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UNIVERSITY OF SAN DIEGO

Hahn School of Nursing and Health Science

DOCTOR OF PHILOSOPHY IN NURSING

NURSE FAMILY MEMBER PERCEPTIONS OF PATIENT DEATH AND NURSING
CARE AFTER WITHDRAWAL OF LIFE-SUSTAINING TREATMENT

by

Deena M. Drake, PhD(c), RN, CNS

A dissertation presented to the
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requirements for the degree
DOCTOR OF PHILOSOPHY IN NURSING

April 2019

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UNIVERSITY OF SAN DIEGO

Hahn School of Nursing and Health Science

DOCTOR OF PHILOSOPHY IN NURSING

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ABSTRACT

Purpose/Aims: This pilot study explored nurse family member perceptions of nursing care and patient quality of death and dying during and after withdrawal of life-sustaining treatment within Intensive Care Units (ICU).

Rationale: Past research that examined physician, nurse, and family member experiences of End-of-Life (EOL) care within the ICU found significant differences between the three groups.

Background: Approximately 500,000 people die within an ICU each year in the United States. End-of-Life and Palliative Care programs focused primarily on physician interventions to improve quality of EOL care have had little impact on family member perceptions of quality of care or patient death, with nurses rating quality lower than family or physicians.

Methods: This descriptive study examined the perceptions of nursing care and patient quality of death and dying using the family member version of the Quality of Death and Dying (QODD) instrument and Family Satisfaction in the ICU (FS-ICU). Qualitative data related to the nurse family member experience was elicited through additional open-ended questions.

Findings: Respondents (N=17) tended to view the quality of patient death somewhat favorably with a total QODD mean score of 60.75 ($SD = 21.05$) on a scale of 1-100. Results also indicated a moderate level of satisfaction with care within the ICU, with a total FS-ICU mean score of 67.75 ($SD = 21.51$) on a scale of 1-100. The FS-ICU care subscale total mean score was 67.82 ($SD = 21.05$), while the FS-ICU decision-making subscale mean score was 69.30 ($SD = 23.48$), indicating the highest level of satisfaction

was with decision making within the ICU. Qualitative extreme positive and negative data supported total QODD, total FS-ICU, and FS-ICU subscale scores. In comparison to previous research, nurse family member satisfaction with care and perceptions of quality of patient death and dying tended to align with nurse rather than family member scores.

Implications: Nurse family members perceive the quality of care and patient death and dying differently than non-nursing family members. To improve their experience of EOL care, further examination of the particular needs of nurse family members is warranted.

DEDICATION

This work is dedicated first and foremost to my incredible wife Lori Stewart, whose love, never-ending patience, and encouragement supported me through the long years of my doctoral journey. Her commitment to life-long learning, self-reflection, and compassion for others continue to inspire and challenge me to be the best version of myself.

Secondly, this work is dedicated to my late grandmother, June Virginia Hoapili. Her love, support, and belief in my potential carried me through the darkest years of my life. Prior to her death, she insisted I would return to school for an advanced degree, an idea I rebelled against at the time. As was the case many times, Grandma was right and I am forever grateful to her for planting that seed.

Lastly, I dedicate this work to all the patients and families I've cared for at End-of-Life throughout the years of my nursing career. Their trust in me, the access they afforded me to the most intimate aspects of their lives, humbled me and broke open my heart. The desire to deliver the best possible care to patients and families during critical illness, up to and including care at the time of death, has been the driving passion behind my academic work and my professional nursing career.

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CHAPTER 1

INTRODUCTION

In 2002, the Centers for Medicare and Medicaid Services (CMS) began working with the Agency of Healthcare Research and Quality (AHRQ) to develop a scientifically rigorous survey to measure patient perceptions of hospital care with the goal of incentivizing healthcare organizations to improve care delivery to the consumer (CMS, 2013). In October of 2006, the first surveys were distributed to recently discharged hospital patients and results first publically reported in March of 2008. Since that time, American hospitals have attempted to measure patient and family satisfaction with hospital services, as well as medical treatments and nursing care in a myriad of ways. Only one healthcare consumer perspective has been systematically excluded from these surveys, that of the families of patients who die within the hospital.

As hospitals and government agencies seek to improve every aspect of the patient and family experience of healthcare, they continue to neglect family perceptions of the care provided at end-of-life (EOL) and the quality of the patient's death. Despite the fact the majority of Americans express a desire to die at home, 63% of deaths within the United States occur in hospitals or skilled nursing facilities and approximately 20% of these deaths occur within intensive care units (Angus et al. 2004; Hall, Levant, &

DeFrances, 2013). In 2014, a report released by the Institute of Medicine (IOM) stated, "...a person-centered, family-oriented approach that honors individual preferences and promotes quality of life through the end of life should be a national priority" (Institute of Medicine [IOM], 2014). To achieve the IOM's goal, EOL research must be focused on the needs of the patient and family, from both the medical and nursing perspective.

Intensive care units (ICUs) offer the most technologically advanced medical and nursing care available to critically ill patients. Critical care nurses are often required to provide care that is ultimately futile and past research has indicated their perceptions of the quality of care delivered at EOL are significantly less than those of physicians and families (Galanos et al. 2012; Gerritsen et al. 2013). Nurses have also been shown to hold strong beliefs regarding what constitutes a good or peaceful death (Beckstrand et al. 2006) and frequently experience distress when they are powerless to provide their patients with care that aligns with those beliefs. What happens when nurses find themselves in the role of family member, with a loved one dying in an ICU? How do their professional experiences inform their perceptions of nursing care and family member death and dying?

Background

The landmark 1995 Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT) was one of the first examinations of patient EOL care within the acute-care hospital setting conducted in the United States (SUPPORT Principal Investigators, 1995). The authors identified three significant issues with EOL care that had implications for further research: (1) a significant number of terminally ill patients died in moderate to severe pain, (2) patients were not being treated in ways

consistent with their wishes, and (3) physicians were largely unaware of their patients' preferences regarding EOL care (Curtis, 2005). Despite almost 25 years of research and the implementation of palliative care programs within the acute care setting, studies continue to show little improvement in these key aspects of EOL care and significant differences in the quality of EOL care between hospitals (Aslakson, Curtis, and Nelson, 2014; DeCato et al. 2013).

The vast majority of medical research regarding EOL in the years following the SUPPORT trial has focused on evaluating clinician barriers to providing quality EOL care, improvement of pain and symptom management, and interventions to reduce patient ICU length of stay through evidence-based interventions (Curtis et al. 2008). Nursing research, on the other hand, has tended to focus on exploring the emotional impact of caring for dying patients and identifying barriers to providing quality EOL nursing care (Costello, 2005; Beckstrand, Callister, & Kirchoff, 2006; Hansen, Goodell, DeHaven, & Smith, 2009). It has only been in the last few years that any attempt has been made to engage family members of patients who died in the hospital setting in efforts to improve EOL care.

Withdrawal of Life-sustaining Treatment

The decision to withdraw life-sustaining treatment (WOLST) for a loved one is often one of the most difficult choices a person will make in their lifetime. When given the difficult choice by healthcare providers between “doing everything” and “letting go”, families struggle with their own grief, the desire to honor the wishes of the patient, and wanting to provide a good or peaceful death for their loved one. This transition from intensive, invasive medical interventions to palliative care is difficult for both families

and healthcare professionals and recent studies have indicated a “good death” is of equal importance to patients, families, nurses, and physicians (Steinhauser et al. 2000; Kring, 2006).

When the decision is made to withdraw treatment from a patient in the Intensive Care Unit, the majority of physician orders are discontinued except pain and symptom management. Due to the pressing needs of other critically ill patients, the medical team frequently reduces their involvement in the care of the dying and focuses their energies on salvageable patients. It is at this time the bedside nurse must set aside the technical aspects of critical care and simply practice the art of nursing to provide a good, peaceful death for their patient while simultaneously supporting the emotional needs of the family.

Good Death

A good death is defined by the Institutes of Medicine (IOM) as one that is, “free from avoidable distress and suffering for patients, families, and caregivers; in general accord with patients’ and families’ wishes; and reasonably consistent with clinical, cultural, and ethical standards” (Field & Cassel, 1997). Patients, families, and healthcare professionals are in agreement about what constitutes a good death: pain and symptom management, having a sense of control, and reconciliation with others (Steinhauser et al. 2000; Granda-Cameron & Houldin, 2012; Kring, 2006; DelVecchio-Good et al. 2004; Shneidman, 2007). Nurses have a strong desire to provide patients with a good death (Kehl, 2006) and consider pain management, clear communication with the patient and family, honoring a patient’s EOL wishes, and the presence of loved ones at the time of death as key attributes of a good death (Granda-Cameron & Houldin, 2012; Miyashita et al. 2007; Kring, 2006).

For the family of a patient dying in the hospital, having a sense of control is important and contributes to their perceptions of a good death for their loved one (Kehl, 2006). Control includes shared decision-making, clear communication with healthcare providers, having decisions regarding their loved one's EOL care honored, and control over the location, timing, and circumstances of death (Steinhauser et al. 2000; Hattori, McCubbin, & Ishida, 2006; Kehl, 2006; Watts, 2012). Although there is congruity in the language nurses and families use in describing good death, in reality nurses often describe the unrealistic expectations and demands of the family as barriers to providing quality EOL care to the patient (Espinosa, Young, & Walsh, 2008).

Investigator Interest

The investigator has been a critical care nurse for over 15 years and has had numerous personal experiences of “good” and “bad” deaths during that time. After witnessing the suffering of families and the discomfort and emotional distress of nurses caring for dying patients with little or no education or training in EOL care, a passionate interest in improving the nursing care delivered to patients and their families was sparked. The investigator made the decision to withdraw treatment on her mother, and was present at the time of her death in an ICU several years ago. This personal experience highlighted how traumatic the EOL process can be and how the actions and communication used by the primary nurse can lessen or heighten the emotional burden of the family.

Conceptual Framework

Clinicians, nurses, patients, and their families may differ in assigning importance to the aspects of a good death (Galanos, Morris, Pieper, Poppe-Ries, & Steinhauser,

2012), yet there is little disagreement regarding the essential components of a good death (Steinhauser et al. 2000; Downey, Curtis, Lafferty, Herting, & Engelberg, 2009). Due to the fact the majority of deaths in the U.S. occur in hospitals, many aspects of a patient's death experience are beyond their control or the control of their family and it is often the healthcare delivery system that ultimately determines whether perception of patient death is good or bad.

This study will use the four theorized empirical domains of the Quality of Death and Dying (QODD) instrument as its conceptual framework (Downey et al. 2009). These four domains include: a) symptom control, b) preparedness, c) connectedness, and d) transcendence. Examples of issues pertaining to each domain are as follows:

Symptom control – having pain under control, having control over what was going on, and being able to breathe comfortably;

Preparedness – having the means to hasten death, if desired, visiting with a spiritual advisor, having funeral arrangements in order, avoiding life support, and having health care costs covered;

Connectedness – sharing physical expressions of affection, and spending time with family and friends;

Transcendence – feeling unafraid of dying, feeling at peace with dying, and feeling untroubled about strain on loved ones.

In response to concerns the QODD lacked theoretical foundations, the four domains of the QODD were developed and devised using Symbolic Interactionism (via Identity Theory) and Existential Psychology (Downey, et al. 2009). In combining these

theories, the authors attempted to address concerns regarding lack of theoretical framework in end-of-life research. As Downey, et al. stated:

Identity Theory and Existential Psychology converge in their emphasis on identity issues, the importance of reflection and the construction of meaning, the role others play in assigning meanings, changes that occur in relative importance of specific aspects of the self-concept over time, and the effects of personal agency versus outside influence on identity formation and integration. (2009, p. 6)

Throughout a person's life, numerous identities are developed (e.g., mother, wife, scientist, runner, etc.) that comprise only parts of the person's whole being. When faced with terminal or critical illness, the "dying person" identity is created and often becomes the dominant identity, eclipsing all others. This may especially be true in the acute care setting where typically a person's identity is subsumed by their status as "patient".

Families also go through identity transitions when a loved one is dying in the ICU. A person caring for a chronically ill family member is relegated to a spectator when an ICU nurse assumes all caregiver responsibilities of the critically ill patient. The role of wife, husband, or daughter may be supplanted by that of patient advocate. If a member of the family is a nurse, do they abandon or maintain this role and how does their professional experience inform their personal experience? It is important for nurses caring for critically ill patients to understand and recognize they are essentially surrogate caregivers, standing in for family members who are either unable to navigate the complexities of modern healthcare or are emotionally unable to care for their dying loved one.

The ICU nurse is a lens through which family view the death and dying process of their loved one. Family perceptions of nursing behaviors, actions, and communication can positively or negatively impact their overall satisfaction with the care delivered in the ICU and more importantly, their experience and perceptions of the patient's quality of dying and death. An ICU nurse caring for a patient during and after WOLST may facilitate or become a barrier to perceptions of a good death depending on their comfort level with death and dying and their connection to the patient and their family.

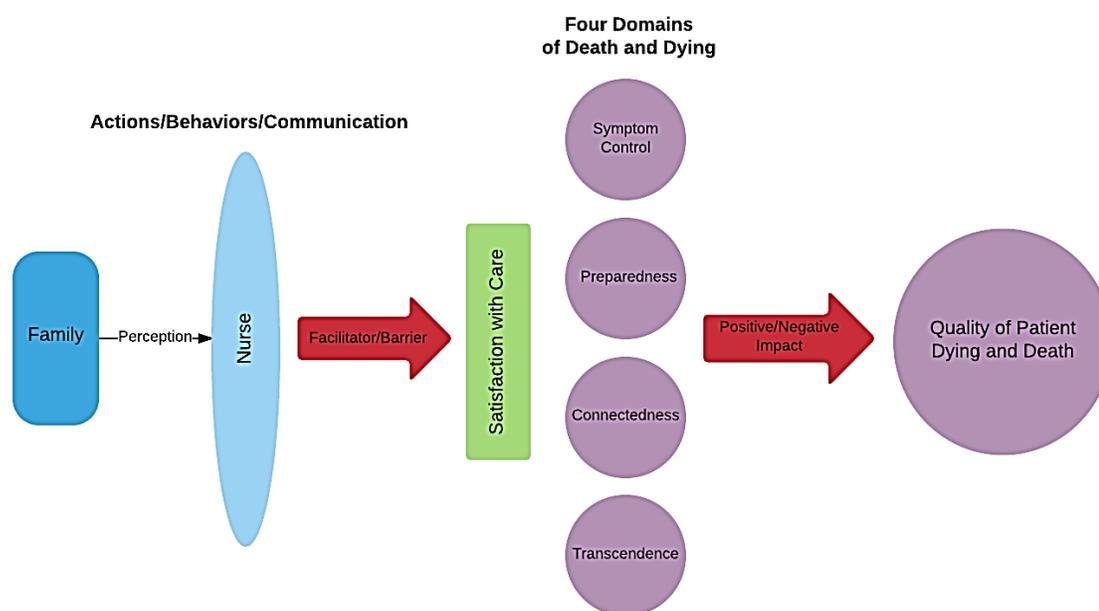


Figure 1. Visual representation of the impact of satisfaction/dissatisfaction with nursing care on Nurse Family perception of quality of patient death and dying.

Proposed Study

The purpose of this proposed study is to explore perceptions of nursing care during and after withdrawal of life-sustaining treatment and perceptions of patient quality of death and dying in an attempt to determine in what ways nursing care might be

improved during this critical time period. This study proposes a quantitative approach to examine nurse perceptions of the quality of nursing care and family member death and dying after WOLST within the ICU. In addition to quantitative data, three open-ended questions will be employed to elicit further detail regarding participant's perceptions of the experience of their family member's death as a nurse.

Specific Aims

The specific aims of this study are to: (1) describe nurse family member perceptions of patient quality of death and dying, (2) describe nurse family member satisfaction with nursing care of the dying patient during and after WOLST within the ICU, and (3) describe the relationship between family perceptions of quality of patient death and dying and satisfaction with nursing care during and after WOLST.

Methods

This proposed study will use purposive sampling of American Association of Critical Care nurses who have had a family member die in an ICU after WOLST. A cross-sectional descriptive survey design will be used to capture quantitative data regarding family perceptions of nursing care and quality of the patient's death and dying. Quantitative data will be collected using two valid and reliable instruments, the Quality of Death and Dying (QODD) V 3.2 and the Family Satisfaction in the ICU (FS-ICU). Family member and patient demographic data will also be collected. Descriptive and inferential statistics will be used to analyze the quantitative data.

Three open-ended questions will also be collected to provide further detail and a richer description of the experience of nurses whose family member died after WOLST in an ICU. Participants will be asked three questions: (1) how do you feel your

experience as a nurse influenced your perceptions of your family member's death, (2) what was your perception of the nursing care of your family member during and after the withdrawal of treatment, and (3) do you believe your family member had a "good death"? Why, or why not?

Directed content analysis will be used to analyze the data collected from the three open-ended questions for common themes related to nursing care and perceptions of patient death. Directed content analysis is used when prior research exists on a subject but further description would be beneficial to the understanding of the phenomena (Hsieh & Shannon, 2005).

Summary

The decision to withdraw life-sustaining treatment for a loved one is a traumatic event for families and often occurs within an ICU after aggressive, yet ultimately futile medical interventions. By the nature of the care they provide, nurses frequently build strong, trusting relationships with patients and their families and for this reason, their actions and communication before, during, and after WOLST play an important role in the family's perception of the quality of the patient's death. Any attempt to study EOL care within the hospital setting must involve all participants in the care delivery but must focus on the perceptions of patients and their families first and foremost. Metrics such as ICU length of stay, presence of Do Not Resuscitate orders in place at time of death, and physician and nursing perceptions of quality of patient death only capture the upstream view. To improve EOL care to patients and reduce the emotional burden of hospital death on families, researchers must carefully yet diligently seek the participation of the recipients of that care.

CHAPTER 2

LITERATURE REVIEW

The historical background and central concepts of the proposed study are examined in this chapter. Specifically, the historical context and concept of a good death, the role of ICU nurses during and after WOLST, family perceptions and satisfaction with EOL nursing care, and nurse perceptions of family member death are explored. Studies focusing on family perspectives of the quality of patient death and dying as well as differences between family, nurse, and clinician perspectives will be discussed. Finally, gaps in the literature will be detailed.

Background

Prior to the 1960's, the term 'good death' was often associated with euthanasia or physician-assisted suicide. Advances in medical technology meant the vast majority of Americans were born and died in hospitals and use of hospice care was in its infancy. Glaser & Strauss's *Awareness of Dying* and Kübler-Ross's *On Death and Dying* brought the experience of dying and death in American hospitals out of the shadows, into public awareness, and initiated a discussion within the medical community regarding treatment of dying patients and what constitutes a 'good' hospital death (Glaser & Strauss, 1965; Kübler-Ross, 1969).

Concept of a Good Death

In 1997, the Institute of Medicine (IOM) defined good death as, “one that is free from avoidable death and suffering for patients, families and caregivers in general accordance with the patients’ and families’ wishes” (Institute of Medicine [IOM], 2014). In the same way that a patient’s level of pain is whatever they say it is, what constitutes a good death is whatever the patient or family considers important at that specific moment in time and may change dramatically from one moment to the next. Researchers have examined cultural determinants, clinician, family, and patient perspectives, sociological, theological, and psychological concepts of a good death (Beckstrand et al. 2006; Bratcher, 2010; Espinosa et al. 2010; Shneidman, 2007). Under what circumstances can a hospital death, especially one in which life-sustaining treatment is withdrawn, be considered a good death?

Patients, nurses, and physicians have been able to agree upon 12 attributes that must be present in order for a death to be considered good (Kehl, 2006):

Being in control

Being comfortable

Having a sense of closure

Affirmation/value of the dying person recognized

Trust in care providers

Recognition of impending death

Beliefs and values honored

Burden minimized

Relationships optimized

Appropriateness of death

Leaving a legacy

Caring for the family

Even under the best of circumstances, few patients or families are able to achieve their conceptualization of a good death in the hospital setting. Modern medical technological advances add to the difficult and complex choices families are frequently forced to make when terminally or critically ill loved ones are receiving intensive and invasive treatment that is ultimately futile. The shift from aggressive treatment to ‘comfort care’ can be jarring and traumatic for families as well as the nurses caring for the patient.

Nursing Relationship with Families

As the primary caregivers at end-of-life, nurses often have a close, trusting, and personal relationship with patients and their families (Zomorodi & Lynn, 2010). Intensive Care nurses are in a unique position to witness the emotional, spiritual, and ethical struggles families often go through while their loved one is dying due to the extensive hours they spend at the bedside and the intimate nature of the care they provide. For families who decide to withdraw life support, the actions of the ICU nurse can positively or negatively impact the experience of a loved one’s death and may lead to complicated grieving (Bussmann et al. 2013; Nelson et al. 2010). While nurses often believe their actions are beneficial to the patient and family, only a handful of studies have attempted to capture the family’s experience of nursing care within the ICU prior to the decision to end life-sustaining treatment (Gutierrez, 2012; Robichaux & Clark, 2006).

Even fewer studies have examined the impact of nursing communication and actions on the family after the decision to withdraw treatment has been made.

Nursing Care and Withdrawal of Life-sustaining Treatment

Research indicates nurses are at the bedsides of patients before, during, and after the WOLST more than any other healthcare provider (Kirchhoff & Kowalkowski, 2010). When a physician writes the order for “comfort care” for a critically ill patient and discontinues all orders except for pain and symptoms management medications, it is the responsibility of the ICU nurse to withdraw all life-sustaining treatments (Espinosa et al. 2010). Withdrawal of life-sustaining treatment often includes weaning and cessation of mechanical ventilation with the assistance of a respiratory therapist, discontinuation of vasopressors, tube feedings, and all other non-essential curative treatments. At the same time, the nurse may be administering and titrating up analgesic and sedative medications. These actions are frequently carried out with the grieving family at the bedside, bearing witness to the final moments of life after WOLST.

In 2005, a preeminent EOL researcher published an exhaustive state of the science paper regarding “interventions designed to improve the quality of care for patients undergoing withdrawal of life-sustaining treatments” (Curtis, 2005, p. S-116). After reviewing the literature, the author endorsed 6 evidence-based interventions to improve EOL care: (1) routine ethics consultations, (2) routine palliative care consultations, (3) standardized order form for withdrawal of life-sustaining therapies, (4) family conferences, (5) quality improvement projects, and (6) a family informational pamphlet (Curtis, 2005, p. S-119). Despite the fact ICU nurses are at the bedside of the critically ill patient 24 hours a day, nursing care is mentioned only briefly by the author,

who states “critical care nurses provide an important component of the care for patients undergoing WOLST and will likely be an important part of successful interventions to improve this care (Curtis, 2005, p. S-124).

A more recent study conducted in Germany suggested ICU nurses should play a more important role in communicating with family regarding EOL care as a way to decrease family anxiety (Hartog, et al. 2015). This recommendation is supported by previous research that has identified clear, honest communication by caregivers (both nurses and physicians) as integral to family satisfaction with EOL care within the ICU (Kaufert, Murphy, Barker, & Mosenthal, 2008; Lind, Lorem, Nortvedt, & Hevrøøy, 2012; Nelson, et al. 2010).

Nursing Research on Family Satisfaction with Nursing Care at End-of-Life

Nurse scientists began studying EOL care in the mid-to-late 1990’s. Initial research focused on dying patients in the hospice setting and identification of patient, family, and provider perceptions of a good death (Kring, 2006; Steinhauser, 2000). After studies indicated the least amount of family satisfaction with EOL care within the acute care setting, researchers turned their attention to hospital deaths and the intensive care unit in particular, where aggressive, invasive EOL treatments are the norm. Due to a variety of constraints, these early studies tended to focus on physician and nurse perceptions of EOL care and quality of patient death.

There are very few studies that have attempted to elucidate specific nursing actions or behaviors that facilitate family perception of quality EOL care. Instead, the vast majority of studies have explored nursing perceptions of a good death. Two separate

studies by the same principal investigator attempted to capture ICU nurses' perceptions of facilitating/supportive behaviors during EOL care.

The first study used quantitative methods to examine the frequency and intensity of supportive behaviors and found family member issues (e.g., family members acceptance of patient dying) ranked highest in both categories (Beckstrand & Kirchhof, 2005). The second study used qualitative methods to capture explicit nursing actions that facilitated quality EOL care (Beckstrand et al. 2006, p. 41). These included:

- Making environmental changes to promote dying with dignity
- Being present
- Managing patient's pain and discomfort
- Knowing and following a patient's wishes for end-of-life care
- Promoting earlier cessation of treatment or not initiating aggressive treatment at all
- Communicating effectively as a healthcare team

Research has demonstrated attending physicians, residents, nurses, and families tend to perceive patient deaths differently (Gerritsen et al. 2013; Friedenberg, Levy, Ross, & Evans, 2012; Levy et al. 2005). Nurses are caught between advocating for the patient's wishes, caring for the family, supporting the medical team, and their own feelings of distress at not being able to do what they think is right for the patient, which is perhaps why they are more critical of the care delivered to dying patients and their families and tend to rate the quality of their death and dying lower than families or physicians (Gerritsen et al. 2013; Galanos et al. 2012). Given these competing and

complex motivations, the use of nurse perceptions of patient quality of death and dying might not provide an adequate proxy for the patient or family perceptions.

Family satisfaction and perceptions of nursing care at end-of-life. Studies focused solely on family perceptions of nursing care at end-of-life in the ICU setting are sparse (Nelson et al. 2010). The Centers for Medicare and Medicaid Services excludes families who's loved one died within the hospital from consumer surveys and few healthcare systems actively seek feedback on the care provided to patients who have died. This aversion to evaluating family perceptions of EOL care within the ICU may have its roots in the concept of death as a failure of medical science rather than a natural consequence of life (Chapple, 2010). From a research perspective, grieving families are considered particularly vulnerable and access to this population is often difficult to obtain.

Past research has found families primarily value nurses who provide their loved one comfort while dying (Nelson et al. 2010). Comfort includes managing pain, maintaining the patient's dignity, and treating the patient as a whole person (Nelson et al. 2010; Bussmann et al. 2013). While respecting the technical expertise of ICU nurses, families desire and value a nurse who demonstrates caring in action as well as words.

Research has also found families have a need to feel they are on equal footing with healthcare providers in terms of EOL decision-making (Wiegand, 2006). To accomplish this, there must be clear, honest, and frequent communication by key members of the healthcare team with the family (Nelson et al. 2010). Vague communication or failure to disclose information in regard to patient prognosis or test results by otherwise competent ICU nurses threatens to damage their relationship with

families (Lind, et al. 2012). In fact, more frequent communication is likely to improve family satisfaction with nursing care than clinical skills (Kaufer, et al., 2008).

Family satisfaction in the intensive care unit. A recent systematic review of instruments measuring family satisfaction in intensive care units determined only two instruments were thoroughly researched and demonstrated strong psychometric properties – the Critical Care Family Needs Inventory (CCFNI) and the Family Satisfaction in the ICU (FS-ICU) (Van den Broek et al. 2015). Of these two instruments, only the FS-ICU specifically measured family *satisfaction* with care. The FS-ICU has been used in 32 published studies and has demonstrated moderate to strong correlation with the family version of the Quality of Death and Dying instrument (Wall, Engelberg, Downer, Heyland, & Curtis, 2007).

A 2014 systematic review of factors associated with family satisfaction with EOL care in the ICU found only 14 studies that met inclusion criteria that included family satisfaction, ICU, and EOL (Hinkle, Bosslet, & Torke, 2015). Of the 14 studies reviewed, 7 included an interventional arm while the remaining 7 were descriptive. No qualitative studies were included.

The greatest contributor to family satisfaction identified by the review was good communication (Hinkle et al. 2015). Identified components of good communication included:

- a. Expressions of empathy and non-abandonment by members of the healthcare team
- b. Enquiring about the need for spiritual care and the provision of that care

- c. Knowing what to expect during the withdrawal of life-sustaining treatment and death

Other key components of increased family satisfaction were:

- a. Symptom management
- b. Extubation prior to death
- c. Family presence at time of death
- d. Shared decision-making
- e. Absence of CPR in the last hour of life
- f. Comfort care orders in place at the time of death

While the authors of the review did not have specific implications or recommendations for nursing EOL care in the ICU, it is clear the overarching themes could be applied to nursing practice as well as medicine. Focusing on the contributions of one discipline to family satisfaction, to the exclusion of the others is problematic. It denies the reality of the ICU environment and the strong, trusting relationships nurses have with patients and their families as well as the collaborative relationship that exists between many critical care physicians and nurses.

Quality of Death and Dying

In a review of current quality of death and dying instruments, a palliative model with five aspects of care including a) physical, b) psychological, c) social, d) spiritual, and e) organization and structure was used to determine how well instruments captured previously agreed upon salient aspects of EOL care (Mayland, Williams, & Ellershaw, 2008). The Quality of Death and Dying (QODD) instrument was found to cover all 5 aspects of care, although physical aspects of care were limited to pain and dyspnea

symptom management. Perhaps most importantly, the QODD was found to have no questions related to the family experience of care (Mayland et al. 2008). Despite this limitation, the QODD is considered the most reliable multi-item measure producing valid scores available for EOL research and (Hales, Zimmermann, & Rodin, 2010; Mayland et al. 2008).

A literature search conducted in PubMed and CINAHL Plus using the terms, 'QODD', 'family', and 'ICU' for studies published between 2005 and 2018 returned a total of 9 articles meeting the search criteria, demonstrating a paucity of rigorous research regarding family perceptions of patient quality of death and dying in ICUs. Although family, clinician, and nursing versions of the QODD exist, it has been most frequently used to assess nurse and physician perceptions of patient quality of death and dying and as detailed above, perspectives differ significantly between groups (Gerritsen et al. 2013; Levy et al. 2005).

Family perceptions of patient quality of death and dying. If the goal of palliative or comfort care is to provide a patient with a good death, can family perceptions of the quality of death be used as an acceptable proxy? While family members are able to provide objective descriptions of care delivered to a dying patient, their ability to subjectively assess the patient's response is more problematic (Hales et al. 2010; Mayland et al. 2008). Indeed, a 2004 study suggested little agreement between different members of the same family regarding their perceptions of the quality of a patient's death, calling into question the validity of the QODD and its overall usefulness as an instrument for improving quality of EOL care (Mularski et al. 2004).

A more recent study attempted to address this concern by using cognitive interviewing methodology to examine the cognitive processes that influence family members QODD scoring (Hales, Gagliese, Nissim, Zimmermann, and Rodin, 2012). Interviews were conducted to determine the judgment strategies family members used when scoring QODD items. Results of this study indicated family members frequently scored items based on a particular perspective (e.g., patient, caregiver, family member) when answering a question, with many respondents using multiple perspectives to score a single item rather than solely their own perspective (Hales et al. 2012). In addition, family members' biases or personal conceptions of a good death often played a more significant role in how they scored questions than did the patient's own priorities or directly stated wishes. An example of this was provided by the authors and described the widow of a patient who welcomed visits by friends and family, viewing them as a source of comfort and support. The patient however expressed irritation with these visits. Despite her knowledge of the patient's feelings, the widow scored the QODD item pertaining to time with family higher than the patient would have based on the importance she placed on that particular aspect of a good death (Hales et al. 2012, p. 200).

Nurse perceptions of family member death and dying. Very few studies have focused on nurse family member perceptions of patient care. In 2014, Giles and Hall conducted a systematic review of qualitative research focused on the needs and experiences of nurse family members of critically ill patients which included seven studies. Two major themes were identified in the studies included for review: (1) dual role conflicts, and (2) competing expectations.

Nurse family members often feel a conflict between their identity as *nurse* and as *family member* (Giles and Williamson, 2015). When a loved one is critically ill, it is nearly impossible for the nurse family member to turn off their “nurse self” and just be daughter, husband, mother, or sibling (Giles & Hall, 2014, p. 1458). The nurse identity quickly emerges in reaction to poor or inattentive care, family member distress, or the need to be in control.

Family, healthcare providers, and the nurses themselves, often have competing expectations of nurse family members (Giles & Williamson, 2015, p. 3103). With their professional knowledge of both medical treatment and nursing care, the nurse family member is often placed in the position of advocating for the patient, monitoring their progress or decline, explaining tests and procedure results to other family members, and generally being “in control” (Giles & Hall, 2014, p. 1459). While some family members expect the nurse to be their conduit to understanding what is happening with their loved one and ensure the patient is receiving good care, others may condemn them for being emotionally detached if they assume the *nurse* role. Conversely, a healthcare provider might resent a *nurse* questioning their treatment plan while it would be perfectly reasonable for a *family member* to do so. These competing and shifting expectations often take a heavy emotional toll on the nurse family member.

A literature search conducted on November 12, 2018 on Ovid MEDLINE® and Cinahl (keywords: nurse, family, death, dying, nurse-family member, and critical), returned a total of 14 studies, all of which were qualitative in nature. Of the 14, none focused on the perception of patient death and dying, nursing care, or the WOLST.

Summary

This chapter has reviewed the literature in regard to End-of-Life (EOL) research. It began with a background of the historical concept of good death. Next, the nurse's relationship with family and nursing care in the context of WOLST was examined. Early and later nursing research regarding family satisfaction with ICU care and perceptions of nursing care during patient EOL were presented. Next, research pertaining specifically to family satisfaction with care in the ICU was reviewed and research regarding the quality of patient death and dying both from the healthcare professional and family perspective was presented. Lastly, research specifically focused on the experience of nurse family members was reviewed.

Gaps in the Literature

Both nursing and medical research into EOL care within the ICU have neglected the voice of the family in the past; instead relying on clinician perceptions of patient quality of death. While the family perspective has slowly been woven into the body of knowledge, some significant gaps continue to exist.

First and foremost is the role nurses and nursing care in particular play in the family's perceptions of the patient's quality of death and dying. As highlighted by the 2015 systematic review of family perceptions of EOL care in the ICU, little attention has been focused solely on the nursing aspects of EOL care (Hinkle et al. 2015). While the QODD and FS-ICU instruments have been used in past research (separately and together), no studies have attempted to use them to focus exclusively on the nursing care provided to dying patients.

Secondly, while EOL research has become more prevalent, few studies have focused on care during and after withdrawal of life-sustaining treatment. This period of time is often the most potentially traumatic, emotionally charged for families of a dying patient. Nursing care can literally make or break the family's perception of the quality of the patient's death and dying. It is vitally important to determine if certain nursing behaviors, actions, and communication facilitate or are barriers to family satisfaction with EOL care and positive perceptions of the patient's quality of death and dying.

Conclusions

The first scientifically rigorous examination of EOL care in the acute care setting was the landmark trial titled Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT) (The SUPPORT Principal Investigators, 1995). Since the SUPPORT findings were published, researchers have focused on improving communication between healthcare providers and the patient and family, pain and symptom management, and reduction of ICU length of stay through reduction of futile treatment (Curtis, 2005). Unfortunately, recent studies have shown little improvement in these key aspects of EOL care and significant differences in quality of care between hospitals (DeCato et al. 2013).

Scientifically rigorous research into EOL care within the acute care setting has tended to focus on the role of the physician in improving the experience both for the patient and their family. The reality is that EOL care is at its core, nursing care. While it is the physician who ultimately takes responsibility for the order to withdrawal life-sustaining treatment, it is the nurse who will carry out those orders and provide the patient with symptom and pain management during their last hours. It is the nurse who

will comfort and support the family through the patient's dying process. It is the nurse who will be at the bedside with the family when the patient takes their last breath. What a nurse does and does not do at this critical time has a strong and lasting impact on a families' perception of the patient's death.

CHAPTER 3

METHODOLOGY

Introduction

The purpose of this study was to examine the relationship between nurse family member perceptions of the quality of patient death and dying and nursing care provided during and after withdrawal of life-sustaining treatment (WOLST) within the ICU. This chapter includes a description of sampling and recruitment, sample inclusion and exclusion criteria, instruments used, and data collection. The specific aims of this study include:

Aim 1 Describe family perceptions of patient quality of death and dying by quantitative methods using the Quality of Death and Dying (QODD) V. 3.2 instrument and three open-ended questions.

Aim 1.1 Describe the relationship between items 23-25 of the Quality of Death and Dying (QODD) V. 3.2 instrument and the total mean QODD score by quantitative methods.

Aim 2 Describe family satisfaction with nursing patient care during and after WOLST within the ICU by quantitative methods using the Family Satisfaction in the ICU (FS-ICU) and three open-ended questions.

Aim 3 Describe the relationship between family satisfaction with nursing care and family perceptions of quality of death and dying after WOLST within the ICU.

Research Design

A prospective cross sectional descriptive survey design was used to study nurse perceptions of family member death. Survey methodology is appropriate for capturing both quantitative and qualitative family perceptions of EOL care. Quantitative research methods were predominantly employed in this study. Recent studies have examined the interpretive quality of the QODD instrument and concluded family perceptions of a patient's death experience are complex, nuanced, and not easily captured (Downey et al. 2009; Hales et al. 2012). No studies have been identified that focus on the impact of satisfaction with nursing care during and after WOLST on the families' perception of the patient's quality of death and dying. For this reason, three open-ended questions were also used to identify themes and characteristics of nursing care that positively and negatively impacted the family.

The quantitative portion of the study used reliable instruments that are known to produce valid data to examine family perception of the quality of death and dying (QODD) and family satisfaction with care within the ICU (FS-ICU) after the patient has expired.

Sampling and Recruitment

After receiving University of San Diego Institutional Review Board level of oversight for the conduct of the study, the investigator recruited members of the American Association of Critical Care Nurses (AACN) through the National Organization's Research Opportunities webpage. A link on the webpage directed

potential participants to an invitation letter (see Appendix A) which prefaced the on-line survey (Survey Monkey). The letter included e-mail and phone contact information for the investigator should the potential participant want to communicate via either of those methods.

Inclusion and Exclusion Criteria

Participants chosen for inclusion in the study were nurses who had experience of a family member death after WOLST in the ICU. A family member was defined as a person with a close, personal relationship with the patient and not restricted to blood relatives. To assess family perception of the quality of death and EOL nursing care, eligible participants must have been present during and/or after WOLST and have experience of the nursing care provided to the patient. Potential participants must have been able to read English and have access to the Internet.

Quantitative Inquiry

A systematic review of measures for quality of death and dying published in 2010 found 18 instruments being used in current EOL research (Hales et al. 2010). Of the measures reviewed, the QODD had the most reliability and validity testing and was based on a conceptual framework derived from previous qualitative EOL research.

Instrumentation

This study used two instruments to assess family perceptions of quality of patient death and dying and satisfaction with care in the ICU. The Quality of Death and Dying (QODD) and Family Satisfaction with Care in the ICU (FS-ICU) instruments have high reliability, are known to produce valid data in this area of inquiry, and are well suited to

this study's aims. Following is a detailed description of the psychometric properties of each instrument.

QODD. The QODD measures family symptom burden, patient-clinician communication, and quality of care. Select participant and patient demographics are also included in the QODD (e.g., age, race, level of education).

Since 2002 there have been multiple versions of the instrument utilized in research. One version of the instrument is completed by family members, significant others, or friends of the dying person, while another version is completed by nurses and other healthcare professionals. The original family version (1.0) has been revised over time to improve instrument psychometrics and has been adapted specifically for patients who die in the ICU. The current family member version of the QODD (version 3.2A) has been deemed the most reliable instrument known to produce valid data measuring family perceptions of patient quality of death and dying within the ICU (Hales et al. 2010) (see Table 1). The family version is available in several languages, including Spanish. The total time to complete the QODD averages less than 10 minutes.

Table 1
Reported psychometric properties of various QODD family member versions

QODD Version	Reliability	Validity	Exploratory/ Confirmatory Factor Analysis
31-item Version, (Curtis, et al. 2002)	Good internal consistency (Cronbach's alpha 0.86)	Good construct validity in measures of symptom burden and patient-clinician communication about treatment preferences	N/A
29-item Version, (Downey, et. al., 2010)	N/A	N/A	Significant departure from fit. ($\chi^2 = 274.296$, $df = 79$, $P = 0.000$, $CFI = 0.848$, $TLI = 0.898$, $RMSEA = 0.110$)
22-item Version 3.2A (ICU specific)	N/A	N/A	N/A
21-item Version, (Mularski et al. 2004)	Moderate inter-rater reliability, interclass coefficient (ICC) 0.54 for frequency scoring and 0.32 for quality scoring. High internal consistency (Cronbach's alpha 0.96)	N/A	N/A
13-item Version (Downey, et. al., 2010)	N/A	N/A	Well-fit model. ($\chi^2 = 47.293$, $df = 35$, $P = 0.080$; $CFI = 0.984$; $TLI = 0.988$; $RMSEA = 0.044$)

The current family member version of the QODD (22-item, version 3.2A) is the only version available that is specifically designed for family members of patients who died in the ICU setting and is recommended by one of the instrument's authors for the purposes of this study (L. Downey, personal communication, October 30, 2015). While no psychometric properties have been reported for this particular version, all previous QODD versions have good demonstrated reliability and validity. The 22-item version QODD will provide quantitative data to describe family perceptions of patient quality of death and dying. This data, in combination with three open-ended questions, will provide a nuanced assessment of family perceptions of patient death and dying in the ICU after WOLST.

The current family member QODD is a self-administered instrument. The first 22 items of the instrument are organized into two parts (frequency and experience), both generating ordinal levels of data (Curtis et al. 2002).

Part one of items 1-22 asks for frequency of certain experiences (e.g., having pain under control, breathing comfortably) with item level responses ranging from 0 (none of the time) to 5 (all of the time), or 6 (don't know).

Part two of item 1-22 asks, in relation to part one (e. g., having pain under control, breathing comfortably) for a rating of the family's experience of that aspect of the loved one's dying. Part two item level responses range from 0 to 10; with 0 being a "terrible experience" and 10 being an "almost perfect experience" (Curtis et al. 2002).

Additional items are added to the QODD V. 3.2 by the instrument's authors for validity testing and are not calculated into the total QODD score. These items were included in this study for validity testing as well. The first item (23) asks the respondent

to rate the quality of the loved one's dying on a scale of 0 to 10 (terrible to almost perfect). The second item (24) asks the respondent to rate the care provided by all providers during the last days in the ICU on a scale of 1 to 10 (worst health care possible to best health care possible). The third item (25) asks the respondent to rate the care provided by the physician during the last days in the ICU on a scale of 1 to 10 (worst health care possible to best health care possible).

The total score of the QODD is calculated in a series of steps. First, all part two (experience) responses are summed. Second, a mean score is calculated by dividing the sum of part two responses by the total number of valid part two responses. Lastly, the mean score is divided by the total range of responses (10) and then multiplied by 100. Part one of items 1-22 are not factored in the total QODD score. The QODD total score ranges from 0 to 100, with total scores on the higher end indicating a better perceived quality of death and dying experience. Per the authors, the creation of a total QODD score is due to preliminary factor analysis not supporting subscale construction (Curtis et al. 2002, p. 19). An additional Likert-10 ordinal scale is included in the QODD to assess the burden of completing the survey (with 0 being no burden, to 10 being a great burden). It was included in the on-line survey to examine the burden of participating in the study.

Two open-ended questions supplemented the QODD data with exemplars of family perceptions of patient death and dying (discussed below).

FS-ICU. The FS-ICU measures total family satisfaction with care in the intensive care unit as well as subscale constructs of satisfaction with decision-making and care. Select participant and patient demographic data is included in the FS-ICU (e.g., age, gender, relation to patient).

The original version of the instrument was developed in 2003 with a Canadian population and contained 34 items (Heyland and Tanner, 2001). In 2006, American and Canadian cohorts were used in a study to refine and determine if the instrument could produce valid data in an US sample, leading to the current 24-item FS-ICU (Wall et al. 2007). The FS-ICU has been translated into several languages including Spanish, German, Chinese, Hebrew, and French. The total time to complete the FS-ICU averages less than 15 minutes.

The 24-item FS-ICU is a self-administered instrument generating total satisfaction and two subscale scores: satisfaction with care (14 items) and satisfaction with decision-making (10 items). An additional 3 items (25-27) are not included in the FS-ICU total or subscale scores. These items deal specifically with perceptions of care if the patient died while in the ICU.

The 14-item satisfaction with care subscale uses a Likert-5 ordinal response scale (e.g., 1=Excellent, 5 = Poor). Five items of the 10-item satisfaction with decision-making subscale use Likert-5 ordinal response scales (e.g., 1=Excellent, 5 = Poor) while the remaining five items have discontinuous responses. Four of the discontinuous items have 5-item nominal response scales (e.g., feeling totally overwhelmed to feeling totally supported), while the remaining item has a two-item nominal response scale.

The FS-ICU total score is calculated first by recoding the 5 discontinuous items into ordinal scales and then transforming them to have the same response values as the rest of the FS-ICU items. Next, all items are linearly transformed by subtracting the lowest possible item value from the actual item value, dividing it by the possible item

range, and then multiplying by 100. The subscale scores are calculated in the same manner.

Both total and subscale FS-ICU scores range from 0-100, with 0 indicating least satisfied and 100 indicating most satisfied. Higher total scores indicate greater satisfaction with care (Wall, et al. 2007).

To address the issue of using ordinal scales for calculating mean scores and other statistical tests requiring a continuous distribution, the instrument authors stated, “because factor analysis can be biased when variables are on an interval scale, we based our analyses on polychoric correlations, which assume that interval level data are representative of an underlying, continuous distribution” (Wall, et al. 2007, p.272). In other words, per previous work conducted the instrument authors, using the assumption of a continuous distribution allows for the use of statistical procedures normally only applicable for continuous data. For purposes of this study, items 25-27 were reported in mean, median, and percentages (see Chapter 4).

The FS-ICU has documented strong reliability with Cronbach $\alpha = 0.94$ for total satisfaction, 0.92 for satisfaction with care, and 0.88 for satisfaction with decision-making. Moderate correlation is demonstrated between the 2 subscales (Spearman's $\rho = 0.73$, $\rho < 0.001$). In addition, the FS-ICU total satisfaction with care and both subscale scores have demonstrated strong correlation with the Family version of the QODD (Wall et al. 2007).

Factor analysis of the 24-item FS-ICU determined the 2-subscale factors explain 61.3% of observed variance with minimal improvement when expanded to a 3-factor model (Wall et al. 2007). Similar factor analysis findings were also demonstrated using

an ethnically and racially diverse ICU and therefore is well suited for heterogeneous populations. Regarding missing data in previous studies, analysis using tests of construct validity demonstrated there was no significant differences between respondents and non-respondents in terms of age and gender (Wall et al. 2007). Select participant and patient demographic data is included in the FS-ICU (e.g., age, race, level of education).

The FS-ICU is considered one of the most reliable instruments for measuring family satisfaction with ICU care. For purposes of this study, the FS-ICU provided quantitative data regarding family satisfaction with nursing care within the ICU during and after WOLST. An open-ended question supplemented FS-ICU data with exemplars of perceptions of nursing care (discussed below).

Demographic Data

Patient and nurse family member data were collected for this study. Demographic items for both patient and family member exist in both the QODD and FS-ICU surveys. Redundant demographic data between the two instruments were eliminated for the on-line survey (all QODD items were retained, while two FS-ICU items were added). Additional nurse family member demographic data collected included: participant's years of nursing experience and primary area of nursing practice (Critical Care or other).

Three open-ended questions were also included in the on-line survey. Responses to these questions were typed into text boxes embedded within the on-line survey. The purpose of this data collection was to obtain the participant's perceptions of family member death in dying and satisfaction with nursing care within the context of being a nurse to supplement the QODD and FS-ICU.

Participants were asked three specific questions:

- 1) How do you feel your experience as a nurse influenced your perceptions of your family member's death?
- 2) What was your perception of the nursing care of your family member during and after the withdrawal of treatment?
- 3) Do you believe your family member had a "good death"? Why, or why not?

Although the focus of this study was on the family experience, certain patient characteristics, such as those listed above, may have significantly impacted perceptions of patient death. This data enabled the researcher to place family perceptions within context, thereby allowing for a deeper understanding of each family's experience.

Quantitative Data Analysis

Portions of the three study aims were analyzed using quantitative analytic methods.

Aim 1 Describe family perceptions of patient quality of death and dying by quantitative methods using the Quality of Death and Dying (QODD) V. 3.2 instrument.

To address aim 1, the total QODD score was calculated and descriptive statistics performed. T-tests were conducted to determine if statistical differences exist between groups (e.g., gender, age, level of education) for the QODD scores.

Aim 1.1 Describe the relationship between each of the items 23, 24, and 25 of the Quality of Death and Dying (QODD) V. 3.2 instrument and the total mean QODD score.

Aim 1.1 is designed to address the validity of the QODD. To address this aim, the mean scores of each of the items (23, 24, and 25) of the QODD and the total QODD mean score were calculated and bivariate correlations were performed to determine if any

association existed between each of the three items mean scores and the total QODD mean score.

Aim 2 Describe family satisfaction with nursing patient care after WOLST within the ICU by quantitative methods using the Family Satisfaction in the ICU (FS-ICU). To address aim 2, the total FS-ICU and 2 subscale scores were calculated and descriptive statistics performed. In addition, T-tests were also performed for the FS-ICU scores and demographic variables (e.g., gender, age, level of education) in order to determine if any differences existed between the demographic variable groups.

Aim 3 Describe the relationship between select demographics, [independent variable (IV)], satisfaction with nursing care (IV), and family perceptions of quality of death and dying [dependent variable (DV)] after WOLST in the ICU. To address aim 3, bivariate correlations were examined between select demographics, total FS-ICU mean score, each of the 2 FS-ICU subscale mean scores, and the total QODD mean score. Had bivariate correlations been found to be significant, a linear regression model would have been constructed to determine the amount of variance in the dependent variable as determined by the independent variables.

Because the FS-ICU total satisfaction with care scores and both subscale scores have demonstrated strong correlation with the family version of the QODD in previous research (Wall et al, 2007), aspects of multicollinearity would have been considered prior to determining the final fit of a linear regression model.

Qualitative Data Analysis

Directed content analysis was used to analyze the qualitative data collected from the three open-ended questions included in the on-line survey. Directed content analysis

is used when prior research exists on a topic but further description would be beneficial to the understanding of the phenomena (Hsieh & Shannon, 2005). Directed content analysis is more structured than summative or conventional content analysis, using previous research and theoretical frameworks to inform initial coding categories and operational definitions.

Categorical Coding and Operational Definitions

Using pre-existing EOL research and theoretical frameworks, the investigator initially identified key concepts or variables as possible a priori coding categories as defined below. Coding categories and operational definitions for the directed content analysis were finally derived from a systematic review by Giles and Williamson (2014) which identified two major themes in the experiences of nurses with critically ill family members.

The categories of *dual role conflict* and *competing expectations* (Giles & Williamson, 2014, 2015) were used for the purpose of examining nurses' perceptions of family member death and dying. Working operational definitions for these categories were:

Dual role conflict – shifting perspectives, nurse-self versus family member-self

Competing expectations – advocating for the patient, monitoring progress or decline, explaining tests and procedure results to other family members, liaison to healthcare team, directing and/or providing care for the patient

The investigator used the following steps to analyze the qualitative data:

Transcripts were read and passages that appeared to represent pre-determined categories of interest were highlighted.

Highlighted passages were read again and coded using the pre-determined categories.

Integration of Quantitative and Qualitative

As previously described above, qualitative data gathered from open-ended questions was used to address the study's first and second aims to describe additional family perceptions of the quality of death and dying and nursing care provided during and after WOLST. This data was analyzed using directed content analysis with initial coding categories based upon the two previously identified themes of *dual role conflict* and *competing expectations*.

In order to integrate the quantitative and qualitative results, each participant's total mean QODD total FS-ICU, and subscales mean scores were compared to the ranked qualitative data to determine if they captured any extreme positive or negative experiences expressed by the participant. Qualitative data supporting and/or contradicting participant QODD or FS-ICU scores were examined and presented as exemplars in the write up of results.

Study Limitations

This study had several limitations. First and foremost, the small sample size does not lend itself to generalization. By limiting participation to nurses only (a predominantly female population), this study does not generalize to other genders or to family members not in the nursing profession. Due to the sensitive and highly personal nature of the phenomenon under study, self-selection bias is a strong possibility. Most importantly, recall of specific events during and after WOLST may be impacted by the passage of time, grief, or other unknown variables.

Summary

This study adds to the growing body of literature regarding family perceptions of ICU nursing EOL care provided to their family member during and after WOLST. By specifically studying family perceptions of quality of patient death and dying and satisfaction with nursing care, possible testable interventions may be designed for future studies in order to improve family outcomes and decrease their emotional burden. Lastly, qualitative findings regarding nursing care during and after WOLST that were either positively or negatively perceived by the family might be incorporated into nursing EOL education.

CHAPTER 4

RESULTS

The purpose of this cross sectional descriptive research pilot study was to examine nurse family perceptions of patient quality of death and dying and satisfaction with nursing care after WOLST in the Intensive Care Unit (ICU). The Quality of Death and Dying (QODD) V3.2 instrument was used to capture perceptions of patient death and dying, while the Family Satisfaction in the ICU (FS-ICU) instrument was used to capture satisfaction with nursing care. Select participant and patient demographics were also collected to determine if specific factors (e.g., age, gender, level of education, ICU length of stay) were associated with perceptions of care or patient quality of death.

Data collection occurred between December 6, 2018 and March 6, 2019.

Participants were recruited through the National American Association of Critical Care (AACN) website under their Research Opportunities page.

Sample Size

Of the approximate AACN membership of 120,000 nurses, only 18 elected to participate in the study. One participant was excluded from data analysis due to a large number of missing responses, leaving a total of 17 participant responses included in the final data analysis. Statistical analyses were performed using IBM Statistical Package for the Social Sciences (SPSS) version 24.

Demographics

A total of 16 respondents provided demographic data for this study. The mean age of respondents was 50.1 ($SD = 11.5$), with a range of between 27 to 63 years. The majority of respondents were female ($n=14$, 87.5%), non-Hispanic ($n=14$, 93.3%), and identified as White or Caucasian ($n=10$, 66.7%). In terms of nursing experience, the majority of respondents ($n=8$, 50%) worked within critical care units, while the mean number of years spent in the profession was 18.9 years ($SD=13.2$). In regard to education, three respondents (20.0%) had an Associate's degree, seven (46.7%) had a Bachelor's degree, and five (33.3%) had a Graduate degree or higher. Descriptive statistics for these demographic variables can be found in Table 2.

Table 2
Participant Characteristics

Characteristics ($n=17$)	N (%)	Mean (SD)	Range
Age	16	50.1 (11.5)	27-63
Gender			
Female	14 (87.5)		
Ethnicity			
Non-Hispanic	0 (0.0)		
Hispanic	14 (93.3)		
Prefer not to answer	1 (6.7)		
Race			
Asian/Asian American	3 (20.0)		
White/Caucasian	10 (66.7)		
Prefer not to answer	2 (13.3)		

Nursing Experience (Years)	14	18.9 (13.2)	2-41
Level of Education			
Associate Degree	3 (20.0)		
Bachelor Degree	7 (46.7)		
Graduate Degree	5 (33.3)		
Area of Practice			
Critical Care	8 (50.0)		
Progressive Care	2 (12.5)		
Medical/Surgical	4 (25.0)		
Emergency Department	2 (12.5)		

Study Aim 1

Describe family perceptions of patient quality of death and dying by quantitative methods using the Quality of Death and Dying (QODD) V. 3.2 instrument.

Quality of Death and Dying Instrument V. 3.2

Nurse perceptions of the quality of a family member's death and dying were examined using the 22-item Quality of Death and Dying (QODD) instrument V. 3.2. The methodology for scoring the QODD was fully detailed within Chapter Three.

As a reminder, per instrument scoring instructions, the *frequency* of certain experiences (e.g., having pain under control, breathing comfortably), measured in part one responses of items 1-22 were not calculated into the total QODD score. The total QODD score was calculated by using only the *experience* of the quality of certain aspects of patient's death and dying (e. g., having pain under control, breathing comfortably), which was measured in part two of items 1-22 using a Likert-type scale with responses range from 0 to 10; with 0 being a "terrible experience" and 10 being an "almost perfect experience".

QODD individual items. Individual item scores were measured on a scale from 0-10, not the 0-100 scale of the total QODD. The perceptions of the quality of a family member's death and dying *experience* scores ranged from 4.88 to 8.12, with a mean score of 6.07 ($SD = 2.10$). The three lowest scoring individual *experience* items were: item 7b, how often the loved one laughed and smiled ($m=4.88, SD =2.94$), item 5b, how often the loved one appeared to breathe comfortably ($m=5.12, SD=3.16$), and item 3b, how often a loved one was able to feed themselves ($m=5.20, SD=2.76$).

The highest scoring individual *experience* items were: items 9b, how often a loved one spent time with family or friends ($m=8.12, SD=1.73$), item 12b, whether all of a loved one's health care costs taken care of ($m=7.93, SD=3.13$), and item 11b, how often a loved one was touched or hugged by family or friends ($m=7.76, SD=3.10$). See Table 3 for each individual item mean score.

Total Mean QODD Score. The total QODD mean score was calculated by dividing the sum of part two responses by the total number of valid part two responses. This mean score was then divided by the total range of responses (10), and multiplied by 100 giving a range of scores between 0-100, with higher scores indicating better perceptions of the quality of a patient's death.

The total mean QODD score was 60.75 ($SD = 21.02$), which indicated the respondents overall experience of their loved one's death was relatively positive.

Table 3
QODD Individual Item and Total Mean Scores

Item	N	Mean	SD
1a. How often did your loved one appear to have his/her pain under control?	17	3.71	.85

Item	N	Mean	SD
1b. How would you rate this aspect of your loved one's dying experience?	17	7.59	1.77
2a. How often did your loved one appear to have control over what was going on around him/her?	17	2.35	1.97
2b. How would you rate this aspect of your loved one's dying experience?	15	6.20	2.51
3a. How often was your loved one able to feed her/himself?	17	1.82	2.07
3b. How would you rate this aspect of your loved one's dying experience?	15	5.20	2.76
4a. How often did your loved one appear to breathe comfortably?	17	3.00	1.28
4b. How would you rate this aspect of your loved one's dying experience?	17	5.12	3.16
5a. How often did your loved one appear to feel at peace with dying?	17	3.41	2.06
5b. How would you rate this aspect of your loved one's dying experience?	15	6.00	3.19
6a. How often did your loved one appear to be unafraid of dying?	17	3.18	2.35
6b. How would you rate this aspect of your loved one's dying experience?	14	5.71	3.52
7a. How often did your loved one laugh and smile?	17	1.47	1.81
7b. How would you rate this aspect of your loved one's dying experience?	16	4.88	2.94
8a. How often did your loved one appear to keep his/her dignity and self-respect?	17	2.35	1.87
8b. How would you rate this aspect of your loved one's dying experience?	16	6.06	2.46
9a. How often did your loved one spend time with his/her family or friends?	17	4.24	.83
9b. How would you rate this aspect of your loved one's dying experience?	17	8.12	1.73
10a. How often did your loved one spend time alone?	17	.82	.88
10b. How would you rate this aspect of your loved one's dying experience?	17	6.12	3.48

Item	N	Mean	SD
11a. Was your loved one touched or hugged by his/her loved ones?	17	1.35	1.22
11b. How would you rate this aspect of your loved one's dying experience?	17	7.76	3.01
12a. Were all of your loved one's health care costs taken care of?	17	1.41	.80
12b. How would you rate this aspect of your loved one's dying experience?	14	7.93	3.13
13a. Did your loved one say goodbye to loved ones?	17	2.35	.86
13b. How would you rate this aspect of your loved one's dying experience?	11	5.91	3.75
14a. Did your loved one clear up any bad feelings with others?	17	2.24	.90
14b. How would you rate this aspect of your loved one's dying experience?	12	5.83	3.59
15a. Did your loved one have one or more visits from a religious or spiritual advisor?	17	1.18	.53
15b. How would you rate this aspect of your loved one's dying experience?	16	7.56	3.01
16a. Did your loved one have a spiritual service or ceremony before his/her death?	17	1.65	.70
16b. How would you rate this aspect of your loved one's dying experience?	14	7.43	3.25
17a. Did your loved one receive a mechanical ventilator (respirator) to breathe for him/her?	17	1.53	.51
17b. How would you rate this aspect of your loved one's dying experience?	16	6.25	3.59
18a. Did your loved one receive dialysis for his/her kidneys?	17	1.94	.24
18b. How would you rate this aspect of your loved one's dying experience?	13	7.62	3.10
19a. Did your loved one have his or her funeral arrangements in order prior to death?	17	1.76	.56
19b. How would you rate this aspect of your loved one's dying experience?	16	6.31	3.09
20a. Did your loved one discuss his or her wishes for end of life care with his/her doctor -- for example, resuscitation or intensive care?	17	1.82	.73

Item	N	Mean	SD
20b. How would you rate this aspect of your loved one's dying experience?	14	5.79	3.36
21a. Was anyone present at the moment of your loved one's death?	17	1.24	.56
21b. How would you rate this aspect of your loved one's dying experience?	17	7.69	3.18
22a. In the moment before your loved one's death, was he/she: (awake, asleep, in a coma or unconscious)	17	2.59	.71
22b. How would you rate this aspect of your loved one's dying experience?	17	6.35	3.22
23. Overall, how would you rate the quality of your loved one's dying?	17	6.76	2.66
24. Rate the care your loved one received from nurses during the last several days of his or her life while in the ICU.	16	8.63	1.50
25. Rate the care your loved one received from his or her doctor during the last several days of his or her life while in the ICU.	17	7.53	2.38
Total QODD Mean Score	17	60.75	21.02

Inferential Statistics. Independent Samples T-tests were performed on select demographic variables (race, relationship to patient, education level, years of nursing practice, area of practice, and both hospital and ICU length of stay) to determine if any statistical differences existed between any of the QODD mean scores by groupings within those variables. Due to the small sample size for each grouping, a number of groups within each of the demographic variables were collapsed and recoded. The results indicated there were no statistically significant differences between any groups for each of the variables.

Study Aim 1.1

Describe the relationship between items 23-25 of the Quality of Death and Dying (QODD) V. 3.2 instrument and the total mean QODD score by quantitative methods.

This aim addressed the validity of the QODD.

QODD Items 23 through 25

Item 23. Item 23 asked the respondent to rate the quality of the loved one's dying on a scale of 0 to 10 (terrible to almost perfect). The mean score of all respondents' experience of the quality of their loved one's death (item 23) was 6.76 ($SD = 2.66$), which strongly correlated with the overall mean score (6.07, $SD=2.10$) of the individual items ($r = .749$; $p = .001$).

Item 24. Item 24 asked the respondent to rate the care provided by nurses during the last days in the ICU on a scale of 1 to 10 (worst health care possible to best health care possible). The mean score of all respondents' experience of care provided by nurses (item 24) was 8.63 ($SD = 1.50$), which demonstrated a weak correlation with the mean individual item score ($r = .274$; $p = .30$).

Item 25. Item 25 asked the respondent to rate the care provided by the physician during the last days in the ICU on a scale of 1 to 10 (worst health care possible to best health care possible). The mean score of all respondents' experience of the care provided by physicians was 7.53 ($SD = 2.38$), which had a moderate correlation with the individual item mean score ($r = .639$; $p = .006$).

Assessment of QODD validity. Items 23, 24, and 25 were used to assess the validity of the QODD. Item 23, which assessed the overall perception of the quality of

death, strongly correlated with the total QODD mean score, whereas care provided by physicians and nurses had only moderate to low correlation (respectively) to the total QODD mean score. As this instrument was developed to assess perceptions of the quality of patient death and dying and not perceptions of care provided, items 24 and 25 do not alter the instrument's validity.

Study Aim 2

Describe family satisfaction with nursing patient care after WOLST within the ICU by quantitative methods using the Family Satisfaction in the ICU (FS-ICU).

Family Satisfaction in the ICU Instrument

Nurse satisfaction with the quality of a family member's care was examined using the 24-item Family Satisfaction in the ICU (FS-ICU) instrument. Mean scores were calculated for total family satisfaction with care in the ICU as well as the subscale constructs of satisfaction with decision-making and care in the manner described in Chapter 3.

FS-ICU Individual Items. Family satisfaction with care and decision-making mean scores ranged from 50.00 to 83.82, with a mean score of 68.22 ($SD = 7.43$). The three lowest scoring individual items were item 13 (atmosphere of the ICU waiting room) with a mean of 50.00 ($SD = 31.01$), item 15 (how often physicians communicated with family) with a mean of 54.41 ($SD = 36.70$), and item 5 (how well ICU staff supported the emotional needs of family) with a mean of 58.33 ($SD = 34.93$).

The highest scoring individual mean items were item 21 (inclusion in decision-making) with a mean of 83.82 ($SD = 27.87$), item 9 (how well nurses cared for the family

member) with a mean of 79.41 ($SD = 18.19$), and item 23 (feeling in control of the care of the family member) with a mean of 77.94 ($SD = 26.34$).

Family satisfaction in the ICU total and subscale mean scores. The total mean score for FS-ICU was 67.75 ($SD = 21.51$), indicating a moderate level of satisfaction with care in the ICU using a scale of 0-100 (with 0 indicating least satisfied and 100 indicating most satisfied). The 14-item satisfaction with care subscale total mean score was 67.82 ($SD = 21.05$), while the 10-item satisfaction with decision-making subscale mean score was 69.30 ($SD = 23.48$), indicating the highest level of satisfaction was with decision making within the ICU. See table 4 for individual item, total, and subscale mean scores.

Additional items. Items 25-27 of the FS-ICU are specific to patients who died while in the ICU and were not calculated into the total FS-ICU or subscale scores per instructions of the instrument authors. Item 25 employed a nominal scale to assess whether the respondent felt their family member's life was prolonged or shortened unnecessarily (with 1 being prolonged unnecessarily and 5 being shortened unnecessarily). The median score for item 25 was 50.00, with the majority of respondents (76.5%) indicating they felt their family member's life was neither prolonged nor shortened unnecessarily.

Item 26 employed a nominal level scale to assess whether the respondent felt the family member was comfortable in the final hours of their life (with 1 being very uncomfortable and 5 being totally comfortable). The median score for item 26 was 75.00, with the majority of respondents (76.4%) indicating their family member was either mostly, very, or totally comfortable.

Lastly, item 27 employed a nominal scale to assess whether the respondent whether they felt abandoned or supported by the healthcare team in the last few hours prior to their family member's death (with 1 being very abandoned and 5 being very supported). The median score for item 26 was 75.00, with the majority of respondents (76.5%) indicating they felt either supported or very supported by the healthcare team in the last few hours of their family member's life.

Table 4

Family Satisfaction in the ICU Individual Item, Total, and Subscale Mean scores

Item	N	Mean	SD
1. The courtesy, respect and compassion your family member (the patient) was given	16	73.44	24.35
2. How well the ICU staff assessed and treated your family member's pain	16	75.00	24.15
3. How well the ICU staff assessed and treated your family member's breathlessness	15	66.67	27.82
4. How well the ICU staff assessed and treated your family member's agitation	12	66.67	30.77
5. How well the ICU staff showed an interest in your needs in terms of consideration	16	65.63	32.76
6. How well the ICU staff showed an interest in your needs in terms of emotional support	15	58.33	34.93
7. The teamwork of all the ICU staff who took care of your family member	16	71.88	23.94
8. The courtesy, respect and compassion you were given by ICU staff	16	70.31	29.18
9. How well the nurses cared for your family member	17	79.41	18.19
10. How often nurses communicated to you about your family member's condition	17	69.12	28.66
11. How well doctors cared for your family member	17	66.18	26.43
12. The atmosphere of the ICU was?	16	64.06	20.35
13. The atmosphere of the ICU waiting room was?	14	50.00	31.01
14. How satisfied were you with the LEVEL or amount of health care your family member received in the ICU?	17	70.59	20.22

Item	N	Mean	SD
15. How often doctors communicated to you about your family member's condition	17	54.41	36.70
16. Willingness of ICU staff to answer your questions	16	67.19	25.36
17. How well ICU staff provided you with explanations that you understood	15	65.00	28.03
18. The honesty of information provided to you about your family member's condition	17	69.12	24.25
19. How well ICU staff informed you what was happening to your family member and why things were being done	15	66.67	26.13
20. The consistency of information provided to you about your family member's condition (Did you get a similar story from the doctor, nurse, etc.)	17	67.65	27.62
21. Did you feel included in the decision-making process?	17	83.82	27.87
22. Did you feel supported during the decision-making process?	17	73.53	27.20
23. Did you feel you had control over the care of your family member?	17	77.94	26.34
24. When making decisions, did you have adequate time to have your concerns addressed and questions answered?	17	64.71	49.26
FS-ICU Total Mean Score	16	67.75	21.51
FS-ICU Care Subscale Mean Score	16	67.82	21.05
FS-ICU Decision-Making Subscale Mean Score	17	69.30	23.48
<u>Additional items</u>			
25. Did you feel your family member's life was prolonged or shortened unnecessarily?	17	51.47	22.48
26. During the final hours of your family member's life, what was their comfort level?	17	63.24	32.01
27. During the last few hours before your family member's death, did you feel abandoned or supported by the healthcare team?	17	77.94	23.19

Inferential Statistics. Independent Samples T-tests were performed on select demographic variables (race, relationship to patient, education level, years of nursing practice, area of practice, and both hospital and ICU length of stay) to determine if any

statistical differences existed between any of the FS-ICU mean scores by groupings within those variables (e.g., education level: undergraduate vs. graduate). Due to the small sample size for each grouping, a number of variables were collapsed and recoded. The results indicated there were no statistically significant differences between any groups for each of the variables.

Study Aim 3

Describe the relationship between family perceptions of quality of death and dying and satisfaction with nursing care after WOLST in the ICU.

QODD and FS-ICU. As a first step to address aim three, bivariate correlations were examined between the total QODD, total FS-ICU, and two FS-ICU subscale scores. While strong correlations were found between the total FS-ICU and its two subscales, no correlation was found between the total QODD, total FS-ICU, and FS-ICU subscale scores (see table 5).

Linear regressions were not performed because there were no significant relationships between the total QODD, total FS-ICU, or total subscale scores.

Table 5
Relationship between QODD and FS-ICU

		FS-ICU Total	FS-ICU Care	FS-ICU DM	QODD Total score
FS-ICU Total	Pearson Correlation	1	.971**	.955**	.084
	Sig. (2-tailed)		.000	.000	.757
	N	16	16	16	16
FS-ICU Care	Pearson Correlation	.971**	1	.858**	.064
	Sig. (2-tailed)	.000		.000	.813
	N	16	16	16	16
FS-ICU DM	Pearson Correlation	.955**	.858**	1	.152
	Sig. (2-tailed)	.000	.000		.559
	N	16	16	17	17

QODD Total score	Pearson Correlation	.084	.064	.152	1
	Sig. (2-tailed)	.757	.813	.559	
	N	16	16	17	17

** . Correlation is significant at the 0.01 level (2-tailed).

Qualitative Data Analysis

To address the qualitative portions of aims one, two, and three, directed content analysis was performed on participant responses to the three open-ended questions included in the on-line survey. Despite the limited sample size, numerous responses demonstrated the themes of *dual role conflict* and *competing expectations* identified in previous research (Giles & Hall, 2014).

The most common theme present in participants' responses was *competing expectations*, in which the nurse family member is expected (either by other family, the healthcare team, or themselves) to advocate for the patient, monitor and explain test results, or step in to assume care if necessary. One participant described how she supported her family by being a resource, "as a nurse and a member of a family that was dying, it makes a big impact to the family being you can support and explain to your other family members of what's going on".

Another participant described her role as patient advocate as being integral to her mother having a good death, demonstrating both *competing expectations* and *dual role conflict*, "I think part of her good death was related to my advocacy. There was conflict between the physicians and myself, they wanted to keep going despite a new organ failing daily".

In regard to the question of how experience as a nurse influenced perceptions of family member death, one participant stated, "as a nurse I was more aware of my

mother's needs, understood her condition, and was aware of the resources available for her". There were both benefits and drawbacks to having professional experience however, as one participant noted, "I felt I was more prepared myself compared to other family members. I also felt hyperaware of everything the nursing staff and doctors were doing and could be doing more of", which also demonstrated aspects of *dual role conflict*.

Quantitative and Qualitative data integration. Responses related to the quality of nursing care were mixed, with one participant praising the care their family member received, "the nurses were fantastic in explaining everything and making sure we were doing ok emotionally". Despite the positive experience of nursing care and a relatively high score on the total FS-ICU and Care subscale (67.71 and 62.5, respectively), this participant had one of the lowest total QODD scores (38.63), which underscores the weak correlation between nursing care and overall perceptions of the quality of patient death perception detailed previously in this chapter.

Another participant who had an especially traumatic experience with the death of her husband, "I feel very, very sad, angry, and hurt...we didn't get a chance to talk to him for the last time and never get chance to say goodbye" had a total QODD mean score of 11.76, yet had a mean of 92.86 on the FS-ICU Care subscale and 85.42 on the total FS-ICU mean score. Despite the overwhelming shock of the sudden critical illness and subsequent death of her husband, this participant appeared to have completely separated the quality of the care within the ICU from the quality of her husband's death.

Overall, the total mean score of the QODD tended to capture participant's extreme positive and negative experiences as reflected in their responses to the question

of whether or not they believed their family had a *good death*. For example, the participant who responded, “All of our wishes for her were granted... she had a peaceful death”, had a total mean QODD of 82.27, while the participant who responded, “Life prolonged needlessly”, had a total mean QODD score of 49.44.

In regard to perceptions of nursing care, both total mean FS-ICU and the Care subscale mean score tended to capture participants’ extreme positive and negative experiences. For example, the participant who stated, “I felt the staff treated my mother with dignity and respect. They were all professional with all the care and compassion” had a total mean FS-ICU score of 94.79 and a Care subscale mean score of 92.86, while the participant who stated, “after withdrawal, very little contact until pronounced” had a total mean FS-ICU score of 42.05 and a Care subscale mean score of 39.58.

Study Burden

In regard to the burden of participating in the study, on a scale of 0-10, with 0 being no burden, to 10 being a great burden, the mean score was 2.63 ($SD = 3.14$), which indicated a perceived low level of burden.

Summary

In summary, the total QODD, and total FS-ICU mean scores and qualitative data analysis indicated respondents were moderately satisfied with both the quality of their family member’s death and with the care they received during and after WOLST. Despite previous research that demonstrated strong correlation between QODD and FS-ICU total scores, the results of this study demonstrated no statistically significant association between the two instruments. Discussion of findings will be presented in the next chapter.

CHAPTER 5

DISCUSSION

The purpose of this pilot study was to examine nurses' perceptions of the quality of care a family member received during and after the withdrawal of care within the Intensive Care Unit as well as the quality of the family member's death and dying. This chapter summarizes the study findings, explores the differences and similarities to previous research, details the strengths and limitations of the study, and discusses implications for further research.

Summary of Study Findings

This pilot study was unique in several ways. First, it focused on satisfaction with care and the perception of quality of patient death and dying within the context of WOLST in the ICU. Second, participation in the study was limited to nurse family members, a population rarely studied. Lastly, previous studies focused on nurse family members only used qualitative methodology.

As previously detailed in Chapter Four, participants in the study (N=17) tended to view the quality of their family member's death and dying somewhat positively. On a scale of 1-100, with scores on the higher end indicating a better quality of experience, the total mean score of the QODD for the study sample was 60.75 ($SD = 21.02$). In terms of

the satisfaction with the care received in the ICU, participants again tended to rate their experience relatively positive with a total mean score for the FS-ICU of 66.40 ($SD = 21.56$) on a scale of 1-100. FS-ICU subscale scores demonstrated similar levels of satisfaction, with a Care subscale mean score of 68.97 ($SD = 20.93$) and Decision-Making subscale score of 69.30 ($SD = 23.48$). There was no correlation between QODD and FS-ICU (total and subscale) scores.

Qualitative data analysis demonstrated both extreme positive and negative experiences of patient death and dying and were supported by the total QODD mean score. Higher total QODD mean scores (greater than 50.0) tended to reflect participants' perceptions their family member experienced a *good death*, while mean scores less than 50.0 were supported by participants' statements, such as, "life was prolonged needlessly", or "his death is very unexpected".

Similarly, examples of extreme positive and negative perceptions of nursing care were reflected in both the participant's total FS-ICU and Care subscale mean scores. Means scores for the total FS-ICU and Care subscale above 50.0 were associated with positive experiences. for example, the participant who stated, "I felt the staff treated my mother with dignity and respect" had a total mean FS-ICU score of 94.79 and a Care subscale mean score of 92.86, while the participant who stated, "after withdrawal, very little contact until pronounced" had a total mean FS-ICU score of 42.05 and a Care subscale mean score of 39.58.

Perceptions of Patient Death and Dying and the Concept of Good Death

An analysis of the concept of a good death identified 12 attributes that need to be present in order for family to perceive a patient's death as good (Kehl, 2006). The

Quality of Death and Dying V. 3.2 instrument was developed and refined to align with these key attributes and was intended for use by family members of patients who died in the hospital or ICU setting (Patrick, Engelberg, and Curtis, 2001). This pilot study utilized the aforementioned version of the QODD (V.3.2) to measure nurse family member perceptions of the quality of death and dying. Additional detail regarding why a participant believed their family did or did not have a good death was provided in response to an open-ended question included in the on-line survey.

Family perspectives on the quality of patient death and dying. In this pilot study, participants had a moderately positive perception of their family member's death and dying. In response to the question regarding perception of overall quality of loved one's dying (item 23), the mean score for all participants was 6.76 ($SD = 2.66$), with scores ranging from 0-10 (on a 0-10 scale). In regard to the overall perception of quality of death and dying (total QODD score), the mean score for participants was 60.75 ($SD = 21.02$) with scores ranging from 11.76 – 94.54 (on a 0-100 scale).

Fourteen participants provided responses to the question of whether or not their loved one had a good death. Of those 14, three did not perceive their family member's death as good, while the remaining 11 felt their family member did have a good death. Participant responses to this question aligned with their total QODD and item 23 scores, with the most negative experience (unexpected death) supported by a total QODD score of 11.76 and an item 23 score of zero.

The original validation study of the QODD (which used a 31-item version) reported a mean score for the total QODD of 67.36 ($SD = 15.06$) (Curtis, et al. 2002). The difference between the mean score of the original study and this pilot study could be

attributed to a variety of factors: 1) sample size differences, 2) the original study sample contained family of patients who died at home, 3) differences in the versions of the QODD used, and 4) the participants of this pilot study may have been influenced by their professional experience of nursing.

Subsequent studies conducted in ICUs used various versions of the family QODD (21, 22, 23, and 31-item). The reported total mean QODD scores for these studies ranged from 60 ($SD = 14.0$) (Mularski, et al. 2005) to 77.7 ($SD = 9.3$) (Levy, et al. 2005), demonstrating a high degree of variability in perceptions of quality of death and dying. Differences in mean scores could be attributed to such factors as variability in End-of-Life care at the participating study sites, refinement of the QODD instrument, and population characteristics. In relation to results of these studies, this pilot study's sample total mean QODD score of 60.75 ($SD = 21.02$) is on the lower end of the spectrum in regard to family perceptions of the quality of death and dying and demonstrates greater variability in responses.

Family, nursing, and physician perspectives of death and dying using the QODD. Perceptions, or the lived *experience*, of the quality of patient death and dying are nuanced and differ between individual family members (Hales, et al. 2010; Mularski, et al. 2004), physicians, and nurses (Friedenberg, et al. 2012; Gerritsen et al. 2013). While these differences are natural and stem from the unique perspective of the observers, they make quantifying the perception of death and dying difficult to generalize to any given population.

This pilot study examined *nurse* family member's perceptions of patient death and dying using the family version of the QODD. A systematic review of measures for

quality of dying and death (Hales, et al. 2010) identified four studies of family using the QODD, two studies of ICU nurses (using the ICU nurse version of the QODD), with an additional two studies of both family and nurses. A literature review performed in November 2018 did not reveal any studies that measured nurse family member's perceptions of death and dying using the any version of the QODD.

The QODD was used by Gerritsen, et al. (2013) in the Netherlands to explore the differences between family, nurse, and physician perceptions of patient death and dying. Although the results of the Gerritsen study were found to be statistically different than previous American studies and therefore not generalizable to the American population, median scores of two individual QODD items from this study (not reported in Chapter 4) were compared to the results of the Netherlands' study, which were reported in median Interquartile Range (IQR) (Gerritsen et al. 2013, p.360).

In comparison to the Dutch study, this study's sample tended to rate the overall quality of care provided higher than family members yet rated the overall quality of patient death considerably lower than family, nurses, and physicians.

Although differences do exist between the results of these studies, they cannot be solely attributed to the nurse as family member perspective due to cultural differences between the U.S. and the Netherlands and the professional differences between American and Dutch nurses and physicians. A more recent study by Gerritsen (2017), which compared a previously described U.S. sample to the Dutch sample referenced above, identified the greatest statistical difference in QODD scores between nurses which may explain some of the variation in results between this pilot study and the 2013 study.

In a U.S. study conducted in 2005, family, nurse, attending, and resident physician perceptions of patient death and dying were examined using the newly created 21-item ICU version of the QODD (Levy, et al. 2005). Results of the study demonstrated significant variation between family member total QODD mean scores ($m=77.7$, $SD = 9.3$) and nurses ($m=66.9$, $SD = 16.3$). Nurse family member perceptions of patient quality of death and dying in this pilot study ($m=60.75$, $SD = 21.02$), demonstrating closer alignment with the nurse perceptions rather than family perceptions.

Family Satisfaction with Care in the Intensive Care Unit during and after Withdrawal of Life-sustaining Treatment

Family satisfaction with care during and after WOLST was measured in this pilot study using the FS-ICU 24-item version. The total FS-ICU mean score was 67.75 ($SD = 21.54$), the Care subscale score was 67.82 ($SD = 21.05$), and the Decision-making subscale score was 69.30 ($SD = 23.48$) on a scale from 0-100, with higher scores associated with higher family satisfaction. Additional detail regarding perceptions of nursing care (specifically) was provided in response to an open-ended question included in the on-line survey.

Results of this study indicated moderately positive satisfaction with overall care and decision-making. Extreme positive responses to the open-ended question aligned with higher scores on the total FS-ICU and Care subscale means scores, while extreme negative responses aligned with lower scores (see Chapter 4). In comparison to a larger study ($n = 1211$) conducted in 2012 in Washington state that reported a mean total FS-ICU score of 76.6 ($SD = 20.6$), Care subscale mean of 77.7 ($SD = 20.6$), and Decision-making subscale mean of 75.2 ($SD = 22.6$) (Osborn, et al 2012), this study's participants

tended to have a significantly lower satisfaction with care and decision-making than a more diverse population.

Components of quality care in the ICU at end of life. Previous research has identified key components of care at EOL associated with increased family satisfaction (Hinkle, et al. 2015). In regard to nursing care specifically, family members are more satisfied when nurses meet *their* emotional needs rather than when they display technical expertise in caring for the patient (Bussman, et al. 2013; Fox-Wasylyshyn, Maher, and Williamson, 2005). Participants in this study who had extreme positive responses in regard to nursing care uniformly described the care and compassion of the nurses, not their technical or medical knowledge as one participant described. “The nurses were fantastic in explaining everything and making sure we were doing ok emotionally”.

In contrast, one participant described the nursing care her mother received in these terms, “I expected to be treated the way I would treat others, especially colleagues. In my situation, I wish the nurses had been more empathetic and involved”. The mean score for participants on item 8 (courtesy, respect and compassion you were given by ICU staff), demonstrated moderately high satisfaction ($m=70.31$, $SD = 29.18$) with this aspect of care, while the mean score on item 6 (how well the ICU staff showed an interest in your needs in terms of emotional support), demonstrated greater variability and somewhat lower satisfaction ($m=58.33$, $SD =34.93$) with emotional support.

Communication and satisfaction with care in the ICU. Various aspects of communication have also been identified as playing a role in satisfaction with care at EOL (Hinkle, et al. 2015). Clearly communicating results of diagnostic exams or labs and their relevance in terms the family can understand, describing procedures, what to expect

during WOLST, and simply talking with the family and getting to know them, improves satisfaction with care (Nelson et al. 2010). See below for individual items on the FS-ICU which address communication:

10. How often nurses communicated to you about your family member's condition (m=69.12, *SD* =28.66)

15. How often doctors communicated to you about your family member's condition (m=54.41, *SD* =36.70)

16. Willingness of ICU staff to answer your questions (m=67.19, *SD* = 25.36)

17. How well ICU staff provided you with explanations that you understood (m=65.00, *SD* = 28.03)

18. The honesty of information provided to you about your family member's condition (m=69.12, *SD* = 24.25)

19. How well ICU staff informed you what was happening to your family member and why things were being done (m=66.67, *SD* = 26.13)

Mean scores on these different aspects of communication (except for the item related to MD communication) closely align with the total FS-ICU mean score of 67.75 (*SD* = 21.54) and support previous research indicating the importance of communication in family satisfaction with overall care in the ICU.

Perceptions of Quality of Patient Death and Dying and Family Satisfaction in the Intensive Care Unit

Quantitative data analysis conducted for this study and detailed in Chapter 4 revealed no association between participants' total QODD and total FS-ICU mean scores despite previous research which demonstrated strong correlation between the two

instruments (Wall, et al. 2007). Indeed, in many cases, participant's total mean QODD score was markedly higher or lower than their total mean FS-ICU score. Analysis of the qualitative data collected for this study demonstrated similar disparities between perceptions of a good death and satisfaction with nursing care.

There could be several factors that impacted the association between QODD and FS-ICU mean scores. First, participants in this study were *nurse* family members and their professional experience may have biased or influenced their perceptions of both quality of death and care. Second, this study had a small sample size and the extreme negative experience of one participant ($m=11.76$) may have unduly skewed the results.

Study Strengths and Limitations

This pilot studied examined nurse family member perceptions of care and the quality of patient death and dying in the ICU after WOLST. Past research of End-of-Life care in the ICU has focused on either the family or nurses, sometimes comparing the two groups to determine differences in perspectives and priorities. This study sought to examine the intersection of these two identities with the family version of the QODD V.3.2 and the FS-ICU instruments as well as open-ended questions. The strengths of this study were its unique sample population and use of the most reliable instruments known to produce valid data for EOL research.

There were several limitations of this pilot study. The most significant limitation is the small sample size of 17 participants which impacts generalizability. Two issues may have impacted study sample size. First, the method of participant recruitment was limited to nurses who visited the American Association of Critical Care Nurses (AACN) website (aacn.org). The study was listed on the "Participate in Research Studies"

webpage, which is not listed on the main page menu and may be difficult to find for casual visitors to the site. Second, the timing of the study listing (beginning of December 2018) may have also been a factor in the low response rate. Another limitation is that the participants were predominantly female (87.5%), Caucasian (66.7%), critical care nurses (50.0%), and chose to participate, all of which may have biased the results. Lastly, participants' recall of the death and dying of their loved one may have been impacted by the passage of time, grief, or other unknown variables.

Implications for Future Nursing Research

Past research has demonstrated nurses tend to view EOL care in the ICU less positively than family members or attending physicians (Gerritsen, et al. 2017, Levy et al. 2005, Levy et al 2012). Results of this study support these findings, with a total QODD mean score for all participants ($m=60.75$, $SD =21.02$), near the lowest family QODD mean score reported in any study ($m=60.0$, $SD =14.0$) (Mularski et al 2005) and a total mean FS-ICU of 67.75 ($SD = 21.54$), significantly lower than the total FS-ICU mean score 76.6 ($SD = 20.6$) for a large U.S. study (Osborn et al. 2012).

This pilot study's results demonstrated disparity between nurse family member perceptions of patient death and dying and satisfaction with care in the ICU after the WOLST and lower levels of satisfaction with care than previous larger study populations. Further examination of this phenomena with a larger, more diverse study population would enhance understanding of the differences and similarities between nurse and family perspectives in regard to family member death and nursing care and add to the growing body of EOL research.

Summary

This pilot study sought to examine nurse perceptions of the quality of family member death and satisfaction with nursing care during and after the WOLST within the ICU setting. Results of this study demonstrated moderate levels of nurse family member satisfaction with care and moderately positive perceptions of the quality of patient death, though significantly lower than family member levels of satisfaction and quality of death reported in earlier research studies. Results of this study also indicated no correlation between satisfaction with care and perceptions of the quality of family member death in contrast to earlier research that found a strong correlation.

Conclusion

Results of this study indicate there are differences in the way nurse family members perceive the quality of a loved one's death, care, and decision-making in the ICU in comparison to family members who are not nurses. These results may provide researchers with potential lines of future inquiry.

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APPENDIX A Letter of Invitation

Dear AACN Member,

My name is Deena Drake. I am a Critical Care and Emergency Services Clinical Nurse Specialist and a doctoral candidate at the Hahn School of Nursing at the University of San Diego in Southern California. I am conducting a research study related to End of Life Care as part of the requirements of my doctoral dissertation. This study has been provided oversight by the University of San Diego Institutional Review Board.

You are receiving this study invitation because you are a member of AACN and have either acute or critical care nursing experience. I am inviting you to participate in this study ONLY if you have personal experience of a family member dying after withdrawal of treatment in an Intensive Care Unit (ICU).

The purpose of my research study is to describe the unique perspective of acute and critical care nurses' perceptions of the quality of a family member's death and dying and satisfaction with nursing care, during and after withdrawal of treatment in the ICU. You will be asked to complete two questionnaires, demographic data, and 3 open-ended questions. This can take approximately 20-45 minutes.

Taking part in this study is entirely optional and will be completely anonymous via Survey Monkey. You may decide to quit participating in the study at any time by exiting

the survey. You may also choose not to answer specific questions if you don't know the answer or feel uncomfortable answering.

The risks of participating in this study are minimal but certain questions may cause emotional discomfort or painful memories in regard to your family member's death and dying. Should you wish to speak with anyone about your feelings the National Mental Health Hotline (1-800-273-8255) has trained counselors available 24/7 and can automatically route you to local resources if needed.

I am happy to answer any questions you have about the study. You may contact me by phone at (xxx) xxx-xxxx or at xxxxx@xxxxx.xxx. You may also contact my chairperson, Dr. Ann Mayo, at xxxxx@xxxxxxxxx.xxx.

Clicking on Next below indicates you agree to participate in this study.

Thank you for your time and participation,

Deena Drake

APPENDIX B Additional Demographic Data

How many years of nursing experience do you have?

Where is, or has been, the majority of your nursing practice?

APPENDIX C Institutional Review Board Study Approval

Institutional Review Board Project Action Summary

Action Date: November 16, 2016 *Note: Approval expires one year after this date.*

Type: ___ New Full Review New Expedited Review ___ Continuation Review
 ___ New Exempt Review

 ___ Modification

Action: Approved ___ Approved Pending Modification ___ Not Approved

Project Number: 2016-11-091

Researcher(s): Deena Drake Doc SON

 Dr. Caroline Etland and Dr. Ann Mayo Fac SON

Project Title: Family Perceptions of Patient Death and Nursing Care within the Intensive Care Unit
 after Withdrawal of Treatment

Note: We send IRB correspondence regarding student research to the faculty advisor, who bears the ultimate responsibility for the conduct of the research. We request that the faculty advisor share this correspondence with the student researcher.

Modifications Required or Reasons for Non-Approval

None

The next deadline for submitting project proposals to the Provost's Office for full review is N/A. You may submit a project proposal for expedited review at any time.

Dr. Thomas R. Herrinton
Administrator, Institutional Review Board
University of San Diego
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5998 Alcalá Park
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APPENDIX D Institutional Review Board Study Renewal

Nov 28, 2018 9:57 AM PST

Deena Drake
Hahn School of Nursing & Health Science

Re: Modification - 2016-11-091 Family Perceptions of Patient Death and Nursing Care within the Intensive Care Unit after Withdrawal of Treatment

Dear Deena Drake:

The Institutional Review Board has rendered the decision below for 2016-11-091, Family Perceptions of Patient Death and Nursing Care within the Intensive Care Unit after Withdrawal of Treatment.

Decision: Approved

Findings: None

Research Notes:

Internal Notes:

Note: We send IRB correspondence regarding student research to the faculty advisor, who bears the ultimate responsibility for the conduct of the research. We request that the faculty advisor share this correspondence with the student researcher.

The next deadline for submitting project proposals to the Provost's Office for full review is N/A. You may submit a project proposal for expedited or exempt review at any time.

Sincerely,

*Dr. Thomas R. Herrinton
Administrator, Institutional Review Board*

***Office of the Vice President and Provost
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5998 Alcalá Park, San Diego, CA 92110-2492
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