanding of families and individuals across the health and illness cycle. The time for studying families is ripe, given the myriad of changes occurring simultaneously in our society. In their zeal to capture this rich phenomenon in theory and research, however, social scientists should learn from history. As Benner & Wrubel write:

> We take the stance that theory about human action and concerns cannot be mechanistic and causal in the formal sense. Theory about human issues and concerns must be descriptive and interpretive. Understanding is the goal (1989, p. 20).

Table 1.

	Empiricism	**Rationalism**	**Interpretive Phenomenology**
Summary	Experience through sense organs is the primary source of knowledge	Reason is the primary source of knowledge and is superior to sense perceptions	"Everyday" meanings and actions interpreted and understood in context
Ground of Knowledge	Foundation provided by interpretation-free facts; brute data	Foundation provided by axioms and principles	Starting place provided by practical understanding
Result	Objective, detached stance aids in explanation	Abstraction from context aids in explanation and prediction	Familiarity with practices and participation in shared culture aids in understanding and articulation of practices
Primary Person	Locke, J.	Descartes, R.	Heidegger, M.
Method:	Use inductive method to reach general principles	Use deductive method to reach formal theories of particulars	Apply interpretive method to text and text analogue to reach understanding

Adapted from Packer & Addison (1989) and Angeles (1981).

Table 2.

MODERN	POSTMODERN
mechanistic	self-organizing
linear	non-linear
deterministic	creative, open
mechanical	ecological
reductive	holistic, interconnected
separated	interrelated semi-autonomous
finished work	process, happening
transcendence	immanence
ahistorical	time-binding
monism	pluralism

Adapted from Hassan, as quoted in Harvey (1992) and Jencks (1992).

Chapter 3

Interpretive Phenomenology as a Method for Studying Nursing Practice and Families' Understandings

ICU nurses have been caring for patients and their families since the inception of critical care seven decades ago (Hilberman, 1975). A much neglected area within family nursing research, however, is the reporting of nursing interventions with families (Gilliss, 1991; Gilliss & Davis, 1992). While many studies have examined the need for nursing interventions, and others have tested specific formal family interventions, few have investigated the practical or everyday family interventions of ICU nurses. This everyday knowledge is largely unarticulated and embedded in nursing practice (Benner, 1984; Benner & Wrubel, 1989). While the skilled "know-how" is accessible to practitioners, its taken-for-granted character evades traditional methods of inquiry designed to describe or test explicit knowledge.

At the outset of this study, my research questions included:

1. What are the similarities and differences between the everyday nursing interventions employed with families of newly admitted ICU patients and families of "chronic" (greater than 14 consecutive days in an ICU) ICU patients?
2. To what extent do nurses' and families' appraisals of nurses' everyday family interventions agree or disagree?

3. To what extent do nurses' and families' expectations and understandings of nurses' and families' roles in the ICU converge or diverge?

Research of this nature required a method that was congruent with studying practical understandings and capturing family level data (Stannard, 1994). One such method is interpretive (or Heideggerian) phenomenology, the aim of which is to understand particular patterns of meaning and action in the lives of those studied, taking into account "the context in which they live, their history, and their particular concerns" (Chesla, Martinson & Muwaswes, 1994, p. 4). This is achieved by studying persons, events, and practices in their own terms (Benner, 1994a). The purposes of this chapter are threefold: to provide pertinent philosophical underpinnings of interpretive phenomenology; to describe the research design of this study; and to discuss the evaluation of an interpretive account.

Interpretive Phenomenology

Interpretive phenomenology is primarily a philosophy and secondarily a research method. The traditional division, however, between "theory" and "method" is an epistemological distinction (as opposed to ontological), which is itself inconsistent with Heidegger's project (Bourdieu & Wacquant, 1992). Accordingly, the philosophical considerations presented in this section provide the underpinnings to the use of interpretive phenomenolgy as a research method.

As was briefly discussed in the previous chapter, human beings, according to Heidegger (1927/1962, p. 236), are "thrown" into an already meaningful world. The world holds meaning because society (and the family) precedes the individual, and thus establishes a shared, public understanding of what it is to be a human being (Chesla, 1995; Dreyfus, 1991a). This shared understanding describes the all-pervasive background of everydayness necessary to understand being and the world (Benner & Wrubel, 1989; Guignon, 1991). Understanding is not the way we know the world, it is the way we are (Polkinghorne, 1983). In the phenomenological perspective, human beings are understood both to constitute, and to be constituted by, meanings (Benner & Wrubel, 1989).

Because a given culture is never static, society continually makes interpretations of the background understanding--for example, what "family" means and what counts as an "intervention," as illustrated in the two previous chapters. Additionally, human beings make interpretations of the current societal interpretation. As such, human beings are self-defining and understand themselves in relation to society's interpretation.

One's self-understanding is essentially defined by one's concerns, because what matters to a person--what is meaningful--determines what shows up for that person in the societal interpretation as well as what stands out or is noticed in any given situation (Taylor, 1989; Wrubel, 1985). As Taylor (1989, p. 34) writes: "We are selves only in that certain issues matter for us. What I am as a self, my identity, is essentially defined by the way things have significance for me." One's concerns not only help to define the individual, but also to set up how one enters a situation, what is seen or not seen, and how one acts in the situation (Chesla, 1995).

An additional characteristic of one's self-understanding is that one makes sense of life as one's life story unfolds. In this way, human beings understand themselves in the world through narratives. As Polkinghorne writes:

> narrative is a meaning structure that organizes events and human actions into a whole, thereby attributing significance to individual actions and events according to their effect on the whole. Thus, narratives are to be differentiated from chronicles, which simply list events according to their place on a time line. Narrative provides a symbolized account of actions that includes a temporal dimension (1988, p. 18).

Narratives become an access into understanding what is and what is not significant for the storyteller, since a story is told about certain things unfolding in a certain way.

Heidegger (1927/1962) calls this self-defining way of being existence. For self-defining human beings, the shared background understanding is necessarily presupposed. In order to interpret the background, one must understand what one is interpreting. As such, we are always in what Heidegger calls the hermeneutic circle of understanding. In explaining this circle, Heidegger distinguishes three aspects of understanding.

Any attempt at understanding begins with one's *vorhabe* or fore-having, which is "something we have in advance" (Heidegger, 1927/1962, p. 191).

Understanding begins with something we already know, because we cannot ask about that which we do not know or in some way partially understand. Further, we always have "something we see in advance" or a perspective on what it is we are asking (Heidegger, 1927/1962, p. 191). This fore-sight includes our skills and practices and is analogous to Kuhn's "disciplinary matrix" (Dreyfus, 1985; Kuhn, 1970, p. 182). Finally, the fore-conception is "something we grasp in advance" or the preliminary sense of what counts as a question and answer (Heidegger, 1927/1962, p. 191). While one may constantly strive to move toward deeper and fuller clarity about one's understanding and preunderstandings, one can never fully explicate all of the assumptions, because many concern taken-for-granted aspects of who one is (Guignon, 1983).

Because understanding is based on what is already known, the process of understanding is circular. As such, all understanding and interpretation takes place within the hermeneutic circle (or spiral) of understanding (Bishop & Scudder, 1990). Since all human beings exist in the hermeneutic circle, there are important methodological implications for interpretive researchers, as one can only interpret what one understands. While life experiences can deepen one's understanding in a particular area, no interpretation is ever "finished," because one continually understands (and, therefore, interprets) portions of text differently at different times.

Existence, and therefore understanding, occurs within the world, which for Heidegger is the "meaningful set of relationships, practices, and language that we have by virtue of being born into a culture" (Leonard, 1994, p. 46). Although we live in multiple worlds, we share commonalities of a multidimensional "one world." There are, thus, not two separate entities (namely, human being and the world), but rather, all that exists is the "world-as-experienced" (Marton & Neuman, 1989, p. 36). Heidegger calls this unified notion of human being and world, "being-in-the-world" (1927/1962, p. 91).

Human beings are always situated in the world, engaging in ongoing projects and relationships. This situatedness creates a "clearing," which allows for entities and possibilities to be disclosed (Heidegger, 1927/1962, p. 171). With each possibility, conditions for impossibility are presented (Warminski, 1987). Mood, practices, skills, habits, concerns, and self-definition (or one's stance) help to define what is disclosed to individuals and groups in any given situation (Benner, Tanner & Chesla, 1996b; Chesla, 1988). Accordingly, human beings are always situated within meaningful activities, relationships, commitments, and involvements that set up both possibilities and constraints (Chesla, 1995).

Human beings spend much of their lives in a mode of being which Heidegger (1927/1962) calls ready-to-hand. In this mode, human beings are engaged in practical activity and transparently cope with smoothly functioning equipment or common objects (Dreyfus, 1991a). Immediate understanding occurs in this mode, as meanings are grasped directly (and without reflection) from the situation. Although these everyday practices are often taken-for-granted, it is our practical skilled know-how on the basis of which everything in the world is intelligible and understood (Reiss, Steinglass & Howe, 1993; Richardson, 1986).

The "implicitness" of the equipment and user is lost when something goes wrong. Heidegger calls this mode the unready-to-hand. With a disturbance or breakdown, aspects of equipment or practical activity often become noticed, allowing for deliberate attention and traditional intentionality (Dreyfus, 1991a). Interpretation occurs in this mode, but it presupposes and extends the implicit understanding of the ready-to-hand.

Because the meaning of objects and practical activity briefly surfaces when there is a disturbance, researchers often focus on this mode (Palmer, 1969). Benner and Wrubel (1989) warn, however, that reading from a mode of breakdown to the ready-to-hand mode may not provide an accurate interpretive account. A skewed interpretation would result, for instance, if one studied family coping in the ICU in an attempt to understand family coping when all members are healthy. In terms of method, both the ready and unready-to-hand levels of involvement are the bases of study in interpretive phenomenology.

With traditional scientific inquiry and theoretical reflection, objects and entities are decontextualized and "disworlded," placing the human being in the present-at-hand mode (Heidegger, 1927/1962). This mode, giving rise to explanation, presupposes the taken-for-granted understanding and interpretation associated with the other two modes of being (Dreyfus, 1991a; Ricoeur, 1991).

One methodological implication of this is that, while family research and theorizing have traditionally sought to explain family phenomena, shared family meanings and concerns are not disclosed at this level of involvement.

Both the ready-to-hand mode of engagement and agency are often disclosed in narratives, as narrative accounts point to the storyteller's everyday practical activities and her/his situated actions in a given situation (Benner, 1994a). An agent has been traditionally defined as "one who, or that which, exerts power upon something and produces an effect" (Angeles, 1981, p. 5). Taylor (1985a) broadens this strategic view of agency to include the agentic powers of participating in and responding to concerns that relate to significance as well as strategic goals. Being an agent includes the capacity to respond to meanings and concerns and to take up projects in one's life. Agency in this view is dialogical, not monological. As Guignon writes:

> Who we are, what we are, is determined by the concrete possibilities we take over in taking a stand on the project of our lives (1983, p. 91).

Most of our self-understandings, however, take shape in action (rather than introspection) flowing from a largely unarticulated understanding (Taylor, 1991). Thus, one's understanding of being is expressed in one's actions.

While this will be more fully described in Chapter 5, nurses' stances with families reflected their familial understandings, assumptions, and expectations, which in turn disclosed certain possibilities and family care options in any given situation. Of these, some possibilities will be acted upon rather than others, based on one's concerns (Dreyfus, 1991a). The possibilities "chosen" further define the human being as the kind of being for whom these outcomes matter.

Agency, and therefore understanding, is closely coupled with temporality, which, for Heidegger, is the time of being human as opposed to cyclical or linear time. The traditional priority assigned to the present is supplanted with temporality, which is the way a human being simultaneously lives in the present, is influenced by the past, and is projected into the future (Benner & Wrubel, 1989). Our actions are structured by our anticipation of the future and our understanding of the past and present.

Language and practices are the mediums of understanding and tradition which are fashioned in dialogue with others. Language, in particular, however, should not be thought of as an entity, but rather as a special kind of tool used by being-in-the-world (Haugeland, 1982; Rorty, 1991). In Heidegger's view, language shapes our understanding, self-definition, world, and the situations in which we find ourselves. As Heidegger writes:

> In order to be who we are, we human beings remain committed to and within the being of language, and can never step out of it and look at it from somewhere else (1959/1971, p. 134).

Yet, as important as language is, it is not something human beings can control or completely formalize (Polanyi, 1962). Language is, as Taylor (1985a) describes, a dynamic web, the whole of which resonates when any part of it is touched by use. Because Heidegger saw language as also including nonverbal expressions and gestures, the methodological import of language to both observation and interviewing is great, as language provides the interpretive text. Finally, any interpretive account is affected by the language used by the participants, as well as by the language available to the researcher.

Research Design

The design of this in-hospital study was descriptive. The project was designed to study nursing practices (as opposed to individual nurses) and practical knowledge as it related to the care of families.

Multiple Data Sources

Multiple data sources were used in an attempt to both articulate everyday family-focused nursing interventions and to understand the extent to which nurses' and families' appraisals and understandings converged or diverged. These data sources included:

1. Repeated audiotaped semi-structured interviews with ICU nurses in small groups.
2. Repeated audiotaped semi-structured interviews with families of critically ill "silent" or non-interacting patients.
3. Repeated clinical observations of nurse-family interactions and activities around the ICU bedside.
4. Review of patients' medical records, noting descriptive and clinical data.
5. Completed nurse and family member demographic questionnaires.

6. Participant observation, including informal conversations with nurses, physicians, other members of the healthcare team, patients, and family members, which resulted in the creation of researcher fieldnotes.

There are four basic types of triangulation: data, investigator, theory, and methodological (Janesick, 1994). This study used data triangulation, insofar as multiple data sources were consulted in developing the interpretive account. Additionally, there are three types of data triangulation: time, space, and person (Kimchi, Polivka & Stevenson, 1991). Time triangulation represents data collection at different points of time. It differs from longitudinal studies since the purpose of time triangulation is to validate the congruence of the same phenomenon across points in time. Space triangulation is the collection of data on the same phenomenon at different sites. This differs from multi-site studies because, in space triangulation, data are collected in two or more settings to discover commonalities across sites. Finally, person triangulation is the collection of data from at least two of the three levels of persons: individuals, groups, or collectives. Data collected from one source are used to validate data from other sources. In this study, data were collected from multiple sources over time and from three different ICUs. This enabled me to use time, space, and person triangulation, which is simply a heuristic tool that strengthens the validity of the findings.

Research Settings

Data were collected at three adult ICUs in a large, nonprofit teaching hospital located in a metropolitan area in the western United States. The sites were selected because they serve different patient populations with different trajectories, thereby allowing me to study families of both newly admitted and "chronic" ICU patients.

Additionally, because of my previous employment in this hospital, I was aware of the general family-focused orientation in the ICUs. Based on my research questions, I deliberately chose sites that enabled me to study nurses' care of families. Had I chosen sites that were less family-focused and more restrictive, for instance, in their family visitation policies, my ability to study nurses' everyday activities with families would have been impaired.

I was familiar with all three adult ICUs by virtue of my previous employment at the study hospital. While I had been a staff nurse in one of the units for two years and had worked as a per-diem nurse in the Critical Care Float Unit for one year (meaning that I worked in all three adult ICUs), I had not worked in the hospital for two years before data collection commenced. Still, my familiarity with the staff and the units was a double-edged sword. On the one hand, my familiarity afforded me access to the research site and to materials that might otherwise have been inaccessible or more difficult to obtain. Additionally, I was aware of many of the taken-for-granted habits and practices that went unsaid. On the other hand, I had worked with many of the nurses who participated in the study, and my familiarity with their habits and routines could have created "blindspots." The impact of my own familiarity with the setting and some of the study participants was a source of reflection throughout the study, and can be considered both a strength and limitation.

Descriptive notes.

All three adult ICUs have similar layouts and differ in their physical design only in the number of patient beds. Units #1 and #3 each have 16 patient beds and Unit #2 has eight. Each ICU is a "specialty" unit, in that each primarily serves a specialty patient population. All three units, though, accommodate "overflow" patients, who are "specialty" patients who were not admitted to the corresponding specialty unit due to either unavailable space or staff. Unit #1 was a combined medical-surgical unit and was the least specialized of the three ICUs. Unit #2 served neurosurgical patients, while Unit #3 served both medical and surgical cardiac patients.

Participants

Nurse Participant Characteristics

Twenty-four nurses both participated in group interviews and completed demographic and practice questionnaires. While 27 nurses consented to participate in the study, three nurses withdrew from the study before any data collection had begun. Two withdrew for personal reasons, and one withdrew almost immediately due to a personal family tragedy. There was a total of 15 small group interviews conducted over a seven-month period. Each nurse was invited to participate in three interviews (with the second set occurring three months after the first round, and the third set occurring four months after the second round). Thirty-three percent of the nurses participated in all three interviews, while 58% participated in two interviews. Two nurses participated in only one interview. Additionally, five nurses were observed while they provided patient and family care.

The nurses constituted a highly experienced group, averaging 13 years of nursing experience (range 4-31 years, median 10.5 years, standard deviation [SD] 7.04) and more than 11 years in critical care (range 2-28 years, median 8 years, SD 7.19). More than 50% of the nurses held a bachelors' degree in nursing, and three had masters' degrees in nursing. The average age of the nurse participants was 37. The majority of the nurses was Caucasian and female, reflecting the composition of the nursing staffs in all three ICUs. Five nurses were of color and only one nurse participant was male. Half of the nurses were in a staff nurse leadership position, which meant that they served as preceptors, sat on unit-based and hospital-wide committees, and served as charge nurses. Nurses were excluded from the study if they did not work at least 60% in one of the ICUs and if their nursing role did not allow them to engage in some direct patient care. All of the nurse participants were bedside nurses, except for one who was in a managerial position that enabled her to provide some direct patient care each month.

Family Participant Characteristics

Only one family had multiple respondents, and the other seven families were represented by one family member only, for a total of nine family member participants. While two of the eight families had more than one family member consent to participate, only one of the families was interviewed when multiple respondents were present. Additionally, two patients of participating study families died before any data were collected (other than preliminary fieldnotes and chart review). The two refusals to participate came from families with multiple respondents. There was a total of 11 family interviews (of six families) and five observations (of three families). Additionally, I spent over 100 hours in the three study units engaging in participant observations and informal conversations with patients, families, and staff concerning general family care practices. Please refer to the table below for the interview (Int) and observation (Obs) schedules:

Table 2. Family Participants' Interview and Observation Schedule

Family / total ICU days	Time elapsed from ICU admission to study induction	Time elapsed from induction to Int T1	Time elapsed from Int T1 to Int T2	Time elapsed from induction to Obs T1	Time elapsed from Obs T1 to Obs T2	Time elapsed from ICU discharge to Int T3
1/14	5 days	0 days	---	---	---	---
2/82	2 days	2 days	27 days	2 days	27 days	5 days
3/48	3 days	4 days	6 days	8 days	8 days	---

Family / total ICU days	Time elapsed from ICU admission to study induction	Time elapsed from induction to Int T1	Time elapsed from Int T1 to Int T2	Time elapsed from induction to Obs T1	Time elapsed from Obs T1 to Obs T2	Time elapsed from ICU discharge to Int T3
4/9	2 days	2 days	—	—	—	—
5/8	5 days	1 day	—	—	—	4 days
6/5	3 days	0 days	15 days	5 days	—	—
7/43	2 days	—	—	—	—	—
8/84	61 days	—	—	—	—	—

Table 2 illustrates that both newly admitted and "chronic" families were inducted into the study and followed over time. Unfortunately, because half of the patients of participating study families died, only two families participated in the third interview following their discharge from the ICU. Of these eight families, seven of them were from Unit #1 and one was from Unit #2. No family data were collected from Unit #3, although fieldnote data and small group interviews with nurses who worked in Unit #3 were collected.

Of the nine family members who participated, four were female and five were male. All family members except one were related to the patient, either by marriage or by blood. In terms of ethnicity, seven family members were Caucasian and two were of color. The family participants' ages ranged from 35 to 74 years old (mean 49 years). Because a number of family participants did not complete their demographic questionnaires, I will not report the other questionnaire findings. Families were excluded from the study if they were not under the "charge" of a nurse participant for some time during their ICU stay, if their critically ill loved one was not "silent" or non-interacting, and if they did not speak English.

Patient Characteristics

Informed consent was not obtained from critically ill patients, as patients were not considered "subjects" in this study. Family member consent enabled me to review the patient's chart. Patients had to be "silent" or non-interacting for the duration of the nurse-family observations for the family to be included in the study. For that reason, families of patients who were expected to be transiently "silent" (routine postoperative cardiac surgical patients, for example) were excluded from the study. Finally, based on my practical experience as an ICU nurse, it was believed that the kind of everyday nursing interventions employed in the nurse-family dyad differed from those employed in the nurse-patient-family triad. Because this was front-line descriptive work, the nurse-family dyad was the focus of the study.

Procedures

Entree into the Research Settings

CHR and institutional approval.

ICU nurse managers for the three ICUs were the initial point of entry. I arranged to meet with the managers in person to discuss my study and answer questions. Letters of support for this project were obtained from the nurse managers and included in the application for UCSF Committee on Human Research (CHR) approval. CHR approval was obtained via expedited review (see Appendices A, B). Following UCSF CHR approval, I sought and obtained approval from the study hospital's Nursing Research Committee to conduct the research.

Unit entree.

I attended each of the three units' nursing staff meetings, introduced myself, and presented the study to those in attendance. A sign-up sheet was passed around for those who were interested in participating. I then contacted each interested nurse from the three ICUs in person and gave them an information sheet about the study (see Appendix E). After written consent was obtained, a demographic questionnaire and a one-page informational sheet describing family inclusion criteria were distributed (see Appendices C, G). The informational sheets were also posted on the bulletin boards in the ICU staff break rooms.

Nurse participants were encouraged to page me on my beeper when a "silent" patient and her/his family were admitted. A "family" was defined pragmatically for this project: a person or group of people who were both identified by the nursing staff as "family" and who considered themselves "family" of the critically ill patient. Once notified of a potential study family, I met the family (usually in the ICU waiting room), introduced myself, and described the study. An informational sheet was given out at that time (see Appendix F).

Once written consent was obtained, I distributed the family demographic questionnaire to each participating family member (see Appendix D).

Data Collection

Medical records review.

Medical records were reviewed on each patient of a participating family to collect information concerning the patient's diagnosis and treatment plan (see Appendix J). The medical record was read primarily as biography, focusing on patterns in the way the patient's story was told through the medical record and to what extent the patient's family was mentioned (Malone, 1995).

Family interviews.

Family interviews were primarily conducted in an empty classroom down the hall from Unit #1. The audiotaped interviews lasted from 40 minutes to, in two instances, nearly two hours. The interviews began with one or more of the preliminary questions outlined in an interview guide I developed before beginning the study (see Appendix I). These questions were intentionally written to be largely open-ended, encouraging participants to engage in storytelling as opposed to abbreviated replies.

Several family members had many stories to tell, and they needed little prompting. In other cases (and always occurring in the initial interview), family members were so close to the critical event that they were unable to think of the present as a story (see Appendix K). In all interviews, I sought to be attuned to participants' nonverbal behaviors (such as a nervously twitching leg or tearing eyes) as well as their verbal cues (a trembling voice, for example). In the one family interview with multiple participants, I watched for dynamics between the family members, including where they sat in the circle of chairs set up for them and how they responded to each other's comments. The audiotaped interviews were then transcribed verbatim.

Nurse-family observations.

After the initial interview, I would attempt to schedule a nurse-family observation between the family and one of the nurse participants who was caring for the patient. One of the primary reasons I conducted so few observations was due to scheduling difficulties. Nurses at the study hospital worked 12-hour shifts. As such, in a given week, a nurse participant might work two or three shifts. In many cases, only one of the nurse participants was following a particular patient and her/his study family. On three occasions with different families, the patient died before I had the opportunity to conduct the observation with the one nurse participant who was following the patient. In no case did I attempt to change the staffing patterns or influence which nurses were assigned to care for which patients.

Once I knew that an observation would be possible, I notified the bedside study nurse and encouraged her/him to put off doing "things" that needed to be done at the patient's bedside until the observation. The rationale behind my suggestion was to ensure that the nurse would spend a period of time at the patient's bedside while I was observing. While the nurses' attention on doing "things" could have affected the nurse-family interactions, most of the things that nurses did while I was observing were minor tasks that required little attention on the part of the nurse (such as changing IV lines and simple dressings).

Observations were conducted at the patient's bedside. I would place the tape recorder with its external microphone in a location that appeared to be central to both the nurse and the patient's family member. In many cases, that meant perching it on the patient's ventilator. In one case, I put it on a table near the patient's bed. I stood outside the circle of involvement, usually behind the patient's bed and off to one side, and recorded fieldnotes as the activities and interactions between the nurse and the family member unfolded. I paid attention to where the parties were standing (or sitting), their conversations, bodily cues, and extraneous noises (of which there were many). I tracked ventilator and IV alarms, overhead pages, and interruptions by other members of the healthcare team (see Appendix M). The observations naturally came to a close after approximately 45 minutes to one hour, as nurses often ran out of "things" to do, and family participants wanted to stretch their legs or go to the bathroom. The audiotaped observations were subsequently transcribed verbatim.

Nurse interviews.

A series of small group interviews was conducted with nurse participants in which narrative accounts of family care were elicited. The interviews were scheduled to coordinate with nurses' work schedules so that participants could attend an interview before or after their shifts. Nurse participants were given a range of possible interview times in notices which I placed in their ICU mailboxes.

Group interviews achieve several purposes, including: creating a context which enables peers to tell stories from practice; allowing for active listening and inquiry with multiple listeners trying to understand the story; enriching the meanings of stories by triggering other similar or contrasting stories; and creating a simulated work environment which enables peers to talk naturally to one another about practice issues (Benner, 1994a).

An interview guide (see Appendix H) was used to start the dialogue in each group interview. Nurses were encouraged to tell stories about families in general and not necessarily stories concerning specific study families. Once nurses started recounting their experiences with families, little probing was necessary. I would ask questions relating to specific study families only if I knew nurse participants in a particular interview group had worked with that family and only then when there was a lull in the conversation. I would pause the group occasionally to clarify or ask an additional question. On a few rare occasions, I would refocus the conversation if other topics began to dominate. The interviews were audiotaped and transcribed verbatim.

Withdrawal from the Field

Throughout the data collection phase of this study, I shared many nurse and family transcripts with my dissertation adviser, some of which were puzzling or unusual and others which I felt reflected the bulk of the data. After the second series of nurse interviews (which corresponded roughly with Family 6), I began to notice repeating patterns and themes. After consultation with my adviser, I decided to stop collecting family data. At that time, however, I still had one final series of interviews to conduct with the nurse participants. While I was setting up those interview times, two additional families (Family 7 and 8) were inducted into this study because, together, they represented a family of color and a "chronic" family. I concluded my data collection with Families 7 and 8 and once the final set of nurse interviews was completed.

Documentation

Fieldnotes.

Fieldnotes were handwritten in a journal which I carried with me whenever I was at any of the three study ICUs. In the journal, I recorded casual conversations which I had with nurse and family participants and other members of the healthcare team. I also wrote down questions, thoughts, and other descriptive material pertaining to the research site or the participants. After interviews and observations, I would speak into my tape recorder to "dictate" my initial impressions and thoughts (see Appendix K). These dictations were sent to the transcriptionist, along with the interview or observation tape for transcription. I also kept observation and interview fieldnotes. These notations described the room we were in, where participants sat, what they were wearing, and various other matters.

Taping and transcription.

All of the interviews and observations were audiotaped using a small tape recorder and an external microphone, except for one family interview when the "pause" button on the tape recorder was inadvertently engaged. Immediately after recording interviews and observations, I would find a quiet, private place so that I could listen to the tape and make sure that the tape recorder had worked. Upon realizing the above-mentioned error, I used my interview fieldnotes to recall and reconstruct the interview, using the participant's own words when possible.

Audiotapes were sent to a professional transcriptionist, who had detailed instructions to transcribe the tapes verbatim onto a computer diskette, including the "uhs," "ums," and "you knows," laughter, and any incorrect grammar. If words or phrases were unclear (which happened frequently in the observations due to competing sounds which were unfamiliar to the transcriptionist), this was noted as ---. After receiving the transcription, I listened to each tape and made corrections, clarified sounds, and removed any names or other identifying characteristics.

Data management.

All transcribed fieldnotes, interviews, observations, and any interpretive memos I made were kept in separate files in the word processing program WordPerfect for Windows version 6.1 on my personal computer, backed up by diskettes and by a tape backup. The transcripts were then formatted to leave three inches on the left-hand side of the page blank for notes and coding (see Appendix L). While I had initially planned on using the qualitative software program, Ethnograph, I decided the investment of time required to learn the new program was not justified for this project. The demographic questionnaire data for both nurses and families was entered into the statistical program SPSS for Windows version 6.1.

Data Analysis

In an interpretive study, data analysis begins with initial data collection (such as conversations related to entree) and continues through the writing process. Interpretive phenomenology is, thus, dialogical in nature. The data analysis associated with this method comprises three interrelated processes: paradigm cases, thematic analysis, and analysis of exemplars (Benner, 1994a).

Paradigm cases.

Interpretation via paradigm cases is usually the first phase of the interpretive process. Paradigm cases can be understood as:

> strong instances of concerns or ways of being in the world, doing a practice, or taking up a project. To identify a paradigm does not require the researcher to identify in advance what he or she is "looking for" (Benner, 1994a, p. 113).

Such was the case with both Family 2 and Family 3. Their stories were similar in that both families were "chronic" (having spent greater than two weeks in the ICU) and both of their loved ones' were critically ill. Yet, the two families' experiences and the nursing care they received differed dramatically. As I read and reread my fieldnotes, interviews, and observations, I came to realize that the husband in Family 2 and the wife in Family 3 had different ways of interacting with the nursing staff.

While struggling to make sense of these two cases, I began to "see" in other families' stories that nurses had different ways of working with and caring for families. I gradually came to understand that these "different ways" represented different relational stances toward families on the part of nurses (see Chapter 5). How the nurse was situated with one family did not necessarily mean that he/she would be similarly situated with another family. Furthermore, the nurse's relational stance determined, in part, what possibilities were afforded to the family and how successful the nurse-family interaction would be. Once I had developed the cases for Family 2 and 3, I was able to examine each of the other family's stories in light of the others, seeking to articulate the ways in which the practical worlds of the participants were similar or different (see Chapter 4).

Thematic analysis.

In the thematic analysis, the text is read several times in order to arrive at a global analysis, whereby meaningful patterns and concerns are considered rather than more elemental units such as words or phrases (Benner, 1994a; Leonard, 1994). As I read and reread the data, I made marginal notations of possible themes, beginning interpretive codes, and interesting patterns. I began to notice, for example, how some nurses described families as "part and parcel" of the patients for whom they were caring, while others described families in a way that competed with nurses' ability to provide patient care.

As themes emerged, segments of data which seemed to represent instances of the theme or exemplars were placed in separate files. For example, "providing families with information" was an early theme in the data. Nurse and family exemplars that illustrated this theme were placed in a file. Once it became clear to me that how and what was provided to families in the form of information differed when the patient was dying, I then moved all of the exemplars concerning the care of dying patients' families into a separate file (see Chapter 6). This change then required me to read the whole text again to search for other ways in which nurses cared for dying patients' families.

Analysis of exemplars.

The third aspect of the interpretive process is the search for exemplars, which are stories that capture the meaning in a situation such that the same meaning can be recognized in an entirely different situation (Benner, 1994a; Leonard, 1994). Through the course of reading and rereading the data, I watched for particular narrative accounts that disturbed or intrigued me and tried to understand the situation as it was experienced by the storyteller. This further informed and influenced my thematic analysis.

The three analytic processes were not as distinct from one another as this discussion might suggest. Instead, there was a movement back and forth from parts of a transcript to wholes, from parts of the entire data set to the whole, and from the analysis of individual or “micro” level practices and understandings to the analysis of more “macro” processes and understandings (Malone, 1995).

Evaluating an Interpretive Account

The standard criteria of rigor for the natural science model include: internal validity, external validity and generalizability, reliability, and objectivity (Sandelowski, 1986). Because the goal of interpretive phenomenology is understanding--not explanation and prediction--it is unreasonable to hold this method to the “gold” standard for scientific inquiry using different assumptions and achieving different ends. As Caputo notes:

> There is no proving and disproving in hermeneutics but only a certain letting-be-seen in which we find (or fail to find) ourselves in the account (1987, p. 81).

Because all human beings are in the hermeneutic circle of understanding, there is no interpretation-free technique with which one can evaluate an interpretive account (Packer & Addison, 1989). There are, however, several characteristics of a good interpretive account, such as coherence, agreement, and the account's practical implications (Benner, 1994a).

With respect to coherence, the question which the researcher and others should ask is, “Does this interpretation ring true to the phenomenon?” Interpretive inquiry should scrutinize and check interpretations by focusing on material that does not appear to make sense (Packer & Addison, 1989). Looking for disconfirming evidence is a strategy which an interpretive researcher can use to avoid reading into the text what is not there (Benner, 1994a). The danger of this is that one cannot interpret what one does not understand, making coherence, at some level, perhaps inevitable (Packer & Addison, 1989). In this study, multiple sources of data were consulted, not to obtain the "true" version of events, but to widen the interpretive lens on the phenomena.

Agreement (and reasoned disagreement) is achieved by having others outside the immediate hermeneutic circle of the text examine the interpretation, as well as by clarifying understandings and interpretations with the participants through the data collection phase (Benner, 1994a; Packer & Addison, 1989). Because all human beings are in the larger hermeneutic circle of understanding, there is no "objective" standard against which an interpretation can be validated (Packer & Addison, 1989). If enough text (data) is presented with the interpretive account, however, readers can judge the fidelity, clarity, insightfulness, and comprehensiveness of the interpretive account of the text (Benner, 1994a).

In this study, several graduate students (both ICU and non-ICU nurses) read many of the early transcripts and were engaged in dialogue about beginning interpretive efforts. Several of these same students read drafts of the interpretive accounts after they were completed in chapter form. The objective in seeking multiple readers was to elicit critical reflection and response from those within the shared community of nursing practice. Their questions, comments, curiosities, and confusions were critical in informing and instructing me about my blindspots, biases, and oversights. Additionally, I presented some of my interpretive findings to a group of critical care nurses and physicians at an international critical care conference. Findings will also be shared with nurse participants' from the three ICUs.

Finally, a good interpretive account must offer increased understanding, and articulate the practices, meanings, concerns, and practical knowledge of the world which it interprets (Benner, 1994a; Packer & Addison, 1989). While each situation studied is "unique" in the sense that it is shaped by particular meanings available to that human being or beings, it is also "general" to the extent that a situation is intelligible to human beings only by virtue of the shared background understanding (Guignon, 1983). The goal of an interpretive account is not to produce generalizations, but rather in-depth understandings of commonalities and differences of the world it interprets (Benner, 1994a).

Conclusion

Before I began this study, there was no question in my mind that ICU nurses cared for families to varying degrees. What was unknown to me, however, were the particular kinds of everyday, taken-for-granted family interventions nurses routinely employed. What I also did not know were what kinds of nursing activities and interventions families of both newly admitted and "chronic" patients believed were helpful. As Gilliss writes:

> We have precious little language to describe what we do for families and so we rely on familiar language with well-worn images that do not capture the nuances of the family phenomena (1991, p. 20).

The power of interpretive phenomenology lies in its ability to uncover tacit, everyday practical activities and to understand participants' lived experiences. If well articulated, this interpretive inquiry offers a rich account of critical care nurses' family care practices and sheds light on families' of critically ill "silent" patients' lived experiences.

Chapter 4

The Families' Stories

"We have 16 different stories going on in our unit when it's full" --Nurse Participant

Stories or narrative accounts reveal meanings, understandings, and practical reasoning, because what is expressed is usually what is significant or worth noticing to the storyteller (Benner, 1984; Benner, 1994a). Further, what is worth noticing is intertwined with a person's self definition[2], which is always situated and bounded by one's culture, life history, and time. What is remembered, therefore, is usually meaningful at some level. Stories may be remembered because the event taught the narrator something new. These kinds of stories have been described as narratives of learning (Benner, 1991; Benner, 1994a). Stories may also be remembered because they embrace or constitute the narrator's self understanding. For example, a wife may have an understanding of how a committed and loving wife of a critically ill husband should act in an ICU. An event that either confirms or disconfirms the wife's understanding will probably be remembered. These kinds of stories have been described as constitutive or sustaining narratives (Benner, 1991). Regardless of the type of narrative, stories shed light on what matters to the narrator, reflecting individual and shared understandings in the situation.

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[2] For a more in-depth discussion of the philosophical underpinnings, please refer to Chapter 3.

This chapter is meant to serve as a brief introduction to the family participants of “silent” or non-interacting critically ill patients. My goal is to provide a sense of each family’s “whole” story. Because each family situation differed, the amount and kind of data collected on each family varied. As such, the reader will see that some families’ stories are fuller and deeper than others. Additionally, nurse participants’ stories were collected. Portions of the nurses’ stories will be presented in the next two chapters alongside and in relation to portions of the families’ stories.

A mention should be made concerning the technical abbreviations used throughout all the findings chapters. My goal in using some of the common ICU parlance is not to trouble the uninitiated reader, but to simplify the narratives so that the precise nature of the technical terminology need not be understood by the reader. I have made liberal use of footnotes to help explain some of the terminology more fully. Critical care readers will be accustomed to these common abbreviations.

Finally, as to the transcription notation, the interviews and observations were transcribed verbatim. Facilitative sounds, such as “aha” were generally not included, nor were “mhums” or “you know” where these were simply a way for participants to pause or hesitate while speaking. All names and some details have been altered slightly to protect family participants' anonymity. Please refer below for other transcription notation[3].

Family 1

The 78-year-old patient, who is the wife in Family 1, had three laparoscopic cholecystotomies within a five-week period at a community hospital in a rural part of the state. Two weeks after her third surgery, she was transferred by air ambulance to one of the study ICUs for cholangitis, sepsis, pneumonia, disseminated intravascular coagulopathy (DIC), and to rule out lymphoma. The patient's sister accompanied the patient to the study site, as the husband in Family 1 was attending his mother's funeral. Two days later, most of the immediate family had congregated at the ICU.

Family participants included the patient's husband; one of the patient's two sisters (who had been the primary caregiver while the patient's husband was tending to his ailing mother); one of the patient's two daughters; and one of the patient's three brothers and his wife (who had been an ICU nurse for 22 years). This family was even larger at one time, however, one son had died in a

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[3] The following notation is used in the interview and observation quotations:
Int: refers to the interviewer
Family Relation (e.g. Husband): refers to the family participant
RN: refers to a nurse participant
...: indicates a pause in the interview
....: indicates one or more sentences were skipped in editing a section of the interview/observation
[word]: indicates that I have added some explanatory note or comment
(word): indicates a participant's response, e.g. (chuckles)

motorcycle accident and one of the daughters died during childbirth. The one living son who was not present had been estranged from the family for 30 years. As the patient's daughter stated when discussing the current family configuration, "My mom's been through a lot."

During the course of her two-week hospitalization in the ICU, the patient would go through even more. She underwent an exploratory laparotomy, was started on dopamine (a vasopressor) to maintain her blood pressure, had multiple procedures performed (including intubation, placement of multiple invasive lines, a bone marrow biopsy, a white blood cell scan, chest tube placement, an abdominal CAT scan, an ultrasound-guided paracentesis, a transesophageal echocardiogram [TEE], and a lung perfusion scan), and was ultimately diagnosed with stage 4 Hodgkin's disease (lymphoma). She died, with her family present, when life support was withdrawn at the end of the two-week hospitalization.

During this intensive period, the patient's family stayed at her bedside or in the waiting room during the day. At night, the husband and daughters went to a local hotel and the patient's sister stayed at her brother's house. Even though the family was able to get away from the hospital at night, this hospitalization exacerbated many family members' prior health conditions. The patient's sister, brother, and daughter had diabetes, which they each found hard to control with the added stress of their loved one's critical condition. The patient's brother, in fact, stayed home the day I interviewed the family, due to his uncontrolled diabetes. Additionally, one of the patient's sisters had terminal cancer and was only expected to live a few more weeks, and the husband's mother had recently died. Finally, the daughter with diabetes had 36 surgeries in the past and was, as she said, "facing a couple more."

The constant threat that their loved one might die, together with the recent and not so recent tragedies this family had endured, left many of the family members thinking about their own mortality. When I first approached the family to ask for their participation in the study (and later in the one interview I had with them), family members discussed many of their illnesses. During one conversation, the sister-in-law pointed to her husband and said, "He's really feeling his mortality." The patient's husband added, "I think we all are."

All of these events had instilled and reinforced a family style of facing crises which family members discussed at great lengths during their interview. When facing a hospitalization, for instance, the patient's husband described a coping strategy he used, namely the necessity to have "mental control." When asked what that meant, he replied, "I can toughen up and take care of the problem and then break up--instead of breaking up and letting the problem go." The patient's sister and sister-in-law agreed with the husband's statement:

> Sister-in-law: I think he reacts--I think most of us react that way.
>
> Sister: We all do, we all do.
>
> Sister-in-law: We just kind of look at things, at least for myself, I look at things in a detached manner.

> Husband: Right, of course....
>
> Daughter: We just do. No matter what we feel inside, we have to put on a facade...
>
> Husband: Everything is happy.
>
> Daughter: That everything is well and...
>
> Sister-in-Law: Everything is well. Laughter and what have you. And I'm sure, well, I can speak for myself, that when all is said and done, then I break down. I'm good for the crisis, but when it's all over, I get off to myself and that part I can't share[4] (Fam 1, Int 1, l. 331).

This style of facing crises appeared to be a shared way of dealing with the multiple tragedies this family had confronted. The husband's maxim was, "You're prepared for the worst and hoping for the best." This coping style and habit of thinking are not unlike the emotional forethought and modulation used by critical care nurses in the midst of a crisis (Benner, Hooper & Stannard, in progress). The stakes, however, were higher for these family members than for nurses, because unlike even the most difficult 12-hour shift, this crisis had been unfolding for weeks and the potential loss to the family was far greater and more dear.

A major issue for this family was the dearth of information provided to them. The husband told me that he felt like a mushroom, because he was "put

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[4] This family has what Tannen has called a "high involvement" conversational style, which is an overlapping conversational style characterized by showing enthusiastic involvement (see Tannen, D. [1990]. <u>You just don't understand: Women and men in conversation</u>. New York: Ballantine, p. 196).

in a dark place and not told anything." At another point, he told me that one has to be a "damn nuisance" to get any information. The patient's sister-in-law, by virtue of her nursing background, constantly felt the tug to explain things to the family, yet wanted to be a family member herself. As she said, "I'm the client. It's not my role to explain things--I mean it is--but not now." The sister-in-law would resort to asking "dumb questions" to "draw the nurses out." She elaborated:

> It's like [one of the patient's daughters] saw a new [IV] bottle [hanging] and she's looking at it. And I said, "Oh! They're giving her breakfast." See, nobody bothered to explain to [the family], "We're feeding her through this central line here." It would have been kind of nice because they're worried she hasn't eaten....If somebody just took about three minutes to say, "This is the way she's eating so you don't have to be concerned whether she's going to get her nutrition" (Fam 1, Int 1, l. 543).

One of the patient's daughters felt that emotional support from the nursing staff was also lacking. As she said, "We have each other, but I don't really feel they've given us, as a family, a lot of support." In fact, the issue of family support was a sensitive issue for some of the family members, as there was a perception that the patient's sister, who initially accompanied the patient to the ICU, was receiving emotional and informational support to the exclusion of the others. Unaware of these issues, I asked the patient's sister during the interview if she had received less support once the entire family had assembled:

> Sister: Oh, no. I think there's still concern. I really do. Because I can go in there and talk to them and [the nurses will] sit and talk to me.

> Sister-In-Law: In fact, they don't talk to the others, I'm going to let you know that up front.
>
> Sister: Maybe so, but I know I...
>
> Husband: Yeah, you're it! We've elected you it, and you're still it!
>
> Sister-In-Law: I guess they have.
>
> Husband: Actually, [the sister-in-law] is the one that can explain it to us.
>
> Sister: Yeah, they tell me, but I forget.
>
> Sister-In-Law: It's just like they saw [the patient's sister] come in and [the nurses] said, "We're going to call the doctors to discuss dah, dah, dah, dah, dah," and I said, "What about her husband? Hey! He's number one, folks! He's the one that signs."
>
> Daughter: That's right.
>
> Husband: Yeah.
>
> Sister-In-Law: You know, it's nice that [the nurses] are thinking of her and thinking of me--but she has a husband and she has two children--and believe it or not, they take precedence over us. We're only secondary....
>
> Sister: I know, but then I was the one that was there when she was really hurting (Fam 1, Int 1, l. 866).

While family dynamics and alliances between family members are at play in any family, the stakes are higher in a critical situation such as this. Because the patient's sister was the first family member on the scene and always appeared to me to be rather forlorn, I can only speculate that the nursing staff saw her as not only *the* family spokesperson for the first 24 hours, but also as the family spokesperson who needed support. Problems arose, however, once the entire family had assembled, as nurses evidently did not reevaluate the family as a whole.

Additionally, the other family members, while all expressing to me the desire to have more information, did not present as the patient's sister did. They were vocal and agitated, whereas the patient's sister was quiet and seemed depressed. The implication for nursing is that while some family members may appear or feel more deserving of support than others, other family members may have that same need which goes unfilled by virtue of their behaviors and general presentation.

Information has been identified as a critical component in coping and family satisfaction in critical care settings (Doerr & Jones, 1979; Nyamathi, 1988; Zawatski et al., 1979), and emotional support and information have both been identified as primary needs in 27 need studies of family members of critically ill adult patients (Leske, 1991b). What has not been adequately researched, however, are the family behaviors and configurations that prompt nurses to offer information and emotional support in the first instance. Additionally, while other families in this study may have felt the need for emotional support, none directly expressed that need to me. Because Family 1 was the only family with multiple respondents in my data set, I can only speculate that nursing interventions (including the provision of emotional support) differ for families consisting of multiple family members from those used with single member families. For example, in the next chapter I will discuss how some nurse participants believed that families consisting of multiple family members did not need as much support from the nursing staff, because they "got it from one another."

Family 2

The 36-year-old patient, who is the wife in Family 2, was admitted to the hospital for a routine total gastrectomy after suffering years of gastrointestinal distress and other gastric surgeries related to a congenital condition. She and her husband were both taking nursing prerequisites at a community college prior to this hospitalization. Family 2 is a blended family with five children, two of whom are adolescents who live with the patient and her husband.

The patient's esophagus was inadvertently perforated during what was supposed to be a routine surgery, causing the surgical team to perform an esophagojejunostomy and feeding jejunostomy, in addition to the scheduled gastrectomy. On postoperative day three, the patient, who was not allowed to eat or drink (NPO) and was "high on demerol" according to her husband, drank some water which was inadvertently left by the nursing staff at her bedside. She started to complain of abdominal distention--an old symptom returning after a brief period of postoperative relief. To cope with the increasing abdominal pain and distention, the patient forced herself to vomit, causing an esophageal anastomotic leak. She quickly developed hypoxia and was transferred to one of the study ICUs with the diagnosis of adult respiratory distress syndrome (ARDS) and sepsis.

Over the course of the first hospitalization plus three additional readmissions, the patient spent six and a half months in the hospital, with 85 of those days spent in the ICU. The patient was aggressively treated but had multiple complications. Her therapies included: six surgeries; continuous veno-venous hemofiltration (CVVH) and hemodialysis; multiple continuous intravenous (IV) infusions (including dopamine, versed, fentanyl, propofol, valium, and total parenteral nutrition [TPN]); multiple blood product transfusions (6 units of fresh frozen plasma [FFP] and 24 units of packed red blood cells [PRBCs]); and multiple procedures (including several re-intubations, invasive lines placed on numerous occasions, CAT scans, renal and abdominal ultrasound studies, TEEs, a thoracentesis, multiple chest tubes placed to drain effusions and treat pneumothoraces, metabolic and swallowing studies, multiple abdominal drains placed in interventional radiology, an electroencephalogram [EEG], and a retropylelogram and bilateral stent placement). For her *Staph Epi* endocarditis, she received an experimental antibiotic from Europe on a compassionate use basis (FDA [Federal Drug Administration] approval granted only in life-threatening situations). Additionally, the patient was ventilated briefly with an experimental ventilator when it became apparent that she was not making progress in weaning from conventional ventilation. The teams consulting in her care included infectious disease, nephrology, neurology, nutritional services, ophthalmology, pain service, pharmacy, physical therapy, psychiatry, respiratory therapy, social work, and urology.

In addition to the esophageal perforation, other iatrogenically induced complications included perforation of her jejunum on her first readmission (two weeks after she was initially discharged). Her second readmission (two days following her previous discharge) was necessitated, in large part, by methadone withdrawal (indicating insufficient methadone tapering). Finally, her third readmission occurred only 24 hours after her previous discharge, and was related to problems with her jejunostomy sutures. In spite of the complicated and repeated hospitalizations, the patient survived and was transferred to a skilled nursing facility to be closer to her family while completing her rehabilitation and recovery[5].

The patient's husband literally "lived" at his wife's bedside for most of her extended hospitalization, and in fact thought of the ICU as his "home." While his wife was critically ill, he kept vigil by her bed for most of the day, leaving only for short breaks and to sleep in the waiting room at night. As will be further described in Chapter 6, keeping vigil enabled the husband to feel useful by actively fighting for his wife's life in a way that he could. Keeping vigil also enabled the husband to dwell with his wife during the unfolding crisis (Darbyshire, 1994).

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[5] At the time of this writing, the patient has returned home and has, along with her husband, begun to take nursing prerequisites again at a community college.

While some families of ICU patients slept in the lounge chairs provided for them in the waiting room, the patient's husband managed to secure an eggcrate mattress from one of the nursing assistants and pillows and sheets from the nurses. He set up a makeshift tent in the corner of the waiting room, which was respected by the other families as his space. Thirty days into the first admission, the patient's husband had gone home to check on his children (who were being cared for by his mother and church members) for a total of six days on separate occasions. He told me, "This is my life right now! My whole surroundings, this is all I've got!"

Because both the husband and the patient were studying to become nurses, many of the ICU nurses identified with them and welcomed the husband to be present and involved at the bedside. It appeared to me that many nurses naturally folded the husband into the care of the patient because he was relaxed, likable, and eager to know what was going on. In this case, the expectation that the patient's husband would be involved in patient care became a cyclical process. The nurses expected his involvement based on how he presented and acted, and because the nurses involved him at the bedside, his expectation of involvement was strengthened. In the first interview I had with him (four days into the first ICU admission), he was unsure if the nursing role included caring for families. Twenty-six days later, he had refined his thoughts on the matter:

> Husband: They're supposed to care for her--everybody--not just the patient, you know? They're supposed to care for family members also....

> Int: You said something sort of interesting just now. You said a nurse is supposed to care for the family as well as the patient. In the first interview we had, you posed it as more of a question, "I don't know if nurses are supposed to care for families too."
>
> Husband: Right, more like, "I don't know what is going on here!" (Fam 2, Int 2, l. 317).

He went on to tell me that it was a nurse's responsibility to evaluate a patient's family and intervene if necessary. He said, "It's right there in the nursing medical book."

The role and responsibility of the professional nurse were not the only matters for which the husband consulted his nursing books. He read about his wife's diagnoses and questioned the nurses about her current status and different treatment options. One nurse participant talked about the husband's active engagement in learning about his wife's condition:

> He knows what her numbers are, he knows when [she's] running a temperature, he knows which nurses are on and what he can do with each one of them...and he knows if she doesn't look good and how to relate to that. Right now he is working with her on the floor [and] he knows that she's getting medication that doesn't work for her. And he knows it as well as or better than anybody else....But he learns those things and knows how to work around the system with all the medications and numbers--what's good for her and [what] isn't good for her--and he's learning more all the time (RN Int 1c, l. 442, #10).

The patient's husband then told me:

> I asked each nurse probably a thousand times the same question, each [nurse] on each shift. And I would ask them the same question again--even though they told me before--[just] to see if they were all in sync (Fam 2, Int 3, l. 42).

Seeking consensus from multiple nurse informants and other healthcare providers provided him with the knowledge and security that he truly understood his wife's condition. This frequent questioning also served as a means of bonding with the nursing staff. Perhaps because his questions were framed in relation to the fact that he was a nursing student, repeated questions were not met with impatience or hostility. Rather, his behavior was tolerated by the nursing staff as the sort of activity in which a new nurse might engage.

By the second interview, the husband told me that he was coping with his wife's life-threatening illness and extended hospitalization by re-framing certain events as learning experiences. In so doing, the husband aligned himself with the other helpers and joined the staff in caring for his wife. As such, he was not seen by nurses as a needy family member, but rather as a concerned individual and fellow nurse-in-training who trusted and valued the information with which the nurses provided him.

This, in turn, further encouraged some of the nurses who consistently cared for Family 2 to understand and interact with the husband as a staff member. Teaching the husband was easier for some nurses than relating to him as a desperately concerned and loving spouse of the critically ill patient. In this way, some nurses related to him principally as a colleague and coincidentally as a family member, rather than vice versa. While this will be more fully explored in the next chapter, nurses who interacted with the patient's husband in this fashion offered him some emotional distance by playfully quizzing him on the normal range of routine lab tests and by teaching him how to read his wife's flowsheet.

Other nurses understood and interacted with the husband differently. They understood him as part of the patient's life, and thus cared for him as an integral extension of the critically ill patient. One nurse encouraged the husband to bring in photos so that everyone could see the patient and husband as they were on the "outside." Other nurses involved the husband in the care of his wife. For example, one nurse asked for his assistance in changing the arterial line tubing down to the hub. This activity, performed every 72 hours on patients with indwelling arterial lines, typically requires two nurses or a nurse and a nursing assistant. In this situation, it required only the nurse and her helper, the patient's husband. I observed the husband eagerly don gloves and occlude his wife's radial pulse while the nurse switched the pressure tubing. This seemingly insignificant act held great significance to the husband. When I asked him why it was important for him to help in his wife's care, he replied:

> So when she comes back to me I can say, "I pulled you like this, and I put pillows behind you, and I held your pressure like this (chuckling), and we changed the line--they let me."....Instead of saying, "I just sat there and didn't do anything for 30 days."....So, you know, it helps me. It makes me feel like maybe I am helping her recover (Fam 2, Int 2, l. 438).

His response illustrates not only the power of the helping role, but also the future-oriented and hope-filled space in which he dwelled.

In addition to helping the nurses care for his wife, the patient's husband vigilantly monitored his wife's care and the surrounding environment. He told me:

> If the TV is not on, I'll usually turn it onto what [she] likes....what she would normally watch if she were at home....And if the fan is going like this (referring to the oscillating motion of the fan), well, we don't like that! [She] likes the fan blowing directly on her (Fam 2, Int 2, l. 581).

At the same time, the husband acknowledged the enormous influence nurses had on the environment, especially with regard to the mood around the ICU bedside. He told me, "If the [nurses are] relaxed, then the whole atmosphere is going to be relaxed. But if they're all tense, then you start getting tense." The husband's attentiveness in tailoring the immediate environment around the bedside to reflect what the patient would want, coupled with nurses skillfully modulating their emotions when the patient's condition was far from stable, helped to create a healing and caring space at Family 2's bedside in the midst of a high-intensity ICU.

The patient's husband also became part of the ICU community. The unit ward clerks who, both historically and currently, served as ICU gatekeepers (Gardam, 1969), transformed from being perceived by the husband as "guards" in his first interview to being people with names in the second interview. By that time, the ward clerks and the nursing staff had even started inviting the patient's husband to join them in their weekend ritual of ordering in Chinese food. This ritual continued even after the patient was transferred to another nursing unit on the ward.

Because the patient was critically ill for so long, many nurses tried to accommodate the "live-in" husband. This meant rules were bent and policies ignored. This, in turn, further encouraged the patient's husband to reciprocate or give back to the ICU community. For example, on Halloween, he decorated his wife's room with a ghost made out of a blown-up glove and a hospital sheet. He brought in candy and encouraged the staff to come to the patient's room to "trick and treat." On the patient's first readmission, the family found itself spending Christmas in the ICU. The husband elaborately decorated the patient's room with forbidden Christmas lights, the prohibition of which the staff overlooked. On Christmas morning, the entire family assembled and opened gifts around the ICU bedside under the glow of the flashing lights.

The extended length of time Family 2 spent in the ICU, together with the husband's outreach efforts to be part of the ICU community, further served to enhance the staff's relationship with him. For example, one nurse invited the husband to stay at her family's house for a hearty meal and a good night's sleep. On another occasion, a physician who was going to perform a medical procedure on the patient seemed truly sorry to have to ask the husband to stop watching the football game at the patient's bedside.

While no relationship between a healthcare provider and a patient or family will ever be equal in terms of power, many of the nurses who consistently cared for Family 2 genuinely cared for and trusted the patient's husband and vice versa. The husband's sense of inclusion is most clearly demonstrated when he described his wife's condition in the second interview. He told me:

> We've been down to 40% (percentage of oxygen the ventilator is delivering to the patient)...but, you know, it's getting better. We even made some other adjustments on her pressure at one time (Fam 2, Int 2, l. 633).

The use of "we" in this instance points to the enabling role the husband felt he had in his wife's care. This sense of inclusion was possible, in part, because of who the husband was as a person and the possibilities that were open to him as a concerned spouse of his world-defining other. This inclusiveness was also possible because of how he was understood and related to by many of the nurses who consistently worked with Family 2.

Emotionally, the husband's sense of community extended beyond the ICU to the waiting room. Four days into Family 2's first admission to the ICU, the patient's husband met another husband of an ICU patient who also had a gastrectomy and complications resulting in ARDS and septic shock. Because of the similarities between the two cases, the two husbands became quite close. One week later, the wife of the other husband died, greatly affecting the husband in Family 2. He bought a sympathy card for the other husband and cried with him in the waiting room.

On an intellectual level, after this incident, the husband in Family 2 sought to "build emotional walls to protect" himself from further trauma. He told me:

> I felt so bad, and yet, I still had to go through this--and here I am, shedding tears for them....So after that, I was kind of like, "Goddamn! I'm not getting involved with anybody else" (Fam 2, Int 2, l. 822).

In spite of his vow, however, he did bond with other patients' family members. When I queried him about this, he told me that his "wall didn't work." The husband in Family 2 encountered a constant tension between being curious and wanting to learn about the other patients and families on the one hand, and getting too emotionally involved with them on the other.

The husband's hope for a full recovery was shared by the nurses and the other healthcare providers caring for the critically ill patient. The patient's code status was never seriously discussed in any of the medical notes in the patient's chart over her entire hospitalization, and the cure-oriented "full court press" was evident in the two experimental therapies used to treat the patient when conventional therapies failed. A full court press can be thought of as a constellation of aggressive and curative therapies coupled with a hyper-strategic and vigilant clinician orientation. Being deemed sufficiently critically ill to warrant hospitalization in the ICU, by definition, makes patients candidates for a full court press. Nonetheless, this patient had multiple organ failures at one point, and the medical team still forged ahead with an aggressive treatment plan. Twenty-six days into the patient's first admission, the husband told me:

> When I first came in, I said, "Oh man! I would never want to work in a place like this!" But then, over time, I thought, "You know, this is really where you can actually do the most for a patient--through

your interventions." You can see the miracles (Fam 2, Int 2, l. 995).

The power and seduction of a biomedical miracle were not lost on the husband. In fact, clinicians and medical sociologists alike have suggested that the promise of a medical miracle is one of the driving forces behind clinicians' use of the full court press in challenging death (Chambliss, 1996; Eisendrath & Dunkel, 1979; Zalumas, 1995; Zussman, 1992). The patient's miraculous recovery, no doubt, further reinforced the husband's and clinicians' belief in this promise.

While this case demonstrates many positive reciprocal relational aspects which grew out of relationships some of the nurses had with the patient's husband, it took hope, trust, understanding, and hard work from both parties to pull it off. Not all families are practically or emotionally situated to be as involved as the husband in Family 2 was, nor are they always given that opportunity. Likewise, some nurses do not allow themselves to get as emotionally involved as many of the nurses did who consistently worked with Family 2. By their nature, family care interventions and activities are constituted by what is accessible to nurses and family members. It is through the nurse-family relationship that nurses and families understand the possibilities and options for care.

Family 3

Family 3 was directly across the hall from Family 2. The 51-year-old patient, who is the husband in Family 3, was transferred by air ambulance to one of the study ICUs from an outlying community hospital with an initial diagnosis of pancreatitis and severe gallstones. Although he had two surgeries well in the past, he had been a healthy individual until two weeks before his admission. He worked as an independent contractor and had been married to his wife for 30 years. They had a 20-year-old daughter who was the pride of the family. As the patient's wife told me, "She's the first one from both sides of the family to go to college." The daughter did not live with her parents, but lived fairly close to the study site, enabling her to visit frequently during the extended ICU stay.

The patient was diagnosed at the study site as having necrotizing pancreatitis and met eight out of 11 of Ranson's prognostic indicators[6]. He was treated aggressively in the ICU for 45 days, and his therapies included: four surgeries (including an initial total pancreatectomy, splenectomy, and cholecystectomy); CVVH; multiple continuous IV infusions (including dopamine, neosynephrine, dobutamine, morphine, fentanyl, valium, and insulin); multiple blood product transfusions (40 units of FFP and 33 units of PRBCs); and multiple procedures (including TEEs [transesophageal echocardiograms], CAT scans, invasive lines placed on numerous occasions, cardioversion for Atrial Fibrillation, a thoracostomy and G-tube placements, a cholecystostomy tube placement and

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[6] A prognostic indicator of pancreatitis which uses select admission findings and certain clinical markers 48 hours after admission. Admission findings include: Age > 55 years old; Glucose > 200 mg/dL; LDH > 300 Iu/L; SGOT > 250 IU; and WBC > 16, 000/mm^3. Forty eight hour markers include: Hematocrit decreased by 10%; BUN increased by 5 mg/dL; Calcium < 8 mg/dL; PaO_2 < 60 mm Hg; Base Deficit > 4 mEq/L; and estimated fluid sequestration > 6L. **The mortality associated with meeting seven or more of Ranson's prognostic indicators is reported to be in excess of 80%.**

cholangiogram, metabolic studies, multiple abdominal drains placed in interventional radiology, and a colonoscopy).

For 14 days after the patient's arrival in the ICU, he was a "full code," meaning that cardiopulmonary resuscitation would be initiated in the event of a cardiac arrest. On the 15th day, the patient's code status was changed to a "partial code" which, in this case, ordered healthcare providers to withhold chest compressions in the event of a cardiac arrest, but allowed them to engage in all other required resuscitative efforts. Once his code status was changed, however, the patient started to improve. Because this was the first real improvement the surgical team had seen, the patient's partial code status was unofficially rescinded on a verbal basis.

The patient's improvement, however, was short-lived. After an additional 21 days of aggressive therapy with no noted improvement, a second family conference was held. At that time, the patient's partial code status was clarified and reordered. While the issue of withdrawing life support was raised at that conference, no decisions were made. After eight additional days of maximal support with no sign of improvement, the patient's code status was changed to a DNR (do not resuscitate), the vasoactive drips were discontinued, and only comfort care and ventilatory support were provided. The patient died the following day.

The wife held constant vigil during the 45-day ordeal, sitting in the patient's room during the day and sleeping in lounge chairs in the waiting room at night. Like the husband in Family 2, the wife in this family also referred to the ICU as "home." She literally did not leave the hospital during the first 30 days, and left only once thereafter in order to make funeral arrangements for her husband. While the wife seemed happy that each of her husband's remarkable recoveries extended their time together, his grave condition further exacerbated the conflicting opinions that healthcare providers held about this case.

The patient's surgeon was eternally optimistic and continually gave the wife encouraging news. In fact, at one point, he angrily told one of the nurse participants that nurses should stop giving the wife the impression that the patient would not survive:

> RN 1: [The surgeon] was getting from [the wife] that people--nurses probably more than anybody--were giving her the impression that [the patient] wasn't going to get well....And he was telling her that [the patient] still had a chance to get well, as far as he was concerned.
>
> RN 2: And this was at the end when I think it was clear to everyone that [the patient] wasn't going to get better.
>
> RN 1: He felt there was still a chance...and that we should keep fighting.
>
> Int: Wow! What was your response?
>
> RN 1: I asked him if he really thought that he could get the patient out of here because the wife was home making plans for a funeral...And he said, "Yes!" (RN Int 1c, l. 551, #10, 13).

The ICU physicians, on the other hand, were more frank with the patient's wife. On Family 3's second night in the ICU, one of the nurse participants described an encounter between an ICU physician and the patient's wife, which greatly shaped the way in which healthcare providers approached the wife from that point on:

> Because [the wife] had recently had a hysterectomy herself...she was hormonal. She had just gotten out of the hospital when he got sick, and he crashed pretty quickly...And so with her hormonal imbalance--I think they hadn't really put her on anything--the poor woman would just sit there in the room and weep and weep and weep....That day was just kind of difficult too...I think it took me the whole eight hours to give him a bath, because it was like, do a few things for him and then go sit with her. I called the chaplain, but I don't think that helped her at all...Then one of the [ICU] doctors had come in [to the room to talk to her], which was the topping on the cake. He told me earlier that he wanted to talk to her and I didn't really know how he worked. Now I know and I'll never have him come to my bedside again! But I just assumed that he wanted to get to know her, because a lot of the docs are pretty good about that. They'll go in and chit chat a little bit. But he just went in and took her out in the hall and said, "You know, 100% mortality," and turned around and left. So then she was even worse than she had been, and I was at my wit's end. So I demanded that the ICU physicians write her for a dose of something. I wanted [them] to give her xanax, but they wrote for some valium instead (both anxiolytic agents). And she took that and finally went into the consultation room and crashed for a while....So that made me feel like, at least, worst case scenario, maybe I did something that kind of helped her through that hump period (RN Int 1b, l. 203, #7).

The nurse's intervention in securing for the wife a one-time order for valium that night was probably helpful, under the circumstances. Because she continued to take the valium (which she obtained from her primary physician at home), however, she was perceived by the healthcare providers as so needy that she effectively became a patient herself. From that point on, many healthcare providers were reluctant to tell the wife any bad news for fear it would once again push her over the edge.

Several nurses, however, still tried to give the wife the "big picture," which usually included providing her with grim updates. The wife admitted to me on one occasion, however, that she "probably screened out a lot of negative information." One of the nurses, in discussing this case in a group interview, said:

> I think people like her look to the doctor as their God almost. The doctor says [the patient's] going to do OK, so they expect him to do OK. And if the doctor says, "I expect [the patient] to turn around in a couple of weeks," you know, they don't look beyond that. They don't look at the possibility that [the patient] won't turn around, because the doctor said he's going to turn around (RN Int 1c, l. 512, #13).

Because the surgical team provided the wife with ever hopeful news, she was given an avenue to avoid reflecting on the possibility that her husband might not survive.

This case, which was characterized by a protracted ICU stay for a near certainly futile course of treatment, was difficult for many of the nurses to bear. In reference to the patient's questionably effective therapies, one nurse told me that she felt this was "a case for the ethics committee." When I asked her if she was going to initiate that action, she said, "No! I don't want to get involved. I just don't take care of him, that's all." Other nurses expressed similar sentiments, while some talked to me about the enormous waste of resources being spent on the patient. While this family did have a small group of nurses who consistently cared for them, the patient's room seemed bleak compared to other "chronic" ICU patients' rooms. The patient's name on the chalkboard at the side of the bed was the only decoration in the room. This stands in sharp contrast to Family 2's room, which was decorated with family photos and intermittently dressed for the holidays.

Except for a few nurses who consistently cared for Family 3, the patient's wife was never taken up by the staff or encouraged to get involved in her husband's care. While she was a constant presence, she always sat in a chair away from her husband's bedside, which made her seem outside the circle of involvement. Additionally, her medication-related disengagement made her seem and feel like she "wasn't really there." She also told me that she believed the nurse's role was to "take care of [the patient]," which may be another reason that she seemed outside the circle. In trying to, as she said, "stay out of the nurses' way," the wife was, perhaps, inadvertently giving nurses the message that she did not want to be involved or included.

The critical view of the wife's valium use may also account for why many of the nurses never encouraged her to get involved. On one occasion, the wife stood up suddenly from her chair in the patient's room and fell over. She admitted to me later that she was taking too much valium that day. That event, however, left an indelible impression on many nurses. On another occasion, when the patient had a bradycardic event and healthcare providers rushed into the room, the wife had difficulty moving out of the way due to the fact that her foot had fallen asleep. Because of the previous event, however, nurses assumed that this second incident was also valium-related. While the wife's valium use was the topic of many staff discussions, no one approached her or directly intervened in any way.

While most of the staff worked around the patient's wife, a few of the nurses who consistently cared for Family 3 attempted to involve her in her husband's care. On one occasion, for example, a nurse invited the wife to assist her in washing the patient's hair. Helping--as opposed to merely observing--transformed the wife. While this interaction between the nurse and wife is more fully described in the next chapter, by the end of the shampoo the wife was fondly caressing her husband's face and happily reminiscing to the nurse about some of the good times she had shared with her husband.

On another occasion, nurses had asked the wife to help them turn the patient. The wife explained how even something that "simple" was meaningful to her:

> [The nurses] even let me put on gloves and I helped turn him. I mean, they needed the help...[But] that was letting me get involved....So, I just put on the gloves and helped them....It was important for me to be able to do that. It was something minor, and like putting washcloths on his face. I mean, I'm sure it does absolutely nothing for him--but it makes me feel better....Most of the stuff, I know, it's not my business to touch or get into. But even doing simple things, like helping to turn him, things like that, make me feel better....Like I'm doing something to help him (Fam 3, Int 2, l. 275).

By helping the nurses turn her husband, the wife felt useful and involved. Because only a few of the nurses worked hard at including her, these meaningful experiences were, unfortunately, few and far between.

While the patient's wife was clearly not part of the ICU community, she was an active part of the family community in the waiting room. She told me:

> It's nice to talk to others. Sometimes I realize, while my husband is really sick...[other] families are even worse. Like [Family 2's] wife, what she's gone through is unreal. I know my husband is really sick and he's still critical...but then I look at some of these other people. You know, two people have died since I've been here, and I figure I'm still pretty lucky (Fam 3, Int 2, l. 395).

Since some of Family 2's effective strategies, such as aligning with the staff, were not options for the wife in this family, she sought emotional support from other families in the ICU waiting room. Her remark also illustrates that social or downward comparison is still relevant to those with the sickest loved ones, as the wife took comfort from the fact that at least her husband had not yet died.

The day before her husband died, however, the wife was in an obvious state of distress. When I asked her if her daughter was coming in, I was informed that she would come after work. The wife explained, "There's no point for both of us to sit around and wait (her emphasis)." When asked if there was anything anyone could do for her, she said, "Not unless you can bring my [husband] back."

I arrived on the unit shortly after the husband in Family 3 died. One of the surgical residents on the case was still completing the necessary paperwork when I asked him if life support had been withdrawn. I was given a curt "No!" in reply. I left the unit and went to the waiting room to learn that the wife in Family 3 had just left the hospital.

Days later, the nurse who cared for the patient on the day he died told me that one of the ICU physicians felt that the patient was "taking too long to die" (the nurse's words). Evidently, the ICU physician called the patient's surgeon and encouraged him to let the ICU team manipulate the amount of oxygen the ventilator was delivering to the patient. The surgeon agreed to the plan, but did not want to tell the wife because she had not wanted her husband's death to be "active" (a nurse's remembrance of what the wife had said at a family conference). The nurse agreed with the plan, telling me later that the wife would have "lost it if she knew." Because the nurse had never actually worked with this family before, she was basing her judgment on what other nurses had told her about the wife in unit and bedside reports.

The nurse went on to describe the physicians' plan as "a chicken shit thing to do." While it is troubling that the nurse was not able to see her own complicity in the withdrawal of this patient's life-sustaining therapies, it is even more troubling that the healthcare team's understanding of the patient's wife was that she was not competent enough to be consulted in the matter.

Initiating and engaging in this paternalistic plan without consulting the patient's wife was clearly a breach of the ethical right of informed consent. However, this case illustrates the poorly articulated clinical and ethical distinctions which clinicians, patients, and families face in the ICU. While I object to the secretive withdrawal of life support, it can be argued that it is likewise abhorrent to embark on and sustain futile treatments. Ultimately, this case was doubly troublesome: the aggressive interventions to save a life where the prognosis was poor, and the active withdrawal of support without clearly communicating with the family.

The patient was admitted with multiple organ failures, causing many clinicians to expect patient death. While healthcare providers are ethically and legally bound to engage in lifesaving measures when there is a reasonable chance of recovery, it is not ethically sound to suspend a patient in the dying process. In this case, had the surgical team been able to grasp the patient's ultimately fatal condition earlier on in the patient's clinical course, they could have judged the patient's therapies as futile during the first family conference, 15 days after the patient was admitted to the ICU. Instead, the team remained hopeful for patient survival and opted to withhold chest compressions in the event of a cardiac arrest. Healthcare providers' reasoning in transitions will be more fully discussed in Chapter 6. While it may be necessary to continue futile life-sustaining therapies for a brief time while a family comes to terms with an impending death, little effort was expended in helping the wife face the inevitable. In fact, she was consistently given mixed messages, ranging from "100% mortality" to the hopeful updates from the patient's surgeon.

Another insight into this complex case was provided by one of the nurse participants, who speculated that the surgical team continued to prescribe questionably effective therapies for the patient in an attempt to disprove the ICU team's prediction of "100% mortality." She told me that the chief surgical resident was furious with the ICU team when he found out about the ICU physician's discussion with the wife on the second night in the ICU. If the nurse's speculation was correct, the surgical team continued to prescribe aggressive therapies in spite of the patient's deteriorating condition, partly because of internal dynamics between the two medical teams and partly because the surgical team could not, for whatever reason, come to terms with the patient's imminently fatal condition.

The ICU team might have viewed this patient's prognostic indicators as a signal to be prudent in their medical management, whereas the surgical team might have understood the indicators as a challenge to overcome with the aid of modern medicine. After all, the surgical team, who was responsible for the husband in Family 3, was concurrently--and successfully--treating the wife in Family 2, who was also critically ill and had multiple organ failures at one point in her hospitalization. The wife in Family 2 survived. It is understandable that a medical team could be more hopeful in treating one potentially terminally ill patient after successfully treating another.

This family's death scene sadly illustrated a social death preceding actual physical death (Sudnow, 1967). The fact that the wife made funeral arrangements 30 days into the 45-day ICU stay shows that, in spite of her hope, she knew that her husband was terminally ill. Although the valium may have blunted the extreme grief and suffering she must have been feeling for those 45 days, it also masked her feelings from the healthcare providers. If the staff had viewed the wife as a competent adult who was silently grieving, it is possible that the care given to this family would have been quite different.

Finally, Family 3's story is not complete without drawing attention to the enormous financial burden that the surviving wife evidently had to bear. Although the wife in Family 3 never discussed finances with me, the husband in Family 2 had discussed finances with her in the waiting room one day. In the last interview I had with the husband in Family 2, he was discussing healthcare costs and used the wife in Family 3 as an example:

> I know [the wife in Family 3] is going home and she's got to ask her relatives for help--even the 20% [co-payment] is going to wipe her...I guess I'm thankful [my wife's] on Social Security and Medi-Cal...everything is covered. But all these [family members in the waiting room] are reading their insurance [policies]...I mean, it's playing a big role (Fam 2, Int 3, l. 405).

The real tragedy in this case is that the wife not only lost her husband of 30 years, but now fears losing her house, her car, and other possessions to help pay for the 20% insurance co-payment stemming from the 45 days of ultimately futile treatment in the ICU.

The fact that the patient's life was sustained for 45 days is, in itself, a testimony to modern medicine. But this case was a costly experiment in which to try to beat the odds. While we will never know how difficult the experience was for the patient, we know that it was extremely trying--both emotionally and financially--for the wife to spend the last 45 days of her husband's life in an ICU as he was suspended in dying. It was also costly for the healthcare providers who were conflicted over the case to care for a terminally ill patient for such an extended period of time. While saving the critically ill patient's life is the *modus operandi* for ICU practitioners, one cannot help but ask: at what cost are we as healthcare providers and fellow human beings willing to push the limits of life?

Family 4

The 44-year-old patient, who is the wife in Family 4, had a kidney transplant a month before this admission for end stage renal disease. She was discharged from the hospital following her successful transplant, but was readmitted two weeks later for a deep vein thrombosis (DVT). After a week of treatment on the ward, she was transferred to one of the study ICUs with the diagnosis of shock liver[7].

The patient and her husband had been together for 10 years. They were both in long marriages ending in divorce before they met each other. Because of her chronic health problems, the patient had never had any children; the husband had four children from his previous marriage. While the patient had been on the kidney transplant list for three years and on peritoneal dialysis for the past year, her husband told me that, prior to this hospitalization, they went sailing every weekend and traveled frequently. The husband, a man weathered by the sun, got teary-eyed whenever he talked about their wonderful life together.

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[7] A serious hepatic collapse, sometimes following sudden relief of common bile duct obstruction of long duration.

The patient was treated aggressively in the ICU for nine days. On her second day in the ICU, she was rushed to surgery for an exploratory laparotomy. The combination of the heparin therapy for her DVT and the underlying coagulopathy from her shock liver condition caused a massive retroperitoneal bleed. Her other therapies included: CVVH [continuous veno-venous hemofiltration]; multiple continuous IV infusions (including fentanyl, dopamine, insulin, and prostaglandin E_1); multiple blood product transfusions (59 units FFP, 8 six-packs of platelets, and 23 units PRBCs); and multiple procedures (including two intubations, invasive lines and drains placed on numerous occasions, and several CAT scans).

In the one interview I had with the patient's husband, he told me that it was difficult for him to stay at his wife's bedside for long periods. During this time, the patient's kidney function was being maximally supported by CVVH, meaning that there were at least six IV pumps in the room for the dialysis filter alone. Additionally, the patient's room was filled with the customary life-supporting machinery, including a ventilator, routine ICU monitoring equipment, and six additional IV pumps for the blood products and IV infusions the patient was receiving. One could tell that the patient was quite ill, just by looking at the number of IV pumps in her room. The patient's husband came to the hospital several times a day, but stayed only briefly. When I asked him why, he replied:

> Well, you know, emotionally it hurts. I can't just sit there and watch my wife lying there, not able to talk, not able to do anything. It just hurts too much (Fam 4, Int 1, l. 102).

While the husband may not have spent a lot of time at the bedside, he seemed to pay more attention to the demands the family placed on nurses than did other families. For example, he limited the number of family members who could be with his wife at any one time, and explained to me that, "the room is too small and there is too much machinery around. You wouldn't want four or five people around the bed--just one or two." On another occasion, the husband realized that many family members were calling in frequently for progress reports. He told me, "That takes the nurse away from caring for the patient." He called the patient's father and said, "You have your people call you and I'll have my people call me, and we'll give them progress reports." These family-imposed limitations were made with the best intentions: to ensure that the nurses could focus their energies and attention on caring for his critically ill wife.

After slow but steady improvement, the patient, on her ninth day in the ICU, had a sudden change in her neurological status. She was emergently intubated and rushed downstairs for a CAT scan of her head, which showed a massive intracerebral bleed. She was promptly returned to the ICU, where her bleed was immediately treated at the bedside by placing a ventriculostomy to reduce her intracranial pressure (ICP). The patient's ICP was initially 71 mm Hg[8], but, within the hour, it approximated her mean arterial pressure (MAP) of 170 mm Hg--a pressure incompatible with survival.

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[8] The normal value for intracranial pressure (ICP) is 10 mm Hg.

Coincidentally, I arrived at the ICU while the physicians were placing the ventriculostomy. As I approached the patient's room, it was obvious that a crisis was unfolding. Curious and nervous medical residents spilled out of the room, and several nurses rushed in and out carrying supplies. I pushed through the crowd and made eye contact with the nurse who was caring for the patient. In an excited fashion, she quickly told me what had happened. I asked her if the patient's family knew, and she told me that they knew the patient had been emergently intubated and had a CAT scan. Apparently, they were in the waiting room. I asked the surgeon at the patient's bedside if she had talked yet with the family. She appeared rather dazed, and told me that she did not plan to talk with them until she had met with her surgical team.

I left the ICU and found the patient's family in a crowded waiting room in another part of the hospital. The family consisted of the patient's husband, one of the husband's sons, and the patient's parents. When I walked in, the husband stood up, looked at me expectantly, and said, "Well?" I told the family that I had just glanced in the patient's room and that the medical team was completing the placement of the ventriculostomy. The husband and son decided to wait outside the ICU doors for further information.

I introduced myself to the patient's parents and sat down with them. The patient's mother tearfully reviewed with me her daughter's chronic health problems and told me of her sorrow and her hope. The mother started to cry, and the patient's father asked me if there was a private place to meet with the doctor. It struck me that family members of dying critically ill patients oftentimes experience one of the most tragic events of their lifetime in a fishbowl[9]. Because the regular ICU waiting room was filled with family members waiting for another patient, and this waiting room was also crowded, I arranged for the family to use the private room that I usually used for family interviews. I escorted the family to the room and told them I would tell the surgical team where they were waiting.

When I returned to the patient's bedside, the Medical Director of the ICU was trying to convince the patient's surgeon that the patient was going to die. Further interventions were useless. The patient's attending physician, a meticulous surgeon who is loved by her patients, was not yet ready to give up. The surgeon, rather desperately, wanted to start the CVVH (dialysis) again and obtain a neurology consult. The Medical Director implicitly told the surgeon that CVVH, in particular, would be a useless intervention, as it is essentially a surrogate kidney and not an antidote for an intracerebral bleed. Yet, providing *any* kind of intervention--intellectually, at least--postponed the patient's death. I observed the Medical Director tell the surgeon that, "When the ICP equals the MAP, the brain is gone[10]." The surgeon seemed shocked to have lost a patient

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[9] I thank Fay Wright for this observation.

[10] Cerebral perfusion pressure (CPP) is the difference between the mean arterial pressure (MAP) and the intracranial pressure (ICP). The physiologic consequence of intracerebral hemorrhage is a loss of cerebral autoregulation which makes cerebral blood flow (CBF) linearly dependent upon CPP. CBF may be decreased if the ICP becomes elevated, leading

(continued...)

and appeared frustrated that nothing more could be done to reverse the turn of events.

This case has many parallels to a study which examined medical residents' perceptions of patient death (Muller & Koenig, 1988). The researchers found that internal medicine residents at a university teaching hospital defined patients as dying only when the physicians determined there was nothing more they could do. Muller and Koenig write:

> Dying is defined, therefore, in terms of the actions--or failed actions--of the physicians. In keeping with the predominant technical bias of biomedicine, "dying" becomes a cultural metaphor which symbolizes treatment failure. The focus of medical work is on "doing," and when everything fails, the patient is "dying" (1988, p. 369).

The researchers additionally listed three physician fears which might further encourage the use of the full court press: fear of failure, fear of death, and fear of malpractice suits (Muller & Koenig, 1988). While any or all of these fears are entirely plausible, I believe there is an additional factor operating in critical care settings, namely holding out for the miracle (or fear of stopping too soon). For some, the hope for a miracle may be couched solely in biomedical terms: a new drug may be available next week, a new procedure could be developed, a new technological gadget could be released that will help pull the patient out of the crisis. For others, the miracle may be more spiritual, such as the patient's

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[10](...continued)
to further ischemic tissue damage and eventual herniation if the problem is not corrected.

will to live or divine intervention. In either the biomedical or spiritual sense, however, few physicians would likely admit to holding such beliefs. Believing in miracles is not rational, nor is it based on randomized clinical trials. So, instead, intensivists often rely on an old habit: perseverance (Chambliss, 1996).

Unfortunately, a miracle did not occur in this case. I could certainly understand the surgeon's disbelief. I, too, was stunned at the patient's sudden downturn and felt conflicted in my role as researcher and nurse. As a researcher, upon reflection, I should have simply stayed near the room and documented the course of events. But, without thinking, I went to the waiting room to be with the family, as I knew the patient's outcome and felt that the family would appreciate seeing a familiar face during this difficult time. As soon as the patient's father asked me if I could find them a private room, I confronted the gnawing fear that was growing inside me that I was no longer in the researcher's role. At that point, however, as a nurse, I felt that I needed to help them find some privacy. After all (I justified to myself as I walked down the hallway), there is very little that I can do, so I might as well do what I can. In this way, my actions paralleled those of the patient's surgeon; like her, I wanted to <u>do</u> something.

After situating the patient's family in the room that I had secured for them, I returned to the ICU to let the surgeon know where the family was waiting. The surgeon immediately joined the family and spent approximately 20 minutes with them. After meeting with the surgeon, the family was obviously quite distressed.

The husband said to me, "It doesn't look good," to which I replied, "No, it doesn't." The family told me they were going out for some fresh air, but they left the hospital altogether. After a negative response by the patient to cold calorics and atropine, the surgeon phoned the family at home to inform them that the patient had been declared brain dead.

This was an unexpected ending for all involved, because the patient's sudden bleed was completely unanticipated by both the staff and family. In the controlled environment of this particular ICU, unanticipated deaths rarely occurred. Numerous physiologic indices of clinical status were so closely monitored that, after spotting a downward patient trend, the healthcare team usually had a window of time to intervene and prepare the family. As is more fully described in Chapter 6, healthcare providers offered families slow-dosed information about their loved one's predicted outcome during this time. But when an unanticipated death occurred, the staff did not have time to prepare themselves or the patient's family.

While the nursing implications of working with families of dying patients are further described in Chapter 6, it is noteworthy to mention that the unit's social worker could not be found during the period of this patient's crisis and death, and the clinical nurse specialist and charge nurse were both busy. Because of this unanticipated emergency, there was pandemonium in the unit. As a result, the family was essentially ignored. While ICUs are inherently intensive, and death scenes all the more so, healthcare providers in acute and critical care settings must recognize, and in some fashion be prepared to address, the plight and needs of grieving families.

While miracles do happen in ICUs, as the husband in Family 2 pointed out, death also occurs there. While death can be "controlled, postponed, and potentially reversed," in spite of the biomedical promise, death can never be eliminated (Muller & Koenig, 1988, p. 354).

Family 5

The 62-year-old patient, who is the mother in Family 5, was admitted to one of the study ICUs following a scheduled frontal craniotomy for a meningioma that was progressively causing her to lose her vision. Other than her failing vision, she was fully independent prior to this hospitalization. The widowed mother in Family 5 lived with one of her daughters, and her other daughter and son lived nearby.

The patient had a rocky postoperative course and spent eight days in the ICU. She was returned to surgery on two separate occasions, 17 hours apart, to evacuate a hematoma in the first instance, and to relieve swelling in the second instance. Throughout all three initial postoperative periods, the patient's Glasgow Coma Scale score was six[11]. Her family had initially congregated at the

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[11] The Glasgow Coma Scale is a scoring system that can be used to document the depth of coma and to follow the clinical course of a neurological deficit. Points are added up which measure eye opening, best motor response, and best verbal response. Scores range from three to 15; the high end indicating no coma or normal.

study site, but, once she had stabilized, only one of her daughters stayed on at the hospital. This daughter was the family member I interviewed on two separate occasions.

The patient's return trips to the operating room shook the family's fundamental faith in medicine. They had not prepared themselves for complications, and, according to the daughter, they were not informed by the surgeon that complications could arise. The patient's daughter told me:

> Nobody told us the risks that were necessarily involved in the surgery. We were told, "Oh, the nerve looks fine! You'll come in Thursday morning 6:00, you'll be in surgery at eight, should be awake by noon, and home by Monday, Tuesday at the latest." "What could happen? Could she have a stroke?" "Um, 5%, but not likely." "Well, what could happen to her?" "Actually, not much of anything. She'll be fine. It's an everyday surgery." This is what we were told, boom, boom, boom (Fam 5, Int 2, l. 105).

While I was surprised to find that the family thought brain surgery was a low risk procedure, from their perspective, this is what they were led to believe. As such, they were stunned when "a simple surgery" did not go as smoothly as it was supposed to. The daughter told me, "Then you start losing your faith. And then, do they know what they're doing? Why did this happen?"

The surgeon's failure to fully disclose the risks of brain surgery to the patient and family highlights the routinization and normalization of heroic medicine. Because this particular surgeon has performed hundreds, if not thousands, of craniotomies, he can no longer "see" that brain surgery is an incredibly heroic and extraordinary medical intervention. To him, "a crani" is simply standard treatment for the patient population with whom he works. Additionally, because this surgeon is quite skilled at what he does and few of his patients suffer major neurological consequences related to his surgeries, he, perhaps, does not see the need to disclose grim, although not altogether unlikely, possibilities. One of the problems with routinization, however, is the lack of preparation patients and families receive.

Four days after her third trip to the operating room, the patient started showing daily improvement. She continued, however, to have a right hemiparesis. The patient's daughter, who spent nights at a friend's house, recalled:

> The doctor called and said, "Oh, your mom is awake." I was excited and I couldn't get here fast enough--only to find [that] she wasn't [as] awake as I had thought. I mean a little bit to him was a lot to him, but it wasn't enough to me (Fam 5, Int 2, l. 224).

In another (but related) instance, the daughter told me that healthcare providers would say to her, "Oh, she's improved." "She's a million times better!" "She's wonderful!", to which the daughter replied, "Well, to us she's not wonderful because she's not herself." So while the patient was, in fact, recovering, she was not the same person that she was before. This highlights the different points of reference used by the patient's family and the healthcare providers. What may seem to the nurse to be substantial improvement based on the patient's neurological exam may not look substantially different to the family. Because this family had an undeniable faith in medicine before their mother's surgical complications and because of the surgeon's framing remarks preoperatively, they had not prepared themselves for the possibility of anything short of complete recovery.

In another situation, the patient's two daughters asked the chief resident a question about their mother's condition:

> Daughter: I asked one of the residents a question--and she's a chief resident--and she couldn't even give us an answer!
>
> Int: Do you remember what the question was?
>
> Daughter: We said, "Well, do you know how long she could possibly stay asleep?"...and she just sat there and shook her head and said, "I really can't give you that answer." Well hello! You're supposed to be the doctor! And she said, "I know, but I just don't have the answer to that." My sister and I were just amazed...I didn't like that answer (Fam 5, Int 1, l. 514).

The patient's daughters probably did not realize that they were asking an extremely difficult question. Because clinical science is rarely black and white, seasoned clinicians always leave themselves open to the possibility that an unexpected event or an unknown complication may occur. As such, during the patient's initially unfolding clinical course, many clinicians provided families with open-ended information so that, as one of the nurse participants said, "I can't get pinned down for it later." While the patient's daughters were unhappy with no answer, they probably would have been equally unhappy with a vague answer, as most of the other study families reported and which will be more fully discussed in Chapter 6.

Some of the ICU nurses who cared for the patient further compounded the trauma for this family. Of the three study units in which data were collected, this particular ICU had the least family-friendly environment. It had the most rigid visiting policy of the three units, and the policy was strictly enforced. Chronic low-level conflict with healthcare providers characterized this family's hospitalization experience. On one occasion, a nurse got upset with the patient's son because he walked into the ICU without phoning first from the waiting room. The daughter said to me:

> I don't call! I just walk in there and if they're doing something, as far as I'm concerned, they can let me know...and that's happened. But this [nurse] just right away yelled at my brother, "Don't come in here without picking up the phone and calling us!" And he told me about it and I walked in. [The nurse] looked at me and she knew I was upset and she said, "What's the matter? You don't look too happy." And I said, "My mom has been here almost a week and I'm not going to...call every time I walk in and out of this place. I mean, I'm not disrupting anybody. I'm coming straight to her room." So after that, she was fine (Fam 5, Int 1, l. 275).

The nurse who was caring for the patient in this situation evidently felt the need to reinforce one of the many unit policies to the patient's son. While the rationale behind this particular policy is to avoid having visitors arrive at a patient's room during an inopportune time (when the patient is on the bedpan, for example), the fact is that many of the nurses in this unit appeared to use the policy to control family visitation at all times.

Members of Family 5 not only experienced access difficulties, but, once they were at their critically ill loved one's bedside, their efforts in helping the nurses to provide some basic patient care were met with resistance. When I asked the patient's daughter about her involvement in caregiving activities, I was told:

> Daughter: In the ICU, the only thing I really did was ask what the equipment was for. As far as helping, no. The [nurses] don't really like you to [help].
>
> Int: You got that feeling?
>
> Daughter: Yeah, that's what I felt and sometimes they would say that (Fam 5, Int 2, l. 328).

While the unit culture and its impact on the social learning of nurses' family care skills will be more fully discussed in the next chapter, this interaction highlights some of the shared familial understandings held by many of the nurses who cared for Family 5. Additionally, because some of the nurses understood the family as "outsiders," the family was not usually invited or encouraged by the nurses to get involved in their loved one's care.

Instead, the daughter had to involve herself in her mother's care whenever she noticed something awry. For example, the daughter described an interaction she had with a nurse concerning a rash on the patient's legs:

> [My mother] had a heat rash between her legs and I said [to the nurse], "Why is it so red?" "She's not moving." "Well, what are you doing for it?" "Oh, putting powder on it." "Well, you should put something under it, it's skin rubbing against skin." "Oh, she'll be fine." "No, she's not fine. And when she gets to where she's feeling better, she'll notice it" (Fam 5, Int 1, l. 758).

In this brief exchange, the daughter suggested to the nurse another practical intervention to treat her mother's heat rash. Instead of embracing the idea or going along with the daughter's suggestion in an attempt to placate her, the nurse simply remarked that the patient "would be fine."

What was both admirable and courageous about the patient's daughter, however, was that she would not settle for anything less than what was, in her opinion, good patient care. The daughter said:

> I'm just like that, because my mama taught me that a closed mouth never gets fed. So, if you're not happy with something, you have to tell them (Fam 5, Int 1, l. 382).

Since the daughter believed that caring for the patient and family went "hand in hand," caring for the family was simply another way for nurses to care for the patient. When asked if it was part of a nurse's role to care for both the patient *and* family, she replied, "Who else would do it?" Unfortunately for this family, many of the nurses who cared for the patient did not share the daughter's belief, which will be more fully explored in the next chapter.

Six days following her last surgery, the mother in Family 5 was transferred to another nursing unit on the ward. I had my second interview with the patient's daughter at that time. Because the daughter was so vigilant and vocal about the care her mother received, she was aware of the impact a "good" nurse could have on both patient and family satisfaction. The daughter told me: "Yeah, I just feel more relaxed when I know they're attentive to [mom]. When you don't always have to get up and say something."

Being so vigilant, however, took a toll on the daughter, as illustrated by her statement:

> You know, you have to be strong. But sometimes you just can't be that strong (voice trembling). You can't. It's too much to bear. And it's sad to think that you have to be angry or upset for someone to listen to you. You shouldn't have to be like that....It's like a matter of life and death (Fam 5, Int 2, l. 384).

In many cases, the patient's daughter had to resort to dealing with nurses the same way they dealt with her, namely in terms of power. She spoke directly to the nurses with whom she had difficulty, and, if that did not improve the situation, she talked with the charge nurse, the nurse manager, and, in one case, the patient's surgeon. Yet all of these encounters were draining on the daughter and took her away from being able to simply be with her mother.

The patient's daughter wanted her mother transferred to a hospital in their hometown so that more of the family could visit and be involved in her mother's care. Fifteen days after her initial surgery, the mother in Family 5 was transferred to a skilled nursing facility in another city to continue her recovery and rehabilitation.

Family 6

The 66-year-old patient, who is the companion in Family 6, had a Whipple (radical pancreatoduodenectomy) operation for adenocarcinoma of the pancreas. He was discharged to home, but returned to the study site four days later complaining of abdominal pain. The patient was managed on the ward for 19 days while he underwent a battery of tests. On the twentieth day, he was taken to surgery to repair an anastomotic leak. It was a complex surgery requiring massive fluid replacement, so the patient was transferred directly from the operating room to one of the study ICUs with an admitting diagnosis of sepsis secondary to polymicrobial intra-abdominal infection.

The patient was treated aggressively in the ICU for 44 days. His therapies included: multiple continuous IV infusions (including fentanyl, dopamine, and insulin); multiple blood product transfusions (12 units FFP and 19 units PRBCs); and multiple procedures (including invasive lines placed on numerous occasions, multiple drains placed in interventional radiology, several CAT scans, and a thoracentesis). The teams consulting in his care included cardiology, gastrointestinal, infectious disease, interventional radiology, nutritional services, physical therapy, renal, social work, and the clinical nurse specialist.

The patient and his same sex companion had been together for 35 years[12], the last two of which had been quite stressful. The companion had a second heart attack and bypass surgery, followed by the death of his brother from AIDS three months later. A month after that, the companion got furloughed from his job. Two months later, a beloved family pet died. A year after all of this, the patient went in for the Whipple surgery, at which time malignant axillary nodes were found. While I am not sure if the patient and companion knew and understood the significance of malignant lymph nodes, the patient's companion

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[12] For ease of presentation, I will consistently use the terms "patient" for the patient and "companion" for the family participant.

told me ruefully at the bedside one day, "He (meaning the patient) was the one who wanted the surgery!"

A major issue for this family was the fact that the companion and patient were a same sex couple and every healthcare provider asked the companion what his relationship was to the patient. He told me:

> But it's kind of hard for me...I'm not his son. I'm not his uncle. I'm not his brother. Everybody asks, "What is your relationship?", and I simply tell them, "I'm the closest thing that he's got out here on the West Coast, because all his family lives in [another state]."....But you know (sighs), they always ask that question....A couple of times I just came out and said, "Hey, look, we're like mates or soul mates."...It's just that I want to keep his dignity, you know? (Fam 6a, Int 1, l. 80).

In addition to the anxiety and worry that *any* family member would have if a loved one was critically ill, the companion had to confront his self-perceived prejudice against his sexual orientation on a daily basis--and do so in a way that protected the patient's "dignity." This issue is complex, because the companion's self-disclosure of his sexual orientation would necessarily bring disclosure for the "silent" patient. While the companion was quick to point out that "no one has batted an eyelash," he had also not openly "come out" to the staff. The patient's companion, thus, entered the ICU as a self-perceived marginalized family member, despite the fact that he had a long-term intimate relationship with the patient.

The companion saw multiple ways in which to characterize his relationship with the patient. Besides couching his relationship to the patient as a "soul mate" or openly "coming out" to the staff, the companion had a third option, namely to claim durable power of attorney for healthcare. Resorting to such contractual terminology, however, would have been impoverished when referring to a lifelong relationship with another human being. Fortunately for this family, the companion was accepted by the staff as "family." This case is a reminder, however, of the potential for discrimination against non-blood/non-spousal relationships in hospitals across the United States and around the world.

The patient's companion spent eight to 10 hours a day with the patient while he was on the ward. Once the patient was transferred to the ICU, however, the companion came twice a day, staying only for an hour or two each time. The companion told me he had "sort of backed off." He spent less time in the ICU in part because he felt there was not as much for him to do. When the patient was on the ward, the companion felt more helpful. He told me:

> I was washing him, helping him go to the bathroom, cleaning him up...straightening out his bed, talking to him, running for ice water...I'd bring his bills in and we'd sit down and write them out and I'd pay them (Fam 6a, Int 1, l. 245).

Once the patient was transferred to the ICU, though, the companion said, "There really isn't a lot you can do up here, you know?" He told me that he was afraid that if he helped turn the patient, for example, he would "do something wrong." The companion's unease in the ICU was similar to the discomfort felt by the husband in Family 4.

Another reason the companion was less involved in the patient's care was that, as he said, "It's hard for me to see him laying there and [him] not being able to know I'm here." The companion told me in the first interview that he was fearing the worst. He said:

> As sick as he is, I don't think he's going to make it. I wish with all my heart that [he would]...he's just so sick, and he's gone through so much, and it's been like a month, and he's weak (getting teary-eyed) (Fam 6a, Int 1, l. 452).

When I asked him what the doctors and nurses had told him, I was given a dubious glance with raised eyebrows and this response:

> Companion: Now, you know what they're going to tell you--they're not going to tell you what they really think. They're going to paint it as rosy as they possibly can without coloring it too awfully bad.
>
> Int: Why is that, do you think?
>
> Companion: Because that's what they're supposed to do. You know, they're not going to say, "He's dying."...They're going to say, "He's doing well. He's coming along."...(sighs) I've been to town before, it's not my first trip to the city...although, it's really funny. In the back of my head, I think he's going to bounce back. But in the front of my head, I'm preparing myself for the worst....I feel guilty about doing that because I think, "You've got to be positive" (Fam 6a, Int 1, l. 461).

Perhaps another reason the companion was not more actively involved in the patient's care in the ICU was that he was protecting himself from additional grief in the event of patient death. This self-protection did not come without a cost, however, as the companion then felt guilty for "backing off" and having negative thoughts.

In terms of information, he told me that he's "only heard the word 'critical' once." More open-ended information was passed on to him frequently by the nurses, however, this information was far from consistent. He told me:

> Each nurse has their own individual outlook on what the medical process should be as far as their part is concerned...You know, some are a little more, what you'd say, holistic. Some are a little more textbook...Each has their own definition of what is going on at that particular time....It doesn't bother me 'cause I think, "Good Lord! These people have been trained...they know what they're doing!" (Fam 6a, Int 2, l. 288).

Unlike the husband in Family 2 who sought consensus in the information provided to him by the nursing staff, and the daughter in Family 5 who was confused by conflicting answers, the patient's companion in Family 6 seemed perfectly able to cope with multiple perspectives and differing information. A major reason he might have been comfortable living with this ambiguity was that he trusted the nurses. By "backing off" in his involvement with the patient, however, the companion was, in some ways, obliged to trust the nurses.

During the second interview, I asked the companion if he had gotten better at asking questions. He replied:

> Oh yeah...you know, it just occurred to me. [The patient] is in this bed and he can't speak for himself. So I've got to be his mouthpiece. I've got to vocalize for him. And if I think something should be done, I've got to make it known, because he would do it for me...I just feel that I have to do what he cannot do right now (Fam 6a, Int 2, l. 985).

This is probably the optimal space for a family member to be in when their loved one is "silent" (as was the patient sample in my study). The companion continued to advocate for the patient for the duration of their ICU stay. After another 15 days on the ward, the patient was transferred to a skilled nursing facility to continue his recovery and rehabilitation.

Family 7

The 34-year-old patient, who is a son in Family 7, was emergently readmitted to one of the study ICUs after his mother found him unconscious in bed. Three days prior to this event, he had been admitted to the study hospital for overnight observation following multiple episodes of hematemesis. He was discharged home to his mother's care, where he lived with one of his sisters and his three school-age daughters. The patient was well known to many of the nurses and physicians at the study hospital, as he had been hospitalized in the ICU on two separate occasions in the past two years for diabetic ketoacidosis and gastrointestinal bleeding.

On readmission, the patient was septic and in a hyperosmolar coma with a Glasgow Coma Scale Score of 3. He was aggressively treated in the ICU for five days with continuous IV insulin and multiple procedures (including intubation, invasive line and feeding tube placement, a CAT scan, and placement of a ventriculostomy). The CAT scan of his head revealed a massive intracranial hemorrhage. It is presumed that the patient's sepsis increased his blood sugar and that his intracerebral bleed was related to a fall in the middle of the night.

Despite aggressive therapy, repeated neurological examinations failed to demonstrate clinical improvement. After 24 hours of treatment, a family conference was held and the patient's code status was changed to DNR. After three additional days of treatment, a second family conference was held, at which time the neurosurgeons told the family that the patient had "less than a 20% chance for a good recovery." The family agreed with the medical team to discontinue active treatment and to provide comfort measures only. In an unusual move, the patient was extubated, invasive lines were pulled, and the patient was transferred from the ICU to the ward for supportive care. He died, with his family around him, two days later.

While some institutions routinely transfer DNR patients from critical care areas to ward settings, the institution at which I collected data does not. When an ICU patient is dying, typically he/she remains in one of the study units, unless the terminal transfer is specifically requested by the patient's family. None of the nurse participants I spoke with knew why the patient had been transferred, however, several speculated that the patient might have been "bumped"[13] during a high census period. It is also possible that the transfer was requested by the family. I had a brief telephone conversation with the patient's mother following the patient's transfer, during which she said, "why have all those things hooked up to him if they weren't going to help?"

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[13] When a patient has been "bumped" it means that a triage decision has been made to transfer the least acutely ill patient out of the ICU in order to admit a more critically ill patient into the last ICU bed.

The patient came from a large family, and was one of three brothers and three sisters[14]. Because many of the patient's siblings had multiple children, the patient had up to 50 family members representing four generations in the waiting room at any one time while he was in the ICU. The family was so large, in fact, that they, as one nurse said, "took over the waiting room," causing other families to complain to the ICU nurse manager. These complaints forced the nurse manager to intervene on several occasions, urging the family to limit the number of family members who came to support one another during this family crisis.

Nurses also tried to limit the number of visitors at the patient's bedside. This particular ICU's visitation policy stipulates a maximum of two visitors around the bedside at any one time, however, the nursing care plan for Family 7 urged nurses to reinforce the "three people maximum rule." While attempts were obviously made to accommodate this family, it is unlikely that allowing three family members in at one time when their loved one was critically ill met the needs of this large, extended family.

In addition to dealing with the sheer number of family members, many nurses found it difficult to convey information to the family. One of the nurse participants described the family and her informing efforts:

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[14] While the patient's mother eagerly agreed to participate in this study, the patient died before I had the opportunity to interview her or observe the nurse-mother interactions around the patient's ICU bedside. Therefore, much of this family's story is drawn from fieldnotes, chart review, and portions of a group interview with nurse participants in which this family was discussed.

> They were a really hard family because they had no background. I spent a lot of time with the family explaining [things], and they just didn't get it (RN Int 2e, l. 607, #14).

Other nurses told me that they had never seen a family in such "profound denial." Because I never had the opportunity to interview the mother, it is not clear whether family members were in denial or simply uninformed.

For example, one of the nurse participants told me that, on one occasion, the healthcare team was trying to explain the gravity of the patient's intracerebral bleed to the family. In response, one of the family members asked, "Why can't he have a brain transplant?" In another situation, the nurse had turned the patient and when several family members walked into the patient's room, one said, "Oh! He turned himself!" While these statements may indicate a refusal on the part of family members to accept the patient's comatose condition, it is more likely that the family simply did not understand the extent and import of the patient's imminently fatal neurological injury.

The family's lack of understanding continued even after their loved one was transferred to the floor. On the day that the patient was discharged from the ICU, I was casually chatting with the ICU charge nurse when one of the sisters in Family 7 phoned the ICU concerned about her brother's insulin dose. The patient's sister told the charge nurse, "He's a diabetic. If he doesn't get his insulin, he'll go into a coma." Unaware of any of the issues surrounding this particular family, the charge nurse directed the sister to the patient's neurosurgeon.

While the patient's sister was concerned about her brother's insulin dose, the already comatose patient was slowly dying--and apparently without his sister's knowledge. Unlike Family 3's case, which was characterized by conflicting orders and mixed messages from the patient's two primary medical teams, and Family 5's case, which represented chronic low-level breakdown with the nursing staff, this case typifies an ill-prepared dying patient's family.

As will be more fully discussed in Chapter 6, nurses played a pivotal role in framing and reinforcing anticipated clinical trajectories and expected patient outcomes to critically ill patients' families. Because the patient was transferred to another nursing unit, however, the patient and family were separated from the healthcare providers with whom they were already acquainted. As a result, the ICU nurses who had consistently worked with the patient and family were unable to continue their reinforcement of family information. While the ward nurses presumably imparted similar information, they were at a disadvantage because they did not already have an established relationship with the family. The fact that the patient's sister phoned the ICU is some evidence that the family felt more comfortable discussing their concerns with nurses they knew. While some of the relationships that developed between the ICU nurses and Family 7 were far from ideal, they were, nonetheless, established nurse-family relationships.

Proponents of the terminal transfer cite increased family access, a more peaceful ward environment, and the economic savings for the institution as its primary merits. Further, by extubating the ventilated dying patient, prolonged suffering on the part of the patient and family is diminished as the patient's death is often hastened. Finally, proponents of this practice argue that the patient is afforded a greater amount of dignity in her/his last moments of life, and the patient's family is given the opportunity to see and be physically close to their loved one without the encumbrance of life-supporting devices (Birnbaum, 1986; Campbell & Frank, 1997; Gerber & Scott, 1996; Salon, 1996).

It is difficult to argue with many of the merits outlined above, however, a major pitfall to the terminal transfer has been highlighted by Family 7's experience. Although the family may not have been any more prepared for their loved one's death if they had remained in the ICU, at least they would have been surrounded by familiar faces during this major family event. Finally, while the patient's untimely death could not have been avoided, many of the family's concerns could have been addressed if Family 7 had received the sustained coaching and attentiveness they needed during this life passage.

Family 8

The 68-year-old patient, who is the mother in Family 8, was admitted to an ICU in a neighboring community hospital two weeks before this admission, after an abdominal CAT scan showed intraluminal air and an overall diagnosis consistent with a small bowel obstruction. She was transferred by ambulance to one of the study ICUs after her clinical status progressively deteriorated. Six months prior to this event, she had a laparoscopic cholecystectomy, from which she had fully recovered. She was a retired counselor, and, as a divorcee, had raised her two (now adult) children by herself.

The patient was aggressively treated in the ICU for 85 days. Her therapies included five surgeries (including a jejunocolectomy, sigmoid colostomy, and splenectomy); multiple continuous IV infusions (including dopamine, neosynephrine, fentanyl, versed, and TPN); multiple blood product transfusions (34 units of FFP, 3 six-packs of platelets, and 44 units of PRBCs); and multiple procedures (including several intubations, invasive lines placed on numerous occasions, CAT scans, a thoracentesis, chest tubes to drain effusions and to treat a tension pneumothorax, a lumbar puncture, multiple abdominal drains placed in interventional radiology, a metabolic study, and a bronchoscopy). Like the patient in Family 2, she received an experimental antibiotic from Europe on a "compassionate use" basis to treat her *Staph Aureus*. The teams consulting in her care included allergy/immunology, dermatology, gastrointestinal, hematology, infectious disease, interventional radiology, nutritional services, ophthalmology, otolaryngology, pharmacy, pulmonary, psychiatry, social work, and the clinical nurse specialist.

While the patient was admitted to the study ICU with advance directives, one of the ICU physicians encouraged the patient's son (who held, for his mother, durable power of attorney for healthcare) to waive these during his mother's first operation. Two days and two additional surgeries later, a family conference was held, at which time the surgeons gave the patient's chance of survival as less than 50%. After consultation with the family, the patient's code status was changed to DNR.

Five days later, the patient had stabilized but was becoming increasingly septic. The surgical team approached the family for permission to surgically re-explore the patient's abdomen, but the family refused. On two separate occasions, the patient was discharged to the ward, only to be readmitted to the ICU shortly thereafter. With each ICU readmission, the patient became a full code again, enabling clinicians to provide aggressive treatment. On the patient's 84th day in the ICU, a family conference was held, and the patient's code status was, once again, changed to DNR. She died in the ICU that day, with her son and daughter present, when her life support was withdrawn.

Several days before the final family conference, I had the opportunity to talk briefly with the patient's daughter[15]. She initiated the conversation by telling me that the nurses had "all been wonderful" and had exceeded her expectations. But after further conversation, the daughter told me, "I feel like my mom has been sucked up into this technological monster." She described the ICU as a dehumanized environment and referred to "loud noises," "objectifying glances," and certain healthcare providers treating her mother "like another piece of

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[15] While the patient's daughter agreed to participate in this study, the patient died before I had the opportunity to interview the daughter. Therefore, much of this family's story is drawn from fieldnotes, chart review, and portions of group interviews with nurse participants in which this family was discussed.

equipment." When I asked her if she felt comfortable saying anything to the nurses about her mother's care, she said that the family felt it would be "a slap in the face" since some of the nurses had "bent over backwards" for the family. The daughter also worried about verbalizing her unhappiness for fear of retribution toward her critically ill and helpless mother.

Remaining silent to protect her mother is an example of the daughter's familial accommodation. Familial accommodation occurs when a family member tailors her/his behaviors and interactions to match what is perceived to be required by the nurse in the situation. While this will be more fully described in the next chapter, some nurses were situated with a patient's family in such a way that they encouraged familial accommodation, rather than altering their own behaviors to match what was desired and/or required by the family in the situation.

Family 8 accommodated not only the nurses, but the patient's surgical team as well. The patient's family, according to several nurse participants, had misgivings about prolonging their mother's suffering. The daughter, in fact, told one of the nurses weeks before the final family conference, "I don't even recognize my mother anymore--that's not my mother." In one of the small group interviews in which this family was discussed, the same nurse continued, "I think, in some ways, they were ready to withdraw [support] then." Yet, the family's resolve to end their mother's agony was made more difficult by the surgical team's "overly optimistic" reports.

Two weeks before life-supporting therapies were finally withdrawn, a family conference was held at which the family gave permission for a final surgery. Another nurse participant, who had consistently worked with the patient and family, described how the surgeon framed the situation to the patient's family:

> The family felt that we were doing too much, so we had a family conference....And I thought, when we went in, that we were going to agree to stop being aggressive with her care. But the surgeon felt that we needed to offer [the patient] a trach and a J-tube (for nutritional feedings). And so that's what happened. And with that on board, [the medical team] could say that everything had been done (RN Int 2d, l. 473, #15).

After her first surgery at the study hospital, the patient was left with only 21 inches of bowel. By the time this family conference was held, the patient had complications involving several organ systems. Assuring that "everything had been done," while under the guise of treating the patient, may in fact have been treating the surgeon, who was evidently unable or unwilling to confront the patient's terminal condition.

It may seem surprising that the family consented to this final surgery, given their concerns about prolonging their mother's suffering. While I did not attend any of the family conferences, I can speculate that *what* the surgeon presented to the family as legitimate treatment options and *how* he presented the choices were influential in shaping the family's acquiescence to the surgical plan. In discussing this family, one of the nurse participants said, "If they're not directed, perhaps it's very hard for them to make that decision." In this case, the family was directed. They were directed with information provided by the surgeon and ultimately convinced to go against their own wishes and better judgment in a last attempt to save their mother's life. Without the medical background necessary to second guess the surgeon, it is unlikely that many families in that situation would have done otherwise.

Further direction came from another medical team two weeks after the patient's final (and questionably necessary) surgery. The ICU team intervened and initiated the last family conference with the surgical team and the patient's family. It was at this conference that a decision was made to withdraw the patient's life-supporting measures. One of the nurse participants who had consistently worked with the patient and family cared for them that day. She described the family's reaction to their mother's death:

> The son and daughter stayed with [the patient]. They were relieved that it finally happened and they could see that [their mother] was comfortable when she died. I'm sure they still had mixed feelings, though, that maybe we went on [with aggressive treatment] for too long (RN Int 2d, l. 505, #15).

One sociologist has suggested that, in this culture, we are in denial of death from birth on (Sudnow, 1967). Nowhere is that denial more evident than in the cure-oriented ICU. Yet, researchers have demonstrated that a majority of patients and their families would undergo intensive care again to achieve any prolongation of survival (Danis, Jarr, Southerland, Nocella & Patrick, 1987; Danis et al., 1996; Danis, Patrick, Southerland & Green, 1988). Practitioners' steadfast belief in the biomedical promise and their dedication to preserving life has enabled many critically ill patients to survive what appeared to be hopeless injuries. That commitment, however, can also blind practitioners to the grim reality that not all patients can survive a critical illness. The courageous and ethical question all involved parties must constantly ask is precisely what the husband in Family 2 asked: "When is enough enough?"

Conclusion

The profound differences between these families' stories illustrate the critical role that the patient's sickness, the family relationship, and the nurses have in shaping the ICU experience for both patients and families. Because all of these families (with the exception of Family 5) were in the same unit within a six-month period and had worked with many of the same caregivers, the differing nurse-family relationships that developed are highlighted. Factors which appear to be crucial to the development of a positive relationship between nurses and families include the synchrony and agreement (or at least a healthy tolerance) of two inextricably intertwined aspects of being: one another's stance and the activities and interventions made possible by one's stance. These aspects and their roles in shaping both positive and less positive relationships between nurses and families will be explored in the next chapter.

While the families and their situations differed greatly, there were many commonalities. All of the families' stories point to the everyday, lived experiences of fear and anxiety associated with their loved ones' critical illnesses. Six families expressed on numerous occasions that they simply wanted their loved one to get to the point where he/she was out of danger. The families could more easily tolerate the long, agonizing wait if they knew their loved one would ultimately survive. Additionally, all of the families' stories demonstrated that being a family member of a critically ill patient was *hard work*. While each family had to "work" on different issues, their stories all conveyed great effort. Families' "work" and emotional labor ranged from learning new medical terminology and how to act in a foreign environment to advocating for their "silent" loved one. Six families were also able to describe similar nursing activities directed toward the family, which will be more fully described in the next chapter. And finally, six of the families alluded to their fears concerning death. How healthcare providers and dying patients' families understood and coped with patient death will be presented in Chapter 6.

While much of the family research in critical care has focused on describing families' needs and testing discrete family-focused interventions, little emphasis has been placed on understanding the relationships that develop between healthcare providers and families. Articulating aspects of nurses' and families' stances and the range of possible activities accessible to both parties in a shared situation will shed new light on why, for example, Family 2 received superb family care, while Family 3 received only spotty family care at best. Additionally, why, when both Families 2 and 3 thought of the ICU as their "home," did Family 2 get invited in, yet Family 3 had to wait on the metaphorical porch? Recognizing that a dynamic relationship exists, and then understanding how that relationship can be nurtured or hindered, will highlight existing and more enlightened caring practices for families.

Chapter 5

Whose House Is It? Toward an Understanding of Critical Care Nurses' Relational Stances and Their Influence on Nurses' Family Interventions and Activities

"Working with families is the hardest part of the job"--Nurse Participant

As service professionals, ICU nurses interact with others constantly. They interact with critically ill patients and their families and a host of other healthcare team members. Given the nearly constant demands from all angles, why did some nurses feel that working with families was the hardest part of their job? Part of that answer may lie in what critically ill patients' families represent to nurses.

Families of critically ill patients symbolize the greater web of relations of which we are all a part. By serving as their loved one's voice and animating their personhood, families of "silent" or non-interacting critically ill patients may have reminded nurse participants of the horror of critical illness and its effect on patients who were persons with lives and relationships that mattered to others. Unable to interact with their loved ones, families often projected and absorbed patients' anxiety, uncertainty, and fear, and expressed these emotions for themselves and on behalf of their ill family members. These familial expressions of love and grief often transformed routine nurse-patient interactions into emotionally charged and highly personalized nurse-family interactions.

Another reason some nurses may have found it difficult to care for families has to do with the prevailing orientation of the typical adult ICU. While this will

Another reason some nurses may have found it difficult to care for families has to do with the prevailing orientation of the typical adult ICU. While this will be more fully described in the next chapter, every practice has a logic, or what Bourdieu (1990) has called its *modus operandi*. While physicians and nurses have different practices, portions of their practices overlap in the ICU. It is this overlapping portion of ICU practice that shares the same *modus operandi*, a distinctive feature of which is that every ICU patient is a potential "save." The logic of saving every ICU patient's life influences the organizational design and operational mechanics of the ICU and orients and situates practitioners with structuring dispositions, or what Bourdieu (1990) has called the *habitus*. The *habitus* can be understood as socially embedded, normative styles and habits of relating to others and objects in a practice (Benner et al., 1996b; Dreyfus, 1991a). The styles and habits of ICU practitioners are oriented toward saving critically ill patients' lives.

Caring for families, however, falls outside the logic and habits of typical adult ICU practice. Clinical competencies and standards of practice, for example, rarely address family care, while unit and hospital policies often address families in terms of what they can and cannot do. This is not to say that nurses who care for critically ill adult patients are not family-oriented; some are. But the nurses who routinely care for families in certain ways are often practicing against the prevailing logic and habits of their peers, as caring for families of ICU patients extends beyond the patient-centered scope of the typical adult ICU and falls outside the average way of caring for critically ill adult patients.

The habits, practices, concerns, and skills which a nurse brings to the situation are all aspects of her/his stance[16] (Benner & Wrubel, 1989). The degree to which a nurse is emotionally available to be with and care for a suffering family in a situation can be thought of as the nurse's relational stance[17]. Patients and families also have their own relational stances, which may or may not be in synchrony with the nurse's stance.

A nurse's relational stance with a given family, to some extent, sets up the kinds of interactions and interventions available to the nurse and family in the shared situation. Furthermore, the extent to which a nurse's relational stance enables the nurse to cope and connect with a patient's family partially determines the success of the nurse-family interaction and subsequent activities and interventions. As such, a nurse's relational stance enables a particular mode of attending to a patient's family (Carse, 1996).

Because family care activities and interventions are constituted by what is accessible to nurses and family members, nurses' relational stances can be

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[16] For a more in-depth discussion of the philosophical underpinnings, please refer to Chapter 3.

[17] This chapter is primarily concerned with a nurse's relational stance as it pertains to her/his care of families. While I will occasionally refer to a nurse's relational stance simply as her/his stance, it is important to realize that one's relational stance is only an aspect of one's more encompassing stance.

thought of as the unarticulated "why" behind the "how[18]" (the "how" being the ways in which nurses cared for critically ill patients' families). Nurse-family interactions and caring practices were captured in this data set through observation of nurses and families at critically ill "silent" patients' bedsides and in nurses' and families' narrative accounts[19]. Many instances of habits, skills, practices, and ways of relating allowed for characterization of nurse participants' relational stances. This is not to say, however, that a nurse's stance is immutable; the degree to which a nurse is open to seeing new possibilities in a given situation, as well as the novelty or similarity of the situation, determines how constant the nurse's stance will be (Benner et al., 1996b).

Because of the very nature of their work, critical care nurses interacted with many kinds of families around patients' bedsides. While certain familial actions and activities prompted and encouraged nurses to understand and interact with patients' families in particular ways, the same could be said for the nurses' actions and activities. Through trial and error learning in specific situations, however, nurses with family care skills learned to tailor their interactional style and family-focused interventions to match what was both desired and required by the patient and family in the shared situation. The purpose of this chapter is twofold: to outline the primary sources from which

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[18] I am grateful to Hubert Dreyfus for this concept.

[19] All nurse participants will be referred to as women in order to protect the one male nurse participant's anonymity.

nurse participants learned relational skills and to articulate the nurse participants' principal relational stances with families.

Learning Relational Skills

As relational skills are a kind of social skill, they are not learned in isolation, but rather by relating to and interacting with others. Nurse participants learned general relational and family care skills from a variety of sources, including familial learning, experiential learning, social learning, and personal learning.

Familial Learning

Basic relational skills specific to one's culture--such as distance and closeness--are learned early in life, as families provide fundamental socialization experiences. Families also teach basic personal relational skills, including verbal and nonverbal ways of relating. Starting as early as eight weeks, infants learn to read and respond to facial expressions (Stern, 1990). Before children even learn to speak, they are introduced to rules and temperaments unique to their families, which concern, among other things, emotional displays, interactional distance, and patterned responses (Reiss et al., 1993; Steinglass, Bennett, Wolin & Reiss, 1989; Stern, 1990). These deep regulatory family structures can be observed as family behaviors which shape daily routines, family rituals, and problem-solving episodes (Steinglass et al., 1989). As such, everyday family interactions influence an individual's style of attachment and engagement to family members and others, and shape one's beliefs, assumptions, and expectations about families and their role in sickness and health (Bowlby, 1982; Feeney & Noller, 1996; Reiss et al., 1993; Stern, 1985; Wright, Watson & Bell, 1996).

These "life lessons" and other taken-for-granted familial influences, which unfold for each human being early on, are carried throughout life and, for the most part, are simply accepted as part of who one is and how one relates to others. Given the pervasive influence of one's background, it is not surprising that these familial learnings are applied to practice when one becomes a nurse. When I asked one nurse participant, for example, how she learned to care for families, she replied, "I don't know. I think just from babysitting my brothers and sisters."

Experiential Learning

By virtue of the intimate domain in which they practice, nurses often must confront and challenge their familial learnings and interpersonal understandings in order to provide bodily and emotional care to strangers. The skill of involvement, identified by Benner, Tanner, and Chesla (1996), is central to a nurse's stance and has to do with the interpersonal engagement or relational connection between the nurse and the patient and family. Learning this skill requires the courage to reflect on one's practice and coping skills while recognizing the plight of critically ill patients and their families. The importance of learning this skill cannot be overemphasized, as nurses who are cut off emotionally from their work are not able to care optimally for critically ill patients' families or to move on to become clinical experts (Benner et al., 1996; Chesla & Stannard, 1997).

A nurse's personal way of relating to others gets reshaped through experiential learning in specific situations, resulting in a professional way of relating to patients, families, and other healthcare providers. Attachment, for example, has both quantitative and qualitative distinctions. To be over-identified with a patient or family is as problematic for a nurse as to be under-identified. One nurse participant described the difficulty she had when withdrawing life-supporting measures on a 17-year-old trauma patient for whom she had cared:

> It was so hard--I argued about everything. I didn't disagree with the decision at all. I thought it was a wonderful decision. But I shouldn't have been the person doing it, because I couldn't do it...Why do I have to take his TPN (total parenteral nutrition) away?...Can't I at least give him tylenol?...Why do I have to stop his antibiotics?...To cross that line, you're not a nurse anymore in that situation. I mean, you are, but you're not acting in the best interest of the patient or family (RN Int 1f, l. 548, #65).

The nurse's identification with the patient in this situation was too complete. While she understood and agreed with the decision to discontinue efforts that were merely prolonging the patient's suffering, she was no longer the compassionate stranger with sufficient emotional distance to carry out this act of kindness (Wuthnow, 1991).

Another nurse participant described a situation in which she was under-involved with a patient's family. In this case, the nurse had difficulty with the patient's brother because he would "get [the patient] really riled up all the time."

The nurse suggested to the brother on several occasions that he "leave the room for a couple of hours" so that the patient could rest. The nurse continues with the story:

> I came on the next morning and he had asked that I not be one of the nurses taking care of [his sister]. He was very angry...and he said, "She's my sister and you're trying to keep her away from me!"...I felt really bad...but it did change my behavior because I thought [about how] we are used to being in control a lot. We come into that room and it's like our domain and we're in control. And I realize that with families, the more artful way of dealing with them is to release control as much as possible (RN Int 1b, l. 737, #16).

The nurse in this situation was sufficiently disengaged from the patient's brother on the previous day that she was unable to understand the brother's position or the patient-family relationship. While, at the time, her actions may have seemed appropriate, on reflection this nurse realized that one of the more "artful" ways of relating to families of critically ill patients is to relinquish "as much control as possible." This insight will perhaps enable this nurse in the future to facilitate an ICU family's ability to reclaim the house[20], and, in particular, the space around their loved one's bedside.

In one group interview, nurse participants struggled to find the words to describe what, in their opinion, was an appropriate amount of attachment to have with a critically ill patient's family. One nurse described a clinical incident in which she had connected with an 83-year-old dying patient's family:

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[20] For a discussion concerning the historical origins of the hospital as "house", please refer to Chapter 1.

> RN: [The patient] came in with a small bowel obstruction...and came to the ICU that morning with sepsis, probably from aspiration pneumonia. She was getting tons and tons of fluid [and was] on epinephrine, neosynephrine, and dopamine (vasoactive drips). When I came in, we made her a no code. We weren't going to withdraw, but we weren't going to pursue [aggressive therapies] any further....I thought she was going to die imminently...but she hung on for a couple of hours. The family was trying not to get in our way, and I just said, "There's not much I can do for her. I'll try to keep her comfortable...why don't you all come into the room?" There were children, grandchildren, great-grandchildren, a brother and sister, 14 people when she died....[The family, however] did have one issue. The [patient's] sister wanted to withdraw life support and the [patient's] daughters didn't want to...I think I was able to make it a non-issue.
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> Int: Do you remember how you did that?
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> RN: The [patient's] sister asked me, "Is she on life support?" And I said, "[The patient] is on a ventilator and she is on drips that are keeping her blood pressure up, but we aren't keeping her heart going per se....What's going to happen tonight is that her blood pressure will go down and ultimately her heart will stop despite our interventions here." I think when people are dying, things become written in stone and it can become a point of conflict between family members. I wanted to halt that right there [so as not to make] it something that the daughter hated her aunt for because one wanted to withdraw and the other didn't.
>
> Int: When you said things become etched in stone, how did you get that idea? Did something happen in your...?
>
> RN: In my own personal life. I had an uncle that died and my mom and my aunt had differences of opinion about his care at that time and they've never been able to get past that....So I was really conscious of not wanting [this family] to have those same kinds of conflicts....But it was a very satisfying experience for me and I think it was for them too (RN Int 1f, l. 6, #65).

Facilitating the family's access to the patient's bedside afforded this nurse the time and opportunity to interact with and learn from the patient's family. Her openness and engagement with the family enabled the nurse to learn who the different family members were and to understand their particular issues and concerns. By virtue of her own life experience, the nurse recognized a familiar family matter and re-framed the issue of life support for the patient's sister and daughters in an attempt to prevent further familial conflict and future disputes.

Later in the interview, this same nurse clarified for the group that she was not "emotionally attached to the patient at all," but had "bonded with the family." The nurse participants in this particular interview were trying to distinguish between "attaching" to and "bonding" with a patient and family. A portion of the interview follows:

> RN 1: But in situations where you become attached to the patient...
>
> RN 2: Or the patient's family...
>
> RN 1: That happens so rarely. I mean, I still want to be caring. I still want to bond with my patient's family...
>
> RN 2: But you can do that without crossing that personal line.
>
> RN 1: You don't want to cross that line very often. I mean, it's only happened to me three or four times maybe, and it's too draining. And I don't think you always...
>
> RN 2: Use your best judgment.
>
> RN 1: You don't always use your best judgment and you're not always the most professional.
>
> Int: What does professional mean?

> RN 1: You're not the best clinician. You become a family member almost and you don't have any objective judgment left (RN Int 1f, l. 504, #64, 65).

These nurses used the word "attachment" to describe an over-identification with a patient or family and reserved the word "bond" to refer to an appropriate degree of connectedness between a nurse and patient or family. In this interview, the nurses' struggle to describe what they considered to be a good quality or kind of relational involvement with patients and families parallels the challenges nurses face when learning interactional skills with patients and families in actual clinical situations.

As will be further described in Chapter 7, nurses are often taught in nursing school to maintain professional distance and to avoid emotional attachments to patients and families, as those attachments may lead to burnout. Many nurses experientially learn, however, that some of the most gratifying nurse-patient-family interactions are when they cared *about*, and not just cared *for*, the patient and/or family.

In this study, over 37% of the nurse participants reported having had some formal family education. Most nurses who had received formal family education wrote comments on their questionnaires explaining the education, such as "a family support group class" or "a CE (continuing education) class on families." Only one nurse remarked that she had formal classes in her undergraduate and graduate programs. Using the SPSS/PC statistical software, the Mann-Whitney rank sum test statistic was used to test whether formal family education influenced nurses' percentile ranking of perceived level of expertise with regard to family care. In the sample, nurses with formal family education rated themselves higher with regard to their ability to care for families than nurses who had not had family education, but the difference was not statistically significant (MW = 75.5, $p = 0.2428$).

The Spearman rank correlation coefficient was calculated to determine the relationship between number of years in critical care and percentile ranking of perceived level of expertise in critical care in general and with regard to caring for families. In the sample, nurses with more experience rated themselves higher both in terms of their level of expertise in critical care in general and with respect to their ability to care for families. Years of experience and family care were statistically significant ($r_s = -0.6021$, $p = 0.002$) and years of experience and overall critical care nursing practice just missed the significance criterion of 0.05 ($r_s = -0.3938$, $p = 0.063$)[21].

Learning the skill of involvement is akin to finding one's voice in writing. After many false starts and much reflection, practice, and guidance from others, one can usually find and make peace with one's own writing style and voice. The same is true for nurses who are learning how to relate to and engage with

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[21] The negative correlation is a function of the fact that nurses' ranking of their expertise on the demographic questionnaires was coded in SPSS such that the lowest number represented the highest level of expertise and the highest number represented the lowest level of expertise (see Appendix C).

others. Through trial and error learning in specific situations, nurses who had success in working with particular families often returned to these interpersonal regions when working with other families. The converse, however, was also true. Nurses who had difficulty working with a particular family often shied away from relational work with other families.

Social Learning

Learning to balance emotional closeness with professional distance when interacting with patients and families is difficult, and is influenced by a nurse's openness to learning from specific clinical incidents and the unit culture in which he/she practices (Benner et al., 1996). The tempo, mood, climate, and culture of any nursing unit make certain kinds of caring practices possible while discouraging others. These factors, as well as the patient population and unit staff, help to shape how a particular unit takes up the ICU *modus operandi* and *habitus*, which, in turn, inform and influence how nurses interact with patients and families.

Social learning was often taken-for-granted in the sample, because the unit culture (much like familial learning) formed a backdrop from which practitioners constantly drew. The influence which a given unit's culture had on nurses' social learning was evident, as many nurse participants told me that they learned family care skills from watching one another. This kind of one-on-one staff development occurred more often, however, in units where the culture and shared understanding supported sensitive family care.

One nurse participant described the socially embedded ethic of family care in one of the study ICUs:

> I learned a lot once I came [to work] here, because in most of the other critical care areas [in which I had worked], they were more like an ER (Emergency Room) environment--like the TV show--where everything is just crashing and burning the whole time and families get really brushed [off]. But when I came here...we had a lot of long-term patients and there was a strong focus on the family as being part of the patient's illness. So I think a lot of it for me was learning by the example I was provided with when I was oriented and the milieu of the unit (RN Int 1d, l. 438, #61).

The unit culture was obvious to this nurse because of the strong contrast to the unit in which she had previously worked. This experienced critical care nurse still had much to learn in terms of family care when she started working in this particular ICU.

A "family-friendly" unit culture can greatly influence nurses' social learning, enabling nurses to share and learn from one another in developing family care skills, both personally and collectively as unit staff. However, the opposite is also true. Chesla and Stannard (1997) studied more than 100 patient and family narratives from ICU nurse interviews and observational notes which focused on family care. They found that less than optimal ICU family care or breakdown between nurses and families occurred frequently in ICUs that had a "family-restraint" culture. Units with restrictive visitation policies, for example, fueled one of the central nursing approaches that constrained family care, namely nurses' efforts to distance families from their loved ones.

Social learning is clearly influential. Nurses learn socially embedded clinical reasoning and caring practices from the social community of which they are part (Benner et al., 1996). Nurses who are already skilled in caring for families will find it more difficult--though probably surmountable--to connect and work with families when practicing in a family-restraint oriented ICU. Nurses who are not expert in working with families, however, and who practice in units with a family-restraint culture, may not have the vision of excellent family care, nor the cultural or institutional encouragement, to develop and/or refine their family care skills (Benner et al., 1996).

Personal Learning

Other nurse participants learned and honed their family care skills based on personal experiences as family members of hospitalized loved ones. One nurse recalled how she felt when her brother-in-law was critically ill in a distant hospital:

> I didn't even ask the questions I probably should have been asking. And so I always approach families that way....I would call and get updates and they [would] give me lots of information. And that's not something I had ever done as a nurse. It really changed my practice. I think I probably [now] respond to families' needs in light of information I had received and needs that I had that...maybe didn't get met at the time (RN Int 1f, l. 964, #65).

Experiencing the family's plight opened up a new understanding of what information about a patient's condition meant and shaped this nurse's practice in a tangible way. She now approaches families of critically ill patients with the understanding that they are not usually situated to be educated healthcare consumers while in the midst of a family crisis. This understanding requires the nurse to take more initiative in informing families, as they may not be able to formulate questions for healthcare providers in the first instance. Additionally, because of her experience of staying connected to her brother-in-law via detailed telephone reports in spite of their physical distance, she has now integrated "virtual visiting" into her care of families who cannot be at their loved ones' bedsides.

Another nurse participant shared a personal tragedy that subsequently shaped her practice of caring for families:

> I was overseas at the time....[my father] was rushed off to [a] hospital because he had an aortic aneurysm and he had [to have] emergency surgery. He didn't live. But my mother went up to [that hospital]. She was pretty shattered [and] it was a long drive...And one of the things that she said to me that I'll never forget--and this is fairly unusual in [the] British...system--she said, "Nobody even offered me a cup of tea." I remember thinking that I would always really focus on the family...And even when I came here and we did hearts, I would always make [it] a point when I was orienting [new] people, I would say, "Now one of the things that you need to do, is to go out [and] introduce yourself to the family, [and] you need to tell them that you're going to update them." And I think for me that was a kind of focal point...a prime concern, I think just because of my mother (RN Int 3d, p. 4, #11).

In this situation, the cup of tea symbolized kindness and attentiveness--elements that were missing when this nurse's mother had to confront the loss of her husband. This nurse participant learned from this personal experience, and now shares with others that attending to families' needs and concerns is an essential component in caring for critically ill patients.

Another nurse participant described what critical care nurses looked like to her when her grandmother was hospitalized in the ICU for a broken hip:

> RN: Nurses attending to machines, tubes, lines, and "things," and not to patients and families. I'd like to think that I don't do that, but we all do to some extent...I mean, we have to. The alarm goes off, you have to [respond].
>
> Int: Did it change your practice?
>
> RN: Yeah, I try to remember what it was like to be in that position, and I try to deal with lines, tubes, and wires...before families come in, if possible. I mean, it's not always possible, but I make more of a point now of introducing myself outside the patient's room, not while I'm busy doing something else. Little things like that, I think, make a better connection with the family (RN Int 1a, l. 208, #31).

The nurse in this situation described her perception of critical care nurses when she was on the other side of the critically ill patient's bed, looking on as a family member. Because she did not like what she saw, this nurse now tries to complete whatever tasks she can before a patient's family arrives. By setting aside distractions, this nurse strives to be "present" when meeting a family, thereby enabling her to better connect with them.

In this study, more than 79% of the nurse participants reported having had a member of their family of origin hospitalized, while 25% reported the same concerning a member of their family of choice. Over 45% of the nurses reported that either/both hospitalization experience(s) changed their practice in terms of caring for families.

These four kinds of learning--familial, experiential, social, and personal--shaped nurse participants' involvement skills and changed their interactional patterns with families. Through the trial and error learning with specific families, nurses learned and developed their own professional style of engagement. This professional way of relating is an interpersonal comfort zone of sorts, which establishes the relational boundaries within which a nurse typically works. Certain patients and families in particular situations, however, encouraged and invited nurses to work outside their usual relational boundaries. One nurse participant spoke of that when she told me, "There are, on occasion, people who really touch a spark in me. I kind of drop all my defenses and they become an important part of my life." As such, a nurse's way of relating, while central to her/his stance, is dynamic and can vary based upon the nurse, patient, family, and situation.

Nurse Participants' Stances with Families

Three principal relational stances characterize how nurse participants typically related to patients' families in the ICU: standing apart from the patient's family, standing at a distance from the patient's family, and standing alongside the patient and family. Each stance holds a different amount of emotional involvement and risk to the nurse and family and made certain interventions and activities accessible to both parties in the situation.

Patients and families also have their own relational stances, which may or may not be in synchrony with the nurse's stance. While I am unable to fully articulate families' stances due to the limited number of incidents describing families' habits, practices, and ways of relating, I am able to point to some of the family behaviors which prompted and encouraged nurses to understand and interact with families in particular ways.

Nurse participants did the best they could, just as human beings do generally. Nurses in this study provided the best patient and family care they could, given their skills, concerns, experiential and personal knowledge, the particular patients and families for whom they cared, and the situation itself. Thus, the nurses' stances should not be understood as traits, deficits, or typologies, but rather as the ways in which nurse participants understood and interacted with patients and families in given situations (Benner, 1984).

Standing Apart from the Patient's Family

"I don't really get close to families because I get tearful and I start crying"--Nurse Participant

Nurse participants who were unable or unwilling to face a family's suffering often worked around the family and typically coped by emotionally disengaging themselves from the grief-stricken family[22]. A nurse who routinely interacted with a family in this fashion can be characterized as having the relational stance of standing apart from the patient's family. Nurses with this

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[22] Because of the nature of my investigation, I focused on the clinical incidents in which nurses stood apart from patients' families, and not necessarily from the patients themselves. For those interested in a discussion concerning nurses who were emotionally disengaged from the patients for whom they were caring, please refer to Rubin, J. (1996). Impediments to the development of clinical knowledge and ethical judgment in critical care nursing. In P. Benner, C. A. Tanner, & C. A. Chesla, Expertise in Nursing Practice: Caring, Clinical Judgment, and Ethics (pp. 170-192). New York: Springer.

relational stance understood and interacted with families as "outsiders." Through minimal contact and limited involvement with a family, a nurse with this relational stance was able to protect her/himself from feelings of vulnerability, profound sadness, and risk associated with emotional exposure.

Overview

One nurse participant discussed a patient's family that had some "trust issues" with whom she had recently worked:

> I can remember this lady...she went on a trip overseas. I forget where she went, but she ended up eating some raw fish which shot her liver....I was so busy with her the first night--I wasn't trying to ignore the family--but...they would just show up at the [patient's] room. Because they had been coming in all day long, I was getting frustrated....and maybe they noticed [the frustration] on my face. Because when I came on the next day, [another nurse] told me that [the family] had talked to her [about me] and [the nurse] explained to them that I was a good nurse, but I didn't have to take the patient again [if I didn't want to]. Well, of course I was going to take the patient again, I wasn't going to let that happen. And it was easier, I guess, at that time for me to just let the [family] in, [because] the patient was more awake and responsive....I didn't have a problem with [the patient], it was just her family. I sometimes get impatient when I'm in [a patient's room] doing something and the curtain is pulled. And the next thing you know, the curtain is open and the family is coming in. And what's going through my mind is like, "The curtain is pulled. Didn't they see [that?]" And I think that's rude, because there's no privacy or respect for the patient--even the doctors do that...And then I end up getting an attitude, and it must show on my face, and then I have to talk to myself and calm down. But I'm glad other people are able to point that out to me when that happens, [because] then I can [usually] take a step back and realize that you only have one mother, one father, or this brother or sister, and if it was [my family], I'd probably do the same thing too...So I have to kind of step out of myself sometimes [and say], "Oh, what the hell?", and let the [family] do what they want to do and [I'll] just run around them and do what I have to do. [But] the second day worked out

> better....there wasn't that negative--it was me, I admit--I mean, I was like, "Don't come in here." I don't know, maybe I was in a bad mood or something (RN Int 2c, l. 551, #12).

This clinical incident illustrates the impact a nurse's relational stance can have on the everyday interactions with a patient's family. The patient's critical condition on the first day situated the nurse in a way that made her "frustrated" when the patient's family kept "coming in all day long." The family's visits were perceived by the nurse as interrupting her patient care. Because the nurse coped in this situation by emotionally disengaging from the patient's family, her emotional access to understanding the importance of the patient to the family and vice versa was blocked.

After informal counseling the next morning by another nurse, this nurse realized that a family only has "one mother, one father, or this brother or sister." The nurse took the patient assignment again, perhaps to prove to herself and others that she could, in fact, work with the patient's family. While the nurse found it "easier" on the second day to "just let the family in," her inability to *care* for the patient's family was still evident. Instead, the nurse *worked around* the family and let them "do what they had to do" while she cared for the patient. In this way, caring for the patient alone remained the nurse's sole objective.

When the patient's condition was critical, the nurse's attentions were focused on the patient. But even as the patient's condition stabilized, the nurse's attentions remained focused on the patient. While the nurse was able to "talk" to herself and change her outward behaviors, these changes were only superficial, as the nurse continued to emotionally disengage herself from the patient's family.

The nurse had difficulty working with this particular family and attributed that to her "bad mood"; however, she also described being "impatient" with families in general. While the nurse's mood could have influenced how she dealt with this *particular* family, it is unlikely that her mood was so constant that it affected how she worked with all families. How the nurse understood and interacted with families *in general* is related to her stance, which in this case can be characterized as standing apart.

In another example, the daughter in Family 5 described an incident involving her mother's nurse who, by virtue of her stance, could not understand the daughter's concerns[23]:

> Like the nurse today...she was so rude...At first I thought she was OK and I asked her about physical therapy for my mother. And she said, "You don't need to worry about that because it's taken care of. [The request] is on her chart." I said, "It was on her chart [since] Monday and nobody has been here to talk about it. What is going on?" "Don't worry about it. It's no concern of yours." And I said, "Well, it is a concern of mine....she's my mother!" (Fam 5, Int 1, l. 209).

Because the nurse in this situation believed that healthcare providers were solely responsible for patient care, she could not appreciate or understand why a visitor would be concerned about medical and nursing matters. In this way, the patient's daughter was understood by the nurse as an outsider or as someone outside the patient's new fictive family consisting of highly trained healthcare

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[23] Please refer to Chapter 4 for a detailed description of this family.

providers (Gubrium & Buckholdt, 1982). These two cases, taken together, highlight many salient aspects characterizing this particular relational stance.

Nurses' Assumptions and Expectations Concerning Families

Nurse participants who stood apart from patients' families understood families as outsiders who interrupted patient care, as illustrated in the following excerpts from three different small group nurse interviews:

> Dealing with families is something that we all find very rewarding, but it does add a stressor to [caring] for a very sick patient because you have families that are inappropriately concerned about things like drool or dribbling or something, and [the patient] may be dropping his [blood] pressure (RN Int 1b, l. 267, #16).
>
> ❧❧❧
>
> I have days when I am very busy with the patient and it seems like an incredible impossibility to deal with the family, you know, they'll say, "Oh, there's blood coming out of his nose" or something and [the patient's] near death and it's not a priority [for us] (RN Int 2c, l. 629, #16).
>
> ❧❧❧
>
> The patient was having a GI bleed and there were so many procedures going on....that you had to care for one or the other--the patient or the family (RN Int 3c, p. 3, #1).

When a patient's condition was critical, nurse participants' primary efforts were directed toward the provision of multiple and instantaneous life-sustaining therapies in an attempt to save the patient's life. This has also been reported by others (Benner et al., in progress). The patient's condition situated nurses such that the patient's family was often understood as a competing good, as illustrated in the third excerpt. In a crisis, most study nurses stood apart from the family, regardless of how they typically understood and interacted with a patient's family during times of patient stability.

Nurses with this relational stance, however, continued to understand families as a competing good, even once the patient had stabilized. Nurses with this stance typically understood the ICU as "their" house. Critically ill patients came to their house to receive nursing care and medical attention. Because patients themselves often represented nursing tasks to be accomplished, visitors from the outside were viewed by nurses as obstacles interfering with their work. The resulting oppositional thinking only made it more difficult for nurses who typically stood apart to tolerate families' "inappropriate" concerns and intrusions of patient (and nurse) privacy.

Being understood and related to by nurses as outsiders, however, was extremely difficult for family participants. Two study families attributed a given nurse's lack of sensitivity toward their plight as family members as an attitudinal problem on the part of the nurse:

> Different nurses have different personalities. I wouldn't want their job, I'll give them that. But [nurses] have to realize that if they're having a bad day, it's definitely not OK to come in with [an] attitude, because people's lives are on the line and [nurses] have to deal with how families are....You have to be able to leave whatever problems you've had outside the hospital when you come to work (Fam 5, Int 1, l. 289; Int 2, l. 395).

* * *

> There's some nurses that don't [joke around]. They don't talk or do anything. They're just here to do their job, like [this one nurse] who's worked the last two nights. She's got a real disappointed look on her face. I don't know, maybe something's going on at home, whatever. But to me, it's reflecting here on her work....and she needs to separate her personal life from work (Fam 2, Int 2, l. 287).

Family participants had no way to explain differences in nurses' emotional availability and responsiveness to families other than attributing them to a nurse's "personality" or personal "problems."

While mood states and attitudinal or psychological problems may, in fact, impede a nurse's ability to connect emotionally with a patient's family on a given day (Rubin, 1996), a nurse who routinely disengaged from families can be characterized as having the relational stance of standing apart. The habits, practices, concerns, and skills which a nurse brings to the situation are all aspects of her/his stance, and, in this way, a nurse's stance is more constant than her/his particular mood in a particular situation. While a nurse's stance is not static, all nurses have habits of relating to and interacting with others in certain situations.

Nurses who typically stood apart from patients' families were described by the husband in Family 2 as being "systematic," which was his way of describing a nurse whose actions conveyed the message, "I'm doing my job, don't bother me" (his words)[24]. In the same interview, the husband elaborated on what this "systematic" style amounted to:

> This is a business...and this is what we do in this business. We don't have time for anything [else]...Process papers, do this, do that. That's systematic (Fam 2, Int 1, l. 720).

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[24] Please refer to Chapter 4 for a detailed description of this family.

This bureaucratic style has also been described by others (Ramos, 1992; Speedling, 1981; Strauss, 1968). Nurses who protected themselves by disengaging from patients' families were not emotionally available to interact with families on the families' terms; rather, families were forced to accommodate the nurses.

Tailoring actions and activities to match what is required by the nurse while dealing with a family crisis can be an exhausting (if not an impossible) task, depending on the family's and individual family members' stances. The husband in Family 2, for instance, appeared to be liked by many nurses because he was easygoing and affable. Yet, his constant questioning annoyed some nurses, as illustrated in the following excerpt from one of the nurse participants:

> I liked the [husband in Family 2], but I didn't take anything [from him] if I didn't want to...you know, he questioned so many things. And you'd try to explain, but sometimes it was hard to explain [something] over and over (RN Int 2b, I. 970, #10).

While this nurse "liked" the husband in Family 2, she did not tolerate his questioning behavior if she "didn't want to." Because behaviors are subtly--and oftentimes not so subtly--negotiated in any interaction (Stern, 1985), one can speculate that the nurse's actions and body language indicated to the patient's husband when he was exceeding her limits. Since the nurse related to the husband on her terms, the husband needed relational skills and attunement in order to read the nurse and tailor his behaviors appropriately.

Not all families, however, had either the emotional energy or the relational skills to successfully accommodate a particular nurse. When this mismatch occurred, a less than optimal nurse-family interaction usually resulted. For example, the same nurse participant described a vigilant family member who behaved in such a way that the nurse eventually asked him to leave the patient's room. The nurse continues with the story:

> [The family member] was watching everything. And I heard that he made the night nurse wash her stethoscope. He wanted her to wash her stethoscope before she touched his mother with it...You know, some things are really hard to deal with. No other family member would ever think to tell you to wash your stethoscope. I mean, I've had families remind me to wash my hands if they're watching for that, that's OK. But to tell you to change your gloves or...not to touch this or that, it's hard....I was trying to be nice, but he was just questioning [everything]....And I was trying to do all these really busy things and he kept interfering with what I was doing. He'd say, "I'm sorry, I'm sorry," but then he'd do it again, and again, and again. And I finally just asked him to go out during [nursing] report. I said there was a rule (RN Int 2b, l. 665, #10).

The son's vigilance in this situation challenged the nurse's expectations of what constituted "appropriate" family behavior. While it can be difficult for a nurse to be told by a family member how to do her/his job, it is likewise ambiguous territory for family members to know exactly where a particular nurse draws the line. This nurse, for example, tolerated family members who reminded her to wash her hands, but would not find it acceptable if family members reminded her to change her gloves. Because the nurse interacted with the patient's son on her terms, the son, in turn, was forced to tailor his behaviors and actions to match what was required by the nurse in this situation.

While the son astutely read the nurse and apologized each time he interrupted her, his vigilance continued to the point where he was asked by the nurse to leave the patient's room during nursing report. Because this particular unit's visitation policy required families to leave during nursing shift change, the nurse's reference to a "rule" was correct. However, this particular nurse (and about a quarter of the nursing staff) rarely enforced the policy. The nurse enforced it in this situation because the son exceeded her limits. Instead of attempting to understand the son's vigilance or reflect on how her behavior contributed to that vigilance, the nurse diffused responsibility away from herself and blamed the unit policy (Brown & Ritchie, 1989; Chambliss, 1996).

The son's behavior and the resulting action on the part of the nurse illustrates why most families attempted to accommodate and work with nurses on the nurses' terms. Family accommodation occurred primarily for three reasons: families wanted to receive, at the very least, visitation privileges; families were afraid of upsetting the nurse for fear of retribution against their critically ill loved ones; and families without previous or contrasting hospitalization experiences simply believed this was how nurses and families interacted.

In this way, familial accommodation exemplifies Foucault's notion of docile bodies. As Foucault (1975/1977, p. 136) notes, "A body is docile that may be subjected, used, transformed and improved." While Foucault's writings on this subject concerned penal institutions, aspects of docility (which implies being easily taught or trained), can apply to both patients and families in any inpatient hospital setting.

Accommodating the nurse for some families was accomplished by minor changes in demeanor or making an extra effort to please. The companion in Family 6, for example, told me, "I always try...when [the nurses] get off duty, to thank them for watching [the patient][25]." Other families, in spite of the nurse or the situation, were not docile. The daughter in Family 5, for instance, was very vocal and insistent that her mother receive good care. This behavior led to chronic low-level conflict with nurses.

Because of the daughter's stance, however, she refused to accommodate nurses who did not care for the family on the family's terms. The daughter told me:

> [The nurses] know that's how I am. I'm just outspoken and I don't care. If they don't like what I tell them, then that's too bad. What are they going to do? Throw me out of the hospital? I don't think so. You know, you just get another nurse (Fam 5, Int 1, l. 469).

The daughter in Family 5 also shared her opinions with other families in the ICU waiting room, which encouraged one family member of another ICU patient to reflect on how she had been accommodating the nurses. The daughter in Family 5 continues with the story:

> I was talking to the other families [and one person said], "Oh, we heard you talk to that nurse. How can you be like that?" I told her, "That's your family member lying there! You have every right to be

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[25] Please refer to Chapter 4 for a detailed description of this family.

> like that!...Don't forget: That nurse is just someone who is watching over [your loved one], but you have every right to ask that something be done! You have the right to ask a question. You have all the right in the world because that's your family in there"...And this one lady who's there now, the next day, she goes, "You know what? One of the nurses upset me and you know what? I just followed right behind her. She ignored me and I followed right behind her. I did just what you told me to do. It felt so much better! (Fam 5, Int 1, l. 712).

This story points to the fact that families come to the ICU with their own relational stances, which may or may not be in synchrony with the nurse's stance.

<u>Allowing Family Visitation</u>

Nurses who typically stood apart from patients' families were able to limit the amount of time they spent interacting with families by strictly enforcing ICU visitation policies. For example, the daughter in Family 5 described an incident in which the nurse disallowed family visitation because of nursing shift change. The daughter continues with the story:

> Daughter: My brother and sister-in-law had driven [in from another city]...at 7:45, which is right about the time the [nursing] shift changed. [My brother] went into [my mom's room] and said, "Hi mom!" When he left a couple of days ago, she couldn't even open her eyes. So he was excited to see that she was alert and that she could grab his hand, and it made him happy. And [the nurse] said right away, "Oh, I can't have all three of you in this room...we've got shift change. You'll have to come back at 8:30." My brother said, "I just drove two hours to see my mother--this is crazy!" And [the nurse] said, "Look, I'm only here to care for your mother"...So he just went flying, he hit the ceiling.
>
> Int: So what did he do?
>
> Daughter: He just stormed out of the room saying, "She wouldn't even be here if the damn surgery had been right the first time!"...And I told [the nurse], "He's just upset because he wants to

> see his mom." And she goes, "Well, I know, but that's not right for him to get upset because I'm just trying to care for your mother." And I said, "I know, but you have to understand, he hasn't seen her in a couple of days. And it's a big improvement and he wants to be with her for a few minutes." So she said, "OK, can you just give me 15 minutes?", and I said, "That's fine, but not 45 [minutes]. You can do whatever you have to do after he leaves" (Fam 5, Int 1, l. 238).

By virtue of her stance, the nurse in this situation understood the family's presence as an interference which competed with her ability to care for the patient. The nurse's comment, "I'm only here to care for your mother" underscores the either/or dilemma which families posed to nurses with this stance. This oppositional thinking prevented the nurse from understanding that facilitating family visitation was simply another way of caring for the patient.

Many researchers have found that critically ill patients fondly remembered their family's presence (Geary, Formella & Tringali, 1994; Holland, Cason & Prater, 1997; Jones, Hoggart, Withey, Donaghue & Ellis, 1979; Turner, Briggs, Springhorn & Potgieter, 1990). The patient, who was more awake than she had previously been, presumably would have liked to have seen her son. By disallowing the son visitation privileges, the nurse was actually not providing the best patient care.

The nurse's emotional access to understanding the patient-family relationship and the family's particular concerns was limited. Her policy-driven behaviors prevailed over her people-oriented behaviors, which prompted the patient's daughter to intervene and negotiate with the nurse to bend the rules.

By taking up the issue and framing it in terms of the patient's improvement, the daughter convinced the nurse to let the brother visit his mother thirty minutes before evening visiting hours had officially commenced.

Care of the family in any healthcare setting is influenced not only by the healthcare providers, but also by the unit and institutional philosophies (Chesla & Stannard, 1997). The particular ICU in which the patient in Family 5 was hospitalized happened to be the least family-friendly unit of the three adult ICUs in my study. When their mother was initially admitted, the family was oriented to the waiting room by one of the nurses. The daughter described the orientation they received:

> We were in the waiting room, and [a nurse] said, "There's a phone right here. You can call [and] we'll let you know when your mother's ready to be seen (Fam 5, Int 1, l. 307).

Orienting the family to the waiting room and not to the ICU or to the patient's room implies that the family will spend more time "waiting" to see their loved one than actually at the patient's bedside. Also implicit in the orienting information was that the family could visit their critically ill mother when it suited the nurses. By making visitation burdensome by forcing families to phone in to ask for permission, nurses further limited and controlled family visitation and ensured that, when families did visit, they visited on the nurses' terms.

"Reluctantly" Giving Family Information

Once a family was at the patient's bedside, often members had many unanswered questions. Nurses who typically stood apart from patients' families limited their emotional involvement with a given family by focusing on the technical aspects of patient care, thereby minimizing their interactions with the family (Chesla & Stannard, 1997). For example, I observed one of the nurse participants work with the heavily sedated and "silent" husband in Family 3 while the wife was at the patient's bedside[26]. Below is a portion of the transcribed observation:

> [Observational Note: RN had applied some of the patient's blood to a portable blood glucose monitor, and was watching the O.J. Simpson trial on TV while waiting for the glucose result. The patient's wife was sitting in a chair along the wall also watching TV.]
>
> RN: [referring to the O.J. Simpson trial] Now as many people that were in that Bronco, why would they determine one month later that there's blood there? OK, glucose 205. Excuse me for a second. Thank you.
>
> [Observational Note: RN titrating the patient's insulin drip.]
>
> Wife: What's it supposed to be?
>
> RN: Mmm?
>
> Wife: Glucose...
>
> RN: Well, basically 70 to 110, but that's for people who don't have problems with their sugar....You know, so you can't say. It depends on what his blood sugar usually runs. Some people can tell if their blood sugar is 3 or 400. They start feeling dizzy, or have spots before their eyes, or [they get] nauseated, or something like that. Then they know their blood sugar is a little high. And they'll test it, and sure enough, if it is, they'll medicate themselves or whatever they normally do....So, basically 70 to 110 is normal, but I don't know if there are many of us out there. So, you never know.

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[26] Please refer to Chapter 4 for a detailed description of this family.

> Wife: I'm just [curious].
>
> RN: No, I know, but I'm just saying, you know, I guess you can call that an average....But I'll never forget. There was this one nurse who was a diabetic. And she would always say, "What's normal?" And it would really make her mad because there's no normal for her.
>
> Wife: For her, yeah.
>
> RN: So if you're a diabetic...there's no normal. So, it all depends (Fam 3, Obs 1, l. 101, #12).

This entire observation was remarkable because the nurse rarely spoke to either the patient or his wife. By focusing on the technical aspects of patient care, the nurse did not solicit questions from the wife until nearly twenty minutes of silence was broken when the nurse commented on the televised trial proceedings. When the nurse announced the patient's glucose result, she invited the patient's wife to ask what it was "supposed to be." While the nurse provided the wife with the normal range for glucose, she also included other extraneous information and summed it up by saying, "it all depends." In so doing, the nurse countered her previous claim and skirted the responsibility of providing the wife with any information.

When I interviewed the patient's wife two days after the observation, she referred to this nurse and said:

> Wife: Maybe it was just her personality....I mean, I've never asked a nurse how long they've been nursing except for this [nurse]...I questioned how long she had been there.
>
> Int: Why?

> Wife: She just didn't seem as organized and didn't run as smoothly as the other nurses did. I mean, I've been very comfortable with all of the other nurses...And with [this nurse], I had the tendency to stay in my [husband's] room [more].
>
> Int: Oh, is that right?
>
> Wife: I don't know why she affected me. I just wasn't as confident in her.
>
> Int: Well, that makes a difference. So you weren't as comfortable leaving the room because...?
>
> Wife: I just wasn't comfortable with her, even though she said she had been [nursing] since 1980 or something....I mean, all the other nurses have been so nice and...if they're doing something and I question it, they just explain it. And [this nurse] could tell me something, and I still knew no more than I did to start with....I felt like I was bothering her [when I] questioned her (Fam 3, Int 2, l. 154).

Because this nurse "didn't seem as organized" to the patient's wife as some of the other nurses, she did not instill confidence and trust, which had the effect of prompting the wife "to stay in [her husband's] room more." In this way, the nurse's perceived lack of competence prompted increased vigilance on the part of the wife. The wife's vigilance is congruent with another study which examined maternal perceptions and behaviors in a pediatric ICU (Tomlinson, Kirschbaum, Tomczyk & Peterson, 1993). In that study, the researchers found that mothers spent more time in the hospital when the acuity of the unit was greater, staffing levels were short, and the primary nurse was less experienced.

While providing family information was an accessible intervention for nurses who typically stood apart, it also increased the likelihood for emotional exposure. For this reason, nurses who typically stood apart often "reluctantly" gave the family information (as the daughter in Family 5 observed), unless it was specifically requested. In another example, the patient's sister in Family 1 mentioned during a group interview with the family that she "liked" a particular nurse[27]. When I asked her why, she replied:

> Sister: Well, [this nurse] explains...what she's doing for [the patient]....
>
> Sister-in-law (with nursing background): She does. [This particular nurse] came in with [specimen] tubes and said, "I'm going to be drawing some blood"....And she told [the patient's sister], "It's OK if you continue to hold her hand. That's not going to interfere." And [this nurse] talks to [the sister] and talks to the patient, which is--excuse me--the way I learned (chuckles)! But, the other [nurses]...seldom do that unless we ask....they usually just come in and say, "Please move aside"....But being a nurse, I realize two things. I see from the nursing point of view, but I also see it from being a patient, or a member whose family is in [the ICU]. You have to address the family [and] the patient. And I find that if you address both of them, you get more cooperation than if you don't.
>
> Daughter: And less hysteria.
>
> Sister-In-law: Yeah, knowledge relieves the ignorance of, "Should I be afraid?"
>
> Husband: Or how afraid should I be? (Fam 1, Int 1, l. 607).

In this case, the family did not expect much in terms of information from the patient's nurse; they simply wanted nurses to "explain" what they were doing both to and for the patient. But "other nurses" (besides the nurse the family liked) "seldom" provided the family with even that amount of information, unless

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[27] Please refer to Chapter 4 for a detailed description of this family.

prompted. Instead, nurses simply asked the family to "move aside." In so doing, the nurses not only conveyed task-oriented behavior, but also demonstrated a lack of physical responsiveness to the family.

I found in my pilot work for this project that some nurses were physically more responsive to patients' families than others. Some nurses contorted their bodies to enable a family to stay at the patient's bedside, while others simply asked family members to "move away" from the preferred spot at the patient's bedside where ICU nurses typically stood. The nurse who encouraged the patient's sister to "continue to hold" the patient's hand while she drew blood appeared to have been more physically responsive to the family than other nurses. While physical responsiveness on the part of the nurse is not necessarily related to the provision of information, it is a bodily cue to the patient's family that their presence at the bedside is both respected and encouraged.

Discouraging Family Involvement

Nurses who typically stood apart from patients' families discouraged family involvement, as familial involvement would necessarily mean that families would spend more time at their loved ones' bedsides. By minimizing their contact and involvement with a family, nurses with this stance were able to avoid painful emotional exposure. This protected stance, however, was also somewhat impoverished, as emotionally disengaged nurses did not see the caring possibilities that familial involvement offered. By way of example, the daughter in Family 5 described an incident in which the nurse asked the family to leave the patient's room while she turned the patient:

> Daughter: I understand that it's the nurse's job to turn a patient...but I have a sister-in-law who's a nurse. She wanted to be in [the patient's room] when they did something to my mom and the nurse said, "You have to go outside. We don't allow people to watch what we're doing"....My sister-in-law said, "I'm a nurse. I want to be here." "Well, you can't. We don't appreciate people watching over us."
>
> Int: So what did your sister-in-law do?
>
> Daughter: She stayed. She said she wasn't going to be treated like that (Fam 5, Int 1, l. 641).

The nurse in this situation not only understood the family as outsiders, but expressly relegated them to that role when she told them they had to "go outside" while she turned the patient. Understanding the family in this fashion set the nurse up to feel threatened by the family, as outsiders "watching over" her could readily judge or misinterpret her patient care. Further, the nurse's emotional disengagement from the patient's family did not allow her to identify closely with the sister-in-law as a fellow nurse. The sister-in-law insisted on staying in the patient's room, in spite of the nurse's protestations, because she "wasn't going to be treated like that."

In the same interview with the daughter in Family 5, she described how she involved herself in her mother's care, in spite of the nurses:

> They are specialists in their field and I'll give them credit. But that's my mother, and I know how she is too. Maybe I don't know how she is in this situation, because we've never dealt with this [kind] of situation [before]. But I know she likes to sit a certain way and I

> know she wants another pillow--more so than they would know--because she's my mother. And sometimes the nurses would get upset...and say, "No! It has to be this way!" And I'm adamant, "No! It's going to be this way." [The nurses] don't have much choice but to give in, unless, like I said, they want to call someone to try to get me moved out of the hospital...But it hasn't [gone] that [far]....I mean, [my mother] had no lotion on her face. Her skin was just peeling. It was dry and flaky, so I put lotion on her [face] and feet. You know, things that [the nurses] weren't doing (Fam 5, Int 1, l. 698).

Understanding the patient's daughter as an outsider legitimized nurses' dismissal of her concerns and her familial knowledge. Nurses' dismissal of family concerns has also been reported by others (Chesla & Stannard, 1997). Because the nurses did not solicit the daughter's input, she, was forced to "adamantly" impart to the nurses her personal knowledge concerning her mother's likes and dislikes. These interactions, however, only served to cultivate further polarity between the nurses and the daughter. For this reason, the daughter's attempts to encourage tailored nursing care of her mother were not appreciated by the nursing staff as acts of love, but rather seen as obstacles to the nurses' provision of patient care on their terms.

The daughter involved herself in her mother's care by "doing things the nurses weren't doing." One can speculate, however, that the daughter's care was invisible to the nurses, as they evidently did not worry about the patient's "flaky" skin to begin with. So while the daughter involved herself in her mother's care, it was either met with resistance or ignored altogether (Strauss, Fagerhaugh, Suczek & Wiener, 1982).

Working with Patients

Because the nurses who typically stood apart from patients' families did so as a way of coping with the intensely emotional demands of the ICU, their emotional access to understanding the import of the relational process with a given family was hampered. As such, many nurses with this stance did not consistently work or follow up with a patient and family for whom they had been caring. The lack of nursing consistency was apparent to the daughter in Family 5:

> The only thing I don't like about [the ICU] is that they change nurses. There's no continuity to it. I mean, I understand that nurses work three days on and four days off, which is fine. But then keep [the same nurse] for those three days and get someone else in for the next three days. [My mother] has had a different nurse every day, and it's ridiculous. I've got to deal with their personalities, and they've got to learn ours and know how we feel (Fam 5, Int 1, l. 197).

While the nurses who cared for Family 5 might have changed assignments for any number of reasons, one reason might be that the patient's daughter was so vocal. In any event, the discontinuity of nursing care was difficult for the family and hindered patient and family care, as nurses did not have the repeated exposure necessary in order to "know" the patient or family (Jencks, 1992; Jenny & Logan, 1992; May, 1991; Tanner, Benner, Chesla & Gordon, 1993).

In another example, one of the nurse participants described a patient who had come into the hospital for an elective cardioversion. In a short period of time, the nurse bonded with the "wonderful" patient and his wife:

> They were an older [couple]. I mean, some people you just click with and those are the people you want to open up to. When [the patient] went home, I said, "If you need anything, here's my name and address. Give me a call and I'll be happy to come over." I knew he was going to be sick when he went home...They never did call or take me up on it, and I never did call them. Sometimes the follow-up is the [most] important part. But I didn't follow up on it. And I remember thinking [when I gave him my phone number], "Oh! I wonder if I did the right thing. Should I have done that?" You know, you think about those nursing school things where you're [not supposed to] cross that barrier (RN Int 2a, l. 1138, #64).

The nurse in this situation had "clicked" with the patient and his wife, such that she was encouraged to work with them in a way that extended beyond her usual relational boundaries. The nurse, however, still wondered whether she had done "the right thing" by giving the patient her phone number. By reflecting back on "those nursing school things," the nurse realized that her emotional attachment to the patient had, in fact, forced her to "cross that barrier." Perhaps that is why the nurse did not follow up with the patient and his wife, even though she acknowledged that "the follow up was the most important part."

While this study agrees with other research demonstrating that nurses and other healthcare providers have had little formal training in working with families (Brown & Ritchie, 1989; Brown & Ritchie, 1990; Chesla, 1996; Chesla & Stannard, 1997; Drotar, 1976; Porter, 1979), few researchers have examined what is actually being taught to nurses (Hanson & Heims, 1992) and the subsequent impact that educational content has on nurse-patient-family interactions. The nurse above, for example, queried whether she had done something wrong when she "crossed that barrier," and, accordingly, cut short her emotional involvement with the patient and family.

Because the nurses who typically stood apart were emotionally disengaged from a patient's family, it should not be surprising that providing a family with emotional support was often an inaccessible nursing intervention. For that reason, families who were primarily cared for by nurses with this particular relational stance often had to rely on the support they received from other helping professionals or find emotional support either from within their own family or from other families of critically ill patients. The daughter in Family 5, for example, described the support she received from other families in the ICU waiting room:

> They're going through the same thing you are. You kind of cheer each other on and, you know, you're here for them and they're here for you (Fam 5, Int 2, l. 496).

Not all of the family participants, however, found the support they received from other families helpful. The husband in Family 2, for instance, "built emotional walls to protect" himself from getting too close to other suffering families. The informal network of support provided by other families was helpful in some situations and not helpful in others. This finding agrees with other studies which have reported families' perceptions of the costs and benefits of the social support they received from other families of hospitalized patients (Darbyshire, 1994; Lynam, 1987; Tomlinson & Mitchell, 1992).

In summary, nurses who typically coped with the inherent grief and suffering in the ICU by emotionally disengaging themselves from a patient's family can be characterized as having the relational stance of standing apart from the family. While many nurses temporarily disengaged from the patient and the family during times of crisis, they did so in an attempt to focus on saving the patient's life. Once the crisis had passed, nurses returned to how they typically related to the family during times of patient stability. Nurses who routinely stood apart from families, however, remained emotionally disengaged, even when their patients' conditions were stable. Their emotional disengagement prevented the nurses with this stance from being able to interact with families on the families' terms; rather, families were forced to accommodate the nurses. Nurses with this relational stance were able to justify their minimal contact and limited family involvement by understanding and interacting with families as outsiders.

Standing at a Distance from the Patient's Family

> *"It was different from that family that you bond with and there's this like love thing. It was a different kind of relationship. It wasn't like I was one of them"--Nurse Participant*

Nurse participants who understood the importance of caring for both the patient and family, but who were typically emotionally unavailable to fully engage and involve themselves with a family, can be characterized as having the relational stance of standing at a distance from the patient's family. Many nurse participants coped with the emotional demands of the ICU by emotionally distancing themselves and understanding and interacting with certain families as staff members or care partners. By relating to a family on a professional and social--yet emotionally distant--level, nurses with this stance were able to partially protect themselves from feelings of vulnerability and grief. Through limited emotional exposure and involvement with a patient's family, nurses with this stance were able to provide basic family care.

Overview

In a small group interview with other nurses, one nurse participant described two families for whom she had recently cared:

> RN 1: I had just gotten back from a big trip and there were two families that I took care of. We had gone to the same places and [one of the family members] saw me showing pictures and...said, "[The patient] and I have gone there. Can I look at your pictures?" So we looked at the pictures and [I] was just listening to his story about their lives....That made [my interaction with them] feel good, because I heard [about the patient as] a healthy person, and what they liked, and [that] we shared the same interests.
>
> Int: What about the second family?
>
> RN 1: [The patient's husband] was talking with his sisters about their trip to Italy. And I said, "I'm one of those people who enjoys looking at other people's pictures"...I'm interested in why [the patient] went there and the different things that she did...And I said, "You should bring some pictures in" because he was talking about their dogs or something. I like it when families do that.
>
> Int: Why is that important?
>
> RN 1: Just to see [patients], instead of lying in bed, seeing them in their garden or seeing them active...Because you don't...
>
> RN 2: You can't imagine them differently.

RN 3: Yeah. I see them as a patient...but it's nothing personal. And when you see pictures, you're like, "Wow!" [When] you see a picture there, for me, you actually see a person.

Int: Does it change the care you give, do you think?

RN 2: No.

RN 4: I think it actually improves it.

RN 3: I think it does mentally.

RN 2: Mentally but not physically.

RN 4: But it adds to it. And I think what [RN 1] was describing was [that] she was being personal. There was a real human being there.

RN 1: There's more personal involvement....But sometimes I don't like that.

RN 4: No, but I bet those are shorter conversations. There's some people who you hit it off with and...then there are some situations when you don't. That doesn't mean you're not very pleasant, but...you don't elicit personal things or ask somebody to bring in a picture.

RN 1: But if you go out to dinner and you meet new people, if you like them, you like them. You talk to them some more. If there's something that doesn't quite click, then...

RN 4: And I think some people don't allow themselves to.

Int: But why is that?

RN 1: Sometimes you feel like you can't get involved, you know, whatever you're dealing with personally that day or that week....What makes you get involved with anyone? Your own...behavior or social grace or whatever.

RN 4: Yeah, I think it's your personality somewhat--the way you react to people...I think some people just naturally get more involved (RN Int 3c, p. 24, #1, 12, 62, 68).

This rather long dialogue between several nurse participants illustrates the impact which a nurse's relational stance can have on her/his everyday interactions with a patient's family. How a nurse is situated with a patient's family determines, in part, how much "personal involvement" a nurse will "allow" her/himself to have while working with the family in the situation. RN 1 described two families for whom she had recently cared that shared some of her interests. These commonalities encouraged the nurse to find out more about these families and to give more of herself to the developing nurse-family relationships. Building and maintaining a relationship, however, necessitated "more personal involvement," which, RN 1 added, she does not always "like."

While RN 1 was drawn to these two families with whom she shared common interests, she was not comfortable straying too far beyond her established relational boundaries. By approaching a patient's family the same way she approaches "new people" at dinner, RN 1 highlights the social, yet emotionally cautious, way of interacting with a family which characterizes this particular relational stance.

Another nurse participant described a hyper-vigilant family for whom she had recently cared:

> RN: We had this patient come from New York for the posterior part of her anterior-posterior spinal fusion. You know, [one of the doctors here] does that special procedure, and so that's why they came all the way out here. They rented an apartment and the three [adult] children and the husband were here, and I got thrown in the fire....I got conned into taking [the assignment]...[and] my patience was tried all night.

> Int: Why?
>
> RN: I hate to say this, but because the family is from New York, they're very strong, aggressive, curt people....[After] these operations, patients have a tremendous amount of pain, and they know this when they have this procedure done. They understand this. I mean, you touched the mom and...it was like, "Oh, my mom needs pain medicine! She has pain!"....There were three [of her family members] attacking me, saying, "Give her pain medication, but not morphine. She doesn't tolerate morphine." I said, "OK, we're going to give her some dilaudid. Everything's going to be alright." "It's not working! You just gave it and it's not working!" "It takes a few minutes to work"...I mean, this [patient assignment] was a one-to-one in terms of the family psychosocial stuff.
>
> Int: And was she a one-to-one?
>
> RN: Not for the patient's sake, but for the family. I mean, the entire night, one person was with the mom, coaxing her, "Mom, do you have pain?" "Yes, I have pain." But there were no signs and symptoms of pain. If you asked [the patient], "How are you doing?" "Fine." But if you asked her, "Do you have pain?" "Yes!"...You know, as much as I tried to tell [the family] that we're walking a fine line, her CO_2 is up because she's not breathing, and we're trying to extubate her, "Well, she needs pain meds. I want to talk to the attending right now!" You know, it's 3:00 in the morning. I said, "Well, let's get the Intensive Care doctor." So the [ICU] resident came out. He almost blew up too. He ended up leaving [and] I had to get [the orthopedic resident] to speak with them. But it was just a trying night with the family. I was mentally exhausted....The patient was fine, she was very nice....She ended up going out [of the ICU] the next day (RN Int 3e, p. 2, #14).

Because the nurse understood the importance of caring for both the patient and the family, she facilitated the family's access to the recovering patient. This intervention alone meets an important family need (Stillwell, 1984), and is the first step in letting families "reclaim the house." However, instead of trying to understand this anxious family's concerns and helplessness with the patient's pain issues, the nurse in this situation attributed the family members' "difficult" personalities to their New York origin.

Because this family knew which analgesics worked for the patient and were not afraid to call the attending physician in the middle of the night, they prompted and encouraged the nurse to understand and interact with them as care partners. By understanding the family in this fashion, however, the nurse correspondingly expected them to behave like fellow staff members. For example, the family "knew" that the patient was going to experience pain after this procedure, so why were they acting so irrationally? By emotionally distancing herself from the content of the "family psychosocial stuff," the nurse was unable to understand the family's plight, or their particular concerns as family members. The nurse's unmet familial expectations left her frustrated and "mentally exhausted." These two examples, taken together, highlight many aspects that characterize this particular relational stance.

Nurses' Assumptions and Expectations Concerning Families

As in the case above, some family members were perceived by emotionally distant nurse participants as both willing and suited to be taken up by nurses as care partners. To further illustrate this, three nurse excerpts from different small group interviews follow:

> They were a very normal family....which to me, would be people who interact rationally. Who seem to understand what you're telling them without having to repeat it over and over...I guess normal is the wrong description to use, but very well adjusted...They all knew everybody by name and they were very

> friendly and thankful. And they would never get in the way. They'd say, "Oh, we're going to go if you're going to do that. We'll be right back" (RN Int 2a, l. 606, #64).

* * *

> [The family's] so concerned about [the patient] and they're so full of love. They're [also] very intelligent. They're not afraid to talk to the doctors (RN Int 2b, l. 607, #10).

* * *

> [The family's] very supportive and very loving, and when they come [into the patient's room], they...ask appropriate questions. Like, "How is she doing?" "Has she required much sedation?" As opposed to the family who focuses on one thing like, "Her heart rate was 108 a second ago and now it's 110. What's wrong?" (RN Int 3b, l. 220, #13).

Because these families interacted with nurses in a "rational," "intelligent," and "appropriate" fashion, they displayed qualities of calmness, intelligence, and collegiality--all of which are important qualities in an ICU nurse. These families also displayed idealized family characteristics, which will be discussed with the next relational stance. A family member who behaved like an ICU nurse by exhibiting these qualities encouraged emotionally distant nurse participants to understand the family member as a care partner. A significant aspect of nurses' understanding families in this fashion was that families' vulnerabilities and experiences *as* family members were discounted or ignored.

In one group interview, for example, several nurses discussed "educated families," and one nurse used the husband in Family 2 as an example: "For instance, he knows as much as we do about everything, and he still learns a little more all the time." The same nurse continued, "But a lot of families learn those things...I enjoy having families like that." The nurse then contrasted the husband in Family 2 with the wife in Family 3:

> It's harder with those families (referring to the wife in Family 3), because you can't talk to them. Like I find I can talk to [the husband in Family 2]. Like just talk to him and [he'll] start relating, really relating to you, almost on your level (RN Int 1c, I. 531, #10).

Nurses who typically stood at a distance particularly enjoyed working with a family who appeared appreciative of the nurses' newly imparted knowledge, such as the husband in Family 2. Providing a family with clinical information was one way in which an emotionally distant nurse could provide basic family care while still protecting her/himself from difficult emotional family involvement.

Of course, family members who were nurses or had some medical background (such as the husband in Family 2) especially encouraged nurses with this relational stance to understand and interact with them as care partners. For example, the sister-in-law of the patient in Family 1 was an ICU nurse. She described the interaction which she had with the patient's nurse before the patient was intubated:

> I said, "Has anybody bothered to explain [this procedure] to [the patient?]" and everybody just looked at me....I wasn't even aware that [the nurse] was in the room, because she was fiddling with the machine...And I was telling [the patient] exactly what they were going to do, what she could expect, how frustrating it would be, and how she must not pull out [the endotracheal tube]....[The patient] started to cry and I said, "I know it's frustrating. I know you don't want it and I know why you don't want it, but it's not for the same purpose." And I'm sure she was thinking of her [daughter who died in childbirth] and [her son who died in a motorcycle accident]. I told her, "I promise you that this is just a temporary thing. It's just to help you through this short crisis and then it will be

> removed...We're not going to let them harm you unless they're trying to do good"...All of a sudden, [the nurse] said, "You explained that to her beautifully!" And [the nurse] wanted to know if I had any medical training, and old big mouth here (referring to the patient's husband) pops out, "Oh yeah!" and he went on to say that I was an RN who had worked in an ICU...After that, I noticed that [the nurse] just couldn't have been more helpful. I mean, she just called it as it was (Fam 1, Int 1, l. 462).

This clinical incident highlights some of the unclear expectations family members with medical backgrounds must confront when a loved one is hospitalized (Olivet & Harris, 1991). The sister-in-law in this situation described the procedure to the patient because no one else had. While the nurse was "fiddling with the machine," the sister-in-law described what intubation would feel like and how the goal differed from when the patient's children had been intubated. In this way, the sister-in-law provided tailored information that meaningfully addressed the patient's concerns.

Once the nurse who was caring for Family 1 discovered that the sister-in-law was actually an ICU nurse, her way of relating to the family changed. As the sister-in-law recalled, "[the nurse] just couldn't have been more helpful." Knowing that she was interacting with a fellow ICU nurse encouraged this nurse to identify more closely with, and relate more attentively to, the patient and family. This nurse's identification and attentiveness to Family 1 stands in contrast to a similar situation in the previous relational stance, in which the nurse became threatened by the family member's disclosure that she, too, was an ICU nurse.

This knowledge, however, may have also encouraged the nurse to expect "rational" ICU nurse behavior rather than frightened and anxious family behavior. When these expectations on the part of the family member were not met, nurses' assumptions, expectations, and usual ways of relating to families as care partners were challenged.

For example, many nurses in different interviews talked about the Romero family. As background, the patient was a 53-year-old woman whose myelodysplasia (which, in her case, was a precursor to leukemia) had been medically mismanaged at a local clinic. She was eventually transferred to the study site and treated successfully with a bone marrow transplant. After she had been home for three months, however, she was readmitted to the hospital with a diagnosis of pneumonia. Her respiratory and renal status progressively deteriorated, and she was admitted to one of the study ICUs for mechanical ventilatory support and continuous veno-venous hemofiltration (CVVH, a type of hemodialysis).

Because the patient had been previously mismanaged, the family was vigilant and vocal. On one occasion, one of the patient's daughters told a nurse participant that she was managing the CVVH unit incorrectly. The nurse continues with the story:

> I said (to the daughter), "Well I know that you've been here awhile and I'm sure that you notice that every practitioner has a different way of doing things and it gets the same results." And she said (in a nagging tone), "Well, you still need more water right there!" Wow!

> "That's not the way I do it, but if it makes you feel better, I'll do it" (RN Int 3c, p. 23, #1).

What especially surprised this nurse was being instructed by the patient's daughter on a highly sophisticated and technical procedure. Nurses in the units in which I collected data rarely corrected one another publicly unless a nurse's activity posed a safety hazard to the patient, family, or staff. By understanding members of the Romero family as care partners, this nurse expected them to behave like fellow staff members; specifically, she did not expect to be publicly corrected with respect to her nursing activities. Because the nurse understood the importance of caring for both the patient and family, however, she accommodated the daughter's request.

Nurses who understood families as care partners also supported families at patients' bedsides as if they were fellow staff members. In the ICUs where these data were collected, nurses generally supported one another by sharing information and technical expertise, joking around, and generally helping one another. Emotional support between staff members (with the exception of joking around), however, was rarely given at the bedside, as nurses typically went to the break room to "blow off steam" and to privately support one another emotionally. Emotional modulation and expressing and supporting one another's emotions away from the patient's bedside is a deeply embedded ethic in critical care nursing practice, as strong displays of emotion can be upsetting to patients, families, and other staff and can negatively impact performance (Benner et al., in progress). One of the problems with this kind of nurse-family relationship, however, is that there was no break room analog for families.

Understanding and relating to family members as care partners created a curious tension between nurses and families. By relating to some patients' families as partners, nurses with this relational stance expected families to carry their fair share of the load, which included, among other things, "being able to deal" with the critical situation as the nurses did.

While many family researchers and clinicians have encouraged critical care nurses across the lifespan to think of families as partners (Ahmann, 1994; Casey, 1995; Rushton, 1990a; Rushton, 1990b), a true partnership connotes equality between two parties (Lowenberg, 1989). Family parity with other healthcare providers, however, was simply not evident in my data. Instead, understanding a family member as a care partner merely shifted some of the responsibility from the nurse to the family without giving the family member additional power. Nurses with this particular relational stance opened "their" house to include certain family members as care partners, but in return expected the families to act like fellow staff members.

Finally, because the nurses who typically stood at a distance lacked the emotional availability to fully engage and involve themselves with a patient's family, their emotional access to understanding a particular family's concerns and issues was hindered. Because nurses with this relational stance understood the importance of caring for the family, they often focused on the ends or the application of certain family-focused interventions. Emotionally protected nurses could offer a family a "technological fix" or discrete technical solutions rather than personally involving themselves directly with the families' emotional burdens (Thomasma, 1994). Nurses' use of a technological fix, however, often created a strategic climate in which a particular family's concerns and issues were ignored.

Facilitating Family Access

An accessible nursing intervention that enabled an emotionally distant nurse to provide basic family care was facilitating a family's access to their critically ill loved one. One nurse participant explained:

> I think there's a way of taking care of the [family] that doesn't always directly involve [the nurse]. I mean...our priority is taking care of the patient. A lot of times the family's questions or inquiries prevent, you know, like we're not really able to take time to sit down with them. In fact, I rarely sit down with someone and actually talk to them about a patient...But we all let [the families] have free access and that tends to reduce their anxiety...And then when they're able to sit in the room and see how we take care of things, they begin to have trust and faith. And for the most part, that's usually how it goes (RN Int 2c, l. 458, #16).

Because this nurse understood the importance of caring for both the patient and family, she typically ensured that families had "free access" to their critically ill loved ones. By disallowing substantial emotional involvement with a patient's family, however, the nurse blocked her ability to make qualitative distinctions between different families (Rubin, 1996; Taylor, 1985a). This prevented her from tailoring her nursing activities and interventions to match what was desired or required by particular families in particular situations. The nurse, instead, offered families a one-size-fits-all intervention that did not "directly involve" her (Walsh, 1993). Still, when compared to the limited family visitation associated with the previous stance, "free access" is a dramatic improvement.

Additionally, by virtue of her family understanding, this nurse fully expected families to have "trust and faith" once they saw how nurses "took care of things." In this way, the nurse expected a family to glean as much from the ICU bedside as experienced critical care nurses do. Yet, few families are emotionally or practically situated to live up to this nurse's expectation, nor do most families necessarily want to. While being understood as a care partner afforded a family member more family care than he/she might otherwise have received, the family member had to accept the terms upon which that care was provided.

Providing Information and Family Education

Nurses who typically stood at a distance often conveyed information to a patient's family using the voice of medicine, in which problems were framed within the technical and logical medical model (Mishler, Clark, Ingelfinger & Simon, 1989). This type of information not only informed families, but often provided them with much needed emotional distance. For example, one nurse participant described a recent patient and family for whom she had been caring:

> The patient that I had the last two days is an elderly woman whose son takes care of her at home. He's very devoted and basically has not left her bedside. And he has many, many questions. So what I've done with him is, as I'm doing something, I explain exactly what I'm doing. Because I know he's going to want to know

> anyway, so I involve him while I'm doing the task. That's how I've been approaching him...[The patient's] had a very rocky course, and they're still not quite sure what's going on with her--other than she's septic--but they're not sure where. And he's very concerned, and appropriately so, but in a way, he can drive you crazy because he's always at you with a question. But I just try to just tell him ahead of time, before he gets on his question spree, exactly what I'm doing and why I'm doing it, and it seems to have calmed him down (RN Int 2c, l. 417, # 62).

By freely informing the son of her activities, the nurse extended her care of the patient to include the family. One does not get the sense, however, that this nurse was open to understanding the son's vulnerability or the patient-family relationship. The nurse talked *to*, not *with*, the patient's son, particularly in her attempts to prevent the son's "question spree." While the nurse was attuned to the son's informational needs and anticipated and answered his questions to the point where he "calmed down" in the nurse's estimation, her way of interacting with the son was much the way an experienced nurse might publicly interact with a less knowledgeable staff member.

Another nurse, in discussing a "difficult" ICU family, told me the following:

> We're dealing with this family who is kind of lashing out in anger and doubt and questioning everything. I don't feel like I'm making a lot of headway trying to help them. I think the best that I can do is give them all the information that they want (RN Int 3c, p.3, #1).

How the nurse was emotionally situated with this family set up some caring possibilities, while closing down others. One of the ways in which the nurse could provide care to this "difficult" family was to "give them all the information" they wanted. This stands in sharp contrast to the nurses who typically stood apart from patients' families and only "reluctantly" provided family information. As information can be characterized as unidirectional and explanatory, simply providing "objective" clinical information does not allow for listening on the part of the nurse, nor does it facilitate open, unstructured communication concerning what matters to a family. In this situation, for example, one wonders if the nurse would have made more "headway" with this family if she had been able to listen to and understand their anger and concerns.

While many nurses with this relational stance cared for patients' families by teaching them about their loved ones' conditions, these teaching activities also served as an effective distancing strategy and coping mechanism for nurses[28]. Providing family information using only the voice of medicine protected a nurse from the emotional involvement of being present and dealing with the family's emotions. Teaching also enabled an emotionally distant nurse to feel helpful by providing families with information that they did not previously have. This might help to explain why two studies found that ICU nurses ranked families' cognitive needs higher than families did (Forrester et al., 1990) and also ranked families' cognitive needs higher than their psychologic or personal and physical needs (O'Malley et al., 1991).

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[28] I am grateful to Pamela Minarik for this observation.

Providing Support and Involving Other Helping Professionals

Some nurses who understood families as care partners supported families at patients' bedsides by engaging them in a kind of informal discourse that can be characterized as joking around. This kind of family support was especially prevalent in cases where the patient and family were "chronic" or had been in the ICU for greater than 14 days (Groeger et al., 1993). For example, I observed one of the nurse participants joke around with the husband in Family 2 about the O. J. Simpson trial and what it would be like to be a juror. Below is a portion of the transcribed observation:

> RN: Nurses have to go to jury duty.
>
> [Observational Note: RN filling out lab slips and selecting the appropriate specimen containers for the patient's next blood draw.]
>
> Husband: They must want to. They want a vacation or something....Hey! Five bucks a day [chuckling]!
>
> RN: This nurse [on the ward] said it's the worst thing....All you do is sit and wait for your name to be called, get interviewed for certain things, and if you're not the right person, you go sit down!
>
> Husband: You can get out of it. She couldn't get out of it because she didn't try!
>
> RN: I don't think it works like that [laughing]! (Fam 2, Obs 2, l. 283, #14).

This playful banter between the nurse and the patient's husband characterized many of their interactions. As with all interventions, however, the timing of the nurse's playfulness was essential to its success. It would have been inappropriate, for example, if the nurse had joked around with the husband when the patient was initially admitted. But, as the days wore on, providing the husband with "comic relief" was a supportive and accessible nursing intervention which the husband appreciated.

In an interview with the husband, he spoke of this nurse and said:

> [She] was good. She got my spirits up. I could kid with her and give her a bad time and that would help me [chuckles]. That got me back up (Fam 2, Int 3, l. 197).

The husband found this kind of nurse-family relationship helpful, as this nurse's way of supporting him nicely complemented the various kinds of support he received from the other nurses who consistently cared for Family 2. In this way, "comic relief" was most effective as a form of family support when it complemented other more personally involved supportive interventions and activities. Providing "comic relief" was also helpful for the nurse, as joking around with the patient's husband kept the conversation on "light" topics which protected her from having to deal with the husband's more serious and grief-filled emotions.

Some nurses found other ways of supporting families that, like joking around, did not require difficult emotional involvement on their part. One nurse participant shared a clinical incident involving a patient's family which subsequently changed how she provided family support:

> We had a patient with cardiomyopathy, and I guess I had taken care of him periodically for a long time. And his wife, for some reason, bonded with me and I didn't know that. Well, he died on my shift, was my patient, and I totally forgot all about it. A few years later, [the patient's wife] comes back. She's remarried [and]

> her second husband has health problems. She remembered me and that I was there when her husband died...It just blew me away because I didn't have a clue as to who this woman was, not one clue. And it changed [my practice], because I realized how we [as nurses] impact [families], even though they sometimes don't impact us....It still blows me away that [the patient's wife] developed this connection with me that I didn't have a clue about...I'm sure to me it was just another day at work, because I obviously didn't bond with them. But [I realized] how important it is to make a little more effort to do a few nice things, maybe get that extra chair or extend the visiting hours, or even get the [family member] a cup of tea. And to [families] it's a big deal, and to us, it's just part of how we care for the patient and family (RN Int 1d, l. 373, #62).

Perhaps the nurse was sufficiently under-involved with the wife's first husband that, in spite of her frequent but periodic care of them, she was unaware of the wife's unilateral connection to her as a nurse (Morse, 1991). Recognizing the difference she made for the patient's wife, however, changed this nurse's practice. She now extends her care of the patient to include the family by doing "a few nice things" for the family. In this way, the nurse is able to attend to and support a family in a professional and social--yet emotionally distant--fashion.

Encouraging Limited Family Involvement

In contrast to the previous relational stance, nurses who typically stood at a distance realized the importance of including and involving the family in their loved one's care. For example, one nurse participant discussed family involvement in one of the small group interviews:

> If nurses "allow" or let family members be involved in patient care, then they feel like they're helping....I found it helps [the family] if you give them a job. I'll say to a family, "You know what would help me most? You're in charge of putting on [the sequential] stockings" or putting tennis shoes on [the patient's] feet, or doing range of

> motion and getting [the family] involved in that (RN Int 3c, p. 22, #1).

In another interview, several nurses discussed the Ramos family. By way of background, the patient was transferred from another hospital with adult respiratory distress syndrome (ARDS), and spent three months in one of the study ICUs before being transferred to a rehabilitation facility to continue her recovery. One nurse described how she involved this family in caring for the patient:

> I remember showing them how to do passive range of motion, because they would be there [around the patient's bedside] and I didn't have the time. "Here, this is how you do it" (RN Int 2e, l. 171, #14).

As discussed in the previous chapter, family participants greatly appreciated being involved and helping with patient care. By encouraging family involvement, these nurses enabled the families to shift from being mere observers to becoming active participants in their loved ones' recovery.

But the nurses' calculated intention behind this discrete family intervention reflected their understanding of families as care partners. Both of these nurses strategically involved families in a way that the familial involvement helped them as nurses. In this way, the families were understood by the nurses as resources to be used. Nurses who typically understood families as care partners were more likely to have this instrumental understanding of families, perhaps because the nurses themselves often felt like resources to be used by nursing administrators.

Working with Patients and Their Families

Nurses who typically stood at a distance recognized the value of providing continuity of care to patients and families, but the extended time spent with families increased nurses' emotional exposure and risk. For example, several nurse participants discussed the effect continuity of care had on the nurse:

> Int: Do you think continuity of care is important for patients' families?
>
> RN 1: Yeah, it's hard on the nurse, but I think it's important.
>
> RN 2: I don't know. I think you need to have the same group of nurses.
>
> RN 1: Now that's a good idea.
>
> RN 2: And the reason I say that is because if that one nurse is gone for a few days, the family can feel really lost...But if you have a core group of nurses...at least you'll have one on for that day.
>
> RN 3: Plus nurses get kind of, I don't want to say burned out, but you know what it's like if you're around the same person forever and ever. They get on your nerves....sometimes you lose your patience. It's hard to tolerate...
>
> RN 2: You just need a change.
>
> RN 3: Yeah, change of pace every day (RN Int 2c, l. 336, #12, 62, 66).

While recognizing the importance of providing consistent care to patients' families, these nurses also described the emotional hardship which continuity of care can place on the nurse. By diffusing the familial burden across a "group of nurses," it afforded nurses a "change of pace every day." This distancing strategy not only prevented emotionally distant nurses from "burning out," but also enabled them to protect themselves from the difficult emotional labor associated with repeated exposure to a patient's suffering family.

Several nurse participants worked almost exclusively with a patient population that typically had a very short ICU stay. Just as many nurses stood apart from the family when the patient's clinical condition was critical, many nurses stood at a distance from the family when it was expected that the patient would either be quickly discharged from the ICU or die imminently[29]. Below is a portion of an interview in which this issue was discussed:

> RN 1: A patient who is coming in [to the ICU after] heart surgery...you gear yourself for short-term. You gear yourself for answering questions. You don't get involved in their personal life so much. I mean, you want to be friendly and efficient, you do your job, but you're not geared up for the emotional long haul, you know?
>
> Int: Your approach to the family is different, is that what you're saying?
>
> RN 1: Well, yeah, I think your approach to the family is different because you have good news first of all, most of the time. I think your approach is dependent on how the patient is doing clinically.
>
> RN 2: And you're not starting a long-term relationship with them-- and they know it and you know it.
>
> RN 1: Yeah. And the other thing, if the patient is doing well...the [family's] not going to need your emotional support. They get it from one another (RN Int 1f, l. 787, #64, 65).

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[29] Please refer to Chapter 6 for a discussion concerning nursing care of dying patients' families.

The nurses quoted above justified their limited involvement with families in terms of the families' expectations, the short duration of the ICU stay, the successful outcome of the surgery, and the intra-familial support that all families must have. Because working with families is a relational skill, it requires "time on task" to master. Many nurses who worked only briefly with families did not have the time to learn and attend to family concerns, nor did they have the benefit of repeated family experiences so that they could more fully develop their family care skills.

In summary, nurses who typically coped with the emotional demands of the ICU by emotionally distancing themselves from a family can be characterized as having the relational stance of standing at a distance from the patient's family. Factors such as the length of time the patient was expected to be in the ICU and the eventual disposition of the patient influenced nurses' emotional availability. By understanding families as care partners, nurses were able to provide basic family care, often in the form of discrete family-focused interventions, while partially protecting themselves from the emotional nature of the nurse-family relationship.

Standing Alongside the Patient and Family

> *"And again, maybe length of time isn't really the important thing, as just really being there, you know, really presencing yourself"--Nurse Participant*

Nurse participants who typically took up caring for families as a practice can be characterized as having the relational stance of standing alongside the patient and family. Nurses with this relational stance understood and interacted with families as extensions of the critically ill patients. Through emotional engagement, openness, and connected learning, a nurse who took up this relational stance tailored her/his activities and interventions to match what was desired or required by the patient and family in the shared situation. A hallmark of this stance was the nurse's ability to understand, interact with, and respond to patients' families on their own terms.

Overview

One of the nurse participants, who had consistently cared for Family 2, was observed while she worked with the "silent" critically ill patient and her husband at the ICU bedside. A portion of the transcribed observational text follows:

> RN: Do you know when [the patient's] dad is coming in?
>
> [Observational Note: RN administering a medication into the patient's IV. Husband sitting in a chair next to the patient's bed across from where the RN was working.]
>
> Husband: I think he's flying down over the weekend....My mother will be back Saturday. She's going to come back and take care of the kids, and I don't know about [the patient's] mother.
>
> RN: Yeah.
>
> [Observational Note: RN facing and listening to the husband while flushing a new pressure tubing setup with saline.]
>
> Husband: Everything's back to "Oh, I had to do this" and "Oh, I had to do that" and "Oh, I had to do all these other things first."
>
> RN: Well, if you need help with it, if you need someone here to run interference...it would be easy for us to talk to her (referring to the

> patient's mother) every day on the phone--whatever kind of support she needs so she feels like she's included--so whatever you want.
>
> Husband: OK (Fam 2, Obs 1, l. 12, #5).

By virtue of this nurse's clinical expertise and finely honed interactional skills, she was able to establish her relational presence by facing the husband, maintaining eye contact, and actively listening to him while tending to several patient-centered nursing tasks. Because the nurse was clinically adept, she was able to skillfully care for the critically ill patient while offering the husband support and intervention.

Nine days after the patient had been admitted to the ICU, the nurse knew enough about this family to understand that both the patient and her husband had a strained relationship with the patient's mother. While the husband, to my knowledge, never did ask this nurse to "run interference" for him, her offer to do so touched him deeply. In an interview with the husband following this observation, he told me:

> All the other nurses have been nice and said "hi" and have been informative about what they're doing with [the patient], but we (referring to the nurse above) talked about the kids, the mother-in-law, this and that....Or [her] asking me if I wanted someone to intervene and [that] she would help, like, "He's got enough to worry about without having to take care of you guys"....She makes sure I'm alright so I can be alright for [the patient] (Fam 2, Int 1, l. 62).

The husband's positive perception of this interaction with the nurse at his wife's bedside highlights the significance of everyday interactions between nurses and families. How and what a nurse says to a patient and family can reveal much about the nurse's emotional engagement and comfort in dealing with them in the situation. In this way, nurses' and families' interactions with one another around the ICU bedside can be thought of as a dance. Engaged and skillful dance partners take cues from one another and respond appropriately by altering their tone, tempo, and movements, resulting in smooth and coordinated dance steps. Inattentive or less skilled dance partners may not pick up on one another's cues or may misread them altogether, resulting in uncoordinated movements and missteps.

Both the nurse and the husband in this situation were emotionally engaged, enabling them to establish a mutually responsive relationship. By involving herself emotionally in caring for both the patient and family, opportunities were opened in the nurse-family relationship. As a result, the nurse was able to learn much more than family facts or bare information; she was able to more fully understand the husband's actions and reactions to his wife's critical illness.

Below is a portion of an interview in which several nurses (including the nurse discussed above, who appears here as RN 2) talked about a particular incident involving this family:

> RN 1: [The husband] was irrational about a white handkerchief one day that I took care of [the patient]. He wanted [his wife] to hold a white handkerchief. Well, the problem was that she was kind of out of it and had no grip, and it was the same color as the sheets. So it would disappear all the time and I said to him, "Can we put a piece of color tape on it? Can we tape it to the wall? Can we pin it somewhere?" But, no, she had to hold it.

> Int: So what was this about? I missed the white handkerchief.
>
> RN 1: It was his mom's or her mom's?
>
> RN 2: It was his mom's handkerchief and it was the one that she took to church....[The patient and her husband had] failed marriages and substance abuse problems [before] they turned to Mormonism.
>
> Int: And so this handkerchief symbolized something?
>
> RN 2: The mother took it to church and everything that had ever happened that was good and related to the church--I don't know what sort of rituals they have--but she had this [handkerchief] and she gave it to [the patient] to help her.
>
> RN 3: That's funny, because he would ask about that handkerchief and I'm like, "I don't do that handkerchief. I'm not doing it, OK?...That's your job!"
>
> RN 1: Well, he was amazingly irrational on the subject of the white handkerchief one day. [The patient] wasn't doing well and he wasn't doing well either (RN Int 2a, l. 687, #5, 64, 65).

This discussion illustrates the impact which a nurse's relational stance can have on the everyday interactions with a patient's family. How a nurse is situated with a family determines, in part, the degree of openness and understanding which the nurse will have when working with the family in the situation. RN 2 more fully understood and honored the significance that the white handkerchief held for the patient and family than did the other two nurses. By virtue of her engaged relationship with this family, RN 2 knew something about the patient's and husband's individual life stories, their relationship together as a couple, and their relationships to their children and their families of origin. This knowledge enabled RN 2 to understand that the white handkerchief, which was given to the patient by the husband's mother, represented love and support from the greater familial web of which the patient and husband were a part. The handkerchief also symbolized Family 2's faith, which had enabled the patient and husband to overcome their problems in the past. Because RN 2 took up family care as a practice, she was able to understand and honor the husband's request in a way that differed from the other two nurses.

RN 1 was able to see the patient's effect on the husband, and attributed the patient's poor condition as the motivation behind the husband's "irrational" request. Although RN 1 did not fully understand the significance of the handkerchief, she attempted to placate the husband by suggesting other alternatives, such as taping "it to the wall" or pinning "it somewhere." Given that RN 1 did not understand the significance and meaning of the handkerchief, her proposed alternatives to having the patient hold the handkerchief were logical. Having the handkerchief "around," however, did not accomplish the same thing for the husband as having his critically ill wife clutch an object that symbolized familiar and religious presence and power. When the husband did not endorse RN 1's suggestions, he was perceived by the nurse as being "amazingly irrational."

In contrast to the other two nurses, RN 3 did not understand, and perhaps even more importantly did not seek to understand, the significance of the handkerchief. Her response, "I don't do handkerchiefs" was a frank refusal to the husband's request and exemplifies emotional distance on the one hand, and a sense of vulnerability and unstable boundaries on the other. By understanding the husband as a care partner, RN 3 involved the husband in his wife's care by making the handkerchief his "job."

The three nurses in this situation had differing levels of understanding, emotional engagement, and openness to the patient's husband. RN 2's interactions with the husband, as illustrated in the observation and interview, highlight many aspects that characterize this particular relational stance.

Nurses' Assumptions and Expectations Concerning Families

Many nurse participants discussed the patient's effect on the family and vice versa, as illustrated in the following excerpts from different small group interviews:

> RN 1: [With this one patient], I could look at the mother in the waiting room when I walked out of the elevator in the morning, and I could tell how [the patient] was doing....Her mother just mirrored her....
>
> RN 2: I was going to say, I thought of [the husband in Family 2]....His world was really small. It was just [the patient's] room and you could see on him how [the patient] was doing (RN Int 2a, l. 554, #5, 64).

* * *

> RN 1: We had this patient for a while that needed to have a CABG (coronary artery bypass surgery) but he was a Jehovah's Witness....He had severe disease. And he started having more chest pain. It really helped him to have his family there....
>
> RN 2: And then there's this other patient. [She's] a 23-year-old girl who's had transposition of the great arteries since birth and has been through procedure after procedure, chronically ill....[Her fiancee's] like moved into her room....He calms her down. I think it makes all the difference that he's there for her (RN Int 2a, l. 583, #63, 64).

* * *

> RN: I was recently a primary on a patient...with end stage liver failure....[Her son] took care of her at home....So, it was like why ignore that part of him--that is him. He takes care of her, she wants him here. She was calmer when he was here (RN Int 2b, l. 3, #9).

Being able to "see" and understand the reciprocal relationship between a patient and her/his family required nurses to "read" both individuals and the family unit as a whole. This perceptual skill enabled nurses to then understand and interact with a family as an extension of the critically ill patient. In the first quotation, two nurses discussed how patients and their conditions affected their families, while the last two quotations point to the family's influence on the patient. Nurses who typically understood patients and families in this reciprocal fashion, thus, were able to grasp that the ICU admission was a family experience--not simply an event that only patients had to endure.

Nurses who understood this reciprocal relationship, however, also typically expected patient-family interactions to manifest love, support, and involvement. To illustrate this expectation, three nurse excerpts from different small group interviews follow:

> The [patient's] family was very courageous and you could tell they all loved each other very much. And through all this stress, they never had an unkind word to say to each other. I mean, the more stressful it got, the more beautiful they were (RN Int 3b, l. 310, #16).

* * *

> Her family came in every day. They were always there. They'd bring in compact discs for her and somebody would always sit and read to her. Their input in her care was just constant. And you know, she ended up walking out of the unit (RN Int 1e, l. 293, #11).

* * *

> And like with [Family 2], [the husband] cared about [the patient] so much. My belief was that she was [still alive] because they loved each other, I mean, both ways. She was sitting in a neuro chair, was barely coherent and hadn't recovered her muscle strength, and she would look at him, and I would think, that's the look, like "I'm still alive, I'm staying. I'm not leaving" (RN Int 2a, I. 1084, #5).

These quotations highlight the kinds of familial characteristics and patient-family interactions that prompted and encouraged nurses who were emotionally available to stand alongside patients and their families. These quotations also represent an idealized version of family as heroic helpers who express a certain kind of love that sustains the critically ill patient. When patient-family interactions appeared to manifest qualities other than love, support, and involvement, nurses' assumptions, expectations, and usual ways of relating to patients' families were challenged. This demonstrates the danger of romanticizing and idealizing love in ways that create unrealistic expectations for families who are threatened by the vulnerability and suffering of their critically ill family members.

As an example, one nurse participant described a critically ill patient and his "controlling" wife for whom she had cared:

> RN: I ended up being the primary caregiver because nobody else wanted to be in the room. I did establish a rapport with [the wife], but I have to say, it was one of the most challenging cases I can remember. I mean, I still distinctly remember how my back would just curl under because [the patient] was a COPDer,[30] hard to maintain...and [his wife would] come in and start taking his clothes off and rubbing him down. It was a challenge. I mean, to find a happy medium where she could be satisfied and feel like she could

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[30] COPDer means that the patient suffered from chronic obstructive pulmonary disease.

> do these things for him...and my being able to manage his care....It was also constantly a challenge to represent things to her so that she would understand and allow me to take care of him...She was very possessive, like she wouldn't let anybody else give him a bath, things like that. Which was fine, but I mean you had to understand her personality and just be ready to face her.
>
> Int: Did you ever feel threatened?
>
> RN: Not for my safety, but I definitely felt like I really had to back down...My point was I didn't want to challenge her. But I had to do my care with him.
>
> Int: And you didn't want to challenge her because...?
>
> RN: Because that was what she needed. She needed to feel like she had control. And she was so out of control and losing her husband and she knew that. I mean, we had really good moments too, where [we'd] sit and talk about her husband, but it was still hard. It was never easy. It was a challenge to the end (RN Int 1b, l. 646, #15).

This clinical incident illustrates mismatched expectations and conflicting ways of relating between the nurse and the patient's wife. Because the wife was perceived as hyper-vigilant, the nurse responded by finding new ways of interacting with the wife that would enable both parties to care for the patient. While the wife demonstrated love, support, and involvement, these qualities were perceived by the nurse primarily in terms of power and control. As such, the nurse's familial expectations were challenged. By remaining open to learning from and understanding the wife, however, the nurse was able to find a "happy medium" in this situation by modulating her usual way of relating and by altering customary patient and family activities and interventions.

By being "ready to face" the wife and "backing down" when the nurse sensed she was exceeding the wife's limits, the nurse accommodated the wife's way of coping in the situation. Altering her usual nursing activities, such as coordinating the patient's bath when the wife was able to be there, meaningfully facilitated the wife's involvement in caring for her husband and helped to prevent further nurse-family conflict.

The nurse and the patient's wife in this situation never related to one another smoothly or achieved interactional synchrony. Their ways of being in and coping with the situation conflicted with one another. Through the nurse's perseverance, openness, and understanding, however, they did ultimately find ways of relating to one another that enabled both parties to care for the critically ill patient. The nurse in this situation struggled to stand alongside the patient and family, as this required that the nurse allow the wife to be with and care for her dying husband on her own terms, and not in the nurse's idealized terms.

Many nurse participants also expected patients' families to express grief, or, at a minimum, tears at some point during their ICU stay. This expectation agrees with what other clinicians have described in terms of neonatal nurses' parental expectations (Zeanah & Jones, 1982). For example, one nurse recalled caring for a patient who was admitted for a routine hepatic lobe resection for hepatic gall stones. The stones were unfortunately diagnosed as cancerous. The patient had multiple complications following her surgery and died two weeks later. The nurse continues with the story:

> The [patient's] family was really shocked. They were very stoic, I thought, in the way they handled it. I don't know...if they broke down at home. But one of the [patient's] daughters broke down in the room when I was there...she finally broke down and cried. But she was really apologetic about it and I was like, "Don't worry about it. I was waiting for somebody to do this. It's very appropriate." I was just being supportive the best I could when she did that, but actually I didn't intervene that much, because this family was very supportive within themselves. They were a very strong family as a group, very supportive of each other. So my intervention was not intervening (RN Int 2d, l. 41, #4).

The nurse in this situation fully expected some family member to cry at some point. After all, their loved one was terminally ill with no hope for recovery. When the patient's daughter eventually "broke down," the nurse read the daughter and the family as a whole and determined that the best intervention was to offer the daughter immediate support at the patient's bedside. Because caring practices are often eclipsed by other more dramatic and patient-centered interventions in the technological ICU, everyday--yet meaningful--family interventions may not seem like interventions at all. So, while this nurse did support the patient's daughter, it was not a one-size-fits-all intervention as provided by many nurses who routinely stood at a distance. Instead, this supportive intervention grew out of the nurse-family relationship and was tailored to the particular family in this particular situation.

After this clinical incident was shared in a small group interview, two nurse participants continued to discuss the issue of emotional displays, and, in particular, crying on the part of family members:

> RN 1: It's interesting how many people don't want to cry....It always surprises me.
>
> RN 2: But I think it's [a personal style]...because I wasn't brought up to cry like that. And initially, I always related better to the [family members] that didn't cry...I felt that I could connect with them...
>
> RN 1: Because you understood them.
>
> RN 2: Yeah...because I could see their agony even though they didn't cry.
>
> Int: So when you were a new nurse here, do you remember a family member crying and how it made you feel?
>
> RN 2: Ah, no...But I always remember comments being made about the family [member] who didn't cry or didn't show emotion. [The family member] might just go and touch the patient and I felt, "No, that's very appropriate" (RN Int 2d, l. 71, #11, 68).

Regardless of how families are understood and related to by nurses, they may modulate their emotions at their critically ill loved ones' bedsides for many of the same reasons that motivate ICU staff to do the same. Emotional modulation on the part of the family may prevent upsetting the healthcare providers and unbalancing others in the patient's room. While nurses who typically related to families with this relational stance were open to understanding and interacting with a family on the family's terms, this dialogue between two nurse participants points to the fact that there are personal, social, familial, and cultural assumptions and expectations about expressing emotions which nurses--and all human beings--bring to bear in any interaction. The nurses who typically stood alongside a critically ill patient and family, thus, expected a family to show their vulnerability during the family crisis. This stands in contrast to nurses who typically stood at a distance or stood apart from patients' families.

Other nurse participants fondly recalled family interactions that went smoothly or remembered families with whom they had "clicked." These stories usually revolved around families that presented or behaved in ways that met nurses' familial expectations and understandings. One nurse, for example, talked about a patient named Sandy and her family for whom she had cared:

> Sandy was [in the hospital] for five months. She had four kids and a husband. She was 34....viral syndrome, cardio hit....I've never seen any person lying in a bed who looked so close to death and who was talking to me. And I've also never felt such emotion in a room, from the physicians, from everyone. Here was this young, beautiful woman who, three days ago, was leading an aerobics class and suddenly was dying. It was so dramatic, the emotion was just dynamic....[The husband] knew that Sandy liked to have her makeup on, and he was so scared of all the technology. She was on the VAD (ventricular assist device), she was on a balloon, she was bleeding, I mean...everything! [31] But he held her hand through it and...stopped getting scared of [the technology]. And a month into [the ICU stay], he was putting lipstick on her [endotracheal] tube! He was right in there (RN Int 1e, l. 171, #63).

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[31] "VAD" in this instance refers to a left ventricular assist device (LVAD) and "balloon" refers to an intra-aortic balloon pump (IABP). The IABP is an intravascular volume displacement device that augments the circulation by displacing aortic blood volume in diastole and promoting ventricular stroke output in systole. IABP can reduce cardiac work, but the heart muscle must be able to maintain the circulation. Mechanical flow assistance (in the form of an LVAD) becomes necessary in the event of circulatory collapse, and acts by reducing cardiac work by diverting blood from the natural ventricle to an artificial pump that maintains the circulation. For more on this, please refer to Quaal, S. J. (1984). Comprehensive intra-aortic balloon pumping. St. Louis, MO: C.V. Mosby.

The patient in this situation had a miraculous recovery and was transferred to a cardiac rehabilitation facility and eventually discharged to home. While this is a dramatic story, what is even more remarkable were the nurse's everyday family-focused activities and interventions that made it possible for the patient's husband to be "right in there."

By virtue of her stance and consistent caregiving, the nurse established a trusting relationship with the patient's husband. The nurse learned through him, for instance, the significance that makeup held for Sandy. While cosmetics may seem like mere accessorizing to some, Sandy's makeup was an important part of who she was. By facilitating family access and involvement, the nurse helped the husband acclimate to the ICU environment and assisted him in providing Sandy with meaningful care. The husband's application of lipstick, for example, can be understood as his contribution toward preserving Sandy's personhood (Benner et al., in progress). By standing alongside Sandy and her husband, the nurse enabled them to be together as a family and assisted the patient's husband in taking an active role in preserving her identity and what was important to her when she was unable to do that for herself.

Finally, a crucial difference between this particular relational stance and the other two stances, is that nurses who typically stood alongside took up family care as a practice, and not simply as a set of family-focused strategies and techniques. In defining a practice, MacIntyre (1981, p. 180) writes:

> a practice...is never just a set of technical skills, even when directed towards some unified purpose and even if the exercise of those skills can on occasion be valued or enjoyed for their own sake. What is distinctive of a practice is in part the way in which conceptions of the relevant goods and ends which the technical skills serve--and every practice does require the exercise of technical skills--are transformed and enriched by these extensions of human powers and by that regard for its own internal goods which are partially definitive for each particular practice.

In this way, a practice can be understood as a socially embedded, historically situated, and shared activity with notions of good internal to the practice itself (Bellah et al., 1985; Benner, 1994b; Benner, 1994c; Taylor, 1989).

Distinguishing a practice from technical skills and family-focused strategies and techniques is important because a nurse's application of the latter in caring for a patient's family can create a strategic climate in which a particular family's concerns and issues are ignored (Leonard, 1996). When the result (for example, the successful application of a discrete family-focused nursing intervention) takes priority, the means (or the nurse-family relational process) gets overlooked and the family is often cared for on the nurse's terms. Yet, it is by way of the interactional process with a patient's family that nurses who typically stood alongside came to understand a particular family's concerns and issues. In this way, the nurses who took up caring for patients' families as a practice were able to provide care on the family's terms, because both the means and ends counted.

Ensuring Family Presence

Nurses who typically stood alongside patients and families worked hard at keeping family units intact. While family visitation in critical care areas remains a highly controversial topic, nurse participants who typically related to patients and families with this particular family understanding grasped the significance of the patient-family relationship such that the word "visitation" was hardly mentioned by them in their interviews. It is also worth noting that family participants did not use the word "visitation" unless access to their critically ill loved ones was denied.

Visitation implies a short-term interlude. Nurse participants who typically stood alongside, however, took up family visitation to mean family presence. As an example, I observed a nurse participant while she was orienting a student nurse at Family 6's bedside. The nurse informed the patient's companion that she was getting ready to change the patient's central line dressing. A portion of the transcribed observation follows:

> Companion: Do you want to be alone while you do that?
>
> RN: Nope, not unless it bothers you.
>
> Companion: It doesn't bother me at all. I've seen it all before (Fam 6a, Obs 1, l. 66).

After this brief exchange, the nurse turned her attention to describing the dressing change to the student nurse. What is noteworthy about this brief interaction between the nurse and the patient's companion is that the family member was the one who initially broached the issue. Because of the nurse's stance, expectations, and her understanding of the patient-family relationship, it did not occur to her that the companion would not be present during this routine procedure. Further, how could the patient's companion demonstrate his love, support, and involvement if he was not present at the patient's bedside?

Another nurse participant talked about Mr. Sadi, a chronically critically ill patient who was in the ICU for eleven months waiting for a heart transplant. The nurse provided the patient and his wife with quiet, private time so that they could lie in bed together. A portion of the group interview in which two nurses discussed this case follows:

> RN 1: They just needed a little closeness because they hadn't had a lot of that.
>
> RN 2: [The wife] wanted to do that?
>
> RN 1: Yeah.
>
> RN 2: And [the patient] wanted her to do that?
>
> RN 1: Yeah.
>
> RN 2: Well, that's a good reason to do it (RN Int 1c, l. 703, #10, 66).

This dialogue between two nurse participants highlights the response-based practice characteristic of this stance. While there were no hospital or unit policies, to my knowledge, that specifically prohibited spousal intimacy, a recent court case concerning a husband's right to share his wife's bed at a long-term care facility points to some of the institutional constraints which may impinge on a nurse's ability to provide care on the patient and family's terms ("Husband", 1996). By standing alongside this patient and his wife, however, the nurse understood the importance of facilitating their intimacy during this prolonged family crisis and ensured that they had quiet, private time together.

While ensuring a family's presence in the ICU reflects notions of good internal to nurses' practice of caring for patients' families, it was not without risk to the nurses who typically stood alongside. Family presence was controversial in all three study ICUs during procedures, nursing change of shift, and medical rounds. Facilitating a family's access when that included small children was another contentious issue. Fear of child-transmitted patient infection and child trauma were the primary concerns surrounding this particular issue, even though pediatric sibling visitation occurs frequently in pediatric and neonatal ICUs without adverse effects to patients or visitors (Ballard, Maloney, Shank & Hollister, 1984; Kowba & Schwirian, 1985; Oehler & Vileisis, 1990; Schwab, Tolbert, Bagnato & Maisels, 1983; Solheim & Spellacy, 1988; Umphenour, 1980). Nurse participants' stories demonstrated, however, that pediatric visitation in the adult ICUs occurred rarely, and, when this practice did occur, the patient was usually gravely ill.

One nurse participant talked about a 42-year-old patient for whom she had consistently cared who was admitted to the ICU for respiratory distress following her bone marrow transplant for acute myelogenous leukemia (AML).

While the nurse was not caring for the dying patient on the day her child came to visit, the nurse "made time" to be with the family:

> RN: [Even though] I had this very busy double, I still spent time with the family and the little boy...[Another nurse] spent a lot of time talking with [the child] about his mom...And it was really cute, because the little boy was on this chair [outside the patient's room] rolling around. He kept peeking in, you know, he doesn't have complex thinking yet. The family was there for hours and finally said, "OK, we're going to go [home] now." [The little boy] said, "No, I don't want to go!" And they go, "Well, what do you want to do?" "I want to go inside and say, 'Hi Mom!'"...So the [child's father] carried him inside...and I'm like, "Screw the [isolation] gown! It doesn't matter, just go inside!" It was so touching when he went [into the patient's room], you know, he made that connection.
>
> Int: And was the patient awake, alert?
>
> RN: She opens her eyes when you call her name, but I don't know how much she's really absorbing. But I think that will stay with [the patient's son] later in life that, "Mom didn't just go away and forget about me. Mom was really sick in the hospital and I got to say something to her." But you can always make time, no matter how busy [my] other two [patients] were. I still spent time with [this] family (RN Int 2e, l. 702, #14).

Being able to see the reciprocal relationship between the patient and family enabled the nurse in this situation to understand the lifelong importance which this intervention would have on the patient's child. Even though she was caring for two other critically ill patients, the nurse "made time" to work with the family. While time can be understood as cyclical, linear, or lived time, it can also serve as the measure of value in one's relationship with another (Daly, 1996; VanManen, 1986). By synchronizing and accommodating her schedule to match that of the family's, the nurse demonstrated to the family how valuable their relationship had become to her.

In Sandy's case, her children came into the ICU to see their critically ill mother before she went to surgery. The nurse continues with the story:

> [After] four weeks, she started to bleed out of the VAD. She was going to go to the [operating room] with the VAD in...[But] she hadn't seen her kids in four weeks and didn't want them to see her [that way]. So we went through this whole thing...and [I] put a sheet over her hand (to cover up the VAD). She had [communicated] to me that she didn't want the kids to see her crying--she was still on the ventilator--the whole thing. Her kids came in, she had lipstick and makeup on. She had my hand under the sheet, and by the time the whole three minute thing was done with the kids, my hand was blue. She was squeezing it so hard and kind of saying, "I'm OK, it's going to be OK." The kids went out and the [physicians], Sandy, and I all just started bawling (RN Int 1e, l. 244, #63).

The nurse and patient in this situation worked hard to create the illusion of normality for Sandy's children (in spite of her grave condition) by ensuring that her makeup was on and that some of her life-supporting technology was hidden from view. Additionally, everyone in the room modulated their emotions so that the patient's children would not be frightened before her perilous surgery. By standing at Sandy's bedside and holding her hand, the nurse helped to absorb some of the patient's grief so that Sandy could calmly go about the business of reassuring her children. This level of emotional restraint, however, could not be sustained indefinitely. As soon as the children left the room, the nurse, patient, and physicians cried, recognizing the unfolding human tragedy before them.

Facilitating Family Connection

As illustrated in Sandy's case, many nurses not only connected with a patient's family, but facilitated the family's physical and emotional connection to the critically ill patient. This is not an easy task for nurses when one considers how foreign the ICU environment must seem to a family, coupled with the critical, and often terminal, condition of their loved one. Family participants described feeling "totally overwhelmed", "frightened", and "intimidated" when they first arrived at the ICU. The companion in Family 6, for example, described his sense of disorientation when his loved one was transferred from the ward to the ICU:

> When [he] was on the ward I could just walk in. But I tripped around this place. I had to push a button to get into the door and [I] just didn't know what to do or what to expect (Fam 6a, Int 1, l. 60).

Nurses who were sensitive to and understood the plight of anxious family members facilitated a family's connection to the patient by orienting the family to the situation at hand, which included interpreting for the family the surrounding equipment, the patient's condition, and the anticipated trajectory or big picture.

The nurse who had consistently cared for Sandy and her family described how she typically presents information to a newly admitted ICU family:

> RN: I explain things in an extremely elementary [way]. [The patient's] going to have cardiac surgery. I draw a plumbing system in a house. "You've got a clot here and we're going to put in new plumbing." That totally makes a difference and [families] can understand that. And I did that [for Sandy's family]. I basically talked with them the way that I would want to have information given to me if I were in the situation.
>
> Int: Which is?

> RN: Which is don't hold anything back. And I usually preface it. When someone starts to get a little bit nervous or looks kind of anxious, I'll ask, "Is this too esoteric? Is there something you want to know? Is there something you don't want to know?" And [families] let you know. Usually most families I deal with want to know. They don't want to feel like they're in the dark (RN Int 1e, l. 152, #63).

This nurse not only makes technical information accessible and understandable to families, but she also carefully reads families to ascertain their understanding and comfort level with the information she presents. In this way, she avoids what another nurse described as "overwhelming families with everything I tell them."

Being able to read individuals and families, however, involved more than nurses' eyes (VanManen, 1986). Nurses who typically stood alongside read patients' and families' responses, noticing individual and familial expressions, behaviors, body language, and tones of voice. For example, when I asked one nurse how she knew it was alright to hug a family member she had just discussed, she replied, "Because she hugged back." This nurse's response-based practice was guided by her perceptual awareness and emotional attunement, which can be thought of as responding to and imitating another's emotional tone (Benner et al., 1996; Stern, 1990).

Other nurses assisted families by interpreting for them their loved ones' conditions and by giving families the "big picture" (Benner et al., 1996). The husband in Family 2, for example, described how nurses helped him in this way:

> There have been times when things [with my wife] weren't so good, renal failure, this and that...I was becoming emotional and [the nurses] were supportive [by telling me] that this was not

> permanent....[They] gave me encouragement that this [condition] had a really good chance of reversing and was because of all the medications. And they really informed me that this was not a death situation here....They helped me get back in control (Fam 2, Int 2, l. 20).

While the framing of information will be more fully discussed in the next chapter, this excerpt highlights the tremendous impact that tailored information can have on families of critically ill patients. Because the patient's husband was a nursing student, he knew enough physiology to understand the significance of renal failure. The nurses who worked with the husband helped him to understand that, while acute renal failure was complicating his wife's recovery, it was not, in and of itself, a terminal condition. By taking the husband's background and concerns into account when providing him with informational and emotional support, the nurses tailored their interventions to match what was required by him in the situation.

Nurses helped families cope with the big picture by providing patients' families with reassurance and encouragement. For example, one nurse explained to the companion in Family 6 why the patient had to have some of his abdominal drains periodically repositioned:

> RN: [The patient's] not really mobile...it's not like you and me, you know, up and down and all over the place. So [the drain] will sit in one place, and unless we get [the patient] in that [one] position for it to drain, it's not going to drain. That's why we need to reposition [the drains] every once in awhile....It's very common for people with [these abscesses] to go down numerous times and have [the drains] repositioned so we can get it all cleaned out (Fam 6a, Obs, l. 355, #8).

Because the nurse in this situation had dealt with many patients with similar conditions, she could reassure the patient's companion by imparting to him some of her experiential knowledge. Painting the patient trajectory for families and providing them with encouragement meant more, however, when it came from nurses with whom families had already developed a relationship. Once Family 2 had been transferred out of the ICU, the husband told me, "The encouragement [from the nurses on the ward] is there, but it doesn't mean as much because we don't know them." This underscores the importance of the nurse-family relationship with respect to the degree of meaningfulness a given nursing intervention will have with a family.

Nurses also helped families emotionally connect with their critically ill loved ones by role-modeling patient touch and involving them in meaningful patient care. For example, I observed a nurse participant meaningfully involve the wife in Family 3 by soliciting her input while she helped the nurse wash the heavily sedated and "silent" patient's hair. A portion of the edited transcribed observational text follows:

> [Observational Note: RN at the side of the patient's bed hanging a unit of blood (PRBC) and talking with the patient's wife, who was seated on the other side of the patient's bed.]
>
> RN: Do you want to [help] shampoo or do you want to relax?
>
> Wife: I'll help you....
>
> [Observational Note: RN now standing behind the head of the patient's bed with the wife standing at the side of the bed.]

RN: Let me see what I have for shampoo. (To patient:) We're going to give you a bouffant hairdo! (To wife:) Looks like his hair has grown a bit, huh?

Wife: Mhum, it has. I'm surprised it's not frizzy....

[Observational Note: RN left patient's room and returned carrying shampoo supplies. RN addressed the patient frequently, explaining what she was going to do before initiating that action (e.g., explaining that she was going to inflate the patient's airbed while she washed his hair).]

RN: Does he like the water hot, cold, warm?

Wife: Warm....

RN: Is the temperature OK?

Wife: Yeah.

[Observational Note: Wife tested the temperature of the water. RN washing patient's hair while wife looks on.]

Wife: (spoken to patient in a sweet voice) You're going to feel so much better! (To RN:) He usually uses Grecian Formula on it. Of course, after a few weeks...

RN: Has it been a few weeks?

Wife: Uh-huh. Two weeks. Feels more like six months (chuckling)....

RN: I feel little bumps [on his scalp].

Wife: Yeah. He gets little bumps like that. He's always hitting them with his comb. Never figured out what caused them....

[Observational Note: RN handing empty water pitchers to wife to refill so that RN can finish rinsing the patient's hair.]

Wife: That worked out pretty cool, didn't it?

> RN: If I wasn't a nurse, I'd be a beautician. OK, we're going in for the final rinse here....Do you find a comb in that bucket?....How does he comb it?
>
> Wife: Yeah, kind of part it and then straight back. He looks so much nicer today!
>
> [Observational Note: Wife now running her fingers through her husband's hair and stroking his forehead and cheek.] (Fam 3, Obs 2, l. 20, #7).

By inviting the patient's wife to assist in washing her husband's hair, the nurse enabled the wife to be a helper, rather than merely an observer. While helping the nurse, the wife was able to connect emotionally and physically with and care for her beloved husband. Additionally, by soliciting the wife's input, personal knowledge, and spousal expertise, the nurse meaningfully involved the wife in what some might consider to be a mundane task. The patient's wife, however, did not take up the activity as a task, but rather as a way in which she could help the nurse and connect with her husband. By the end of the shampoo, the wife was fondly caressing her husband's face and happily reminiscing to the nurse about some of the good times she had shared with her husband.

In another case, one of the nurses who had consistently cared for the Ramos family learned from family members that the patient prided herself on her meticulous appearance. When the patient's daughter pointed out to the nurse that her mother's nails were getting long, the nurse suggested to the daughter that she "trim or paint" them for her mother. While the nurse could have easily trimmed the patient's nails herself, she instead encouraged the patient's daughter to get involved in helping preserve what was important to her mother. After this nurse's simple invitation, all of the patient's family members shifted from being observers to being meaningfully involved in the patient's care. By consistently working with the patient and family, the nurse in this situation stood alongside them by involving them in caregiving activities that mattered to both the patient and the family.

While critical care areas are designed and staffed to provide short-term, curative, patient-centered therapies, nurses who typically stood alongside patients and families recognized the need to care for both patients *and* their families. The nurse who had consistently worked with Family 2 shared her thoughts with me on this matter:

> That's what you're trying for...you're trying to completely acclimate [families] to the environment and to feel comfortable. They stop at the desk and talk with the [ward clerk] for 10 minutes, they come back and visit with the nurse along the way, and they come to the room where their family member is, and they read the flowsheet. I don't care if [families] pull the chart....they're really here to advocate for the patient. That's what it's all about (RN Int 1a, l. 241, #5).

As illustrated in the excerpt above, nurses with this kind of family understanding fully recognized that the ICU was not "their" house--the house belonged to healthcare providers, patients, and their families. Thus, these nurses understood that one of the goods internal to their practice was acclimating families to the situation at hand so that families could physically and emotionally connect with and advocate for their critically ill loved ones.

Building and Maintaining the Nurse-Family Relationship

While the nurse quoted above attempted to make families of critically ill patients "comfortable", family participants described feeling the most comfort with the entire situation once they had established a relationship with one or two nurses. Developing trust and rapport with a family requires a nurse to have relational skills, emotional availability, and a level of engagement such that an openness to understanding the family is possible. Establishing a relationship also takes time, which is why many nurses with this relational stance attempted to consistently care for the same families over time.

One nurse, for example, described a spinal fusion patient from the East Coast for whom she had cared. The patient's sister accompanied her to the hospital, but had only anticipated a two-week hospitalization. Because of respiratory complications, the patient was hospitalized in the ICU for four weeks. The nurse continues with the story:

> RN: [Because of] nursing consistency, although I was only there for three days a week, we kind of bonded. They still write letters to me....[Because of my] following up and following through, it seemed to make it easier [for them to] deal with the complication of having to stay out here longer.
>
> Int: Can you think of specific things you did?
>
> RN: [The patient] liked to watch certain television shows, so we'd put that on the grease board in the room and also in the care plan. Because she was in a lot of pain, there were specific things that I did--things that helped, certain positions--and we put that in the care plan. [The patient's sister and I] worked together...And I told the sister that she was the one person that would always be there every single day, the nurses may change. And she could help us

> help her sister the best. [The patient's sister] really liked being involved with the care planning...and felt comfortable saying, "It's on the care plan, here it is." She could show people who were not familiar with that patient's care how to do the dressing changes, how to do the positioning, or which sedation worked best for the patient (RN Int 1b, l. 49, #9).

While consistent caregiving certainly helped forge the relationship between this nurse and family, trust and rapport were also established because both parties were engaged and emotionally available. Because of her relationship with the patient's sister, the nurse was able to incorporate the sister's input so that the care provided to the patient was, in fact, tailored to the patient. Additionally, the nurse recognized and emphasized to the sister the important role which families play in assuring continuity of certain caregiving practices. This nurse-family relationship enabled the nurse to care for the patient's sister by involving and soliciting her input, which, in turn, enabled the nurse, sister, and other healthcare providers to better care for the critically ill patient.

One of the nurse participants who consistently worked with the Ramos family talked about the importance of providing them with continuity of care:

> I think the biggest difference we made with this family [was] having consistent people there that had established a relationship with the family as well as [the patient]....[The patient] didn't really enter into the relationship as much, because she was out of it so much. I mean, we kind of knew [the patient] through the family...But you could see the visible relief on their faces when they would see a familiar face taking care of her, or even if you were just in the same [area]. And if there was someone taking care of her that they didn't know, just going away from your assignment, checking in on her, and saying, "Hi, how you doing? How is she doing?", and just touching base with them. And when they saw you there...somehow it seemed better for them (RN Int 2e, l. 82, #6).

Through repeated encounters with the Ramos family over the patient's three month ICU stay, the nurses who were emotionally available and open came to know the family, and, with their assistance, also came to know the critically ill "silent" patient (Jenks, 1993; Jenny & Logan, 1992; May, 1991; Tanner et al., 1993).

Providing patients and families with continuity of care was a major theme in many of the nurse participants' stories. Institutional changes, however, such as the erosion of "primary nursing," the advent of new technologies (for example, the continuous veno-venous hemofiltration or CVVH that required "trained" nurses), and the influx of per diem, float, and registry nurses, made it more difficult for nurse participants to provide consistent care. Despite these institutional constraints, nurses who typically stood alongside patients and their families worked hard at "following" the families for whom they had cared, even if that meant simply going away from their other patient assignment to "check in" or say "hi." "Following up" with a patient and family in this way not only demonstrated nursing innovation, but also indicated to the family that the nurse cared.

Likewise, nurses appreciated and relished the moments when families "followed up" with them. This was accomplished primarily through visits once the patient had been discharged from the ICU or by contacting the nurse via phone call or letters. Family follow up, however, occurred most frequently with the nurses who had established close relationships with patients and their families, as illustrated in the following two excerpts from different small group nurse interviews:

> [I took care of] a little old lady that...was [in the ICU] up until two months ago...when she went to a skilled nursing facility (SNF)....Her family was having a really hard time being separated from this hospital. They called me at home...and they wanted to send her back here....So I talked to the SNF person and we talked about [some of the family's issues] (RN Int 2b, l. 181, #10).

* * *

> [My] relationship [with Family 2] is still going on and this started [eight months ago]...I mean [the patient's husband] called me this weekend to tell me what was going on (RN Int 2a, l. 653, #5).

These quotations underscore the importance of the means or the relational process itself, as it was through these reciprocal nurse-family relationships that nurses were able to directly and positively shape patients' and families' hospitalization experiences, and families were able to shape, inform, and extend nurses' family care practices.

In this way, "following up" by either party was perceived by nurses and families as a sign of care. The converse was also true, in that many of the nurses who did not receive visits, phone calls, or letters from families knew that the lack of family follow up was possibly a reflection on their patient and/or family care. As one nurse said when describing a particular patient for whom she had cared, "She's the only person that's come back to see me, but that's another issue."

Thus, providing continuity of care was another notion of good internal to nurses' practice of caring for patients' families. By focusing on the means or the nurse-family relational process itself, nurses with this particular family understanding were able to build and maintain the nurse-family relationship. This, in turn, enabled nurses to tailor the ends or their family-focused activities and interventions to match what was desired or required by the particular family in the particular situation.

Continuity of care was also used to prevent further nurse-family conflict. In the case of the Romero family, several nurses who had cared for the patient did not easily interact with the family. In response, the charge nurse handpicked a nurse participant with family care skills to care for the patient and family. The handpicked nurse described her initial impressions of the family, who were perceived as difficult by many nurses:

> When I started working with the family, I felt that I was being highly scrutinized...[but] I'm a perfectionist anyway, so I just...continued to do my ordinary work. And I think what they wanted and what they enjoyed was not just efficiency, but someone who showed warmth to the patient, even though the patient wasn't really aware. She was very, very sick. But just maybe when you did something, touching her, stroking her, telling her that you were going to turn her....I felt they were a very involved family and wanted you, as a nurse, to be equally involved--not only in [her] care--but emotionally [as well] (RN Int 3d, p. 5, #11).

Not all of the nurses who cared for this patient and family had the emotional availability to engage with either the patient or family at the level this nurse did. In fact, one of the patient's daughters told another nurse participant that she felt most of the nurses looked "at the job only as a paycheck." By understanding the Romero family's expectations and responding to them by providing the family with tailored continuity of care, the nursing staff worked out a solution to prevent further nurse-family breakdown. In order to meet the family's expectations, a group of nurses who were both skilled at CVVH and who demonstrated "warmth" or caring practices provided consistent care for this patient and family.

Consistently caring for a patient and her/his family served many purposes, not the least of which was to establish a trusting nurse-family relationship. Many nurse participants believed it was a sign of trust when a family was willing to leave their loved one's bedside. This belief was pervasive, as indicated in the following excerpts from four different small group interviews with nurse participants:

> I think I've made a difference when I'm caring for somebody who's that sick and the husband...trusted me enough to say, "I haven't left the hospital in three days. I'm going for a walk" (RN Int 1a, l.175, #5).
>
> ❧❧❧
>
> [The family said] something to me last night. They said, "Anytime you or [two other nurses] are here, we sleep much better at night. So we're going home now" (RN Int 3e, p. 26, #14).
>
> ❧❧❧
>
> I always take it as a compliment when a family feels they can leave when I'm taking care of their family member....Because I think that means they trust me (RN Int 2b, l. 111, #9).
>
> ❧❧❧
>
> Like the daughter today, since she knew I'd been there and I kind of knew what was going on, she actually left for four to five hours and got a break (RN Int 2c, l. 246, #66).

This "trust work" (Strauss et al., 1982) on the part of the nurse served a dual purpose: to lay the groundwork for the development of a relationship and to stand in for families so that they could "get a break" from the ICU.

Several study families emphasized the importance of being able to "get away" from the ICU bedside. The family participants who expressed this, however, were the families who had free access to their loved ones and who had established trusting relationships with some of the nurses. One of the nurse participants expressed the importance of developing trust with a patient and family:

> I know one of the first goals I have with a patient...will be to try to gain trust with them so that they can trust me. Because then, I think, it allows them to go back to the business of healing themselves...Once they can [trust] and relax--and same with families--then the families can take care of themselves too (RN Int 1b, I. 97, #15).

Nurses who inspired trust enabled families of ICU patients to "take care of themselves" by affording them the opportunity to leave their critically ill loved ones' bedsides knowing that the nurse they trusted would stand in for them. Standing in for a family meant that the nurse would care for the patient while incorporating and representing the family's concerns in their absence. This stands in contrast to the nurses who typically stood at a distance or stood apart from patients' families. As was discussed earlier in this chapter, nurses who were typically emotionally distant or disengaged did not usually inspire trust and could not usually represent the family's concerns. For those reasons, they often promoted increased familial presence and vigilance.

As in any balanced relationship, the exchange between two parties goes both ways. Nurse participants who typically stood alongside maintained the relationships they had forged with patients' families by "sharing." Nurses who were engaged and emotionally available used self-disclosure as a way to give something back to the nurse-family relationship. When used consciously, self-disclosure is a way of reducing the power discrepancy between the nurse and the family (Candib, 1995; Morse, 1991). When used non-reflectively in the course of sustaining a relationship, it is simply a way of opening oneself to the relationship. Another nurse described her non-reflective use of self-disclosure when working with the Romero family:

> RN: And I think once [this family] started feeling more comfortable with the environment [and] the nurses, [then] they had that sharing.
>
> Int: What is sharing?
>
> RN: Like when I went into [the patient's room], [the patient's daughter] started talking about her mom. And we talked a little bit about my family, and then she gave a little bit more about her family...But it was like, "Yeah, we all have families, and this is how our family works"...Instead of just being the nurse in there taking care of her mom and that's it. It's the person that's there too (RN Int 3d, p. 9, #8).

In this case, sharing personal aspects from her own life with the patient's daughter came about naturally while this nurse worked with the patient and family. This "give and take" between the nurse and daughter fostered the continued growth of the nurse-family relationship. The nurse's stance enabled the nurse to engage with the daughter as a concerned self, rather than as a detached professional self (Darbyshire, 1994). This is similar to Gadow's (1980) notion of existential advocacy, whereby a nurse uses her/his entire self in the course of maintaining the nurse-family relationship.

Some nurses loosened their professional relational boundaries to the extent that they befriended certain families with whom they had developed deep and trusting relationships. For example, one of the nurses who consistently cared for Family 2 offered her family's house to the patient's husband as a place to sleep after Family 2 had been in the ICU for three months. The husband in Family 2 told me about the nurse's offer:

> She offered her home to me...She said she talked to her husband and I could come over and get a good night's sleep...That was last week. And then she offered it again when [my wife] was awake and could hear. [The nurse] said, "Do you want to come over, have a good meal, a good night's sleep?" And I said, "Tell your husband thank you very much and thank you, but I can't"...But you know, she has heart. I know she cares, more than just a job (Fam 2, Int 3, l. 758).

When I asked the nurse about her offer, she replied:

> RN: I felt...if [the patient's husband] just had a reprieve. I knew completely what it was like to work with him, what the dynamics were. I mean, I wouldn't have any hesitation of [having the patient's husband] wake up in the morning and have breakfast at my house. It wasn't a stretch for me to imagine that.
>
> Int: So how many times have you done this in your career?
>
> RN: Not very many. I think as the years go by, though, I have fewer barriers...I just don't have as much belief in the [traditional care] delivery [model] anymore, like, "My shift is over, got to go!" I just don't believe in that anymore (RN Int 2a, l. 1069, #5).

While this may seem like a classic case of over-involvement on the part of the nurse, her offer to the patient's husband can also be understood as an act of friendship. Because the husband in Family 2 had essentially lived in the ICU for the past three months, this nurse felt he needed a "reprieve." While the nurse was probably not surprised that the husband politely refused her offer, she, nonetheless, meaningfully extended her care to the patient's family by offering her friendship to the patient's husband.

Some of the primary concerns surrounding over-involvement with a patient or family on the part of a nurse are that a nurse's professional judgment may get clouded or the nurse may become territorial in her/his care of the patient and/or family (Morse, 1991; Rushton, Armstrong & McEnhill, 1996). While these issues are real and can occur, they should not stop a nurse from reflecting, redrawing, and redefining her/his professional relational boundaries when the nurse is involved in a mutually responsive relationship.

In another interview, a nurse participant who was in an administrative position described her relationship with Mr. Sadi and his wife with whom she had befriended:

> RN: I think I made a huge difference for a patient who had been in our unit for about a year waiting for a heart transplant...While he was waiting for his transplant, he went from a pretty normal interactive patient to a psychological mess essentially...He was really close to giving up on a few occasions and wanted to die, and because he...felt his family was dependent on him, he wanted the same kind of thing to happen to his family. So there were a lot of really severe psychiatric problems that he ended up having, but I saw him every day and I kind of became the contact person whenever he was out of control. I never directly cared for him [as a bedside nurse], but I seemed to be somebody that he trusted. I [would] come in from home to see him when he was really in trouble, and [I] stayed with him at night sometimes, if he was

> having a bad time. So we developed a really good relationship....I think I became a little closer to his wife in the immediate postoperative period. [The patient] did really well after the transplant, but then had a lot of problems afterwards with side effects from [his] medications...He's also in this country as an immigrant....about every six months he has to go lobby before the immigration [people]. His wife has been the sole bread winner in a family-owned dry cleaning business they have--she's kind of kept the family together financially. I got pretty close to her. In fact, periodically, she calls me at home and wants to go through some of the things that are going on...to see if she's going crazy or if this is a normal thing. And there have been a few episodes [where] he's been readmitted because he's severely depressed to the point of their splitting up, and they've needed a lot of intervention to kind of get them back on track. And I can't provide that, I've been really up front...All I can do is say, "As a professional person and as your friend, I think you need to get some counseling"....Even though he hasn't been a patient for two years, he still calls! And I get phone calls from his wife saying, "He's in the car. He won't get out of the car."
>
> Int: And what do you do when she says that?
>
> RN: I talk to her. I mean, she's a very impressive, remarkable woman....So basically what I would tell her is that I thought she was doing a really good job and that I was really proud of her. I felt really honored to have been a friend of hers and that she was a really good example for all of us to follow....She's got five kids, zero money, and in threat of being deported every 20 minutes. Personally, I don't know how she keeps it together, but she's very strong (RN Int 1d, l. 39, #61).

In this case, the nurse cared for the patient and his wife in different roles, but in strikingly similar ways. While Mr. Sadi was hospitalized in the ICU, the nurse directed her attention toward helping him regain some control, balance, and perspective. She came in from home on her off hours and sometimes stayed with him at night when he was "really in trouble." Once Mr. Sadi was discharged, the nurse's focus shifted to his wife. The nurse's phone consultations, initiated by the patient's wife, were also aimed at helping the wife regain some balance and perspective.

While few would argue that this administrative nurse's emotional commitment to the patient's well-being represented over-involvement on her part, many might claim that about the nurse's relationship with the patient's wife. This nurse understood her own actions as one would help a friend in need. Other researchers have identified nurses' "friendships" with patients and families as being both valuable and central to perceiving the hospitalization experience positively (Darbyshire, 1994; Weissman & Appleton, 1995). While these two cases were the only nurse-family friendships in my data set, it is important to point to this rare but meaningful extension of care to patients' families on the part of nurses.

Even putting friendships to one side, opening oneself so fully to a relationship with virtual strangers who are coping with a life and death family crisis (as was frequently the case with a nurse who stood alongside a patient and family) requires a nurse to have interactional skills, emotional availability, and a source of emotional and/or spiritual renewal after the relationship comes to a close. These relational qualities are helpful for families as well, but the onus to work with and care for the family on their terms falls to the nurse who stands alongside a patient and family. Nurse participants with this family understanding were able to build and maintain a relationship with a patient and family such that the nurse was able to enter their world, consisting of meanings, shared understandings, and concerns.

Entering another's world, however, requires skill, timing, and openness, and a keen ability to read the family. One nurse participant told me, "When I'm entering a family, I try to keep very low key." Another nurse participant, when asked how she learned to care for families, told me:

> [I'm] learning all the time. [I'm] learning how a [family] does it and how they manage. You know, it's pretty amazing [for these families] to give up [their] lives...and wait here while [their loved one] is unconscious!...I just try to ask a lot of questions and try to figure out who they are and what's going on with them (RN Int 1a, l. 349, #5).

This nurse's reply indicates her sensitization to a family's plight when the life of one of their family members is threatened. Additionally, by asking questions and remaining open to learning from families with different life histories, expectations, and relationships, this nurse is able to interact with and respond to the unique patient and family in the situation.

Understanding and working with a family's world-defining concerns and issues--some of which are familiar and some of which are foreign--can require tremendous emotional labor on the part of the nurse. By way of example, one of the nurse participants who consistently cared for the Romero family listened to the patient's daughter as she expressed concern regarding certain nurses who cared for her dying mother. The nurse discussed in an interview how she responded to the patient's daughter when the daughter attempted to split the nursing staff:

> [The daughter] was like, "[That nurse] was not nice." I said, "Well, some [nurses] don't want to get too close to your mother because it hurts when they go. And some people just put up that barrier to keep themselves away"...For some reason our philosophies about her mother were the same and it worked. I mean, I'm always the same nurse I think, and there's some families I don't get along with...Maybe the relationship's OK, but you don't do that clicking, where you get to know all of their kids, and who's playing soccer, and what not....I know after this, [after Mrs. Romero] is gone, I'll probably take some fast moving patients for awhile. [Patients] that are just going to come in and go out, and I won't have to really get into who they are and what's going on. After things like this, I have to take a long break, because even though we (referring to the Romero family) got along extremely well, I would leave every day and [have to deal] with it. I mean, I hope I'm never in that situation with either of my parents or my family (RN Int 3e, p. 48, #7).

By virtue of this nurse's stance, she was able to establish a deep and trusting relationship with the Romero family. In so doing, she was able to work with and care for them within their world. While this close relationship and identification to their plight afforded the nurse the opportunity to stand alongside the patient and family, it also put a human face on suffering. She could imagine how devastating it would be if either of her parents or other family members were in a similar situation. This nurse coped by "dealing with it" at the conclusion of each shift, so that she could come back and help the Romero family during the next shift.

Confronting so much anguish with every family in every situation, however, is not a sustainable practice. For that reason, after the inevitable death of Mrs. Romero, this nurse planned on taking a “long break,” by caring for “some fast moving patients.” By renewing herself emotionally in this fashion, one can speculate that this nurse will not be situated with patients and their families during her “break” as she was with the Romero family. While she is the “same nurse”, her way of relating to patients and families probably varies, depending on her emotional availability, the particular patients and families for whom she is caring, and the situation itself. In this way, a nurse’s stance, along with her/his activities and interventions, is very much dependent on the particulars in any given situation.

Other nurse participants spoke of needing “a mental break” and finding “ways to renew oneself” once an intense relationship with a patient and family had come to a close. Another nurse participant coped with the emotional labor of relational work by recognizing the inherent rewards. She said:

> I have to say, of all the patients over the years that I remember...[the ones that I was closest to]...were the most rewarding. And I don’t mean to sound like...I’m the masochist nurse that wants to get close to [all] these people. I mean, it can really hurt a lot and stay with you, and it’s really uncomfortable, and no one likes to feel bad. But there’s also a greatness somehow in connecting with people and sharing that pain and helping them through a situation like that, that I find [gives me] the most tremendous rewards in nursing (RN Int 1f, l. 476, #6).

By finding meaning in “connecting” with others, this nurse was able to deal with the pain of closely identifying with and caring for other human beings. While disengaging from patients and families might provide this nurse with a respite, it would also distance her from the meaning-filled caring practices which actually sustain and renew her nursing practice.

The nurse who befriended Mr. Sadi and his wife spoke of how her relationship with them changed her as a nurse and fellow human being:

> I think we have a lot to learn from those kinds of life episodes. And as hard as it is, I wouldn't want to wall myself off from the opportunity to have [experiences like that], because it changed me...It didn't make me hard, it made me more open [and]...sensitive to the fact that people's lives are really bunk when they're sick, and [nurses] can make a difference (RN Int 1d, l. 358, #61).

Closely identifying with and befriending Mr. Sadi and his wife enabled this nurse to understand more fully the vulnerability associated with being ill, as well as the enormous difference nurses can make for patients and their families who find themselves in that position. Because the nurse came to this realization through her emotional engagement and involvement with a specific patient and family, her level of relational commitment to them can never be mandated or prescribed for other nurse-family relationships. Relationships are, by their nature, highly specific and context-dependent. As Benner and Phillips write, "If the helping professional acts on general principles to 'act caringly'...the caring practice will suffer" (1994b, p. viii). In this way, every nurse-family relationship is bounded by certain particularities, including the nurse's and family's emotional availability, their interactional skills, and the situation itself.

In summary, nurse participants who took up caring for patients' families as a practice and who understood the family as an extension of the patient can be characterized as having the relational stance of standing alongside the patient and family. By understanding, interacting with, and responding to a patient's family on their own terms, nurses with this stance were able to tailor their family-focused activities and interventions to match what was desired or required by the patient and family in the shared situation. One of the most fundamental ways nurses helped to maintain the integrity of a given family unit was to coordinate and ensure a family's presence and facilitate their physical and emotional connection with their critically ill loved one. Through sustained and repeated interactions with a family around the patient's bedside, nurses with this stance were often able to establish a trusting relationship, and, in some cases, a friendship with the patient and family. This relationship with a patient's family enabled nurses to place the patient within the context of her/his family and vice versa. These relational processes with patients' families, in turn, informed and extended nurses' practice of caring for patients' families.

Conclusion

These findings, which extend and build on the interpretive work of others (Benner, 1984; Benner et al., in progress; Benner, Tanner & Chesla, 1992; Benner et al., 1996; Chesla, 1996; Chesla & Stannard, 1997), demonstrate the complexity and the context-dependent nature of everyday nurse-family interactions. The degree to which a nurse was emotionally available to be with and care for a suffering family was inextricably intertwined with how the nurse was in the situation, which can be thought of as the nurse's relational stance.

The habits, practices, concerns, and skills which a nurse brings to the situation are all aspects of her/his stance. Because relational work is a social skill, a nurse's relational stance was, to some degree, affected by the family's behaviors. A nurse's stance made certain activities and interventions possible, and also determined, in part, how successful the nurse-family interaction would be. The three relational stances which characterized the manner in which nurse participants typically related to patients' families each involved a different amount of emotional engagement and risk to the nurse and family.

Feelings in the modern technological view of the self have become a "thing" to be controlled, either for the patient and family's well-being or to protect healthcare providers from their own emotions (Benner et al., in progress; Benner & Wrubel, 1989; Hochschild, 1983; Lutz, 1996; Menzies, 1960). Additionally, the Cartesian legacy, which (in simple terms) separates emotional involvement from rationality, has further encouraged emotional detachment for the sake of unclouded knowledge (Benner, Stannard & Hooper, 1996; Bordo, 1986).

This study has demonstrated, however, that it was through the nurse's emotional engagement and involvement with a patient's family that the nurse was able to understand a particular family's concerns and issues and provide care for the family on the family's terms. Nurses who managed their emotions to the extent that they typically interacted with patients' families in an emotionally distant or disengaged manner were less able to understand and make qualitative distinctions between different families' concerns and issues. As such, their ability to provide meaningful family care was hampered. Fully engaging and involving oneself with a patient's family, however, should not be understood as a prescriptive way to care for all families in every situation, but rather as the optimal way of caring for families in situations in which that level and kind of engagement and involvement is possible.

Chapter 6

How Nurses and Families Face Death in the ICU

"I think, sometimes, families need to hear that there isn't much hope left...but that's a really, really hard thing to say"–Nurse Participant

With the advent of modern medicine, death as a natural human passage has been understood by many practitioners, patients, and families as an unnatural event--to be challenged, postponed, and denied. In the 70 years since the first ICU opened its doors to care for critically ill adult patients, technologic and scientific advances have enabled practitioners to cure, in many cases, what was once considered incurable, as well as to reverse the irreversible and salvage the unsalvageable. Yet even the biomedical promise has its limits. Published ICU mortality rates vary widely among institutions, units, and patient populations, with one multi-center study reporting actual mortality ranging from 59% to 158% of predicted mortality (Knaus, Draper, Wagner & Zimmerman, 1986). In this study, 50% of the family participants confronted the death of their loved one while in the ICU.

But ICU clinicians, by their own understanding of their mission, strive to save patients lives and do not necessarily acknowledge the pervasiveness of death in the ICU. As a critical care nurse for the past ten years, I have participated in the shared death-denying culture of the ICU. In fact, I could not even "see" the prevalence of the death themes in my own data until it was pointed out to me by my dissertation adviser.

Once this "blindspot" was identified, I was able to realize that every small group interview with nurse participants contained narratives revolving around end-of-life decision making and nurses' care of dying patients and their families. Family participants, on the other hand, typically referred to death in more indirect ways, highlighting the hope-filled spaces in which they primarily dwelled. Because healthcare providers' and families' understandings of the clinical situation often differed, their way of being in and coping with the situation varied. The purpose of this chapter is twofold: to articulate the convergence and divergence of three situational understandings experienced by most practitioners and families, and to describe how these shifting understandings made certain actions and interventions possible.

Situational Understandings

Situational understandings, or reasoning in transitions, can be thought of as individual and collective experiential transitions characterized by changes in understanding as the clinical situation unfolds. The clinical course of any given critically ill patient varied tremendously, ranging from a rapid unfolding over several hours to a gradual unfolding over several days, weeks, and even months. At the onset of a critically ill patient's ICU course, healthcare providers' and the family's understandings were situated by the patient's critical condition. As the patient's clinical situation unfolded, accumulating patient evidence informed the understandings experienced by the involved parties. These shifting and evolving transitions influenced how practitioners and families understood the critically ill patient's trajectory and expected outcome, and shaped the possibilities for action and intervention.

Situational understandings were captured through nurses' and families' narrative accounts. These context-dependent and situated understandings are a kind of practical reasoning in which "the focus is on the knowledge or understanding gained or lost in the transition or move from point A to point B" (Hooper, 1995, p. 408; Taylor, 1989). This is in contrast to criterial or snapshot reasoning, which spells out all the relevant criteria and essential characteristics at one point in time (Benner, 1994c). Because a critically ill patient's condition fluctuated, situational understandings were often overlapping, uneven, and ambiguous. As such, healthcare providers and families did not make static comparisons at discrete points in time, but rather reasoned in transitions as the patient's condition changed. In so doing, clinicians and families considered what they had learned from the changes in the patient's condition over time.

As discussed in the previous chapter, nurses and families bring to the shared situation their own habits, practices, concerns, and skills. These aspects together can be thought of as one's stance, which influenced how one experienced these situational understandings (Wrubel, in progress). For example, healthcare providers who were attuned to the clinical situation and open to following the patient's clinical course as it unfolded made use of the gains and losses in their understanding. The three situational understandings which most practitioners and families of dying patients experienced were:

fighting for the patient's life; shifting focus based on changing clinical relevance; and facing death.

Fighting for the Patient's Life

> *"Cost shouldn't even be an issue when it comes to treating a patient...Spend it all just to save [my wife]"--Family Participant*

Healthcare providers' and the family's understandings were situated by the patient's critical condition at the onset of her/his ICU course. Clinicians typically fought to save the patient's life by employing a "full court press," which can be thought of as a constellation of aggressive and curative therapies together with a hyper-strategic and vigilant clinician orientation. A patient's family also fought for their loved one's life by maintaining a presence in the ICU and by typically supporting and encouraging the use of the full court press. Both practitioners and the patient's family hoped that their fighting efforts would prevent patient death. Thus, at the onset of a patient's ICU experience, healthcare providers' and the family's understandings and hope for patient survival converged.

Healthcare providers' use of the full court press was heavily influenced by the organizational logic of ICU practice, or what Bourdieu (1990) has called its *modus operandi*. While physicians and nurses have different practices, portions of their practices overlap in the ICU. It is this overlapping portion of practice that shares the same *modus operandi*. As was briefly discussed in the previous chapter, a distinctive feature of the ICU *modus operandi* is that every ICU patient is a potential "save." This logic influences the organizational design and operational mechanics of the ICU and orients and situates practitioners with structuring dispositions, or what Bourdieu (1990) has called the *habitus*. The *habitus* can be understood as socially embedded, normative styles and habits of relating to others and objects in a practice (Benner et al., 1996; Dreyfus, 1991a).

The *modus operandi* and *habitus* are not simply privately held beliefs, but rather the taken-for-granted understandings and practices collectively shared by practitioners. ICU practitioners both constitute and are constituted by the *modus operandi* and *habitus*, which is to say that practitioners shape and influence the logic and habits of the ICU and are, themselves, shaped and influenced by the ICU logic and habits.

Because they are taken-for-granted, the *modus operandi* and *habitus* are largely invisible to practitioners. For that reason, nurse participants did not explicitly discuss their initial hopes for patient survival. Yet, everything about the ICU is geared toward saving patients' lives, ranging from the design and layout of the unit to the specialized training and orientation of the healthcare providers. Even the pre-admission patient screening, which occurs in "closed" ICUs, assures that only viable--yet critical--patients are admitted to the unit (Carson et al., 1996).

One of the nurse participants discussed the patient evaluation process in a small group interview and described a time when she, in her role as charge nurse, denied admitting a critically ill--but inappropriate--ICU patient:

> I got a call from the ED (emergency department) with a [potential ICU] patient. As I explored the situation, the patient was 60 years old with metastatic rectal cancer, agonal respirations, and blown pupils. She also had a hospice nurse. [The patient] blew her pupils that morning and the hospice nurse called the family to say, "I think today is the day that she's going to die. You might want to come and say goodbye." Well, the family got there and freaked. They called the paramedics. The patient was intubated and brought to the ED on dopamine (a vasopressor). I refused to let them bring [the patient] to the unit. I said, "This is a patient who wanted to die, that's why she had a hospice nurse. It's inappropriate to bring a patient like that to the ICU, because once she's here, everyone will be aggressive and that's so unfair to her"...The patient actually went to a nursing unit on the ward and died four hours later (RN Int 3b, l. 773, #13).

In her role as charge nurse and official gatekeeper, the nurse in this situation used her authority to deny ICU admission to the terminally ill hospice patient. The nurse wisely understood that once the medically futile patient was admitted to the ICU, she would be considered a potential "save," and aggressive and invasive procedures would be used to prolong her inevitable death. In light of the ever-encroaching business mentality in healthcare, the nurse's ethical agency becomes apparent. The nurse could have admitted the patient to ensure that the ICU remained full; instead, however, she realized that admitting the patient would be "unfair," as it would cause needless suffering, both to the dying patient and her surviving family.

Family participants were more explicit than nurses in terms of expressing initial hopes for their loved one's survival, as illustrated by the following excerpts from three family participants:

> I feel like we're going to get her back home--at least I hope so (Fam 1, fieldnotes).

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> I want her to stay [in the ICU] until we go home. I hope we have that chance (Fam 2, Int 1, l. 551).

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> I've got to, you know, hope for the best...and try to keep thinking that [this critical illness] is going to turn itself around (Fam 6, Int 1, l. 405).

To hope means to believe in possibilities (VanManen, 1986). Family participants expressed, both directly and indirectly, their hope and belief in the biomedical promise and the possibility it allowed for their loved ones' survival.

Nurses fighting to save the patient's life cared for families as outlined in the previous chapter, but only to the extent allowed for by the critical nature of the unfolding clinical situation. Nurses' primary efforts, when dwelling in this initial situational understanding, were directed toward the provision of multiple and instantaneous life-sustaining therapies in an attempt to save the patient's life (Benner et al., in progress). Nurses who typically understood and interacted with families as extensions of the critically ill patients realized that, while care of the family was important, patient care was their first priority. Given this situational constraint, a practical and accessible way that nurses could care for a critically ill patient's family--while still fighting for the patient's life--was to provide the family with carefully worded information[32].

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[32] To avoid redundancy with the previous chapter, I have focused exclusively on articulating nurses' informing efforts with families for two of the three situational understandings. Nurses experiencing

(continued...)

While informing efforts on the part of nurses were primary features in all three situational understandings, the goal or *telos* of the informing activity differed with each experiential transition. When critically ill patients were initially admitted, their conditions were often ambiguous and their eventual dispositions uncertain. Nurses, therefore, provided families with open-ended information in an attempt to inform and alert families to possible patient complications and clinical contingencies.

For example, one of the nurse participants discussed a postoperative patient, who had just undergone a liver resection, for whom she had cared:

> [The patient] came in with a pressure of 140, I got report, she was stable. Then my other patient crumped, and as everyone migrated over there, this patient plummeted her pressure to 60...I'm practically resuscitating her on my own because there's no one around! She needed some blood, and ended up getting like 10 units of packed cells and some cryoprecipitate. Her husband would come in once in awhile...usually during a stable moment...so he wasn't really aware of what was going on. He was in the room once when the surgeon was there, but she never went in to talk to him. So I said to him, "Since she's come up...". I mean, her flowsheet was like 140, 60, 140, 60, 140, 60! I said, "She's dropped her pressure several times and we've had to give her a lot of blood....There's a possibility that she's bleeding. She may need to go back to the OR (operating room)." But the [surgical] team didn't say anything [to the patient's husband]. They waited until the next morning [when they had to take the patient back to the OR] (RN Int 2e, I. 271, #7).

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[32](...continued)
these two transitions, however, also cared for families as outlined in the previous chapter, but only to the extent allowed for by the critical and uncertain nature of the unfolding clinical situation.

In the midst of providing multiple and instantaneous life-sustaining therapies to the bleeding patient, the nurse realized that, while the patient's husband had been in and out of the patient's room several times, he was usually only present during "stable moments." As such, the husband was not fully aware of his wife's critical, yet unstable, condition.

While the nurse was not certain that additional surgery would be necessary, the patient's clinical trend was worrisome. Because the nurse had seen many other similar and dissimilar situations and had experientially learned how to recognize and grasp recurring patterns, she had developed clinical forethought, which refers to the educated, experiential, and clinical expectations regarding future events that affect the patient and family (Benner et al., in progress; Hooper, 1995). The nurse's relational stance with the patient's husband, together with her clinical forethought, prompted her to alert him to the possibility that his critically ill wife might require additional surgery. The nurse's actions in this situation stand in contrast to the surgical team, which waited to inform the patient's husband until the team was certain that surgery would be required.

Nurses were loath to commit to certainty, however, when the clinical trajectory and expected patient outcome were far from known. One reason nurses were especially hesitant to give families more concrete information as the clinical situation initially unfolded is that the nurses themselves often did not yet have a clinical grasp of the patient and her/his anticipated trajectory. Clinical grasp is a way of practical knowing that relies on the perceptual and recognitional ability to notice salient aspects in a situation (Benner et al., 1992; Hooper, 1995). Providing families with open-ended information enabled nurses to buy time--which often led to a better clinical grasp and, inevitably, more certainty--while still tending to families' informational needs.

When patients were unstable or doing poorly, nurses provided open-ended information with accompanying changes in their demeanor to match the tone of the message they were imparting, as one nurse participant described:

> When a patient comes back from surgery and they're stable, I might go out to the family with a big smile and say, "The surgery was a success! Come on in. He'll be waking up soon. Everything's fine!" As opposed to the unstable patient who comes back on a balloon pump and tons of drips. Then I don't approach [the family] with a big smile. And I'll tell them, "You know, he's had some trouble" (RN Int 1f, l. 849, #64).

Nurses tended to couple less positive clinical reports with congruent emotional responses to alert the family to the fact that their loved one was not progressing as expected. A nurse's change in demeanor is a form of emotional modulation. When a patient's condition was very critical, nurses learned to dampen their own emotional demeanor when talking to the patient's family, as families often responded to a nurse's reaction by reflecting a similar reaction. In this way, nurses served as pacemakers by setting the tone for the nurse-family interaction (Stern, 1985).

Nurses were keenly aware, however, that providing news that was clearer or more certain than the clinical situation revealed might unduly upset the patient's hopeful family. Typically, nurses attempted to impart initial family information in a fashion that conveyed the ambiguity of the situation, as described below by one of the nurse participants:

> I try to be a little negative in a positive way. I don't really give families a lot of hope, but I don't take it away from them either, because families go home and think about every word that came out of your mouth (RN Int 2a, l. 159, #65).

Sensitively informing a patient's family and delivering negative news in a "positive way" requires finely honed interactional skills. Nurses learned how to impart these subtle messages, in large part, by watching one another and through trial and error learning in actual clinical situations.

This open-ended information, or "dancing" as the husband in Family 2 called it, required a significant amount of interpretive effort on the part of families. For instance, the companion in Family 6 told me[33]:

> I think [healthcare providers] are reluctant to tell you exactly how bad it may be. You have to sort of read between the lines of what you're seeing and what they're saying to know the severity (Fam 6, Int 2, l. 361).

Families not only "read between the lines" of what healthcare providers told them, but also searched for clues that would provide either confirming or disconfirming evidence to support their interpretations. The companion in Family 6, for instance, misunderstood that it was an ominous sign when his loved one was changed from a one-to-one nurse-patient assignment to a double (meaning

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[33] Please refer to Chapter 4 for a detailed description of this family.

two patients to one nurse). In fact, when the situation is understood as fighting for the patient's life, moving to two patients per nurse is a sign that both patients are more stable. In another example, the wife in Family 3 wondered why she was occasionally "allowed" to listen to morning rounds, when, in fact, the physicians might have simply forgotten to close the patient's door as they routinely did when they were involved in academic discussions and hypothetical training exercises[34].

The husband in Family 2 recalled his frustration at not knowing how to decipher the open-ended information with which he was provided[35]:

> Like when we first came in, [healthcare providers] said, "Your wife is very, very sick." Well, what does that mean?...For all I know, it means she's on her death bed (Fam 2, Int 3, l. 461).

While highly developed interactional skills were necessary on the part of nurses in order to deliver initial family information in a sensitive fashion, families also required highly developed interpretive skills in order to understand the subtle messages they received.

Patients who were only transiently critically ill, such as open-heart surgical patients with uneventful recoveries, were typically transferred out of the ICU in a matter of days or once their conditions stabilized. As such, the family of a transiently critically ill patient may only experience this one situational

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[34] Please refer to Chapter 4 for a detailed description of this family.

[35] Please refer to Chapter 4 for a detailed description of this family.

understanding. If, however, a critically ill patient experienced complications during her/his ICU stay (as was often the case), mounting clinical evidence usually forced healthcare providers and the family to dwell, at least temporarily, in the situational understanding I will describe next.

Other patients, such as the wife in Family 4, died unexpectedly[36]. When an unanticipated death occurred as the clinical situation was initially unfolding, it was an upending experience for all involved, in large part because the staff did not have time to prepare themselves or the patient's family. In this way, unexpectedness is socially constructed by the practical orientation of the involved parties and their attempts to save the patient's life. In these cases, healthcare providers and the family did not have the opportunity to cope gradually with the impending loss (for which the next two situational understandings allowed).

Shifting Focus Based on Changing Clinical Relevance

> *"It was very intense working with [the patient] because she would get a little better and you'd get hopeful, and then she would fly back down"--Nurse Participant*

As ominous indicators of patient deterioration accumulated, there was a dawning recognition on the part of many or all involved that patient survival was unlikely. This recognition, however, was uneven and overlapping with the situational understanding of fighting for the patient's life, in part because minor markers of disease progression and/or patient distress were treated immediately

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[36] Please refer to Chapter 4 for a detailed description of this family.

with increasingly aggressive therapy. Because the patient usually responded (at least initially) to therapies that mirrored her/his changing condition, the patient's deterioration in the controlled environment of the ICU was rarely a quick descent to death.

Nurses' narratives pointed to this experiential transition, as they moved from fighting for the patient's life and hoping for patient survival to shifting their focus with changing clinical relevance. Changing clinical relevance, as identified by Benner, Tanner, and Chesla (1996), can be defined as the recognition of contextual and situational changes that require actions other than those planned or anticipated (Dreyfus & Dreyfus, 1986). What was previously anticipated was patient survival. But as hope for survival faded with mounting clinical evidence, hope for a "dignified death" took precedence. With this new understanding, actions and interventions became accessible that were previously inaccessible when the involved parties were fighting against even the awareness of possible patient death.

For example, one of the nurse participants described a 60-year-old patient that underwent an esophageal pull-up for gastric cancer:

> [The patient] got progressively worse and had all this ascites, and [the surgeons] went in and did an exploratory [laparotomy] and [found that] he had inoperable liver cancer. He was dying. They finally made the decision that they weren't going to do anymore and they were moving toward withdrawal [of life support]. I had him one night, as half of a double, and I could have done a lot of tasky things...but that wasn't important. I put that aside and just tried to allow time [for his daughter] to talk...[The daughter] obviously had some issues that she needed to just kind of say out loud. They

> didn't get on very well, but in the past couple of years they were kind of coming back together, and now this. [She felt] guilt, lots of guilt. And she would just sit by his bedside and put her head on his chest and hold his hand. And she talked to him. He was out of it, I mean, he wasn't really aware that anyone was there, so she had a really hard time. And it's very difficult when you're busy...to find the time where you can try to do some of that work. But maybe length of time isn't really the important thing, as just really being there, you know, really presencing yourself (RN Int 2e, l. 646, #6).

The nurse and daughter both understood that the patient was dying. By virtue of the nurse's reasoning in transitions, activities which were previously understood by her as crucial to the lifesaving mission became mere "tasky things," which were put aside so that the nurse could spend more interactional time with the patient's daughter. In spite of her other competing patient assignment, the nurse understood both the imminence and significance of the patient's life passage. As such, the nurse was emotionally engaged and open to understanding and responding to the daughter's pain and feelings of loss.

If the patient's condition had been such that the nurse and/or the healthcare team was still hopeful for patient survival, it is unlikely that the nurse would have understood and responded to the clinical situation in the way that she did. Likewise, the daughter's understanding that her father's death was imminent prompted her to act in the manner she did. As such, the activities and interventions that were accessible to the nurse and daughter were very much dependent on their shared understanding of the imminence of death.

As illustrated in the case above, many nurses shifted their focus from providing patient-centered care to providing care to the patient and family as hope for patient survival faded. As such, nurses dwelling in this situational understanding cared for families as outlined in the previous chapter. Additionally, by virtue of their round-the-clock presence at patients' bedsides, nurses played a prominent role in framing and reinforcing anticipated clinical trajectories and expected patient outcomes to patients' families. This slow dosing of information occurred frequently, both informally at patients' bedsides and on a more formal basis at scheduled multidisciplinary family conferences.

One of the nurse participants, for example, discussed how she and other clinicians typically provide information to families in stages:

> Right after surgery, sometimes, you just don't know. So you [give families' information] in a very round about way...You're doing that to give the family time to come to terms with [a potentially grim prognosis], but you're also doing that because you don't really know for sure...But as the days go by, you try to make [the information] a little more concrete...It's so ingrained in us, it's a way we all practice. Always give [families] a little hope until it becomes really, really obvious that there isn't any left (RN Int 2a, l. 136, #65).

The goal of nurses' informing efforts changed as the patient's condition worsened. As nurses recognized the relevance of the patient's deterioration, nurses' provision of open-ended family information became more focused and concrete in an attempt to prepare the family for the grim possibility of patient death.

In another example, a nurse participant described her coaching efforts as she prepared the Ramos family for a family conference in which end-of-life issues would be discussed[37]:

> There was a point where [the patient] was stuck at the same ventilator settings for weeks, and we couldn't get her below 70% FIO_2. And this is a woman who had ARDS (adult respiratory distress syndrome) and had been on 100% FIO_2 for at least a month. So [I'm thinking] fibrosis of the lung, will she ever get off the ventilator? Would she even make it? At that point, given the information I had and the [patient's] trend...I began to plant some seeds...First I asked the family, "What do you think is going to happen here?" And they said, "We hope...that she'll get out of [the ICU]." Then I went through the process of planting the seeds [about the upcoming family conference], "These are some of the questions that the physicians are going to ask you. You might want to think about them [ahead of time] so that you're not surprised by them. How far do you want to go in resuscitating her?" and then helping them to understand what that meant (RN Int 2e, l. 323, #6).

Because this nurse had participated in many family conferences, her experiential knowledge enabled her to coach the family and prepare them in advance for this uncharted experience (Benner, 1984). By "planting some seeds," the nurse encouraged the patient's hopeful family to dwell reflectively on the culturally avoided and emotionally charged issues surrounding end-of-life decisions which they would soon have to confront.

Nurse and family participants alike believed that only "honest" information should be given, as illustrated by two excerpts from different small group interviews with nurses and two excerpts from different family interviews:

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[37] Please refer to Chapter 5 for a description of this family.

> RN: I think we need to be honest...I won't tell families lies or false information, I don't think it does any good (RN Int 1c, l. 606, #66).
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> ❧
>
> RN: I think [families] look to us for honesty and explanation...They expect us to be the person that will provide the truth (RN Int 2c, l. 530, #62).
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> ❧
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> Wife: I like for them to tell me what's really going on (Fam 3, Int 2, l. 489).
>
> ❧
>
> Daughter: They need to be completely up-front and honest of what's really going on. Don't try to curve it (Fam 5, Int 1, l. 631).

While honest information, as an abstraction, was desired by both nurses and families, nurses found informing efforts difficult when they recognized the relevance of the patient's deteriorating condition, but the patient's family was still dwelling in the previous situational understanding and hopeful for their loved one's survival.

The ethical principle of honesty and truth-telling collides with the limits of knowing the truth precisely and also with the suffering imposed on a family having to face the hard truth. Compassionate truth-telling requires dialogue and relationship, timing, attunement, and meeting the other (Benner, in progress). When truth-telling, on the part of the healthcare team was not delivered in a compassionate way, family participants became distraught.

The wife in Family 3, for example, was provided honest, albeit brutal, information by a physician on her second night in the ICU, when the physician told her, "You know, 100% mortality." The physician's proclamation greatly unnerved the wife, who was barely even able to discuss it with me one week later:

> I got really upset, because I don't know if I misunderstood the doctor or what, but, I, I thought he told me that (voice trembling slightly), you know, it was, he wasn't, you know, going to make it (Fam 3, Int 1, l. 89).

In another instance, the daughter in Family 5 shared with me that the surgeon told her "in a drastic way" that her mother would need to return to surgery when he said, "We've got to go back in right away or we could lose her."[38]

Yet, there are multiple layers of truth (Benner, in progress). There is the statistical probability form of truth, which can be understood as factual, medical truth. But there is also the human or lifeworld[39] shattering truth where the implications of the truth--the information--have a multi-layered impact (Benner, in progress). As Benner writes:

> The responsibility between the one dying, the family, and those caring for the one dying is mutual though distinct. When the situation is changing from that of hope and possibility to almost certain death, the ambiguity of the situation makes traversing two distinct world and languages both necessary and uneven (in progress, p. 3).

Hope does not have to exist at the expense of accurate and honest medical information. Nurses described many families who were well informed but still hopeful. In fact, a family's "knowing" that death would occur showed up

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[38] Please refer to Chapter 4 for a detailed description of this family.

[39] Lifeworld is a term initially used by Edmund Husserl and Martin Heidegger, and refers to the world of human experience.

in almost every nursing narrative involving a dying patient and her/his family, as illustrated in the following excerpts from four different small group interviews:

> He told you that he knew it was very grim. But he also told you that he needed that hope (RN Int 1b, l. 178, #15).
>
> * * *
>
> I think they knew. They knew in their hearts that this was the time, but I think they really didn't want to let go emotionally (RN Int 2e, l. 821, #2).
>
> * * *
>
> Intellectually, she knew that he was going to die, but emotionally, she could not let him go (RN Int 2d, l. 539, #11).
>
> * * *
>
> Her boyfriend knew [she was going to die], because he was very upset, but not completely off the wall screaming (RN Int 2c, l. 956, #66).

A family's "knowing" has several possible meanings. Its pervasiveness in the nursing narratives might have simply indicated the import nurses placed on their informing efforts. While physicians are generally expected to provide a patient and family with diagnostic and prognostic information, much of the responsibility for assisting the family to understand the implications of the prognostic information for their lifeworld falls to nurses. As such, nurses understood, both ethically and legally, that they were partially responsible for the provision of family support and coaching as the family translated the clinical information into their lifeworld understanding. To that end, nurses may have also pointed to a family's "knowing" to demonstrate that the family was, in fact, adequately informed by the nurses and other members of the healthcare team.

A family's "knowing" can also be interpreted as an expectation on the part of nurses that the family will cope "gracefully" and grieve "appropriately" when their loved one eventually dies. As will be described in the next section, being prepared was an important condition for a "dignified death," both for the healthcare providers and the patient's family. In this way, the expectation that a family of a dying patient would cope gracefully and grieve appropriately are unstated needs on the part of the healthcare providers. Despite this expectation, a family's "knowing" that death would occur did not necessarily make the moment when death was confronted any easier.

Finally, nurses may have referred to a family's "knowing" to indicate that, while the family knew that their loved one would die, this family knowledge did not necessarily translate into acceptance. While healthcare providers could not force a family to dwell in their shared situational understanding, they could force on the family knowledge about the inevitability of patient death. When patient mortality seemed certain, healthcare providers' informing efforts directed at the dying patient's family intensified. This was especially the case when a patient's family remained hopeful for their loved one's survival in spite of mounting clinical evidence suggesting otherwise.

Even healthcare providers who were fairly certain about a patient's eventual death often experienced shifts in their situational understanding as the patient's condition transiently improved. For example, one nurse participant described her shifting understandings as the patient's condition waxed and waned:

> Yesterday, [the patient] was so depressed and I thought, "Why are we doing this to her? She doesn't want to live." Today she looks good, you know, she's smiling, her wound's healing....So I could see this picture of her making it (RN Int 1c, l. 637, #10).

The nurse's reasoning in transitions was influenced by her emotional engagement, openness, and attunement to the patient and to the patient's unfolding and uncertain clinical course. By virtue of the nurse's shifting understanding in response to the patient's changing condition, the nurse moved from questioning the patient's will to live to "seeing this picture" of patient survival. Reasoning in transitions without certainty enabled the nurse to press into the future differently, depending on the patient's clinical condition.

Emotional involvement, however, often became increasingly difficult for the nurses who expected patient death. One nurse recalled caring for a young patient who had been in a car accident. His neurological injuries were severe, and the physicians only gave the patient a 5% chance of survival. The nurse continues with the story:

> No one invested any time with the patient or family, because no one wanted to get involved. They were like, "He's going to die anyway. He's going to herniate"...But he actually woke up for me...So I went to [his mother] and said, "I think he's awake. You might want to go and talk to him." So she did and he opened his eyes and mouthed [around the endotracheal tube], "Help me"...And, in fact, [the patient] didn't die. He went to rehab...and actually had some gross movement of his arm by the time he left (RN Int 3b, l. 503, #13).

In spite of the patient's grim prognosis, the nurse remained open to following the patient's unfolding clinical course. Engaging with a patient who was, by most accounts, hopelessly injured was not without emotional risk to the nurse. But her skills of involvement with the situation and with the patient and family enabled the nurse to remain open to recognizing the changing clinical relevance (Benner et al., 1996).

Healthcare providers often recognized the inevitability of patient death and experienced the shift in understanding well in advance of the patient's family. This occurred for two primary reasons. First, while many of the nurses had emotionally bonded with the patient and/or family, the deteriorating patient was still not their loved one. Confronting the mounting evidence that suggested eventual patient death, while not easy, was usually easier for the nurses than it was for the patient's family. Second, if the healthcare providers had worked in critical care for at least a moderate amount of time, they were often accustomed to making this experiential transition, painful as it was. Many families, on the other hand, had never before faced death, and, perhaps more importantly, had never before faced a family member's death. These two reasons alone positioned healthcare providers and the dying patient's family to diverge in their understandings of the shared clinical situation, for they often lived in two very different experiential and emotional worlds.

For example, many of the nurse participants in different interviews discussed the Romero family[40]. A nurse described how one of the family

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[40] Please refer to Chapter 5 for a description of this family.

members was “in a different place” than the rest of the family and the healthcare team:

> Last night, I was talking with [one of the patient’s daughters] because she’s kind of getting to the point, along with the other siblings, of wanting to withdraw [life support from her dying mother]. And she was just talking about her mom and how she struggled to raise the four kids and all this. And I’m trying to [imagine], you know, “What does [this daughter] see and hear?” Because [the patient] doesn’t even look the same as she did last week or even two weeks ago. How can [the daughter] even recognize this person as her mother? I mean, she’s swollen and her hair is gone. So [the daughter’s] coming from a totally different place. I think the other kids have worked through that, but that’s where [this one daughter] was, still holding on to her mom and the life that she’s lived (RN Int 3c, p. 11, #1).

Even trying to dwell imaginatively in the same situational understanding as the patient’s daughter was impossible for the nurse because, at that point, she had already recognized the relevance of the patient’s quickly deteriorating condition. What the nurse saw was dependent on her stance and understandings. Because the nurse had made the transition, she was in a new factual world such that what she noticed had changed. The nurse saw the patient, with her swollen body and balding head, in a way that was probably impossible for the still hopeful daughter to see.

Even if the daughter had shared the same understanding as the nurse (namely, the recognition of inevitable death), it is unlikely that she would perceive her mother as the nurse did. The nurse only saw the critically ill patient once she was hospitalized in the ICU, whereas the daughter had a lifetime of maternal memories to draw upon that both shaped and colored her perceptual awareness.

The daughter might remember, for instance, the many times over her life that she caressed her mother's silky hands. Regardless of her understanding, the daughter might still focus on the silkiness, not the swelling, of her mother's hand. As such, the nurse and daughter would probably never experience this situational understanding in the same way. This is a distinction between a clinical understanding and an interpersonal lifeworld understanding.

Seeking consensus regarding end-of-life decisions was especially difficult for the involved parties when there were divergent understandings of the shared clinical situation. Nurses' narratives demonstrated that all possible permutations occurred in the ICU, such as nurses and physicians sharing an understanding that diverged from the family's understanding, nurses and families sharing an understanding that diverged from the medical team's understanding, and physicians and the family sharing an understanding that diverged from the nurses' understanding. Conflicts occurred most frequently when healthcare providers' shared understanding regarding the inevitability of patient death diverged from the family's understanding that patient survival was still possible.

By way of example, two nurse participants from different interviews described some of the difficulties they had in discussing end-of-life issues with the Wu family:

> [The patient] was in his 70's, had a bad outcome from a CABG (coronary artery bypass graft surgery). Never really woke up, really tough case. Balloon pump, MAP (mean arterial pressure) of 40 for like a whole 24-hour period. CAT scan showed multiple areas of infarct in his brain, really poor prognosis. But [the cardiac surgeon]

> always gives [patients] five days to a week to be sure, because sometimes they are just really slow [to recover], especially if they took a big hit....But it was really hard to communicate with the family [because] there was a huge cultural gap where they didn't pick up on our subtleties....The [cardiac surgeon] had a meeting with the family a week post-op, and really laid it down on the line, and they still weren't hearing it (RN Int 2a, l. 20, #65).

Another nurse fills in the end of the story:

> The language barrier was so upsetting to me because I wanted to be able to help them understand. They finally got a niece [to come to the hospital] who kind of understood why we couldn't fix the brain...but she kept saying, "He was walking and talking before this surgery. He wasn't sick." But they didn't understand that an ejection fraction of 18% is very sick[41]. It's like, how do you explain that?....We had three family conferences....and everybody said the exact same thing, maybe in a different way, but they heard it 10 different times during the day. It was a large family, so everybody had to hear it and then we had to wait three, four days, they'd come back, hear it again, wait more, and then finally it started to sink in....And after a lot of talking, grieving, and support, they were finally able to let him go. They withdrew [his life support] and he passed very quickly (RN Int 2d, l. 147, #63).

This case was doubly vexing for the involved parties because of the tremendous cultural and language barriers, in addition to the fact that the healthcare providers' shared understanding of the clinical situation differed from that of the family. While the healthcare team and the dying patient's family eventually reached a consensus decision regarding the withdrawal of the patient's life-sustaining therapies, it was only after many informal and formal conversations

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[41] Ejection fraction is the index of left ventricular function. Normal is 65%.

between the nurses and physicians involved in the case and the many members of the patient's family.

When patient death was framed and understood by healthcare providers as a medical event, there was often little patience or understanding for the family's position, as demonstrated by the nurse above when she described how the healthcare team presented their case to the patient's family and then had to "wait three, four days" before "it started to sink in." Understanding death as a medical event takes only the patient into account and discounts the impact death will have on the patient's family. When healthcare providers understood death in this medical fashion, it influenced how and when they approached the patient's family to discuss end-of-life issues.

In another example, a nurse participant discussed a case involving a critically ill "silent" patient who was not recovering as expected and the role which his vigilant wife played:

> [The patient] had a CABG and valve [replacement surgery] a few years ago. He takes Fluconazole for a chronic yeast infection, but he is also on Coumadin. And that with the Fluconazole gave him a nice big bleed in his head and he had to have an evacuation, and on, and on, and on[42]. So here we are, he's been sick for three weeks and his wife comes and holds his hand and talks to him every day after she finishes lecturing...But he wasn't getting any better. So everybody's like, "OK, Monday, we'll have a family conference and get [permission from the wife] for a DNR (Do Not Resuscitate order)." So, we got the DNR [order] and [the patient's] a chemical code only. And then, they're like, "We'll talk

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[42] Fluconazole is an antimicrobial agent and Coumadin is a blood-thinning agent.

> Wednesday about withdrawing"....By the end of Tuesday night, [the wife] said, "I just feel like I've been railroaded. You've made him a DNR and you're withdrawing tomorrow." And she went home, talked to her son, and got on the phone and said, "I don't want [the withdrawal of my husband's life support to happen]. Please make it very clear that's not what I want. I just got railroaded." And she's such a strong woman, everybody was just like, "There's not much we can do"....I mean, this was her husband of 30 some years and she was going to fight to the bitter damn end....A day later, [the patient's] tracking, he's following commands. I mean, this man is going to get out of here!....So, today's family conference was great, because [the wife] knew about the conference two days in advance, she had her son there, she had slept, and we had good news (RN Int 2d, l. 276, #63).

In this case, while there were no confounding cultural or language barriers between the healthcare providers and the dying patient's family, there were other sources of uncertainty. As such, there was still a divergence of understandings that existed between the healthcare providers and the family.

Because the healthcare providers were certain of the patient's eventual outcome and understood death solely as a medical event, their timeline for making important end-of-life decisions was both rigid and compressed. The patient's wife, fortunately, was unwilling to follow the medical team's established timeline, as her husband dramatically improved the day that his life support was to have been withdrawn.

In contrast, healthcare providers who understood death as a family event took the dying patient's family and their understandings of the clinical situation into account when planning and acting on important end-of-life decisions. One of the nurse participants discussed a case in which she realized that death was an uncertain human relational or family event:

> [The patient] had liver failure and came to us to get worked up for a transplant. Both he and his wife were young, in their 30's...But he didn't do well and [the family] saw that over several days. So, [the healthcare team and the patient's family] agreed that [life] support should probably be withdrawn. But then another family member would fly in from [another city] and the whole thing would start over again. It was extremely frustrating for me because I just knew this man should be dead...But I read an article in a nursing magazine and it said that sometimes [families] just need to come to the realization on their own. And once I realized that, I was fine....I mean, [the family] has to sit there and realize that [the patient's] not going to get better. He finally died on his own....But I know now that everybody is not going to click and come to the same realization at the same time (RN Int 1b, l. 348, #7).

In this situation, when the nurse understood death as a medical event, she became frustrated and morally outraged that the dying patient continued to be supported by life-sustaining therapies when he "should be dead." Once the nurse understood death as a family event, however, she became more patient and understanding of the experiential transition process through which the family had to pass.

While physical death occurs in the dying patient, the social level death is felt in the patient's surviving family. The perception of death lingers at the family level long after the physical death has occurred. Because ICU clinicians face death daily, their individual and collective reasoning in transitions often become transparent to them. These situational understandings take on greater significance to the patient's family, however, as a loved one's death can threaten the very identity and world of the family. Since reasoning in transitions are accompanied by changes in the healthcare providers' and family's comportment or actions, it is incumbent upon all parties to remain attuned to the unfolding clinical situation and to intervene in ways that are true to the patient's interests and condition (Benner, 1997).

Facing Death

> *"I thought I spent the day very profitably with the family as they were saying goodbye to their family member. But I thought, "I wonder if I'm going to be able to continue doing this?" Because it's not necessarily a valued interaction anymore"--Nurse Participant*

As patient death became certain, healthcare providers and the dying patient's family experienced this final situational understanding. Nurses' narratives pointed to this experiential transition, as they moved from, on the one hand, understanding the relevance of the patient's deteriorating condition and helping the family to grasp that patient death was likely, to, on the other, coordinating and facilitating a "dignified death" for the patient and family. With this new understanding, actions and interventions became accessible that were previously inaccessible when the involved parties were still uncertain as to whether the patient would ultimately survive the critical illness.

For example, one of the nurse participants discussed a dying patient and his wife for whom she had cared:

> [The wife] and I were having a discussion of CPR, no CPR, and the one thing I said to her that really brought about what I wanted for this patient was a death with dignity and comfort and somebody there at his bedside. And she said, "You said the words I've been

> looking for, a dignified death. I don't want him to suffer, I want him to be comfortable." And that's when she realized that if we decided to do CPR, it wouldn't be a dignified death--and it wouldn't--and it wasn't going to prolong his life....She knew he was going to die, but it wasn't until I said "death with dignity" that she knew how she wanted his death to be (RN Int 2e, l. 529, #8).

In this situation, the nurse and wife both understood that the patient was dying. This understanding allowed them to discuss openly what was previously avoided. Because the nurse had cared for many other dying patients and their families, she was able to draw on her experiential knowledge and share with the wife her vision for a peaceful and comfortable life passage. In so doing, the nurse assisted the patient's wife in articulating how she "wanted [her husband's] death to be."

While many nurse participants discussed the notion of a "dignified death," the phrase covered a range of meanings. To illustrate this, one nurse participant described a "good" death scene in which she had participated:

> Like this one family, they said, "We want all this [technologic] stuff out," and they put on music, and they prayed and talked with each other. And they were all there holding [the dying patient's] hand...You know, they had accepted it and they weren't fighting about it, and [the patient] appeared comfortable with medication (RN Int 3b, l. 722, #16).

This example pulls together all of the aspects which nurse participants identified in relation to a death with "dignity". Nurses, thus, understood a "dignified death" to mean a peaceful and comfortable dying patient who was surrounded by peaceful and comfortable family and staff. This is, of course, an idealized death scene which is impossible to achieve in all instances. While the practical manifestations of a "dignified death" varied in each situation, many nurses described their efforts to achieve this ideal.

A central and necessary condition for the realization of a "dignified death" was that of preparation. Many nurses believed that a patient's family would only experience peace and comfort with their loved one's death if they were prepared for that eventuality. Several nurse participants in one interview discussed the importance of preparation:

> RN 1: Preparation makes the difference between a "good" death and a "bad" death....
>
> RN 2: Yeah, the "bad" ones, I think, are when it's totally unexpected and you don't have time to prepare....
>
> RN 3: I think the key word is prepared. When [families] are prepared, when all their questions have been answered...and they feel like they're part of the process, it's much better for them. And I think the unexpected [deaths]--the codes--are really hard on families, because they need that connection, the feeling of being with their loved one at the end (RN Int 3c, p. 8, #1, 12, 62).

In order to prepare a dying patient's family, nurses and physicians continued to meet with the family, both informally and formally, to ensure that they understood that their loved one's death was imminent. In this way, nurses' informing efforts overlapped with the previous situational understanding, especially in cases where the family was still hopeful for patient survival.

Death, for the most part, was a controlled event in the ICU. A patient's failing organ systems were supported by multiple devices and therapies, which could be manipulated, to a certain extent, to suspend the patient's dying process. As such, a patient's life support usually afforded healthcare providers the time to prepare the dying patient's family. In spite of this technological assistance, however, family preparation was not always possible.

For example, several nurse participants in different interviews discussed a memorable case in which the patient's unexpected death, coupled with the patient's unprepared family, created pandemonium in the unit and crisis in the family. As background, the 60-year-old patient became suddenly ill one night and suffered a cardiac arrest. She was resuscitated and brought to one of the study ICUs, at which point she arrested again. While the healthcare team successfully resuscitated her a second time, the patient's death was imminent. The patient's family arrived at the ICU, only to learn that their loved one was suddenly dying. A nurse participant continues with the rest of the story:

> The family was very expressive, both physically and verbally. One guy punched out the wall, one [family member] had a seizure in the room, another [family member] had a heart attack, and another [family member] passed out. In fact, the whole nursing unit was crazy, because we had to keep getting gurneys to take the family members down to the ER (emergency room). And then, one of the [patient's] daughters got really upset and grabbed [her mother] and said, "I'm taking my mother out of here!" But the patient was on a ventilator and we said, "Put her down now!" And she said, "I'm taking her out [of here] now!" It was really inappropriate...It was out of control. We got the Chaplain and he said a prayer. We had a family conference, but it was just one thing after another...The family just wasn't able to cope...it was like, "We can't let her go!" (RN Int 1e, l. 880, #3).

This tragic case underscores the importance of preparation when facing death. While this family might have behaved in a similar fashion and experienced comparable health problems if their loved one's deterioration had been more gradual, a slowly unfolding patient death would have at least allowed the healthcare team time to prepare the family and to marshal support, if necessary, from other helping professionals who could have assisted the family in coping with this major family crisis. This case also highlights the fact that, while healthcare providers and families may not want to experience imminent patient death, they often had no choice.

Being prepared was also important for clinicians. Healthcare providers who were still hopeful for patient survival in spite of mounting clinical evidence to the contrary were unable to prepare the family for the patient's fatal outcome, and, perhaps more importantly, were often unable to let the dying patient die. For example, one of the nurse participants discussed a recent case involving an 82-year-old chronically critically ill patient who coded unexpectedly:

> We have a vascular patient who has been [in our unit] for 45 days. He's got bad heart failure, and he'll probably never get off the ventilator....But everybody just really adores that man...and his wife knows all the nurses....He had an episode last Saturday where he had a V-fib arrest. And it really hit us hard. I mean, he's very fragile, very sick, and he may not even make it out of the unit. He's been trached and has multiple, multiple problems, but it was like, no, we weren't ready to let him go (RN Int 1d, 609, #62).

This case demonstrates how emotional engagement and lack of preparation on the part of the involved healthcare providers influenced how they reasoned in transitions and experienced the patient's rapidly evolving clinical course. Here the healthcare providers experienced death as a lifeworld event and not as a clinical inevitability. Because of the healthcare providers' situated understandings, the patient's V-fib arrest was untimely. In this way, timeliness is socially constructed by the practical orientation of the involved parties and their ability to recognize impending death.

Whether clinicians and the patient's family were ready or not, when a dying patient's condition reached a certain point, death occurred. The final phase of the patient's dying trajectory (Glaser & Strauss, 1968) can be thought of as the point at which end-of-life decisions had been made, life support had been withdrawn (or the decision had been made not to withdraw support), and the healthcare providers and the patient's family were simply waiting for the death to occur. Certain factors--such as the patient's physiologic reserves, the condition or illness from which the patient was dying, and whether the patient's life support had been withdrawn or not--determined whether this final phase ranged from minutes to days.

While nurses were primarily responsible for providing patient and family care during all stages of a patient's illness, their responsibility as front-line providers became especially apparent during the final phase of the patient's dying trajectory, as the physicians and the rest of the healthcare team turned their collective attention to other patients who were still viable. Medical rounds on a patient in this final phase became perfunctory, and physicians spent less time talking with the patient's family. Unless the nurses directly involved physicians (which usually occurred only if inadequate analgesics had been prescribed), physicians were notably absent during this final phase. As such, care of the patient and her/his family during this final phase was carried out by nurses.

Nurses ensured patient and family comfort by domesticating the immediate environment around the dying patient's bedside[43] and by providing the dying patient with comfort measures, which can be understood as a myriad of comforting practices (Benner, 1997). In terms of domesticating the environment, several nurses described transforming the sterile ICU patient room into a room that was tailored to the patient and family. Nurses often removed extraneous lifesaving equipment, dimmed patient lights, turned off the patient's cardiac monitor, lowered the side rails on the patient's bed, and placed tissues and chairs for family members around the dying patient's bedside.

By way of example, one nurse participant described a patient's death that she recently attended:

> RN 1: There were children, grandchildren, great-grandchildren, a brother, sister, 14 people in the room when [the patient] died....I taught [the family] how to read the monitor and told them what I expected would happen...I said, "Ultimately, [her] blood pressure will go lower and her heart will start to slow down. Her breathing is not going to change because of the ventilator, but her heart will slow down and then it will probably stop." I wasn't always physically in the room, but I was never more than a few feet away and I was always visible to them...And [one of the family members] would say, "Oh! The blood pressure is going down even more! Oh, look. Now it's in the 50's."

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[43] I am grateful to Susan Thollaug for this observation.

> RN 2: They get so focused on those numbers.
>
> RN 1: But that's how they know. I think that's real, concrete proof.
>
> RN 2: But I've been in situations [where the patient is dying] and we've shut the [cardiac] monitor off. Then the family seems to focus more on the person than the numbers.
>
> RN 1: It's true, they were watching the monitor very much so. But I felt like it was a wake, because they were at ease and comfortably talking about her life, and what a sweet woman she was, and what they remembered. So, watching the monitor wasn't really uncomfortable for them...I had the alarms turned off, so when her heart finally stopped, one family member cued into it and the rest of them said, "What's happened?" and I said, "Her heart stopped" and I turned off the monitor and ventilator. Everyone sobbed for a little while, but then the crisis passed, and they all sat in the room some more talking about her life....I felt like it was my family's wake, because by the end, I knew who the cousins were and who the second cousins were. But it was a very satisfying experience for me and I think it was for them too (RN Int 1f, l. 84, #65).

The nurse in this situation attended responsively to the patient's family by telling them what they could expect and by remaining close to the patient's bedside. By turning off the patient's alarms and placing chairs in the room for the patient's large family, the nurse domesticated the environment around the bedside and made the family feel welcome. Her openness and engagement with the family enabled the nurse to learn who the different family members were and to participate more fully with the family during their loved one's life passage, as the patient's death became a human passage rather than a medical event.

As discussed earlier in this chapter, nurses were keenly aware that adequate analgesia was required in order for the patient (and family) to experience a peaceful and comfortable--or "dignified"--death. As such, the comfort measures most often described by nurse participants were directed toward the relief of the dying patient's pain and suffering. As an example, one of the nurse participants described a dying patient with AIDS for whom she had cared:

> [The patient was admitted to the unit] the day after his birthday. He had just turned 48. And he and his friends were all planning to go [away] and have this big birthday bash, because most of them had AIDS and were losing friends rapidly. So all his friends were in his room....Anyway, the patient was out of it, but you could tell he was in pain....So I gave [the patient] a bunch of morphine, and [his friends] put some country-western music on. It was kind of neat, because it was like a big party. Anyway, in the end, they all thanked me and one of them wrote me a long letter about how he had seen many people die over the years. He had always thought that hospital deaths for AIDS patients were the worst. But what we had done that day proved to him that we could be compassionate people, even with all the technology around (RN Int 3e, p. 38, #7).

The nurse compassionately cared for the dying patient and his family of friends by ensuring that the patient was comfortable during his last few hours of life and by following the family's lead in tailoring the death scene to match what was desired and required by his family of friends in order to achieve closure. Because the patient's sudden exacerbation of his underlying illness prohibited their "birthday bash," the nurse instead assisted his friends in creating a "party" atmosphere at the dying patient's bedside. Given that nurses spoke of "death with dignity" to mean a peaceful and comfortable dying patient surrounded by peaceful and comfortable family and staff, the dying patient's "party" thrown by his friends and facilitated by the nurse was simply another form of this idealized death.

Nurses also facilitated family cohesion and closure by providing consistent care to the dying patient and family, eliciting the sharing of family stories, and involving interested family members in postmortem care. As discussed in the previous chapter, nurses who typically understood the family as an extension of the critically ill patient recognized the importance of consistent caregiving in building and maintaining the nurse-family relationship. When the patient was dying, nurse participants described the provision of consistent caregiving primarily in terms of staying over after their shift had ended to complete their work with the dying patient's family. This practice is illustrated in the following excerpts from two nurse participants in different interviews:

> [The patient] died during my shift. In fact, we were over-staffed and I wanted to go home, but I just didn't feel like I could go home on the [family]. So I stayed until [the patient] passed away and until the family felt like leaving (RN Int 1f, l. 84, #65).

* * *

> We withdrew support late in the shift. And they were short the next shift, so I stayed over another four hours, just to kind of finish up with [the family]...I didn't want them to have a new face for the last hour or two of her life....And it wasn't that big of a deal, but I guess it was for them, because about a week and a half later, they brought me two dozen roses!....So even though it was a sad outcome, [the patient's family] felt supported and that, pretty much, was the only goal I had for them (RN Int 2b, l. 50, #9).

Nurses who continued to provide care to the dying patient and her/his family after their shifts had ended did so out of respect for the relationship that had developed between the nurse and the patient and family, but also to provide the family with a "familiar face" during the uncharted and emotionally charged passage of their loved one's life. As these nurses were bearing witness to the death in particular ways shaped by the nurse-family relationship, a new person would not be able to enter the situation and help the family in the same way. These nurses responded to the ethical responsibility of being in a relationship with the patient's family, and, in so doing, facilitated the family's closure with this major family event.

In another example, a nurse participant shared an incident that became a paradigm case for her--a powerful clinical experience that turned around her preconceptions of caring for a dying patient's family in the ICU (Benner, 1984):

> When I first came here to work, I took care of a bone marrow transplant patient who had pulmonary edema and [ended up getting] intubated. She was my age, and had two little kids and a husband who were totally devoted to her...I had just come here from [another institution], and even though it was an [ICU], the unit was a lot different. [At this other institution], we got a lot of trauma overflow...they were mostly acute...and we had a strict visiting policy. It was like a lot of the ICUs that you read about....But this husband really wanted to be involved. He was there for hours and made tapes for her. She, over time, got gradually worse and worse--to the point where she was on 100% [oxygen] and [we] had maxed [out on] everything--she was going to die. I took care of her night after night...and even though she probably wasn't really a one to one...they left her a one to one, and I was able to sit with her at night....The three of us had a relationship consistently over a two week period...They were extremely close. I mean it was an incredible relationship....And the night that we extubated her, he brought in their minister and the three of us were at her bedside when she died. She wanted to be extubated and say a couple of words to her husband before she died. I was sobbing hysterically....Her husband was comforting me. I mean, I was so out of control. I was totally ineffective as a healthcare provider. It was like my best friend had died....I just hadn't had that kind of relationship with a family member [before]. He had gotten to be like a member of my family. And he wrote me for a long time after [that]....but I went home that morning, and thought, "I'm in the wrong business." You know, I just can't handle it. I think why this

> family made a difference for me, [is that I] recognized that families offered a lot more than just being in my way when I'm trying to do something....I mean, I know that I definitely came out [of this] a better person...even though it was incredibly sad (RN Int 1d, l. 262, # 61).

By virtue of the nurse's consistent caregiving to the patient and family, an intense relationship developed over a two-week period. While the nurse believed that she was "totally ineffective," her connection with the patient's husband and her compassionate response to his wife's death enabled her to share his grief work through her tears. In sharing the husband's sorrow, what was private and individual became social.

Nurses also facilitated family cohesion and closure by eliciting the sharing of family stories around the dying patient's bedside. Expressing family stories and shared experiences involving the dying patient enabled the patient's family, in the midst of their pain and sorrow, to recognize the joy that they had in their relationship with the dying patient. For example, one of the nurse participants described an interaction she had with a dying patient's granddaughter:

> Two or three weeks ago, I took care of a large Hispanic family. The patient, who was dying, was the matriarch of this family....A lot of [the family members] relied on her and looked up to her--she was like the guiding force in a lot of their lives....The youngest granddaughter started talking about her relationship with [the patient]. And I listened and tried to reflect on the positives, like, "Being in touch with such a strong woman, you have to have some of her strengths to help you through this." It's always challenging to do that kind of work (RN Int 1f, l. 198, #6).

The nurse in this situation further encouraged the grieving granddaughter to talk about her relationship with the dying patient by attentively listening to her stories and compassionately responding to them. Enabling the granddaughter to express her deep feelings to an understanding and responsive "stranger" facilitated family cohesion by making the family bonds and strengths visible and public.

While eliciting family stories can help facilitate family cohesion, the stories themselves often animated the dying patient's personhood and made the family's pain and sorrow accessible to the nurse. One of the nurse participants shared a painful clinical incident that turned around her preconceptions of working closely with a patient's family in the ICU:

> RN 1: A long time ago, when we first opened [one of the ICUs], [I took care of a patient]...He was like 36...[He had] an elective procedure and went out to the floor and had a cardiac arrest...Anyway, [he] came back to the unit, and because he was so young and viable, they put a ventricular assist device (VAD)[44] in him...When we got into report, the patient had just come back and his chest was open....He was on lots of drips, so of course, I'm like, "I'll take him!"....So, I get back there, and he's bleeding...He was a mess....So I started my nursing duties, and to me, he's just a guy. So [someone] said, "His wife wants to come in, do you mind?" And I said, "No, sure," and I went around the corner to say hello to her...and she was eight months pregnant. This beautiful woman...who's also a nurse, she's eight months pregnant, and they have a little 2-year-old at home and I'm like, "Oh, God!"...By this time we're realizing there's no way this guy is going to live...and she had that impression as well....She just reminisced about their lives together and how she was engaged to someone else when she met him. [She] just went through basically all her memories of

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[44] "VAD" in this instance refers to a left ventricular assist device. Mechanical flow assistance (in the form of a VAD) becomes necessary in the event of circulatory collapse, and acts by reducing cardiac work by diverting blood from the natural ventricle to an artificial pump that maintains the circulation.

him, and they were just heart wrenching. Even to this day, I get the chills thinking about it, because I was standing there, and she said, "You don't understand, I will never find anyone to fill his shoes." She said, "I can't believe this is happening to me." And I cried and she was crying, and it was just such a tangible loss, that it was really overwhelming. I had to go home after he died, because I was such a wreck. I dreamt about them for months.

RN 2: Funny how these patients become part of your life, too.

RN 1: I know and I never bargained for that. You know, I thought I was going to get a cool patient to take care of, and here I am falling apart...She was just trying...to sing his praises, so that I didn't see him [the other] way...

RN 2: As a mess.

RN 1: Yeah, [and] she wanted me to realize, for whatever reason, what kind of human being was dying here.

Int: So, did you initiate the reminiscing?

RN 1: Yeah, I initiated it....because I was asking her some questions about him...She sat by his side, and stroked his head and talked to him, and he just kind of died....So, anyway, to sum that whole thing up, I really feel like I gave a lot of myself that night, so much so, that even just talking about it years later, I get choked up. I mean, when you think about, "When am I going to meet the one?", well, meeting the one is one thing, but then...

RN 3: Losing the one.

RN 1: Yeah, can you imagine? That's not even in your mind.

Int: And so after that, were you able to get close to families again?

RN 1: You know it's funny....I've always [been] able to give clinically, you know, a facilitator, a helper, and I care, but I'm not involved completely and personally.

RN 2: You can't get involved like that all the time.

> RN 1: No, but once in a while it happens. And when it does, you realize that's the dangerous point, and no one can pay you enough to do that. I mean, you don't even do that for yourself sometimes....I want to be caring and empathetic, but I don't want to lose myself like I did that night (RN Int 1f, l. 263, #6, 64, 65).

The nurse in this situation offered to take this "cool patient" assignment because the patient's critical condition (supported by "lots of drips" and sophisticated machinery) afforded the nurse many clinical challenges. What she had not "bargained for," however, was the emotional vulnerability which she would feel after meeting and interacting with the patient's wife.

The patient was initially perceived by the nurse as an object to whom to deliver nursing care. He was an anonymous "mess" symbolizing to the nurse many clinical tasks and nursing activities. Upon meeting the patient's wife, however, the nurse's understanding and involvement with the situation and the patient changed. The wife was not only a "beautiful woman," a fellow nurse, and eight months pregnant with their second child, but also was immensely in love with her dying husband. Through the patient's wife, the nurse learned about who the patient was as a husband, a father, and a fellow human being. The wife's reminiscing animated for the nurse the patient's personhood and made the family's profound suffering, grief, and loss palpable.

Because this nurse so closely identified with the patient's wife, his death also forced the nurse to think about future losses which she might face. This case so greatly affected this nurse that she now protects herself from that kind of emotional exposure with other patients and families. She gives "clinically," but does not involve herself "completely and personally" as she did that night. This illustrates the danger that over-involvement with a patient or her/his family can have on a nurse.

Finally, nurses also facilitated family closure by involving interested family members in postmortem care. While postmortem care can be thought of in procedural terms, such as the cleansing and preparation of the dead body for removal from the unit, it can also be understood as a therapeutic nursing ritual. As a nursing ritual, it is seldom witnessed by--much less, open to involvement with--other hospital personnel and the patient's family (Wolf, 1988). Yet, several nurse participants described in different interviews a family member's involvement and participation in their loved one's postmortem care.

As an example, one of the nurse participants described a patient for whom she had cared who died during a medical procedure:

> I told the [patient's wife] that I was going to do [his postmortem care], and she asked me if she could help. And the wife had a wonderful dynamic presence about her....She was an incredibly passionate woman, and I got the impression that they had a wonderful relationship....And she came in and helped me bathe him and lay him out. And it took us both about an hour to do that, but it was the most loving, caring thing I'd ever seen someone do....I was really upset about the death, because it happened with the procedure, and I felt the procedure was pretty rough. But our doing this together was like a catharsis, it was very moving, and I felt it gave her something to do. And then her son came in and kind of helped at the end, as well....It seemed like a very cherished experience (RN Int 3d, p. 16, # 11).

By facilitating the wife's involvement and participation in her husband's postmortem care, the nurse enabled the wife to participate in a profound act of closure. In her laying on of hands, the wife was able to lovingly touch and clean her husband's body for the last time and symbolically remove any evidence of his suffering. While a patient's death *is* a family event, the patient's family rarely, if ever, gets to participate in this last caring act. Nurses' facilitation of family involvement in postmortem care (to the extent that it is desired) offers possibilities to both parties engaged in this meaningful act--possibilities that would not be accessible to either party acting alone.

Conclusion

These findings, which extend Benner, Hooper, and Stannard's (in progress) domains of critical care nursing practice and build on the interpretive work of Benner, Tanner, and Chesla (1996) and Hooper (1995), articulate what many clinicians know from their everyday practice--namely, that healthcare providers and the dying patient's family do not necessarily experience a given situational understanding in the same way or at the same time. Situational understandings or reasoning in transitions can be thought of as individual and collective experiential transitions characterized by changes in understanding as the clinical situation unfolds.

Conflict between nurses, physicians, and families occurred when one party experienced a shift in understanding and attempted to change the dying patient's clinical course before the other parties experienced the same transition. Allowing all parties the time to reason in transitions for themselves would greatly reduce the possibility of conflict and the potential for clinician burnout and survivor trauma. This is what typically occurred when death was understood as a family event, which is to say when healthcare providers took the dying patient's family and their understanding of the clinical situation into account when planning and acting on important end-of-life decisions.

Understanding death as a family event falls under a larger approach to ethics that emphasizes the established relationship between the healthcare providers and the patient and family. This has been described as an ethic of care (Benner, 1996; Lindseth, 1996; Martinsen, 1996). This approach differs from the standard decisional ethic, which assumes that the parties have no established relationship. This study has demonstrated, however, that many ICU nurses and families do develop relationships with one another which offer possibilities for connected knowledge, trust, meaning, and understanding. To the extent that these relational possibilities exist, they should be utilized when approaching end-of-life decisions and other clinical/ethical issues.

Chapter 7

Reclaiming the House: Implications for Practice, Education, Healthcare Administration, and Research

"...that's probably when it occurred to me that families should be included rather than excluded"--Nurse Participant

To reclaim is to "bring back, as from error, to a right or proper course," and is complementary to the postmodern notion of "finding one's voice" (American Heritage Dictionary, 1992, p. 1509; Frank, 1995). Through the course of this research, I sought to understand the voices, practices, and concerns of ICU nurses and families of "silent" critically ill patients and to make their everyday interactions and activities visible.

This study points to aspects of everyday clinical practice that are under-valued and overlooked. While several studies investigating patients' and families' perceptions of nursing care found that nurses' caring behaviors and interactions were important to patient and family satisfaction (Burfitt, Greiner, Miers, Kinney & Branyon, 1993; Holland et al., 1997; Irurita, 1996; Potinkara & Paunonen, 1996; Warren, 1994), no studies could be found that demonstrated "why" some nurses exhibited caring behaviors and others did not. In addition to describing the "how"--which is to say the ways in which nurses cared for critically ill patients' families--this study also articulated the "why" behind the "how."

The degree to which a nurse was emotionally available to be with and care for a suffering family was inextricably intertwined with how the nurse was in the situation, which can be thought of as the nurse's relational stance. The habits, practices, concerns, and skills which a nurse brings to the situation are all aspects of her/his stance. A nurse's relational stance made certain activities and interventions possible and determined, in part, how successful the nurse-family interaction would be. In this way, nurses' relational stances can be understood as the "why" behind the "how."

Three relational stances characterized the manner in which nurses typically related to patients' families, namely: standing apart from the patient's family; standing at a distance from the patient's family; and standing alongside the patient and family. These three stances each involved a different amount of emotional engagement and risk to the nurse and family.

Additionally, this study articulated three situational understandings which most healthcare providers and families of dying critically ill patients experienced, namely: fighting for the patient's life; shifting focus based on changing clinical relevance; and facing death. Situational understandings, or reasoning in transitions, can be thought of as individual and collective experiential transitions characterized by changes in understanding as the clinical situation unfolds. The nurse's and family's reasoning in transitions influenced how they understood the critically ill patient's trajectory and expected outcome, and, together with their respective stances, shaped and situated the possibilities for action and intervention.

This study also described critical care from the family's perspective. Families' accounts of critical care were a very different kind of discourse from the traditional medical account, which typically excludes the family's experiences. The families' stories held the emotional human content of suffering and loss that medical discourse tends to keep at a distance. Patients' and families' concerns were typically separated from the clinical story in an attempt by healthcare providers to cope with the human suffering for which they were often partially responsible. Bridging the gap between the family's lifeworld and the medical world of the ICU by bringing the family's concerns into the medical dialogue could inform clinicians' understandings and further guide their clinical judgments.

By their nature, nurse-family interactions and family care interventions and activities are constituted by what is accessible to nurses and family members. This study demonstrated that it was through the nurse-family relationship that nurses and families understood the possibilities and options for care. If we are to realize more enlightened ways of caring for families in critical care settings, a greater understanding of existing family care practices must be achieved. The purpose of this final chapter is to address some of the barriers to providing family care and to offer implications for practice, education, healthcare administration, and research.

Barriers to Nurses' Provision of Family Care

Healthcare, in general, is in a state of crisis. The rippling effects of changing healthcare financing have been felt from healthcare administrators to bedside nurses and the patients and families for whom they care. Because administrators have become increasingly concerned about the growing number of uninsured patients and the sky-rocketing costs of patient care, along with falling inpatient activity and the dwindling resources to pay for patient care, skill mix changes and layoffs have occurred in hospitals around the country (American Hospital Association, 1994-95; Burda, 1994; Perlman, 1995; Smith, Danforth & Owens, 1994). Additionally, hospitals' reengineering efforts and work place redesign have resulted in the creation of nursing float pools, the cross-training of staff, and the shift from primary nursing to team nursing (Birnbaum, 1986; Walleck, 1994).

All of these changes have had an enormous impact on nurses' ability to provide family care, as many nurses are struggling to provide even safe patient care. Caring for patients and their families takes time (Gunn, Nightingale & Cable, 1989). But with decreasing registered nurse staffing levels and with increasing patient acuity, patient-nurse ratios, and use of unlicensed assistive personnel requiring nursing supervision, time is limited for bedside nurses. Nursing float pools have made nurses' efforts at providing continuity of care more difficult and have isolated and removed nurses from their unit-based communities of knowledge, memory, and learning. Additionally, the shift from primary nursing to team nursing has moved the bedside nurse further away from the patient's bedside. This has curtailed many nurse-family interactions, as these interactions often no longer occur while patient care is being provided.

Yet, this study has demonstrated that the nurse-family relationship often fostered knowledge, trust, and understanding. Building and maintaining a relationship with a family required a nurse to have relational skills, time (or at least the ability to provide consistent care over several shifts), and unit-level support. Given the healthcare changes that have already occurred and those expected in the future, nurses' abilities to provide meaningful family care will be further challenged.

This study also demonstrated that it was through the nurse's emotional engagement and involvement with a patient's family that the nurse was able to understand a particular family's concerns and issues and provide care for the family on the family's terms. In contrast, nurses who protected themselves by disengaging or distancing themselves from patients' families were not emotionally available to interact with families on the families' terms, rather families were forced to accommodate the nurses. Thus, nurses' and family members' emotional availability and openness in the shared situation made certain actions, activities, interventions, and interactions possible while closing down others.

Not surprisingly, many nurses in this study reported that engaging in relational work with a critically ill patient's family was oftentimes emotionally and existentially difficult. Nurses who were engaged and involved with a critically ill patient's family were open to experiencing feelings of vulnerability, stress, and risk. When the critically ill patient was dying, nurses often felt profound sadness and conflict among themselves, other healthcare providers, and the patient's family. Yet, with cutbacks in healthcare, many hospitals have eliminated positions and programs that provided assistance to nurses and other staff in working through their feelings associated with the demands of relational work. With less time to spend interacting and reflecting on one's relational work with patients and families, it is little wonder that some nurse participants reported feelings of stress in connection with the provision of family care.

Nurses in this study who had success in working with particular families often returned to those interpersonal regions when working with other families. The converse, however, was also true, as nurses who struggled in their interactions and interventions with a particular family often shied away from relational work with other families. Traumatic interactions with patients' families often set up for nurses future stances of disengagement and family avoidance. Without the institutional support of providing nurses with education, assistance, and consultation from others, nurses' relational skills may not advance and family care may be hindered.

Finally, most nurses reported having very little formal education to prepare them for their interactions with patients' families. In a survey of 468 baccalaureate and higher degree nursing programs accredited by the National League for Nursing (NLN), virtually all undergraduate schools reported teaching the nursing process as applied to families (Hanson & Heims, 1992). Critical care areas, however, were the least used settings for family nursing clinical experiences. Labor/delivery/newborn units, community health agencies, and ambulatory/home health settings were the most frequently used settings for clinical experiences pertaining to family nursing (Hanson & Heims, 1992). This underscores the bias in healthcare and educational institutions regarding the importance of families in certain age- and location-specific settings. As such, graduate nurses new to critical care may be ill-prepared by their nursing education insofar as relational and involvement skills with critically ill patients and their families are concerned.

While these barriers present current challenges and future threats to nurses' provision of meaningful family care, this study also found nursing innovation in the face of dramatic changes in healthcare. To that end, specific implications of this study are offered for practice, education, healthcare administration, and research.

Implications for Practice

This study has shown how the everyday interactions between nurses and families made certain activities and interventions possible. Yet many nurses and nurse managers overlook the use of "self" and its importance in relational work with others. Consistent nursing care of a patient's family, for instance, often forged a relationship between the nurse and family. The established relationship, in turn, made certain interactions and interventions accessible to the nurse and family members that were previously inaccessible.

Idealizing positive nurse-family interactions when a patient's condition was stable and simply comparing them, for example, to less positive interactions when a patient's condition was critical fails to take into account the differing situational contexts. This study articulates situated family care such that nurses provided the best family care they could given their skills, concerns, experiential and personal knowledge, the particular patients and families for whom they cared, and the situation itself. Thus, family interventions and options for care were always bounded by the situation and the relational stances of the nurse and family.

This study has further demonstrated that four kinds of learning--familial, experiential, social, and personal--shaped nurses' relational and involvement skills with families. A nurse's personal way of relating to others was reshaped through experiential trial and error learning in specific situations, resulting in a professional way of relating to patients, families, and other healthcare providers.

The tempo, mood, climate, and culture of any nursing unit make certain kinds of caring practices and social learning possible while prohibiting others. Nurses who practiced in a "family-friendly" unit culture were able to share and learn from one another in developing family care skills, both personally and collectively as a unit. This study complements findings from previous research which found that less than optimal family care or breakdown between nurses and families occurred frequently in ICUs that had a "family-restraint" culture (Chesla & Stannard, 1997). While nurses who are already skilled in family care may find it more difficult to work with families when practicing in a family-restraint oriented ICU, nurses who are not expert in working with families may lack the vision of excellent family care and the institutional and unit encouragement to develop and refine their family care skills.

Still other nurse participants learned and honed their family care skills based on personal experiences as family members of hospitalized loved ones. Experiencing first-hand the family's plight opened up new understandings for many nurses and changed their interactional patterns and family care practices in tangible ways.

These four kinds of learning would have an even greater impact if nurses shared their experiences and family care stories from their practice. Sharing stories of practice can increase nurses' skills in recognizing patient and family concerns; communicating with patients and families; reflecting on ethical comportment and engaged clinical reasoning; and articulating experiential, social, and personal learning and clinical knowledge development (Benner et al., 1996). This study agrees with previous research that supports the practice of having nurses present their narratives of clinical learning to one another in order to transmit and extend subtle clinical lessons learned (Benner et al., 1996; Darbyshire, 1994).

Creating the interpersonal and institutional space in which to both tell and actively listen to patients' and families' stories can complement nurses' narratives of learning and provide a "lived" account of each unfolding clinical situation. Listening to a patient and family's whole story would enable healthcare providers to see beyond a list of patient procedures and would allow for new understandings of the patient and family's plight. These understandings can provide clinicians with guidance--and in some cases, corrective action--to intervene in ways that are true to the patient's condition and to the patient and family's interests (Benner, 1997). Through reflection and dialogue with others, nurses and other healthcare providers can extend their care to include patients' families and further their care of patients and families.

This study also calls into question many of the family policies and unit rules that currently exist in ICUs. Because most families in this study were encouraged to stay with their critically ill loved ones, nurse-family relationships developed that made tailored family-oriented activities and interventions possible. In light of these findings, family visitation rules should be recast as guidelines, which would allow nurses to take into account the uniqueness of each patient and family and the demands and possibilities of each nurse-patient-family situation.

Some family participants were not always able to keep vigil in the ICU. In this study, family members described the importance of "virtual visiting" or nurses' provision of information over the telephone. Detailed information kept families connected to their critically ill loved ones' when the families were unable to be physically nearby. This finding calls into question unit and hospital policies which prohibit the provision of telephone information to close friends and family by nurses and other healthcare providers.

The extent to which families are encouraged to get involved in caregiving activities should also be re-examined in light of these findings. Involvement in patient care enabled family members to be helpers and not merely observers. Additionally, involvement in careplanning and caregiving activities assisted the healthcare team to plan and implement personalized patient care and facilitated a family's emotional and physical connection to their critically ill loved one.

Nurses and nurse managers should re-evaluate care delivery in their units as it relates to continuity of care with patients and families. Developing trust and rapport with a family required a nurse to have relational skills, emotional availability, and a level of engagement such that an openness to understanding the family was possible. Establishing a relationship also took time, which is why many nurse participants attempted to consistently care for the same families over time. Providing continuity of care to patients and families requires a commitment on the part of nurses and nursing administration to ensure that continued relational work between nurses, patients, and families is possible.

Finally, this study highlights the import and significance of patients' families and articulates many of the options and possibilities for care that were disclosed in given situations by virtue of a family's presence and contributions. While clinical competencies and standards for practice rarely speak to family care, unit and hospital policies often address families in terms of what they can and cannot do. Understanding patients' families as integral to the patient care team and recognizing the valuable contributions they can make in that role, would enable families to reclaim the house and would greatly benefit and advance patient and family care.

Implications for Education

This study found that many nurses were ill-prepared for the emotional demands of caring for suffering patients and their families. As Benner, Tanner, and Chesla note:

> In our educational settings we have long taught the power of critical thinking, judgment, distancing, and disengaged reasoning. We have all but ignored the centrality of emotional engagement to learning, thinking, and being with others. There are traditional reasons, even prudent reasons, for this emphasis on disengaged critical reasoning and silence on relational skills and engaged reasoning. It is easier to teach critical thinking, disengagement, and judgment, than it is to teach openness, being with, dwelling, engagement, and discerning qualitative distinctions (1996, p. 309).

Because family care skills are social skills and learned, in large part, experientially by nurses, dialogical classroom and clinical experiences should be utilized alongside the traditional didactic approaches to better prepare future nurses for their everyday interactions with patients and families. For example, small group projects can make public nurses' first-hand narrative accounts of being a family member of a hospitalized loved one. As nurse participants reported that these personal experiences changed their family care practices, disclosing their narrative accounts might transform other nurses' practices.

The use of narratives and other reflective exercises can help nursing students address five central issues: learning to perceive or identify relevant clinical problems; learning to address the limits of formalism by situating clinical problem solving according to the most relevant goals and intents; learning to reason in transitions about the particular clinical situation; learning the ethical skill of problem engagement and interpersonal involvement; and learning to take a stand as a responsible agent by making clinical judgments, acting on them, and advocating for the patient and family (Benner et al., 1996).

While several studies have found that nurses and other healthcare providers' orientation to families were positively influenced by their educational preparation (Gill, 1993; Porter, 1979), nurses in this study and others have indicated that they had little formal training in family care (Brown & Ritchie, 1989; Brown & Ritchie, 1990; Chesla, 1996; Drotar, 1976; Porter, 1979). Teaching family concepts in basic nursing education is essential in order to sensitize and prepare nurses for providing family care (Bell, 1997).

This study also demonstrated that nurses reasoned in transitions as a patient's clinical condition unfolded. As a nurse gained a situated understanding of a particular patient and family in a specific situation, new interventions and activities became accessible. But nursing education has typically relied on nursing care plans and other instructional devices which emphasize analytic thinking and planning (Benner et al., 1996). These devices may actually limit the possibility of a nurse's being open to a clinical situation as it unfolds. To that end, this study suggests that students be taught practical ways of knowing, thinking, and reasoning (Hooper, 1995). Additionally, because patient death was an everyday event for ICU nurses, more emphasis should be placed on sensitizing and preparing students to confront patient death in their practices and to help others to face death.

Implications for Healthcare Administration

Many of the implications for healthcare administration offered here overlap with the practice implications. Hospitals have become resource-poor environments for consultation and skill advancement in family care (Chesla & Stannard, 1997). As this study and others have highlighted, ICUs are the domain of patient-centered specialists, and decisions about a patient's care often involve as many as six or eight specialists in various body systems (Chesla & Stannard, 1997). Yet, few hospitals have individuals who specialize in family systems. While many family scholars have argued that nursing care targeted at the family unit constitutes specialty level practice commensurate with graduate nursing preparation and supervised clinical experiences (Chesla, Gilliss & Leavitt, 1993; Gilliss, 1991; Robinson, 1995), masters' prepared clinical nurse specialists and educators have increasingly lost their jobs under reengineering efforts or have been re-assigned to develop care maps and critical pathways. As such, nurses in many units lack role-models who can guide and assist staff in working with patients' families (O'Keefe & Gilliss, 1988).

As previously discussed, many hospitals have eliminated or diminished resources which enabled nurses' to provide family care. While education--

especially in the form of family workshops and skill-building sessions--would undoubtedly benefit nurses, ongoing consultation and support of bedside nurses by staff experienced in family systems work could infuse individual and unit-level knowledge and family care skills (Chesla & Stannard, 1997).

Administrators can also create and enhance the work climate by ensuring that clinical learning is possible. This requires, first and foremost, adequate staffing with a blend of skill levels on all shifts (Benner et al., 1996). Additionally, with the creation of nursing float pools and the increasing number of part-time staff, administrators can promote the sharing of knowledge, memory, and clinical learning by encouraging nurses to share stories from their practice. Finally, promoting nurses' care of families necessitates a commitment, on both the unit and hospital levels, to ensure that relational work is possible. This includes re-evaluating family policies and rules, patient and family care practices, and healthcare providers' relational skills.

Implications for Future Research

This study found that families of critically ill "silent" patients have needs, but also bring with them to the ICU their own histories, resources, habits, practices, and skills. This can be thought of as the family's stance, which may or may not be in synchrony with the nurse's stance. Thus, this study extends beyond the "needs" studies and articulates the family behaviors which prompted and encouraged nurses with different levels of emotional availability to understand and interact with families in particular ways. Families, in fact, who were perceived by nurses as "needy" prompted and encouraged nurses to work around them and discount their concerns and experiences. Additionally, nurses who managed their emotions to the extent that they typically interacted with patients' families in an emotionally distant or disengaged manner were less able to recognize, understand, and respond to families' needs.

This is in contrast to nurses who typically stood alongside patients and their families. Nurses who understood, interacted with, and responded to a patient's family on the family's own terms were typically able to provide family care that was tailored to match what was desired or required in the shared situation. A nurse's stance, together with the patient's family, made certain family-oriented activities and interventions possible. Future research efforts should seek to articulate families' stances and their subsequent impact on ICU nurses' practical activities and interactions.

This study suggests the need for further research examining the everyday nursing interventions and activities with families consisting of multiple respondents. While recruitment efforts could be difficult, such an investigation would be invaluable, and could shed new light on how nurses care for and work with multiple family members around the critically ill patient's bedside. Additionally, future research could build on this work and examine how nursing interactions and activities with patients' families change to include the critically ill patient when he/she is interacting.

This work could also be extended to follow families across the acute care continuum, starting with patient admission and ending after the patient was discharged home or patient death occurred. While longitudinal interpretive studies are more difficult to conduct (due, in large part, to recruitment issues, expense, and participant attrition), such longitudinal study findings could reveal specific issues and concerns that might otherwise be inaccessible.

Future research efforts should also be directed toward articulating how nurses care for patients' families across the lifespan. While neonatal and pediatric nursing practices differ from each other and from adult nursing practices, caring knowledge and notions of good are socially embedded in the practice of nursing, regardless of specialization (Benner et al., 1996). Examining how neonatal and pediatric nurses take up the practice and care for families would broaden our understanding of both nursing practice and family care.

Research is also needed to evaluate and understand how nurses' practical interventions and activities with families are influenced by their level of skill acquisition. Doherty (1985) theorized that clinicians can involve themselves with a patient's family on five distinct levels, which represent a developmental sequence on the part of the clinician. This study demonstrated, however, that nurses' practical interactions and activities with families varied substantially based on the clinical situation, the family, and the nurse's emotional availability in the situation. Research employing purposive sampling of nurses from advanced beginner to expert could draw out distinctions in terms of family care between nurses' different clinical worlds.

Finally, in this study, three out of eight families' loved ones were too ill to be discharged home, and, as such, were discharged to long-term care (LTC) facilities to continue their recovery. Interpretive studies examining LTC nurses' and other healthcare providers' family care practices and skills would greatly enhance our understanding of how patients and families receive care over the entire illness trajectory. Such studies are also needed to understand the long-term impact of the family caregiver during the acute stage of the illness.

Conclusion

While most ICUs are not yet in the place where families can reclaim their rightful place as involved and caring participants in their loved one's ICU experience, this study has demonstrated that many nurses were able to meaningfully involve families in their loved ones' care. Additionally, this study found that many ICU nurses and families developed relationships with one another that offered possibilities for connected learning, trust, meaning, and understanding. The power of articulation lies in the promise that some nurses may consider their own practices when reading these stories, and that this articulation may enable them to better understand themselves and their own practices and empower them to translate this understanding to their care of critically ill patients and their families.

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Appendices

Appendix A.

University of California, San Francisco
Nurse Participant Consent to Participate in a Research Study
Project Title: Nursing Interventions with Families in Critical Care

Purpose:

Daphne Stannard, RN, MS, CCRN and Patricia Benner, RN, PhD of the School of Nursing are conducting a study investigating which nursing activities family members of critically ill patients think are helpful. We would like to ask you to participate in this research.

Procedures:

If you agree to participate in this study, you and other nurses participating in the study will talk with Daphne for a total of three hours, divided into three one-hour interviews. The interviews will be tape-recorded. Additionally, Daphne will observe nursing activities in relation to family members of a critically ill patient for whom you are caring on two different occasions for 1 and ½ hours each. You will also be asked to fill out a form that asks some basic information about your nursing background.

Risks/Discomforts:

Talking about your experiences and being observed may be difficult or unpleasant. However, you are free to talk only about those aspects of the intensive care unit experience that you want to discuss, and you may refuse to answer any particular question. You are also free to stop the interview and/or observation at any time. Participation in the study may involve a loss of privacy, but several precautions are taken to avoid this. For example, the tapes are transcribed to written form and, after completion of the study, the tapes are erased. The tapes and transcriptions are locked in a cabinet at all times. Your names are not marked on the data; only code numbers are used. Only Daphne and her supervisor, Dr. Benner, will have access to the code numbers. Your name and other identifying characteristics will never be identified with any story or portion of the interview that is published.

Benefits:

There are no direct personal benefits to you. However, the information you provide will help health care providers to better understand what activities are helpful to families of critically ill patients. Sometimes nurses enjoy talking about their practice, and sometimes an interview or observation helps them clarify ideas or see things a different way.

Costs/Reimbursement:

There will be no costs to you for being in the study. There is no reimbursement for the interview or observations.

Questions:

You have talked with Daphne about this study and have had your questions answered. If you have further questions about the study, you may contact either of us at:

Researcher: Daphne Stannard, RN, MS, CCRN
Doctoral Student
Department of Physiological Nursing, Box 0610
UCSF School of Nursing
San Francisco, CA 94143
Home Telephone: (415)441-1407
Pager: (415)458-9257

Supervisor: Patricia Benner, RN, PhD
Professor
Department of Physiological Nursing, Box 0610
UCSF School of Nursing
San Francisco, CA 94143
Office Telephone (415)476-4313

Rights:
If you have any comments or concerns about participation in this study, you should first talk with one of the researchers. If for some reason you do not wish to do this, you may contact the Committee on Human Research, which is concerned with the protection of volunteers in research projects. You may reach the committee office between 8:00 AM and 5:00 PM, Monday through Friday, by calling (415) 476-1814, or by writing: Committee on Human Research, Box 0962, University of California, San Francisco, CA 94143. The approval number for this project is H184-08441-04.

You have received a copy of this consent form. Your participation in this study is completely voluntary. You have the right to refuse to participate and the right to withdraw from this study without any jeopardy to your employment status in the intensive care unit.

YOU ARE MAKING A DECISION WHETHER OR NOT TO PARTICIPATE IN THIS STUDY. YOUR SIGNATURE INDICATES THAT YOU HAVE DECIDED TO PARTICIPATE AFTER READING THE INFORMATION ABOVE AND DISCUSSING ANY QUESTIONS WITH DAPHNE STANNARD.

Signature of Participant/Date	Signature of Researcher/Date

Appendix B.

University of California, San Francisco
Family Member Consent to Participate in a Research Study
Project Title: Nursing Interventions with Families in Critical Care

Purpose:
Daphne Stannard, RN, MS, CCRN and Patricia Benner, RN, PhD of the School of Nursing are conducting a study investigating which nursing activities family members of critically ill patients think are helpful. We would like to ask you to participate in this research.

Procedures:
If you agree to participate in this study, you will talk with Ms. Stannard for a total of three hours, divided into three one-hour interviews. The interviews will be tape-recorded. Additionally, Ms. Stannard will observe nursing activities in relation to you, the family member, at the bedside on two different occasions for 1 and ½ hour each. You will also be asked to fill out a form that asks some basic information about your family and this hospitalization.

Risks/Discomforts:
Talking about your experiences and being observed may be difficult or unpleasant. However, you are free to talk only about those aspects of the intensive care unit experience that you want to discuss, and you may refuse to answer any particular question. You are also free to stop the interview and/or observation at any time. Participation in the study may involve a loss of privacy, but several precautions are taken to avoid this. For example, the tapes are transcribed to written form and, after completion of the study, the tapes are erased. The tapes and transcriptions are locked in a cabinet at all times. Your names are not marked on the data; only code numbers are used. Only Ms. Stannard and her supervisor, Dr. Benner, will have access to the code numbers. Your name and other identifying characteristics will never be identified with any story or portion of the interview that is published.

Benefits:
There are no direct personal benefits to you. However, the information you provide will help health care providers to better understand what activities are helpful to families of critically ill patients. Sometimes family members enjoy talking about what has been useful from their point of view and sometimes an interview or observation helps them clarify ideas or see things a different way.

Costs/Reimbursement:
There will be no costs to you for being in the study. There is no reimbursement for the interview or observations.

Questions:
You have talked with Ms. Stannard about this study and have had your questions answered. If you have further questions about the study, you may contact either of us at:

Researcher: Daphne Stannard, RN, MS, CCRN
Doctoral Student
Department of Physiological Nursing, Box 0610
UCSF School of Nursing
San Francisco, CA 94143
Home Telephone: (415)441-1407
Pager: (415)458-9257

Supervisor: Patricia Benner, RN, PhD
Professor
Department of Physiological Nursing, Box 0610
UCSF School of Nursing
San Francisco, CA 94143
Office Telephone (415)476-4313

Rights:

If you have any comments or concerns about participation in this study, you should first talk with one of the researchers. If for some reason you do not wish to do this, you may contact the Committee on Human Research, which is concerned with the protection of volunteers in research projects. You may reach the committee office between 8:00 AM and 5:00 PM, Monday through Friday, by calling (415) 476-1814, or by writing: Committee on Human Research, Box 0962, University of California, San Francisco, CA 94143. The approval number for this project is H184-08441-04.

You have received a copy of this consent form. Your participation in this study is completely voluntary. You have the right to refuse to participate and the right to withdraw from this study without any jeopardy to the critically ill family member in the intensive care unit.

YOU ARE MAKING A DECISION WHETHER OR NOT TO PARTICIPATE IN THIS STUDY. YOUR SIGNATURE INDICATES THAT YOU HAVE DECIDED TO PARTICIPATE AFTER READING THE INFORMATION ABOVE AND DISCUSSING ANY QUESTIONS WITH MS. STANNARD.

______________________________ ______________________________

Signature of Participant/Date Signature of Researcher/Date

Appendix C.

Nursing Background Questionnaire

Date:

_____$_{01}$ ID Code

Personal Background: Age:_____$_{02}$

_____$_{03}$ Gender: 1=Female 2=Male

_____$_{04}$ Ethnicity:
1=African-American 2=Asian 3=Caucasian
4=Hispanic 5=Native American 6=Other:______

_____$_{05}$ Religion:
1=Catholic 2=Jewish 3=Protestant
4=No Religion 5=Decline to State 6=Other:______

_____$_{06}$ Unit In Which You Currently Work:

1=Burn 2=Cardiac 3=Med-Surg 4=Emergency
5=Medical 6=Neonatal 7=Neuro 8=Pediatric
9=Recovery 10=Respiratory 11=Subacute 12=Surgical
13=Telemetry 14=Trauma 15=Other:______

Year(s) In This Unit:_____$_{07}$
Year(s) In Nursing:_____$_{08}$
Year(s) In Critical Care Nursing:_____$_{09}$

_____$_{10}$ CCRN Certification:
1=Yes 0=No

_____$_{11}$ Position Title:
1=CNI 2=CNII 3=CNIII

_____$_{12}$ Relationship Status:
1=Single 2=Co-habitating 3=Married
4=Separated/Divorced 5=Widowed 6=Other:________

_____$_{13}$ Annual Family Income:

1=0-10,000 2=11-20,000 3=21-30,000
4=31-40,000 5=41-50,000 6=51-60,000
7=61-70,000 8=71,000 +

The following questions refer to your family of origin (mother, brother, aunt, cousin, etc.):

_____$_{14}$ Do You Consider Yourself Close To Your Family?: 1=Yes 0=No

_____$_{15}$ Has Anyone In Your Family Been Hospitalized Before: 1=Yes 0=No

If Yes, Briefly Describe:

How Involved Were You In The Hospitalization(s) And How Involved Did You Want To Be? (if you need more space, please continue on the back of this page):

The following questions refer to your family of choice (whomever you consider to be your family):

_____$_{16}$ Do You Consider Yourself Close To Your Family?: 1=Yes 0=No

_____$_{17}$ Has Anyone In Your Family Been Hospitalized Before: 1=Yes 0=No

If Yes, Briefly Describe:

How Involved Were You In The Hospitalization(s) And How Involved Did You Want To Be? (if you need more space, please continue on the back of this page):

_____$_{18}$ Have Any Of The Above Experiences Changed Your Practice In Caring For Families?:
1 =Yes 0=No

If Yes, Briefly Describe:

Education and Practice:

_____$_{19}$ Basic Nursing Education: 1=Diploma 2=AD 3=BS/BSN
4=MS/MSN 5=Doctorate

_____$_{20}$ Highest Degree In Nursing: 1=Diploma 2=AD 3=BS/BSN
4=MS/MSN 5=Doctorate

_____$_{21}$ Highest Degree Outside Of Nursing:

_____$_{22}$ Are You Currently In School?: 1=Yes 0=No

_____$_{23}$ If Yes, What Degree Are You Pursuing?

_____$_{24}$ Have You Ever Received Any Formal Training/Education On How To Work With Families?:
1=Yes 0=No

If Yes, Briefly Describe:

_____$_{25}$ Comparing Yourself To Your Peers, What Percentile Would You Rank Yourself Regarding Your Overall Critical Care Nursing Practice **On An Average Day**:

1=Upper 5% 2=Upper 6-20% 3=Upper 21-40%
4=Middle 41-60% 5=Lower 40%

_____$_{26}$ Comparing Yourself To Your Peers, What Percentile Would You Rank Yourself With Regard To Caring For Families **On An Average Day**:

1=Upper 5% 2=Upper 6-20% 3=Upper 21-40%
4=Middle 41-60% 5=Lower 40%

<u>Employment:</u> Please list all of your jobs in nursing, beginning with your current job. If more space is needed, please continue on the back of this form.

1. Total Number Of Years_____$_{27}$ And Months_____$_{28}$ In Position

_____$_{29}$ Type Of Institution: 1=For-Profit 2=Not-For-Profit 3=County
4=Federal 5=Teaching 6=Other:______
_____$_{30}$ Type Of Unit:
1=Burn 2=Cardiac 3=Combined Med-Surg
4=Emergency 5=Medical 6=Neonatal 7=Neuro
8=Pediatric 9=Recovery 10=Respiratory 11=Subacute
12=Surgical 13=Telemetry 14=Trauma 15=Other:______

What You Considered Your Clinical Specialty:

2. Total Number Of Years_____$_{31}$ And Months_____$_{32}$ In Position

_____$_{33}$ Type Of Institution: 1=For-Profit 2=Not-For-Profit 3=County
4=Federal 5=Teaching 6=Other:______
_____$_{34}$ Type Of Unit:
1=Burn 2=Cardiac 3=Combined Med-Surg
4=Emergency 5=Medical 6=Neonatal 7=Neuro
8=Pediatric 9=Recovery 10=Respiratory 11=Subacute
12=Surgical 13=Telemetry 14=Trauma 15=Other:______

What You Considered Your Clinical Specialty:

3. Total Number Of Years_____$_{35}$ And Months_____$_{36}$ In Position

_____$_{37}$ Type Of Institution: 1=For-Profit 2=Not-For-Profit 3=County
4=Federal 5=Teaching 6=Other:______
_____$_{38}$ Type Of Unit:
1=Burn 2=Cardiac 3=Combined Med-Surg
4=Emergency 5=Medical 6=Neonatal 7=Neuro
8=Pediatric 9=Recovery 10=Respiratory 11=Subacute
12=Surgical 13=Telemetry 14=Trauma 15=Other:______

What You Considered Your Clinical Specialty:

4. Total Number Of Years_____$_{39}$ And Months_____$_{40}$ In Position

_____$_{41}$ Type Of Institution: 1=For-Profit 2=Not-For-Profit 3=County
4=Federal 5=Teaching 6=Other:______
_____$_{42}$ Type Of Unit:
1=Burn 2=Cardiac 3=Combined Med-Surg
4=Emergency 5=Medical 6=Neonatal 7=Neuro
8=Pediatric 9=Recovery 10=Respiratory 11=Subacute
12=Surgical 13=Telemetry 14=Trauma 15=Other:______

What You Considered Your Clinical Specialty:

Unit Information

What Is Your Definition Of Family?

What Is The Definition Of Family Used In Your Unit?

_____$_{43}$ Are There Written Policies Pertaining To Families In Your Unit? 1=Yes 0=No

If Yes, What Do They Generally Say?

_____$_{44}$ Are The Written Policies In Your Unit Pertaining To Families Followed On A Daily Basis?
1=Yes 0=No

If No, How Do The Policies Differ From Daily Practice?

_____$_{45}$ Are There Shift Differences In Your Unit With Regard To Working With Families?
1=Yes 0=No

If Yes, What Are They?

_____$_{46}$ Do Nurses In Your Unit Try To Work With The Same Patients And Families On A Consistent Basis? 1=Yes 0=No

Why Or Why Not?

Is There Anything Else You Want The Researchers To Know About Yourself, Your Background, Or Your Unit?

Thank You For Your Participation!

Appendix D.

Family Background Questionnaire

Date: ______$_{01}$ ID Code

<u>Personal Background:</u> Age:_____$_{02}$

_____$_{03}$ Gender: 1=Female 2=Male

_____$_{04}$ Ethnicity: 1=African-American 2=Asian 3=Caucasian
4=Hispanic 5=Native American 6=Other:______

_____$_{05}$ Religion: 1=Catholic 2=Jewish 3=Protestant
4=No Religion 5=Decline to State 6=Other:______

_____$_{06}$ Annual Family Income: 1=0-10,000 2=11-20,000 3=21-30,000
4=31-40,000 5=41-50,000 6=51-60,000
7=61-70,000 8=71,000 +

_____$_{07}$ Highest Educational Degree Obtained:

1=Less Than 7 Years Of School 2=Junior High School
3=Some High School 4=High School Graduate
5=Some College 6=College Graduate
7=Graduate Professional Training 8=Other

_____$_{08}$ Current Employment/Profession: 1=Professional 2=Technical 3=Other:______

_____$_{09}$ Relationship Status: 1=Single 2=Co-habitating 3=Married
4=Separated/Divorced 5=Widowed 6=Other:____________

What Is Your Relationship To The Critically Ill Patient?

_____$_{10}$ Has This Family Member Ever Been Hospitalized Before? 1=Yes 0=No

If Yes, Give Dates And Kind Of Unit:

_____$_{11}$ If Yes, Has The Previous Experience(s) Helped You In Dealing With This Critical Care Admission? 1=Yes 0=No

If Yes, In What Ways:

How Involved Were You In Previous Hospitalization(s) And How Involved Did You Want To Be? (if you need more space, please continue on the back of this page):

_____12 Have You Ever Been Hospitalized Before? 1=Yes 0=No

If Yes, Give Dates And Kind Of Unit:

_____13 If Yes, Has The Experience(s) Helped You In Dealing With This Critical Care Admission?
1=Yes 0=No

If Yes, In What Ways?:

_____14 Do You Consider Yourself Close To Your **Family Of Origin** (Mother, Brother, Aunt, Cousin, etc.)? 1=Yes 0=No

_____15 Do You Consider Yourself Close To Your **Family of Choice** (Whomever You Think Of As "Family")?: 1=Yes 0=No

Unit Information

_____16 Did Anyone Tell You About This Unit's Family Policy, Especially With Regard To Visitation? 1=Yes 0=No

If Yes, What Were You Generally Told?

_____17 Were You Given Any Written Information About These Policies? 1=Yes 2=No

_____18 Do The Nurses Tend To Follow These Policies? 1=Yes 0=No

_____19 Have You Noticed Shift Differences In How Nurses Enforce The Family Policies?
1=Yes 0=No

If Yes, What Are They?

If You Could Create The Ideal Family Policy, What Would It Look Like?

_____20 Have Certain Nurses Been Consistently Caring For Your Family Member?
1=Yes 0=No

Is There Anything Else You Want The Researchers To Know About Yourself Or Your Family?

Thank You For Your Participation!

Appendix E.

Nursing Interventions with Families in Critical Care

About the Research:

This qualitative study will examine the everyday, practical nursing activities affecting newly-admitted and "chronic" families of critically ill patients at the ICU bedside. Family-nurse interactions at the bedside will be observed, and family and nurse participants will be interviewed about the everyday bedside activities and interventions.

About the Researchers:

Daphne Stannard is a Doctoral student in Nursing at UCSF. She has been an ICU nurse for 9 years, and is currently working in the Post Anesthesia Recovery Units at Mount Zion and UC Parnassus. This project is for Daphne's dissertation, and Patricia Benner, RN, PhD is supervising the study.

What Does this Research Require of Me?

If you agree to participate in this study, you, along with 15-20 other nurses from the adult ICUs will be asked to volunteer approximately 6.5 hours over a maximum period of 10 months, which includes: 3 small group audiotaped interviews with other nurse participants (1 hour each); 2 observations of nurse-family interactions at the ICU bedside (1.5 hours each); and completion of a demographic questionnaire (30 minutes). While other ICU nurses may know you are participating in this study, your name and other identifying characteristics will never be used with portions of interviews or observations that may be published.

What Does this Research Do for Me?

This research will hopefully provide a better understanding of nursing practice in caring for families in ICUs. At the end of the study, Daphne will present the study findings at one of your staff meetings.

Daphne Stannard, RN, MS, CCRN
Doctoral Student, Department of Physiological Nursing
UCSF School of Nursing
(415) 441-1407

Appendix F.

Nursing Interventions with Families in Critical Care

About the Research:

This study will examine the everyday, practical nursing activities affecting families of critically ill patients at the ICU bedside. Family-nurse interactions at the bedside will be observed, and family and nurse participants will be interviewed about the everyday bedside activities and interventions.

About the Researchers:

Daphne Stannard has been an ICU nurse for 9 years and is currently a Doctoral student in Nursing at UCSF. This project is for Ms. Stannard's dissertation, and Patricia Benner, RN, PhD is supervising the study.

What Does this Research Require of Me?

If you agree to participate in this study, you, along with 19 other families from the adult ICUs will be asked to volunteer approximately 6 hours, which includes: 3 audiotaped interviews with other members of your family who agree to participate (1 hour each); 2 observations of nurse-family interactions at the ICU bedside (1.5 hours each); and completion of a demographic questionnaire (10 minutes). While ICU nurses and other families may know you are participating in this study, your name and other identifying characteristics will never be used with portions of interviews or observations that may be published.

What Does this Research Do for Me?

It is hoped that this research will provide nurses and other health care providers with a better understanding of activities and interventions which families of critically ill adults find helpful.

Daphne Stannard, RN, MS, CCRN
Doctoral Student, Department of Physiological Nursing
UCSF School of Nursing
(415) 441-1407

Appendix G.

Nursing Interventions with Families in Critical Care

Family Inclusion Criteria

In order to participate in this study, patients and families must meet the following criteria:

***the family must be under the "charge" of a nurse participant**

***the critically ill patient must be "silent" for the duration of the observations (ie. intubated and sedated; sedated and paralyzed; comatose)**

***the family must be English-speaking**

If you are caring for a patient and family meeting the above criteria, please contact Daphne Stannard at:

Pager: (415) 458-9257

--OR--

Home Phone: (415) 441-1407
leave a message with your name, unit, date, and time

THANK YOU!!!

Appendix H.

Suggested Interview Questions and Probes for Nurse Participants

Clinical Situations Where Nurses Made a Difference
Adapted from Patricia Benner

In working with families of critically ill patients, can you describe a recent patient care situation in which you made a difference?

- Can you give a brief patient/family history to familiarize me with the patient and family?
- Describe the context of the incident (shift, time of day, resources).
- Describe what happened in detail with as much dialogue as possible.
- Why was this situation critical to you?
- What were your concerns at the time? What were the conflicts?
- What led you to deal with the family?
- Can you describe more specifically how you "dealt" with them?
- Can you identify any rules you use when working with families of critically ill (ie. certain populations)?
- What family responses do you look for to see if your activity/interventions are effective?
- What were you thinking about as the situation was happening?
- What were you watching out for in this situation?
- What were you feeling during and after the incident?
- What were the hunches you had about this family?
- What were your priorities at the time?
- Did your priorities change during the situation? How?
- Did anything take you by surprise during the situation?
- Have you worked with families with similar problems before?
- Did a prior family come to mind when you were working with this family?
- What was the primary source of your learning about dealing with families?
- Were there things you learned from books/lectures that guided you with this family?
- What guidelines would you give other nurses for managing this situation?
- Would that change if talking to a beginner? an expert?
- What did you find most satisfying about the situation?

In working with families of critically ill patients, can you describe a clinical situation that changed the way you deal with families (use above probes)?

In working with families of critically ill patients, have you noticed any differences between newly admitted families and "chronic" families?

Appendix I.

Suggested Interview Questions and Probes for Family Members

Clinical Situations Where Nurses Made a Difference
Adapted from Patricia Benner

Can you tell me how you got here and what it has been like for you as a family?

Tell me about the intensive care unit itself. What's it like to see this place through your eyes?

Since you've been here, can you describe a recent situation where the nurse made a difference?

- Describe the context of the incident (shift, time of day, family members present).
- Describe what happened in detail with as much dialogue as possible.
- Why was this situation critical to you?
- What were your concerns at the time? What were the conflicts?
- What were you thinking about as the situation was happening?
- What were you watching out for in this situation?
- What were you feeling during and after the incident?
- What were your priorities at the time?
- Did your priorities change during the situation? How?
- Did anything take you by surprise during the situation?
- Have you been in a similar situation before?
- Did a prior family experience come to mind when you were dealing with this nurse?

Can you describe a clinical situation that changed the way you deal with nurses? (use above probes)

Have there been things the nurses have done at the bedside that you felt were particularly helpful? Not helpful?

Do you have a routine worked out among yourselves while you're visiting your family member? Do you have a routine worked out with the nurses?

If you were going to tell a good friend your best advice on how to deal with having a family member in the intensive care unit, what would you tell him or her?

Do you have any general advice for health care providers who work with families of critically ill patients?

T3: What did ICU nurses do to help ease the transition from the ICU to the floor? What could make the transition easier?

Appendix J.

Patient-Family Demographic Sheet

Face Sheet Date/Time: **Today's Date:**

Pt Name:
Birthdate:
Marital Status:
Religion:
Age:
Ethnicity:
Employ Status:
Language:
Occupation:

Contact Type:
Relation:
Name:

Insurance: Y N State Fed Other:
Diagnosis Explaining Admission:
Source of Admission: ER Other:
Source:
Est. LOS (in days):
Type of Admission:
Hx:

Current Dx:
Intubated: Y N
Vasopressor Rx: Y N

Current ICU Day:

##

Hospital Readmission? Y N
ICU Readmission? Y N
Comments:

D/C Dx:

Tot. ICU Days=
Tot. Hosp Days=

Appendix K.
FIELDNOTES
8/10/95

These are observations and impressions of the interview that happened 8-9-95 with Family 1, Interview 1. Only the husband (H.), one of the daughters (D.), the sister (S.), and the sister-in-law (L.) were present to be interviewed. We went into M980 for the interview and S. and L. seemed to have somewhat of an alliance. They sat next to each other. S. is staying at L.'s house. L.'s husband is sick due to the stress of all this, so he stayed home. H. sat next to L. and S. D. came in a little later and sat on the other side of the group, separated by a chair from me, and separated by three chairs from S. and L. So, it will be interesting to watch the bedside dynamics when the whole group gets together, because I do think there are some factions within this family.

It became especially obvious that there was some kind of family issue, in that S. was the one who accompanied the patient down to the study site. I guess she's always been considered the family spokesperson by the nursing staff and they've directed all the information to her. The nurses have approached D. about procedures and consent, when in fact, H. should be the one who consents. L. is really clear about that because she has a nursing background. When this came up in the interview, I could tell S. was sort of annoyed that she shouldn't have been the primary spokesperson. I think this probably goes back to the fact that S. cared for the patient for a month and a half--day in and day out--and probably has some ownership issues about who provided care and who should be considered the primary spokesperson. That was the only moment of tension in the interview and I decided to let it go. If this had been a therapy session, I might have followed up on it, but I didn't feel like it was appropriate to open up that issue at that time.

The interview went fine. It was difficult to engage them in storytelling, but I suppose now, in retrospect, that's to be expected because they're still very much in it. They haven't constructed stories yet. They have stories of past events that they told me about, but they didn't yet have any coherent narrative of this ICU experience. That was frustrating for me, but I suppose that's something I'm going to have to live with during these initial interviews, because they probably won't have a lot of narrative structure to them. Of course, this being my first interview, I felt like it due to my inadequate interviewing technique, so that's just something to pay attention to once I get this transcript back.

Appendix L.
RN Int 2d (Continued)
4/4/96

RN 11: And maybe it's also more important to have people following. You know, I think that's become very important, because you know people and they've gained the trust in you. So, if it's, you know, some days obviously are more busy than others. But if you have a really busy day, that the family knew you before and you chatted to them, and they know that you, you know, they've enjoyed you, and they know you give good care, then if you're really busy and not available so much that next day, I think they still feel the care is good.

RN 68: Mhum.

RN 11: You know, I think that's become more important and even maybe more difficult to achieve (chuckles).

RN 68: But it's good because you know the person.

RN 11: Yeah, yeah.

RN 68: In a different way. You know the families, you can do things without thinking. Without having to go through the conversation that someone new going into it would have to go through.

Int: So are you able to achieve consistency, in say, the two units that are here?

RN 11: //I think people try to follow, people try to follow.

RN 15: For the most part.

RN 68: I think there's certain instances where the obvious is the better. I mean, our population is so in and out and there's a thread of 3 or 4 patients that are in, in, in (chuckling and with others). Then there's the group that sort of like follows the in, in, in ones for awhile and then, "I'm getting headaches."

Int: Mhum.

RN 68: "I'm not following her anymore."

RN 11: Yeah, but you might go and say "Hi" to them, even if you don't follow.

Fam: When she first came in, you talked about running shoes or something like that.

Nurse: Yeah.

Fam: We have some bowling shoes...

Nurse: Because you're athletic, you're going to bring them in (chuckling) ?

[Observational Note: ICU Resident peeks his head in the patient's room].

Resident: What's your pleasure for what she should be getting? (referring to other patient RN is covering for lunch break).

Nurse: (To resident:) She's on a Fentanyl drip until this morning, right?

Resident: — Fentanyl —

Nurse: (To resident:) Sure. (To Family:) Well, the whole thing is so that her feet, see like with high tops, will keep her bent.

Fam: OK.

Nurse: Her ankles from being extended, keep them flexed.

Fam: Right (clearing throat).

Nurse: But you could can do the same thing. You can do exactly the same thing while you're standing there.

[Observational Note: Husband doing passive ROM to patient's right ankle].