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The Family Experience of Participating in an ICU Support Group: A Pilot Study

Rebecca Marie Scharpe
Minnesota State University - Mankato

THE FAMILY EXPERIENCE OF PARTICIPATING IN AN ICU
SUPPORT GROUP: A PILOT STUDY

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REBECCA M. SCHARPE

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Rebecca M. Scharpe

This thesis has been examined and approved by the following members of the thesis committee.

Sandra K. Eggenberger, PhD, RN, Advisor, Professor of Nursing

Karen Willette-Murphy, PhD, RN, Professor Emeritz

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ABSTRACT

THE FAMILY EXPERIENCE OF PARTICIPATING IN AN ITENSIVE CARE UNIT
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The purpose of this study was to describe the experience of family members participating in an intensive care unit support group. The family experience of an adult family member's critical illness is filled with emotional distress, suffering, and difficulty coping. Few family nursing interventions to care for family members of ICU patients have been researched. Research is inconsistent regarding the value of a support group in the ICU setting of a hospital.

A qualitative design, using hermeneutic phenomenology was chosen. Five interviews were conducted with seven family members. The experience of participating in an ICU support groups was analyzed within Van Manen's (1990) framework of lived space, lived relation, lived body, and lived time. An overall pattern of gaining strength was uncovered. Within the support group experience, families found their lived space occupied by trying to understand, wherein subthemes of exchanging information, decision making, and sense of direction were identified. Being not alone was a reflection of families' lived relation with subthemes of nursing presence and being together with other families. The life world of lived body was identified as comforting. After initial experiences of vulnerability with others in the support group and intensive care unit setting, families found comfort by sharing their story and sharing suffering. The final life

world of lived time was experienced by family members as pausing; an opportunity to take a break from the experience of having a loved one as a patient in the ICU. Findings suggest support groups can be a useful intervention for ICU nurses to help families gain strength to endure the stressful experience of having a family member hospitalized in the ICU.

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CHAPTER I

Introduction

Hospital systems began creating intensive care units (ICUs) in the 1950s when technological advances such as the ventilator and defibrillator emerged with a need for closer monitoring of postoperative patients (Hilberman, 1975). Since their inception, ICUs have been primarily patient centered, enforcing strict visitation limits on family and allowing limited care for family members of the individual experiencing the illness (Molter, 1979). Yet, the family experience with an adult family member's critical illness is filled with emotional distress, suffering, and difficulty coping (Davidson, 2009; Eggenberger & Nelms, 2007a; Hupcey, 1999). Currently, the practice of ICU nurses are striving not only to provide care to critical patients but also to care for and support the patients' family members. This paper presents a background of family care in the ICU, the family support group as an intervention to sustain family members of patients in the ICU, and the results of a qualitative pilot study describing the experience of family members participating in an ICU support group.

Background

Research focused on families of patients in the ICU began in the 1970s (Verhaeghe, Defloor, Van Zuuren, Duijnstee, & Grypdonck, 2005). In 1975, Hampe (as cited in Verhaeghe et al., 2005) was one of the first researchers to investigate family needs of male ICU patients by interviewing their wives. Findings suggested families'

needs were to be near the patient, to be able to help him, and to know he is as physically and emotionally comfortable as possible (Verhaeghe et al., 2005). The personal needs of the wives in this sample included the need for information, to communicate feelings, to receive comfort and support of their family, and to be accepted and supported by health-care professionals (Verhaeghe et al., 2005).

In 1979, Molter developed the Critical Care Family Needs Inventory in order to better assess the needs of family members in the ICU. The needs inventory included 45 need statements constructed from the results of interviews with family members. The highest ranked needs of family members included: to feel there is hope, to feel that hospital personnel care about the patient, to have the waiting room near the patient, and to be notified of changes in the condition of the patient (Molter, 1979, p. 334). The Critical Care Family Needs Inventory has been used in multiple international studies to continue to assess the needs of families. The needs for information, proximity, and hope continue to be highly ranked by family members (Verhaeghe et al., 2005). Personal needs of family members are least ranked (Dyer, 1991; Yang, 2008), while family members "give absolute priority to everything that concerns the patient" (Verhaeghe et al., 2005, p. 505).

A significant result of family needs research is that more ICUs are adopting flexible visiting hours. In the 1960s, "visitation was restricted because little was understood about the impact on the patient or the family, including children" (Cullen, Titler, & Drahozal, 2003, p. 62). The perceived barriers of open visitation are that it is too tiring for the patient, may increase the patients' heart rate and blood pressure,

impedes the delivery of care, or exhausts family members (Sims & Miracle, 2006). This thinking has been discredited by research. Findings suggest flexible visitation can help facilitate communication with family members and support their need for information (Sims & Miracle, 2006).

Only a few interventions related to family have been studied and have influenced the practice of ICU nurses. One intervention is targeted toward family assessment, which has been presented as an interview with patients and family members to better identify needs (Leahey & Svavarsdottir, 2009). Another method of family assessment is a Family Assessment Form (Blanchard & Alavi, 2008). This is a short form completed by people visiting the unit to identify their connection to the patient providing an opportunity for nurses to learn about the patient and their family (Blanchard & Alavi, 2008). Mitchell, Chaboyer, Burmeister, and Foster (2009) tested the involvement of family in the care of the patient. By including family members in massage, baths, and eye care "family members perceived more respect, collaboration, and support than a group of family members who were not included" (Mitchell et al., 2009, p. 550).

Diaries are an additional intervention to support family members coping with a critical illness. "The diary is a notebook left at the patient's bedside, in which health professionals and relatives describe the events as they take place and the patient's reactions to them" (Roulin, Hurst, & Spirig, 2007, p. 893). When the content of the diaries were reviewed, Roulin et al. (2007) found the diaries to provide a narration of the illness and treatment, patient's activities and behavior, narration of events occurring at home, expression of feelings by family, encouragement, and well-wishes. The diaries

were dated and signed communicating the presence of those who were with the patient during the illness (Roulin et al., 2007).

Research has also identified that nurses are the individuals who most often have the potential to meet the needs of family members (Molter, 1979; Stayt, 2007; Verhaeghe et al., 2005). Nurses may be unaware of the needs of family members or their impact on the critical care experience of family members. In a study comparing nurses' perceptions of family needs to family perceptions of needs, Kinrade, Jackson, and Tomnay (2009) found nurses often underestimated the needs of family members. Verhaeghe et al. (2005) reported nurses often fail to correctly assess the needs of family members and that the amount of nursing experience "correlates negatively with the ability to assess the needs of family members" (p. 506). Hupcey (1999) found family's relatives view their role with the patient as much more important than the nurses' view of the family's role. In interviews with nurses, Stayt (2007) found significant conflict for nurses between caring for the patient and caring for the family members. Stayt reported nurses experienced difficulty finding a balance between emotionally investing themselves in their patients and families, while also trying to maintain a professional role. In addition, Stayt reported that nurses "frequently expressed that they were fearful of saying the wrong thing or being unable to answer families' questions adequately" (p. 626). Davidson (2010) also reported that nurses provided accounts that feelings "of not knowing how or not being able to meet families' needs increased daily stress on the job" (p. 35).

Problem Statement

Few interventions for nurses to care for family members of ICU patients have been researched. The use of family support groups as a nursing intervention aimed at caring for family members of ICU patients is the focus of this study. Support groups have been used for patients and families in multiple patient care areas including mental health, oncology, and palliative care (Butow et al., 2007; Chien & Norman, 2009; Henriksson & Andershed, 2007; Henriksson, Benzein, Ternestedt, & Andershed, 2011). However, research is inconsistent regarding the experience of family members' participation and perceived value of a support group in the ICU setting.

Research Question

The research question addressed in this study is: What is the experience of family members participating in an ICU support group while their family member is hospitalized with a critical illness?

Purpose

Three primary purposes of this study include:

1. Describe the experience of family members participating in an ICU support group.

2. Identify both positive and negative responses of participating in an ICU support group as described by family members.

3. Explore the use of support groups as an intervention for families of ICU patients.

Significance

More interventions are needed for nurses caring for family members of patients in the ICU. The experience of having a family member as a patient in the ICU can be traumatic. A review of research completed by Davidson (2010) found that "between 33% and 80% of family members of ICU patients experience long lasting (> 90 days) anxiety, depression, and symptoms of post-traumatic stress disorder" (p. 35). A nurse-led support group may be a cost effective intervention for family members. A support group can help meet the needs of family members, including need for information, assurance, and support. Emotional support for family members is essential and family support groups may fulfill this need. Support groups are relatively common throughout health care, yet limited research is available to establish their effectiveness with family members of ICU patients. Research related to family support groups contributes to the knowledge base of family care in the ICU and nursing practice in this setting.

Assumptions

These assumptions were made prior to the implementation of this research.

1. Individual and family health are linked.

2. The family experience when a patient is hospitalized with a critical illness is filled with distress, therefore family members will need extra support.

3. Providing additional support to one member of a family can impact the entire family.

4. A support group may provide added support to families, supplementing family care provided by the nurse assigned to care for the patient.

5. Bringing together families with similar experiences is helpful to participants.

Definition of Terms

Family – "a group of individuals who are bound by strong emotional ties, a sense of belonging, and a passion for being involved in one another's lives" (Wright & Bell, 2009, p. 46); "individuals who have a significant relationship with the patient" (Gavaghan & Carroll, 2002, p. 66).

Intervention – "any treatment based upon clinical judgment and knowledge that a nurse performs to enhance patient/client outcomes" (McCloskey & Bulechek, 2000, p. 3).

Support Group – an open group meeting once a week to provide information and emotional support for family members of patient in the ICU, "mutual support and sharing of experiences among people who live similar situations, with the potential to prevent the development of misguided coping patterns and encourage healthy behaviors" (Oliveira, Medeiros, Brasil, Oliveira, & Munari, 2008, p. 433).

Theoretical Framework

The theoretical framework for this study combined the theory of social support (Schaffer, 2009) and the Calgary Family Assessment and Intervention Model (Wright & Leahey, 2005). The theory of social support stated that "through communication with clients and their family members, nurses can intervene to promote strength or strengthen social support" (Schaffer, 2009, p. 164). Social support is necessary for coping with life's stressors (Schaffer, 2009). This theory further delineates social support into emotional, informational, instrumental, and appraisal support (Schaffer, 2009). Emotional support is the experience of feeling liked, respected, or loved (Schaffer, 2009).

Informational support involves providing information (Schaffer, 2009). When providing

aid or service, one is providing instrumental support (Schaffer, 2009). Appraisal support

affirms one's actions or statements (Schaffer, 2009). ICU support groups may provide

these four types of support by respecting participants, allowing for expression of feelings,

providing a service (i.e., arranging a needed care conference or placing a social work

consult), answering questions and offering information, and affirming for family

members they are not alone because family members of other patients may share their

experiences.

Perception and timing are additional important factors to social support theory.

The effectiveness of social support is enhanced when both the provider and the recipient

recognize a need (Schaffer, 2009). "Research data suggest that the perception of the

availability of support is more important for health and well-being than the actual

receiving of support" (Cohen, Gottleib, & Underwood, 2001, as cited in Schaffer, 2009,

p. 168). Timing is also an important factor because the individual's need for support

changes over time (Schaffer, 2009). For example, individuals may need more emotional

support at the time of a family member's admission to the ICU. As they begin to face

their loved one's crisis, they may require informational support.

The Calgary Family Assessment and Intervention Model is an "organizing

framework for conceptualizing the relationship between families and nurses that helps

change to occur and healing to begin" (Wright & Leahey, 2005, p. 23). The assessment

model has three major categories: structural, developmental, and functional (Wright &

Leahey, 2005). Structural assessment involves who is in the family and can include a

genogram and ecomap (Wright & Leahey, 2005). Developmental assessment addresses

the "unique path of the family" (Wright & Leahey, 2005, p. 92) including both

predictable and unpredictable events (Wright & Leahey, 2005). "How individuals

actually behave in relation to one another" is a component of functional assessment

(Wright & Leahey, 2005, p. 123).

Functional assessment is further bracketed into instrumental assessment and

expressive assessment. Instrumental assessment considers routine activities such as

eating, sleeping, meal preparation, and daily health care activities (Wright & Leahey,

2005). Expressive assessment includes nine categories: emotional communication,

verbal communication, nonverbal communication, circular communication, problem

solving, roles, influence and power, beliefs, and alliances and coalitions (Wright &

Leahey, 2005). Wright and Leahey (2005) add that "if a family is not coping well with

instrumental issues, expressive issues almost always exist" (p. 125).

The intervention model serves as a companion to the assessment model. This is a

"strengths based, resiliency oriented model" (Wrighty & Leahey, 2005, p. 153). The

model focuses on effective family functioning in three domains: cognitive, affective, and

behavioral (Wright & Leahey, 2005). Interventions are designed to promote, improve, or

sustain functioning in these domains (Wright & Leahey, 2005). This model also believed

that change in one domain affects the other domains (Wright & Leahey, 2005). Wright

and Leahey (2005) believed nurses can only "offer interventions to families, not instruct,

direct, demand, or insist on a particular kind of change" (p. 154). Providing

commendations, offering information, validating or normalizing emotional response,

encouraging the telling of illness narratives, drawing forth family support, and

encouraging respite are interventions supported by this model (Wright & Leahey, 2005).

Through discussions with families during support group sessions both elements of

family assessment and family interventions can be accomplished. Structural,

developmental, and functional assessments can be made when families share their stories

and discuss their experiences. In addition, the nurse or nurses facilitating the support

group can provide interventions as suggested by Wright and Leahey (2005).

Summary

Experiencing a family member as a patient with a critical illness can be

distressing (Davidson, 2009; Eggenberger & Nelms, 2007a; Hupcey, 1999). Research

has identified the significant needs of family members of ICU patients. These include a

need for proximity, assurance, and information (Verhaeghe et al., 2005). The support

group is an intervention for nurses to use that can help provide information and foster

hope for family members. A support group can promote social support for families.

Within the support groups, the interventions suggested by Wright and Leahey (2005) can

be utilized.

CHAPTER II

Review of Literature

An admission to the ICU hospital setting creates a stressful experience for both patient and family (Eggenberger & Nelms, 2007a; Hughes, Bryan, & Robbins, 2005; Paul & Rattray, 2008). Family members may experience significant anxiety and depression (Davidson, 2010). In addition, family members face uncertainty about the ICU environment and the prognosis of their loved one that can affect their psychological well-being (Paul & Rattray, 2008). Research has identified the common needs of family members to be a need for information, proximity, and hope (Verhaeghe et al., 2005). One intervention that may target the family members' need for information and hope, while also providing emotional support, is an ICU family support group. This chapter includes a review of literature that introduces research regarding the experiences of family members with a loved one hospitalized in the ICU and the use of a family support group as a nursing intervention.

Search Methods

An extensive literature review was completed from February 2010 to October 2011. The search engines Academic Search Premier and CINAHL were used and the search terms included: *intensive care unit, critical care unit, family nursing, intervention, family integration, communication, nursing, nursing actions, family, strategies, support group, and family group* in varying combinations. Articles were limited to adult ICUs

excluding pediatric and neonatal ICUs. Articles must have been peer reviewed and printed in English.

A total of 85 articles were reviewed and divided into groups. Seventeen articles described support groups. Supportive articles included 47 articles discussing family needs, family experiences, and nurses' experiences. Ten intervention studies were identified. Five articles were background articles pertaining to visitation and family presence during cardiopulmonary resuscitation. The remaining six articles were assigned to the category of other and primarily discussed the ICU environment. This chapter focuses on the family experience supportive articles and support group articles.

Family Experience

Of the 47 support articles reviewed, 11 discussed the experience of family members with a loved one as a patient in the ICU. Research has confirmed that family members of ICU patients experience a significant amount of emotional distress (Chui & Chan, 2007; Eggenberger & Nelms, 2007a; Halm et al., 1993; Hughes et al., 2005; Johnson, et al., 1995; Kleiber et al., 1994; McAdam, Dracup, White, Fontaine, & Puntillo, 2010; Paul & Rattray, 2008; Paparrigopoulos, et al., 2006; Van Horn & Tesh, 2000). A family member's admission to the ICU, whether planned or unplanned, often with a life-threatening condition, leaves family members facing potential loss (McAdam et al., 2010). The following 11 articles discuss the experience of family members and are reviewed according to their method of investigation.

Quantitative

Five articles gathered quantitative data to evaluate the family experience of having a loved one in the ICU. Measures included the Iowa ICU Family Scale, Edmonton Symptom Assessment Scale-Revised, Impact of Event Scale, Impact of Event Scale Revised, Hospital Anxiety and Depression Scale, Center for Epidemiological Studies Depression Scale, and Spielberger's State Trait Anxiety Scale.

Van Horn and Tesh (2000) and Halm et al. (1993) used the Iowa ICU Family Scale to calculate stress response scores. Both studies presented statistically significant elevated stress response scores. Van Horn and Tesh determined women have higher stress response scores than men. Van Horn and Tesh reported increased stress response scores as length of stay increased, while Halm et al. found stress response scores to be higher at the beginning of the hospitalization.

Van Horn and Tesh (2000) and Halm et al. (1993) identified an increase in unhealthy habits of family members. Both studies reported changes in eating habits, with Halm et al. reporting an increased consumption of junk food and fast food. Halm et al. also reported families experienced an increased use of cigarettes, alcohol, and over the counter and prescription drugs. Both studies reported that family members slept less hours and experienced a poorer quality of sleep. In addition, increases in waiting, talking, praying, and visiting the patient were reported by both studies. McAdam et al. (2010) used the Edmonton Symptom Assessment Scale-Revised to describe the symptom experiences of family members. "Greater than 90% of family members reported being

tired, anxious, sad, and scared, as well as having a poor appetite and overall poor well-being" (McAdam et al., 2010, p. 1080).

Multiple tools have been used to measure anxiety and depression among family members of ICU patients. Using the Impact of Event Scale-Revised, McAdam et al. (2010) found 42 of 74 (56.8%) family members had a score greater than or equal to 1.5, indicating that they had a significant risk of developing post-traumatic stress disorder (PTSD) symptoms. Paparrigopoulos et al. (2006) found 26 of 32 (81%) family members scored greater than 30 on the Impact of Event Scale, indicating symptoms of PTSD. Chui and Chan (2007) found 94 of 133 (70.7%) family members experienced a high level of stress (scores greater than 20) using the same scale. These three studies also found that women experienced higher degrees of stress than men (Chui & Chan, 2007; McAdam et al., 2010; Paparrigopoulos et al., 2006).

Using the Hospital Anxiety and Depression Scale, McAdam et al. (2010) found overall levels of family members' anxiety and depression to be moderate to high. Paparrigopoulos et al. (2006) found severe depression among family members at initial assessment using the Center for Epidemiological Studies Depression Scale and Spielberger's State Trait Anxiety Inventory. These symptoms were found to be significantly decreased at second assessment (Paparrigopoulos et al., 2006). Women were additionally found to exhibit higher levels of distress and more persisting symptoms than men (Paparrigopoulos et al., 2006). In a review of literature, Paul and Rattray (2008) noted that "during the early ICU period, moderate to high levels of anxiety, depressive symptoms, and posttraumatic stress are exhibited, predominantly in women

and spouses" (p. 284). Paul and Rattray reported that these symptoms may or may not decrease over time, with some relatives facing psychological effects up to 2 years after hospital discharge.

These quantitative studies confirm that family members experienced excessive amounts of stress, anxiety, and depression. In addition, the research found women experience higher amounts of symptom burden than men. Qualitative studies may be helpful to further explain the phenomenon of a family experience with an adult family member hospitalized in the ICU.

Qualitative

Five qualitative studies were found that sought to describe the family experience. Of the five studies, three conducted interviews (Dreyer & Nortvedt, 2008; Eggenberger & Nelms, 2007a; Hughes et al., 2005), one used an open-ended question on the Iowa ICU Family Scale (Johnson et al., 1995), and the last study used daily logs of feelings completed by 52 family members (Kleiber et al., 1994). Reviewing these studies, four common themes emerged: emotional response, uncertainty, family unity, and information.

The emotional response of having a family member in the ICU was noted in all five studies. Kleiber et al. (1994) reported that family members experience a range of negative emotions including fear, anger, hate, sadness, exhaustion, and fatigue. In addition, family members note feelings of relief and happiness as the patient starts to improve (Kleiber et al., 1994). A wide variety of emotions were reported by Johnson et al. (1995), including feelings of being alone, sympathy, guilt, worry, anger, happiness,

withdrawing, need to be strong, irritable, depressed, grateful, and hopeful. A range of emotions from fear and shock to frustration and guilt were reported by Hughes et al. (2005). Dryer and Nortvedt (2008) found families reported "rapid changes in feelings" (p. 553). Eggenberger and Nelms (2007a) reported families being "engulfed in a gamut of emotions, worry, anxiety, guilt, frustration, loneliness, discouragement, anger, in addition to sadness and fear" (p. 1624). These studies underline the strong emotional reactions families experience when a loved one is admitted to the ICU.

Uncertainty was another common reaction families experienced. Eggenberger and Nelms (2007a) reported "families' time was constantly filled with uncertainty and unknowing" (p. 1624). The uncertainty was described as the main reason for emotional imbalance by Dreyer and Nortvedt (2008). Feelings of uncertainty were reported by Johnson et al. (1995) and Kleiber et al. (1994). Kleiber et al. additionally noted that "the unknown was specified as the root of concern by some of the subjects" (p. 72).

Family members also experienced an act of family unity. Families reported an increase in responsibilities and change in roles to meet physical tasks and emotional needs as the result of an absent family member (Johnson et al., 1995). Kleiber et al. (1994) found individuals reported an appreciation of family in their daily logs. Eggenberger and Nelms (2007a) reported "families also spoke of their appreciation for their family togetherness and expressed intensified family connections and communications" (p. 1623). However, Eggenberger and Nelms also noted that some families can experience conflict as a result of differing views regarding treatments.

The emotional responses of families have an impact on the amount of information they are able to seek, receive, and absorb. Hughes et al. (2005) found the "first 24-48 hours appears to be the critical period wherein relatives absorbed very little information and emotions were at the forefront" (p. 26). Dreyer and Nortvedt (2008) reported that during the first hours to days of a patient's admission to the ICU, families reported "they knew they had been given information, but could not properly remember the content" (p. 553). Family members also reported they often had to actively seek the information and experienced a "lack of consensus between different members of the staff" (Dreyer & Nortvedt, 2008, p. 554).

Family members experience the ICU with varied emotional reactions and heightened uncertainty. These reactions lead to a distressing experience. Often, family members are able to look to each other for support. However, ICU staff needs interventions that will help families cope with these emotional reactions.

Support Groups

The initial work of ICU family research stated, "since many relatives have similar needs, the use of a group process to deal with them should be investigated" (Molter, 1979, p. 339). Halm et al. (1993) suggested support groups as a strategy to meet family needs in the ICU. This review of literature presents findings related to the use of family support groups in health care followed by studies of family support group use in the ICU.

Support Groups in Health Care

Five studies described the use of family support groups in the health care areas of mental health, palliative care, and families of those with a disability. Chien, Chan,

Morrissey, and Thompson (2005) found that support groups for families of schizophrenia patients demonstrated significant improvements on family's and patients' level of functioning. In a literature review, Chien and Norman (2009) found there is "consistent evidence of the short-term positive effects of mutual support groups on the physical and psychosocial health conditions of patients with schizophrenia and other psychotic disorders and their families" (p. 1621). Chien and Norman reported the benefits of group participation to include increased knowledge about the illness and treatment, reduced burden and distress, enhanced coping, and enhanced social support. Through research on support group use for family caregivers of someone with a disability, Munn-Giddings and McVicar (2006) found that family members reported personal gains of empathy, emotional coping, experiential knowledge, practical information, and peer support.

In a study on support groups for families of palliative care patients, Henriksson and Andershed (2007) reports relatives of terminally ill patients benefitted from the support group. Benefits of the support group included relief in their day-to-day lives, an opportunity for rest and exchanging of experiences, and increased insight and understanding (Henriksson & Andershed, 2007). In 2011, Henriksson et al. again found a palliative care support group as positive experience for family members, covering topics of interest, meeting needs of information, practical care, emotional support, and assurance of quality patient care for family members, while also reflecting on their lives with a severely ill family member. The support group was described as an effective intervention to initiate contact and support family members (Henriksson et al., 2011).

Support Groups in ICU

Research focused on the use of family support groups in ICU is limited with only

four studies found for this literature review. The studies often do not yield significant

quantitative differences. Halm (1990) found no significant differences between support

groups and control groups on a state trait anxiety inventory at pre- and post-test.

However, support group participants did experience a significant reduction in state

anxiety scores between pre- and post-test. The group facilitator identified themes of

support groups to include: satisfaction with nursing and medical care, fear of the

unknown, coping responses, and acceptance of critical illness (Halm, 1990). Halm

recommended analyzing qualitative data to understand the benefits of support groups that

may not be represented in quantitative studies. Halm stated that "the family members

perceived many benefits of the group milieu such as sharing with other people in similar

situations, instilling hope, reducing anxiety, and learning new coping mechanisms" (p.

70).

Sabo et al. (1989) found no significant change in stress levels, feelings of hope,

and social support between control and support groups. Sabo et al. reported challenges

with support group attendance, attributing this to a felt stigma associated with group

therapy, location of group being a distance from the ICUs, and the timing of the group

sessions was not necessarily consistent with times of family crisis. However, family

members who attended reported they would attend again (Sabo et al., 1989).

Daly, Kleinpell, Lawinger, and Casey (1994) found no significant difference

between intervention group and control group using the Critical Care Family Needs

Inventory. Support group participants reported more of their needs being met, although it was not significant (Daly et al., 1994). Daly et al. also noted that small sample sizes (20 intervention participants, 20 control group participants) may have contributed to the nonsignificant results. In addition, of those who attended the support group, "all rated the meetings as helpful" (Daly et al., 1994, p. 419).

An additional element to support groups is provided by Sacco, Stapleton, and Ingersoll (2009) who included family members of former ICU patients. Sacco et al.'s findings suggest that "support groups can increase communication about what to expect during and after a patient's ICU stay and provide a mechanism for patients' families to discuss the families' concerns with others who have had similar experiences" (p. 44).

Gap in the Research

Additional research is needed to fully explore the use of support groups in the ICU. No qualitative studies were found that address family support group use in the ICU use and the experience of family members participating in an ICU family support group.

Summary

Families of ICU patients experience a variety of emotional reactions, heightened uncertainty, a reliance on each other, and need for information (Dreyer & Nortvedt, 2008; Eggenberger & Nelms, 2007a; Hughes et al., 2005). Support groups have been proposed as a method to help meet the needs of family members while also providing emotional support. Support groups have been shown to be helpful for families of mental health and palliative care patients (Chien et al., 2005; Chien & Norman, 2009; Henriksson &

Andershed, 2007). There is a need to more fully explore the potential for this intervention to provide nursing care of families of critically ill patients.

CHAPTER III

Methodology

The goal of this study was to describe the experience of family members participating in an ICU support group. A review of literature found support groups to be beneficial to families of patients hospitalized in mental health and palliative care (Chien et al., 2005; Chien & Norman, 2009; Henriksson & Andershed, 2007). Literature suggests that support groups may also be useful for families of ICU patients (Halm, 1990; Molter 1979). This chapter describes the methodology used for this research study including design, setting, sample, protection of human subjects, data collection, data analysis, rigor, and limitations.

Design

Based on the review of literature, a qualitative approach was selected to collect the desired information. A qualitative approach, using hermeneutic phenomenology, allows for a deeper description of the experience and was therefore used to describe the experience of participating in an ICU support group. Van Manen (1990) described phenomenology as "the study of lived or existential meanings; it attempts to describe and interpret these meanings to a certain degree of depth and richness" (p. 11). In using this method, the emphasis is placed on the meaning of a lived experience (Van Manen, 1990). "The object of human science research is essentially a linguistic project: to make some aspect of our lived world, if our lived experience, reflectively understandable and

intelligible" (Van Manen, 1990, pp. 125-126). The primary goal of the study was to understand the lived experience of family members participating in an ICU support group.

Setting

This research study took place in a 21-bed ICU located in a 350-bed, level two, Midwestern hospital serving more than 200,000 patients each year. This is a general ICU admitting patients with medical, surgical, cardiac, and neurologic diagnoses. At this hospital weekly support groups were routinely held in a waiting room located close to the ICUs. Posters were displayed in the ICU waiting rooms inviting visitors to attend the support group sessions. In addition, prior to the start of a support group session family members on the ICU were invited to attend. Support groups were co-facilitated by a mental health clinical nurse specialist and an intensive care nurse. The mental health clinical nurse specialist was the primary leader with experience in psychiatric nursing and facilitating support groups. The intensive care nurse was a nurse on the unit who is available to provide information and answer questions specific to the ICU and the critical illnesses the family members face. Throughout data collection, the researcher served as the intensive care nurse dedicated to this usual intervention.

Sample

All family members of inpatients in the ICU at this hospital who have participated in an ICU support group were invited to participate in the study. For purposes of this study, family members are self-defined; family is who they say they are. Group participants were eligible if they were 18 years or older and able to speak and understand

English. Any vulnerable populations (i.e., decisionally impaired, elderly with dementia, minors, non-English speakers, pregnant women, and prisoners) were excluded from the study.

Protection of Human Subjects

Approval for this study was obtained from both Minnesota State University, Mankato's and the hospital's Institutional Review Boards (see Appendix A and Appendix B). Participants were informed of the purpose, procedure, potential risks, and benefits through an informational sheet and informed consent (see Appendix C and Appendix D). The voluntary nature of the study was explained in an addition to the measures to ensure confidentiality. Each participant was given a copy of the consent form (see Appendix D).

Only the researcher had access to the completed consent form and family contact information. Contact information was used only for the purpose of arranging participation in the study. The audiotaped interviews, transcripts, and background forms were coded excluding any participant information. All consents, tapes, and study documents were maintained by the researcher in a locked file cabinet. Due to potential discomfort or emotional distress when reflecting on a lived experience, participants were informed of their right not to answer a question or stop the interview at any time. Each participant completed the interview without a refusal to answer or skip a question and without emotional distress. The mental health clinical nurse specialist was available to follow up with any families if distress was identified or continued after the interview.

Data Collection

At the conclusion of each regularly scheduled ICU support group, participants received an informational sheet describing the purpose, procedure, risks, and benefits of the study (see Appendix C). Families who were interested in the study completed the contact information portion of the informational sheet and returned it to the researcher or later placed it in a pre-addressed envelope that was mailed to the researcher through intraoffice mail. The researcher then contacted the family to schedule a time to conduct the interview. Interviews were conducted at a time convenient for the family that was close to the time of transfer of their critically ill family member from the ICU. This was done to allow the families to participate in multiple support group sessions.

Interviews were conducted in a conference room located close to the ICU to maintain close proximity to their critically ill family member. Interviews were conducted individually or in family groups. Family members were encouraged to be interviewed together in order to bring forth the *family* experience of participating in an ICU support group. Informed consent was obtained and a copy given to the participants (see Appendix D). Participants then completed a family background form (see Appendix E). Each interview began with the opening statement, "tell me about your experience participating in an ICU family support group." Follow up questions were used to further explore their experience. The lived experience was the focus of the interview and emphasis was placed on eliciting their perceptions. Interviews were recorded and transcribed by a professional transcriptionist. Recruitment of participants continued until the researcher believed that saturation had been met. Burns and Grove (2009) stated,

"saturation of data occurs when additional sampling provides no new information, only redundancy of previously collected data" (p. 361). At the completion of five interviews, the researcher began to feel participants expressed reoccurring themes.

Data Analysis

The researcher listened to the audio tape of each interview in order to gain an understanding of the whole experience. The interviews were then listened to a second time with the life world themes identified by Van Manen (1990) of lived space, lived relation, lived body, and lived time in mind. Next, transcripts of the interviews were read word for word identifying words and phrases that reflected each life world theme. Van Manen's holistic approach to isolate a theme states to "attend to text as a whole and ask what sentious phrase may capture the fundamental meaning or main significance of this text as a whole?" (p. 93). A phrase or theme is then formulated to try and express that meaning. When reading transcripts, attention was paid to words, quotes, and feelings. With the life world themes in mind, the researcher reflected upon which statements fully depicted the life worlds of Van Manen? The words, phrases, quotes, and feelings of the four life worlds were then cross checked for duplication.

Theme words were then formulated to reflect the experience of participating in an ICU support group within Van Manen's (1990) four life worlds. Themes and subthemes were developed upon further reflection and dialogue with the research advisor who has experience in family practice and family research. Van Manen described a theme as "the experience of focus, of meaning, of point" (p. 87), "the sense we are able to make of something" (p. 87). Once themes were developed, the transcripts were analyzed line by

line, ensuring each element was included within the themes. The Merriam Webster

Dictionary (Mish, 2004) and Oxford College Dictionary (Pearsal, 2007) were used to

verify the meanings of the words used as themes. The theme words were also

investigated within the nursing literature to determine if the meanings of the theme words

used in this study matched the meanings currently being used in nursing. The theme

words were then presented to the mental health clinical nurse specialist facilitating the

ICU support groups to ensure representativeness.

Rigor

Burns and Grove (2009) described rigor as "striving for excellence in research

through the use of discipline, scrupulous adherence to detail, and strict accuracy" (p.

720). In qualitative research, rigor is associated with openness, relevance,

epistemological and methodological congruence, scrupulous adherence to a philosophical

perspective, thoroughness in collecting data, and consideration of all the data in the

analysis, and the researcher's self-understandings (Burns & Grove, 2009). The four

criteria of credibility, dependability, transferability, and confirmability are most

commonly used to evaluate qualitative research (Ryan, Coughlan, & Cronin, 2007).

Credibility refers to the "faithfulness to the description of the phenomenon in

question" (Ryan et al., 2007, p. 743). Throughout this study, the researcher worked to

immerse herself in the words of participants throughout the support groups, interviews,

and data analysis.

Dependability, also known as auditability, is demonstrated by a clear path of

research (Ryan et al., 2007). Each step of the research and decisions for them are clearly

documented. In order to develop themes, the researcher listened to the tapes of the

interviews with Van Manen's (1990) life world themes in mind. Words and phrases that reflected each theme were recorded. Transcripts were read as a whole, and then more specifically to determine words and phrases that reflected each life world. Themes and subthemes were developed within each life world. Journal and field notes taken during the 7 months of recruitment were also consulted during thematic development to help contribute to rigor.

Transferability, also known as fittingness, "refers to whether or not findings can be applied outside the context of the study" (Ryan et al., 2007, p. 743). Participant quotes are used to enhance the judgment of transferability.

Finally, confirmability establishes that findings are clearly representative of the data (Ryan et al., 2007). In this study, the transcripts were read and theme words approved by a doctorally prepared nursing advisor with extensive experience in qualitative family research. In addition, the mental health clinical nurse specialist reviewed the themes and subthemes and confirmed their representation of what she viewed within the family support group sessions.

Limitations

The limitations of this study include a small sample size limited to a specific ICU. Due to short ICU stays, support group sessions are composed of different participants each week, limiting the development of group cohesiveness. Of the small sample size, one interview was poorly recorded, which required the researcher to recall and document interview data. An additional limitation is that families who are more likely to seek support are more likely to participate in research. The researcher, who was present

during the support group sessions, conducted the interviews with families which may have influenced participant responses. The researcher was also a nurse working on the ICU and had cared for the critically ill family member of one participant. An additional limitation of the study is that it was conducted by a student researcher who is a novice in qualitative research.

Finally, although the researcher's intent was to interview family groups, this was only accomplished with one interview due to family member's availability. The time of day of the support group may have impacted this, as support group sessions were conducted in the afternoon and often only one family member was present. Other family members may have had other obligations. This may limit the full understanding of the whole family experience.

Summary

This chapter presented the methodology used for a qualitative study describing the experience of participating in an ICU support group. The concepts of design, setting, sample, protection of human subjects, data collection, and data analysis in relation to the study were reported. The researcher's demonstration of rigor and limitations of the study were also discussed.

CHAPTER IV

Analysis of Data

The goal of this study was to describe the experience of family members

participating in an ICU support group. Additional goals included identifying positive and

negative responses of participating in a support group and exploring the use of a support

group as an intervention for families of ICU patients. This study used Van Manen's

(1990) phenomenological research approach to interpret the lived experience of

participants. This chapter presents a description of the sample and a discussion of the

findings.

Description of Sample

This study explored the experiences of family members participating in an ICU

support group. Seven family members consented to participate in the research study.

One interview, family C, was conducted as a family group, while the other interviews

were conducted with individual family members who chose to participate in this research

study.

Participants completed a family background form, and this data is presented in

Table 1. The participants included six females and one male. The ages ranged from 36

to 62. The relationships of the participants to the patient include four daughters, one

grandson, one granddaughter-in-law, and one spouse. Diagnoses of the hospitalized

family member included peritoneal cancer, anoxic brain injury, heart failure and fall,

aspiration pneumonia, and stroke. The patient's stay in the ICU ranged from 1 to 12 days

at the time of the participant's interview. Three of the participants reported having a

family member in the ICU prior to this hospitalization, while four reported this as their

first encounter with the ICU. All participants denied any previous participation in a

support group.

Table 1

Demographic Profile of Participants

	Family A	Family B	Family C: Participant 1	Family C: Participant 2	Family C: Participant 3	Family D	Family E
Gender	F	F	F	F	M	F	F
Age	41	55	62	36	36	48	52
Education	College	College	HS	College	College	Graduate School	College
Relationship to ill family member	Daughter	Spouse	Daughter	Grand-daughter-in-law	Grandson	Daughter	Daughter
Religious	Catholic	Protestant	Catholic	Baptist	Atheist	Christian	Protestant
Ethnicity	White	White	White	White	White	African American	African American
Age of ill family member	68	55	88	88	88	84	84
Diagnosis of family member	Primary Peritoneal CA Stage 4	Anoxic Brain Injury	Heart Failure, Fall	Heart Failure, Fall	Heart Failure, Fall	Aspiration Pneumonia	Pneumonia,Stroke
Length of stay in ICU	7-8 Days	7-8 Days	1-2 Days	1-2 Days	1-2 Days	3-4 days	11-12 Days
Previous support group participation	No	No	No	No	No	No	No
Previous family member admission to ICU	No	Yes	No	Yes	No	Yes	No

Patterns, Themes, and Subthemes

This study used Van Manen's (1990) phenomenological research approach to interpret the lived experience of participants. A pattern, themes, and subthemes emerged from the data analysis. This section of the paper first discusses the overall pattern, followed by the themes and subthemes.

Overall Pattern: Gaining Strength

The overall pattern of Gaining Strength was used to describe the family experience of participating in an ICU support group. Merriam-Webster defines strength as "the quality of being strong, the ability to do or endure" (Mish, 2004, p. 708). For families, the support group provided an opportunity to gain strength when encountering the difficult experience of having a family member in the ICU. The remaining themes are addressed using Van Manen's (1990) four life worlds: lived space, lived relation, lived body, and lived time. The life world lived space was described as Trying to Understand, with subthemes of Exchanging Information, Decision Making, and Sense of Direction. Lived relation described participants' feelings of Being not Alone, with subthemes of Nursing Presence and Being Together. The life world of lived body was reflected as Comforting with subthemes of Sharing my Story, Sharing Suffering, and Experiencing Vulnerability with Others. Lived time was described as Pausing. Table 2 presents the findings according to Van Manen's life worlds.

Table 2

Patterns and Themes of Life World Existentials

_____

Pattern: Gaining Strength

Lived Space: Trying to Understand
        Exchanging Information
        Decision Making
        Sense of Direction

Lived Relation: Being Not Alone
        Nursing Presence
        Being Together

Lived Body: Comforting
        Sharing my Story
        Sharing Suffering
        Experiencing Vulnerability with Others

Lived Time: Pausing

_____

Lived space: trying to understand. According to Van Manen (1990), "the space

in which we find ourselves affects the way we feel" (p. 102). Lived space is an "inquiry

into the way we experience the affairs of our day to day existence" (Van Manen, 1990, p.

103). The participants in this study found their new physical space of being a family

member of a patient in the ICU impacted by their need to understand. As families

described their experience of trying to understand, three subthemes emerged: exchanging

information, decision making, and sense of direction. Quotes from participants will be

used to help illustrate the subthemes.

Exchanging innformation. As family members discussed their experience participating in an ICU support group, they reflected on the information they gained from participating. The Oxford College Dictionary defined information as "facts provided or learned about something or someone" (Pearsal, 2007, p. 695). The exchange of information was reflected both between participants and the facilitators but also between participants and other group members.

During support groups, facilitators were able to learn more about the needs of the family members and make appropriate recommendations. The following statements from families expressed their needs for support. Family B's husband was hospitalized in the ICU with an anoxic brain injury. During the support group sessions she spoke of her son, who was clinically depressed and having a difficult time facing his father's critical illness. Through the support group, she met the mental health clinical nurse specialist and felt comfortable calling her between sessions for support.

> There's information that can be gained. I even called (the facilitator) during the week to ask some questions about my other son, and so it was really helpful to be able to know a name of someone to help. (Family B)

Facing a new diagnosis of primary peritoneal cancer, Family A was feeling overwhelmed about how to help her mother. Participating in the support group helped her realize there were resources available to assist her. Consults were placed to social services to help with planning transitional care for her mother and a visit from the cancer support nurse in the hospital was arranged.

It was also nice to get more information from you as where else to look for support. I can get information from that, oh, there are cancer people right here that I could talk to or a social worker is here because I haven't talked to a social worker. I could also get some additional resources. (Family A)

During support group sessions, family members were often referred to social workers, child life services, cancer support nurses, or palliative care.

Information pertaining to the patient was also exchanged between facilitators and family members. Verhaeghe et al. (2005) stated family members "expect information about the daily care of the patient, about the reasons for particular treatments, about the ICU as such, the equipment and the various disciples present in the unit" (p. 503) from nursing staff. One participant reflected on the information she received that she was unable to obtain from the physician.

You all were actually there with information at hand, so anything I asked, you had an answer, right there to the point, and I felt that was very helpful because something I was uncomfortable asking the doctor, because I know he was kind of in a hurry, and I came in during the time he was talking and I want him to repeat everything all over again because I came in during that time. But to go back and get more clarification on the respiration, the whole respiratory thing, what is that? How long does he keep that in there? What's the duration? What gets taken out? Where do we go from there? So to get more clarity was beneficial to me. (Family D)

Family D's use of the words "respiratory thing" refers to her mother needing a ventilator. The researcher notes that explaining the ventilator was a frequent topic of support groups. Families had probably been informed about the ventilator before by both nursing staff and physicians, but the topic is so foreign, it requires repeating.

Participants also frequently exchanged information with each other. This family member shares how she received helpful information from another family member in a support group session.

It was very informative, the other person that was there, I thought she was helpful in explaining what she learned while she was going through ICU with her husband. And I felt the information that what she shared was very helpful because I didn't know any of that. (Family D)

Family members participating in support groups have spent different lengths of time in the ICU. Some have experienced previous admissions to the ICU while it may be a first time for others. Support group participants often exchanged information, with the facilitators being present to ensure the reliability of the information.

Decision making. The participants' need for information and trying to understand was also represented by participants who reported being in a state of decision making.

I think it's very beneficial to establish, for a hospital to have those types of support groups because people are in a state of decision making. (Family D)

Family members of ICU patients face many decisions from the care of the patient to their own personal care. One participant reflected on her decision to go home for a few hours leaving her husband in the ICU.

When I talked about that I would need to leave for a bit, and it felt horrible to me and she kind of paved the way for that to be an easy decision. (Family B)

Decisions regarding the care of the patient often have to be made without the patient's input. When patients are hospitalized in the ICU and under sedation and ventilation, they are unable to make care decisions for themselves. ICU physicians and nurses look to family members to make these decisions, sometimes between continuing or withdrawing life support. The following participant quote provides a family example of being in a state of decision making regarding treatment.

It's that time when every family has to go though, at some point in life, and it's one of those life moments that you have to make that decision of what's best.

(Family D)

Family members reflected on being in this state of decision making during ICU support group sessions. Through discussing this decision and exchanging information, participants recounted gaining a sense of direction.

Sense of direction. Families reported the support groups helped give them a sense of direction. Merriam-Webster (Mish, 2004) defines sense as "to be or become aware of" (p. 656) and direction as "management, guidance, the course or line along which something moves, lies, or points" (p. 203). The following quotes highlight families' descriptions of needing direction.

I'm just thinking about what comes next with my mom, what's the next

doctor, what's the next test, and not thinking about the supportive person.

(Family A)

She can't breathe on her own. The only other option is a tracheotomy and

that's ok. I can prepare for that. I feel at peace about the situation. (Family D)

I got some questions answered and that gave me some direction. (Family

B)

Family members often spoke in support groups about what the next step was. By

discussing treatments their family member was undergoing, participants could prepare for

the next steps. Participants reported the ICU support groups helped them gain a "sense"

of what to do next.

Families experienced trying to understand as a part of their lived space in an ICU

support group. Reflections of trying to understand were presented in subthemes of

exchanging information, state of decision making, and sense of direction.

Lived relation: being not alone. Van Manen (1990) described the life world of

lived relation as "the relation we maintain with others in the interpersonal space that we

share with them" (p. 104). Support groups are an interpersonal experience and families

reflected that by participating in a support group they gained realization that they are not

alone. This feeling of not being alone was demonstrated through nursing presence and

the being together with other families.

Nursing presence. Merriam-Webster (Mish, 2004) defines presence as "the fact

or condition of being present" (p. 568). Present is further defined as "being in view or at

hand" (Mish, 2004, p. 569). Participants reflected on the presence of the group facilitators as "being there for me."

I felt like talking during the support group, you were there for me versus me being the person that's there for everyone else. (Family A)

Somebody listening to me for no judgmental whatever, just to hear it and for me to not be giving. Just being heard. (Family A)

It did feel good that someone was caring enough to want to know how I was feeling. (Family B)

It's helpful because you're not just in the hospital in the room waiting for the patient to recuperate or just going through the motions, there is a staff person to talk to you and to help, answer your questions, and get you the information. There is someone there, so I was very pleased with the group. (Family D)

To have the staff there available to us, you know, and take the time to share with us and to say, 'you know, we're here for you.' (Family D)

Families members often assume the role of caregiver in the hospital, they viewed their position was to be there for the patient. Participants demonstrated that the support group gave them the realization that "someone was also there for me."

Being together. In addition to learning they were not alone, family members also realized other families were experiencing this too. Through ICU support group discussions, families reflected on shared emotions.

It's not just a chance to gain for yourself, that may be someone else is going to go through the same feelings. (Family B)

I thought she was a godsend because she was open and you know honest about what she's going through with she and her daughter. (Family D)

Support groups are an interpersonal experience and in participating, families experienced being together. Families share their experiences both past and present. For example, a support group participant's family member may be hospitalized with a stroke. Another participant in the support group may have had a family member experience a stroke in the past. Even though their family member is not currently hospitalized with a stroke, they share their experiences of what it was like and how their family recovered. The researcher recalls a support group session where a participant was in grief over the current physical limitations of their family member who had a stroke; a fellow participant related similar feelings and offered feelings of hope by explaining how their family member had recovered.

The life world of lived relation was reflected by participants in this study as the realization of not being alone through this experience. The presence they felt from the nurses facilitating the group and through being together with other families helped participants gain strength.

Lived body: comforting. Van Manen's (1990) life world of lived body states "we are always bodily in the world" (p. 102). We first meet people through the body (Van Manen, 1990). The body can both reveal and conceal (Van Manen, 1990). The participants in this study reported feeling comfort during the support group. When one participant was asked about her experience, her simple reply was "comforting" (Family C: Participant 2). Comfort is defined by Merriam-Webster as the "freedom from pain,

trouble, or anxiety; to give strength or hope to" (Mish, 2004, p. 143). Kolcaba's (2009) theory of comfort defines comfort as "the immediate experience of being strengthened by having needs for relief, ease, and transcendence met in four corners (physical, psychospiritual, sociocultural, and environmental); much more than the absence of pain or other physical discomforts" (p. 254). The lived body experience of comforting was reflected through sharing my story, sharing suffering, and experiencing vulnerability with others.

Sharing my story. Participants in this study gained comfort by sharing their story. Support groups begin with introductions. Family members introduce themselves and their relationship to their loved one in the ICU, and often recount the details of how they ended up in this situation. One participant gained comfort by telling the story for a different purpose during the support group.

> It was just nice to talk to somebody else. I repeat this story over and over with
> my family and they're just sucking from me. So, I felt like it was very nice to
> have somebody else that was hearing my story and having something to say back
> to me versus me being the giver. (Family A)

She considered herself the leader in her family and was continually serving as a resource. Telling her story in this role did not provide comfort. But being able to tell her story for the purpose of sharing it with a group and feeling the facilitators' genuine interest in her experience was comforting.

Participants also reported feeling comfortable talking to others about their story.

I guess I felt more relaxed because she was open and sharing hers (story), and I thought, 'well, we're here for this purpose to support one another so me opening up was very comfortable. (Family D)

They were open enough to talk to me. I was hearing about their family members, and felt comfortable telling them about mine. (Family E)

Whether they were telling their story for the first time with others or telling it for a different reason, family members found comfort in telling their story.

Sharing suffering. In addition to sharing their story, participants also reflected on sharing suffering amongst the support group members. Suffer is defined by the Oxford College Dictionary as "experience or being subjected to something bad or unpleasant" (Pearsal, 2007, p. 1371). The ICU experience can bring out feelings of stress, anxiety, and depression (Chui & Chan, 2007; Halm et al., 1993; McAdam et al., 2010; Paparrigopoulos et al., 2006; Van Horn & Tesh, 2000). Participants' experiences participating in an ICU support group involved the sharing of suffering.

I thought it was nice to hear somebody else with it. A lot of people are going through yucky stuff. (Family A)

The information the other lady shared was hard to handle. But I heard a lot of things she was saying and I listened about her experience, and it kind of opened up my mind. (Family D)

You felt bad for their situation too. You know, you're worried about your loved one and then you hear about theirs, and it's like, it kind of makes you feel

like, oh, they're going through the same thing too. So you kind of feel bad for

them also. (Family E)

Families share their stories and, in turn, share their suffering. The stories of

suffering may be hard for participants to hear, but it may also be comforting to know that

others are suffering in the same ways they are.

Experiencing vulnerability with others. Despite that families reported comfort,

there was also an aspect of vulnerability experienced by participants. The Oxford

College Dictionary defines vulnerable as "exposed to the possibility of being attached or

harmed, either physically or emotionally" (Pearsal, 2007, p. 1345). Participants in this

study described initial feelings of reluctance to share with others in this group setting.

I was halfway thinking how much am I going to want to talk and ask

questions? (Family A)

The thought of participating last week was a little difficult. When you

have things like this happen to you, you feel protective of your family members

and yourself because it's already too much to have. (Family B)

Support groups are important things, but they're hard. They're hard to let

yourself, most of us want to feel like we're invincible and that we can handle

everything, so to let down my guard enough to say, you know, I can be part of

something where we share and care about each other. (Family B)

Now, all of a sudden, you know, things are out of your hands and control.

 (Family D)

These experiences demonstrate a felt vulnerability by participants. Some family members felt vulnerability admitting they needed some support while others felt an initial vulnerability in sharing with others. Participants' experience of sharing my story, sharing suffering, and experiencing vulnerability led to an overall feeling of comfort in the life world lived body.

Lived time: pausing. The fourth and final life world described by Van Manen (1990) is lived time. Lived time is reflected by "subjective time as opposed to clock time" (Van Manen, 1990, p. 104). Lived time is how we experience time, "the time that appears to speed up when we enjoy ourselves, or slow down when we feel bored" (Van Manen, 1990, p. 104). Participants reported the support group as a break or pause from the passing of time in the ICU. Merriam-Webster defines pause as a "temporary stop; a period of inaction; to stop, rest, or linger for a time" (Mish, 2004, p. 529). Participants reported the support group provided the ability to reflect and pause.

It gave me a bit of a break, and then I can be there for my family again. (Family A)

It took your mind off your situation for a minute. And let you just let the other people share their stories and concerns. (Family E)

Gave me more time to process things and to think about it all. (Family D)

The life world of lived time is felt differently by each individual; some may see time flying by while others feel it standing still during the same experience. The participants in this study recounted the support group as a pause to rest, reflect and rejuvenate during their time in the ICU.

Summary

An analysis of the interviews with participants in an ICU family support group produced the findings of this study. Participants were asked to reflect on the lived experience of participating in an ICU support group. An overall pattern of gaining strength was revealed through the data analysis. The experiences are further described using Van Manen's four life worlds. The theme of trying to understand was used to describe the life world of lived space with subthemes of exchanging information, decision making, and sense of direction. Being not alone described the life world of lived relation with subthemes of nursing presence and being together. The life world of lived body was depicted as comforting with subthemes of sharing my story, sharing suffering, and experiencing vulnerability with others. Pausing illustrated the life world of lived time. Definitions of each theme were presented and participant quotes were given to support the selection of these themes and subthemes. The next chapter offers further discussion of this data analysis.

CHAPTER V

Summary, Discussion, Conclusions, and Recommendations

The purpose of this study was to describe the experience of family members participating in an ICU support group. Additional aims included distinguishing both positive and negative responses of participating in an ICU support group and exploring the effectiveness and possibilities of using support groups as an intervention for families. This chapter summarizes the research. A discussion of the findings and conclusions is presented, followed by implications for nursing practice, nursing research, and nursing education.

Summary

Both quantitative and qualitative studies reported families experiencing emotional distress including feelings of stress, anxiety, depression, shock, vulnerability, and fear (Chui & Chan, 2007; Eggenberger & Nelms, 2007a; Halm et al., 1993; Hughes et al., 2005; Johnson et al., 1995; Kleiber et al., 1994; McAdam et al., 2010; Paparrigopoulos et al., 2006; Paul & Rattray, 2008; Van Horn & Tesh, 2000). Only a few nursing interventions were studied that could influence practice such as: family assessment (Blanchard & Alavi, 2008; Leahey & Svavardottir, 2009) involving family in the care of the patient (Mitchell et al., 2009) and diaries (Roulin et al., 2007). Four studies were found that addressed the use of a support group for families of ICU patients; however, small sample sizes often contributed to nonsignificant results. The studies demonstrated

some positive findings regarding support group use including families reporting more of their needs being met (Daly et al., 1994), a reduction of anxiety scores (Halm, 1990), and increased communication between staff and family (Sacco et al., 2009).

A qualitative approach using hermeneutic phenomenology was needed to gain a deeper and more complete understanding of the intervention of a support group for family members of critically ill patients. The study took place at a Midwestern hospital with family members who attended an ICU support group being invited to participate in an interview that focused on reflecting on the lived experience of participating in an ICU support group. Data analysis was completed within the framework of Van Manen's (1990) life worlds. Themes of each life world were then formulated and verified by the nursing literature and experts in family nursing and support groups.

The overall pattern of gaining strength described the experience of participating in an ICU support group. The experiences are further described using Van Manen's (1990) four life worlds. The theme of trying to understand described the life world of lived space with subthemes of exchanging information, decision making, and sense of direction. Being not alone described the life world of lived relation with subthemes of nursing presence and being together. The life world of lived body was depicted as comforting with subthemes of sharing my story, sharing suffering, and experiencing vulnerability with others. Pausing illustrated the life world of lived time.

Discussion

The overall pattern of gaining strength was used to describe the experience of participating in an ICU support group. Families who participated in the support group

described their experience as a positive one that offered benefits of information and emotional support. In a qualitative study examining families caring for a stroke member at home, Niyomthai, Tonmukayakul, Wonghongkul, Panya, and Chanprasit (2010) reported that "family strength has been shown to be positively linked to families overcoming stressful life events" (p. 18). Moloney (1995) found women described "their inner strength as a quality that developed out of the experiences of their lives" (p. 106). Having a family member hospitalized in an ICU is a significant life experience. By being given an opportunity to reflect on this experience within a support group and a corresponding follow up interview, participants were able to see themselves gain strength. Through gaining understanding, learning they are not alone, and being comforted participants felt this inner strength.

Within Van Manen's (1990) life world of lived space, participants found themselves trying to understand this new space of being a family member of a patient in an ICU. Family members enter the ICU in a state of crisis, many experiencing shock and fear at their family member's admission (Eggenberger & Nelms, 2007a). The ICU is a technical environment with equipment very foreign to family members, and they found themselves trying to understand this new environment.

Information has been well-documented as a priority need of family members (Davidson, 2009; Henneman & Cardin, 2002; Molter, 1979; Verhaeghe et al., 2005). The family members in this study reported similar findings with the exchange of information contributing to a family member's ability to gain strength. In a study describing next-of-kin empowerment in the ICU, Whalin, Ek, and Idvall (2009) found continuous

information to be of "crucial importance" (p. 2584). In addition, Whalin et al. stated that "all informants wanted straightforward information about what was going on and what was expected to happen in the nearest future" (p. 2584). Family members described elements of finding strength through the ongoing exchange of information occurring during a support group.

The participants described themselves as being in a state of decision making. Davidson et al. (2007) found that patients and their families needed more decision-making help from the ICU team and recommended a shared decision-making model. A shared decision-making model encourages frequent communication between the ICU team and family members often in the form of family meetings (Davidson et al., 2007).

In a study addressing family meetings, McDonagh et al. (2004) found "ICU clinicians spent 70% of the time during family conferences speaking and 30% of the time listening to family members" (pp. 1486-1487). Their research findings indicated that allowing family members more time to talk and ICU clinicians dedicating more time to listen, family satisfaction improved (McDonagh et al., 2004). While a support group is not a replacement for family meetings, it does give family members another opportunity to talk with dedicated listeners. The group can allow more time for families to reflect on the decisions they face, ask new questions that have surfaced, and allow nurses to respond to unanswered questions.

In addition to being in a state of decision making, family members reported that support groups helped give them a sense of direction. Eggenberger and Nelms (2007a) found "the essence of family experience with an adult family member hospitalized in the

ICU is 'being family' through never ending waiting close to the ill loved one in a constant state of uncertainty about what may happen next" (p. 1625). Through the support group, participants could gain a sense of the next steps for the patient and themselves.

Davidson (2010) introduced facilitated sense-making as a middle range theory aimed at supporting family members of ICU patients. Facilitated sense-making assists families to make sense of what has happened and make sense of their new role as family member of a patient in the ICU to help decrease feelings of fear and helplessness (Davidson, 2010). Participants in this study reported using the support groups to gain a sense of direction. Exchanging information, state of decision making, and sense of direction described families' experience of trying to understand their lived space; together these subthemes provided increased knowledge and increased strength.

Van Manen (1990) described the second life world of lived relation as "the relation we maintain with others in the interpersonal space we share with them" (p. 104). Family members reported that by participating in an ICU support group they learned that they are not alone. This realization was reflected through the presence of nursing and being together with other families.

Participants reported that the support group provided them with the feeling that the facilitators of the group were there strictly for them, rather than caring for others. This can be described as nursing presence. Presence has been discussed by noted nursing theorists including Margaret Newman, Jean Watson, and Rosemarie Parse (Bunkers, 2012). Parse (as cited in Bunkers, 2010) stated that "true presence is a special way of

being with in which the nurse is attentive to moment to moment changes in meaning as she or he bears witness to the person's or group's own living of value priorities" (p. 13). Participants viewed it as their role to be present for their ill loved one, they reflected that is was helpful to also have a support person there for them. In a review on the theory of social support, Schaffer (2009) stated that perception of support may be as important as the actual receiving of support.

In addition to nursing presence, family members reflected that other families were also sharing this experience. In a support group setting, family members can share their similar experiences of having a loved one as a patient in an ICU. In work with ICU families, Molter (1979) recommended a group setting. "A group process allows for sharing and support among the relatives and also allows one staff member to work with several relatives" (Molter, 1979, p. 339). Nursing presence and being together helped participants realize they are not alone allowing overall feelings of gaining strength.

On reflections of their experience participating in an ICU support group, families reported they felt comforted by participating. This lived body life world (Van Manen, 1990) of comforting was reflected through sharing my story, sharing suffering, and experiencing vulnerability with others.

The experiences reported by family members demonstrated that family members want to tell their story. Eggenberger and Nelms (2007b) reported "family interview sessions revealed that families wanted to tell their story and have their voices heard" (p. 287). The experience of participating in an ICU support group involved families sharing their stories. For some this may have been the first time they were asked to share their

story; others found the group setting had a different purpose for sharing their story, and therefore felt comforted.

In addition to sharing of stories, families in the support group study also reflected that they shared suffering. The experience of having a loved one as a patient in the ICU is difficult and can bring feelings of stress, anxiety, and depression (Chui & Chan, 2007; Halm et al., 1993; McAdam et al., 2010; Paparrigopoulos et al., 2006; Van Horn & Tesh, 2000). As families shared their stories, they also shared their suffering. While hearing others stories may have been hard, families were comforted by this expression of feelings. Wright and Leahey (2005) noted that providing opportunities for family members to feel acknowledged and affirmed has tremendous healing potential.

Families also reported experiencing initial vulnerability when participating in an ICU support group. Families reported being overwhelmed with their situation and were unsure of how much they would want to share and ask questions in front of others. Previous ICU support group research does not address concerns of vulnerability from support group participants. This could be due to the use of quantitative methods that did not measure vulnerability. Sacco et al. (2009) reported that support group attendance may have been impacted by a stigma associated with group therapy. Although not expressed by participants, this stigma could have been associated with their feelings of vulnerability. While the participants expressed vulnerability, each reported feeling comfortable in the group once they began participating. Sharing my story, sharing suffering, and experiencing vulnerability with others were reflected as an overall theme

of being comforted in the life world of lived body (Van Manen, 1990) helping families

gain strength.

The final life world of lived time (Van Manen, 1990) was reflected by

participants' experiences of pausing. For participants, the support group gave them a

break from the stressful ICU experience. This type of pause gave them time to reflect on

their situation and the situation of others. Reasons for this finding could be that the focus

of the support group was always on the family members. While the story of their ill

loved one was shared, the discussion revolved on how the family member was feeling,

whether they were able to get sleep, eat properly, and find support from their other family

members. Family members of ICU patients may be so focused on their loved ones they

forget to take time for themselves. The support groups itself allowed family members to

pause and reflect on their situation. This pause allowed family members to gain strength

to continue to face this experience.

Conclusions

The experience of participating in an ICU support group contributed to an overall

pattern of gaining strength. This research supports previous findings that families are

trying to understand the experience of having a loved one in the ICU by needing

information, facing decisions, and gaining a sense of direction. For these participants, the

support group helped them with these needs. This study also confirmed previous

research that family members want to share their story. The sharing of stories also leads

to the sharing of suffering among group members, but participants found comfort in this

experience. The group offered further support to families through the presence of nurses

being strictly there for them and learning that other families had similar experiences. This research presents an aspect of vulnerability associated with support group participation. However, vulnerability was often reported as initial feelings that seemed to decrease as family members began participating in the group. An additional finding of this research is that family members viewed the support group as a time to pause and reflect on their experience, giving them a break from the stressful ICU environment to devote time for themselves and their needs.

The participants viewed the support group as helpful, indicating support groups could be a useful intervention for families of ICU patients. Positive responses of participating in an ICU experience supported families' need for information, state of decision making, and sense of direction. Participants experienced nursing presence and the being together with other families. Participants are given the opportunity to share their story and take a break. A possible negative response of the support group experience involves feelings of vulnerability. Sharing their suffering can be considered both a positive and negative response as it may be hard to hear other people's stories, but comfort was perceived as a result of this sharing.

Recommendations for Nursing Practice

Research findings from this study present an ICU family support group as a useful and positive intervention for families of ICU patients. A family support group can increase efficiency of nursing care by setting aside dedicated time to provide care for multiple family members. Alleviating some of the family distress and suffering and increasing their comfort through support groups have potential to provide quality and

efficient family nursing care in the ICU. The frequency and timing of the support group

is important to consider. Conducting the group sessions during shift report time when

families are often asked to leave the ICU to protect patient confidentiality offers families

a purposeful direction. Family members may initially experience vulnerability when

faced with sharing in a group or due to a perceived stigma associated with support

groups. Changing the name of the group from support group to ICU Family Meeting

may help reduce this stigma and lessen vulnerability.

Ongoing education should be provided to nurses in the ICU with a focus on the

family experience and evidence based nursing interventions to care for families. By

participating in an ICU family support group, nurses have the opportunity to gain

increased insight into the family experience. Nurses have a moral obligation to ease

suffering and distress of patients and families (Wright & Leahey, 2005). Furthermore, if

the family is viewed as a recipient of care and primary social support network for the

patient, then nursing should be dedicated to family nursing and providing interventions

such as support groups.

Recommendations for Nursing Research

Further studies to explore the use of ICU support groups with larger sample sizes

are needed. Randomized controlled trials could measure family satisfaction comparing

families who participated in a support group with families who did not. Additional

research questions addressing specific elements of support groups could include, What is

the most effective length of time and frequence for an ICU support group? What types of

facilitator(s) are best? What communication strategies are being implemented in a family

support group? Long-term studies may also be helpful exploring support group

reflections at 3 or 6 months after the experience. This could also help determine if

families need ongoing support, because research suggests families experience symptoms

of PTSD (Davidson, 2010; McAdam et al., 2010).

An additional qualitative study may target the staff response to the support group

and/or response to serving as the intensive care nurse facilitating the group. In this study,

the researcher gained an increased insight into the family experience, more so than is

gained by interacting with the family on the nursing unit. This insight may contribute to

increased understanding of the family experience and assist in a nurse's delivery of

family-centered care.

Recommendations for Nursing Education

The researcher recommends that nursing education include care of the family in

nursing curriculum. Henneman and Cardin (2002) stated "family members are now

active participants in planning the care of their loved ones" (p. 12). This is not only true

in the ICU but within all areas of health care. Nursing students need experience

communicating with and caring for families. Support groups are used throughout many

areas of health care and nursing students can be introduced to the elements of a group and

how it is used as a nursing intervention.

Summary

The experience of participating in an ICU support group was described by the

overall pattern of gaining strength. Families in this study found the experience

characterized further by exchanging information, state of decision making, sense of

direction, nursing presence, being together, sharing my story, sharing suffering, experiencing vulnerability with others, and pausing. These experiences indicate that an ICU support group can be a useful intervention to contribute to the overall goal of family-centered care.

Families of patients hospitalized in the ICU experience distress and suffering during a family member's critical illness; yet, families are expected to be the primary social network of the patient. Nurses have a moral obligation to support and comfort family members during a critical illness to maintain family health. Caring for both patients and families is essential to family nursing practice during a critical illness experience and family support groups may be a family nursing intervention that advances practice in that direction.

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APPENDICES

APPENDIX A

IRB APPROVAL LETTER FROM

MINNESOTA STATE UNIVERSITY, MANKATO

MINNESOTA STATE
UNIVERSITY
MANKATO

April 15, 2011

Dr. Sandra Eggenberger
School of Nursing
360 Wissink Hall
Minnesota State University, Mankato
Mankato, MN 56001

Rebecca Scharpe
4147 Nokomis Ave
Minneapolis, MN 55406

Dear Sandra and Rebecca:

Re: IRB Proposal, Log #3824 entitled *"The Family Experience of Participating in an ICU Support Group"*

Your IRB Proposal has been approved as of April 15, 2011. On behalf of the Institutional Review Board I wish you success with your study. Remember that you must seek approval for any changes in your study, its design, funding source, consent process, or any part of the study that may affect participants in the study. Should any of the participants in your study suffer a research-related injury or other harmful outcome, you are required to report them to the IRB as soon as possible.

The approval of your study is for one calendar year from the approval date. When you complete your data collection, or should you discontinue your study, you must notify the IRB. Please include your log number with any correspondence with the IRB.

This approval is considered final when the full IRB approves the monthly decisions and active log. The IRB reserves the right to review each study as part of its continuing review process. Continuing reviews are usually scheduled. However, under some conditions the IRB may choose not to announce a continuing review.

Sincerely,

Patricia Hargrove

Patricia M. Hargrove, Ph.D.
IRB Coordinator
CC: File

APPENDIX B

IRB APPROVAL LETTER

FROM HOSPITAL

IRB Study Approved: 3324-3E NEW, Scharpe, Rebecca

allina-noreply@keyusa.com
Sent: Thursday, April 07, 2011 5:37 AM
To: Scharpe, Rebecca M

IRB has approved the study with the following details:

Study ID: 3324-3E
Study Title: The Family Experience of Participating in an ICU Support Group
Principal Investigator: Scharpe, Rebecca
Review Type: EXPEDITED
Approval Date: April 07, 2011
Form: NEW

The form submitted for the protocol referenced above has received IRB approval. Please log in to https://allina.keyusa.net to view the details of this approval.

Please inform the IRB immediately of any changes or modifications to the protocol, consent form, or supporting documents prior to initiation. This requirement includes protocol amendments, changes in the number of participants, etc. In addition, all subjects enrolled must fulfill all inclusion/exclusion criteria; any exceptions must have prior approval from the IRB. You must also notify the IRB immediately of the early removal of a participant (for any reason), if any participants experience serious adverse events, or of events that occur at a frequency or intensity greater than described in the approved consent form.

It is your responsibility to submit an annual Continuing Review Form to this office. Your study must be renewed on or before March 21, 2012. If your study has been completed or terminated prior to that date, please submit a final report of your project.

If you have any questions or concerns, please call the IRB administrative office at (612) 262-4920.

APPENDIX C

INFORMATION SHEET

Research Study: The family experience of participating in an ICU support group.

You are invited to participate in a research study conducted by Rebecca Scharpe, RN, graduate student at Minnesota State University, Mankato. Participation in this research study is completely voluntary. You are a potential subject if you have participated in one ICU Support Group Session at United Hospital.

Purpose of the Study:
The purpose of the study is to describe the experience of participating in an ICU support group. Additional purposes include: distinguishing positive and negative experiences of participating in an ICU support group and determining if ICU Support Groups are an effective intervention for families of ICU patients.

Procedures:
If you agree to be in this study, you will be asked to complete a demographic/background information sheet and an audio-taped interview with the researcher about your experience. Interviews can be completed individually or with your family.

Risks/Benefits:
Minimal potential risks from participating in this study may include feelings of discomfort participating in an interview or distress discussing your experience. You can choose to stop the interview at any time. You may choose to skip any questions. Potential benefits include the opportunity to share your experience, new realizations from telling your story and the possibility of helping others by contributing to the current research on family support groups.

Confidentiality:
Any information that is obtained in connection with this study will remain confidential and be available only to the graduate student researcher and the advising faculty member.   No individual data will be identifiable in any report or publication. Nurses on the unit or the support group leader will not be aware of your participation in the study or your responses in the interview. Therefore, the care of your family member will not be affected by your participation in this research study.

Participation and Withdrawal:
Participation in this research study is completely voluntary. You may choose to participate or not to participate. You may withdraw from the study at any time.

For further information:
If you are interested in participating in this research study or have any questions or concerns about this research study please submit your contact information in the enclosed envelope to one of the health unit coordinators.

Rebecca Scharpe, RN United Hospital
Minnesota State University Graduate Student
Phone: 612-968-9080

Research Study: The Family Experience of Participating in an ICU Support Group
Please write your name and contact information below if you are interested in participating in the study.

NAME _____

Family Member's Room # _____

Phone number you would like to be called at to arrange an interview _____

Please submit this information in the enclosed sealed envelope to the Health Unit Coordinator on 3900, 3920, or 3940. They will place the envelope into interoffice mail, where it will be received by the research investigator. All contact information will be kept confidential.

APPENDIX D

INFORMED CONSENT

Consent Form

Research Title: The Family Experience of Participating in an ICU Support Group

Investigator: Rebecca Scharpe, RN at United Hospital, Masters Student at MN State
University
Sandra Eggenberger, PhD, RN, Faculty Advisor at MN State University

Conflict of Interest Statement: This is a non-funded, non-sponsored study that is being completed for a graduate student's thesis work.

Subject Selection: You are a potential subject if you have participated in one ICU Support Group Session at United Hospital. Participation in this research study is completely voluntary; you may choose to participate or not. There is no cost to participate in this study. You will not be paid for participating in this study.

Purpose of the Study: The purpose of the study is to describe the experience of participating in an ICU support group. Additional purposes include: distinguishing positive and negative experiences of participating in an ICU support group and determining if ICU Support Groups are an effective intervention for families of ICU patients.

Size of Study: Up to 75 subjects will be enrolled in the study.

Procedures: If you agree to be in this study, you will be asked to complete a demographic/background information sheet and an audio-taped interview with the researcher about your experience. Interviews can be completed individually or with your family.

Risks: Possible risks from participating in this study may include feelings of discomfort from being interviewed or distress discussing your experience. You can choose to stop the interview at any time. You may choose to skip any questions.

Benefits: Potential benefits include the opportunity to share your experience, new realizations from telling your story and the possibility of helping others by contributing to the current research on family support groups.

Confidentiality:
Any information that is obtained in connection with this study will remain confidential and be available only to the graduate student researcher and the advising faculty member. No information that could identify you, such as names or phone numbers, will be used when the results of the study are published or presented. Nurses on the unit or the support group leader will not be aware of your participation in the study or your responses in the interview. Therefore, the care of your family member will not be affected by your participation in this research study.

Participation and Withdrawal:

Participation in this research study is completely voluntary. You may choose to participate or not to participate. You may withdraw from the study at any time. Your decision to participate or withdraw in this study will not affect the care of your family member at United Hospital.

Contacts & Questions: The researcher conducting this study is Rebecca Scharpe. You may ask any questions you have now. If you have any questions later you can contact her at 612-968-9080. You may also contact Dr. Sandra Eggenberger, faculty advisor overseeing this study, at 507-389-6821.

If you have any questions about your rights as a research subject, or complaints about this research study, please direct them to the Allina Institutional Review Board Administrative Office at 612-262-4920 or MSU IRB Administrator at 507-389-2321.

You will be given a signed copy of this form.

Statement of Consent

I have had the opportunity to ask questions and have had my questions answered. I have been given enough time to consider participating. I agree to participate.

_____
Printed Name of Subject

_____   _____
Signature of Subject   Date

_____   _____
Printed Name of Person Obtaining Consent   Role in Study

_____   **_____**
Signature of Person Obtaining Consent   Date

APPENDIX E

FAMILY BACKGROUND FORM

FAMILY BACKGROUND FORM

1. Gender: □ Male   □ Female

2. Age: _____

3. Highest level of education completed (please choose one):
   □ Less than high school   □ High School   □ College   □ Graduate School

4. Relationship to Ill Family Member (please choose one):
   □ Spouse: Wife/Husband
   □ Partner
   □ Child: Daughter/Son
   □ Sibling: Brother/Sister
   □ Parent: Mother/Father
   □ Grandparent: Grandmother/Grandfather
   □ Other (please specify _____)

5. Religious Affiliation:
   □ Protestant Christian   □ Hindu   □ Atheist
   □ Catholic   □ Buddhist   □ Other (please specify):
   □ Muslim   □ Agnostic
                                             _____

6. Ethnicity:
   □ White Caucasian   □ Latino/Non-Hispanic   □ Native American
   □ African American   □ Asian   □ Other (please specify):
   □ Hispanic   □ Pacific Islander
                                                   _____

7. Age of Ill Family Member: _____

8. Medical Diagnosis of Ill Family Member: _____

9. Length of Time Family Member Hospitalized in the Intensive Care Unit:
   □ Less than 1 day   □ 7-8 Days   □ 15-16 Days   □ 23-24 Days
   □ 1-2 Days   □ 9-10 Days   □ 17-18 Days   □ Over 25 Days
   □ 3-4 Days   □ 11-12 Days   □ 19-20 Days
   □ 5-6 Days   □ 13-14 Days   □ 21-22 Days

10. Have you participated in a support group other than the ICU Family Support Group?
    □ Yes
    □ No

11. Have you had a family member hospitalized in the intensive care unit prior to this?
    □ Yes
    □ No