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The Met and Unmet Needs of Families of Patients in the ICU and Implications for Social Work Practice

Abstract
This qualitative research study seeks an understanding of the experience and needs of family members of patients in an intensive care unit (ICU) at a large, metropolitan hospital. This study utilizes a self-developed, semi-structured interview, transitioning the findings of the The Critical Care Family Needs Inventory (CCFNI) (Molter, & Leske, 1983) into open-ended interview questions. The interviews query participants about their needs related to their family member's stay in the ICU, their interactions with the health care team and any recommendations they wished to offer to family members of patients in the ICU and to the health care team. The twelve interviews were coded and the findings are reported using "issue focused" analysis as described by Weiss (1994). The interviews yield multiple needs of family members of patients in the ICU including the need for: communication, information, visitation, vigilance, assurance, and "realistic hope." The interviews also reveal that the advice offered by the participants to both future family members of patients in the ICU and to the health care team caring for patients and families mirror their own indicated needs. Discrepancies in the findings, as well as in the "advice" offered, suggests additional research in this area is warranted. Additional research investigating interventions designed to meet the families' needs and the role of social work in the ICU in meeting these needs is also indicated.

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A DISSERTATION

in

Social Work

Presented to the Faculty of the University of Pennsylvania

in

Partial Fulfillment of the Requirements for the

Degree of Doctor of Social Work

2010

_____

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Heather Sheaffer

2010

Dedicated to Mom, Mikie and Eddie

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ABSTRACT

THE MET AND UNMET NEEDS OF FAMILIES OF PATIENTS IN THE ICU AND IMPLICATIONS FOR SOCIAL WORK PRACTICE

Heather Sheaffer

Lina Hartocollis

This qualitative research study seeks an understanding of the experience and needs of family members of patients in an intensive care unit (ICU) at a large, metropolitan hospital. This study utilizes a self-developed, semi-structured interview, transitioning the findings of the *The Critical Care Family Needs Inventory* (CCFNI) (Molter, & Leske, 1983) into open-ended interview questions. The interviews query participants about their needs related to their family member's stay in the ICU, their interactions with the health care team and any recommendations they wished to offer to family members of patients in the ICU and to the health care team. The twelve interviews were coded and the findings are reported using "issue focused" analysis as described by Weiss (1994). The interviews yield multiple needs of family members of patients in the ICU including the need for: communication, information, visitation, vigilance, assurance, and "realistic hope." The interviews also reveal that the advice offered by the participants to both future family members of patients in the ICU and to the health care team caring for patients and families mirror their own indicated needs. Discrepancies in the findings, as well as in the "advice" offered, suggests additional research in this area is warranted. Additional research investigating interventions designed to meet the families' needs and the role of social work in the ICU in meeting these needs is also indicated.

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Chapter I.

Intensive Care: The Family's Experience

Specialized care for critically ill patients in the United States has expanded exponentially since 1958, when the first intensive care unit opened its doors in Baltimore, Maryland (Grauer, 2008). Approximately 65.5% of all hospitals in the US provide critical care (Halpern, Pastores, & Greenstein, 2004) and this number is growing steadily. A number of studies have explored the social, psychological, and financial impact of an intensive care stay on patients and their families, less is known about how social workers can best meet the needs of families with a critically ill family member.

Research arising out of the field of nursing has indicated that the families of patients in the intensive care unit have a variety of needs and stressors related to their intensive care experience. Needs that have been identified by families include the need for information, assurance and support. However, nursing research also indicates that such family needs often go unrecognized and hence remain unmet (Kotkamp-Mothes, Slawinsky, Hinderman, & Stauss, 2005; Molter, 1979). Even in situations when families' needs are known to the ICU staff, studies have indicated that these needs are not always addressed by healthcare providers, whose focus tends to be on the medical needs of the patient (Bijttebier, Vanoost, Delva, Ferdinande, & Frans, 2001).

Social workers are trained to work with families to address their psychosocial needs. However social workers, like other members of the medical team, may be unaware of the particular needs of families in the intensive care unit. Moreover, social workers tend to interact with intensive care families only in the context of understanding the

biopsychosocial needs of the patient, not the needs of the family system. The attention to the patient and not the family system may be the result not only of the constraints of current hospital social work practice, focusing on discharge planning, but the lack of empirical evidence joining social work roles in the intensive care unit with current literature detailing the needs of families of patients in the intensive care unit. This study aims to help bridge that gap by attempting to learn from the families themselves about their perceived needs and how they believe these needs can best be met.

Intensive Care

Intensive care or critical care began with a simple concept- congregate the most acutely ill patients together where they could be watched more closely by the healthcare team (Knaus, Draper, Wagner, & Zimmerman, 1986). Watching the most ill patients more closely allowed healthcare providers to intervene more quickly when medical crises arose. This simple yet revolutionary change in healthcare spawned the development of intensive or critical care medicine as a specialty.

Since the opening of the first intensive care unit at Baltimore City Hospital (currently John Hopkins Bayview) in September 1958, the specialty of intensive or critical care has grown and expanded exponentially (Grauer, 2008). Approximately 65.5% of all hospitals in the United States (U.S.) provide critical care (Halpern, Pastores, & Greenstein, 2004) and this number is steadily increasing. It was estimated in 2006 that there were 5980 intensive care units in the United States providing care to approximately 55,000 patients per day (Angus et al., 2006). While the number of overall hospital beds in the U. S decreased by more than 25% in the late 1980 and throughout the 1990's, the number of intensive care beds grew by more than 30% (Halpern et al., 2004). This shift in focus is a reflection upon the changes in medical care and

technology as well as the aging of the U.S. population and the "increased…burden of acute and chronic illness" associated with the graying of America (Kelly et al., 2004, p. 1220).

Intensive care represents between 11.5% and 30% of all hospital costs (Brilli et al., 2001; Halpern et al., 2004; Rose & Shelton, 2006). To put the financial impact of intensive care into a large context, 1%-2% of the gross domestic product of the U. S. is attributed to the costs associated with intensive care services (Brilli et al., 2001; Halpern et al., 2004; Jakob & Rothen, 1997; Kelly et al. 2004; Rose & Shelton, 2006). Needless to say, the financial impact of intensive care on both the microcosm of the hospital and upon the macrocosm of the U.S. economy is significant and expected to grow and expand well into the future.

Intensive care has impacts beyond financial considerations. With advances in medical technology allowing the treatment of illnesses and injuries previously thought untreatable, as well as the aging of the population, there is no reason to expect admissions to intensive care units to decline. With increases in admissions to intensive care, come increases in poor outcomes and deaths. "The number of deaths in ICUs, (intensive care units), in the U.S. is increasing and this trend is expected to continue" (McCormick, Engelberg & Curtis, 2007, p.930). One study related that approximately 20% of all Americans die during or shortly after a stay in the ICU, further emphasizing the potential needs of families of patient both in the ICU and following (McCormick et al., 2007). Latour (2007) took this challenge further by reminding us that as healthcare technology advances, the ICU environment will evolve, and healthcare providers will need to evolve their practice to meet the changing critical care environment.

The intensive care unit offers patients sophisticated medical interventions and specialized staffing not available to patients on non-intensive care units of the hospital. Each patient's needs are considered prior to transfer to intensive care to assure that the patients who need intensive

care services are receiving intensive care services as “demand for intensive care exceeds supply” (Joynt et al., 2000).Often patients are admitted to the ICU after experiencing a sudden, unexpected traumatic event such as an acute illness or injury. However, some patients are admitted to ICU following planned medical procedures such as surgery for stabilization and monitoring. The predominant reasons for ICU admission as reported in 2006 were respiratory insufficiency, postoperative care and heart failure (Angus, et al., 2006). Regardless of the reason for the admission to the ICU, the patient’s medical status is often unclear and may be in a state of rapid flux. This state of flux stresses the patient and the patient’s support system. This situation serves as a reminder that the patient in not admitted to the hospital alone. He or she is part of many systems in the community including a system he or she defines as “family.”

The Family

When thinking about a patient’s admission to an intensive care unit one must first remember the patient is a person, a human being, who is connected to the world outside of the walls of the hospital. These connections often include relatives and friends who, for the sake of this dissertation, will be termed *family*. I have chosen to use the word family in this writing to represent all those who may be viewed as loved ones of the patient not just those who share common ancestry with the patient in the traditional Western sense of familial relationship. In current American society, many choose to identify others significant to them as family although they have no blood or marriage ties. The term family was also chosen for its ability to evoke a sense of closeness or companionship as to best portray the intimacy of the relationship between the family and the patient. The experience of the family during the patient’s hospitalization in the intensive care unit is the central area of interest in this research.

Bond, Draeger, Mandleco, and Donnelly (2003) related "the whole of the family is greater than the sum of its parts" (p. 64). This statement about families in the healthcare setting attests to the complexity of working with families who are dealing with stress of a family member in intensive care. Each individual's reactions to the healthcare encounter are personal and unique. Each individuals needs are also personal and unique. However, the reactions and needs of each individual member of the family also combine to be expressed as one in the healthcare setting as well. Hughes, Bryan, and Robbins (2005) stated that "for optimal care, patients cannot be regarded as an individual entity." Patients are part of a family unit and, if true holistic care is to be achieved, nurses and medical staff in a critical care unit must provide care equally for relatives and for critically ill patients" (p. 23). We are challenged to consider the care of the family as vital as the care of the patient. We are also challenged to balance the individual care of each family member with the care of the family as a whole.

Admission to the ICU and the Crisis That Follows

The admission to intensive care is often, although not always, unexpected and the patient's condition is usually unstable (Daly, Kleinpell, Lawinger, & Casey, 1994; Delva, Vanoost, Bijttebier, Lauwers, & Wilmer, 2002; Freichels, 1991). One can easily imagine the turmoil felt by family members when someone they love is admitted to the intensive care unit, be the admission planned or unplanned. The term intensive care itself evokes an emotional reaction for those who have any familiarity with the implications of admission to such an area of the hospital.

Research tells us admission to the intensive care unit is "viewed as a crisis for both patients and their families" (Lee & Lau, 2003, p. 491). When a family member is admitted to the intensive care unit, the family is often left feeling that a catastrophe is in their midst. Uncertainty

about the patient's condition and prognosis become the focus of the family's energies. With the shift in energy comes a shift in the function and role of each family member.

The family immediately experiences an upheaval in daily routines as they attempt to come to grips with the illness or injury of their family member. Days are spent at the patient's bedside and in hospital waiting rooms and cafeterias. Time begins to stand still.

Each family member must make difficult decisions regarding their level of involvement in the patient's hospitalization. Will time off from work be taken? Who will care for children or adults needing care giving services? Will activities previously thought of as "normal," such as spending time with friends, be put on hold? What about holidays or family celebrations? Family members are torn between the needs of their family member and their own needs.

Maxwell, Stuenkel, and Saylor (2007) indicated that the admission to an intensive care unit by definition indicates "a life-threatening situation and can precipitate severe stress within a family" further emphasizing the sense of crisis within the family (p. 368). This severe stress is a result of "uncertain prognosis, fear of death or permanent disability, role changes, financial concerns and unfamiliarity of the intensive care environment" (Bijttebier et al., 2001, p. 160). Delva and colleagues (2002) told us that "if this situation continues the relatives find themselves in a condition of physical and psychological exhaustion and disorientation, experiencing feelings of helplessness and desperation" (p. 22).

Emotional Reactions of the Family to the ICU

Admission to an intensive care unit is not only stressful to the patient but the patient's support system as well. Lee and Lau (2003) related that "stress evolving from such situation[s] usually makes family members feel disorganized and helpless; as a result, they often show difficulty in mobilizing appropriate coping resources" (p. 491). Verhaeghe, van Zuuren, Defloor,

Duijnstee, and Grypdonck (2007) stated that "family members are overwhelmed with despair, anger, guilt, denial and fear for the loss of their relative" (p.1489). Families unable to cope with a loved one's intensive care stay may experience an emotion crisis.

Families may experience feelings of "anxiety and insecurity" that are only "increased by the stressful circumstances inherent to intensive care units" (Delva et al., 2002, p. 22). These stressful circumstances include "the medical and technological equipment, the constant monitoring of the patient, the alarm signals" (Delva et al., 2002). When family members visit their family member in the intensive care unit, they are bombarded by unfamiliar sights and sounds. The unit is not a quiet place. It is filled with the sounds of alarms and the mechanical noises of machines regulating bodily functions of the patients. The unit is also not private. The patient is constantly monitored, meaning that nurses and other healthcare providers rotate in and out of the patient's room incessantly while family members attempt to spend private time with their family member. The patient may not appear as expected or remembered. The patient is often attached to multiple machines and monitors providing the supportive care required to sustain life. The patient's face may be obscured by a breathing tube or oxygen mask. The patient's arms may be tethered to the bed to prevent the accidental dislodging of intravenous lines or catheters. The patient's torso and legs are often kept covered by bedding, further masking the signs of injury or the evidence of serious illness. Needless to say, the intensive care unit is a unique setting presenting challenges to not only patients and their family but healthcare providers as well.

Family members of patients in intensive care obviously are a distinct population, and research indicates, a growing population in the U.S. As numbers of critically ill patients increase, numbers of family members needing support and intervention will increase as well. The increase

in families in crisis in the hospital implies new roles for social workers and other healthcare professionals in the intensive care setting.

The Growing Crisis

As the patient remains in the intensive care unit, the family's sense of crisis often grows. Delva and colleagues (2002) related that as a loved one remains in the ICU, his or her family members may begin to experience feelings of "exhaustion, disorientation, helplessness and desperation" (p. 22). After the initial shock of the patient's transfer to intensive care begins to wear off, the family may become increasingly more exhausted by days spent in waiting rooms and nights with limited sleep. Bijttebier and colleagues (2001) and Delva and colleagues (2002) have revealed that family members may experience significant disorientation and confusion-possibly related to the high levels of stress and exhaustion inherent to the setting. Families also feel helpless and desperate as they seek guidance in understanding the medical status of their family member and the milieu of the intensive care unit.

Hupcey (1999) related that the patient's primary wish is for the family to be ever present at the bedside in her qualitative study of patients, families and nurses (n=30 patients). This wish further stresses the family's ability to cope with the patient's intensive care unit stay. Takman and Severinsson (2005) indicated families report interruptions in sleeping and eating patterns while a relative is in the ICU, while the patient, feels a sense of security and safety when a family member is always available to provide comfort. The needs of the patient from the family member often begin to outweigh the need of the family member to care for him or herself.

Williams (2005) detailed that a relative's ICU admission "can trigger feelings of distress, anxiety, fear and helplessness" within his or her family members (p. 6). This level of stress can hinder a family member's coping abilities and thus affect the family's ability to provide support

to his or her relative (Lee & Lau, 2003). As the family member becomes exhausted, his or her coping mechanisms become exhausted. It has been shown that family members experience levels of distress similar to that of the patient themselves (Kotkamp-Mothes, Slawinsky, Hinderman, & Strauss, 2005) and some believe that the family may experience levels of distress greater than that of the patient, as the patient is often unaware of the situation and of his or her emotional state due to his or her medical condition or treatments.

The Family's Role in Intensive Care Unit

The patient's family's role is to focus on the needs of the patient while attempting to maintain life outside of the intensive care unit. Many family members feel ill prepared to provide the level of support to his or her family member as expected, leading to feelings of helplessness and overstrain (Kotkamp-Mothes et al., 2005). This helplessness and overstrain spills out from the intensive unit into the family's life beyond the ICU walls. Family member's daily lives outside the hospital are suspended while a loved one remains hospitalized in the ICU.

While the family is dealing with the stress related to the patient's hospitalization, the family's life outside of the hospital continues as well. Each family member must attempt to find a balance between caring for the patient and caring for him or herself. Finding the time and energy to carry out simple everyday task becomes difficult. Routine activities such as paying bills or reading the mail may seem impossible.

One or more family member(s) is designated to carry out concrete tasks for the patient outside of the hospital. This can be particularly stressful given the nature of the circumstance that precipitates admission to the ICU. For example, the patient may not have prepared legal documentation allowing others to sign checks to pay mortgage payments or health insurance costs which may result in severe consequences to the patient if these financial obligations are not

met. The family may then become financially burdened as they attempt to keep up with the patient's bills.

Decision Making Issues

Another area creating much distress for families is decision making regarding what treatments their loved one may or may not receive. If the patient is unable to make his or her own care decisions, one family member is designated the formal decision maker. The designation of the decision maker occurs in one of two ways. The patient may have designated a decision make prior to becoming incapacitated or, if not, the legal next of kin is assigned the decision maker role. This issue is extremely important as family members may be asked to withdraw or withhold treatments such as removing the patients from a ventilator or electing to forgo initiating dialysis treatments.

Difficulties surrounding decision-making occur frequently in the intensive care unit. Many of these difficulties arise when the patient is unable to express his or her treatment goals to the medical team. Maxwell and colleagues (2007) stated "approximately three-quarters of all patients [in the ICU] are unable to participate at the time when difficult decisions about the goals of treatment are made" (p. 368). When the patient is unable to relate his or her wishes, the family of the hospitalized patient is asked to make decisions on behalf of their seriously ill or injured family member with no background understanding of the medical setting or medical decision-making while experiencing high levels of stress (Hupcey, 1999). Because patients in the intensive care unit are often incapable of making their wishes known to their family or the care team, the family is left to make choices on behalf of their loved one with little guidance.

Oh and Lee (2002) commented that families are often asked to choose between equally distressing alternatives in a time of extreme stress. These alternatives include choosing between

aggressive treatment and palliative care. Family members may be experiencing anxiety or depression that can hinder their ability to make medical decisions in the best interest of the patient (Pochard et al., 2001; Takman & Severinsson, 2005). One can imagine the potential implications of impaired family members making life or death choices for their loved one in the intensive care unit. One can also imagine the damage to the family if the choices made lead to negative results for the patient or if the choices made by one family member are not in line with values of other family members.

Family Coping

Stress and coping are inherent aspects of the experience of families of patients in the intensive care unit. Lazarus (1966) defined stress as the term for "the whole area of problems that includes the stimuli producing stress reactions, the reactions themselves, and the various intervening processes" (p. 27). Taking the stress definition one step further, stressors are defined as "those life events or occurrences of sufficient magnitude to bring about change in the family system" (Hill, 1949). As has already been discussed in detail, the family members of patients in the ICU are experiencing multiple changes in the family system as a result of their relative's admission to the hospital. These changes may result in families experiencing high levels of stress and often a sense of crisis.

McCubbin, Joy, Cauble, Comeau, Patterson and Needle (1980) related that "stress or crisis is defined as the interaction of a particular type of event with its perception" (p. 857), meaning the perception of the family becomes the measure of the stress experienced. Lazarus (1966) related that the "capacity of any situation to produce stress reactions depends upon the characteristics of the individual" (p. 5) however, many families of patients in the ICU have been showed via multiple research studies to experience high levels of stress. This stress response is

not only apparent while the relative is in the ICU but also long after the admission. Just short of half of all families of patients (n=104) studied by Jones, Skirrow, Griffiths and colleagues (2004) reported symptoms associated with post-trauma stress disorder (PTSD), depression and anxiety six months following the patient's stay in the ICU. Interestingly, a high level of psychological distress in the patient appears to correlate with high levels of stress in relatives (Jones, Skirrow, Griffiths, et al. 2004). Azoulay, Pouchad, Kentish-Barnes, and colleagues (2003) related similar findings. In their study of 94 relatives of patients 90 days after the ICU stay, 33% were found to have symptoms consistent with a moderate to major risk of PTSD.

McCubbin and colleagues (1980) indicate that a family who is already struggling with the challenges of a family member in ICU such as role adjustments and financial turmoil, may lack the "expressive" and "instrumental resources" to deal with any additional changes or stressors that may arise (p.857). This phenomenon has been described as "pile up" (McCubbin, et al., 1980, p. 861). Attempts to deal with "pile up" may demonstrate one way people cope with multiple stressors.

Coping is defined as the "capacity to cope with opportunities, challenges, frustrations, threats in the environment" and the "capacity to manage one's relation to the environment so as to maintain integrated functioning" (Murphy & Moriarty, 1976, p. 337). Coping is often viewed in one of two conceptualizations. The first relates to coping as in the "pile up" phenomenon. In this view, how one deals with each specific situation is examined individually (Johansson, Hildingh & Fridlund, 2002). Reaction to each situation or stress is an individual phenomenon. The second conceptualization looks at coping as a high level defense mechanism (Johansson, et al., 2002). In this view, coping is seen as a trait or style that is consistent across all situations. In this view, we would expect family members who appear to have difficulty coping with the stress

of having a relative in the ICU to experience difficulties in coping across other stressful situations. Their reactions would be someone predictable and consistent over time.

Family members of patients in intensive care may be unable to provide themselves any kind of self care. Quiet reflection or relaxation is a luxury for which families of patients in the ICU do not have time. As previously indicated, family members often are unable to eat or, as I have witnessed on many occasions, survive on foods found in the vending machines near the intensive care unit or on fast food brought to the ICU waiting room by well-meaning visitors. Lack of sleep, lack of exercise, poor nutrition and an inability to relax or even take a break from the intensive care unit can lead to disaster.

Lack of time or energy to focus away from the ICU takes it tool on families both as individuals and in the family's ability to relate to one another. Family relationships may become strained as ICU stays lengthens. As the stress of the patient's hospitalization mounts, the stress on the relationships with the family mounts. Family members may begin to notice differences of opinion among family members or differences in coping styles. Family members may begin to argue. They may separate into camps around particular decisions related to the patient's care and treatment. Resentment may build as particular family members seem to be going on with their lives outside of the hospital while others are focused at the bedside.

Both the stressors and needs of family have been found to vary little across differing demographics. Hickey and Leske (1992) indicated that needs of families are fairly consistent across age, relationship to the patient, gender and patient diagnosis. This consistency of needs across families of varying demographics further emphasizes the potential universal difficulties and stresses experienced by families in the ICU.

Chapter Summary

Patients are admitted to an intensive care unit after experiencing a significant illness or injury. The intensive care unit is equipped and staffed to provide patients, who are critically ill, life sustaining care and treatment. This level of intensive medical intervention not only affects the individual in the hospital bed, but all those who surround the bed to provide comfort and support to the patient. Consequences to the patient's loved one, his or her family, are significant and require attention to assure the best outcome for both the patient and the family.

Family members of intensive care patients are under extreme stress. Research indicates family members may be experiencing feelings of anxiety, depression, hopelessness, despair, fear, exhaustion and desperation (Delva et al., 2002; Lee & Lau, 2003; Verhaeghe et al., 2007). These feelings can trigger emotional peril for both individual family members affected by the patient's intensive care stay and for the family as a whole.

This emotional upheaval the family is experiencing is also accompanied by other stressors. Families of intensive care patients are unfamiliar with the ICU environment and may be overwhelmed by the sights and sounds common the unit. Family members may be shocked by the physical appearance of their loved one and may have difficulty enduring the constant alarm bells sounding the seemingly ceaseless interruptions of visits by intensive care staff.

Life outside of the hospital continues for families of patients in intensive care although they may be limited in their ability to participate in what was once their everyday lives. Days and nights are spent in hospital waiting rooms. Meals become whatever food is easily accessible from a vending machine or the hospital cafeteria. Simple errands and necessary task of daily life are put aside. Sleep becomes an extravagance. To make matters worse, the family is often also

attempting to maintain the basic tasks fundamental to the patient's life outside of the hospital as well.

The patient's family may also be asked to make difficult treatment decisions on behalf of their family member. Unfortunately, many patients are admitted to intensive care following unexpected circumstances. These patients are often not prepared for such an event and have not designed a decision-maker to act on their behalf. Once a family member is designated decision-maker, the decisions they face may be heart wrenching. The designated family member is often left to filter through choices about treatments they do not understand with little or no guidance from the intensive care staff.

As the previous discussion reveals, the experiences of families in the intensive care unit have been well documented in the research literature, although most existing studies do not employ qualitative methods that would provide a more nuanced understanding of the impact of intensive care on families. Understanding the families' needs related to the intensive care stay, as they perceive them, and how these needs can best be addressed by social workers, is also an important area for continued exploration.

The psychosocial stressors experienced by family members of patients in the ICU present a challenge to the healthcare system of the intensive care unit-a system not designed to meet both the physical needs of the patients and the psychosocial needs of the patient's loved ones or family members. The intensive care unit staff is trained to focus on the needs of the patient and not necessarily on the needs of the patient's family. The next chapter provides a review of the literature on family needs in the ICU, and the social worker's role in attempting to meet these needs.

Chapter II.

The Needs of Families in Intensive Care Unit

Families in the ICU

"Major illnesses can have a substantial impact on the lifestyles and finances of patients and their families. Nonetheless, 70% of patients and their families would be willing to undergo care in the intensive care unit (ICU) again, even if such care were to extend their life only 1 month" (Swoboda & Lipsett, 2002, p. 459). This statistic reminds us that although a stay in the ICU can substantially negatively impact patients and families, the care provided in the ICU is viewed as a necessary evil by those who find themselves touched by critical illness.

Intensive care was created to provide intensive medical treatment to the most ill or injured patients in the hospital. These patients require constant monitoring and sophisticated medical intervention or therapy. The unit is filled with the hum of machines and the constant ringing of alarm bells requiring the immediate attention of the healthcare team. The treatment of the patient's family in the intensive care unit varies from ICU to ICU. Policies about visitation, and thus access to the patient by loved ones, are inconsistent not only from hospital to hospital but within the same hospital. This inconsistency appears to be a significant source of stress for families and thus for patients. While the patient is receiving constant care and attention, the patient's family is often left without adequate supports to meet his or her needs. Delva and colleagues (2002) indicated that during the first few days of a patient's hospitalization, the patient is the center of attention while communication with the family by doctors and nurses takes a lower priority. Families must rely on their own supports during this challenging time while also attempting to support their loved one in the ICU. This is particularly concerning as Leske (1998) indicated the benefits of family participation in alleviating patient stress and

improving patient outcomes. “Family adaptation or resiliency can affect patients’ outcomes, both short-and long-term, either positively or negatively” (Bond, Draeger, Mandelco, et al., 2003, p. 64). Patients are admitted to intensive care after experiencing a significant illness or injury. Admission to intensive care may be planned, such as following a scheduled surgery, but the admission is often unexpected and jarring to the patient and his or her family. The patient’s medical condition is usually unstable and his or her chances for survival unclear. The admission to the intensive care unit is stressful for both the patient and his or her family and may trigger a variety of negative psychological symptoms (Williams, 2005).

The patient may or may not be cognizant of the events unfolding within them or around them in the ICU. “Only 5% of patient in the ICU can report their end-of-life preferences, their symptoms, or participate in treatment decisions” (Mosenthal, 2005, p. 304). The inability of the patient to participate in treatment decisions requires the active participation of the patient’s family in decision making. Families are asked to make life or death decisions on behalf of their loved one, often without the necessary information to make the choices posed to them. Families understand less than 50% of what doctors tell them about prognosis, diagnosis and treatment options of the patient for whom they are making decisions (Pouchard et al., 2001). Because families do not understand the choices offered families experience extreme levels of stress. The stress of decision making is compounded by the uncertainty of the patient’s condition or prognosis for recovery.

Research indicates that families experience anxiety, depression, hopelessness, despair, fear, exhaustion and desperation (Delva et al., 2002; Lee & Lau, 2003; Verhaeghe et al., 2007) while a loved one is in the ICU. These feelings not only affect each family member experiencing the emotions but affect the patient and the healthcare team as well. The stress of the family can

be a source of stress for the healthcare team and for the patient (Bouman, 1984; Doerr & Jones, 1979). This is particularly of concern as the support of the family has been identified as a main need of patients during their stay in the ICU. Hupcey (2001) found that "family presence in the ICU helped instill hope, a sense of control, trust in providers, and the opportunity to have gaps in knowledge filled-in, all resulting in the helping the patient to feel safe while in the ICU" (p. 207). The presence and participation of the patient's family is a key factor in helping patients feel supported during the intensive care unit stay. In a study of 35 intensive care unit patients in Taiwan, Chen (1990) learned that the primary support to patients was the family, followed by friends and other relatives, and finally the healthcare team. Hupcey (2001) stated that "in terms of married patients, those who had higher hospital support, as measured by the number of spousal visits, required less pain medication and recovered quicker than those married patients with low hospital support" (p. 207). Families appear to recognize this instinctually and gravitate to the patient's bedside. The desire to be by the patient's side seems to satisfy both the patient's needs and the family's needs. McAdam and colleagues (2008) related that the family role of "active presence" is important to many families, as the 25 family members interview in their descriptive study perceived their loved one "felt safe" and "more comfortable" when a family was present at the bedside (p. 1098).

Recognizing and Addressing Family Needs

Early in the study families of intensive care patients, Molter (1979) recognized that the intensive care unit staff concentrates on the needs of the patient leaving little time to deal with the needs of the patient's family. The needs of the family are often not recognized until the family demonstrates inappropriate coping behaviors at the bedside or until a family member directly seeks assistance in coping. However, in either case, the bedside staff may be unequipped

to handle the psychosocial needs of the patient's family while providing direct care to the patient. The needs of family members are "frequently neglected" (Kotkamp-Mothes et al., 2005, p. 217)) since healthcare providers are primarily focused on the needs of the patient. While the needs of the critically ill patient are primary, the needs of the family cannot be ignored.

The stress of the patient's relatives translates into stress for the medical team (Bouman, 1984). As the sense of crisis grows in the intensive care unit, family members may begin to outwardly express their emotional turmoil related to their loved one's hospitalization. This emotional turmoil may then lead to the expression of negative behaviors directed toward other family members, the medical team or even the patient. Negative family behaviors and threats of negative behaviors are a significant concern for the staff of the ICU.

Hupcey (1999) recognized the need for nurses to intervene with families in the intensive care unit. She related that nurses have the responsibility to care for not only the patient but also the patient's family. Bijttebier et al. (2001) agreed, indicating that staff members of the intensive care unit have "the intention of giving family support…but the reality is often that the needs of the family are largely ignored or forgotten" (p.160). Given this reality, an assessment of the resources of the intensive care unit may be necessary to ascertain if other staff members may be available, and possibly more appropriately trained, to provide the support patient's families are indicating they need.

Verhaeghe and colleagues (2007) disagreed with the assessment that families do not receive intervention because of time or staffing constraints. Instead, Verhaeghe and colleagues (2007) indicated that families in the ICU do not receive the attention they need because their needs are wrongly assessed by the healthcare team. This viewpoint advocates for on-going assessment and intervention based on the assessment of needs.

Bijttebier et al. (2001) indicated that "many healthcare professionals are not sufficiently aware of the family needs and perceived needs identified by research do not always guide practice" (p. 161). Bijttebier et al. (2001) reminded us that that while some healthcare professionals are aware of the needs of patient's families discovered through multiple quantitative research studies, they do not always use the research findings to guide their day to day work. Healthcare professional may be overtaxed by other needs, such as patient care needs or needs of coworkers, to provide the kind of support families seek. Many healthcare practitioners do not appear to recognize that meeting the needs of patient's families in the intensive care unit actually may lead to better outcomes for their patients.

Lee and Lau (2003) indicated if the "immediate needs" of the family can be met both the family and the patient benefit (p. 491). Meeting the immediate needs of the family relieves the family's immediate feeling of crisis and allows the focus of care to return to the patient. The family may also experience a feeling that their needs have been recognized and acknowledged. Addressing the immediate needs of the patient's family may also minimize negative behaviors of the family that impact the healthcare team, the family unit, and ultimately, the patient. Multiple research studies have shown that as the needs of families are addressed and ameliorated, better outcomes result for both patients and the family system (Hughes et al., 2005; Leske, 1986; Leske 2000; Verhaeghe et al., 2007). These studies take Lee and Lau's (2003) findings further by relating that it is important to meet more than just the immediate needs of families. Families have expressed a variety of needs, occurring throughout the patient's stay in the intensive care unit. Meeting the needs of families and reducing their stress can result in better outcomes for both patients and families.

Review of studies including 120 relatives of patients in the ICU between the late 1970's and early 1990's in the U.S. (Delva et al, 2002), indicated that a patient's family member's need for information and assurance is primary in coping with a loved one's hospitalization. A later study of nurse's (n=14) perceptions of family member's contributions to patient care by Williams (2005) concluded that family members' needs also included the need to be provided honest information, the need to feel cared for by the ICU staff, and to feel the patient is being provided reassurance and support. These needs, as expressed by family members of patients in the intensive care unit, clearly demonstrate the role of the ICU staff in caring for both the patient and the family.

In 2007, the American Association of Critical-Care Nurses published national guidelines for family-centered care based on a review of the research (Leske & Pasquale, 2007). The guidelines included recommendations for interventions to meet the five areas of needs that appear to be "universally experienced by most family members" of patients in the intensive care unit (Leske & Pasquale, 2007, p. 32). These family needs were: receiving assurance; remaining near the patient; receiving information; being comfortable and having support available (Leske & Pasquale, 2007). Meeting these needs became the basis of the national guidelines. The guidelines incorporated recommendations for providing family-focused care that involved on-going assessment, planning, intervention and evaluation. While the guidelines are quite comprehensive, I will summarize the more salient recommendations that relate to this dissertation. The assessment recommendations included: initiating contact with family early in the patient's ICU admission; instilling realistic hope; and assessing the family member's coping strategies, strengths and culture. The planning recommendations included: determining what the family needed the most in the immediate moment; involving other health professionals as needed; and

using daily care conferences to include family members in decision-making and care planning. Intervention recommendations included: determining the family spokesperson; providing family members with access to the patient; function as an advocate for the family; and provide consistent information, in terms clear and understandable to the family. The evaluation recommendation included: soliciting feedback from families; providing a variety of structured meetings between families and staff; and provide on-going education to staff to develop the knowledge and skills to work best with families of patients in the ICU (Leske & Pasquale, 2007). The national guidelines offer a synthesis of the most recent research in the field

Factors Influencing the Family's Ability to Provide Support to the Patient

Hupcey (2001) indicated in her study of 20 transplant patients' sources of support and behaviors, it was indicated that the "major source of support was the family/friend of the patient however 45% also mentioned health care providers are supports" (Hupcey, 2001, p.207) The ability of families to support their loved one in the intensive care unit is influenced by several factors. In Pouchard and colleague's (2001) study, 920 Hospital Anxiety and Depression Scales were completed by family members in multiple intensive care units throughout France. The results indicated symptoms of anxiety or depression were present in 72.7% of families of patients in the ICU. This high level of anxiety and depression may negatively affect family members' ability to support the patient and to make decision in the best interest of the patient, should the patient be unable to decide for him or herself. Pochard and colleagues (2001) also indicated that depression may impair comprehension and, conversely, poor comprehension may be an indicator of depression.

This high level of emotional distress may also influence the ability of family members to continue carry on life outside of the hospital. Simple day-to-day task must be delayed while

family members sit vigil at the patient's bedside. Family members must negotiate with their employers to allow time off from work if possible. Some family members will be unable to take time off from work, shifting responsibility for the care of the patient to family members who either do not work of those able to take time off from work. Families with significant financial issues or those in jobs without paid time off may experience several financial hardships precipitating from a loved one's hospitalization. Families may wish to meet the companionship needs of their loved one in the ICU but may be unable to do so due to multiple pressures creating yet another level of stress of family members, the family system and ultimately, the patient.

When families are experiencing high levels of distress, "they may be unable to support the patient and in fact may translate their stress to the patient" (Leske, 1998, p. 130). The family's response to the intensive care stay can affect not only the patient's well-being but his or her ability to recover from illness or injury (Van Horn, Fleury, & Moore, 2002, p. 186). The family's level of stress or distress is a clear indicator of the potential outcomes of both the family and the patient. Leske further indicated that "unmitigated family stress may manifest itself in distrust of hospital staff, noncompliance with the treatment regimen, anger and dissatisfaction with care, and even lawsuits" (1998, p. 130). With this understanding comes an understand of the importance of the healthcare team supporting the family during the intensive care stay to prevent negative behaviors that may affect the patient, the family and the healthcare team.

Family members see themselves as having important roles in the intensive care unit. The three main roles of family members, as detailed in Hupcey's (1999) qualitative study of 11 relatives of ICU patients, are supporter, caregiver and protector. The family provides the patient emotional support, physical care and advocacy. Emotional support includes listening to the patient's fears and concerns. Physical care includes tasks such bathing the patient or swabbing

the patient's mouth. The role of protector may include advocating for the patient's interests while the patient is unable to advocate for him or herself.

Crisis Theory in Relation to Families

When considering the experience of families of patients in the ICU, it is helpful to frame the experience of families through crisis theory. Crisis is a difficult concept to define. Crisis is an individual experience-defined by its impact on the individual and may vary widely from one person to another thus the reason the term crisis cannot be simply defined (O'Hagan, 1984). The individual who experiences a disruption of his or her intrapsychic environment or external world will attempt to regain a sense of equilibrium in response to this disruption or crisis. This regaining of one's equilibrium is dependent upon one's previous experiences with crisis and one's openness to interventions designed to facilitate recovery (O'Hagan, 1984).

Families of patient's in the ICU are often described as being in a state of crisis. As O'Hagan (1984) related, this sense of crisis is as individual as each family member. One may feel devastated by the admission of a loved one to the ICU, while another does not reach a sense of crisis until the patient's prognosis takes a turn for the worse. Because the experience of crisis is individual, each member of the patient's family should be assessed individually and provided interventions specific to his or her needs.

The family unit may also be in crisis during a loved one's stay in the intensive care unit. Roles within the family may shift to accommodate for the loved one's new role of patient within the family system. The family may also be left without clear direction, particularly if the patient was identified as the family leader or decision-maker. Additional crises arise for the family unit if the patient is the family's primary wage earner or is responsible for the care of children or others unable to support themselves independently in the community.

Crisis theory is very closely tied to family therapy. The increase in interest in the family in crisis coincided with the increased interest in family therapy. “Family crisis intervention emerged as a synthesis developed in family therapy and crisis intervention” (O’Hagan, 1984, p. 151). This synthesis then expanded to include considerations of the environment’s impact upon the family’s experience of the crisis situation. This expansion to include a consideration of the environment is yet another reminder of the importance of the physical environment of the intensive care unit and how this setting affects the patient’s family. Inclusion of the effect of the environment also includes the effect of each family member’s environment outside of the hospital. Each family member exists in a web of relationships and roles unique to each person, influencing how the crisis is perceived. In other words, the individual’s life situation prior to and during the crisis can compound the crisis of a loved one’s hospitalization.

The concern for treating or intervening with the family also arises from the recognition that “family adaptation or resiliency can affect patients’ outcomes, both long and short term, either positively or negatively” (Bond et al., 2003, p. 1402). The family’s ability to cope with the crisis of a loved one’s intensive care stay can affect not only the family but the patient. These effects can be seen both at the time of the immediate crisis and following the resolution of the crisis. Family roles may shift during the crisis and previously supportive relationships may become strained. The family may find itself unable to support its members through the crisis. This change in function of the family may offer an opportunity for intervention as “at times of crisis, individuals are more susceptible, more open to therapeutic intervention” (Bond et al., 2003, p. 1403). This reality points to a role for expanded social work services for families of patients in the intensive care unit.

Social Work in the Intensive Care Unit

In the 1970's, the focus of hospital social work practice began shifting from the patient and family to the patient alone. As Caroff and Mailick (1985) note, "in [an] attempt to differentiate themselves from nursing and enhance their status, hospital social workers identified themselves with the medical profession and accepted a framework for clinical work with the individual patient as central" (p. 18). The choice to center social work practice on the individual rather than the family left the domain of the family open to interventions from professions other than social work. This trend continues in many hospital settings today.

Currently, caring for the patient and family in the ICU is often the role of nursing, however as technology requires more nursing attention, time limitations may negatively impact the care of the family. The shift in nursing roles may offer social work an opportunity to reclaim the care of the family. However, social work in hospitals has acquiesced to the culture and pressures of the health care setting. Patients turn over rapidly-entering in the hospital for directed care or treatment then exiting the hospital once the treatment has concluded. The social worker's interventions are often limited by the brief episode of care and usually are focused on assessment and discharge planning. Time to develop relationships with the patient and his or her support system are quite limited.

In the intensive care unit, social work intervention is also often limited but not solely due to the accelerated pace of the hospital stay. In the current health care climate where financial benefits of interventions are expected, social work in the ICU has suffered. Much of hospital social work practice focuses on discharge planning. The majority of patients in the ICU have typically not moved from intensive care to the community so their needs, and the needs of their families, may be overlooked to address the more immediate discharge needs of patients

elsewhere in the hospital. With discharge planning as the focus of social work services in the hospital, patients and families have taken a back seat. The financial demands of managed care have shifted social work services out of the ICU until recently.

The advent of community facilities able to provide critical care is beginning to shift social work focus back to the ICU but not necessary back to the psychosocial needs of patients and their families. Financial pressures and the explosion of patients requiring intensive care beds has created a new role for social workers however the role is that of discharge planner not necessarily that of social worker. While social workers assisting families as their loved ones transition from the ICU to community facilities use a variety of clinical skills, the focus of the intervention is not only the patient's and family's needs but rather the need of the hospital to profit financially and to free up ICU beds.

This abandonment of the family by social work has left gaps in care, as "nurses have been hesitant to incorporate families into patient care" (Hickey & Leske, 1992, p. 647). This hesitancy may reflect nursing's limited understanding of the potential roles of the family in the ICU and may also be an indication of nursing's "apparent lack of confidence in their ability to provide care to families in crisis" (Hickey & Leske, 1992, p. 647). Hickey and Leske (1992) related that nurses are inadequately prepared by their education or experience to fully handle families in crisis. Nurses may be prepared to deal with the immediate, pressing problems that families present, due to time pressures and stressors of the ICU, they may be unable to proactively work with families to prevent problems from turning into a crisis.

With the healthcare team in the ICU overwhelmed by the needs of patients' families, and social workers' attention directed to discharge planning and the needs of the patient, an obvious gap in services is revealed. Families are without an ally in the intensive care unit focused on their

specific needs and experiences. While nursing is working to sensitize and educated nurses about the benefits of incorporating families into the care of the patient in the ICU, social work education and professional practice guidelines have already prepared social workers to intervene with families. McCormick et al. (2007) related that social workers "have specialized training for working with families of seriously ill or injured patients, the ICU represents a potential opportunity for social work involvement" (p. 930). Hospital social work practice may be refocused on meeting the needs of both patients and families. Rose and Shelton (2006) state

> The theoretical background of social work and the specific training social workers receive make them ideal professionals to work with families and critical care teams… Social workers are trained in individual and family therapy, and many social workers are trained in techniques specific to the biopsychosocial concerns related to illness, medical crisis and/or palliative care. Additionally, social workers are oriented to be advocates for people in need, and social work training in advocacy skills are particularly helpful to families in the foreign environment in the ICU where they may feel distressed and disempowered. Furthermore, social workers, who are strongly oriented toward a Strengths Perspective (Graybeal, 2001), rather than focusing on pathology or dysfunction, can identify family strengths, such as resiliency, support resources and other positive forces which may positively impact on family coping and decision-making (p. 6).

While social workers' education and training prepare them to work with families; they, like other members of the medical team, may be unaware of the specific needs of families in the intensive care unit and thus those needs go unaddressed. Social workers currently interact with families in the context of understanding the biopsychosocial needs of the patient, not the needs of the family system. The attention to the patient and not the family system is the result not only of financial constraints, it may also be a result of the lack of empirical evidence joining social work roles in the intensive care unit with current literature detailing the needs of families of patients in the intensive care unit.

Opportunities for Social Work Practice

The lack of research about the role of social work in the intensive care unit in meeting the perceived unmet needs of families of patients provides an opportunity. As this proposal has detailed, a wealth of research exists in the nursing literature about the needs of families while a loved one is a patient in the ICU. These needs appear to be consistent across demographics, even continents, and endure throughout the ICU stay. The needs of families as reported in the literature have varied very little since the initial research study focusing on the needs of families of patients in the intensive care unit nearly 30 years ago. This consistency in unmet needs, and volume of empirical research, provides a wealth of evidence on which to base social work practice recommendations. This research proposes to illuminate the experience of the families of patients in the intensive care unit and possibly integrate the needs of families with recommendations social work practice in the intensive care unit. The families will be asked to not only validate previous research findings detailing the needs of families of patients in the intensive care unit but also encouraged to offer opinions as to means of meeting these unmet needs.

Chapter III.

Research Setting and Methodology

Statement of the Problem and Research Questions

A family member's admission to the intensive care unit is often perceived as a crisis by the family. Whether the admission is planned such as following a schedule surgery or unplanned such as following a tragic accident or sudden illness, an ICU admission signals a tremendously stressful event. Patients and families are thrust into a setting, the intensive care unit, of which they may be unfamiliar. The unit is filled with sights and sounds, including the site of their incapacitated loved one that compounds the stress.

Initially, the patient receives all the health care team's attention while the patient's family is cast aside. All efforts are focused on saving the patient's life. The family is marginalized, relied upon as the surrogate decision-maker for the patient who is often unable to make decisions due to her or her medical condition. While decision-making is a vital role of the family, the family's ability to act in the best interests of their loved one may be compromised by their reaction to the patient's hospitalization.

Families experiencing the intensive care stay of family member have many needs related to the hospital stay. These include the need for information, assurance, proximity, support and comfort. These needs appear to be consistent across age, relationship to patient, gender and patient diagnosis (Leske, 1992). Kleinpell and Powers (1992) indicated the needs for assurance, comfort, and support often remains unmet by the healthcare team while the need for information and proximity to the patient were usually met. However, anecdotally, I have witnessed families clamoring for information. I have been involved as a social worker and member of a hospital

Ethics Committee with countless families begging for any and all information related to their family member as well as overall enhanced communication with the healthcare team.

The unmet needs of family members of patients in the intensive care unit have been well documented via quantitative studies for more than 30 years. However, few qualitative studies looking beyond the responses to survey questionnaires have been published. Most quantitative studies published are based on research utilizing the Critical Care Family Need Inventory (CCFNI).

The Critical Care Family Needs Inventory

Much of the research relating to the needs of family members of patients in the intensive care unit utilizes the Critical Care Family Needs Inventory. The Critical Care Family Needs Inventory (CCFNI) identifies and measures the needs and concerns of families of the critically ill. A 46 item, four-point Likert scale was first developed by Molter (1979) through literature review and interviews with graduate students of nursing. The inventory was then slightly modified by randomly re-ordering the needs statements and titled "The Critical Care Family Needs Inventory" (Molter & Leske, 1983).This version of the CCFNI has been the utilized in dozens of research studies throughout the world over the last 30 years.

In Molter's (1979) initial study, the 46 items, or needs, were ranked in importance by 40 relatives of critically ill patients via a structured interview. The 10 most important needs of families identified in this landmark research were: to feel there is hope, to feel hospital personnel care about the patient, to have the waiting room near the patient, to be called at home about changes in the condition of the patient, to know the prognosis, to have questions answered honestly, to know specific facts concerning the patient's progress, to receive information about the patient once a day, to have explanations given in terns that are understandable, and to see the

patient frequently. These need statements became the basis of multitudes of future studies, most quantitative in methodology and administered by nurses.

Families related that the top 10 needs indicated in this initial study by Molter (1979) were met about half of the time. Families seemed to have very low expectations of the healthcare team. It seems that in 1979, families thought nurses were too busy to care for the family given the complex care needs of patients in the intensive care unit. They also believed the team was responsible for caring about the patient but not for caring about the family. The healthcare team focusing only on the needs of the patient and not the family is known as patient-centered care. The patient and his or her wishes and needs are the center of the healthcare encounter and the focus of all attention. This view of the patient's stay in the intensive care unit is consistent with my experience of current social work practice in the intensive care unit.

The CCFNI created by Molter and refined by Leske resulting in a Likert-type survey tool utilized in dozens of studies worldwide assessing the needs of family members of patient in intensive care. However, the CCFNI has weaknesses. It was developed by a nurse researcher in conjunction with student nurses thus has the needs included where needs felt important to this particular group of nurses. The inventory also has a limited capacity to capture needs not indicated in the inventory. The CCFNI has an open ended question section at the end of the tool however responses to these questions do not seem to be reported in the literature. The lack of reporting of the responses to the open-ended questions provides an opening for further research utilizing the CCFNI questions in a qualitative study. The nursing focus of the CCFNI also provides the opportunity to utilize the CCFNI questions focusing on the role of social workers in the intensive care unit.

Factor analysis of the CCFNI revealed the following five dimensions: need for support, comfort, information, proximity and assurance (Leske, 1991). Studies following Molter's have "consistently shown that the information, assurance and proximity needs were ranked above support and comfort needs" for families of patient in the ICU (Lam & Beaulieu, 2004, p. 143). Takman and Severinsson (2003) further related that "significant others in ICUs in Australia, Belgium and China reported similar needs, such as feeling that the healthcare professional care about the patient and being assured that their loved one is receiving the best possible care, receiving information once a day, obtaining honest answers to questions, being informed about the patient's progress and expected outcome, and finally being informed about changes in the patient's condition" (p. 23). These needs rankings also do not appear to fluctuate even after weeks in the intensive care unit (Freichels, 1991) thus the need for intervention to meet these needs remains constant as well.

Research based on the CCFNI has found that needs associated with information appear to be a primary need of family members of the critically ill. Auerbach and colleagues (2005) related that "the most pressing single documented need of patients' family members during ICU hospitalization is access to clear, understandable, and honest information about the patients' medical condition" (p. 202). Johnson and colleagues (2005) indicate that families rank communication even higher in importance than clinical skills. This need for information is universal regardless of age, gender, socio-economic status and educational levels (Leske, 1992) and like other needs, remains throughout a patient's stay in the ICU.

Families require information to understand and integrate their loved one's hospitalization into their lived experience. Understanding and integration is achieved by effective communication between the medical team and the family. However, effective, even adequate,

communication does not readily occur in the ICU. Heyland and colleagues (2005) related that in French study of family members of patients in the ICU, half of family members failed to comprehend the diagnosis, prognosis or treatment of their loved one after meeting with a physician. In a study of 48 families in intensive care units in America, “almost half of the families experienced conflict with the health care personnel during their family member’s stay and the majority of conflicts related to inadequate communication” (Heyland et al., 2003, p. 76). Families have indicated the need for communication and information in dozens of studies for nearly 30 years however the healthcare team in the intensive care unit has not yet successfully met this need.

Johnson and colleagues (1998) utilized a 14 item version of the Critical Care Family Needs Inventory to measure the perceptions of the healthcare team’s ability to meet family’s needs in the intensive care unit. The study found the three most important dimensions of the healthcare team from the perspective of the family included: attitude, communication and comforting skills. In fact, families felt more satisfied with the care of their loved one if the family had on-going communication with the same provider. Because physician teams change as do nurses, social workers may be helpful in bridging the communication gap created by the daily, sometimes hourly, shift in direct care providers.

Curtis and colleagues (2005) indicated that while recent recommendations call for improved communication with families, studies appear to offer limited explanations as to how communication is actually improved. This begs the question-what do families have to tell us about how to meet their communication needs? What recommendations do families have for healthcare providers-specifically for social workers to improve communication in the ICU?

In my experience working in multiple ICU's in multiple hospitals throughout Pennsylvania in the last 15 years, I have witnessed families desperate for psychosocial intervention while hospitals redirected resources elsewhere. The burden of not only caring for patients but caring for the emotions of families has fallen to bedside nursing, while social workers have been asked to redirect their practice to discharge planning.

The current limited research base of social work practice in intensive care settings with families has lead to the development of social work practices with families that do not address the needs or desires of families. For example, social workers are primarily responsible for discharge planning related activities. While patients in the intensive care unit are beginning to be discharged to alternative levels of care in the community such as long term acute hospitals, social workers, and often healthcare practitioners, may not readily see a role for social work with the patient and family. Families unfamiliar with the healthcare setting may not seek out the social worker when they feel they need assistance. In my experience, this has resulted in families not receiving social work intervention despite the family's psychosocial needs. When offered social work support, most families readily accept assistance in communicating with the team and assistance in clarifying questions about the treatment or discharge plan. Families also appear to respond to social workers' validations of their fears and concerns for their loved one.

The second issue noted in reviewing the literature and research related to social work in the adult hospital setting is that focus is on the social worker's interaction with patients not families indicating that the needs of the family have not been a primary focus of practice by hospital social workers. Much of the literature about family work in the ICU revolves around the interactions between nurses and doctors and families, not social workers and families. Research on the experiences and needs of family members in hospitals is limited to primarily a

quantitatively obtained list of needs (Verhaeghe et al., 2007). Meeting these needs is not addressed by social workers in the social work literature.

As the role of the social worker with families in the hospital evolves, opportunities for ongoing research grow and change. As detailed earlier, the role of the social worker in the ICU will continue to be of importance as the number of patients admitted to the ICU grows. Research taking the CCFNI another step to include the voice of the family as interpreted through a qualitative study is warranted resulting in the following research questions: How do families describe their main perceived needs while their loved one is a patient in the intensive care unit? How are these perceived needs met or not met in the eyes of the family? How do families recommend these need be met-what specific interventions would families find helpful?

The results from this study cannot be generalized to other populations as this is not the goal of qualitative research.

Research Design

Aims

This research conducted for this dissertation was a qualitative study designed to explore the needs of families of patients in the intensive care unit. The data from the study illuminated potential roles for social work in assisting families to meet these needs. The goals as to better understand not only the families experience of having a loved one in the intensive care unit but to better understand their needs from the healthcare team to develop interventions to meet these unmet needs. Families were encouraged to offer suggestions and advice to meet their specific needs or concerns.

Methods

The research methodology of the study was face to face semi-structured interviews, asking families open-ended questions about their views and experiences while their loved one was a patient in the intensive care unit following the specific methodologies for qualitative interviewing, data analysis and report writing conceptualized by Weiss (1994). Utilizing "issue focused" analysis of the interviews as described by Weiss (1994). The responses to the interview questions were interpreted with the hope of uncovering "what has been learned from all respondents about people in their situation" (Weiss, 1994, p. 153). The analysis of the interviews focused on what could be learned from "any and all respondents" rather than what may have been learned from one respondent or from one issue (p. 154). However, the interview data gleaned from individual interviewees regarding specific issues of concern were also included in the analysis in cases where the interview content revealed information potentially useful for future research consideration.

After the Institutional Review Board of the University of Pennsylvania approval was granted on May 4, 2009 (see Appendix B.), interviews were conducted with 12 family members of patients in intensive care from May to August, 2009. The interviews were then coded, as were on-going memos written by the researcher indicating any information that informed the interpretation. These memos included non-verbal responses of participants. The coding linked the respondent's comments to categories or concepts that were developed through both the interviewing process and as a result of literature review and researcher experiences prior to the initiation of the study. After the initial coding where what Weiss terms "meaning units" (Weiss, 1994, p. 154) were identified in each interview, the "meaning units" in the form of speculations, groupings and comments were sorted into more formal categories. Weiss follows this process of "sorting" (Weiss, 1994, p. 155) with what he calls creating excerpt files of these categories of data. While I initially followed this same course of data organization, I found that the themes hidden in the interviews revealed themselves quite readily making the process of creating another level of organization that separated the interview data into artificial segments feel tedious and unnecessary. Continuing with a modified use of Weiss (1994), the themes were organized and summarized to identify what material did not fit the main lines of the story but rather offered variants of interest. Weiss (1994) terms this process "local integration." The coding process was finalized by the "inclusive integration" of all the previous levels of coding (Weiss, 1994, p. 160). Weiss (1994) indicates this process is the knitting of "a single coherent story" (p. 160). During this process, I began to conceptualize a framework for moving from one theme to another in the writing of the final chapters of this dissertation. I also attempted to consider how to utilize the material I believe to be important, and of interest, that did not fit into the main themes identified in through inclusive integration.

Eleven interviews were conducted with eight female and five male family members (one interview had two participants). The interview questions were only slightly revised throughout the research process as the interview responses appeared consistent and moved toward informational saturation early in the process. Each individual interview, including the completion of the consent form and gathering basic demographic information, lasted between thirty minutes and ninety minutes depending upon the degree of elaboration of the interviewee as well as the participants' communication style. The interviews were conducted in multiple private locations near the intensive care unit where the participants' family member was receiving care at the time of the interview. The interview locations included conference rooms, private offices and resident's quarters.

Locating appropriate space to conduct the interviews presented an on-going challenge throughout the research process. An acceptable interview space had to be located at the time of each interview as no space was consistently was available for use and no space was available to be reserved in advance. This led to me, the interviewer, rushing around the intensive care unit seeking an acceptable interview space where audio recording was possible. The limitation of space required that one interview be conducted in the resident's quarters; a small apartment-like space on the ICU complete with the resident's open suitcase and unmade bed, an extremely distracting and odd experience. As the study progressed, I learned that if I scheduled interviews outside of "regular" visiting hours for the ICU, I could almost be assured that a consult room would be available for my use. In future research, I would recommend this course of action to limit distraction and ease the interview process.

Each interview was audiotape recorded and transcribed verbatim. Field notes and memos were also utilized. All identifying information was expunged from the interview transcripts to

protect the confidentiality of all participants. The tapes were stored in a locked cabinet during data collection and will be destroyed one year following the conclusion of the study and completion of this dissertation.

Sample

A convenience sample of those who identified themselves as "family" was recruited from a Surgical Intensive Care Unit (SICU) at a the Hospital of the University of Pennsylvania. "Family" has previously been designated in this research study as anyone who is connected to the patient outside of the hospital including both relatives and friends. For the sake of this study, the term family was expanded to recognize the non-blood, non-kin relationships that may support the patient in the community. I wished to allow each "family" to self-select a member to participate in the qualitative interview with no restriction on relationship to the patient. Interestingly, all the participants for the study were in fact blood-relatives of the patient in the ICU. The majority of the sample was patient spouses with two participants identifying as the daughter of the patient and one identifying herself as the sister of the patient.

The inclusion and exclusion criteria: any family member unwilling to sign the consent form; anyone under the age of 18 was also ineligible to participate as are those for whom English is not his or her primary language as the consent form will on by available in English. Only family members of non-Trauma surgery patients in the intensive care unit for at least 48 hours were approached for participation. Finally, in the original study design, only one family member per patient was considered to participate in the study however, one interview was conducted jointly with the spouse and the adult child of the patient at the request of the participants. This interview was coded indicating and considering each participant's responses separately.

Recruitment

The convenience sample of participants was recruited from family members of patients in the Rhoads 5 Surgical Intensive Care Unit at the Hospital of the University of Pennsylvania. The final sample included 12 participants. Seven women and five men participated in the interview process; two daughters of patients in the ICU, one sibling and 9 spouses. Consent was obtained from the Nurse Manager of this unit to recruit families of patients from his specific patient care area of the hospital. The researcher worked with the nurses on this unit to identify family members potentially interested in participating in the study. The Social Workers and Clinical Resource Coordinators for this specific unit also assisted in recruiting possible participant families and introduced the proposed research to families utilizing a recruitment script created by the researcher as appropriate. Five potential study participants who expressed interest in participating in the interview process ultimately did not complete the interview. Two participants refused once contacted, both expressing concern about the time required to complete the interview. Both related concerns about leaving their family member to meet with the interviewer giving the limited duration of visiting hours however neither was willing to meet with the interviewer outside of visiting hours. Three potential participants were unable to meet with the interview due to changes in their family members' medical status and/or transfer to other areas of the hospital.

The Director of Clinical Resource Management and Social Work at the Hospital of the University of Pennsylvania expressed her support of this research and allowed her staff to assist in the project. Although I was employed at the Hospital of the University of Pennsylvania during the duration of the study, I assured that no dual relationships existed with families who consented to participate in the proposed research. I was not the social worker assigned to Rhoads 5 and had

no direct responsibilities to the patients or families on the unit. I also declined to participate in any Ethics Committee interactions with families on Rhoads 5 during data collection.

Family members who consented to participate in the research were asked to review and sign a consent form approved by the IRB (see Appendix B.). The form included counseling resources in the event that any family member who consented to participate experience any discomfort or wish to see therapeutic services as a result of participating in the interview (see Appendix A.)

Instrumentation

I utilized a self-developed, open-ended interview guide to conduct qualitative interviews of consented participants (See Appendix A.). The interview guide was not significantly changed throughout the course of the interviews. The order of the questions was modified as needed during the course of the interviews for flow and ease. The interview sought to elicit in-depth, explicit information about the experience of family members of patients during the intensive care stay. Families were asked to detail their unmet needs. The interview questions were informed by the five factors of the Critical Care Family Needs Inventory (Leske, 1991). These include the family members' need for: communication, realistic hope, support, comfort, and proximity. The questions also sought information to formulate an understanding of the family member's recommendations for practice or interventions in the intensive care unit specifically related to meeting the unmet needs of family members of patients in the ICU. The family member/participant was addressed as expert of his or her own experience and was asked to provide expert advice to the care team. Family members were also asked to offer hypothetical "advice" to future families of patients in an ICU setting. The majority of participants appeared very comfortable in offering advice to both future ICU family members and to health care

practitioners. Much information was obtained from this line of questions and is detailed at length in the next chapter.

Chapter IV.

Findings

Communication and Information

Research has indicated the need for quality communication between the healthcare team and the patient's family for more than 30 years-initially through the groundbreaking writing of Molter (1979), then refined by Leske (1991) and followed by numerous subsequent studies. Analysis of the interviews of this study also seem to indicate not only the perceived vital nature of communication between the healthcare team and the family of the patient in the ICU but also the continued concerns of family members who expressed feeling the communication and information they received from the healthcare team to be inadequate to meet their needs.

"It made me angry. It made me more angry, because it's like, you know if that happens all the time then you're obviously not listening, because you're looking medical, I'm looking human" (T. daughter of patient in the ICU). In this quote, T. is commenting on her struggles communicating with the healthcare team about her mother's needs. T. related multiple attempts to communicate her mother's reactions to medications to her mother's doctors without success.

"Ok, um, the physicians, the residents whoever they are, they call me for permission to do whatever, alright, but unless I say you've got to call me afterwards, and really stress them out, I never hear any results" (D. wife of the patient in ICU). At the time of the interview, D.'s husband had been in the intensive care unit for seven weeks. She related to consenting on his behalf for multiple procedures during both face-to-face interactions as well as via telephone calls. She expressed that while the physicians readily contacted her to ask to permission to provide invasive treatments to her husband, they did not contact her following procedures to

discuss the outcomes. “No one has just sat down and explained everything to me. I think my biggest thing has been [the lack of] communication.”

Many families wished to speak with the attending physician rather than a resident physician or the patient’s nurse but related communicating with the attending was often difficult for multiple reasons. G. related a communication concern expressed by other participants as well “on one occasion, in the medical intensive care unit, I wanted to get a hold of the attending physician. He wasn’t on the floor.” G. then explained the difficulties of locating and contacting the attending physician for information if he or she was not available on the ICU at this time of his visit. The ICU staff did not readily offer contact information for the attending physician, and when contact information was provided to G., it was a telephone number to the physician’s academic, not clinical, office. G. appeared distressed when relating waiting six hours to receive a return call from the attending physician.

Some families related an inability to identify who was the current attending physician for their family member. “They were telling us yesterday that there was an Italian guy… And I remember her saying he was just coming on so maybe they changed” (W., wife of patient, who related that she was told upon her arrival to the ICU on the day of the interview that her husband’s attending for that day was a woman not “the Italian guy”). D., wife of an ICU patient, related that “I think the main doctor that brought us in, did the surgery, I don’t think he has reached out at all to me” (this “doctor” as indicated by D. is not her husband’s attending doctor but D. does not appear to know who the attending doctor is at the time of the interview). Communication with the attending physician is vital for families of patients in the ICU. The attending physician directs the patient’s care. If the family cannot identify, and contact the

attending, the family seems to experience a sense of confusion and lack of understanding of the direction of the care plan.

One of the other circumstances that appeared to hinder communication was the constant change in physician staff "we are now working on our seventh attending physician. The attending physicians change every twelve days in the Medical ICU. They change here in the Surgical ICU every seven days" (G.). G. related that the constant change in physician delayed the progression of the treatment plan as each new attending physician had to "catch up" to understand the previously proposed treatment plan and decide how to progress. As G. stated, this change occurred weekly in the ICU where this study was conducted.

The continual change in nursing staff also greatly affected the mother/daughter participants who were interviewed jointly. W., the patient's wife, stated "and you never have the same nurse more than two days so I guess they are on two days and they are off." Her daughter, P., went on to say as if completing her mother's thought, "you just get to know them and they are gone." This turnover of staff seems to effect the family's perception of communication with the healthcare team. G. states:

> the nurses at most are on two or three days in a row with my wife and then you get somebody new…I found there were nurses rotating through who weren't even regular MICU, medical intensive care unit nurses. They were filling in for the day, were not familiar with the plan, what my wife's plan was…nurses who I saw before and who treated my, helped my wife, were in the unit but they were somewhere else.

G. went on to say that having the same nurse consistently helped the nurse to not only know his wife and the plan but also to "communicate back and forth" between the family and the healthcare team. He related that having the same provider over time also allowed him to "build up some rapport or trust and then about that point they change and you have to start all over

again" (G.). The rotation of staff whether physician or nurse seemed to be a key element in the perceived communication gaps in the ICU for these participants.

While a limited number of participants had no concerns about communication with the health care team, C., husband of the patient, related challenges with communication he encountered in the ICU of another hospital before the patient was transferred to the Hospital of the University of Pennsylvania, "they want to stonewall you, or treat you condescending or talk about all other kind of things at other hospitals. I haven't found that here." C. found his experience at the University of Pennsylvania a welcome change from his experiences in community hospitals. He stated his communication was "absolutely very good" with the healthcare team he encountered in the ICU.

Participant B., the husband of a patient in the surgical intensive care unit for one week, related what he felt was a very positive experience with communication in the ICU " they call me, they keep me informed, you know, every time something happens, they call me." B. perceived that his wife's physicians would contact him if needed. He did not appear to expect to hear from the physician team while at home unless there was an issue of concern. B.'s wife had been hospitalized previously on multiple occasions including an admission for a successful organ transplant. He related positive experiences during these previous admissions and seemed to indicate that he fully expected the experience of this hospitalization to be similar. When asked about communication, he stated "I find nothing wrong with the doctors and nurses…communication is good with the doctors…the nurses are really great, they really are."

Patient's daughter, T., expressed concerns during the interview about her mother's physician team not "hearing her" on an issue she felt was significant to her mother's healing. She related these concerns to the health care team on multiple occasions during her mother's ICU

stay. Once this issue resolved through a series of conversations with her mother's physicians, T. related that the team "really have gone out of their way to try to help me...everyone calls and if they don't get you, they call you again…I think that the team has been magnificent here honestly." Multiple conversations, capped by a conversation with a resident physician that T. perceived as turning around her mother's care, changed her entire perception of communication with the team. T. related another example of communication with the medical team following her discussion with the resident physician:

> I think that right after when you have the surgery and the doctor comes down, talks to you, consult. I think that's awesome, I think that's great, it just, you know, it's exactly what you need to, to know.

Communication: Forging Partnerships

Families expressed the desire to discuss the care and treatment of the patient in the ICU with the healthcare team rather than be merely informed of the patient's status or other issues. Some families in the study appeared to want to be included in the care and treatment of their family member rather than remain an observer. I have termed this phenomenon of wishing to join with the healthcare providers in the ICU "forging partnerships." An example of the family's desire for forging partnerships: "A couple of times I've walked in on the team standing outside the door and I've stood there through their report and then afterward, I've asked questions about that, but it's only been through luck that I've just happened to be there" (D., patient's wife). D. related a wish to participate further in the process of decision-making about her husband's care and to feel a part of the healthcare team rather than an outsider to the process. Another family member (H., spouse of patient) expressed his interest in being included in the healthcare team's bedside rounds:

> I will tell you that, uh, I've often been included in the rounds, if I'm there when they came around….they would say hello H., and would turn to me and ask if I

> had any specific concerns. There are times when I also passed along bits of information, observations of my own and generally that was always met with at least an appreciative response.

As this participant indicates, inclusion in "rounds," and thus the decision-making process for the treatment planning for the patient, was an important event for him. "Rounds" or "rounding" is a daily meeting of the healthcare team providing direct care to the patients in the ICU. The healthcare team gathers outside of each patient's room and circulates (rounds) around the unit discussing each patient individually. During the discussion, the patient's medical status is updated, concerns and potential concerns are discussed and a treatment plan for the patient is developed. This daily process typically does not include either the patient or the patient's support system. It is important to note that the participant quoted came to the hospital in time for rounds whenever possible although "rounding" by the healthcare team occurred outside of the designated visiting hours for the intensive care unit. The impact of visiting hours on the participants of the study will be discussed in greater detail later.

Information

The second type of communication concern expressed by many of the study participants was challenges in receiving information. The need for information is differentiated from communication as previously detailed. Requests for information are viewed in this arena as the need for data rather than communication in the more participatory sense. Participant family members commented that they received little information, incomplete information or contradictory information throughout their family member's stay in the ICU. However some family members commented very positively about the amount of information received and the means in which information was provided.

D., who experienced multiple issues in communicating with the team, also expressed difficulty in receiving the information she needed. Her husband had a significant complication following his admission to the ICU. She stated she was unaware of the severity of his medical condition or how long the complication had existed until she was inadvertently informed by an unknowing physician. “I was here every day but I didn’t know what to ask… I guess that’s the big thing-no one just sat down and explained everything to me” (D.) D. perceived that since she did not ask for detailed information about her husband’s complications or the implication for his potential recovery, very little information was offered to her.

P. expressed a similar concern. W., P.’s mother, visited her husband daily in the ICU. She began keeping meticulous notes in a series of notebooks. Her notes also included detailed questions she requested the team to respond to daily. When asked about her experience in obtaining information and receiving answers to her questions, P. related her mother’s experience “I think that you ask. I mean you come in the morning and she [W.] asks her questions and you [speaking to W.] have your questions and I think that some of the nurses have been more informative that others” (P.). W. agreed with her daughter’s statement. She related experiencing difficulties in getting questions answered but stated she perceived this limitation was a function of requesting information from the nurses providing care to her husband rather than the physician staff. She believed the physician staff was able to provide more comprehensive, detailed information “that’s why I am so interested in speaking to the attending” (W.). P. then indicated in response “I want to know what’s going on. I think that it’s important everyday for the attending or whomever can get hold of the information to take a minute or two with the patients and families” (P.) W.’s challenges in receiving the information she requested overlapped with

her previously documented difficulties in communicating with the team and in contact the attending physician responsive for her husband's care plan.

T. seemed to express a similar circumstance in her obtaining information about her mother however she seemed to perceive the situation differently than P. and W. "I felt like the doctor was giving me the medical portion and they [the nurses] were giving me the day to day" (T.). T. indicated that she felt both perspectives were helpful and comforting. She then stated she felt that the health care team had "really gone of their way to help" (T.). Other participants made similar statements about their experiences in communicating with the team and in receiving information. Participant C. related about receiving information from the doctors: "They would come up to me and tell me here, do you want to know? Do you want to know more? It was great. They always gave me the status every day" (C.). B. husband of the patient stated "When I'm here and they know I'm here, a doctor will come in and talk to me. They keep me advised of what's going on so communication is good with the doctors" (B.). M. also the husband of the patient related:

> Everyone that comes in lets you know what's going on and how it's going and what they are going to do. What they expect and whether she's doing better than they expect. I can't think of anything they aren't doing. They come in. All the doctors talk to you. The nurses tell you.

One participant indicated significant challenges in communicating with the health care team. He indicated that his concerns led him to doubt the information he received from the doctors and nurses caring for his wife "it just wasn't, it didn't make sense to me" (G.) G. went on the say that he had denied consent for a procedure to receive the information he was requesting. "very frustrating, very, it seems very sometimes, different parts are working against each other instead of together. One hand doesn't always appear to know what the other hand is doing so you ask the questions" (G). As the interview progressed, G.'s

statements about lack of trust of the team expanded and contradicted some of his earlier comments. He related that he felt the health care team was responsive to his requests for information but "do I always believe it when I hear day after day... I might not believe it…there have been times when I thought, in the other ICU, I was being misled" (G.). G. continued and commented again that he felt he was "misled" but did not offer any further details.

Trust

Trust of the medical team was a need related by multiple participants in the study. Trust was not a need specifically identified in the literature utilizing the CCFNI to assess family needs but may be viewed as an aspect of the need for communication and information. In the study presented, participant, G., articulated in clear terms and in more than one circumstance concerns about trusting the medical staff during his wife's stay in the intensive care units at the hospital. Other participants also seemed to indicate concerns about trusting the team caring for their family member. For example, P.W. stated "it's just really blown my mind" when explaining in detail her struggle to have her husband's tracheotomy tube replaced. P.W. and her daughter, P.D., seemed to have lost trust in the medical team as the patient's care plan did not progress as was initially indicated to them. Mother and daughter related receiving "contradictory" information that left them "Feeling-what's the answer? What's the answer? Let's do something here" (P.W.). The women did not seem to have faith that the medical team would follow through with the plan they had come to believe was the best option for the patient. With the loss in faith came a loss in trust and seemed to escalate the sense that the patient's family must remain vigilant and persistent to assure that their family member received the care the family felt was needed.

Vigilance and Visitation

Participant family member, C., related the most dramatic example of the need for trust, the need for proximity and the perceived need for vigilance as a family member of a patient in the ICU. C. visited his wife daily in the ICU, spending hours at her bedside. He indicated that visiting with his wife was essential to his wife's survival, stating "I feel like if you're not there a lot of times, things can slip through the cracks. I feel like a couple of times, I've saved her" (C.). C. detailed his efforts to participate in his wife's care and treatment, what I have termed "vigilant participation." C. related that he felt responsible for overseeing his wife's stay in the ICU. He observed her, scrutinized the team's responses to changes in her status and relentlessly "complained" in his words when the care or treatment did not meet his expectations. C. stated that his interventions had saved his wife's life on multiple occasions. He indicated that a level of vigilant participation is imperative for families of patients in the ICU and recommended that families "pay attention" to prevent the death of their family member (C.).

B. also related the need for proximity to his wife during her time in the ICU "so I don't have to come, like I said, if I don't come every day, I don't feel right, so I come every day anyhow" (B.). He indicated that he visited not only because he felt it was the right thing to do but because he recognized how much his wife relied upon his visits. He also commented that his visiting "makes her feel more safe" (B.). T. made a similar comment "I try to be here for her as much as possible" (T.). This sense of safety and comfort supplied by the presence of a family member in the ICU is consistent with the family presence literature previously discussed.

I found one comment from B. particularly significant. His thoughts moved from simple visitation to how visitation is viewed by the medical team and the potential implications for his wife. B. stated:

> Ya, but you know what I've found out? Generally speaking, when you have a family in the hospital, if you're there every day, or somebody in the family is there every day, then you get the nurses and the doctors to know you are there so there's not too much they're going to miss if they know you're going to be there every day asking questions so they are generally pretty well on top of it.

This comment seemed to echo the sense of vigilant participation in his wife's care that C. also expressed. Both men appeared to be saying that it is not enough to just visit they must be present and be involved for the best possible outcome for their family member. This takes the previously understood need of proximity to another level of understanding.

The expressed visitation needs of family members varied widely. Some participants expressed that while proximity (visitation) was important to them, they appreciated the limited visiting hours offered by the ICU. V., sister of the patient related "he's not serious enough that there would be anything to staying through the night and I would assume that in the hospital when people are dying, that they would bend the rules and you would have the ability to stay" (V.). E., wife of the patient, indicated that the limitation in visiting hours allow her to continue to carrying on her life outside of the hospital. She also commented that the limited visiting allowed her time and permission to "go home and just cry" (E.).

Participant G. indicated that he visited at will despite the posted visiting hours of 11am to 8pm. He stated "they'll bring me in…it's never really been a problem for me." This appeared true for the majority of the participants-only one study participant related difficulty accessing the ICU during hours not designated for visiting. Limited visitation, if enforced, may have presented an unmet need for the families of patients in the ICU. In this ICU, during this study, the need for visitation seemed to be well met.

Assurance and Realistic Hope

The literature indicates that family members of patients in the ICU have a need for what Leske and Pasquale (2007) termed "realistic hope" (Molter, 2007, p. 41). "Realistic hope" is hope or optimism about the patient's current medical status and potential for recovery balanced by honesty about how the patient is really doing and what is anticipated in the patient's recovery into the future. This need has found to be universal in prior research and is consistent with the statements of those participating in this study as well.

Participant D. related an experience with contacting the physician who accepted her husband to the hospital as a transfer from an outside hospital. She had not heard from this particular physician in seven week and upon contacting him, he related that the team was "getting him better" (meaning getting the patient better) but related no detail. D. stated "well it's not, that's not helping me, he's not getting better" (D.). It did not appear to be helpful to D. to hear that the team was "getting him better," this statement seem to relate unrealistic hope in D's perception. She did not see her husband getting better and did not understand her husband's care plan or his prognosis from the physician's rather limited comment.

T. related a different experience of discussing her mother's status and prognosis with the doctors and nurses. She felt the nurses were positive about her mother's condition and potential for recovery but the doctors were "pretty negative" (T.). However she went on to relate that "I take responsibility in that my mom's health is not well and I would rather you tell me the truth than not but it still felt very gloomy to talk. Know that you are going to get more bad news" (T.). When asked directly if this bad news might be the doctor attempting to be realistic, T. stated "right, it was, it was very painful" acknowledging that although it was painful for her to hear her

mother's condition, she believed that the physicians were being honest with her about how her mother was doing and she had a need to know the full picture, both positive and negative.

When asked about the need for realistic hope, B. stated "I've found I really want to know." M. indicated "they tell you what they are hoping and what they are trying to expect." In his statement, he seems to be saying that the team tells him but what is hoped for what also what can realistically be expected. This communication appears to meet M.'s need for a balance between optimism and reality. C. related he received what he perceived as "a very accurate, realistic picture. There was no fluff" and he appreciated this style of communication. E. similarly commented:

> I like to be told upfront what's going on-if I should be concerned that he is really getting serious, ya know, please tell me. My gut said a few times, is he dying? I mean should I be prepared? So, I, ya know, and they say, no, it's just a slow process step by step, the longer he's in the ICU the tougher it is and we will just take him to all the tests to see what he's not coming around-why he's not alert.

E. indicated she felt that the team had been realistic in their communication with her about her husband's condition and she was very appreciative of this honesty. G. also felt that the team was attempting to "answer the question the best they can" when he asked for updates about his wife's condition and prognosis but he was continually plagued by a sense skepticism about the information he received "I might not believe it."

Interestingly, participant P. W. related that "positives" from the team were essential for her stating "we hold on to the positives that we hear." She seemed to wish to hear good news rather than realistic news about her husband although she kept a daily journal of questions and the team's responses-both positive and negative. This may indicate some ambivalence on her part as well as her role as the communicator to the rest of her large expended family and many, many friends.

Clearly, assurance and realistic hope were needs for the families of the patients in this study. Family members asked for, and by their report, received assurance often coupled with expressions of concern. Family members appeared to appreciate what they viewed as honest, "no fluff" communication about what was occurring in real time and what they could expect in the future (C.).

Emotional Support

Emotional support is another area of need expressed by family members of patients in the ICU in numerous previous studies. Previous studies (what studies) indicated that family member's wished to feel supported and cared for by the health care team. This need was not so clearly defined in the study presented. Family members appeared split in their wish to receive emotional support from their doctors and nurses.

When asked about his need to receive emotional support from the team, G. commented "personally, I'm not looking for support." P.W. related that while she found the emotional support offered by the team "very caring, very compassionate" she didn't feel it was important to her. C. indicated that support from the staff was "not necessary…I got enough [support outside of the hospital]." E. had a similar response about her need for support but with a different rationale. When asked about supportive needs, E. related that she often just wanted to go home and be alone "I just like to be by myself when I get home…so just deal with it the way that I can" as a means of coping with her husband's stay in the ICU. She related it helped when nurses were particularly "gentle" with her but she did not feel the need to receive support from them.

M. felt differently about receiving emotional support from the staff. When asked if it was important to him that the team ask how he was doing he indicated that it was in fact important to him. He went on to say "ya, they all seem to really care." From his comments, M. indicated that

he thought the nurses cared for both him and his wife, which seemed to provide him a measure of comfort and support.

Comfort

The family members were asked if they felt comfortable in the ICU. All commented that they did however many seemed surprised by the question. Feeling comfortable in the ICU did not appear to be a central need of the family members. I found it interesting that family members did not even appear to have even considered their own comfort in the ICU however family members related another need that may be thought of as comfort or convenience-parking.

Multiple study participants related issues with parking at the hospital. These issues ranged from the location of the parking garages to the cost of parking while visiting. When asked what would be helpful to her or to future family members of patients in the ICU, V. related

> the only think that could be more helpful is to have that, the distances you have to walk from the front all the way up there [to the ICU] is tremendous. I don't know what they do when people really are sick? I said they ought to have… these little jitney things that run back and forth or golf carts.

V. was concerned about ill family members of patients attempting to walk the distance from the parking garage to the ICU (a few city blocks). Later in the interview, she revealed she that had a knee injury that made walking very painful. In V's case, the distance of the parking to the ICU was not just about comfort or convenience but about preventing physical distress and allowing an ill or injured family member visit the ICU.

Participant M. stated "the one thing I got to complain about here, that's parking." M. explained that the cost of parking was a stress for him. Although he did not openly state that he was having difficulty affording to visit, it was clearly implied by his distress about the daily cost. Participant E. related "it would be easier if he was closer and less expensive for parking" again emphasizing the negative impact of the cost of parking.

Advice from Study Participants

Participants in the study were asked to provide advice to future families of patients in the ICU and to the healthcare team caring for patients in the ICU. The advice offered by the participants reflects the needs, both met and unmet, of family members of patients in the ICU. The advice also reflects the lived experiences of family members at the moment their husband, wife, father, or brother struggled with critical illness just down the hall from the interview room. The advice and reflections also open a window into the emotional state of the participants at the time of the interview and throughout the ICU encounter.

Advice for Future Families

Visitation: Involvement in Care

When C. was asked what advice he would offer to another family that comes to the Hospital of the University of Pennsylvania for treatment, he commented about his perceived importance of being at the patient's bedside and being involved in your family member's care as much as possible saying

> I do feel one thing, I feel like if you're not there a lot of time, things can slip through the cracks…the only thing that I can say for the person that you care about, you need to be there and… be active because the squeaky wheel gets the oil or whatever the phrase is…if I can say to anybody, anywhere, pay attention to what's going on

B. also related advice to families about the importance of visitation but to meet a different need than the need that was expressed by C. B. stated

> Because I have been, I have been to the hospital and I have seen people that, they don't get any visitors, it's depressing to them and then the family really doesn't know what's going on because they're not there to ask the questions so and I know if effects people when you don't go see than in the hospital, it does

Later in the interview he went on to say

> My biggest thing is...when you have people in the hospital…visit them. Make sure somebody's there every day, even if you have to do it in shifts, cause it does two things, it makes the patient feel better and it makes the staff know they can't get away with anything 'cause you're going to be there most of the time…other than that, that's the only thing I would tell them to do

B.'s comments indicate his belief that patients need families to visit to for both emotional support and to monitor the staff. B. indicates that patients become "depressed" if they receive no visitors, saying "I just want to come and see her so she could see my face and… and think I didn't forget about her." Visitation is assumed to provide the patient with support not available to patients who must rely only on the staff to meet all of their needs.

Visitation: Monitoring the Staff

The second aspect of the importance of visitation expressed by B. was the importance of visiting to monitor the staff's care and treatment of the patient. He felt the staff would be less likely to attempt to "get away with anything" if the family was present with the patient as much as possible. Later in the interview B. indicated

> cause I know, like I said, I've been to the hospital and I see people that just leave their family members there and I don't think they get the care they would normally get if somebody was there every day…it's probably just human nature because they have so much other stuff to do but that's the way it works. And it's in all hospitals, alright, because I've been to a couple of different ones

Clearly B. believed that frequent visitation resulted in better patient care. Considering B.'s comments, the need for proximity takes on a new twist.

Visitation: Patient Support

G. also advised a need for family visitation and involvement in the ICU as did participant V. and participant T. T. suggested future family members "they need to come

in" to visit the patient as much as possible. She used her visits to encourage her mother to "heal" and indicated that in her belief system, this was necessary for her mother's recovery. T. related

> Family definitely needs to play their part, they play a very important role in the healing process. Um, I think that the turning point for my mother to decide to get the feeding tube was that my son is graduating the year and prom and she was like my grandson-I'm going to miss my, this is her last grand and she's like I've never missed anybody walk down the aisle. You know, I've never missed these things for any of my grandchildren and, the thought, and she knows my son adores her, the thought of not being there for him kicked in for her, you know, I started telling her that I went to get the prom clothes and this and that and then the thought of her not being there for him really hit home for her…you know those things really make a difference in that patient, like, um, so I think from our standpoint we need to be there for our loved ones, period. And more visits and of course keeping it intact and you know, I like being quiet and discrete and you know respecting the unit. Um, like, definitely being there for the family.

"Pushing for Information"

Participant D. related a particularly difficult time receiving the information and communication she needed about her husband during his stay in the ICU. When asked what advice she would offer for future family members of patients in the ICU, she related

> Keep pushing. Keep pushing for information, yeah, push everyday and anybody you can. You know, and if you have to lose it and start, you know, do that too because, uh, I mean I don't like to do that but after, you know, four weeks and we weren't getting anywhere, I just had to say hey, hey now but you know, of course, my biggest thing is where would you take him, this is one of the top ten hospitals. Where would I take him? Back down the shore where there's hardly anything? No, I don't think so. So you're kind of stuck. You feel kind of like, you know, you don't have any place to turn, so, yeah, but the biggest thing is for them to keep pushing and find out what they want and if they don't have medical knowledge at least I have some and I have my daughter but if they don't have that. Now my girlfriend's husband is over in the Founders building, she has a son-in-law who is a doctor and she gets a lot more information because he's a doctor and he comes after visiting hours in the evening and he knows exactly what to ask and what to you know. So, but if it was just her, she wouldn't know anymore, you know, wouldn't know as much as I know because, so, um, you know, if they know a doctor or someone in the healthcare field, to try to get them involved in it because it's a lot easier to get the real answers and to know the questions to ask.

> You know, because just us off the street-people off the street-they don't know the questions to ask

Draw on Community Resources

D. seems to be expressing the need for communication and information so commonly related in the literature about the needs family members of patients in the ICU. She advises future family members to seek assistance from their support systems in the community to obtain the information they are seeking and to interpret the information they are receiving.

During her interview, D. also said "no and like you say, I, to tell them to take care of themselves because that's a big thing. If you don't take care of yourself, you're not any good to anybody." She wanted to advise family members about the importance of self care while their family member is in the ICU as did participant PD. PD related

> And make sure you take care of yourself and that our big thing with her [indicating her mother]. Keep eating and sleeping and trying to get something to take your mind off stuff, too, I mean. We actually put her screened in porch together and it was 7:00 at night after a long day here but it took her mind off it for a while.

Ask Questions

M. advised that future family members of patients in the ICU "ask" if they have questions as did participant E. stating "if you have questions, ask." Neither participant elaborated any further than to advise to ask questions. E. changed the conversation from a question of advice for future families to her reflections on coping with a family member in the ICU. She related that

> each one [family member] has to deal with it in their own way, ya know I believe, I, that I don't, I have family member in my family that haven't come and I don't hold anything against them. Everyone deals with it, just like grief, everyone deals with grief in their own way..it's up to the individual person and family.

Be Prepared

PW advised that family members “be prepared for the ups and downs.” PW’s husband’s condition varied widely from day to day. She did not know what to expect each day she visited and wanted to warn future ICU families to prepare themselves for the daily challenges. PW also joked that she would advice family members to “go to your primary and get something for your nerves-I could not come in here each day without it.”

Advice for the Healthcare Team

Vigilance and Involvement

C. related his need for the healthcare team to involve him in his wife's care-an extension of his advice to future families and his perception of the need for families to be vigilant and involved. He related "if a healthcare person really isn't sure that's her normal behavior or not, and you know, I know these kind of things." It appears C. is pointing out his perceived value to the healthcare team and his need to be an active participant in his wife's treatment in the ICU.

Participant T. also advised the healthcare team to work with families from the time of admission to understand the patient better through the family's experiences. This appears similar to C.'s thoughts about the potential role of the family in the care and treatment of the patient. T. said

> that initial interview, before they get, when you're getting admitted to the hospital, I think that taking five minutes to ask-what is that you want me to know about mother before, or you loved one before, we take here in here? You know because today I'm dealing with [patient's name], tomorrow I might be dealing with a whole completely different person. Like, I think, that the thought of not having a will, my mom said they ask you, do you have a will? And they ask if she ever and she said "you know what, I don't think I do." Well I think the next question should be, is there anything you want to tell us right now? And sign. That will give us a little direction, like when we had to make the decision about the feeling tube. I had to make the decision, I made the decision to say yes but then she came back to herself and doctor X. realized that, you know what [patient name] is her old self again now and she's very capable of making her own decisions which two days ago she wasn't or a day ago she absolutely wasn't able to and she said "no, I don't want the feeding tube"…You asked the initial question but you didn't go deep enough. You asked me to do a will, a living will, I said no. Then at that point is the perfect time to say is there anything you want to tell us now or give your daughter the rights to do or, you know, that would help this be a safe or easier transition for you?

Communicate with the Family

The need expressed by T. is the need for communication between the hospital staff and the patient/family. T. is not asking for information, she is asking the hospital staff to communicate with her and her mother about her mother's hospitalization and potential implications. She is advising the hospital to assist patients and families in planning ahead for the ICU stay by assisting patients in completing an advanced directive (the "will" she mentioned).

D. also indicated that she would advise the healthcare team to communicate with the patient's family members stating

> I think they could probably make a point of talking to them. That, that would be my biggest thing. Um, you know, up here I know a couple times I've walked in on the team standing outside his door and I've stood there through their report, and then afterwards I've asked questions about that, but it's only been through luck that I've just happened to be there

As has been detailed previously, communication is an expressed need of family members of patients in the ICU. In D.'s case, she expressed the need for both herself and for future families by advising the healthcare team through her comments within the study. M. advised that the team communicate with families to "just explain to them what to expect and what to look for so it's not a big surprise if the happens and if it don't, good."

"No Advice"

B. had no advice for the healthcare team saying "I really don't [have any advice] cause I'm so satisfied with the way they're working with me now." When asked for his advice for the healthcare team M. said "nothing that I can think of-they've been perfect down the line." E.'s advice to the healthcare team had a similar sentiment. She stated

> Just continuing doing what you are doing because they come in they tell you what they are doing. They are excellent if there is concerns and if you ask questions. They explain everything and so, just have to wait it out and hope for the best, that's all.

Findings Summary

Participants commented on multiple areas of needs of family members of patients in the intensive care unit as well as identified advice for future family members of patient in the intensive care unit and for the health care practitioners caring for patients and their families. The predominant needs appeared to be the need for communication and the need for information. Communication concerns included families feeling that the healthcare team was not listening and their concerns were going on answered. Families requested to communicate directly with attending physicians rather than resident doctors or nurses but families found this possibility was hampered by the constant rotation of staff and their inability to even identify the attending physician. Families also related a wish to be included in decision-making and participate in rounds rather than just receive information-termed "forging partnerships." And finally, a few families had no concerns about the communication they received while their family member was a patient in the ICU.

Families related challenges in receiving the information that they either wanted or felt they needed to understand their family members' medical status and/or prognosis. Some indicated that they received little to no information about their family member or that they receive information that "didn't make sense" leading to feelings of being misled by the health care team. This feeling of being misled was related by multiple family members in more global sense as a feeling of needing to trust the health care team.

The next area of findings of the study was visitation and vigilance. Families indicated a need to be present at the hospital as much as possible for two main reasons: to support the patient and to monitor the care. Family members related they believed that their family member benefitted from their presence at the bedside some felt constant presence was most helpful while others related that less visitation was just as beneficial to their family member. Some family members indicated the need to be at the bedside as much as possible to prevent medical errors and to interpret their family members' symptoms to the team, termed "vigilant participation." One family member went so far as to say that he felt he had saved his wife's life on multiple occasions with his presence and involvement at the bedside.

Family members detailed needs for assurance and "realistic hope." Family members indicated a need for assurance, or to receive positive feedback about their family members' condition or prognosis, from the medical team. Nearly all family members related the need for "realistic hope" which is hope or optimism about the patient's current medical status and potential for recovery balanced by honesty about how the patient is really doing and what is anticipated in the patient's recovery into the future.

Emotional support and comfort were two additional areas of need assessed in the study. The need for emotional support of the family members by the health care team was not well defined by the family members' statements. This potential need did not appear to be a consideration of the participants nor did the potential need for family members to feel comfortable in the ICU. When asked questions about comfort, family members appeared surprised-as if they did not expect a consideration of their comfort.

The participant family members were asked to provide advice to future family members of patients in the ICU and to the health care team caring for patients in the ICU. The advice to future family members seemed to echo the needs detailed previously. The participants advised of the importance of visitation to both support the patient and to watch the health care team to assure their family member receives the highest level of care. They counseled eventual family members of patients in the ICU to be prepared to ask questions and to push for the information and communicate they need. And finally, they encouraged families to be prepared for the ups and downs of their family members' stay in the ICU and to seek community resources to help them through this experience.

The advice offered for the health care team also paralleled the needs of family members of patients in the ICU as related by the participants. The health care team was directed to involve the family in the patient's care and treatment in the ICU including in care planning. The participants also recommended that the health care team communicate with the family throughout the health care encounter and to recognize the family as a resource able to provide information and input valuable to the care and treatment of the patient. However it is also important to note, that a few family members indicated "no advice" to the health care team as they felt the team was doing the best job possible already.

Chapter V.

Discussion, Implications, and Conclusions

Discussion

As the participants have indicated through their words, this study confirmed the findings of studies occurring throughout the world over the last 30 years that have chronicled the needs of family members of patients in intensive care. Family members expressed the need for communication, information, assurance and proximity to the patient. These areas of need appear to be "universally experienced by most family members" of patients in the intensive care unit (Leske & Pasquale, 2007, p. 32). However, the need for comfort did not appear to be a primary consideration for this group of family members, although this need was indicated by Leske and Pasquale (2007) in their chapter of the "Protocols for Practice," nursing protocols based on a review and assimilation of the literature through 2007 that detailed the experiences of family members of patients in the ICU.

The expression of challenges in communication abound in the study. These concerns included family members feeling that the healthcare team was not listening to their concerns and family members believing they were being actively ignored. These feelings are consistent with what has been detailed in the literature. Kotkamp-Mothes and colleagues (2005) described the needs of family members who are "frequently neglected" while Delva and colleagues (2002) related that during the first few days of a patient's hospitalization, the patient is the center of attention while communication with the family takes a lower priority. Unfortunately, the family members in this study did not indicate that communication improved during their family members' stay in the ICU. The need for communication and in most cases the challenges in communication, remained constant throughout the ICU encounter.

Family members suggested the potential benefit of participation in rounds (termed "forging partnerships") with the staff on the ICU to improve communication, however this option is not currently available in the setting of this study due to limited visiting hours and other factors such as limited time for practitioners to spend with families and the perception that the family may have little to nothing to offer to the patient's treatment. Limited visiting hours are not recommended in the literature (Armstrong et al. 2007), however this practice continues in the ICUs at the setting in which this research was conducted. Family participation in rounds is also not a standard practice and only occurs at the discretion of the attending physician.

Families attempted to circumvent this gap in communication by being ever-present at their family member's bedside or by spending countless hours in the waiting room. This presence served three primary goals: 1) being available when the attending doctor visited; 2) monitoring and implicitly pressuring the staff to provide the best care possible; and 3) supporting and protecting the patient. McAdam and colleagues (2008) related that the family role of "active presence" is important to many families (p. 1098) and Hupcey (2001) found that "family presence in the ICU helped instill hope, a sense of control, trust in providers, and the opportunity to have gaps in knowledge filled-in, all resulting in helping the patient to feel safe while in the ICU" (p. 207).

The perceived benefit of this ever-presence varied from family to family. Some families related that they were able to communicate with the physicians and other health care providers since the health care team could not care for the patient without encountering the family. Other family members related that although they were at the bedside all day, they did not receive the information or communication they hoped for. Those who related the need for family presence to monitor the staff indicated that their presence not only assured their family member received the

best possible care but also, in some cases, family members felt they had literally saved the patient's life by alerting the staff to changes in the patient's condition not recognized by the doctors or nurses. Family members felt very strongly that presence at the bedside benefited the patient not only through improvements in care but also by offering the patient a sense of safety and comfort. This sense of safety is consistent with the literature. Hupcey (2001) indicated that the "major source of support was the family/friend of the patient" (p.207).

Participation in the decision-making related to their family members' care and treatment was identified as an area of need for families. With nearly three quarter of all patients in the ICU unable to make decisions for themselves, family members are vital to this process (Maxwell et al., 2007). Family members recognized the magnitude of this role and seemed in be indicating that more communication might assist in the decision-making process. In a similar vein, families related challenges in receiving the specific information they needed to make the decisions they felt to be in the best interests of their family member. This facet of the need for communication and the need for information was again not being met for the majority of family members in the study.

Some participant family members indicated that they received little or no information about their family member's medical condition or prognosis during the ICU stay. With the majority of patients in the ICU unable to communicate or if able to communicate, lacking decision-making capacity and advocacy agency, this finding is very distressing. It is not clear why this situation occurs. In one case, the patient experienced multiple, severe complications that, from the family member's perspective, were not shared with the family. It is possible the health care team purposefully concealed the complications but it is also possible that the family member was informed but was unable to understand or assimilate the information provided.

Pouchard and colleagues (2001) indicated that families understand less than 50% of what doctors tell them about prognosis, diagnosis, and treatment options of the patient for whom they are making decisions.

For some of the family members, information about the patient was relayed, however the information received was met with skepticism. Family members did not believe what they were told about the patient's medical status or hope for recovery leading to high levels of distress in the family and potentially in the patient. Leske (1998) suggested that "unmitigated family stress may manifest itself in distrust of hospital staff, noncompliance with the treatment regimen, anger and dissatisfaction with care, and even lawsuits" (p. 130). The mistrusting family members expressed great dissatisfaction with the care, and high levels of anger. While the need to trust the health care team has not been identified in prior research as a primary need of family members of patients in the ICU, in this study when this need went unmet, it appeared to overshadow the other potential needs of families.

A review of studies of family members of patients in the ICU between the late 1970's and early 1990's indicated that a patient's family member's need for information and assurance is primary in coping with a loved one's hospitalization (Delva et al., 2002). This need for assurance and "realistic hope" was expressed by the participants of the study as well. Family members indicated a need for reassurance from the health care team that their family member was progressing as expected but also that the condition and prognosis of the patient was not being overstated. The family members insisted on "realistic hope" rather than unfounded positivity.

The advice offered by the family members as to how support for ICU families might be improved reflects what they described as their own unmet needs. Family members asked that the health care team seek out the family rather than the family

needing to take the lead in communicating with those caring for their family member. They asked for open, two-way communication and information sharing. The health care team is encouraged to see the family as a help to the patient, recognizing that the family knows the patient better than anyone and may offer a perspective on the patient that is valuable to the patient's healing. The family members interviewed in this study suggested that other family members seek the information they need unabashedly, asking as many questions as they must to get to the answers they need. They also suggested that family members prepare themselves for the emotional challenges of having a family member in the ICU and seek supports in the community.

Findings Differing from the Literature

One area of need detailed in previous studies, comfort, did not appear to be an unmet need for the participants in this study. The respondents did not even appear to have considered their comfort needs. They had very little to say when asked for details about their experiences and feelings in this area. Family members also did not see a need for the health care team to offer them emotional support, another aspect of comfort. Families commented that they were focused on the patient not on themselves. This is an interesting finding worthy of further discussion and exploration.

Family members requested to communicate directly with attending physicians rather than resident doctors or nurses but found this option was hampered by the constant rotation of staff. The rotation of staff hindered the establishment of relationships and appeared to seriously damage the development of trust in the health care team. One family related an inability to even identify the attending physician, the health care

provider ultimately responsible for the direction of the care and treatment of their family member.

The need for "vigilant participation" rather than the mere need for proximity to the patient is also an area varying from the literature. Some families in the study took the need to be close to the patient to an extreme. Family members indicated concerns that if they were not present with their family member, monitoring the care provided and monitoring the patient's condition in close detail, he or she, may die. The perceived need for this level of vigilance to protect the patient is potentially a new finding of interest.

Implications

The initial study of the family members of patients was published by Molter in 1979, more than 30 years ago. Since that time, dozens of studies have followed that identified unmet needs of family members of patients in the ICU. These needs include: the need for communication and information sharing between the family and the health care team; the need for reassurance from the medical team and to feel comfortable in the ICU; and finally the need to be close to the patient during the ICU stay. These needs have remained unchanged over time and fairly consistent across age, relationship to the patient, gender and patient diagnosis (Hickey & Leske, 1992). The findings of this study reveal that these unmet needs continue to be present despite multitudes of articles and practice recommendations suggesting ways to meet the unmet needs of family members.

At the setting in which this research was conducted, the protocols for practice written for critical care nurses as well as the protocols published for other critical care practitioners have not been adopted. The protocols offer specific recommendations for

improving the experiences of family members and thus the potential outcomes of patients These protocols have not yet been fully adopted by the setting of this study.

It is unclear why the setting in which this research was conducted has not incorporated many of the directives recommended in published best practice protocols for critical care practitioners. For example, in my experience as a hospital social worker, hospital staff is uncomfortable with unlimited visiting hours. Some staff have expressed concern that open visiting hours may put patients at risk since screening visitors is more challenging outside of regular business hours. Other staff have indicated that family presence at the bedside can impede care and in some cases, slow down care if the family asks many questions or has concerns they wish to discuss. Hospital administration may fail to see the need to hire sufficient numbers of staff to eliminate the continuous rotation of doctors and nurses and provide continuity of care for patients and their families. The health care providers might also fear lawsuits, leading them to choose to limit their interactions with family members as a way of avoiding scrutiny.

Meeting the unmet needs of patients' family members is a multilayered, multifaceted problem that cannot be tackled without sweeping changes. On the positive side, the increasingly competitive nature of the healthcare market may force hospitals to adopt policies that are more consumer friendly and do a better job addressing the unmet needs of patients and family members. In the current climate, hospitals must constantly work to improve services and responsiveness to their current and potential patients and their family to win their business. Ultimately, if hospitals hope to remain competitive in the market, the needs of the consumers must not only be recognized but attempts to meet the needs must be actively pursued.

The care of families also raises ethical issues. Hospitals must consider the implications of continuing to engage in practices that ignore the needs of family members. Physicians, are duty-bound "do no harm," however decisions are made on a daily basis that do emotional harm to family members of patients in the ICU, whether knowingly or by neglect.

Educational and Training Implications

This study's findings point to the need for improved education and training for those providing care to the families of patients in the ICU. While information about evidenced-based practices is widely available for nurses about the needs of families of patients in the ICU, such best practices have not been fully incorporated into daily practice at the study site. It would be overly simplistic to attribute this training-practice gap to nurses themselves. The gap occurs at the facility level. While individual nurses are at the bedside providing direct care to patients and families, their practice is directed by the institution. It follows that educational efforts aimed at the institutional leadership may be a necessary first step in altering practice. The educational needs of physicians are also apparent and again, may require initial intervention by an educated leadership structure to influence individual physician behavior.

The educational and training needs of social workers are similar to the needs of nurses and doctors. However the consideration of the educational needs of social workers cannot begin until social work is recognized by institutional leadership as a needed service in the ICU. Currently, the availability of social work services to patients and families is limited in the intensive care unit studied. Initial educational efforts must include efforts to provide the justification for adequate social work support in the ICU.

Practice Implications

Without significant changes over the past thirty years in the needs of families of patients in the ICU, and the on-going inability of health care providers to consistently meet those needs, current practice methodologies must be evaluated. This is especially important as the number of intensive care units increase as do the numbers of patients receiving intensive care.. The findings of this study suggest that health care providers still have some distance to go when it comes to fully integrating best practices for providing family support in the ICU. This study revealed a wide separation between the health care team and the patient/family. An analogy for this perceived separation is that of two worlds functioning independently of one another in a parallel fashion,both busily working towards goals decided upon without input or cooperation from the other world, all while orbiting and caring for the same sun, the "sun" being the patient. From the comments of the study participants, these two worlds do not interact in an optimal way. Each could greatly benefit from the wisdom and experience of the other but conventional practice prevents the exchange of ideas. Conventional practice also leads many from the health care world to see the family as an obstacle to the care of the patient rather than a partner in that care. The health care team may not recognize what the family has to offer. This lack of understanding greatly limits the ability to move forward in providing the best care to the family and thus the best the care to the patient.

Incorporating the family into the ICU (joining the health care team and the family system) begins with providing the family the communication and information they need. This joining primarily requires a shift in physician and nursing practice although much of the need for change rests with physicians. In this new practice model, opportunities for

family members and physicians to interact would increase. Family members would be empowered to ask questions and physician would be empowered to answer fully and completely, offering hope when warranted and concern when not. Family members would participate in daily rounds on the unit if they wished. They would be supported in visiting their family member as much or as little as they chose without concern that the less time they spent at the bedside, the worse the care their family member would receive or the less information and communication they would receive. Family members would be offered emotional support and their comfort would be made a stated priority.

Implications for Social Work Practice

These changes in practice result from the recognition of the family member's role in the ICU that of caregiver, decision-maker, advocate and supporter of the patient. This understanding gained through the comments of the participants of the study has significant implications for social work practice in the ICU. The role of social work in the ICU studied has been primarily that of crisis manager and discharge planner on a consult basis. As more and more patients transition from this ICU to community settings, usually long term acute care hospitals, the social worker is viewed as merely responsible for moving patients along the continuum of care. I believe this view of social work is primarily based upon the limited availability of social workers in this ICU.

Once adequate social work support is made available to the ICU, social workers must begin to build a new conceptual framework for working with families of critically ill people, a practice framework that differs from many other areas of the hospital. In much of hospital, the patient is unit of interaction or the primary client. In the ICU, this model is not entirely applicable since the patient may be unable to participate in

interactions with the social worker. The family becomes the unit of interaction, and in essence the primary client, until the "real client," the patient, emerges. In optimal practice, patient and family-centered care would be practiced throughout the hospital with the needs of both patients and families/support systems receiving intervention to meet their specific needs.

Psychosocial assessment is the basis of all interventions in hospital social work, however the typical psychosocial assessment is an evaluation of the patient not of the patient and family. In the new model of practice utilizing the study's findings, assessment of the family becomes a key aspect of work with the family. The family's strengths and challenges as well as articulated needs are considered in conjunction with those of the patient. Assessing the family, rather than merely asking the family about the patient, may draw the family into the health care encounter as a partner rather than relegating the family to a secondary position.

Social workers must also take a more active role in the ICU to meet the family's needs. As the only constant presence in the family's health care encounter due to the rotation of the staff in the unit, the social worker is in a unique position to advocate for the family. This advocacy may take the form of facilitating communication and information by coordinating family meetings or in assisting family members to relate the care wishes of the patient when difficult decisions are eminent.

Social workers also have the training and skills to provide short-term supportive counseling to families. Although emotional support was not identified as a need of participants in this study, that need may become more apparent if other needs, such as the need for communication, are met. The social worker can also evaluate the coping abilities

and styles of families and assist families in utilizing these strengths during their family member's stay in the ICU.

Study Limitations

The study has multiple limitations, with one of the main areas of concern being the sample size. Twelve participants is a relatively small sample size that prevents generalization. Additionally, the sample was recruited by staff members who developed at least cursory relationships with the potential participants prior to introducing the study. These relationships provided an almost pre-screening of potential participants, thus precluding potential participants who may have wished to self-refer. Allowing self referrals in response to recruitment materials posted in common areas of the hospital may offer interesting results, as would recruiting participants who have a history of past ICU experience rather than just those who currently have a family member in the ICU. Finally, the convenience sample was selected from one ICU location only thus limiting the variability of patient diagnosis and reason for admission to the ICU to only those receiving specific surgical interventions.

My participation in the study presents a limitation as well. The participants were aware of my employment at the research site, as well as of my status as a doctoral student. Many were aware of my role at the hospital as a social work supervisor either from asking me my position directly or from reviewing the employee identification tag I wore during the interview. It was clear that some of the study participants viewed me as part of the health care team by their responses to some of the questions. I was addressed as part of what was happening on the unit, either positively or negatively, which caused me to wonder what biases may have been revealed because of my "insider role".

Future Research

A larger qualitative study with a larger sample is recommended in the future-possibly to include participants from multiple ICU within the same facility or from intensive care units in multiple facilities. Analysis of multiple quantitative studies found little differences in the needs of family members of patients in the ICU across multiple demographics. It may be telling to conduct further analysis that considers responses by gender, age, relationship to the patient, experience with ICU care, and patient diagnosis.

The findings of this study also point to the need to study social work practice in the ICU. The study asked no direct questions about social work and thus the practice implications proposed here are based on extrapolations and interpretations of the participants' comments combined with my own understanding of social work values and knowledge of the profession's skill base. It would be highly beneficial to social workers working in ICU settings to have knowledge of social work practices in the ICU obtained from empirical research. There is an obvious dearth of research in this area at this time. Without adequate research, evidence-based practice for social workers in the ICU is not possible.

Finally, the study points out the need to begin evaluating interventions specifically designed to meet the needs of patients and families in the ICU. Leske and Pasquale (2007) published comprehensive protocols for nursing practice in the ICU. These protocols provide a blue print for interventions that may be implemented and evaluated by all practitioners in the ICU not just nurses. Social workers have the opportunity to implement practices with patients and families both independently and in

concert with nurses that are the next step in providing the highest quality, most responsive health care to patients and families in the ICU.

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Appendix A.

Initial Interview Guide

Demographics:

Age:
Sex:
Loved one's first name:
Relationship to Patient:
Patient's reason for ICU admission: (if not expected, get detail)
How many days loved one in ICU:
Is this first experience in ICU: (if not, get detail)

I'm interested in hearing about how your needs have been met or unmet by the healthcare team in the ICU.

Before we start talking about your experiences with the hospital staff, can we talk about how you've been affected by your family member's hospitalization?

1.) How has your loved one's hospitalization affected your life?
    Probes:
    a. Your home life?
    b. Your relationships?
    c. Your work life?

2.) Tell me about how the hospitalization has affected other members of your "family?"

3.) How do you handle, on a daily basis, having your relative in the hospital? How could the hospital staff make your job easier?

4.) Now can you tell me about any needs that are not currently being met by the healthcare team? Let's first try to make a list of those needs and then go back and talk about each one in detail.
    Probes : (examples to be provided from each of the 5 dimensions of the CCFNI)
    a. Need for support: Sometimes people feel they would like receive emotional support from healthcare providers-is this a need for you? Can you say more?
    b. Need for comfort: Do you feel comfortable in the ICU? How about with the staff?
    c. Need for information: Sometimes people feel they are not receiving the information they need -can you tell me about your communication with the medical team? Are you receiving the information you need?

d. Need for proximity: Sometimes family members are restricted from being with the patient because of the ICU visitation rules. Have you experienced any barriers like this to being with your loved one?
e. Need for assurance: Are you receiving the assurance you need?

5.) Can you tell me about anything else the healthcare team is missing when it comes to your needs?

6.) How would you tell the healthcare team to help families in your situation?

7.) How could the medical team work better with you?

8.) We've talked about how your needs have not been met, can you tell me about any positive things the healthcare team did?

Debriefing Questions:

9.) Are there any areas of your interactions with the healthcare team that we haven't discussed?

10.) What advice would you have for other families in terms of their relationship with healthcare professionals?

Appendix B.

University of Pennsylvania
Office of Regulatory Affairs
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Emma Meagher, MD, IRB Executive Chair
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INSTITUTIONAL REVIEW BOARD
(Federalwide Assurance # 00004028)

04-May-2009

Ram A Cnaan
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PRINCIPAL INVESTIGATOR: Ram A Cnaan

TITLE: The Unmet Needs of Family Members of Patients in the ICU and Implications for Social Work Practice

SPONSORING AGENCY: NO SPONSOR NUMBER

PROTOCOL #: 809776

REVIEW BOARD: IRB #8

Dear Dr. Cnaan:

The above referenced protocol and was reviewed and approved by the Executive Chair (or her authorized designee) using the expedited procedure set forth in 45 CFR 46.110, category 6, and 7, on 01-May-2009. This study will be due for continuing review on or before 30-Apr-2010. Approval by the IRB does not necessarily constitute authorization to initiate the conduct of a human subject research study. Principal investigators are responsible for assuring final approval from other applicable school, department, center or institute review committee(s) or boards has been obtained. This includes, but is not limited to, the University of Pennsylvania Cancer Center Clinical Trials Scientific Review and Monitoring Committee (CTSRMC), Clinical and Translational Research Center (CTRC) review committee, CAMRIS committee, Institutional Bio-safety Committee (IBC), Environmental Health and Radiation Safety Committee (EHRS), and Standing Conflict of Interest (COI) Committee. Principal investigators are also responsible

for assuring final approval has been obtained from the FDA as applicable, and a valid contract has been signed between the sponsor and the Trustees of the University of Pennsylvania. If any of these committees require changes to the IRB-approved protocol and informed consent/assent document(s), the changes must be submitted to and approved by the IRB prior to beginning the research study. If this protocol involves cancer research with human subjects, biospecimens, or data, you may not begin the research until you have obtained approval or proof of exemption from the Cancer Center's Clinical Trials Review and Monitoring Committee.

The following documents were included in this review:
- HSERA submission 04/24/09
- Cover letter 04/24/09
- IC form 04/24/09
- Interview guide
- Recruitment materials
- IRB response document

When enrolling subjects at a site covered by the University of Pennsylvania's IRB, a copy of the IRB approved informed consent form with the IRB approved from/to stamp must be used unless a waiver of written documentation of consent has been granted.

If you have any questions about the information in this letter, please contact the IRB administrative staff. Contact information is available at our website: http://www.upenn.edu/regulatoryaffairs/Contact.html.

Thank you for your cooperation.

Sincerely,
IRB Administrator

Consent for Interview

Introduction and Purpose of Study:

I am a graduate student in the DSW program at the University of Pennsylvania School of Social Policy and Practice. As part of the requirements for the completion of the DSW, I will be conducting and analyzing interviews of family members of patients in intensive care.

Please ask any questions that you have about participating at any time. I want you to have the information you need to make a decision to participate or not that is best for you.

What is involved?

The interview will last about forty five to ninety minutes. I will make an audio recording of the interview and may take written notes. You will also be asked to complete a brief background survey
that will take no more than 5 minutes.

The interview will ask your opinions, views and experiences as a family member of a patient in the intensive care unit. Your specific thoughts about your needs as a family member of a critically ill person will be explored.

Confidentiality:

The information you share will be kept confidential. I will not share information about whether or not you participate in this research study with anyone including the health care team caring for your family member.

Anything with your name on it, such as signed consent form, will be kept in a locked file cabinet,

separate from your interview tapes and transcripts of those tapes. One year following the completion of
my dissertation, I will destroy any audio recordings, interview notes, interview transcripts, and any other
materials related to this research study.

Benefits of participating:

Although being interviewed will not help you directly, your answers will provide information that may
help in understanding the experience of family members of the critically ill. The interview also provides
you the opportunity to recommend ways the health care team may assist family members of the critical
ill. You may also find it interesting to share your own story.

Risks of participating:

There are no known risks of participating. If answering some of the questions makes you uncomfortable, please let me know. We can stop the interview for a few moments, or you can decide to stop participating entirely. Should you continue to feel upset in the next few days, please be in touch with me and I will provide some suggestions about resources for talking about your concerns.

Compensation

If you decide to participate you will be given a $5 gift card to the Java & Jazz coffee carts after this
consent form is signed.

If you have questions about the project, please feel free to contact me:

Heather Sheaffer, MSS, LCSW

University of Pennsylvania, School of Social Policy and Practice

h_sheaffer@yahoo.com

717-514-4840

Your participation is completely voluntary:

You do not have to participate in this research. There will be no negative consequences if you decide not to participate. No one will know whether you participate or not. If you don't participate, it will not affect the care of your family member or anything else.

If you do decide to be interviewed today, you can stop the interview at any time. You can also refuse to answer any questions that you don't want to answer.

By signing this consent form, I am indicating that I have had all of my questions about this project answered to my satisfaction and that I have been given a copy of this consent form.

Participant signature: _____

Participant printed name: _____

Date: _____

Interviewer signature: _____

Interviewer printed name: _____

Date: _____