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ICU Family Members' Experiences with Bereavement:

A Qualitative Descriptive Approach

by

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THESIS

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### **Dedication and Acknowledgements**

Many thanks to Jennifer McAdam and DorAnne Donesky – these doctoral trained nurses held my hand repeatedly as I sweated this out and connected to my academic within. Many thanks to my family who watched me disappear and reappear this last year. Without Katie Kilburg, life as a graduate student would have been lonely, thanks for the companionship from afar.

**ABSTRACT**

*Objective:* To describe family members' experiences with bereavement 13 months after the death of a family member in an adult ICU.

*Definition:* Bereavement is an undefined time period after the death of a loved one, when family members or friends may experience grief and mourn the loss of the deceased. In varying degrees this may include physical, cognitive, behavioral and spiritual / religious experiences for the family member. For some people this period can be stressful and cause distressing symptoms.

*Design:* An exploratory, descriptive analysis using semi-structured interviews.

*Setting:* Interviews were conducted over the telephone. Handwritten responses were received by mail.

*Participants:* 17 family members of 17 deceased ICU patients from two ICUs in a tertiary medical center in the Western United States represent the sample for this study.

*Methods and Results:* A qualitative, descriptive technique was used for data analysis. Two independent raters coded transcripts of audiotaped interviews, handwritten responses to open-ended survey questions and one unsolicited letter in order to assess family members' experiences with bereavement support provided by the ICU. Comments from family members were categorized into themes focusing on ICU family bereavement experiences. Three main themes emerged and consisted of: 1) bereavement as a unique experience for each family member, 2) situations occurring during the ICU encounter remained significant for family members beyond a year after the death, and 3) social, cultural and spiritual events after the death hold importance for ICU family members over time.

*Conclusions:* Bereavement is a notable experience for family members of deceased ICU patients. The themes identified in this study add insight into the experiences of these surviving family

members. The results of this study may guide future clinical interventions to help support bereaved ICU family members.

**Keywords:** *ICU, family bereavement, bereavement intervention, qualitative study.*

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## **Introduction**

Adult intensive care units (ICU) are harsh chaotic environments, fraught with miscommunication, physical environments that demand family separation, and complex relationships between family members and medical staff. Multi-factor stressors such as these can disrupt normal function of families in the ICU (Söderström, Saveman, Hagberg, & Benzein, 2009). Those families, who have a member die in an adult ICU may experience anxiety, depression, stress, and other new symptoms (Azoulay et al., 2005; Pochard et al., 2005). Prior to the death of a loved one in an ICU, family members are significantly at risk for experiencing new symptoms that can make the bereavement period more challenging. While there is an absolute necessity for the nursing and medical teams to focus on the ICU patient for lifesaving measures, consideration of the health of the ICU family is important as well.

Bereavement is an undefined time period after the death of a loved one when family members or friends may experience grief and mourn the loss of the deceased. In varying degrees this may include physical, cognitive, behavioral and spiritual / religious experiences for the family member. For some people this period can be stressful and cause distressing symptoms (Thompson et al, 2016). After experiencing the family member's death, the ICU family may themselves suffer from symptoms that can include anxiety, depression, stress, prolonged grief and posttraumatic stress disorder. This cluster of symptoms has been labeled "post-intensive care syndrome-family" (Davidson, 2009; Gries et al., 2010; Siegel, et al., 2008). Professional organizations recommend caring for bereaved family members through organized bereavement programs based on the individual needs of the family (Hudson et al., 2012; Truog et al., 2008). Scientific evaluation of programs that aim to benefit families in bereavement is a growing area of research among nursing and other disciplines (Stroebe, Hansson, Schut, Stroebe, & Van den



Blink, Emmy Illus, 2008). While there is increasing interest, much is unknown about what ICU family members want and need in terms of bereavement support. Therefore, the purpose of this secondary analysis is to describe family members' experiences with bereavement 13 months after the death of a family member in an adult ICU.

### **Review of Literature**

Literature directly focused on adult ICU family bereavement experiences is limited. In a United States-based study, Warren (2002) examined the lived experiences of critical care family members' bereavement. Purposive sampling was used to obtain twenty three (n=23) ICU family members who lost a loved one in a university hospital ICU setting. Using Heidegger's philosophy that all experiences can be expressed in words, the researcher applied a hermeneutic system to categorize bereavement experiences. This system allowed the researcher to identify five "not helpful / not satisfying" themes and three "helpful / satisfying" themes that resonated throughout the bereavement period. The five "unhelpful" themes included inaccessibility of physicians; not knowing the cause of death; possible inadequate treatment; staff lacking compassion; and not being present at the time of death. The "helpful / satisfying" themes included easy access to information from the hospital team; unrestricted visiting to lessen family separation; and clear support for family member needs including follow-up in bereavement. One strength of the study was that the methodology was clearly defined by the researchers, which could promote reproducibility. The demographics were homogenous, almost exclusively female (n=22 female, n=1 male). Finally, no mention was made regarding family members who chose not participate, leaving the reader wondering about the barriers to participation in the study.

In a study at a university setting from the United Kingdom, Voisey, Davies, Parry-Jones & Stallard (2007) described a five-year study of critical care bereavement follow-up. Family

members were interviewed two to four months after the ICU death. A total of 780 families (47% of ICU deaths) agreed to participate in the family sessions with an ICU consultant / attending physician and an ICU nurse. Interview sessions were recorded and analyzed for content. The most common issues raised for bereaved family members included: specific questions regarding the patient (56%); review of notes and other information regarding the death (35%); desire to contact other health professionals (21%) and clarifying misunderstandings surrounding the death (18%). If needed, the family member was referred for appropriate treatment such as counseling. Researchers who developed the study believed that answering families' questions at two to four months after death in an ICU would assist in dealing with grief during bereavement. The researchers noted that only a small percentage of participants (6%) requested professional counseling as follow-up to the interview session. A major strength of this study was that it included an extended five-year data collection period and captured a large sample of bereaved ICU family members. One concern was that the researchers do not report demographics of the participants, leading the reader to wonder about those not represented in the sample.

At a teaching hospital in the Netherlands, van der Klink and colleagues (2010) performed structured telephone interviews with family members (n=51) of ICU decedents four to sixteen months following the ICU death. Using qualitative data the authors reported that 35% of the respondents (n=18) desired more bereavement follow up. The main theme was inadequate communication that led to frustration by respondents who reported dissatisfaction with ICU care. Ten percent of respondents (n=5) noted that they had "remaining questions" and believed that contact with a doctor or ICU staff would have assisted their grieving process. The authors conclude that follow up bereavement services, with an emphasis on clear communication and greater empathy and sympathy from care teams, are necessary to assist ICU families with

bereavement. One of the strengths of the study was that the researchers used survey tools previously validated in other studies, and translated and adapted them to their setting. Experts were consulted to check accuracy and intent, ensuring internal validity and consistency of the survey tool. One concern was maturation among the participants who had difficulty remembering specific details of the ICU events after four or more months. This was especially true for ICU family members interviewed after more time had elapsed since the death. Prompting by the researchers on certain details may have biased or skewed the data, potentially leading to misinterpretation of themes found in the qualitative analysis.

These studies demonstrate how interview data can highlight the lived experiences of ICU family members. Common themes emerged from the three studies for bereaved family members including the need for better communication between family members and practitioners and the importance of someone from the ICU following up by contacting the family and checking in on their bereavement experience. However, two of the three studies were conducted outside the United States where healthcare experiences and practices can differ. Samples were drawn from university hospitals or teaching hospitals. The samples consisted largely of female family members. In addition, these studies represent experiences of family members in ICUs five to fifteen years ago. Changes in ICU treatment protocols, including the development of ICU palliative care teams, may impact the outcomes for families who experience a death of a loved one in a modern adult ICU. Thus, an updated description is needed of the current bereavement experiences of ICU family members in the United States would be valuable. The present secondary analysis adds to the literature by illuminating the experiences of ICU family members with direct report of their experiences in their own words. Additionally this study provides suggestions from the ICU family members on how to improve the bereavement experience.

## **Bereavement and Grief Theory**

Most theorists approach bereavement through the examination of grief and how the bereaved person heals from grief. Granek (2010) defines bereavement as the loss of a loved one by death, and defines grief as the distress resulting from bereavement. The roots of bereavement and grief theory stretch back to the early 1900's and the work of Freud. In a simplified description of Freud's grief work, he focused on how successfully or unsuccessfully an individual is able to let go of emotional attachments to the person who died. A return to health includes the integration of those attachments to other living relationships. In "Mourning and Melancholia," Freud states that grieving and "mourning involves grave departures from the normal attitude to life, it never occurs to us to regard it as a pathological condition and to refer it to medical treatment. We rely on it being overcome after a certain lapse of time, and we look upon any interference with it as useless or even harmful" (Freud, 1917 – as quoted in Granek [2010] pp. 252). Many iterations of grief and bereavement theory have arisen from these words.

Balk and colleagues (2004) suggest that more recent theories on grief and bereavement may be influential for those designing interventions and studying outcomes of bereavement programs. In the late 1990's Shut (1999) proposed a "Dual Model of Orientation" suggesting that pathological grief is kept at bay as the bereaved adult oscillates between two contrasting needs in grief, loss-oriented and restoration-oriented grief. To maintain health, the bereaved person must be loss-oriented and face grief by staying in the pain and loss and also be restoration-oriented and focus on the practicalities of the present and future, successfully suppressing thoughts associated with their loss. Gillies and Neimeyer's "Meaning Reconstruction Theory" (Gillies & Neimeyer, 2006; Neimeyer, Burke, Mackay, & van Dyke Stringer, 2010) suggest healthy bereavement is experienced when the bereaved can find meaning

in experiences related to the loss. Such meaning is sought and obtained in a number of contexts including individual, family and community structures, and will often have a spiritual and/or cultural significance. Many other models of grief and bereavement have been posed since Freud's work. Additionally other sub-theories exist regarding bereavement and grief, but those discussed here are seen as most relevant to ICU family bereavement. From a practitioner's perspective, these iterations of bereavement and grief theory lend guidance to practice. These theorists share the commonality that grief and bereavement is a natural processes requiring a certain passing of time to resolve. Each views the bereaved person as having a health challenge, and describes a particular healing path back to wholeness.

When developing bereavement interventions, appropriate caution is required so that they do not disturb or interfere with the natural process of grief, which might indeed cause harm or be truly useless (Hall, 2014). The director of the Centre of Palliative Care in Australia, Christopher Hall (2014) suggests that subscription to a single model can lead to failures in empathy and listening, and ultimately failure to address the needs of bereaved people. Hall believes that grieving is a very individual reaction and because of this uniqueness, grieving eludes a one-size-fits-all approach. In the context of the adult ICU where the chaotic environment is known to create harsh realities for ICU family members, ICU family members' bereavement and grief will most likely take many forms. While recognizing every ICU family members' bereavement experience is unique, this study also identifies with tenets from the Meaning and Reconstruction theory as proposed by Neimeyer and colleagues (2010). Using this theory to guide bereavement support assists in understanding how the ICU family member makes meaning of the death. Also, it allows a better understanding of the individual family and community structures that are significant in assisting the family member in their personal bereavement.

## **Methods**

This study was a secondary analysis of qualitative findings from a pilot study (McAdam, Jones, & Puntillo, (2016) in preparation). The main purpose of the pilot study was to evaluate the effectiveness of a nurse-led bereavement program offered to family members of deceased ICU patients. It assessed the impact of the program on their symptoms and satisfaction with ICU care when compared to family members that did not receive the care. Institutional Review Board (IRB) approval was granted in 2013 and the pilot study concluded in March of 2016.

## **Setting**

The study occurred in two ICUs at a university hospital in a large urban center located in the western United States. One ICU was cardiac focused (CICU) and the second was medical / surgical focused (MSICU). Both ICUs had a dedicated staff of nurses, physicians, chaplains, social workers and other support staff.

## **Bereavement Intervention**

The nurse-led bereavement program in the MSICU included:

- A bereavement packet containing information on grief, funeral planning, financial arrangements, obtaining death certificates and local grief support resources. A team including representatives from the hospital's Patient Relations, Spiritual Care Services, Palliative Care Services and a transplant donor network developed the brochure.
- A pre-printed condolence card signed by hand and a practical tasks resource packet, both sent separately at one week after the death.
- A telephone call at four to five weeks by a bereavement team member to assess how family was doing and identify any additional needs.
- Another follow up call at six months to provide opportunities for feedback to the ICU and

additional assessment of family member needs.

- A card on what would have been the patient's birthday was sent, reiterating the ICU's continued support and remembrance of the patient.
- An opt-out option was offered to family members throughout the program.

The CICU standard of care included:

- No formal nurse-led bereavement program
- Some, but not all families received the same bereavement packet as in MISCU. Nurses only occasionally gave packets to some families but no formal plan or pattern guided this intervention.
- A few, but not all families received a handwritten condolence letter at two weeks after the ICU death. Again this was an unplanned intervention with no guiding standard or consistent effort.

### **Procedure**

Through the use of census logbooks, all consecutive ICU patients who died in the MSICU and the CICU were identified when one year had passed since their death. For families in the intervention group, research contact at thirteen months ensured that the family member received a full year of bereavement support. The researchers also concurred that waiting until the thirteenth month honored the sensitivity of the first year of bereavement before asking family members to participate in research.

After the list was established, the medical record of each deceased patient was reviewed to obtain contact information for the family member listed as next of kin. A letter invited the family member to participate, describing the objectives and how to participate in the study. An opt-in card and a consent document were included with the invitation. Family members had two

options for participation: one - complete a mailed packet of surveys by pen and paper; or two - complete the surveys online via computer. The six Likert-type scales that made up the surveys are described in depth in the pilot study (McAdam, et. al., (2016) preparation). A third option if they completed one of the first two options, was they could choose to share more about their bereavement experiences through a telephone interview.

Family members who completed the surveys and chose to share more about bereavement experiences received a telephone call from the co-principal investigator (JM) Verbal confirmation of family member consent to participate was confirmed at the beginning of each call. Recording of the interview was noted and the participant agreed to be recorded. The smart phone application “TapeACall Pro” by Epic Enterprises (version 2.2, available via MacIntosh App store) was used for recording. The same researcher (JM), a PhD prepared nurse with extensive experience working with ICU families, conducted all the interviews. A pre-scripted open-ended series of questions was asked pertaining to bereavement experiences in all the interviews. The script used open-ended questions to encourage family members to provide rich detail about their experiences. (See Appendix A)

### **Subjects**

Inclusion criteria for this study consisted of the family member who was listed as next-of-kin for the patient who died and completed the survey portion of the pilot study. Then they could opt in for the interview or provide written data on the open ended question on the ICU Family Satisfaction Survey.

### **Data Analysis**

All interviews were transcribed verbatim from recordings using a commonly available word processing program (Word for Mac, version 14.6.1, 2011). Identifying information was



eliminated in the transcript and original recordings were deleted following transcription. After a second reading, repeated non-meaningful phrases such as “you know,” “like,” and “ummm” were removed from the transcript to further clarify content. Line numbers were used to allow further reference to specific content (Chenail, 2012). This secondary analysis also used data collected from the Family Satisfaction with Care in the Intensive Care Unit (FS ICU) survey sent to opt in family members. The tool has 27 questions with Likert responses and three additional open-ended, fill-in-the-blank questions (Heyland et al., 2002). All hand-written data from the fill-in-the-blank questions, as well as an unsolicited hand written letter from one participant, were included and prepared for analysis as noted above. In addition, family member and patient characteristics were obtained from both the demographic portion of the FS-ICU and the patient demographic survey. Data included such variables as: age, gender, race/ethnicity, education, relationship to patient and whether they lived with the patient, diagnosis of the patient and code status.

Using techniques similar to those described by Murphy and colleagues (2007), the co-principal investigator (JM) and the research assistant (CJ) independently read each transcript separately and identified recurring ideas or thematically rich passages. They met and offered what they considered to be meaningful descriptions of the family members’ bereavement experiences. These experiences were then sorted into themes. Differences of opinion about the themes and examples of those relevant sections of the transcripts were reviewed over the course of several analysis meetings. The co-principal investigator (JM) and the research assistant (CJ) reached agreement regarding the themes and relevant passages. Final themes and examples of specific family member bereavement experiences were reported as descriptive information.

## Results

A total of 40 family members were enrolled in the pilot study – Thirty (n=30) family members from the MSICU who received the bereavement intervention and ten (n=10) family members who from the CICU who did not receive the intervention. Of the original 40 participants, seventeen (n=17) were included in this secondary analysis (43%). The group (n=17) was comprised of fourteen family members (n=14) 47% of those who received the bereavement intervention and three family members (n=3) 30% of those who did not receive the intervention. Seven family members who experienced the death of a family member in an adult ICU (n=7) participated in the telephone interviews (18%). An additional ten ICU family members (n=10) wrote hand written responses (25%) on the open ended questions on the FSICU survey and one family member (2.5%) also included an unsolicited hand written note. Some family members who participated in the interviews also included written responses. Three additional interviews were excluded because family members did not complete the surveys as required by the IRB, two were for unknown reasons, and one family member noted lack of time due to family circumstances.

Family demographics are reported in Table 1. The majority of family members in the analysis were female (70%). The group included mostly spouses of ICU decedents, with nearly twice as many wives (n=9 wives, n=5 husbands) and only a few other family relations represented. The median age of family members was 64 years with a range from 44 to 83. The group was predominantly White (n=14) with a few Hispanics (n=3). The group was well educated with the majority having finished graduate or professional school (n=10) or college (n=6), one participant did not report education level.

Three main themes emerged and consisted of 1) bereavement as a unique experience for each family member 2) situations occurring during the ICU encounter remained significant for family members beyond a year after the death, and 3) social, cultural and spiritual events after the death hold importance for ICU family members over time.

### *Bereavement as a Unique Experience*

Multiple family members in the study stated that bereavement was an individual experience and that every situation was different. This theme of bereavement being a “unique experience” was seen across interviews and written responses. This particular statement from a family member captures this theme:

- “You know everyone’s experience is different, my husband had a long term illness. I had dealt with a lot of the grief through his illness too. So that was a little bit different than just losing someone [quickly].” (wife, age 58)

The theme “unique experience” carried over into the family members’ opinions regarding the bereavement interventions that were offered. Some ICU family members were supportive of the ICU reaching out and found the support very helpful:

- “You can’t ever know which particular thing is going to help the most. I think just reaching out and making an attempt, that might help people the most.” (husband, age 73)
- “I did appreciate the cards that came from the ICU unit. One came at six months then I really appreciated when they sent me a card that said it has been a year. I can share it with someone, like the card that said, ‘we remember taking care of him.’ It is unique because not a lot of people say that, his legacy lives on. All those things help.” (wife, age 58)

- “I received the condolence card from the ICU. I thought it was wonderful. I even felt like I could write back.” (wife, age 68)

However, some family members had concerns about the ICU reaching out or shared that they did not need bereavement support from the ICU:

- “Reaching out done by someone who knows the patient [speaking of the family physician] is more meaningful than those things that came from the ICU.” (wife, age 83)
- “In my particular case, I did not use the bereavement packet. I have very good family support.” (wife, age 58)

#### *Situations Significant for Family Members beyond a Year after the Death*

Family members in the study repeatedly shared events that happened during the periods both before and after death of the loved one in the ICU. It is important to note here that this theme is not a criticism of ICU care or of the providers of care. In deriving this theme researchers noted that the family members had detailed clarity in their recall of events that had occurred in the ICU. These events were still crisp memories for family members, retold as if they happened just a short while ago. The theme reflects how events in the ICU later changed or influenced the bereavement experience of family members. Holding onto either positive and / or negative memories from the ICU experience may influence the bereavement experience for ICU family members.

The situations that came up repeatedly involved separation at the time of death, waiting room issues and communication with health care providers. Separation of family members at death may have occurred because of ICU rules, or physical structure, or other circumstances that led to the patient dying without a family member at bedside. This came up for several family

members. Anecdotally, nurses report that family members do seem to sometimes hold on until other family members arrive, and sometimes seem to wait to die until the family members leave the room. Some of these quotes may capture this phenomenon while others point to the complexity in an ICU to create ideal situations where families can pass these milestones together.

- “I wasn’t with my husband when he died. I’ll always regret that. I should have been right there. I go in there, and one eye is still open, looking for me. They were having some problems stabilizing him. We were asked to leave the room. Then, we heard the code blue and realized it was his room. I did not expect him to be well, but I did not expect him to die.” (wife, age 83)

The patient’s room and the waiting room in the ICUs were a source of frustration and created stressful memories during the ICU time for many of the family members. Multiple comments about this were prevalent in both the hand written responses and in the interviews.

- “My husband was only in the ICU for seven hours. I would have wanted to have a chair nearby his room instead of going to the waiting room. I had driven five hours from [home], while he was flown there. If I had known they had called a code on him, I could have stopped it. As it was, they tried to revive him for half an hour before I knew. He suffered so many years. He did not need to die this way. I know everyone was doing the best for him. But if I could have stayed by him, I might have saved him some suffering and held his hand.” (wife, age 69)
- “They need some place or facility for families to go and rest and be near. More support during the ICU would have helped us out, somewhere to sleep mainly.” (wife, age 76)

- “There is a room inside the waiting room. I knew when the doctor escorted me in to talk; it was not going to be pleasant. I wish it didn’t feel so stereotypical of a bad soap opera.” (wife, age 51)
- “I think the quality (or lack of quality) of comfort in the ICU can make a difference between life or death. I feel this is one of the greatest shortcomings of [this] ICU. The ICU environment was absolutely mind numbing. Restful sleep is nearly impossible (for the patient). How can this not impact healing?” (husband, age 63)

Specific relationships with care providers were also presented as either a source of stress or comfort for family members that they remembered distinctly after a year.

- “[My wife] was in another hospital’s ICU for 30 days, then spent 65 days in [this] ICU. She was exposed to a lot (double underlined) of doctors and nurses. I think bedside manner is a huge factor. Some were outstanding in this regard, some were just awful...bedside manner has more of an impact on the patient than anything else.” (husband, age 63)
- “There is no doubt in my mind that the vast majority of doctors and nurses cared a lot – even though in order to maintain their own mental health, they probably have to maintain a certain amount of emotional distance from the patient.” (husband, age 63)
- “Every day we dealt with a new physician who was not familiar with my wife’s condition or treatment history. We had to start from scratch explaining and answering the same questions over and over again.” (husband, age 63)
- “The three doctors who spoke to me the night my husband got worse, they are angels. The words they told me help me to carry on with my life today. Nurses [list of names] are also angels.” (wife, age 57)

*Social, Cultural and Spiritual/Religious Events after the Death Hold Importance*

Several family members discussed events and instances that held a special meaning for them after their loss.

- “I got the ice cream freezer out and I looked inside and there was a note, he probably did this three years ago because we had not made ice cream since. It was a note that was in his handwriting, and it said ‘Let’s get the stuff to make ice cream to make after mom’s dinner.’ So little things like that, that make you remember the relationship you had, the experiences you had.” (wife, age 58)

Several family members mentioned the importance of some kind of memorial.

- “It is not so much for me, but his memory. The physician said because of his long relationship with (the hospital) there will be a special plaque with his name on it in the office.” (wife, age 58)
- “I visit the gravesite every few weeks, that helps me, that gives me peace.” (wife, age 76)

Some family members reflected on the broad support in their lives and how this has helped in the grieving process. They discussed not only their own family for support but outside resources as well. In addition to this, religion and spirituality were mentioned throughout many of the interviews.

- “I have support, church, daughters, grandkids, friends.” (wife, age 76)
- “My daughter lives 80 miles away, but she has been extremely supportive. The two of us are doing well to support each other.” (wife, age 68)
- “The grief has been very stressful. I have found a grief counselor who could see me three times. She was wonderful. That has been very beneficial. She connected me to

a grief group at hospice, even though my husband was never on hospice.” (wife, age 68)

- “We are very religious, so it helps me to go to church.” (wife, age 76)

## **Discussion**

The purpose of this secondary analysis was to describe family members’ experiences with bereavement 13 months after the death of a family member in an adult ICU. In addition, families in this study shared what they felt was important from the ICU that may have helped or hindered their bereavement experiences. Because of the sample size, the researchers did not feel it was applicable to distinguish between participants who had received the bereavement intervention and those who did not receive the intervention. The themes we have identified may help shed light on the ICU family experience and influence practitioners as they develop interventions for bereaved ICU family members in the future.

Family members described bereavement as a unique experience and that may preclude a standardized bereavement support. Cutcliffe (2002) stated that while all of us pass through bereavement in our lives, the experience is generally unique for everyone. This can pose a challenge to ICUs when developing bereavement support programs where it is more convenient and feasible to give standard care based on a one size fits all philosophy (Hall 2014). Laurie & Neimeyer (2008) examined the uniqueness of bereavement in relation to ethnicity and how that may influence individual bereavement experiences. Nurses in an ICU may need to contact the family directly in order to get a sense of the particular support they may need. It may be as simple as one family member in the study suggested, “I think just reaching out and making an attempt, that might help people the most.”



Family members reported events and situations in the ICU that still left an impression on them over a year later. Some researchers have found that efforts to improve intensive care unit quality should be focused on domains and processes that families value most (Nelson et al., 2010). This suggests that ICUs need to continue to address protocols such as visiting hours and family presence during code type events. One of the greatest gifts clinicians can give to family members is to allow them to be present during the last moments of life as it offers them the opportunity to give comfort, share love, and say good-bye (Marrone & Fogg, 2005). Although not feasible for all ICUs, purposeful design interventions for updating patient rooms and waiting rooms to permit more family involvement in care, if possible, is shown in the literature to have great positive impact on ICU patients and families (Brown & Gallant, 2006). This theme also brings to the forefront a constant reminder that practitioners must be mindful of the impact of their very presence for ICU family members. Recent studies on mindfulness practices in ICU practitioners show a reduction in perceived provider stress (Raab, 2014). Studies in palliative care show that caring, competent professionals working as integrated teams can provide high-quality palliative care for critically ill patients and their families (Nelson et al., 2012). These mindful care practices show potential to lead to more satisfactory ICU family member communication and interactions with practitioners.

Finally, family members shared the helpfulness and importance of social, cultural, and spiritual/religious events as they moved through the bereavement period. Memorials have been shown to be one of the rituals that meet certain universal needs, including confirmation of the reality of the death, stimulation of memories of the deceased and provision of support to the ICU family (Platt, 2004). Memorials may be one way for ICUs to expand bereavement care. Besides memorials, developing a legacy for family members to carry forward may be helpful. One

family member noted that working with a disease-focused research foundation had become her “biggest purpose and comfort” after losing her husband to the particular disease. She felt that raising money and awareness connected her to her husband and gave “his life purpose, as the money will be used to train staff and continue research.”

### **Strengths and Limitations**

Nearly half (47%) of the participants in the pilot study chose to participate in this qualitative portion of the study, indicating participants’ willingness to share their bereavement experiences. Recurring themes were discoverable using semi-structured interviews to collect experiences after bereavement in ICU family members. The sample was homogeneous and included mostly older, educated, white, female, a common phenomenon in this type of research that may be improved with advances in study design to support a broader sample. It sheds light on the experiences of spouses who lose partners in an adult ICU. The study setting was an urban academic environment so the needs of family members from rural, or other community settings are unknown. Clinicians may find the illumination of family member voices to be useful to direct future interventions in academic ICUs seeking to support bereaved family members.

### **Conclusion**

The findings from this study focus on the experiences of ICU family members’ bereavement. While it appears that only a small number of family members will face a pathologic bereavement period, the experience can generate a spectrum of health challenges for family members. Support, both during and after the ICU experience, appears to be needed and wanted by many people and is a recommended standard of care. This may help alleviate some suffering during this difficult time. Finally, this study highlights the need for continued research in the area of how the ICU can best support families as they deal with bereavement.

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## Appendix A. ICU family member demographics

\*) Frequency describes number of participants, except age range and median age.

Characteristics	Frequency*
Gender	
Male	5
Female	12
Age (years)	
Range	44 – 83
Median	64
Relation to the patient	
Wife	9
Husband	5
Sister	1
Daughter	1
Friend	1
Race	
White	14
Hispanic	3
Level of education	
Professional	1
Graduate	9
College	6
Missing	1
Type of group	
Intervention	14
No intervention	3



## Appendix B. Script for telephone interview

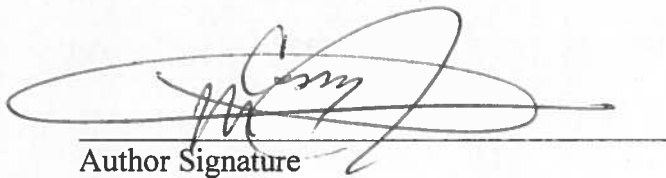
1. Introduce self, title, and position at [study site]. *“Hello, my name is [insert name]. I am calling from [this] School of Nursing and am part of the research team that is working with the ICU [CICU or MSICU] where your loved one was a patient.”*
2. Offer condolences. *“I would like to express my condolences to you and your family for your loss”*
3. Explain the purpose of the call. Let the family know that the telephone call will be recorded. Inquire if they are still interested in participating in this portion of the study. If no, thank them for their time and participation in the study. If yes, obtain verbal consent and continue to # 4. *“You indicated that you would like to share your bereavement experiences with us. I will be asking you some open-ended questions about your bereavement experiences. You may feel free to decline to answer any of these questions. In addition, you may add whatever you feel is important for us to hear about your experiences. These conversations will be recorded. Are you still interested in participating in this portion of the study?”*
4. Start with some basic questions to keep the conversation going. These are to help guide the conversation and will be modified based on how the family member answers or responds to the questions. *How have things been going for you? Have you been experiencing any feelings of stress, anxiousness, depression, etc.? Are you currently using any bereavement services or programs such as support groups? Would you like to share anything from your ICU experience? Anything that was helpful? Anything that was unhelpful? What would you like to share with me regarding your bereavement experiences? Is there anything you think the ICU (or hospital) could have done to help you during this difficult time? Do you have any other questions?”*
5. If at any time the family member seems to be in great distress, encourage them to make an appointment with their primary medical provider.
6. Thank them for their time and provide them with the PI’s contact information xxx-xxx-xxxx and to call with any questions.

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