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Family Experiences with ICU Bedside Rounds: A Qualitative Descriptive Study: A Dissertation

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Family Experiences With ICU Bedside Rounds:
A Qualitative Descriptive Study

A Dissertation Presented
by
SHAWN CODY

Submitted to the Graduate School of Nursing
University of Massachusetts Worcester
in partial fulfillment of the requirements for the degree of

DOCTOR OF PHILOSOPHY

Nursing

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Family Experiences With ICU Bedside Rounds:
A Qualitative Descriptive Study

A Dissertation Presented

by

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ABSTRACT

FAMILY EXPERIENCES WITH ICU BEDSIDE ROUNDS: A QUALITATIVE DESCRIPTIVE STUDY

2015

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The hospitalization of a family member in an intensive care unit can be a very stressful time for the family. Family bedside rounds is one way for the care team to inform family members, answer questions, and involve them in care decisions. Few studies have examined the experiences of family members with ICU bedside rounds.

A qualitative descriptive study, undergirded by the Family Management Style Framework developed by Knafl and Deatrick (1990, 2003) and Knafl, Deatrick, and Havill (2012), was done at an academic medical center examining families who both participated and did not participate in the family bedside rounds. The majority of families who participated (80%) found the process helpful. One overarching theme emerged from the data of participating families: *Making a Connection: Comfort and Confidence*. Two major factors influenced how that connection was made: consistency and preparing families for the future. Three types of consistency were identified: consistency with information being shared, consistency about when rounds were being held, and

consistency with being informed of delays. The second major contributing factor was preparing families for the future. When a connection was present, families felt comfortable with the situation. When any of the factors were missing, families described feelings of anger, frustration, and fear. Family members who did not participate described feelings of disappointment and frustration about not having participated.

As healthcare providers, what we say to families matters. They need to be included in decision-making with honest, consistent, easy-to-understand information.

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CHAPTER I

STATE OF THE SCIENCE

Introduction

Family is the most important unit in our society; it is the place where social, emotional, intellectual, and cultural development occurs. The family unit can be affected by a health crisis, which may disrupt overall family functioning (Jacobowski, Girard, Mulder, & Ely, 2010). Additionally, families can experience high levels of anxiety and depression associated with their loved one's illness (Azoulay et al., 2003). Critically ill patients are often unable to participate in treatment choices, necessitating family members to act as primary decision makers regarding treatment options (Curtis & White, 2008; Heyland et al., 2002). Thus, involvement by a family member as a surrogate participant is important to communication and shared decision-making with healthcare providers (Kon, 2011). However, we rarely study family member perspectives such as their view of the illness, their future role in the management of the condition, and/or family functioning overall.

Family-centered research in the critical care environment has been limited, focusing mainly on family satisfaction, communication, and decision-making regarding families in the critical care environment (Roberti & Fitzpatrick, 2010). Asking family members if a healthcare provider communicated with them or if they are satisfied with their loved one's care fails to capture what these family members are feeling or how to better deal with the situation. These complicated concepts are influenced by several mitigating factors that are described later in this chapter. Studies of families' experiences with critically ill patients indicate that poor communication contributes to higher rates of

depression, anxiety, and mistrust of healthcare providers (Jacobowski et al., 2010). A poor understanding of information is reported by 30–50% of family members of these patients, all of which can affect family functioning. In addition, inadequate information contributes to futility of care and extending the dying process, thus increasing the length of stay and increasing the frequency of unnecessary tests (Jacobowski et al., 2010). Yet we fail to consider what a lack of accurate information does to overall family functioning.

Communication with family members has been used as a marker to measure the well-being of the patient (Heyland et al., 2002; Jacobowski et al., 2010). Sending a consistent message to family members has been identified as important, especially in the critical care setting where multiple team members are participating in care (Heyland et al., 2002). However, no studies to date have measured how consistent communication (family rounds) influences family members in preparing for their loved one's discharge, or the family's future role in management of their loved one's illness, or overall family functioning during the crisis.

The Institute of Medicine (2001) recommended that healthcare teams move away from a traditional disease- or clinician-centric model to a patient-centered one. In 2005, several critical care societies in Europe and North America developed a consensus statement in strong support of patient-centered care of critically ill patients and their families (Davidson et al., 2007). The authors concluded that adopting a patient-centered approach would lead to better clinical outcomes. The report recommended that, to achieve a patient-centered approach, healthcare providers focus on the following areas: decision-making, family coping, stress of staff related to family interactions, cultural support of the family, spiritual/religious support, family visitation, family environment of

care, family presence during rounds, family presence during resuscitation, and palliative care. The consensus statement indicated that patient care decisions need to be consistently shared between the critical care team and the patient's family (Davidson et al., 2007). This included family members acting as patient surrogates, being a voice for the incapacitated, critically ill patient to assure that the plan of care is consistent with the patient's wishes. Using shared decision-making between the surrogate family member and the medical team increases family satisfaction with care in the ICU (Curtis & Tonelli, 2011). When utilizing a family-centered decision-making approach, healthcare team members must also assess the family's willingness and level of comfort with this shared decision-making (Azoulay et al., 2003; Curtis & White, 2008). Thus, family rounds may help facilitate improved family functioning.

At the University of Massachusetts Medical Center, in early 2012, the critical care leadership developed a bedside-rounding program (henceforth called bedside, or family rounds) by providing a set time 5 days a week when families could meet with the care team at the patient's bedside to share information, ask questions, and develop a plan of care. The intent of the meeting was to share information that would facilitate shared decision-making. This type of family support was provided to encourage families in their role to actively respond to their loved one's illness and care and improve family functioning. Over an 8-month period from September 2012 to April 2013, only 37% (79 out of the 213 families we had approached) of the families chose to participate in these bedside rounds. The reasons families chose not to participate are unknown. In addition, little is known about what the experience was like for those families who did participate in the bedside rounds. Therefore, the purpose of this qualitative descriptive study (using

the Family Management Style Framework [FMSF]) to undergird the study) was to explore family perspectives of intensive care unit (ICU) bedside rounds as a contextual influence that may support family functioning.

The specific aims of the study were the following:

1. Describe the experiences of ICU-patient family members who participated in bedside rounds, considering their perspective in their view of the illness, their future role in management of the condition, and its long-term consequences on individual function and family functioning overall.

2. Describe the experiences of ICU-patient families who chose not to participate in bedside rounds and their perspectives regarding its value, their illness view, and future involvement in care.

The purpose of this chapter is to review the empirical literature on the science of family members of patients admitted to ICUs, to define what is known on the subject, to describe the experiences of families with ICU family information rounds, and to identify knowledge gaps that support the focus of this study. Research has focused primarily on communication, satisfaction, and decision-making with little attention paid to overall family functioning. The researcher describes studies with ICU family members related to communication, comprehension, satisfaction, anxiety, depression, and decision-making, all of which can affect family functioning.

Communication

Communication failures between the ICU care team and patient families have been identified as a major cause of dissatisfaction in several studies (Anderson, Kools, &

Lyndon, 2013; Schiller & Anderson, 2003). Communication failures have not been examined in relation to long-term family functioning. Communicating with families of patients in the ICU is a complicated process requiring specialized training on the part of the healthcare team (Curtis & White, 2008). Poor communication may contribute to family anxiety, depression, an increase in the risk of contradictory information, and mistrust of the care team (Jacobowski et al., 2010). A secondary qualitative study (Henrich et al., 2011) explored 23 ICUs across Canada and identified more detailed problem areas: These included lack of communication with the care team, exclusion of the family or patient from communications, and lack of directness about the patient's status.

A study in France (Pochard et al., 2001) reported that lack of an available physician or nurse to speak with families about the patient's condition contributed to increased symptoms of anxiety (OR 1.36, $p = 0.02$, 95% CI [1.04–1.79]). Heyland et al., (2002) found that respondents who rated completeness of information provided by the ICU staff as excellent (OR 16.0, $p = .001$, 95% CI [5.8–43.9]) or very good were much more likely to give an overall rating of their ICU experience as completely satisfactory (OR 5.3, $p = .001$, 95% CI [1.9–14.8]). However, many of these ICU studies did not provide conceptual clarity, focusing only on satisfaction as a marker for “family communication.” No study could be found that explored more deeply into information issues such as understanding what will be required post-ICU for disease condition management, or what role(s) family members may need to play in day-to-day management of their loved one's condition.

Similar quantitative findings have been reported whereby providing family members access to current patient information was positive. For example, in the 2003 study mentioned earlier, Schiller and Anderson conducted a survey post-discharge with family members who had participated in family rounds. Although only 34 (39%) of 117 families responded, the results supported that “just knowing” that family members could ask questions and that having access to a knowledgeable physician on a daily basis were important (Schiller & Anderson, 2003).

Further attempts have been made to measure the effect of structured family interdisciplinary rounds. Jacobowski et al. (2010) conducted a small intervention study in a 26-bed ICU with one group ($n = 89$) and a historical control ($n = 98$) to explore enhancement and facilitation of communication with end-of-life planning. Post-hospital phone interviews were conducted with family member participants using the 23-item Family Satisfaction in the Intensive Care Unit (FS-ICU) scale (Heyland & Tranmer, 2001). Despite the limitation of the design due to the small number of respondents ($n = 22$), the study found significantly higher scores for the intervention group on frequency of physician communication ($p = .004$), supported decision-making ($p = .005$), and adequate time for questions ($p = .02$) compared to the historical controls (test statistics not reported; Jacobowski et al., 2010). There were no significant differences between the groups in frequency of nurse communication, willingness to answer questions, understandable explanations, honesty of information, treatment information, consistency of information, and being included in decision-making. Again, the focus on satisfaction (prone to social desirability bias and a conceptually poor match for communication) does

not explore other important contextual issues such as family functioning and preparedness for future roles in management post-discharge.

Comprehension

Another necessary factor for adequate communication to occur that has been studied is comprehension. Comprehension issues (or lack thereof) with family representatives were apparent in several studies conducted in France. Azoulay et al., (2000) found that over half of the 76 families they interviewed, whose loved ones had spent time in an ICU, lacked comprehension of diagnosis, treatment, and plan of care. A family's lack of previous exposure to the ICU environment was reported to be a factor in poor family comprehension. Physicians and nurses (numbers of each not reported) who were also interviewed concurred that 54% ($n = 41$) of the 76 families had inadequate levels of comprehension. Other studies suggested that the following factors are associated with poor comprehension: age (the patient and/or family member), language barriers, and lack of relatives who work in healthcare (Azoulay et al., 2002; Jacobowski, 2010).

As a result of the 2000 qualitative study of Azoulay et al., an intervention was developed and conducted across 34 ICUs at multiple medical centers (Azoulay et al., 2002). The purpose was to test if a specially designed family information leaflet would improve family comprehension and satisfaction. There was a greater comprehension and satisfaction for those in the intervention group ($n = 87$) by 40.9% compared to 11.5% in the non-intervention group ($n = 88$; Mann-Whitney test, statistics not reported, $p < .0001$).

Although such studies were important on a very basic level, a need existed to further explore within the family context the subtle issues such as how the family defines their situation. It was critical to explore if family rounds also facilitate their

understanding of the situation during both the acute stage and for the future and what their role will be moving forward to better assist families during this stressful time.

Satisfaction

Typically, satisfaction has been the primary endpoint when measuring how well healthcare providers are meeting the needs of family members of ICU patients.

Satisfaction is typically defined as the fulfillment or gratification of a desire or need (Heyland et al., 2002). Patient and family satisfaction has been described as a complex emotion influenced by the gap between expectation and perception (Stricker et al., 2009). Positive satisfaction has long been linked to quality patient and family outcomes; thus, it is used as a marker of good practice. In critical care, satisfaction is thought to be an important domain because desirable health status may not always be possible (Heyland et al., 2002). Several quantitative scales have been developed in this population to measure satisfaction of patients and family members, including the Critical Care Family Satisfaction Survey (CCFSS; Wasser, Pasquale, Matchett, Bryan, & Pasquale, 1998) and the FS-ICU scale (Heyland et al., 2002). The scales measure several domains of patient and family satisfaction, including assurance, information, proximity, support, comfort and help to family members (Wasser et al., 1998), and care of the family, care of the patient, professional care and the ICU environment (Heyland et al., 2002).

Heyland et al. (2002) measured satisfaction with overall ICU care using the FS-ICU scale; but it did not focus specifically on family rounds. The scale consisted of 34 items measured on a 6-point Likert-scale (possible range of scores = 0–100). The reliability of the FS-ICU is very good with reported Cronbach's Alpha of .88 and .92 for the two subscales measuring satisfaction with overall care and satisfaction with decision-

making. Respondents that rated courtesy, compassion, and respect shown to the patient as excellent or very good were much more likely to be more satisfied with the overall ICU care (OR 4.9, $p = .001$, 95% CI [2.6- 9.5]).

Baker et al. (2000) analyzed family support and satisfaction data from an earlier intervention study whereby clinical nurse specialist support included communication and decision-making assistance. They randomized patients ($N = 740$) and their families to either usual care or the intervention. They measured satisfaction, communication, and decision-making with a binomial (agree, disagree) instrument and reported that those who received the family support intervention had greater satisfaction with communication issues (AOR 2.0, 1.2–3.2). Results also indicated that communication scores were positively associated with satisfaction (reported as Kruskal-Wallis test, $p < .001$) when patient preferences for care were followed.

Thus far, qualitative studies that explore what types of family ICU interventions might benefit family functioning have been limited. A qualitative study ($N = 880$) was conducted in Canada that measured family satisfaction across many ICUs (Henrich et al, 2011). Researchers conducted focus groups at multiple sites using a standardized interview format. Numerous themes emerged that contributed to family satisfaction, including quality of staff, compassion and respect shown to the family and patient, communication, and physical space. Although these general findings support previously described quantitative findings, satisfaction has been used as a catchall variable and has not provided a lens into what types of supports in the ICU setting can impact family functioning. Therefore, focusing on the FMSF components and contextual influences provided a more detailed window into the ICU experience, assisted by family rounds, and

how the family rounds supports family functioning, or what needs to be altered to improve satisfaction.

Decision-Making

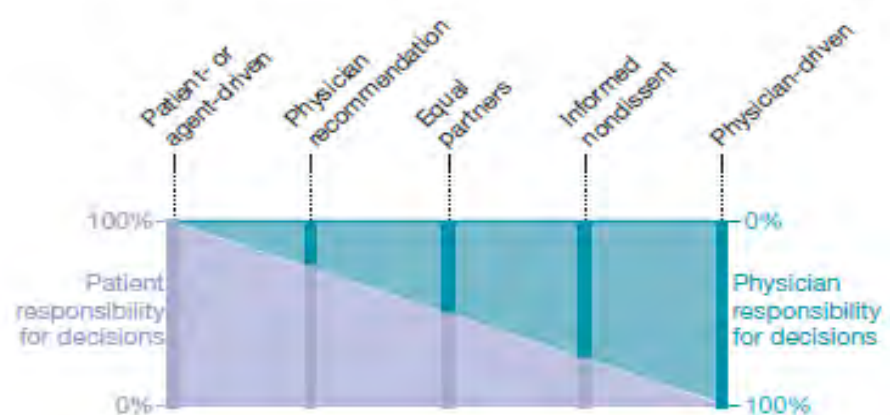
Decision-making in the ICU has undergone many changes over the past 20 years. Two decades ago, decisions about care of the critically ill were made primarily by the patient's physician with little input from others (Kon, 2010; Luce, 2010). Beliefs at that time included that the physician would always act in the patient's best interest, and at all time avoid harming the patient (Luce, 2010). Little attention was paid to preparing families for life after ICU care.

More recently, the medical community and society in general are urging the use of shared decision-making among patients, families, and healthcare providers (Kon, 2010). It has been described as "the most ethical and appropriate approach across the full range of medical decisions" (Curtis & Tonelli, 2011, p. 840). The goal of shared decision-making is to make decisions consistent with the patient's wishes. Shared decision-making includes the assessment of family support, and depending on treatment choices, what kinds of day-to-day management may be required once the patient goes home. In general, shared decision-making involves the sharing of responsibility for the control over medical decisions between the medical team and the patient or the patient's family (Curtis & Tonelli, 2011). It involves using the resources of the care team and incorporating team input into discussions with the patient, when possible, and with their family (Gristina, DeGaudio, Mazzon, & Curtis, 2011). Family rounds have been used to support this philosophical change in healthcare (Chewning et al., 2012).

Chewning et al. conducted a systematic review (2000–2011, $N = 115$ articles) of shared decision-making that included a variety of clinical settings such as hospitals,

physician offices, outpatient clinics, and dentist offices (Chewning et al., 2012). They reported that 63% of the patients and families from the 115 reviewed studies preferred shared decision-making. They also compared this preference to the empirical literature before 2000 and found only a 50% preference, reflecting a philosophical shift in how decisions are made in healthcare. The analysis also indicated that in the highest acuity population (studies involving a cancer diagnosis or invasive procedure), 77% of respondents wanted to participate in care decisions. The authors went on to state that all of the reviewed studies identified a subset of patients and families who wanted to delegate decision-making. In their conclusion, they noted the importance of eliciting from the family and patient their preferences regarding participating in decisions. They also cautioned that the decision to participate in care is not static, and can change as the treatment continues and/or changes. Family rounds are a possible strategy to ensure this option is offered and discussed routinely. Exploring how family rounds affect family functioning specifically is critical.

One model describes shared decision-making on a continuum (Figure 1 below).



*Figure 1. Shared Decision-Making Continuum. From “The Shared Decision-Making Continuum,” by A. A. Kon, 2010, *Journal of the American Medical Association*, 304, page 904. Copyright (2010) by American Medical Association. Reprinted with permission.*

At the lefthand side of the continuum, the caregivers provide only knowledge and the family or patient make all decisions. At the opposite end, the physician makes all decisions with little input from the family. In the middle, the family and care team act as equal partners (Kon, 2010). The patient and family should be at the heart of all decisions made. Where on the continuum the patient or family wants to participate is the key to success. This requires the care team to be active listeners. A major variable of this model is the family's place within the continuum, which will change depending on both psychological and physical factors (Kon, 2010).

Family Member Anxiety and Depression

Patient and family member mental health variables such as anxiety and/or depression have been reported in the empirical literature as being affected by the level of communication, satisfaction, and decision-making when a family member is in the ICU. Family rounds have the potential of diminishing these often-measured markers that can affect family functioning as a whole. A 2001 study sought to measure the level of anxiety and depression among family members ($N = 920$) of ICU patients across 43 hospitals throughout France (Pochard et al., 2001). Family members completed the Hospital Anxiety and Depression Score (HADS) tool while the patient was still in the ICU. The HADS was developed in the early 1980s to measure anxiety and depression, specifically in nonpsychiatric populations (Zigmond & Snaith, 1983). The scale was originally developed and validated (r_2 ranged from +0.76 to +0.41, $p < .01$ for anxiety), (r_2 range from +0.60 to +0.30, $p < .20$ for depression) in primary care settings and has been used successfully in many hospital settings (Pochard et al., 2001). The self-reported scale has 14 questions, with scores of 0–3 (seven questions evaluating anxiety and seven,

depression). A score of 10 or greater for either category indicates some level of anxiety or depression (Zigmond & Snaith, 1983).

Results indicated that over 69% ($n = 635$) of family members reported high levels of anxiety and over 35% ($n = 322$) some level of depression. Women were found to be at higher risk for symptoms of anxiety, OR 2.42, $p = .001$, 95% CI [1.67–3.52] and depression, OR 2.0, $p = .001$, 95% CI [1.40–2.84] compared to men (Pochard et al., 2001). A significant factor contributing to family's anxiety was lack of a room dedicated to family meetings, OR 1.80, $p = .01$, 95% CI [1.10–2.96]; contributing significantly to symptoms of depression was no waiting room space, OR 2.50, $p = .009$, 95% CI [1.25–5.02] (Pochard et al., 2001). This finding was also supported in subsequent studies (Azoulay et al., 2003; Heyland et al., 2003).

Other factors found to be associated with anxiety or depression included age of the patient (the younger the patient, the greater the amount of depression) (OR 0.79, $p = .02$, 95% CI [.67–.97]). Azoulay et al. (2003) reported that of the 160 family members who participated, 60% ($n = 96$) suffered high levels of anxiety and 39% ($n = 62$) had some level of depression. The researchers also reported that the family members who wanted to participate in care were more likely to have symptoms of anxiety or depression. It is not known if the family members had opportunities to participate in bedside rounds, or if, after the patients were discharged, the family anxiety subsided.

A similar design was utilized in an intervention study conducted in France that used an information leaflet and in-depth family conferences to encourage family members to talk (Lautrette et al., 2007). Family members were recruited into the study if the care team believed that the patient would die within the next 48–72 hours.

Participants ($N = 56$) were interviewed by telephone 90 days after the patient's death. Participants were given the HADS and the Impact of Event Scale (IES) measurement tools. The IES assesses symptoms related to post-traumatic stress disorder (PTSD) (scores range from 0 (no PTSD symptoms) to 75 (severe PTSD symptoms). The researchers classified the participating family members as having low or high IES. Results indicated that participants in the intervention group ($n = 56$, median IES score 27) had significantly lower IES scores than the participants in the control group ($n = 52$, median score 27 (interquartile range, 18–42) vs. 39 (interquartile range, 25–48), $p = .02$). The intervention group also reported fewer symptoms of anxiety (45% vs. 67%, statistical test not reported, $p = .02$) and depression (29% vs. 56%, $p = .003$; Lautrette et al., 2007). These findings are particularly significant as one-third to one-half of the intervention group families reported symptoms of anxiety or depression or both. Similar findings were found in a qualitative exploratory study (Hughes, Bryan, & Robbins, 2005). Participants reported high levels of shock, fear, anxiety, and guilt that were alleviated to some degree when the healthcare team communicated more frequently.

Summary

Patients admitted into ICUs are among the highest risk in our society. They are usually too impaired by their illness to participate in care decisions. Thus, the care decisions often fall to the families of the hospitalized patient. This situation commonly results in a stressful time for both the family and patient. How the care team communicates with family members is a major factor in their ability to make decisions and minimize the anxiety and depression that is common in these families.

Almost all studies to date have focused primarily on the outcome variable of satisfaction as the major empirical indicator as to whether healthcare providers are meeting the needs of family members whose loved one has been admitted to the ICU. While satisfaction is a reasonable measure of meeting immediate patient needs, it does not necessarily represent family preparedness or family functioning for when the patient leaves the ICU or goes home. Likewise, focusing only on the variables of family communication and decision-making does not provide a complete picture of family functioning. This study examined the experiences of family members in the ICU setting with family rounds using the FMSF, which allowed identification of patterns and typologies of family functioning. Family rounds appear to contribute positively to family functioning, yet no studies until this one have described why and how they support families. A rich description of the family experience with family rounds and why some families choose not to participate offer important information that can be used to improve and/or individualize this type of family support. This knowledge may prove crucial as the patient transitions to home, at which time the family is called upon to manage treatments and medications independently.

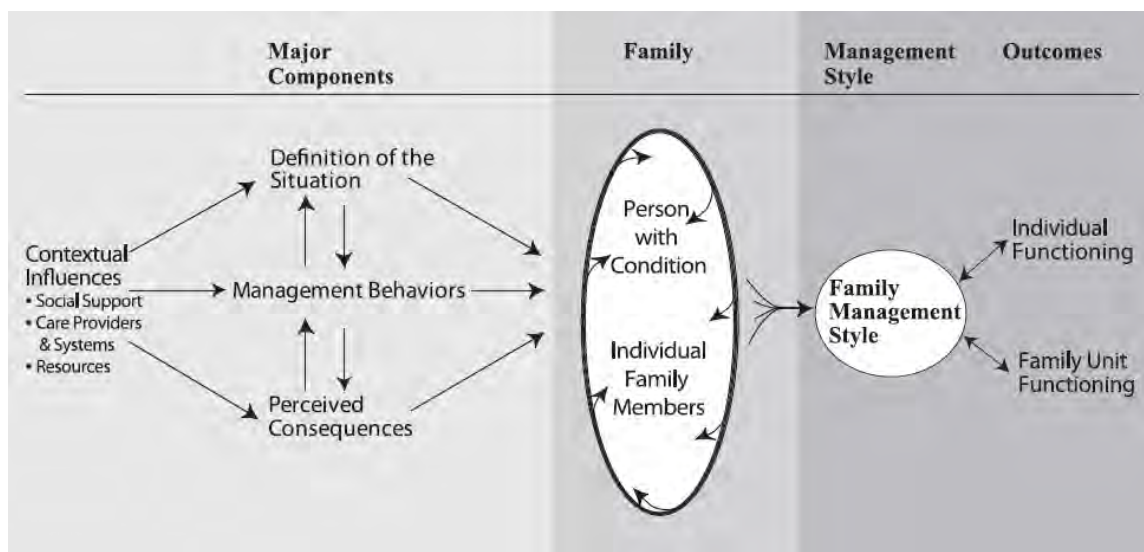
CHAPTER II

STUDY FRAMEWORK

Introduction

The Family Management Style Framework (FMSF; Knafl & Deatrick, 1990, 2003; Knafl, Deatrick, & Havill, 2012) was used to undergird this research. According to Beck (2009), a conceptual model is necessary to serve as a guiding framework that allows the application of structure and to categorize concepts. A central theory in qualitative work is especially important because it allows for the accurate analysis of data in the representation of the findings (Sandelowski, 1993). It also provides a fundamental basis for subsequent theory development and research (Knafl & Deatrick, 1990).

The FMSF enables identification of patterns and typologies of family functioning in a wide variety of families and situations as they confront healthcare issues (Wiegand, Deatrick, & Kanfl, 2008). Thus, with the focus of this study on the experiences of family members with family rounds in the ICU, the FMSF provided structure for the initial interview questions and analysis process. A visual of the most recent framework (Figure 2) appears on the next page. It illustrates the FMSF's key components and dimensions, which will be referred to throughout the chapter.



*Figure 2. Revised Family Management Style Framework. From “Continued Development of the Family Management Style Framework,” by K. A. Knafl, J. A. Deatrick, and N. L Havill, 2012, *Journal of Family Nursing*, 18, page 25. Copyright (2012) by the Author(s). Reprinted with permission.*

Development

The FMSF was developed by Knafl and Deatrick (1990) as an aid to understanding how families function when a child has a chronic illness. Early studies focused on the variety of ways that families responded to chronic childhood illness (Kendall & Shelton, 2003; Knafl, Breitmayer, Gallo, & Zoeller, 1996). The 1996 study of Knafl et al. identified five distinct management styles in families with chronically ill children. These styles included thriving, accommodating, enduring, struggling, and floundering. This study not only assisted researchers to identify different management styles, but it was also the precursor for the development of the FMSF.

Management Style Components

Early work of the conceptual model identified three family management style components: definition of the situation, management behaviors, and perceived consequences (Knafl & Deatrick, 1990). It emphasized that the three identified

components taken together could provide a framework for conceptualizing and examining how families respond to chronic illness. The early model emphasized the interaction of family members' definitions of the situation, their management behaviors, and the perceived consequences of a chronically ill child on family functioning. This model also laid the groundwork for identifying more specific patterns of family responses to illness (Knafl & Deatrick, 2003).

Definition of the situation is specified as the subjective meaning that the family and its members attribute to the chronic illness. It is essential to understand how individuals perceive their situation, as it informs how they will respond (Knafl & Deatrick, 1990). Those reactions are subjective to the individuals involved. Within this component, there are several dimensions to be considered: the child's identity (parents' view of the child's strengths and vulnerabilities); view of the condition (parents' perspectives about the cause, seriousness, and course of the chronic condition); management mindset (parent perspectives on manageability of child's medical treatment); and, when there are two parents, parental mutuality (shared or discrepant parental views on management).

The second component of the model is management behaviors. These are "discrete behavioral accommodations that family members use to manage on a daily basis" (Knafl & Deatrick, 1990, p. 9). The dimensions linked to this component include (a) parenting philosophy (short- and long-term goals, beliefs that guide the overall day-to-day management) and (b) management approaches (strategies used to manage the chronic condition on a daily basis). The behaviors can range from how individuals react to meet daily challenges to problem-solving schedule changes. Management behaviors

and definitions of the situations are closely dependent on each other (Knafl & Deatrick, 1990). How families define events that occur associated with the chronic condition will partially influence how they react to it, and their reaction will be determined by their definition. The arrows on Figure 2 depict the interaction between the different components of the model.

The third component of the framework is perceived consequences; it is defined by the actual and expected long-term clinical, social, and emotional outcomes for both the child and the family that influence the management behaviors and definition of the situation. It relates to both the family focus of the effect of the chronic condition on life (e.g., We just deal with it and it doesn't change what we plan to do); and future expectations (parent perspectives affect the chronic care implications on the family's future).

Contextual Influences

In addition, in the 2012 version of the framework (based on further analysis of family data), Knafl et al. modified the sociocultural context of perceived influences, a category of influence that can affect family management. These include factors that either support or impede family management, and are now labeled as contextual influences, as management underscoring the potential influence these variables may have on family functioning. Thus, having access to a strong social network in the community, healthcare providers who partner well with the family, school, and community resources that are supportive of the child's needs can affect family functioning in a positive way. The three major components and the contextual influences help to provide an essential framework for understanding and guiding research focused on family functioning.

All of these factors are thought to impact how families understand and manage the illness of a family member. The model does not attempt to define the family, but rather leaves that definition up to the individuals being studied.

Adaptations for Expanded Use

The Revised FMSF was also thought to allow for better recognition of vital cognitive and behavioral aspects of the families' experiences with illness and identify areas of strength as well as weaknesses (Knafl et al., 2012). Also, the model at this point was ready for expansion to other areas of research and practice besides chronic illness in children, such as adult caregivers caring for adult family members. More recently, the FMSF has been adapted to better understand family care dynamics in a variety of situations, including care for adults at the end of life in the ICU (Wiegand et al., 2008) and caring for adults with dementia (Beeber & Zimmerman, 2012). It has also been used in both qualitative and quantitative designs, and in cross-sectional and longitudinal collection methodologies.

Each component with associated dimensions is described in more detail in Table 1 on the next page.

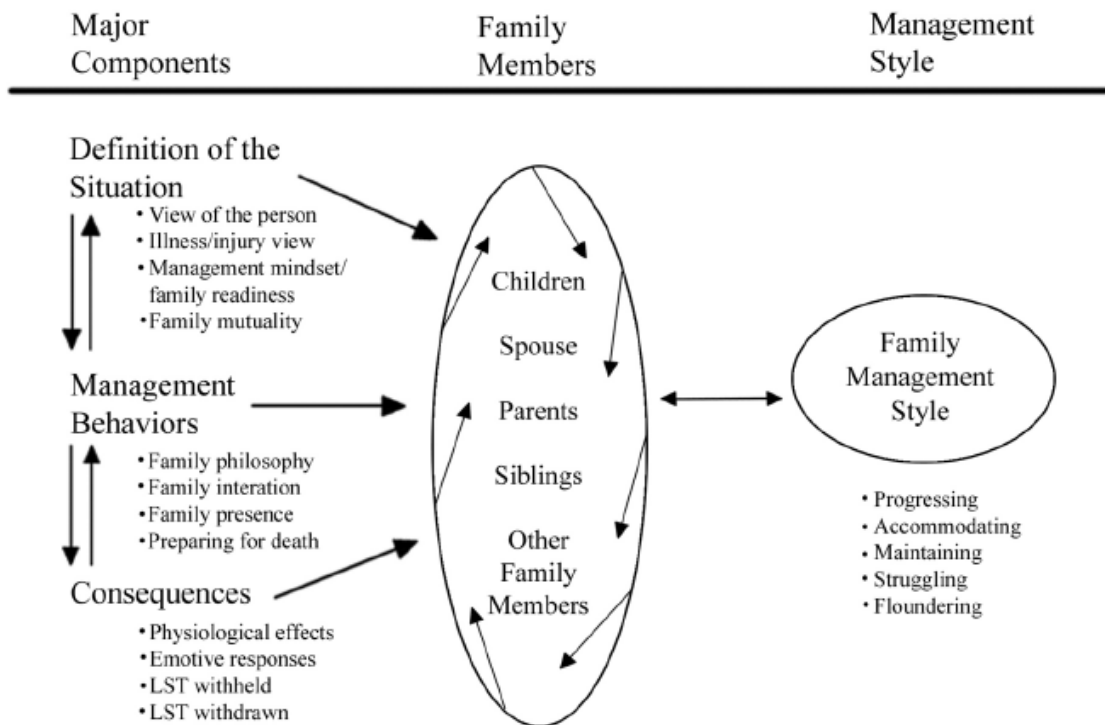
Table 1

Comparison of Major Components of the Family Management Style Framework

Study	Definition of the Situation	Management Behaviors	Perceived Consequences
Knafl and Deatrick, 2003	<p>Child Identity: Parental views of the child and his or her abilities.</p> <p>Illness View: Parental understanding and beliefs about the child's illness.</p> <p>Management Mindset: Parental views of ease or difficulty of carrying out treatment regimen.</p> <p>Parental Mutuality: Views on the degree to which they hold shared or complimentary perceptions.</p>	<p>Parenting Philosophy: Parental goals, strategies, and behaviors linked to caring for a child with chronic illness.</p> <p>Management Approach: Parental orientation to illness management and their associated behaviors.</p>	<p>Foreground: Parental views of the extent to which the illness is a dominant focus of family life.</p> <p>Future Dread: Parental belief that their family and child's future wellbeing is seriously jeopardized as a result of illness.</p>
Beeber and Zimmerman, 2006	<p>Older Adults Identity: Focused primarily on the caregivers' views on normalcy for the adult with dementia.</p> <p>Illness View: The caregivers' belief about the severity and extent of the dementia.</p> <p>Management Mindset: The ease or difficulty in carrying out daily care.</p> <p>Family Mutuality: The extent the caregivers' views varied from other family members</p>	<p>Caregiving Philosophy: The goals, priorities and values that direct the overall method of the care of the older adult with dementia.</p> <p>Management Approach: The caregivers' estimation of the degree that they have a comfortable routine in caring for their family member</p>	<p>Family Focus: Defined as the caregivers' assessment of the balance between the care of their family member and the rest of daily life.</p> <p>Future Expectations: Described as what was in store for both the older adult and the caregiver</p>
Wiegand, Deatrick, and Knafl, 2008	<p>View of the Person: How family members viewed their ill or injured family member.</p> <p>Illness/Injury View: How families viewed the illness or injury. Provided important data concerning the understanding of the severity of the illness/injury.</p> <p>Management Mindset/Family Readiness: Willingness to discuss withdrawal of life-sustaining treatment (LST) as a possible outcome.</p> <p>Family Mutuality: Extent that family members have shared or discrepant views of the illness/injury and the course of treatment.</p>	<p>Family Philosophy: Family goals, priorities, and values that guided overall approach.</p> <p>Family Interaction: Ability of family members to talk to one another and keep each other informed. Ability to integrate roles/responsibilities.</p> <p>Family Presence: Ability to be at the hospital and to return home to rest.</p> <p>Preparing for Death: Plan withdrawal of LST event. Plan for after death, funeral prep, life without the family member.</p>	<p>Physiological Effects: Changes in eating/sleeping patterns for family.</p> <p>Emotive Responses: Include emotions experienced by the family.</p> <p>LST Withheld: Ability for the family to make the decision to withhold.</p> <p>LST Withdrawn: Ability for the family to withdraw LST.</p>

Bingham and Haberman (2006) used the FMSF to undergird a qualitative descriptive study that examined the influence of spirituality on family management of Parkinson's disease, which affects primarily older adults. Five distinct categories emerged from the analysis. Categories included depending on belief and faith to manage the situation, providing purpose and meaning in living with Parkinson's disease, establishing a connection with God by praying, establishing a connection with other individuals, and feeling a sense of gratitude and hope. The study showed the adaptability of the FMSF for helping to identify family beliefs and variability.

The Wiegand et al. study (2008) adapted the FMSF (Figure 3) related to the withdrawal of life-sustaining therapy from adults in ICUs. The analysis was based on an earlier hermeneutic phenomenological study conducted by Wiegand (2006). Grounded by the FMSF, typologies were identified that were shared by many of the families interviewed. This model assisted the researchers to identify how families defined and managed situations differently (Wiegand et al., 2008). Five family management styles were identified for each family. These included progressing, accommodating, maintaining, struggling, and floundering. Utilization of the FMSF helped researchers identify typologies of families going through the withdrawal of life-support. This can aid healthcare providers to focus interventions based on each family strength and/or weakness (Wiegand et al., 2008).



*Figure 3. Family Management Style Framework. From “Family Management Styles Related to the Withdrawal of Life-Sustaining Therapy From Adults Who Are Acutely Ill or Injured,” by D. L. Wiegand, J. A. Deatrck, and K. A. Knafl (2008), *Journal of Family Nursing* 14, page 22. Copyright (2008) by Sage Publications. Reprinted with permission.*

Beeber and Zimmerman (2012) adapted the FMSF for families caring for older adults with dementia. The qualitative secondary analysis intended to translate data from two previous studies and apply the FMSF and adapt components from the framework specific to families caring for older adults with dementia. Data were re-coded into the FMSF components of definition of the situation, management behaviors, and perceived consequences. Four dimensions were identified based on the data analysis for the definition of the situation component. These dimensions included the older adult’s identity, illness view, management mindset, and family mutuality (Beeber & Zimmerman, 2012). Two dimensions emerged from the management behaviors: caregiving philosophy, and caregivers’ estimation of the degree to which they have a

comfortable routine in caring for their family member. The perceived consequences component also had two dimensions: family focus and future expectations. The study successfully adapted the FMSF to identify and categorize the needs of caregivers of older adults with dementia.

A systematic review conducted by Knafl et al. (2012) examined 64 published articles that utilized the FMSF. The authors described the framework examining “the intersection of condition management and family life” (p. 12). It has been used in a wide variety of research settings and conditions. The framework continues to be adapted and has been used in a variety of patient and family situations. It is particularly useful in qualitative studies when examining the family’s reaction to a particular disease or condition of a family member.

Conclusion

The framework has been shown to be adaptable in multiple situations across the entire lifespan, and for multiple conditions as well. Family management has been defined as the family’s role in responding to illness and health-related issues (Deatrick & Knafl, 1990). Studies have identified family typology that exists for families experiencing a wide variety of health-related issues (Wiegand, 2012). Therefore, the FMSF was deemed useful for this study, as it allows the examination of multiple perspectives on family management and emphasizes differences in family roles and expectations (Baraket, 2012). The Family Management Style Framework allowed this author to explore family rounds as a contextual influence and how it impacts on family functioning in the intensive care unit.

CHAPTER III

METHODS

Introduction

This study used a qualitative descriptive design to explore the experiences of family members with ICU bedside rounds. Family members who were relatives of patients in one of two medical ICUs were asked to participate. I sought two family categories: those who participated in bedside rounds and those who did not. The FMSF (Knafl & Deatrick, 1990, 2003; Knafl et al., 2012) was used to undergird the study. This conceptual model identifies three family management style components that comprise family functioning within the context of chronic illness, as follows: definition of the situation, management behaviors, and perceived consequences (Knafl & Deatrick, 2003).

The purpose of this chapter is to describe the methods used for the study. The procedures for data collection, management, and data analysis are described in the pages that follow. In addition, trustworthiness components, human subject considerations, study limitations, and timeline are identified.

Qualitative Descriptive Design

Qualitative methodology is especially useful when a better understanding of illness and how it is experienced are needed (Morse, 2007). Data are in the form of words, stories, and experiences that are analyzed into a formal structure. Qualitative description is a distinct method of naturalistic inquiry that utilizes everyday language and low inference interpretation (Sandelowski, 2000, 2010). The goal of qualitative description is descriptive and interpretive validity. It seeks to understand the multifaceted experiences, events, or processes entrenched within the human context (Sullivan-Bolyai,

Bova, & Harper, 2005). Participant observation is an important piece of the interview process, as well as the interview itself. Body language, nonverbal cues, and voice inflection are all important signs to take note of from the participants. Field notes are also used to record the participants' actions and emotions, and to describe what the researcher is feeling and thinking (Morse, 2007).

According to Sandelowski (2000, 2010), precise description must be conveyed from the participants. Interpretive validity is the accurate description that participants give to the phenomena in question. The goal of interpretive validity is reached by having subjects describe their experiences and interpreting those responses while staying close to data. Qualitative description allows for a comprehensive summary from the participant's viewpoint using common, everyday language (Sullivan-Bolyai et al., 2005).

Setting

Recruitment of eligible subjects took place in the medical intensive care units (MICUs) at UMass Memorial Medical Center, University Campus, in Worcester, MA. These units are 16 beds each. The attending physician staff is the same for each unit on a rotational basis. The nursing staffs are separate. The evidence-based care and procedures are identical for each unit. The units share the same nursing and physician management team. The average length of stay in the two units is 4.3 days, with a range of 1 day to as long as 3 months. Typical medical conditions treated include respiratory failure, sepsis, multiple organ failure, and gastrointestinal bleeding.

All families are informed of the bedside conferences upon their first visit to the unit using a brochure and nursing staff discussion. Signs are also posted in the waiting room of each unit. Family rounds take place 5 days a week from 11:30 a.m. through

12:30 p.m., or longer if there is a need at the patient's bedside. The participants in the bedside conferences include the unit attending physician, the patient's nurse, nurse practitioner (NP), and respiratory therapist. An informal structure is used for the conference, usually including a brief description of the patient's condition, plan for the day, and goal of therapy. Families are encouraged to ask questions, offer input, and share their feelings.

Sample

Ten families, a minimal starting sample, who participated in family bedside rounds were approached, utilizing purposeful sampling techniques. Purposeful sampling allows researchers to select information-rich cases for in-depth study that illuminate questions (Patton, 1990). Information-rich cases allow researchers to maximize what can be learned by selecting participants with a unique view of the issue being examined, and from those who might be willing to share their experiences. The researcher checked with the nurse manager and staff to recruit those family members who seemed willing to share their unique views, family members who had a range of experiences in the ICU, including families who participated in the bedside conferences and those who did not. The interviews were held with a single family member; if more than one from the same family were available, the researcher's choice was based on receptivity and comfort level. Participants continued to be recruited until emerging themes become apparent and informational redundancy was achieved. In addition, an attempt was made to recruit a minimum starting sample of 10 family members who chose not to participate in family bedside rounds to gather information on their perspectives, with a similar sampling plan until informational redundancy was reached.

Inclusion criteria for the study were family members (a) who acted as family members (biological or implied) representing a patient in one of the participating ICUs; (b) whose loved one had been transferred from the unit and was no longer under the care of the ICU team or had been discharged from the hospital for up to 2 weeks; (c) who were 18 years of age or older; and (d) who were able to read, write, and understand English. Exclusion criteria were family members (a) whose loved one had died; (b) who were not able to read, write, or understand English; and (c) whose loved one was not in one of the medical ICUs.

Recruitment

After institutional review board approval was obtained, the researcher approached the unit administrators to conduct an education session about the study with physicians, NPs, and ICU nurses who provide the direct care. Informational brochures were made available in the waiting rooms and in the admission packets given to all families upon admission to the ICU. The researcher was available on the unit at least 2 days per week during the time the bedside conferences were occurring (11:30 a.m.–12:30 p.m.) and in the evening to recruit participants. Recruitment of participants occurred when the patients were still in the ICU, but interviews occurred after the patient has been discharged from the unit. A family member was asked by the researcher and/or the nurse manager distributing study brochures about their willingness to be contacted about the study while the patient was still in the ICU. In addition, the nurse manager made brochures available during daily patient care rounds for distribution and to answer questions about the study. The nurse manager notified the researcher of families who were interested in participating in the study.

Data Collection

Demographic data were collected from the participants during the interviews, which included age, sex, relationship to patient, and time the patient was in the ICU (See Appendix A). The initial open-ended questions were undergirded by the FMSF, with many opportunities to probe answers (See Appendix B). This qualitative approach with one-to-one semistructured interviews was used to gain rich descriptions of the family members' perspectives. Key to the interview process was the opportunity for the investigator to use focused probes to either clarify, expand, or collect more specific samples of data. It was necessary that the interview guide be more prescriptive than other forms of qualitative inquiry (Appendix B). This allowed for the expert knowledge of the researcher to better focus on the area of interest (Sullivan-Bolyai et al., 2005). In addition, participant observation was used throughout the interview, recording personal reflections, feelings, and what was observed into field notes.

Procedure

The researcher contacted those family members he or the nurse manager had identified, told them about the purpose of the study, and inquired about their willingness to participate. Family members who gave consent to participate were scheduled for an interview at a mutually agreeable location, such as the participant's home, in the hospital, the rehabilitation center, or in the Graduate School of Nursing (GSON). Parking vouchers were provided for interviews that took place at the GSON or hospital. A signed informed consent was obtained after a thorough explanation of the study was given. Participants were asked to complete a short demographic form that included their relationship to the patient and the length of time their family member was in the ICU (Appendix A).

Qualitative data collection was conducted using the interview guide (Appendix B). All interviews were electronically recorded. Total interview time took up to 60 minutes. Data collection, analysis, and interpretation were conducted simultaneously according to the principles of qualitative description and qualitative content analysis, using constant comparative analysis techniques (Hsieh & Shannon, 2005). Field notes were reviewed immediately after each interview to add detail where needed to maximize insights into the setting.

Participant observation and field-note data were incorporated into the transcripts and threaded throughout the analysis process. Thus, after the first interview was completed, summarized, and data were recorded, the next interview occurred. The process allowed for each interview and perspectives to inform the next one, and questions were altered as necessary to focus the exploration of the phenomena.

Data Management

Data were reviewed for completeness. After each qualitative interview, field notes were reviewed for completeness and clarity. Field notes, observations, memos, and personal reflections were included in all data review to record the gestalt of each interview. An audit trail was maintained. Recordings were listened to immediately after each session to assure the recordings were clear, and the researcher recorded chunks of data after initial summation. Verbatim transcriptions using a professional transcriptionist were done from the recordings, converting them into text files, which were then coded by hand. Demographic data were summarized by hand. After transcription, the researcher cross-checked each transcription with the audio recording for accuracy. Audio

recordings, field notes, and demographic data were maintained in an encrypted, password-protected, laptop computer. All data sources will be destroyed in 5 years.

Data Analysis

Qualitative descriptive data collection involves the use of moderately structured open-ended interviews. Data analysis should go beyond simply counting words or phrases, but really seek to understand and classify large amounts of text into categories that represent similar meaning (Hsieh & Shannon, 2005). Each transcript was summarized providing a gestalt of the interview, then the analysis techniques described by Miles and Huberman (1994) were utilized. The series of steps described by them included the following:

- coding of the data from field notes and observations
- recording insights and reflections from the data
- identifying similar phrases, themes, and patterns
- searching for similarities within and across the data
- making generalizations about the data
- examining generalizations in relation to what is known about the phenomena

Timing of the data analysis began as soon as possible after the first interview and continued throughout the data collection phase. Qualitative content analysis techniques were used to review all subjects' understanding of each item through a process of coding and categorizing the patterns of the subject matter. Broad coding categories were created based on the FMSF (Knafl & Deatrick, 1990, 2003; Knafl et al., 2012). These included definition of the situation, management behaviors, and perceived consequences.

However, as is typical of qualitative description, if the framework restricts the emergence

of themes, framework concepts will be dropped, allowing for the naturalistic organization of data from the participants' voices. This was the case in my experience and will be described in detail in Chapter IV.

The researcher moved back and forth in an iterative process from transcription and coding to identify the main issues that were heard. An inductive reasoning process was utilized, allowing for categories to come to light out of the data. As themes emerged in the analysis from the interviews, other categories or subcategories were utilized as the data dictated. Themes, categories, and subcategories were continuously reviewed, expanded, merged, or modified as necessary to maximize clarity, validity, and reliability.

Trustworthiness

Trustworthiness is necessary to evaluate the value of a qualitative study. According to Lincoln and Guba (1985), to establish trustworthiness, the researcher must ask, "How can an inquirer persuade his or her audiences (including self) that the findings of an inquiry are worth paying attention to?" (p. 290). Techniques described by Lincoln and Guba (1985) were used to augment and document the data quality for this study. They describe four essential steps to evaluate trustworthiness. Credibility is defined as the confidence the researcher has as to the truth of the findings. Activities that are required to support credibility include doing member checks with participants to verify contextual meanings and assessing how relevant the participant's comments are in relation to others in the study. It can also include peer debriefings, which is having another researcher evaluate the data to determine that the conclusions were accurate. Member checks assure that what the researcher heard was indeed what the respondents were saying. Member checks were conducted with 3 participants. In addition, committee

members independently read several of the transcripts and compared them to the identified codes to assure accurate meaning.

The second step essential to establish trustworthiness is dependability, which assures that the findings are consistent and could be repeated if another researcher used the same participants and study design. This can be validated through external audits (Lincoln & Guba, 1985). A detailed audit trail was included on how data were coded, changes made to the codes, and when those changes were made. I also continually reviewed both the data, field notes, participant observation, and audit trail with my committee chair to assure the themes being identified were accurate and complete.

The third step is confirmability, which substantiates that no bias is involved in the data analysis, and that the study results are shaped by the respondents and not the researcher. This was assured by again having committee members review data and the detailed audit trail to provide transparency of the entire study process.

The fourth and final step to establish trustworthiness is transferability (Lincoln & Guba, 1985). Transferability establishes that the findings are applicable to other groups of people similar to external validity and generalizability. This is not necessarily a goal of qualitative descriptive research. These data collected through a qualitative descriptive approach are a rich, thick description of the experience (Sandelowski, 2000) in question rather than deep, interpretive details and may not be transferable to other situations. Nevertheless, publication of the study findings will allow for others in the family ICU research community to determine if there are similar findings or application to their patient and family populations.

Reflexivity

Reflexivity is an important step for the researcher to follow in a qualitative study. Reflexivity is defined as the researcher's ability to recognize that his/her background and experience may affect the research (Malterud, 2001). The topic of investigation, methods used, and conclusions arrived at are all subject to potential bias by the researcher. The researcher must be aware and be able to minimize this bias and to allow these data to come out. The researcher's 30-plus years of critical care experience was an important factor to consider in reflexivity. My own experiences, feelings, and observations were discussed frequently with my committee chair to assure that critical self-reflection was maintained as the data were analyzed to help minimize any bias.

Limitations

The researcher was not able to assure that all family members in the MICU at the time of the study were approached to be in the study. It is impractical to believe that all family members could be approached during the data collection phase. The families who participated in bedside conferences represented only one small portion of all hospitalized ICU patients, so there may have been a lack of diversity. Data collection took place over a 1-year time period, so it was not representative of all families of hospitalized critical care patients. This study examined family members' ICU experiences in two medical ICUs in a single hospital, and may not be representative of all family members of hospitalized patients. Only English-speaking families were approached for the purposes of this study, which may have limited full family perspectives of family rounds, especially from a cultural diversity perspective. The family members who chose not to participate in the family rounds may have been underrepresented. However, I attempted

to recruit at least 10 nonparticipating family members by indicating to them how important their perspective is to exploring how to improve care and family communication in the ICU.

Human Subjects Considerations

Protection of human subjects was maintained throughout the study. Approval of the study was obtained through the Institutional Review Board (IRB) of the University of Massachusetts School of Medicine. Written informed consent was obtained prior to the study, and participants were informed they could withdraw from the study at any time. Nonverbal cues of participant distress were observed, recorded, and discussed with the participant(s) during the interview process to assure they wanted to proceed. Privacy was maintained at all times by conducting the interviews with each family separately. Each participant or group was assigned a unique study identification number that was used on all documents and recordings.

There were no anticipated physical risks to the participants. There was a potential for psychological risks related to participants, especially if they were recounting stressful situations while their family member was hospitalized. Signals of psychological risk were not observed. The investigator remained alert for any signs of increased stress during the interviews and offered to stop the interview or refer the participant to either their primary care provider or help them identify mental health resources in the community.

The transcriptionist signed a confidentiality agreement and was instructed to not transcribe any information that may have been able to identify an individual (names, etc.). The researcher referred to all data by the number only. All data, field notes, and

transcriptions were kept in a locked file cabinet in the researcher's home. Analysis was done on a password-protected laptop computer

Chapter Summary

This chapter summarized the design and methods of the study. Individual interviews and qualitative descriptive methods were used. Study participants were recruited while their family members were patients in one of two ICUs at UMass Memorial Medical Center and were interviewed after their family member had been discharged from the care of the ICU team. The Family Management Style Framework was used to undergird the study.

CHAPTER IV

RESULTS

Introduction

Qualitative descriptive methodology was used to describe the experiences of families with the ICU bedside rounds. The purpose of this chapter is to report the study findings. The results yielded rich descriptive summaries of family members' experiences that included themes for both those who did and did not participate in the bedside rounds. A total of 19 family members participated in the study, with four families who chose not to participate in the family bedside rounds and 15 who attended at least one family round during their loved one's time in the ICU.

The majority of those who participated in the bedside rounds (n =12, 80%) described the rounds as a helpful process. The bedside rounds allowed them to get information, to ask questions, and to have a better understanding of what was happening with their family member and what was needed for them to get his/her health status improved. Many (n = 7) reported the format of getting information at a set time in a structured format to be very beneficial.

One overarching theme emerged from the data, which was *Making a Connection: Comfort and Confidence*. Family rounds provided information and answers to questions, thus eliminating some of the unknowns and making sense of what was happening. Two major factors that influenced how well the connection was made were described by the participants. The first major factor was related to *consistency*. Three types of consistency were identified: *consistency with information being shared, consistency about when family rounds were being held, and consistency with being informed of delays*. When

rounds were held as planned it made everything better, but the absence of consistency was the source of much anger, frustration, and anxiety, making it difficult for family members to make the connection. The second major contributing factor was *preparing families for the future*, which described how rounds helped with setting expectations and, with regard to short-term goals, discharge planning, and family members' roles in the loved one's care management.

Another theme emerged that described the experience of the study for the four participants whose families did not participate in the bedside rounds. This theme was *Disappointment and Frustration*. The individuals had different reasons for not participating, but all expressed being disheartened to some degree and frustrated that they were not able to take part in the bedside rounds.

Participants

A total of 94 family members were approached in the ICU between December 2013 and September 2014. All but two of the potential participants I approached said they were interested in participating in the study, but in the end, for various reasons, 75 family members chose not to participate. There were 39 potential participants who did not call me back despite my continued attempts to contact them a total of three times each. Another 18 potential participants were excluded because their hospitalized family member died either in the ICU or shortly after discharge. Others contacted me that they were no longer interested ($n = 9$), or did not have the time ($n = 7$). One participant agreed to meet with me in a restaurant but did not show up. When contacted afterward, she indicated that she had forgotten and that she was not really interested. The last missing participant met with me, gave consent, and was then interviewed, but I did not properly

record the conversation. When I attempted to contact her to possibly reschedule, she did not have the time to be interviewed again. In the end, I had enlisted 19 family-member participants who provided signed consent and whom I interviewed. The results of these interviews are revealed in the pages that follow.

Participant Demographic Description

Detailed demographic data were collected at the time of each interview and are reported in Table 2. The mean age of the participants was 55.2 years (range 31–76) with 89% ($n = 17$) female and 11% ($n = 2$) male. The majority of participants were the patients' wives (47%, $n = 9$), with daughters coming in second (26%, $n = 5$), and 47% ($n = 9$) of the participants reported that they lived with the hospitalized family member.

Table 2
Participant Demographics

Category	Total Participant Response	Percent
Sex	17 female	89%
	2 male	11%
Age	$N = 19$	Mean: 55.2 years Range: 31–76 years
Relationship	Wife ($n = 9$)	47%
	Daughter ($n = 5$)	26%
	Sister ($n = 2$)	10%
	Son ($n = 1$)	5%
	Brother ($n = 1$)	5%
	Sister-in-law ($n = 1$)	5%
Previous ICU experience	Yes ($n = 14$)	74%
	No ($n = 5$)	26%
Lives with family member	Yes ($n = 9$)	47%
	No ($n = 10$)	53%
How often participant sees family member	Lives with them ($n = 9$)	47%
	More than weekly ($n = 6$)	32%
	Weekly ($n = 3$)	16%
	Monthly ($n = 1$)	5%
Where participant lives	Within 25 miles of hospital ($n = 17$)	90%
	Over 25 miles from hospital ($n = 1$)	5%
	Out of state ($n = 1$)	5%
Patient's first ICU experience	Yes ($n = 10$)	53%
	No ($n = 9$)	47%
Number of patient's days in the ICU	$N = 19$	Mean = 8.05 days Range = 2–34 days

The participants reported that 74% ($n = 14$) had a different family member who previously had been a patient in an ICU; thus this was not their first exposure to an ICU setting. In addition, 53% ($n = 10$) reported that it was this particular family member's first experience in the ICU. The mean number of days in the ICU was 8.05 (range 2–34). The median was 5 days in the ICU.

When the participants were asked how they were made aware that the unit held family bedside rounds, over half (57%, $n = 11$) reported they had seen a posting on the waiting room wall that described the family rounds process. An additional 21% ($n = 4$) said that a member of the ICU team told them, either the RN ($n = 3$) or resident physician ($n = 1$), and 11% ($n = 2$) reported that they had been told by other family members. One of these families described not being aware of the family rounds for the first 6 days of their family member's 17-day stay. She described that on the 7th day she heard another family speaking about it in the waiting room, and only then noticed the posted sign describing the family bedside rounds. Only 11% ($n = 2$) reported being unaware of family rounds.

Family Experiences of Those Who Did Participate

The majority of family members who participated in the bedside rounds ($n = 12$, 80%) found them to be a helpful process and were happy they participated. One family member described rounds as having a daily “roadmap” to follow. The expectations for the family members from bedside rounds were to get test results ($n = 6$), plan for the day ($n = 8$), to be kept updated ($n = 9$), and to prepare for discharge from the ICU ($n = 4$). One person said, “I had a good impression of the family rounds. They were very good

with the information and helped me feel comfortable, explaining everything to me. I was pretty comfortable with it.”

All interviewed family members reported that the information covered was related to their loved one’s plan of care, such as test results, schedule for the day, and what the healthcare teams were concerned about. The majority ($n = 12$, 80%) described family rounds as helpful for patient-related information. However, in this group of 12 participants, four of them reported issues with the process that will be described later in this chapter. Only three family members stated that the family rounds healthcare team could have used simpler terms in their information-sharing, but the majority ($n = 11$) said that they had had the opportunity to ask questions. The content covered at family rounds was consistent in that a plan of care was discussed 93% ($n = 14$) of the time. It was also reported that the team covered test results regularly ($n = 10$) and what the goal of the day was. The plan of care was important for families to understand short-term goals, what milestones their loved one needed to achieve in order to move out of the ICU and to progress toward wellness. In addition, it helped alleviate some of the unknown, which was a significant contributing factor to their fear and anxiety. Family rounds also provided the benefit of pulling the information and care together. One participant described it this way:

You know, when they come in and talk about “here are all the things that we’ve reviewed” and “here’s how we’re formulating our plan,” it’s like, oh yeah, there’ve been a lot of things in the works.

Most participants ($n = 8$) went into the family rounds discussion with the goal of gaining information or knowledge, and several ($n = 6$) reported they were better able to

process what was happening to their critically ill family member and felt better with that knowledge.

Making A Connection: Comfort and Confidence

The major overarching theme that emerged from the data was what participants described as something more than the plan or the numbers: *Making a Connection: Comfort and Confidence*. This was described by eight (53%) families without any prompting, and by four families after prompting. Participants described the family bedside rounds as being more than the healthcare team just sharing information or the plan of the day, but about them being able to convey genuine caring and respect to the family and the patient as individuals. It could be manifested in several ways, all related to treating the patient and family as persons. *Making a Connection* was manifested in several ways, including the care team introducing themselves to the patient and family, explaining why they were there, or simply answering the family member's questions in a simple and thoughtful way.

The study participants described a feeling of comfort as being an important component of making the connection. It was described by several (n = 4) participants as the ability of the care team to offer consistent answers to our questions and allowing us the time needed to answer all their questions. Some (n = 3) also mentioned that the tone of voice used by the team members was important. One participant stated, "Just being brought into the conversation, being talked "to" and not "at" made me feel better."

Participants described the connection as a very calming experience. One family member shared her experience with the growing frustration she saw in her husband's face during family rounds. She asked her husband afterwards the meaning of his frustration,

and he was able to communicate that he could not hear what was being said. The wife was then able to share that information with the team and the fact that her husband, the patient, was deaf in one ear. During the next family rounds the healthcare team made a point to stand on his unaffected hearing side and confirmed with the patient that he was able to hear the conversation. They even were all able to laugh together about it afterward. This action by the team reinforced for both the patient and his wife that their involvement in the treatment plan mattered to the team. Other families ($n = 2$) described the connection as making eye contact; one said that the attending physician sitting on the side of the bed at eye level with the patient was making a connection. Another described it as a touch on the shoulder. One participant stated, "They can provide me with extra information if they feel that I need it. That to me is the kind of connection that I'm looking for in the ICU." These examples shared by participants were important factors in helping them feel confident and comfortable, and that their concerns were taken seriously.

Of the families who participated in the bedside rounds, 40% ($n = 6$) reported that they had absolutely no problems with the process. They were completely satisfied with how everything worked. All said unequivocally that they had made a connection with at least one member of the team. They were given information about their family member's condition that they understood. They knew why their loved one was in the ICU and what was needed to be done for him or her to progress out of the unit and eventually to return home. One participant stated, "They were invaluable." The information was reportedly consistent and accurate, and rounds occurred as scheduled with the entire team.

When the connection was in place, it appeared to fill a void even when there were no definitive medical answers as to what was going on with the patient or perceived lapses in care. A few families ($n = 3$) shared that they felt the team was very honest with them. There were sometimes more questions than answers, especially early in their loved one's hospitalization. In these situations, the participants shared that the care team told them they were not sure what was going on, but were able to share what might be causing the problem and what was being done to get to the root of the problem. This sharing of the unknown, although frustrating for the family, seemed to bring the care team a little closer to the family as they were able to share the frustration together and work toward finding the source of the patient's illness.

Consistency With Communication

A major contributing factor as to whether a connection was made or not was related to the *consistency with communication*. Three different types of consistency were identified by participants that were of importance to them, as follows: (a) consistency of the information being shared (all team members sharing the same information), (b) consistency about when family rounds were being held, and finally (c) consistency in information as to why families were kept waiting in certain situations. When communication consistency was present, the families reported a sense of calm, confidence, and collaboration; the connection was there and was strong. When not present, participants reported episodes of fear, mistrust, and confusion.

Inconsistency was at the root cause of many of the problems shared by family members. The first type that emerged was the consistency of the information they were receiving. Family members gave several ($n = 4$, 26%) examples of information being

shared at family rounds that was not consistent, and it was exacerbated by the fact that rounds were also not occurring on a consistent basis, so the family had no direct means to validate what they were feeling. One family gave an example of receiving information one day, and having that information contradicted by the team on the following day. This occurred with the same family where rounds were not occurring on a regular daily basis. The family member stated, “The doctor or nurse, another doctor, they all told us about an incident. And then the next day a fellow came in and said that never happened to him (the patient).” This caused extreme anxiety and mistrust among the family. The family member also described a situation where one member of the team told a family member what type of pneumonia the patient had, when the family was being told all along that the team was unsure of the type of pneumonia. This created a whole series of issues with the family members. The participant said,

Maybe the doctor was just mistaken and got the wrong information, I don’t know. Wherever she got her information, from when she was saying this did not occur, and we said that it did. I think she should have stopped, instead of insisting it hadn’t happened.

The family member described for me that while these breakdowns in communication were occurring, all she really wanted to know was that her loved one was getting all of the appropriate treatment that she should.

When communication was not consistent, participants disclosed that they questioned every aspect of the care process. Issues raised by them included lack of trust and caring. One family member described concern that the ICU team was not communicating with the patient’s primary care provider, whom they knew and trusted, or

the other care teams. She described an incident with a procedure that she knew had already been done:

Someone came in and said, “Well, you know, if they want to do an MRI on my father later, he’ll have to do this.” But they had already done the MRI the night before, and that person just hadn’t gotten the word yet and so we had to say, “Well no, that test was done.” I understand that there are a lot of different work groups that are involved in the care of my father, each with their own rules and the communication does eventually happen, I’m sure.

This lack of consistent information caused this family member to lose confidence in the whole team. Lack of confidence led to higher levels of stress and anxiety.

The second type of consistency issue that emerged from the data described by the family members was the actual times that rounds were held. Several families ($n = 5$) related that when they were expecting the rounds to occur, they did not on at least one occasion. One participant described making a special trip into the hospital to attend the family rounds at the appointed time and that not having them occur was especially frustrating. Although the families expressed understanding about how busy the team was, they were especially upset when the rounds did not occur. Thoughts of something going wrong and such questions as “Is my family member getting what he or she needs?” led to increased fear, anxiety, anger, and frustration.

The third form of inconsistency shared by family members was that waiting and not knowing the reason for the wait was the cause of significant frustration. This could also have been categorized as setting and meeting expectations. This form of inconsistency was described by 27% ($n = 4$) of the families who participated. It caused

family members significant angst. These participants shared that they experienced increased levels of anxiety and frustration when delays in information occurred and these delays were not communicated to them. It caused one family member to question the expertise of the care team, and two others to question if the team was being totally truthful with them. One family member described how the waiting made her feel very anxious. She was not aware of the reason for the delay. She stated, “I was kind of like pacing, looking out the window, like out the door, kind of like ‘Hello, I’m here!’” Another family member said, “It seems like you’re sitting there and waiting and just time is going by and nothing is really happening.”

Setting Expectations and Preparing for the Future

Family rounds was described and closely linked to the conceptual framework of future expectations. This concept was described by several family members ($n = 7$) and was thought to be an important part of the information they were receiving. When expectations were shared by the care team, it helped families prepare for what was going to happen, both in the short term while the patient was still in the ICU, and as their loved one improved and transitioned out to their next level of care. It was perceived by families to be a very positive contribution of the bedside family rounds. When expectations were not shared, family anxiety and mistrust filled the void.

Participants described preparing for the future in several different ways. In the very short term, when the plan of care was discussed and expectations were reviewed, families reported feelings of confidence, connection, and trust. In a similar way, sharing the long-term expectation, or what would be required after their loved one’s discharge from the ICU was equally important. One participant stated, “It was while she was in the

ICU that I even got an inkling about rehab. So that helped prepare me for starting to look into rehab choices and requirements, which was huge.” Both short- and long-term expectations were vital components to assisting the family member and the patient transition to returning them to the next stage of recovery. One family member described it as having a “roadmap.” Setting expectations allowed families to prepare in the best way possible, as in waiting for a test result or outcome of a breathing trial in the short term or beginning to look at rehabilitation facilities or what home services may be necessary to bring a family member home. The roadmap in either case allows families and patient to begin to prepare for what lies ahead. When prepared, families have more confidence and less anxiety. By beginning to prepare families while in the ICU for what will happen after their loved one leaves the unit, the families were better able to manage their uncertainty about what would happen in the future.

As important as sharing and setting expectations are, when they are not adequately done, similarly bad experiences ensue, which family members described. By not knowing what to expect or what is to come, participants described more anxiety, mistrust, and lack of confidence. One family member shared this:

One minute they were going to move him out to the floor and, before I knew it, he was preparing to be discharged home. I didn’t know what was happening. I’m like “Whoa, wait a minute!”

Overall, however, the family participant responses to the bedside family rounds were strongly positive—quite the opposite to the responses of those family members who did not participate in the rounds.

Family Experiences of Those Who Did Not Participate

Disappointment and Frustration

Of the family members who did not participate ($n = 4$), all stated that they would have preferred to do so if the opportunity had arisen. One study participant was unable to make the scheduled meeting time, two were unaware that rounds were occurring, and one family member described coming into the hospital on three different occasions expecting to have rounds, only to find out they were not being held at the designated time. All of these situations resulted in overall disappointment in not being able to participate. One family member aptly stated, "I would have accommodated whatever time they were going to happen."

Family members who did not attend the bedside family rounds reported that part of the reason they did not participate was that the times of the sessions were not convenient for them. One family member described coming in early in the morning each of the 4 days his/her loved one was in the ICU and finding that the rounds were not taking place. This individual stated,

I was frustrated to think that I had waited after coming in specifically early, purposefully to be able to meet with them and talk to the doctors exactly about what was going on, because for the first 48 hours they weren't very sure exactly what was happening.

Another family member also shared that since the family had a limited ability to communicate with the healthcare team, they did not understand why the team members were wearing masks upon entering the room: "When my father asked why, I don't know if they (the care team) were forthcoming with that information." The family member

described her father, the patient, as feeling afraid when he saw that the caregivers were wearing masks and neither he nor the family was informed why.

All four of these family members expressed significant frustration in not participating in bedside rounds and reported they did not feel like they were getting enough communication about their loved one's condition. Of note, the patients of these four families were only in the ICU 2–4 days.

Summary

Nineteen family members of ICU patients were interviewed to explore their experiences with ICU bedside rounds. Four of the families had not participated in the rounds, and 15 had participated. The majority of those who participated ($n = 12$, 80%), found the family bedside rounds helpful.

For the families who did participate in the bedside rounds, one major overarching theme emerged from the data: *Making a Connection: Comfort and Confidence*. Two major factors that influenced how well that connection was made were described by the participants. The first major factor was related to *consistency*. Three different types of consistency were identified: *consistency with information being shared*, *consistency about when family rounds were being held*, and *consistency with being informed of delays*. When rounds were held as planned, it made everything better, but when consistency was absent, it was the source of much anger, frustration, and anxiety, and it made it difficult for family members to make the connection. The second major contributing factor was *preparing families for the future*, which revealed how the family bedside rounds helped set expectations and, regarding short-term goals, discharge planning, and the family's role in the loved one's care management.

For the families who had not participated in the bedside rounds, the one major finding was *Disappointment and Frustration* about not having done so. Although several reasons were given for not having participated, all families were extremely unhappy with not having had the opportunity to do so.

CHAPTER V

DISCUSSION

The purpose of this study was to describe family members' experiences with family rounds using a qualitative descriptive method. The main findings suggest that the family rounds process, when conducted consistently with accurate information-sharing, kept families informed, improved decision-making, assisted the family and providers to set mutually agreeable goals, and helped prepare families for the future with regard to discharge planning and their role in their loved one's home care management. However, when rounds were held inconsistently or when inconsistent information was shared with family members, mistrust of the entire team developed.

The families who did not participate experienced *Disappointment and Frustration* and reported there were several reasons why they could not (or would not) participate. All family members who did not participate stated they would have preferred to do so.

First, these finding will be discussed in relation to the study's conceptual framework: Knafl and Deatrick's Family Management Style Framework (FMSF; 1990, 2003) and Knafl, Deatrick, and Havill's Revised FMSF (2012). Second, the study's major findings will be compared to prior empirical evidence. Finally, this chapter will present implications for the practice of family bedside rounds in the ICUs and propose areas of possible improvement and future research.

Conceptual Framework

The Family Management Style Framework (Knafl & Deatrick, 1990, 2003; Knafl et al., 2012) was used to undergird this research. The FMSF helps researchers identify patterns and typologies of family functioning in a wide variety of families and situations

as they confront healthcare issues (Wiegand, Deatrick, & Knafl, 2008). The FMSF comprises three major components: definition of the situation, management behaviors, and perceived consequences. All of these components are thought to impact how families understand and manage the illness of a family member.

The specific aims of this study reflected these major components. Specific Aim #1 sought to describe the experiences of ICU-patient family members who participated in bedside rounds, considering their perspective in their view of the loved one's illness, their future role in management of the condition, and its long-term consequences on individual function and family functioning overall. Specific Aim #2 sought to describe the experiences of families who chose not to participate in bedside rounds and their perspectives regarding its value, their illness view, and their future involvement in the loved one's care.

Although the FMSF provided a useful underpinning by which to assess the family's experiences, it did not fully account for all of the key and contributing factors that emerged from the data. Of the three components cited by Knafl and Deatrick (1990, 2003) and Knafl et al. (2012), only two (definition of the situation and perceived consequences) emerged from the data as major themes or contributing factors. Management behaviors did not appear to be a primary component of the family members' experiences. Definition of the situation is described as the family's perspective of the condition their ill family member currently has and their perspective on how they will be able to manage their loved one's illness (Knafl & Deatrick, 1990, 2003; Knafl et al., 2012). This emerged from the data in the form of discussions with the care team and receiving a daily "roadmap" for the families to follow, and having their questions

answered. The third component of the FMSF was present in those data that emerged related to perceived consequences. Knafl and Deatrick (1990, 2003) and Knafl et al., (2012) define this component as the actual and expected long-term outcomes and the implications for the family in the long term. This component emerged as a contributing factor, *setting expectations and preparing for the future*. Many families (n = 7) thought this to be an important part of the information they were receiving.

The component that did not emerge from the data was management behaviors. Knafl and Deatrick (1990, 2003) defined this as the “discrete behavioral accommodations that the family members use to manage on a daily basis” (Knafl & Deatrick, 1990, p. 9). None of the primary themes were related to this component. In addition, the primary theme of *Making a Connection: Comfort and Confidence* was not totally accounted for in the FMSF for families who did participate in bedside rounds. Although not a perfect fit based on the findings, the FMSF was an important guiding framework to allow the application of structure and categorization of initial concepts (Beck, 2009).

Relationship to Prior Empirical Evidence

Family-centered research in the critical care environment has been limited in the past, focusing primarily on family satisfaction, communication, and decision-making regarding families in the critical care environment (Roberti & Fitzpatrick, 2010). Past studies have failed to capture what family members were feeling and how to better deal with the situation. Prior studies of families’ experiences with critically ill patients indicated that poor communication contributes to higher rates of depression, anxiety, and mistrust of healthcare providers (Jacobowski et al., 2010). Sending a consistent message to family members has been identified as important, especially in the critical care setting

where multiple team members are participating in care (Heyland et al., 2002).

Communication breakdowns between the ICU care team and patient families have been identified in several studies as a major cause of dissatisfaction (Anderson et al., 2013; Schiler & Anderson, 2003). This study confirmed that *communication* was an important factor for the families interviewed. What emerged from the data was that when communication is present and done well, families reported feelings of comfort and trust. When families experienced communication issues, including inconsistency, lack of a clear message, misinformation, or no information, these were all factors described by participants that led to feelings of mistrust, anger, frustration, and anxiety.

Typically, satisfaction has been used as the primary endpoint when measuring how well healthcare providers are meeting the needs of family members of ICU patients. Patient and family satisfaction has been described as a complex emotion influenced by the gap between expectation and perception (Stricker et al., 2009). This study did not measure family satisfaction. Only one major theme emerged from this study, *Making a Connection: Comfort and Confidence*, which was described by 53% of the family members using terms such as assurance, genuine caring, and comfort. Similar themes have been reported in the literature as being domains of satisfaction (Heyland et al., 2002; Wasser et al., 1998).

The medical community and society in general over the past several years have been urging shared decision-making among patients, families, and healthcare providers (Kon, 2010). The goal of shared decision-making is to make decisions consistent with the patient's wishes (Curtis & Tonelli, 2011). In order to be involved in shared decision-making, families must be informed of both the short- and long-term plan of care. *Setting*

expectations and preparing for the future was one of the major factors that influenced how well *Making a Connection: Comfort and Confidence* occurred. When expectations were shared, it helped families prepare for what was going to happen, both in the short and long term.

The theme of *Making a Connection: Comfort and Confidence* has not been described in previous studies, although the contributing factors of *consistency of information* and *preparing families for the future* have been described as important components to patient satisfaction (Schiller & Anderson, 2003), trust of the care team (Jacobowski et al., 2010), and shared decision-making (Luce, 2010).

Consistency of information has been well described in previous studies as being important to family members dealing with the illness of a loved one in an ICU setting (Henrich et al., 2011; Jacobowski et al., 2010). The participants of this study identified the *consistency of the information being received*, *consistency of when rounds were occurring*, and the *consistency of being informed of delays* as important factors. Consistency (or lack thereof) contributed significantly to their experiences, either positively or negatively.

This study confirmed that it is important for family members to be involved in the care of their loved ones. It is equally important that they receive a clear, understandable message as to the plan of care, time frame, and mutually agreed-upon goals. How and what the healthcare team communicates to families matters.

The consistency of the information being shared with family members has been well described in past studies (Anderson et al., 2013; Schiller & Anderson, 2003). When family members received a consistent message as to the plan of care, they reported

feelings of satisfaction and trust, of making a connection. When messages were mixed or unclear, families reporting feelings of anger and frustration. Team members must be astute as to what message is being given to the family and what the agreed-upon plan of care is.

When ICU family rounds are done consistently and regularly, it allows the family members a feeling of *Making a Connection: Comfort and Confidence*. When not done consistently, it can lead to breakdowns in communication, and feelings of anxiety, frustration, and anger. It is crucial that families be included in decision-making for their critically ill family member and that they be kept informed of delays as they occur. Of equal importance is the fact that the information shared with families be consistent from all caregivers, and that families be kept aware of delays, changes to the plan of care, and problems (complications) that may arise. Failure to do so brings forth feelings of anger, mistrust, frustration, and anxiety.

Implications for Practice

Three specific implications for practice emerged from the study results:

- Increasing family awareness about ICU family rounds
- Educating the healthcare team members about the importance of making a connection with the family, providing rounds and information consistently, and shared decision-making
- Engaging the nursing staff to conduct post-round debriefing with the family members

Increasing Awareness of Rounds

To increase family awareness about rounds, an informational flier could be developed and given to family members upon their loved one's admission to the ICU. This simple intervention has been described as successful at other institutions related to the bedside-rounding process (Azoulay et al., 2002; Lautrette et al., 2007). In addition to the flier, part of the standard orientation checklist done by all RN staff when a patient is first admitted to the ICU needs to include information about family bedside rounds. This will ensure that information about the availability of family rounds is given to all family members verbally and in writing. Lastly, reinforcement of this information will be shared with families by having the nurse ask all family members if they received the information and if they have any questions. If they were not participating, we could ask what we might do to allow them to participate (different time, phone conversation, etc.). This could also be an opportunity to discuss with the family the benefits of the process for them and their loved one.

Educating the Team

Education of the healthcare team would focus on the importance of family bedside rounds, the need to present information consistently, how to connect with family members (i.e., understanding the basics of therapeutic conversations, such as active listening, eye contact, etc.), and the processes for engaging family members in shared decision-making.

Webinars and e-learning programs would be created specific to the role of each member of the team, whether licensed independent practitioner or RN. This program could be added to their annual competency list. The program could be introduced at

faculty meetings for physicians and staff meeting for nurses to assure buy-in. Key concepts of the education would focus on shared decision-making, therapeutic conversation and its impact on the family. Part of the education would include setting expectations with nurses that they would ask a set of questions aimed specifically at establishing a framework for making a connection. The following questions proposed by Bell (2013) would be asked of family members upon arrival at the ICU:

- We routinely invite families to a family meeting to learn more about your experience of this illness and how we can be most helpful to you. What are you most worried about right now?
- What has been the biggest impact of this illness on you?
- What is the biggest impact on your family? On your marriage (children, etc.)?

Nurses would be instructed to ask families these questions on a daily basis:

- What do you need most from me as I care for your family member today?
- In our time together, if you could have just one question answered, what would that question be?

Post-Round Debriefing Session

The post-round debriefing session with family members can assure nursing staff that the family is getting and processing their received information, allowing for true shared decision-making. The debriefing could include these questions proposed by Bell (2013):

- Have you had a chance to tell your story?
- How did you experience our session today? Was it useful?
- Does this way of working fit for you?

- Are we meeting your expectations and needs?
- Is there anything you need more or less of in our work together?

Nurses could then document the family's response to the family round session and provide feedback to the team during meetings as a means to improve over time the quality of communication and the delivery of family rounds.

Implications for Research

Future research on ICU family rounds should include studies that examine the impact of family rounds over time. This study focused only on the in-patient experience. It is not known if family rounds help patients and their families transition to other settings (e.g., home, long-term care, rehabilitation). Also, we excluded from this study the families of patients who died in the ICU. Exploring how family rounds help families prepare for and cope with the death of their loved one would be another important area of research inquiry. Finally, a randomized clinical trial to determine the best way of educating providers to deliver effective ICU family rounds would be an important next step for supplying the evidence needed to improve the delivery of this intervention.

Limitations

The study was limited to two medical adult ICUs at an academic medical center. All of the participants were English speaking. If I had spoken through an interpreter to non-English-speaking family members from different cultures, it is unclear if the same findings would have emerged. It is interesting that virtually all (98%) of the 96 family members approached were initially interested in talking to me, and that in the end only 19 agreed to speak with me after their family member was transferred from the ICU or discharged from the hospital. It seems likely that having only 19% of the 98 family

members approached agree to participate in the study created some bias. Why the low rate of family participation occurred is unknown. Some possible reasons include that once their family member was transferred from the ICU, the family was too busy with their loved one in the new environment and had no time to participate. One way that could have been avoided would have been to speak to family members while their relative was still a patient in the ICU. Further potential bias is that I did not approach families who were reported to be in crisis at the time I was on the unit, families of patients not likely to survive, or families of patients with mental health or substance abuse issues.

Conclusion

The experiences of family members with ICU bedside rounds were explored in this study, which utilized qualitative descriptive methodology. The specific aims of the study were guided by Knafl and Deatrick's Family Management Style Framework (1990, 2003) and the Revised FMSF of Knafl et al. (2012). Overall, the vast majority of family members found benefit in being included in the bedside rounds process. They were able to stay informed, set mutually agreed-upon goals, be updated about findings, and have their questions answered. Getting consistent information was important to the participants of this study, as has been shown in previous studies (Curtis and White, 2008; Henrich et al., 2011; Jacobowski et al., 2010).

When done consistently, ICU bedside rounds allow family members a feeling of *Making a Connection: Comfort and Confidence*. When not done consistently, it could lead to breakdowns in communication, and feelings of anxiety, frustration and anger.

As healthcare providers, what we say to family members and how we say it matters. They need to be included in decision-making with honest, consistent, easy-to-understand information, and options available to them and their loved ones. Only when families have all of this information can they be true participants in their loved one's care.

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APPENDIX A

PARTICIPANT DEMOGRAPHICS QUESTIONNAIRE

1. I am (indicate 1): Male Female

2. I am _____years old

3. I am the patient's:

Wife	Husband	Partner	
Mother	Father	Sister	Brother
Daughter	Son	Other (Please specify):_____	

4. Before this most recent event, have you been involved as a family member of a loved one in an ICU (Intensive Care Unit)?

Yes No

5. Do you live with the person who was in the ICU? Yes No

If no, then on average how often do you see the patient?

More than weekly Weekly Monthly Yearly Less than once a year

6. Where do you live? In the city where the hospital is located?

Out of town?

7. Was this your family member's first admission to the ICU?

8. **How long** was your family member in the ICU? _____ days

APPENDIX B

INTERVIEW GUIDE

Aims/Conceptual Area	Main Question	Probes
Introduction/Opening	<p>Introduction of the study/purpose.</p> <p>Did you participate in the family bedside rounds?</p>	

	IF YES	
Definition of the situation/Illness View	<p>Can you tell me a little bit about your impression of the bedside rounds?</p> <p>With the information you heard during bedside rounds, how helpful was it to explain why your family member was in the ICU?</p> <p>What was your understanding of your family member's condition before they were admitted</p>	<p>If so, in what way was it helpful?</p> <p>How did it help clarify the situation?</p> <p>What other types of information would be helpful to receive?</p> <p>Has the rounding process enhanced your understanding? If so, how?</p>
Future involvement in care/management behaviors	<p>What type of information shared during family rounds did you find helpful to the time after your family member left the ICU?</p>	<p>Did you understand your family member's treatment plan? Did rounds help clarify what was needed? What kind of help the patient would need in the future?</p>
Future expectations/perceived consequences	<p>How could we improve bedside rounds to make it more helpful after discharge from the ICU?</p> <p>Were you kept updated as to any changes (good or bad)?</p>	<p>If so, how?</p> <p>Was the information you received understandable?</p>

Aims/Conceptual Area	Main Question	Probes
Introduction/Opening	<p>Introduction of the study/purpose.</p> <p>Did you participate in the family bedside rounds?</p>	

	IF NO	
Definition of the situation/ Illness View.	<p>Can you tell me why you chose not to participate in bedside rounds?</p> <p>How did you receive information about your family member?</p> <p>Was the information timely and clear?</p>	<p>Did you receive enough information?</p> <p>What could have improved it?</p>
Future involvement in care/management behaviors	<p>Were you aware that daily bedside rounding was available to you?</p> <p>Why did you not attend?</p>	<p>Not a convenient time?</p> <p>Would another time have been more convenient?</p>
Future expectations/perceived consequences	<p>Is there anything we could have done that could allow you to attend bedside rounds?</p>	<p>If so, what?</p>