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The purpose of this study was to report the stories of critical care nurses as they cared for patients receiving full-curative treatment, knowing that these patients would not survive and needed goals of care decision-making (GOC-DM). Phenomenological inquiry was used to guide the mindset for this research to gain insight into the nurses' lived experience and to understand the meaning of such experiences. Phenomenology of Practice (Van Manen, 2014) was used to develop a phenomenological mindset. Munhall's process of phenomenological inquiry was followed during the interviews and analysis of the data (Munhall, 2007).

Phenomenology was applied to enter the nurses' lifeworld with the proper mindset and to collect stories that were rich in experiential content to provide insight into the human experience. One experience was presented as a lived experience description and the others were sorted using thematic analysis. This organized the stories to enable exploration into the context and meaning of this phenomenon. The factors that influenced the nurses lived experiences developed into the following themes: (1) The nurses' judgement and appraisal of the patient situation; (2) The nurse-family-patient relationship; (3) The nurse's actions related to goals of care decision-making and (4) The emotions experienced by the nurse. The nurse's willingness to be engaged, level of energy, expertise, and degree of flexibility were also important factors that affected their lived experience when caring for these patients. The nurses described their experiences

as family members struggled with life and death decisions and emphasized that every situation was different due to variations in the human interactions as incorporated into the thematic elements.

The nurses in this study described a critical care environment in which the physicians took a proactive approach to GOC DM. Nurses described that certain aspects of decision-making, such as prognosticating and telling bad news, was the doctors' responsibility. The nurses saw their role to advocate for the patient, update and educate the family, and serve as a go-between with families and the health care team. Nurses were able to participate in decision-making when there was certainty in the patient's prognosis, a connection and trust between themselves and family members, and feeling valued and able to contribute. It was important to facilitate relationships with family members to foster trust and connection. The nurses described situations in which they felt that they were torturing the patients. Nurses should learn to recognize such difficult situations early to reduce conflict, to preserve family trust, and decrease staff burnout. In addition, programs should be offered and led by nurses, bioethicists, and professional organizations to community groups about the need for and usefulness of advanced directives.

The findings from this study have implications for nursing practice, education and research. Suggestions for practice are that healthcare providers be engaged and work together as a team and within their roles to facilitate GOC DM for patients. Nurse educators should include GOC DM case studies in simulated training exercises, present patient cases to encourage discussions of GOC DM in clinical seminars, and teach courses on the ethical principles that surround GOC DM. In addition, training and simulation exercises to improve communication, collaboration, emotional awareness, conflict resolution, self-care, and knowledge in palliative care and ethical practices are important, especially in prelicensure programs. Further research should include qualitative inquiry into the lived experiences of patients, family members, and other health care professionals in different settings and circumstances for GOC DM. Also, examination and evaluation of policies, procedures and guidelines for GOC DM should be conducted using systematic policy mechanisms and practice standards.

THE LIVED EXPERIENCES OF CRITICAL CARE NURSES WHILE CARING FOR PATIENTS THAT ARE NOT EXPECTED TO SURVIVE

by

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CHAPTER I

BACKGROUND AND SIGNIFICANCE

The purpose of this study was to explore the experience of critical care nurse caring for a patient that was not expected to survive. The phenomenological perspective was selected as a method of inquiry to explore meaning and to gain a better understanding of the complexities and meaning within this experience. The practice experience of the investigator provided a lens into the nurses' insights and actions encountered while caring for their patients. Nurses provided stories that they described and shared. This approach serves as a means of reflection to those within professions and it is also sensitive to everyday social and personal aspects of living (Van Manen, 2014). Nurses shared memories of a wide range of personal encounters while providing care for patients who remained full code and were in need of decision-making which exposed nurses' struggle, perseverance, and the rewarding experiences.

Descriptions of experiences were explored in face-to-face interviews with critical care nurses where they shared their experiences and were asked to reflect on their feelings, actions, and thoughts related to that experience. This first chapter will provide background on the phenomenon of interest, provide justification for studying this phenomenon, and delineate assumptions and definitions.

Phenomenon of Interest

In undertaking research with critical care nurses working with ICU patients, it is important to understand the complexity of what has been described the "World of the ICU", which is a fast-passed environment focused heavily on technology and managing complex patients (King & Thomas, 2013). Death is something that can be delayed with technology and often occurs when medical options have been exhausted. Nurses have different ways of knowing due to their proximity to the patient and the process in which they are socialized into the profession. Carper (1978) described four patterns of knowing: empirics as the science of nursing, esthetics as the art of nursing, personal knowledge in nursing, and ethics as the moral knowledge in nursing. Nurses' willingness to describe actions and outcomes provides examples to enhance and refine practice. Suggestions and interventions are important for the skills required for working with this patient population are may or may not be taught in nursing school. However, nurses must obtain them in the practice environment (Espinosa et al. 2010).

The medical and nursing literature provides suggestions for nursing actions such as education on the surrogate decision-makers role, organizing family meetings (White, 2011), assessing patient values, and providing family members with information, education and support during everyday activities (Adams et al., 2014; Norton, Tilden, Tolle, Nelson, & Eggman, 2003). Several studies that have examined the nurses' role in goals of care decision making to include that of patient and family advocate (McAndrew & Leske, 2015; Peden-McAlpine, Liaschenko, Traudt, & Gilmore-Szott, 2015; Perrin, 2001; Robichaux & Clark, 2006), mediator (Perrin, 2001), coordinator, support person, and educator (Jezuit, 2000).

Justification for Studying this Phenomenon

Death is a common occurrence within critical care units in the United States based on the average 2012 patient mortality of 12.4% (Zimmerman, Kramer, & Knaus, 2013). Further, reports indicative deaths in the ICU vary based on the severity of the patient's illness and age can range from 10-29% (SCCM, 2017). Patients spend considerable time in the Intensive Care Unit (ICU) prior to dying. Almost 14% of a national sample of US Medicare enrollees spent seven or more days in an ICU during the last six months of life (Dartmouth Atlas of Health Care, 2014). Patients are admitted to the ICU with various medical and surgical conditions and are treated with various curative and life-supportive measures.

For critically ill patients who do not respond adequately to treatment to make a meaningful recovery, decisions are required to determine goals of care (GOC) and direction of treatment during end-of-life. Such decisions occur frequently and are challenging for all parties involved (Chulay & Burns, 2010). Nurses spend the most time of any professional at the bedside interacting with critically ill patients and their family members. This places nurses in a unique position to extend a therapeutic presence to those persons experiencing change and loss (Adams et al., 2014). This distance provides nurses a unique perspective into the issues surrounding decision making and opportunities to become involved. White (2011) suggests that the nursing ethic of caring combined with patient/family centeredness allows the nurse to facilitate various aspects of surrogate decision-making. Yet, it is documented that nurses for various reasons choose not to be involved in goals of care decision-making (GOC DM) even when they are certain that the patient will not survive. Varying nurses' involvement in GOC DM suggests that there is an underlying cognitive and emotional process that determines the nurses’ course of action. It is therefore important to gather a deeper understanding of the nurses’ experience and search for meaning within this experience.

Study Purpose

The focus of this study was to describe the nurses’ experience of caring for a patient that was not expected to survive.

Definition of Terms

For the purposes of this study, the following definitions are used:

1. Adult critically ill patients: a heterogeneous group of hospitalized patients with various illnesses that may require technological support and frequent monitoring (SCCM, 2017). Patients vary in the acuity of illness, underlying comorbidities, requirement for technological support to maintain adequate hemodynamic parameters, and resilience. The need to make decisions about the direction of treatment are most often focused on the patients in the ICU who are the sickest and most dependent on technology for survival. These patients are often unable to be involved in their own health care decisions due to the acuity of their illness.
2. Goals of care decisions: these are the difficult choices that patient representatives, known as surrogate decision makers (SDMs), and the medical team must determine the trajectory of care, from full treatment or agreed upon limitations in care such as

Do Not Resuscitate (DNR), to no escalation in care or comfort care. The term “goals of care” decision-making has become a more politically correct phrase rather than “end-of-life decision-making” (EOLDM) for this newer phrase is less likely to offend family members who are not ready to make that final decision. The goals of care at end-of-life for such a patient can be full treatment—indicating that the patient and family members prefer everything be used to save a patient’s life, which may be a realistic or unrealistic expectation based on the situation. Other decisions can be for comfort care where treatments are limited or stopped, and the focus is on the comfort of the patient. The patients receiving full treatment are considered to be critically ill whereas those receiving comfort measures accept that they are dying (Crighton, Coyne, Tate, Swigart, & Happ, 2008) or the prognosis is not survival.

3. Surrogate decision maker (SDM): a legally-designated proxy or closest relative to the patient who is responsible for making medical decisions for patients unable to speak for themselves. Providers rely on the SDMs to make medical decisions for the patient (Buchanan & Brock, 1990; Foreman, Milisen, & Fulmer, 2012).
4. Advanced directives: the written wishes of the patient which can guide goals of treatment decisions. Advanced directives may be detailed and specific or vague and not helpful in all situations that relate to quality of life, nuances of treatment and the complexity of critical care (Gutierrez, 2012a; Metty, 2012).
5. Patient and family centered care: This model of care suggests that nurses and health care providers accept the multi-dimensionality of the patient, respect the patient’s choices and collaborate with the family and health care team to meet the patient's

needs (Bell, 2015). It is “designed to meet physical cognitive, emotional and spiritual needs, regardless of a patient’s age or infirmity; it takes into account culture, traditions, values, beliefs, and language; and it evolves with patient and family needs” (IOM, 2015, p. 28).

6. The process of decision-making for critically ill ICU patients: decision-making involves multiple separate judgements about intervention-related choices during the duration of the hospital stay (Metty, 2012). Once an intervention is decided upon, several decisions are required based on the patient’s responses to the previous interventions (Metty, 2012). High stakes decisions need to be made quickly in situations such as impending respiratory-cardiac arrest or when emergent procedures are required to keep a patient alive. Less intensive decisions can be made over several days, such as deciding treatment options for placing a gastrostomy tube and a tracheostomy. The process of making these decisions requires knowledge of the patient’s wishes, of the risks and long-term benefits and outcomes of such treatments, and the acceptance of the possible death of a loved one. Such decisions guide the direction of patient care, either full curative treatment, a Do Not Resuscitate (DNR) order or transition to comfort care. Decisions are challenging and complicated endeavors for nurses, physicians and patient family members because of the emotions involved, the subjective nature of the decision, and frequently not knowing what the patient’s wishes are based on his or her current situation (Scheunemann, Arnold, & White, 2012).

7. Nursing care: The care in the ICU refers to the medical and nursing tasks and treatments that are required to meet the patient's intended goals of either healthful living or peaceful dying. The care that nurses provide is defined by the nursing professional scope of practice and with institutional policies and procedures to ensure the consistent delivery of safe, high quality, and evidenced-based actions (Bell, 2015). Health care institutions develop policies and procedures to guide nursing practice. Nurses work together within a unit develop similar patterns for practice which can vary from other units within that institution (Kim, 2015). Critical care nursing practice is complex and multidimensional. Care of individuals in various contexts and situations requires a variety of nursing actions with the goal of optimizing the patients' health, recovery, or meet a good death (Kim, 2015). Critical care units are specialized care areas where patients require close monitoring due to an actual or potential life-threatening situation (Bell, 2015). Nurses working within critical care units are expected to process the technological skills in combination with competencies in clinical judgement, advocacy and moral agency, caring practices, collaboration, systems thinking, response to diversity, facilitation of learning, and clinical inquiry (Bell, 2015, p. 6). Providing care is more than technique and following rules. The American Association of Critical Care Nurses (AACN) recognizes that healthcare members must work together to attain a Healthy Work Environment to meet patient care needs and goals. This model suggests that the professional work environment affects nurses' ability to provide care. To provide care, nurses must be competent, be willing to partner with patients, family members,

and the health care team, and adjust the plan based on the patient’s unique needs (Bell, 2015). A level of self-determination exists where nurses have the autonomy to develop expertise and accountability for their practice (Bell, 2015).

Phenomenon Discussed within a Specific Context

Critical care nurses provide nursing care within Critical Care Units for patients of varying acuity of illness and ability to recover. For some patients, death is imminent, and decisions need to be made quickly, while for others critical illness is prolonged with ongoing discussions about potential outcomes and preferences related to quality of life. Critical care nurses often describe themselves as being in the middle of the decision-making process, as they do not have the authority to authorize treatment decisions but can influence the decision-making process (Calvin, Kite-Powell, & Hickey, 2007; Calvin, Lindy, & Clingon, 2009; Gutierrez, 2012c).

Nurses are challenged to provide family members with the physiologic realities of treatment and a caring environment as families make decisions for loved ones (American Nurses Association, 2016; Bell, 2015). Nurses spend more time with hospitalized patients than any other profession and are trained to use assessment and critical thinking skills to evaluate patients’ responses to treatment (Arbour & Wiegand, 2014). Nurses often are the first to acknowledge that a patient will not have a meaningful survival (Popejoy, Brandt, Beck, & Antal, 2009). As a trusted source of information for patients and family members, nurses can provide education and help family members understand the realities of a situation (Jezuit, 2000). Trust can be quickly broken when family members are not ready or willing to acknowledge the patient’s condition, or family members take offense to how the updates are delivered (Calvin et al., 2007). Broken trust can lead to an adversarial relationship between the nurse and the patient's family members. The patient’s care binds the nurse to the patient’s bedside and unless skillfully resolved, situations can escalate to conflict (Badger, 2005).

Nurses provide information and updates regarding patient and family issues and needs to the medical team. Nurse-physician relationships can become strained when nurses do not agree with the plan of treatment or when suggestions are not acknowledged (Popejoy et al., 2009). Nurses must be careful in what they disclose about the patient’s condition out of fear of upsetting the physicians or family members (Calvin et al., 2009). McAndrew and Leske (2015) refer to this as a balancing act, where nurses must adapt their emotions, expectations, level of collaboration, communication and role performance for each patient situation. Being out-of-balance can cause the nurse to suffer or feel morally distressed (McAndrew & Leske, 2015).

The process of GOC DM may be challenging because decisions are not easy and multiple treatment modalities or medications are available for treatment. Often a decision involves withholding or terminating potentially life-sustaining therapy. The process necessitates differentiating between an acutely ill patient that may recover and a patient that is not expected to recover (Bloomer, Endacott, O’Connor, & Cross, 2013). Kruser, Cox, and Schwarze (2017) coined the term “clinical momentum” to describe how medical treatments and tests for critically ill patients are triggered by one decision and cascade into many interventions to fix various patient issues, creating a force that is difficult to interrupt or stop.

The role of the critical care nurse has evolved as a nursing specialty over the past 70 years that coincided with advancements in knowledge and technology in intensive care units (ICUs). Nurses provide care to patients who rely on equipment and treatments to support their organs with devices such as hemodialysis machines, ventricular assist devices, mechanical ventilators and extracorporeal membrane oxygenation. Nurses witness treatments aiding in the patients' recovery and saving numerous lives. Nurses observe what happens to the patients that do not recover completely or die.

Critical care nurses have societal and professional expectations and their own cultural beliefs about death and dying and struggle with the reality of death in everyday practice. Death and dying perception differs based on one's age, gender, experiences, cultural, social and economic backgrounds, spiritual and religious beliefs, and geographical location (IOM, 2015). As the population of the United States is diverse, there are many different viewpoints about death, which can affect the opinions and goals during the GOC DM process.

The societal expectation of fighting disease until the end and 'not giving up' may prevent a person from accepting their own death as a potential outcome. Being surrounded by other people holding this belief can make patients feel uncomfortable talking about death for fear of disappointing or letting down loved ones. The timing of death is difficult to predict, when and how it will occur and how long it will take (IOM, 2015). The life expectancy in the United States has increased over the past century due to medical innovations such as antibiotics, improved diagnosis, treatments, medical and surgical practices. Death is thought of as something that can be controlled or delayed with medical and/or surgical treatments and through applied technology.

Goals of care decisions have been a challenge within critical care units for decades. The Study to Understand Prognosis and Preferences for Outcomes and Risks for Outcomes and Risks of Treatment (SUPPORT), a landmark trial in the early 1990's, drew attention to the lack of knowledge that physicians had about patients' wishes for Cardiopulmonary Resuscitation, the amount of time that patients spent in the ICU prior to dying (at least 10 days), and that a large percentage (50%) of patients suffered moderate to severe pain (Connors et al., 1996). Results indicated that the issues surrounding end-of-life decision-making was much broader than just a lack of providing prognostic information to SDM (White, 2011), and the extent of patient suffering was unacceptable. Findings resulted in numerous initiatives, such as nurses and physician dyads working together to develop seven quality indicators (QI) for quality ICU care. These indicators include shared decision making, enhanced communication between clinicians and with family members, continuity of care, and support for family members (Clarke et al., 2003). Many efforts focused on improving communications between the healthcare team and family members through the use of structured family meetings (Curtis et al., 2002; Lilly et al., 2000; Machare Delgado et al., 2009) and during multidisciplinary rounds (Jacobowski, Girard, Mulder, & Ely, 2010). Studies have investigated the use of mediators to facilitate decision-making. Watkins, Sacajiu, and Karasz (2007) used bioethicists as mediators, Moore et al. (2012) and White et al. (2012) incorporated specially trained critical care nurses as family support coordinators or specialists who worked with patient family members. The mediator roles showed promise, although tasks were time consuming and not fiscally realistic in most ICUs. The shared decision-making model with multidisciplinary collaboration, ongoing effective communication and emotional support of family members continues to be the most effective solution within the medical literature. Nurses have been identified as important members of this team due to the close relationships with family members and proximity to the bedside.

Ethical principles are important in the GOC DM process. The process includes four major ethical components: respect for autonomy, beneficence, nonmaleficence, and justice. Autonomy involves self-determination, where an individual makes their own health care decisions and provides informed decisions about their health care (Metty, 2012). Individuals can designate who will make decisions for them in situations of incapacitation or it defaults to the closest family member. This person(s) become the patient's surrogate decision maker(s) (SDM). Those acting in the SDM role are expected to use "substituted" judgement and base decisions about treatment on the values and wishes expressed by the patient, with perceived knowledge of what the patient would choose if he or she were competent and able to make decisions (Clint Parker & Goldberg, 2016; Delgado, 2010). In circumstances where the patient's wishes are not known, decisions should be made based on what is most beneficial to the patient's wellbeing (Buchanan & Brock, 1990; Metty, 2012). Beneficence and nonmaleficence refer to avoiding harm and minimizing suffering, and the ethical principle of justice represents a fair balance and distribution of risks and benefits (Metty, 2012). Following these ethical principles through surrogate decision-making can become a complex process when it involves critically ill patients and their SDM.

In the United States, the approaches and understanding of GOC have been impacted by a health care ideology and philosophy that evolved in the 1970's, when Americans were promised the best quality and equal care, the ability to choose their own health care provider, and controlled individual cost due to third party insurance payers (Engelhardt Jr, 1998). Most ICU treatments are normally not rationed in the United States, and 17.9% of the United States gross domestic product goes into healthcare and it is projected to grow to 19.7% by 2026 ("CMS.gov," 2018). Americans are responsible for their own medical decisions based on the ethical principle of autonomy and when persons are incapacitated, a person in the role of the SDM may make these decisions for them. Ideally, the SDM is guided by an advanced directive, patient values or what is in the patient's best interest (Buchanan & Brock, 1990; Metty, 2012). Health care providers are legally bound to consult with and follow the requests of SDMs when making medical treatment decisions (Seymour, 2000). The physician or medical provider controls the aggressiveness of a patient's care and plays a major role with patient's family members during the goals of care decision making process.

The American Association of Critical Care Nurses (AACN) suggests that ICU nurses be proficient in addressing ethical issues in situations where the use of technology to extend a patient's life is not beneficial, and to be competent in delivering end-of-life care (Bell, 2015). The American Nursing Association (ANA), in their 2016 position statement states that "nurses and other health care providers have a responsibility to establish decision-making processes that reflect physiologic realities, patient preferences, and the recognition of what clinically may or may not be accomplished" (p. 1). The role and responsibility of the Registered Nurse (RN) is to deliver compassionate and all-inclusive care to patients who are dying and their family members (ANA, 2016). While nurses provide patient care, they observe, recognize, interpret and react to the needs of both the patient and the family. Thus, nurses possess valuable information that may be crucial to the decision-making process (Chulay & Burns, 2010). The vantage point at the bedside allows nurses contribute insight into GOC DM issues that the patient or family may be facing (Dillworth et al., 2016). In addition, the nurses' constant presence and knowledge of the patient's condition can encourage family members to trust and rely on nurses to answer questions and to provide medical condition updates and information (Chulay & Burns, 2010).

Assumptions

The following assumptions were established for this study:

1. The stories of critical care nurses were based on how they perceive actual events and circumstances surrounding care of patients not expected to survive and GOC decision-making in the ICU.
2. Using individual interviews allowed nurses to share how they experience their role in the GOC process with the patient-SDM unit, the inter-disciplinary team and their institution.

3. Participants interacted with patients and perceived their role differently based on their level of education, amount of experience, self-perceived competency and personal and cultural beliefs.
4. That nurses were willing to talk to and engage with that patient's family members about the patient's condition and status.
5. That nurses had a role in talking to family about goals of care decision-making.

Delimitations

The study was be limited to:

1. Critical care nurses who were actively practicing at the bedside within a critical care unit with two or more years of experience.
2. Nurses who agreed to share their personal stories for this research study.

There were several potential limitations to this study. Nurses self-selected when they volunteered to participate in this research study. These nurses may have done so because they were more interested and/or involved in GOC DM, and therefore their perceptions may have been be different from those that were not interviewed. Based on observation, critical care nurses feel a need to share their experiences surrounding patient care and are often unable due to issues surrounding confidentiality and challenges surrounding death and dying. This study provided nurses with a means to share their experiences and talk about their practice with an attentive listener.

Approach

Nurses' involvement in goals of care decision-making has been examined using various approaches within qualitative and quantitative methodology. Phenomenology of practice is a quest for deeper understanding into the nurses' experience during the decision-making process. The goal of care decision-making process involves many human experiences converging around a specific point in time with immense ramifications. As phenomenology is based on over a century of philosophical discourse, applying this technique to an issue in practice presents an opportunity to better understand the underpinnings and thought process within this method.

A practice perspective is important for this researcher has considerable years of critical care experience. Through inquiry and practice into this phenomenon, this researcher has been able to find balance along with a voice when caring for these patients and family members during this crucial time. At the same time, this researcher was aware that other nurses struggled in this role or perhaps approached it very differently in their everyday practice. The techniques outlined by Van Manen in Phenomenology of Practice (2014) present exercises that were useful for bracketing and provided a fresh perspective on how nurses experienced the decision-making process.

Phenomenology is a philosophy that concerns itself on the nature of true phenomenon and the reality of human existence and experience. As phenomenology is a philosophy, there are many different approaches and perspectives that are continuing to evolve. Phenomenology is defined as a reflective practice used to understand the meaning of human experiences (Van Manen, 2007). It involves looking at the world with wonder and a curiosity for meaning (Merleau-Ponty, 1989; Van Manen, 2007). The researcher must be clear-headed and thus free from the influence of theory, preconceptions, and presumptions (Van Manen, 2007). The goal of phenomenology is to gain a deeper understanding of the pre-reflective human experience and meaning related to a given phenomenon.

Munhall (2007) provides seven processes as a guide for students as they navigate the phenomenological research process. These seven processes are: 1. Immersion; 2. Coming to the phenomenological aim of the inquiry; 3. Existential inquiry, expressions, and processing; 4. Phenomenological contextual processing; 5. Analysis of interpretive interaction; 6. Writing the phenomenological narrative; 7. Writing a narrative on the meaning of the study. Van Manen provided a detailed description of his method in his 2014 book Phenomenology of Practice. The general steps and procedures of Munhall and Van Manen will be combined into a sequence of general steps during the analysis.

Major Contributors to Phenomenology

Phenomenology has unique philosophical underpinnings are different from other qualitative methodologies. Defining how one sees the world phenomenologically has a long philosophical history. Husserl, credited as the founder of phenomenology, challenged the positivist empiricist thinking of his time and believed in the importance of experiential knowledge. He described that "The world is the totality of objects that can be known through experience, known in terms of orderly theoretical thought on the basis of direct present experience” (Husserl, 2007 p. 52). Husserl believed knowledge is rooted in human consciousness and comes from questioning the meaning of human existence (Smith, 2006). It is subjective knowledge, located within the human-spiritual domain, where one learns how to be fully human. He believed the meaning or essence of a phenomena is discoverable by applying a method that captures the pure human experience. Husserl describes this as “The whole world as placed within the nature-setting and presented in experience as real, taken completely ‘free from all theory’ just as it is in reality experienced, and made clearly manifest in and though the linkings of our experiences, has now no validity for us, it must be set in brackets, untested indeed by also uncontested” (Husserl, 2004, p. 110). Bracketing, or the setting aside of various assumptions, allows the researcher to see the meaning of the pure lived experience (Van Manen, 2014). Epoché describes the act of bracketing or suspending what one takes for granted to achieve a natural attitude (Van Manen, 2014). Eidetic reduction is used to expose the universal features of an experience (Reeder, 2009). Husserl defines Eidos as pure essence, a unique idea, characteristic, or underlying meaning that is understood “either in its singleness, or though comparison with others as a ‘common element’” (Husserl, 2004, p. 52). Eidetic reduction involves immersion into the data with a naïve view to expose pure consciousness followed by looking for the “right beginnings” within consciousness (Husserl, 2004). His approach is transcendental as it examines and describes the intentional objects of consciousness (Van Manen, 2014).

Heidegger, an important contributor to the philosophy of phenomenology, suggested a goal to “Let that which shows itself be seen from itself in the very way in which it shows itself to itself “(Kaelin, 1988, p. 36). Heidegger’s philosophy examines Dasein, defined as the state of being. Human Dasein is the state of being in the world and can only be understood within the framework of human space, time, and history (Heidegger, 1982; Kaelin, 1988). The state of being-in-the-world creates reality and defines the human existence (Kaelin, 1988). To adequately understand human experience, it is necessary to provide details describing the participants' and the researcher's situated context. This is because one's experiences and one's perception of these experiences are predicated on the environment, the embodied mind, time, culture, and relationship with others (Munhall, 2007).

Summary

Goals of care decision -making with critically ill patients is a challenge for all parties involved. It is very personal for patients facing death and their family members confronted with the loss of a loved one. Healthcare providers struggle with the moral, ethical, cultural, and economic nature of these decisions. In the ICU, nurses spend more time at the bedside with patients and family members than any other medical professional. The bedside nurse is positioned where he or she witnesses and experience the entire situation first-hand.

The literature suggests various roles for critical care nurses to assist in this decision-making process. Those roles include active involvement during patient/family meetings by contributing during the discussion, providing clarification and information, and observing the family to ensure that they understand what is discussed (Noome, Dijkstra, Van Leeuwen, & Vloet, 2016). Family members find it helpful when nurses support decision-making by remaining unbiased, provide only factual information that is free of personal opinions, and supporting the decisions that the family has made (Adams et al., 2014). Family members often experienced a high level of anxiety and potential symptoms related to stress and depression (Azoulay, Chaize, & Kentish-Barnes, 2014) to which nurses could potentially mediate and mitigate.

Approaching the topic with curiosity and wonder and describing the phenomena in narrative formats assisted in capturing the nurses' voices and realities. Munhall (2007) believes that the phenomenological approach has the potential to change and improve nursing practice. The phenomenological approach was used to assess, understand and analyze nurses lived experience during end-of-life decision making for their critically ill patients. Search for meaning in these stories and to allowing nurses to recognize this meaning in their own practice (Van Manen, 2017) was an important contribution of this study. This study focused on the meaning and experience of the critical care nurse while providing care to critically ill patients that are not expected to survive to gain better understanding of the nurses in goals of care decision-making.

CHAPTER II

REVIEW OF THE LITERATURE

This review was designed to explore critical care nurses' perspectives around caring for patients that may die and nurses' involvement in goals of care decisions at end-of-life. Nurse experiences and interactions within this environment and goals of care decisions were examined from previous study in the literature.

Phenomenological studies are often performed before the literature is reviewed to ensure a naïve view. Munhall (2007) suggests delaying the literature review because there is then more to bracket and because the direction of the research may change as the researcher reflects on the phenomenon. As this researcher practices as a registered nurse within the critical care setting and has practical knowledge of the process surrounding goals of care decision-making, a broader understanding of the phenomena aided in self-reflection. A review of the literature provided a deeper understanding of the situational, ethical, decisional, and relational aspects of this phenomenon and provided a broader perspective and understanding of this experience and participants. This wider perspective enhanced self-awareness in practice and enabled the sense of wonder and curiosity in the target audience regarding the complexity of goals of care decision-making (GOC DM) and how other nurses experienced this phenomenon.

The Milieu of the Critical Care Nurse

The setting that surrounds Goals of Care decisions for critically ill patients involves the patient and their family members, the nurse, the medical team, the interdisciplinary team, and societal, ethical, cultural, and legal norms and expectations. Treatment within the intensive care unit (ICU) is based primarily on a curative model, with technology and supportive measures used to maintain a critically ill patient. Critically ill patients fall into a pattern of clinical momentum, where, practitioners' motivation to treat various symptoms and family members hopes for recovery leads to a chain reaction of interventions and treatments (Kruser et al., 2017). Not all patients are able to recover, and death is common. Patients often spend several days in the ICU prior to dying. Medical conditions, such as multisystem organ failure, cardiovascular failure and sepsis are the most common causes of death of ICU patients ("SCCM | Critical Care Statistics," 2017). These conditions can be sustained with life support measures, confining the patient to the ICU while progress is evaluated, and trajectory discussed. Because of the medications and technologies available in the ICU and effectiveness in sustaining patients, most timely deaths occur only after a decision is made to withdraw medical support (Gerstel, Engelberg, Koepsell, & Curtis, 2008). While such decisions occur frequently, these decisions remain challenging (Delgado, 2010).

Nurses describe the environment surrounding GOC DM as a complex interplay of emotions, exhaustive treatment, and deliberations to decide the best actions for the patient (Calvin et al., 2009; Robichaux & Clark, 2006). Nurses base the need for goals of care discussions based on their perception of patient suffering and their judgements related to the patient's ability to regain a sufficient quality of life or make a significant recovery (Calvin et al., 2009; Robichaux & Clark, 2006). Nurses report that some surrogate decision-makers (SDM) are able to make a decision while other SDM insist on maximum treatment (Robichaux & Clark, 2006). Physicians vary widely on the ability to predict patient outcomes, acknowledge the possibility of death, and communicate with patient family members (Robichaux & Clark, 2006). Family members experience emotions ranging from sadness and grief to conflict and anger during GOC DM (Abbott, Sago, Breen, Abernethy, & Tulsky, 2001; Gutierrez, 2012b). Hansen at al. (2012) use the metaphor of "being on a train" to illustrate what Kruser et al. (2017) call clinical momentum. When the goal of treatment is to keep the patient alive, then technology, interventions, and treatments continue and multiply until all options are explored and exhausted. The goals are then readdressed, and the treatment trajectory redirects its momentum to achieve the new goal. Nurses administer medications, titrate drips, maintain technology, and assess the response of the patient. "Stopping the train" when in motion is challenging (Hansen et al., 2012).

Burdens on Surrogate Decision-Makers

Family members can experience a great deal of stress, anxiety and depression (Azoulay, Chaize, & Kentish-Barnes, 2014; White, 2011). Family members may feel very strong emotions and become overwhelmed and not be able to think clearly or retain information (Gutierrez, 2012b; White, 2011). Many family members are not prepared for the ICU decision-making role and may lack confidence in their ability to navigate the necessary tasks involved in this process. Family members often rely heavily on clinicians to provide and interpret medical information (Majesko, Hong, Weissfeld, & White, 2012). Accepting the possibility with the death of a loved one often takes time. Family members are emotionally impacted due to their loved one's critical illness and goals of care decisions are difficult. Even though it is painful, family members prefer to have shared decision making, where the medical team and family decision-makers partner to made goals of care decisions (Davidson & American College of Critical Care Medicine Task Force 2004-2005, 2007). To maintain family members' communication of the unfolding events about a loved one's condition requires factual, skilled and frequent communication and can consume clinician time.

Some family members describe a systematic process that they follow to negotiate this process while others do not follow a systematic process (Gutierrez, 2012; Limerick, 2007; Vig, Taylor, Starks, Hopley, & Fryer-Edwards, 2006). Family members may have moral, religious or cultural beliefs that influence the desired aggressiveness of treatments at end-of-life (Carr, 2011; Johnson et al., 2010; Mazanec, Daly, & Townsend, 2010). In 1-4% of ICU patient deaths, family members, for various reasons, insist on all care possible, which results in conflict and emotional distress for all parties involved (Prendergast & Luce, 1997; Smedira et al., 1990).

Physician Involvement in Goals of Care Decisions

Physicians, in the intensivist, surgeon or attending roles, are the professionals ultimately responsible for guiding the family through the decision-making process and assuming the moral and legal responsibility of predicting a patient's chances of recovery by prognosticating outcomes (Brilli et al., 2001). Physicians vary in the ability to communicate and explain prognostic information to family members (White, Engelberg, Wenrich, Lo, & Curtis, 2007; White, Engelberg, Wenrich, Lo, & Curtis, 2010) and various ICU units have different milestones that trigger these discussions (Baggs et al., 2007). Goals of care discussions are time consuming and the physician may have difficulty finding time in busy schedules (White, 2011). A physician or surgeon may delay GOC DM for many reasons, which may include an unwillingness to accept failure, clinical momentum, and a culture of avoidance (Liaschenko, O'Conner-Von, & Peden-McAlpine, 2009; Pavlish, Brown-Saltzman, Fine, & Jakel, 2015). The nurses in the Robichaux and Clark (2006) study provided an example of ongoing physician-driven treatment in a patient with long-term complications after an organ transplant. Physician researchers and professional organizations such as the Society of Critical Care Medicine and the American Thoracic Society have been proactive in examining various interventions and providing recommendations for improving physician performance in decision-making.

Physicians cannot unilaterally refuse to provide basic life-sustaining support and treatments to patients even when there is minimal benefit in providing treatment (Truog & White, 2013). The American College of Chest Physicians clarified the use of the terms "futile" and "potentially inappropriate" care in such situations (Bosslet et al., 2015). The term futile can only be used in the rare situations when a treatment or medication is not capable of producing any physiological response. If there is a physiologic response to the treatment, then the therapy is called potentially inappropriate care (Bosslet et al., 2015; Bosslet, Kesecioglu, & White, 2016). Physicians can refuse to provide care that is considered futile for moral and ethical reasons but should do so only after they meticulously explain their reasons to the SDM and there is agreement (Bosslet et al., 2015). When conflict is intractable, expert consultants, such as palliative care, ethical, and legal committees can mediate to facilitate communication and resolve conflict (Bosslet et al., 2015). If the conflict is not resolved, the patient continues to receive curative treatment until the patient dies or the SDM modifies the goals of care.

Luce and White (2007) advises healthcare providers to be cognizant of their own underlying beliefs about prognosis, quality of life, resource utilization, and economic gain. These can influence how they approach GOC DM and generate conflict with family members. Healthcare providers must be aware of their own motivation for engaging in GOC DM discussions and determine if they are trying to protect themselves from these emotions or if they are truly honoring the autonomy and wishes of the patient. In previous studies, family members were aware of these biases in their health care providers and therefore expressed the need for honest and factual information that was free of personal opinions (Adams et al., 2014; Norton et al., 2003).

Patient Issues Related to GOC DM

Patients can request in their advanced directive or communicate verbally that they wish to have every possible intervention to save their life. SDM can request every potential treatment for a critically ill patient. Mack et al. (2010) observed that 17% of terminally ill oncology patients were aware of their prognosis and still wanted life-extending treatment. A 2013 Pew Research Center survey discovered that 31% of Americans thought that doctors and nurses should do everything possible to save a patient's life (Lipka, 2014). GOC DM becomes a challenge for incapacitated patients who are unable to reevaluate this decision and change preferences and desired wishes based on their current situation (Bailey, 2002; Schenker, White, & Arnold, 2014). Often, family members feel obligated to enforce loved ones' wishes. If patients do not respond to treatment and continue to deteriorate, discordance in treatment goals can develop between healthcare providers and family members (White et al., 2016). When this situation occurs, clinicians are responsible for effectively communicating and negotiating suitable resolutions with the family using an approach that provides emotional support, incorporates the patient's core values and educates the family on treatment options (Truog & White, 2013).

Uncertainty in patient prognosis is a major concern for physicians, nurses, and family members. Various prognostication models are available for medical professionals to use but are not absolute predictors of outcome potential (Moreno, 2014). While having early discussions about goals of treatment are beneficial and recommended (Lilly, Sonna, Haley, & Massaro, 2003), physicians often wait for several days of treatment so there is time to accumulate evidence before they provide prognostic data and recommendations to family members to stop treatment. Family members struggle with uncertainty and feel the need to remain hopeful (Turnbull, Davis, Needham, White, & Eakin, 2016). In such situations of delayed communication, family members were unprepared for such advisement from physicians. Rather, family members envisioned a more optimistic outcome than what they had been presented (Lee Char, Evans, Malvar, & White, 2010). Many family members considered other factors, such as the patient's character or appearance and their own religious beliefs, intuition, or level of optimism in perceiving the patients ability to recover (Boyd et al., 2010; Zier et al., 2008). Family members struggle with uncertainty about doing the right thing. This uncertainty may last long after the medical decision is made (Kirchhoff et al., 2002). As a family member stated months after the death of a loved one: “I wonder if I would have said, well, let’s take him off for just 12 hours and let this medicine work … There are a lot of ifs that you think of after …” (Kirchhoff et al., 2002, p. 202). Nurses rely on physicians to convey prognostic information to family members and find delays in communication and unrealistic expectations of family members a source of frustration (Espinosa, Young, Symes, Haile, & Walsh, 2010). Nurses often realize, before physicians, that a patient is not likely to survive treatment (Robichaux & Clark, 2006). However, nurses are not ultimately legally responsible for the final decision.

When making goals of treatment decisions, the patient’s quality of life and functional status are considered under the ethical principle of best interest, while previously written or expressed wishes are incorporated under the principles of advanced directive or substituted judgment (Bailey, 2002). Such decisions are value-based that involve knowing the patient’s goals and what conditions they are willing to accept (Adams, Bailey Jr., Anderson, & Thygeson, 2013). Thus, it is important to gain an understanding of the patient’s values in order to understand the patient as a person (Scheunemann et al., 2012).

Quality of life is a consideration in patients who survive critical illness as these patients may suffer a prolonged sequela of symptoms or may never fully recover. These patients may lapse into a condition known as chronic critical illness (CCI). CCI is defined as prolonged mechanical ventilation, brain dysfunction, and neuromuscular weakness in critically ill patients (Nelson, Cox, Hope, & Carson, 2010). Patients with this condition are challenging within the ICU for they survive the initial disease process that brought them into the ICU and continue to have major systemic issues and critical needs. CCI was first identified in 1985 and is characterized by a sequela of metabolic, endocrine, immunologic, and neuropsychiatric dysfunctions (Campbell & Happ, 2010). Patients with CCI experience many unpleasant physical and psychological symptoms during the course of their illness and residual effects often persisted after discharge (Nelson, Kinjo, Meier, Ahmad, & Morrison, 2005; Nelson et al., 2004). These patients shoulder a high symptom burden: pain, dyspnea, thirst, dry mouth, hunger, lack of energy, psychological symptoms such as sadness, worry, and nervousness, and impaired communication (Nelson et al., 2004). When SDM select the full treatment option for a patient who cannot wean off medical technology, they are often not aware of the consequences of the decision and the suffering that the patient will endure (Nelson et al., 2005). For these patients, there are three potential outcomes: 1. High physiological requirements keeping them in the ICU or a step-down unit for a prolonged stay followed by eventual death, 2. Able to be weaned to a lower level of support which allows them to be transferred to a skilled nursing facility or home with family members providing their care, or 3. The patients are weaned off all technological support and liberated from the ICU. The one-year survival of these patients varies from 40-50%, and the survivors are left with various physical and cognitive deficits (Carson, 2012). It is challenging to make goals of care decisions for this patient population for their illness trajectory can be lengthy and vary based on the family's expectations and the patient's level of resilience.

Nurses Role in GOC DM

Nurses described themselves as having a variety of roles in GOC DM in studies conducted within the United States. These roles include patient and family advocate (McAndrew & Leske, 2015; Peden-McAlpine, Liaschenko, Traudt, & Gilmore-Szott, 2015; Perrin, 2001; Robichaux & Clark, 2006), mediator (Perrin, 2001), coordinator, support person, and educator (Jezuit, 2000). While these nursing roles often occur simultaneously, each will be reviewed individually.

Mediator Role in the Communication Process

Nurses described themselves as being positioned in the middle of the family and physicians in the GOC DM communication process (Calvin et al., 2007; Gutierrez, 2012c). The amount of time spent at the bedside with the patient and family members provides nurses with a unique vantage point to observe the family member's readiness for decision making (Calvin et al., 2007). Often nurses felt as though they 'walked a fine line' in what they told family members, out of fear of upsetting the physician or the family members (Calvin et al., 2007, 2009). The concern of being too influential limited what nurses would discuss out of concern that they would be projecting their own values and beliefs onto the families (Liaschenko et al., 2009). Nurses relied on physicians to have difficult conversations, as prognosticating outcomes was not perceived as a nursing role (Calvin et al., 2007, 2009; Gutierrez, 2012c; Reinke, Shannon, Engelberg, Young, & Curtis, 2010). Nurses were concerned about sparking conflict with SDM, as a hostile environment makes it difficult to provide patient care. Therefore, many nursing roles around GOC DM involved having to convince the physicians that it was time to talk to the family or securing physician approval and collaboration (Perrin, 2001). A nurse provided a scenario of being caught in the middle between family members and the patient, where family members did not respect or follow through on the patient's wishes (Gutierrez, 2012c). This nurse still considered it to be the physician's responsibility to follow through and resolve this discrepancy.

The patient's proximity to death motivates the nurse to discuss GOC DM with family members (Gutierrez, 2012c). If the nurses were convinced that the patient had a very poor chance of survival, nurses employed various techniques to encourage the physician to talk to the SDM. The nurses would ask the physician to come to the bedside and see the patient, encourage the family to participate in multi-disciplinary rounds, arrange a family meeting, and ensure that all physicians involved in the patients' care were collaborating with each other (Perrin, 2001). If the patients were able to talk, nurses would ask them about their wishes and share that information with physicians and family members (McAndrew & Leske, 2015; Peden-McAlpine et al., 2015; Perrin, 2001; Robichaux & Clark, 2006). Nurses felt stuck in the middle. They knew they needed to communicate to advocate for patients (Calvin et al., 2007; Cypress, 2011; Dillworth et al., 2016; King & Thomas, 2013; McAndrew & Leske, 2015; Perrin, 2001; Robichaux & Clark, 2006), but nurses did not feel listened to and felt powerless in altering the course of treatment (Calvin et al., 2009; Dillworth et al., 2016; Gutierrez, 2012c; McAndrew & Leske, 2015; Robichaux & Clark, 2006).

Patient Advocate

Nurses suggested that being a patient and family advocate was an important role in GOC DM (McAndrew & Leske, 2015; Peden-McAlpine et al., 2015; Perrin, 2001; Robichaux & Clark, 2006). Chafey, Rhea, Shannon, and Spencer (1998) interviewed 17 practicing nurses to define advocacy. The resulting definition identified four nursing actions directed toward patients and family members: relating, empowering, coordinating aspects of care, and intervening to protect (Chafey et al., 1998).

Nurses described their advocacy role as recognizing and questioning when treatments are ineffective and carefully sharing the information with the patient's family members (McAndrew & Leske, 2015). Nurses would share this information with physicians and encourage the team to talk to the family (Calvin et al., 2007). In this manner, nurses encouraged communication between the patient, family members and the health care team (McAndrew & Leske, 2015). Nurses reported the importance of preparing family members emotionally for a potentially poor outcome and the nurse offered updates and information on the patient condition and treatments to amend patient and family expectations (Cypress, 2011). Nurses explained the motivation for such advocacy behavior was to minimize patient suffering (McAndrew & Leske, 2015). As a Medical ICU Nurse stated, "because we are more hands on, and we see the anguish that the patient is going through that the doctors and family might not get to see" (Zomorodi & Lynn, 2010, p. 91). Preventing suffering motivated a nurse to tell an intern: "…well, then go carry out your plan… I am NOT doing this. And they did make her a no code shortly after and she did die" (McAndrew & Leske, 2015, p. 363). This nurse was able to prompt the physicians to readdress the treatment plan and change the goals for that patient.

Robichaux and Clark (2006) interviewed 21 expert nurses, of which six of them provided narratives where the nurse advocated for the patient. One nurse provided a scenario where a ventilated patient wrote a clear message about not wanting to have any more surgeries. The nurse shared this information, but both the patient's husband and physician insisted on one more surgical procedure before withdrawing treatment (Robichaux & Clark, 2006). Two other scenarios were presented, a nurse advocating that a patient's advanced directive request that limited the duration of mechanical ventilation to seven days be upheld. Another situation involved arguing for a patient who made a verbal statement requesting not to be intubated but the wish was over ridden by the patient's daughter (Robichaux & Clark, 2006). Advocating in these situations required the nurse to assertively, skillfully, and ethically 'speak' for the patient.

Nurses' attempts to advocate may not produce the desired change in patient's plan of treatment and can leave the nurse feeling emotionally distressed (Robichaux & Clark, 2006). Speaking up and advocating for one's patient involves risks. An environment where nurses feel threatened, intimidated, or abused by physicians, experienced a lack of support, and were concerned about their job security reduced nurses' ability to advocate (Chafey et al., 1998). Committees, such as ethics and palliative care services vary in their availability and effectiveness in resolving ethical dilemmas (Robichaux & Clark, 2006). Nurses often utilized other nurses support in difficult patient situations (Robichaux & Clark, 2006). Some patient care situations escalated and become more challenging than what nurses could handle. In circumstances of extreme conflict, lack of trust, and unrealistic expectations from family members or physicians, nurses sought support from nursing management and the multidisciplinary team.

Educator and Communicator

Nurses reported that the role of discussing goals of care with family members was important. Seventy percent of nurses surveyed reported that they "often" had goals of care conversations with patient family members and only 13% reported discussing information about palliative care services with family members (Anderson et al., 2016). The researchers noted that only in situations where death was certain, and most likely imminent, that experienced nurses would initiate conversations with the patient's family members so they had time to prepare for the death (Gutierrez, 2012b). In situations where death was not imminent, nurses waited until physicians discussed the prognosis with family members. The unit culture and hierarchy can affect what the nurses are able to tell family members. Some physicians set boundaries on the type of information nurses can provide to family members and physicians can react negatively when perceiving nurses are overstepping their role (Popejoy et al., 2009).

Family members sought to obtain more information by asking the nurses for their opinions (Fry & Warren, 2007). Prompted by the family members inquiry, the nurse may seize the opportunity to share his or her perspective. A medicine ICU nurse stated to Badger (Badger, 2005) in an interview: "if they are going to ask us how things are and how the patient is doing – we're going to tell them. Sometimes that causes conflicts because they don't want to hear what you have to say" (p. 519). Nurses had to be very careful and assess what family members were expecting before following through with discussions. Otherwise, attempts at communication could ‘backfire’ and lead to conflict (Calvin et al., 2007).

Nurses have been less than forthright when communicating bad news to family members. Adams et al. (2014) interviewed 32 family members of critically ill patients who had a poor outcome potential. Few of these family members recalled nurses being forthright about the patient’s poor prognosis. Based on the family member’s recollection, it was more common for nurses to ‘hint’ that the patient was not improving while focusing on the uncertainty of the situation. While talking, nurses used nonverbal cues, such as tone of voice, facial expressions and body language to convey a grim message (Adams et al., 2014). Being subtle did not always deliver the intended message and some nurses were willing to become more assertive. A nurse in the Badger (2005) study stated that she became more forceful in her communication style by becoming “brutally honest” which resulted in disagreement and conflict.

The educational needs of SDM and family members appear limitless and the literature offers advice regarding potential nursing roles. Nurses can provide the appropriate education about the patients diagnosis and treatment and describe interventions and the potential consequences (Liaschenko et al., 2009; Reinke et al., 2010). As the SDM may have many questions, encouraging and being available to answer those questions is very helpful (Anderson et al., 2015). White (2011) suggested that nurses could fill this gap by providing education to patients and family members on the surrogate decision-makers role.

Facilitator Role

A team approach assisted nurses to meet the patients' needs for GOC DM. Collaboration within the multidisciplinary health care team improves the nurses' ability to advocate (Chafey, 1998). Being included in communication ensured that nurses had a full understanding of the patient prognosis, goals and decisions. The updates provided them with information to share with family members and consulting physicians (Peden-McAlpine et al., 2015). Collaboration provided an opportunity for nurses to voice concerns, to have questions answered, and to be involved in the plan of care. Nurses can provide valuable insight into the holistic needs of the patient that complement the medical treatment model (Espinosa et al., 2010). The nurse may lack knowledge or experience on how to talk to and what to say to family members in difficult patient situations and the guidance the group provides can be a source of support and validation.

Nurses were in the position to provide updates to the family regarding the patient's condition but were cautious when the information pertained to a change in the patient's status. Nurses in many studies reported it was not their role to tell family members bad news (Calvin et al., 2009; Gutierrez, 2012c; Slatore et al., 2012). When a patient's status declines, family members often have many questions and could become emotional. Thus, nurses preferred that a physician be available to answer questions pertaining to the effectiveness of medical treatments and concerns about the patient's outcome (McAndrew & Leske, 2015). When important decisions need to be made as a result of a change in the patient's status, family members prefer to hear prognostic information from the physician (Wiegand, 2006) with the facts provided in a direct manner using language that was understandable (Norton et al., 2003).

Health care providers often arrange a formal meeting with family members and surrogate decision-makers in a private conference room to provide updates and to discuss goals of care decisions. Nurses can orchestrate that such meetings by setting up the time, location, and arranging stakeholder attendance. While the nurses claimed an intermediary role during such meetings, the logistics related to staffing and patient care, limited nurses' ability to attend these meetings themselves (Ahluwalia, Schreibeis-Baum, Prendergast, & Reinke, 2016). When nurses were able to participate, they often felt under-empowered and under-valued to contribute meaningfully to the discussion (Ahluwalia et al., 2016). Thus, nurses felt that being physically present at these meetings was not a good use of their time. In a survey by Anderson et al. (2015) of almost 600 nurses, a lack of training, not being asked for their perspective, unclear role expectations, and emotional burden were identified as the most frequent barriers to nurses participating in such meetings.

Nurses perceived themselves to be in the position to coordinate, advocate, and translate for patients and family members (Ahluwalia et al., 2016). Even when they could not attend the meeting, nurses found it helpful to be informed on what was discussed so they could translate, reinforce and clarify with the family (Reinke et al., 2010; Slatore et al., 2012). As one nurse stated "I think it is always important for the nurse to be in the room when physicians are talking to the family so you can hear what they say, and you can reinforce it later; 'cause the families do tend to have questions afterwards when the doctors leave" (Slatore et al., 2012, p. 414). After the meeting, nurses would then 'fill in the gaps' and provide additional information to clarify what was discussed to ensure that family members had a clear understanding (Gutierrez, 2012c; Reinke et al., 2010; Slatore et al., 2012).

Supportive Role

Nurses reported that asking questions about what the patient was like before his or her illness and showing an interest in personal information was important for creating a bond with family members (Liaschenko et al., 2009). Such an interaction provided an opportunity to discuss family expectations, level of hopefulness, beliefs about quality of life and patient preferences (Peden-McAlpine et al., 2015; Reinke et al., 2010). A meaningful relationship allowed the nurse to be supportive of the family members and allowed them to provide information that moved the family member forward in the decision-making process (Adams et al., 2014; Popejoy et al., 2009). Family members appreciated having a bond and believed that maintaining a dialogue with the nurse was an important means of gathering information about the patient's condition (Fry & Warren, 2007; Wiegand, 2006).

Functional relationships with family members and the healthcare team are important for nurses to provide patient care (Pavlish et al., 2015). Nurses encouraged family members to spend time at the bedside to see what their loved one was experiencing. Family members at the bedside could observe how the patient was responding to treatment, allowing the nurses to present a realistic picture of what was occurring (Gutierrez, 2012c; Robichaux & Clark, 2006) and prepare the family for the possibility of death (Badger, 2005; Calvin et al., 2009). Alternatively, if a family is not ready to accept a poor prognosis, even with family at the bedside longer, the nurse may still avoid discussing end-of-life topics because that discussion may upset the family and harm the nurse-family relationship (Pavlish et al., 2015).

Barriers to Nurse Involvement

Nurses expressed frustration with physicians in several of the studies. When asked what a ‘pressing issue’ was for older patients, a nurse responded “doctors mislead patients and families as to the possible outcomes of the patient’s conditions” (Dillworth et al., 2016, p. e6). Physicians may delay relaying prognostic information to family members for various reasons. Physicians often prefer to wait until treatments and interventions are completed and outcomes evaluated. When multiple teams of physicians are directly involved in a patient’s care, differences in opinions within and between teams can delay the formation of a plan (Baggs et al., 2012). Attending physicians in ICUs often change every week or two. With each turnover, communication is delayed while the physician establishes a relationship with the family and gains an understanding of the patients status (Baggs et al., 2012; Espinosa et al., 2010; Zomorodi & Lynn, 2010). Physicians in the consultant role may have a narrow focus based on specialty and provided the family very limited information based on one organ system (Hansen et al., 2012). Nurses reported these delays difficult to cope with, especially when they were certain that the patient would not survive and the care they provided had a limited benefit (Espinosa et al., 2010). Earlier communication was desirable since family members preferred more frequent updates from clinicians about the patient’s status and the response to treatment (Fry & Warren, 2007; Wiegand, 2006).

Caring for critically ill patients is time consuming and the nurse is often occupied while managing complex treatments and technologies. Many nurses found it difficult to communicate with family members while providing patient care (Popejoy et al., 2009). Nurses reported frequent phone calls from multiple family members to be an intense obstacle when providing care for ICU patients (Beckstrand & Kirchhoff, 2005; Beckstrand, Callister, & Kirchhoff, 2006; Crump et al., 2010).

Not all nurses choose to become involved in GOC DM, as a neuroscience ICU nurse describes that some nursing colleagues “are task oriented, and leave the main decision making to the physician …it’s a lot of emotional turmoil. I think nurses sometimes don’t want to deal with it because it’s not that simple” (Calvin et al., 2007, p. 147). Nurses differed in how willing they were to engage. As a nurse stated to Chafey et al (1998 p. 49)

> I think some of us try to do everything that’s needed for the patients, and others just try to meet the minimal requirements. It’s a job and they’ll do it to the degree that they need to, to get the job done, but they lack that caring component.

Many nurses were unclear of their role in the end-of-life decision-making process and expressed a lack of education in this area (Anderson et al., 2016). Hansen at al. (2012) observed that nurses taking care of patients with end-stage liver disease did not consider minor life sustaining treatments, such as the transfusion of blood products and the addition of vasopressors, as important topics to discuss with family members.

The emotional toll that nurses felt due to the absence of decision-making was verbalized by nurses in almost every study. Nurses viewed working with critically ill patients who may die ‘as part of the job’ but struggled with the emotional needs and indecisiveness of the patients’ family members (Badger, 2005). It was difficult for nurses to sympathize with family members whose hesitancy permitted ongoing treatments that appeared painful (Badger, 2005). Nurses expressed frustration when family members continued to insist on all care possible when the long-term benefits were limited (Calvin et al., 2007; Espinosa et al., 2010; Popejoy et al., 2009; Robichaux & Clark, 2006). Nurses felt helpless when physicians were overly optimistic, not honest with family members, or delayed conversations (Calvin et al., 2007, 2009). Nurses who remained quiet and do not comment reported feeling internally conflicted (Jezuit, 2000).

Some patient conditions appeared to cause more moral distress than others and have a lasting impact on the nurse. Witnessing suffering can have a profound effect on the nurse and maintaining a balanced approach is necessary. McAndrew and Leske (2015) identified the central theme to end-of-life decision-making to be a balancing act, where nurses and physicians constrained emotions when working with patients and family members and remained objective in the professional role. Imbalance occurs when a clinician becomes too emotionally invested in a patient situation, which affects performance, communication and collaboration with team members (McAndrew and Leske, 2015). Due to the intimate nature of working with people, it is not easy or always possible for a health care provider to remain emotionally distant. Advocating for patients requires some form of emotional connection (Chafey et al., 1998). The researchers concluded that being involved in GOC decision-making was both challenging and rewarding when a nurse is balanced and leads to moral distress when there is imbalance (McAndrew and Leske, 2015). When faced with a difficult family situation, one nurse provided an example of emotional distancing:

> I basically become indifferent. Close my mouth. Because my opinion in those situations matters but it doesn't…if a family is stark fast on an idea it's not my place to change their beliefs. So basically, I just become very objective, um numbers, infections, and you know very methodical in I pull my emotional side out of it and I am then just a nurse taking care of a patient and helping the family, but just being the nurse (McAndrew & Leske, 2015, p. 362).

Another nurse presented a story of how they coped with a very difficult patient situation "we had to rotate care because we would go insane. I mean enough is enough. I felt so tired for her, and I would never have my loved one like that. But our hands were tied" (Robichaux & Clark, 2006, p. 486). Maintaining balance and finding the appropriate emotional distance is an ongoing challenge for critical care nurses. Prolonged exposure to situations with moral and ethical issues and conflict is damaging and can impact how nurses engage with healthcare providers, patients and family members (Foreman, Milisen, & Fulmer, 2012).

Ethical dilemmas and moral distress are emotional challenges that nurses face during GOC DM. An ethical dilemma is a situation in which the practitioner is presented a choice between two equally unfavorable alternatives (Hamric, 2007; Metty, 2012). Moral distress refers to "when one knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action" (Jameton, 1984, p. 6). Distress occurs when what was perceived to be the right thing to do was blocked and one must act against a personal value (Metty, 2012). Calvin et al. (2009) found that moral distress in nurses is intensified with ongoing, relentless medical treatment, as the nurses are the ones who 'carry out orders' and are in the position to observe how treatments affect the patient. Nurses with higher moral distress scores rated a lower satisfaction with the quality of care provided, the ethical environment, and had a lower perception of collaboration with physicians (Hamric, 2007).

Addressing moral distress and empowering nurses is important to maintain engagement in the GOC DM process. When nurses 'turn off their emotions' or avoid caring for terminally ill patients, they are not delivering optimal care and are unable to meet the SDM decision-making needs (Espinosa et al., 2010). Strategies to help nurses cope include empathizing with patients and families, seeing humor in situations, laughing, learning from experience, talking to others, and knowing when to 'retreat' to a safe distance from a situation (Badger, 2005b, Espinosa et al., 2010). Zomorodi & Lynn (2010) found that a work/life balance is crucial. Maintaining a life outside of work and not thinking about patients during non-working hours is important.

Summary

Intensive care units within the United States provide state of the art technology to cure and maintain critically ill patients. Not all patients are able to recover and the challenge in goals of care decision making is a very complex process. This review of the literature illustrated that nurses have been identified as mediators, communicators, advocates, and support persons in the GOC DM process. There are many challenges in the GOC DM process and nurses in a difficult position as they are placed in the middle of the decision-making process. Nurses are not ultimately responsible for the final decision, but nurses are in the position to communicate with family members and physicians that it is time to act. However, it is known that not all end-of-life patient situations can be resolved through GOC DM.

This literature review provided some solutions to the challenges in GOC DM. Emphasis are on a team-based approach with increased communication and collaboration, earlier goals of care discussions and more honest conversations with family members (Norton et al., 2003). Suggestions included that nurses provide education about the surrogate decision-making role, provide detailed daily updates to family members, encourage and answer questions, and work with SDM before, during, and after physician-family meetings. However, it is not known how nurses perceive these interventions and how helpful they find them in practice.

A phenomenological research study focused on nurses' current lived experience of GOC DM contributes to what is known about the nurses' experience. Providing new knowledge using Van Manen's phenomenology of practice was a unique way to capture nurses experience and how they perceived this phenomenon. The main goal was to better understand critical care nurses' lived experience when caring for patients who are not expected to survive by capturing the nurses' voices. In this study, critical care nurses were asked to describe their experiences while working with the family members of patients in need of GOC DM. The importance of nurses' perspectives was because they were participants and close observers of this process and had genuine insight into this phenomenon.

Phenomenology of practice was used as the framework to capture the nurses' voices in a lived experience description. The goal was to expose the situational and contextual meaning of a phenomena based on how it was perceived and experienced by those involved. The technique proposed by Van Manen was unique because it incorporated the philosophical teachings of the first and second-generation phenomenologists. Methods to assist in bracketing assisted the researcher to bracket and to enhance reliability and trustworthiness. This was important for the researcher who works closely with this phenomenon as a practicing ICU nurse. Based on the findings of this literature review, Van Manen's phenomenological technique has not been used to examine the lived experience of nurses as they care for patients in need of GOC DM. Therefore, this study contributes nursing knowledge by providing lived experiential accounts of the nurses in goals of care decision making.

CHAPTER III

THE PHENOMENOLOGICAL METHOD OF INQUIRY

Qualitative research methodology uses words as data to explicate the meaning of behaviors and the subjective world (Braun & Clarke, 2013). Since the inception of qualitative research in the mid-19th century, various research qualitative paradigms have evolved, each containing unique assumptions, values and practices that define how research is conducted (Braun & Clarke, 2013). The ontological and epistemology is what differentiates and defines each paradigm. Ontology explains the nature of reality as it relates to human knowledge, perception, and behavior (Braun & Clarke, 2013). Epistemology defines the nature of knowledge, what is possibly to know, what is its meaning, and how is it generated (Braun & Clark, 2013). Qualitative research paradigms are selected based on the researcher's goals and study population. The topic for this study was critical care nurses' experience for patients in need of goals of care decision-making. The literature review described several self-perceived nursing roles and it failed to document the process of how nurses experience GOC DM. Therefore, the phenomenology method of inquiry was used to examine the lived experiences of practicing nurses surrounding goals of care decisions for a critically ill patient that was not expected to survive.

Many past and contemporary phenomenological philosophers have and continue to discuss of the source and explanations of meaning within the lived human experience within various contexts and dimensions (Munhall, 2007, Van Manen, 2014). Upon these foundations evolved Van Manen’s phenomenology of practice. Van Manan described the goal of Phenomenology of Practice is to “open up possibilities for creating formative relations between being and acting, between who we are and how we act, between thoughtfulness and tact”(Van Manen, 2007, p. 13). Phenomenology of practice describes and interprets one’s state of being and actions in events that unfold in daily interactions within one’s environment.

Phenomenology of Practice

The philosophical assumptions of phenomenology of practice focuses on pathos, which in the context of life refers to “the general mood, sensibility, sensuality, and felt sense of being in the world” (Van Manen, 2007, p. 20) Practice grasps the world pathically as opposed to theoretically:

> Professional knowledge is pathic to the extent that the act of practice depends on the sense and sensuality of the body, personal presence, relational perceptiveness, tact for knowing what to say and do in contingent situations, thoughtful routines and practices, and other aspects of knowledge that are in part pre-reflective, pre-theoretic, pre-linguistic (Van Manen, 2007, p. 20).

The methodology for Phenomenology of Practice focuses on two aspects: reduction and vocative. Reduction involves reflection on the pre-reflective experience, also known as the living moment, and bracketing by the researcher of one’s preconceived notions (Van Manen, 2007). Reduction aims to remove “any barriers, assumptions, suppositions, projections, and linguisticalities that prevent the phenomena and events of the lifeworld to appear or show themselves as they give themselves” (Van Manen, 2014, p. 221) Vocative involves linguistics and writing to portray the prereflective experience.

Van Manen suggests that by reflecting and writing, a researcher creates a narrative illustrating and exposing the essence of a phenomena. The purpose of the narrative is to allow the reader to feel and understand the meaning of the phenomena within the realm of human experience of being (Munhall, 2007). These narratives provide examples encountered by people that expose the important aspects and configuration of the phenomena (Munhall, 2007).

Van Manen and Munhall propose that phenomenological thinking is not linear and following prescribed steps can restrict a researchers exploration into the meaning of being human in experience (Munhall, 2007). Van Manen provides several exercises in epoché-reduction to assist the researcher with bracketing and reduction. The bracketing exercises include heuristic reduction, hermeneutic reduction, experiential reduction, and methodological reduction (Van Manen, 2014). The bracketing exercises are followed by five reflective exercises: eidetic, ontological, ethical, radical, and originary reduction, which help to expose the special qualities of a phenomenon and assist in reduction (Van Manen, 2014).

The vocative phenomenological method involves writing a narrative to capture the phenomenon. Van Manen describes the following methods: revocative, evocative, invocative, and convocative. An important part of the narrative description is the narrative anecdote describing various aspects of how the phenomenon is experienced (Van Manen, 2014).

Phenomenology of practice provides an approach that is not fossilized in one philosophical approach or philosophers view but is open to evolving with contemporary phenomenological scholars (Van Manen, 2014). It concerns itself with various aspects of practice, both how it is experienced by professional groups and in everyday living. It views the world as “not only rational and logical, and thus in part transparent to reflection – it is also subtle, enigmatic, contradictory, mysterious, inexhaustible, and saturated with existential and transcendent meanings that can only be accessed through poetic, aesthetic, and ethical means and languages” (Van Manen, 2014 p. 213).

There have been several qualitative descriptive studies that have used thematic analysis to describe the nurses’ role, issues encountered, and coping techniques (Badger, 2005; Calvin et al., 2007; Cypress, 2011; Gutierrez, 2012c; Hinderer, 2012; Jezuit, 2000; King & Thomas, 2013; Liaschenko et al., 2009; McAndrew & Leske, 2015; Pavlish et al., 2015; Popejoy et al., 2009; Reinke et al., 2010; Robichaux & Clark, 2006; Slatore et al., 2012; Zomorodi & Lynn, 2010). Few studies have engaged in a deep exploration to understand the nature of nurses’ lived experiences and derived meaning in what it is like to care for patients during the GOC DM process. Phenomenology of practice was selected as a method (in combination with Munhall’s seven step process) for this study to provide rich descriptive and interpretive narratives that captured the meaning and experiences of critical care nurses from various perspectives.

Phenomenology as a research method has deep roots within philosophy and aims to address the nature of reality and of human knowledge. Van Manen has integrated the philosophical underpinnings of his predecessors into a framework to attain and share the meaning of human experiences within the human sciences framework. Munhall incorporated these philosophical frameworks into the nursing research arena to enhance the utilization of phenomenology in nursing in a manner that is consistent with other disciplines. The approaches described by Munhall and Van Manen were complementary and were utilized together to examine the nature and meaning of nurses' experiences in GOC DM.

Design

The purpose of this phenomenological study was to describe the nature and meaning of critical care nurses lived experience caring for patients in need of goals of care decision-making. The nurses were asked to share stories describing their lived experience. These stories were explored thematically and explored for meaning within the practice of nursing (Richards & Morse, 2007). Nurses' involvement in goals of care decision-making was generally be defined as intentions and interactions that nurses have with surrogate decision makers of patients with poor projected outcomes related to future treatment and goals of care.

Sample and Setting

The goal of the phenomenology interview was to collect rich experiential descriptions of the lived experience of a phenomenon. Therefore, it was important to find participants willing to talk about their experiences surrounding the phenomena of interest and to share their personal stories (Munhall, 2007). The goal was to gain experientially rich descriptions of the phenomena. Rather than patterns and saturation, the method allowed for examination of the uniqueness of experience that provided an insight into the phenomenon that may have only occurred in one lived experience (Van Manen, 2014). The total number of interviews necessary for a phenomenological study differs based on the complexity of the question and the richness of the accounts. The strategy was to collect enough experiences to allow for scholarly and reflective writing and not too many for it encouraged shallow reflection (Van Manen, 2014).

The exact sample size for phenomenological studies is difficult to predict a priori. It was anticipated that a maximum of 20 interviews would be required. The participants met the inclusion criteria of a) Registered Nurses, b) currently employed within the critical care settings with two years or more of adult critical care experience and c) who had cared for at least one patient who was critically ill and not expected to recover. The sampling technique was purposive based on the inclusion criteria and the nurse's ability to relay rich experiential accounts. Streubert and Streubert (1991) recommended that a researcher interview several samples of participants with different backgrounds and experiences to identify broader essences of the phenomenon in question. Including nurses with different levels of experience and from different settings may have increase the variation within the sample, so a richer picture of the phenomena was presented. Variation in the sample was obtained by including nurses with varying years of experience (for example, from 2-5, >5-10, and >10) and across different ICU specialty foci (at least two different foci).

Primary recruitment for this phenomenological study occurred at a university-affiliated Magnet-designated academic medical center in the southeastern United States. The researcher contacted the nurse managers via email of three adult critical care unit to inform them of the study and to secure leadership buy-in. Several approaches were used to recruit participants. Recruitment posters describing the study and inviting nurses to participate were posted in the bathrooms and staff bulletin boards and a recruitment script was presented in person to ICU nurses. Each mode of recruitment documents relayed the study purpose, time requirement, compensation, and emphasize that participation was voluntary. Staff were assured that contacting the researcher would not obligate them to participate in the study, but to help them learn more about it so that they could make an informed decision. When contacted, a recruitment follow-up email explained the study was sent to interested nurses along with the option to schedule an interview. This recruitment script broadly described the phenomena of interest so nurses had time to reflect and contemplate experiences (Streubert & Streubert, 1991).

Interviews were conducted during non-working hours, outside of the clinical workspace or direct patient care areas and spanned approximately 30 to 60 minutes. Any setting that was conducive to thinking, such as the participants home or a coffee shop, for example, was considered as an appropriate location (Van Manen, 2014). The participants selected locations of their choosing, either at the hospital or at a coffee shop. A consent form that detailed the study, the risks and benefits of participating, and confidentially was reviewed with the participant and signed prior to starting the interview.

The option for a second contact was included within the consent in case the researcher required additional clarification and explanation, or the participant wished to expand on the experiences that he or she shared in the first interview. The participants were provided with the primary investigators contact information with the option to email additional details of their experiences as they were remembered. None of the participants emailed any additional details after their interviews and a need for a second interview was determined not to be additive.

Protection of Human Subjects

A consent form contained the parameters of this study and notified participants of their rights and risks of participating. Within the consent, the participants were asked if they were willing to participate in a second interview or contacted by email if needed to keep that option open. Nurses were made aware that participation was voluntary, and they had the right to withdraw at any time. The application, recruiting documents, consent forms and interview guide were approved by the University of North Carolina at Greensboro Institutional Review Board (UNCG IRB). Additional reviews and permissions were granted by the Nursing Research Council at the participating hospital.

Data Collection and Management

Data collection and management followed Munhall's (2007) third procedural step of existential inquiry and expressions. The phenomenological interview required a phenomenological mindset, and thus the researcher practiced gaining the proper attitude and practiced the preliminary exercises drafted by Van Manen (2014). It was important for the researcher to decenter by reflecting on her own biases, assumptions and beliefs involving goals of care decision-making (GOC DM) to avoid tainting the interviews and data with preconceptions (Munhall, 2007). The goal was to 'unknow' the phenomena and to develop a sense of wonder in the experiences and meaning of others. The researcher maintained a reflective research journal detailing her research journey beginning with Van Manen's preliminary exercises.

The purpose of the phenomenological interview was to gain pre-reflective experiential responses from critical care nurses and an interview guide structured the interviews (Van Manen, 2014). Pre-reflective responses are the experiences as they occur in the moment and thus free from interpretation. The researcher used 30 to 60 minutes for each interview with a focus on lived experience descriptions to capture personal stories in the pre-reflective state and did not focus on opinions, assumptions, interpretations, beliefs or judgements (Van Manen, 2014). During individual interviews, the researcher asked the interview question and allowed the participant to talk without leading or interrupting. The main question was: Think of a time you took care of a critically ill patient(s) that was full code with continuing aggressive measures and not expected to recover and was in need of goals of care decision-making. Please share your story, your experience and what you encountered during the decision-making process for this patient. When there was a pause, probing for meanings in actions and thought processes encouraged the participant to continue to explore their actions through conversation (Munhall, 2007). Participants were encouraged to continue to discuss the phenomena until they felt it had been thoroughly explored. The researcher provided light refreshments during the interview. These interviews were conducted in person and were recorded with a digital voice recorder. The researcher wrote field notes to document observations, impressions, and reflections after each interview and throughout the analysis. These notes included additional details such as interviewers' observations and thoughts as well as participants' emotions, demeanors, postures, and information not captured by the digital recorder. Transcripts and field notes were de-identified with a participant number and pseudo name. Demographic information such as age, type of ICU where experience occurred, years as Registered Nurse, Years of ICU experience were collected at the time on the interview. Following the completion of the first interview, the participants received a thank you card with $20 cash and with a message inscribed "Thank you for sharing your experiences. If you think of anything that you would like to add, please call or email at #". The participant signed a receipt to attest that compensation was received.

Audio recordings were transcribed verbatim and verified by the researcher for accuracy. An experienced scholar randomly selected audiotapes to verify with transcript content for accuracy. Audio files, field notes and transcribed interviews were stored on a password protected external hard drive in a locked cabinet and in the study folder within BOX.uncg.edu which has data security protection suitable to store high risk data. Audio files were deleted from mobile recording devices after transcripts are verified and files transferred to the secure hard drive and Box.uncg.edu.

Data Analysis

Analysis followed the process detailed by Munhall for existential and phenomenological contextual processing, analysis of interpretive interaction, and the writing of the phenomenological narrative as described previously. Existential processing allowed the investigator to examine the interview transcripts to search for the meaning of the phenomena. Each interview transcript was carefully reviewed several times. The goal was to interpret each participant's story for personal expressions of meaning while maintaining the integrity of their account (Munhall, 2007). The researcher was immersed in the data reflecting and contemplating on the meaning of each transcript until insights, awareness and understandings appeared (Munhall, 2007). The LED from interview three provided the most detailed experiential account and was therefore included in the results section. The experiential components of this interview transcript were converted to a lived experience description as outlined by Van Manen (2014) and analyzed holistically and line by line.

Epoché and reduction followed the four preliminary exercises of heuristic, hermeneutic, experiential and methodological reduction suggested by Van Manen (2014) to help the researcher with bracketing and to develop an open mindset suitable for phenomenological thinking. *Heuristic reduction* involves looking at the world with a sense of wondering attentiveness which draws attention to the phenomenon or events that are often taken for granted (Van Manen, 2014). *Hermeneutic reduction* requires an openness to a genuine understanding the phenomenon by continuously questioning assumptions and conclusions and by overcoming personal feelings, preferences, inclinations or expectations regarding the phenomena in question (Van Manen, 2014). *Experiential reduction* focuses on the phenomena as it is lived in space, time, corporeally, and relationally, with a concreteness that is free of theory, generalizations, and preconceived notions of what is real (Van Manen, 2014). *Methodological reduction* requires a customized approach or method that allows the researcher to gain access to the feelings and experiences of participants in a situation at a specific time with the goal of producing valid phenomenological results (Van Manen, 2014). This researcher approached this study with a sense of wonder and curiosity to how other nurses experience situations involving goals of care decision-making as a primary mode of bracketing. This approach was incorporated into both the interviews and maintained throughout the analysis. The researcher dwelled on the participants transcripts and reviewed them many times to understand what the nurses were describing and the nurses' experiences within this phenomenon. The procedures for thematic analysis was followed in which codes and themes were identified and the experiential accounts sorted to make them amenable to further analysis. The researcher kept a journal detailing this analysis as well as a reflective journal that detailed the researcher's thoughts as she sought to understand the meaning of this phenomenon.

Phenomenological contextual processing assisted the researcher examine and describe how each participant was contextually situated within the life-world (Munhall, 2007). It included the situated context of nurses practicing within critical care units which included their worldview, cultures, norms, and the control they had of their experiences. The researcher examined the contingencies that nurses experienced in their life worlds that promoted or deterred actions and decisions. The characteristics of the critical care environment, how nurses embodied their role, role expectations and definitions, and how nurses interpreted their relationships with others was described.

Munhall's (2007) fifth step, interpretive interaction, allowed the researcher to examine how nurses derived and assigned meaning to their experiences within the situational context of the critical care unit. Expressions of meaning were described and interpreted to portray the nurses' individual life worlds. Van Manen's (2014) five reductive approaches: eidetic, ontological, ethical, radical and originary assisted in uncovering the uniqueness of this phenomena.

Munhall’s (2007) sixth step, writing the phenomenological narrative, was the next phase of analysis. This step allowed the researcher to articulate and animate the experiences of the nurses in GOC DM so that it will resonate with the reader. Writing exercises using the revocative, evocative, invocative, convocative, and provocative methods guided the writing. A narrative was written with a phenomenological attitude to expose phenomenological insights.

Munhall’s (2007) final step, writing a narrative on the meaning of the study, applied the findings of this phenomenological study to nursing practice. The purpose of the summary was to enhance the reader’s understanding of the phenomena and provide suggestions for practice.

Trustworthiness and Credibility

The researcher recruited nurses within the critical care units within at the hospital where she was employed. She recruited only nurses that she did not work with regularly or have a personal friendship to prevent influencing the data collected. Nurses were interviewed away from the workplace in a location of their choosing and were encouraged to describe their stories in as much detail as they could remember.

Analysis of data began immediately after the first interview was transcribed. A reflective journal guided by the four preliminary exercises of heuristic, hermeneutic, experiential and methodological reduction helped the researcher to explore her assumptions regarding this phenomenon and to maintain an open mindset.

Phenomenology does not claim to have interrater reliability as it is hoped that with each exploration of the phenomenon, new and interesting insights are received (Van Manen, 2014). Credibility and trustworthiness in this study was enhanced by 1. Sample composition with nurses who had varying experience levels and critical care specialty.
2. Interviewing a sample of 10-20 nurses that captured a variety of nurses' voices.
3. Capturing the nurses' voices accurately. A second experienced scholar reviewed and verified the analysis separately from the PI and then compared and discussed results. A third experienced scholar reviewed interpretations and examined the results for accuracy.

Inquiry into the nature and meaning of nurses' experiences surrounding GOC DM followed the processes described in this chapter and as provided by Munhall (2014) and van Manen (2014). Twelve nurses were recruited to participate in individual interviews that were audiotaped, verified for accuracy and interpreted for meaning. The researcher maintained a phenomenological mindset and extrapolated narratives that described and interpreted the meaning of the nurses' experiences.

CHAPTER IV

FINDINGS

The sample contained a convenience sample of 12 critical care nurses. These 12 nurses shared more than 30 stories in which they described their experiences of caring for patients that they believed would not recover. Interviews ranged from 34 to 60 minutes in length. Eleven nurses were female, one nurse was male. As there was only one male nurse, he was assigned a female pseudo-name to protect his identity. Each nurse was able to provide accounts describing a rich experiential description of their experiences. Participants had a wide range of critical care nursing experience with an average of 10.5 (range 2-21) years of total Registered Nurse experience and 7 (range 2-17) years of ICU experience. The average age of the nurses was 37 years of age with a range from 29 to 53 years. The nurses worked in various specialties. The majority of the nurses (9) described their specialty to be Medical ICU, one identified as a Cardiac ICU nurse, and two identified as surgical-trauma ICU nurses.

Most stories described the nurses' experiences in the current workplace while a few occurred at other hospitals. Some nurses chose to describe experiences that occurred earlier in their career. All of the stories that the nurses shared occurred at large academic medical centers located in the eastern United States. Some of the nurses shared one story that they found was influential or memorable while other nurses shared up to five stories to describe the different aspects of this phenomenon.

Table 1

Participants in this Study

Pseudo-name	**Years of RN Experience**	**Years of Critical Care Nursing Experience**	**Number of Patient Stories Shared**
Alexa	20	7	1
Briana	9	7	2
Cassi	2	2	1
Daphne	9	9	1
Emily	10	4	4
Felicia	21	17	4
Grace	8	8	2
Hannah	7	5	2
Irene	21	17	2
Jordan	13	10	4
Kelly	3	3	5
Leslie	5	4	3

As nurses shared their experiences of caring for patients fitting this description, it became clear that this phenomenon was complex. Their lived experiences were explored from a phenomenological viewpoint through stories. Grace, a nurse with 9 years of ICU experience, suggested that there are layers if deeper meaning and understanding of this phenomenon: "We take care of so many critically ill patients that have been full code and continued aggressive measures that it’s hard, I think it’s a process, and it is interesting to reflect on, I think like, even the development of self and the interpretation beyond that.”

Critical care nurses’ practice involves skillsets to care for very sick patients. Alexa described how she evaluated a patient’s status and the approach she used to update the patient’s family:

> Before I walk into my patient's room, I look over the labs, and from these values, I can tell if the patient is doing a little bit better or worse. I could see she was actually doing worse each day. When I go into the room, I am always truthful with the patient and the patient’s family, usually a patient that sick won’t ask many questions, but um, I try to be truthful with family members when they ask how she is doing as compared to the previous day and how comfortable the patient appears. I just tell them the truthful information about the patient and let them conclude on their own if the patient is getting better or worse. Who am I to say anything, you know? It’s a lot of areas to juggle, we look on a patient very holistically, but the patient’s family doesn’t have this ability to look holistically, they just look at the patient.

Alexa looked at the patient’s trending laboratory data and level of comfort to determine if the patient was improving. She elaborated on her technique after her interview to describe that she evaluates the patient’s condition based on their laboratory values, chest x-ray, vital sign trend, oxygen levels and vasopressor requirement. When she evaluated the patient’s status, she looks at how many of these markers were improving or worsening and presents those as “truthful information” when updating the patient’s family members. In this way, Alexa was able to communicate objectively and provided the information that she felt that the family member needed early in the day. She then continued to provide care and treatments for the patient for her 12-hour shift. She indicated, based on these parameters, that this patient’s condition was slowly deteriorating. This analysis examined stories and experiences similar to this situation to glean experiential accounts and a deeper understanding into the nurses’ experience. One Lived Experience Description (LED) provides the initial context for these situations.

A Lived Experience Description

Cassi, a nurse with two years of ICU experience, described a patient situation that occurred when she was six months into her critical care nursing career. This was her first experience of caring for a patient in such a dire situation. This anecdotal account described the details of what she experienced and felt throughout this experience.

> I took care of the patient for a full shift, was managing all these things and then spoke to the partner on the phone and had a really good conversation in terms of being able to update this person and felt like we made a connection. I always feel that it is important to make a connection because you can get so much more information, especially since the patient arrested, you know, unwitnessed. And there were so many unknowns we didn't know, and wanted, and probably goals of care and those things, conversations were going to be very difficult. So, I felt like we made, or had established, a good connection.
>
> When the partner finally did visit, he glanced at his partner in the bed and asked me, "What do you think, if we turn off the sedation, would he wake up?" I was careful in choosing my words, aware that my perception may be clouded as I knew that the prognosis was terrible. I carefully replied, "Well, I'd anticipate that um, there would be no change because I have not seen any response thus far." Suddenly his posture changed, he looked at me intensely and said in an abrupt voice "I can tell that you're anticipating pessimism, you need to have optimism. The people caring for him have to be more optimistic because that's what helps the situation." His response caught me off guard and after this conversation I pulled back, just giving objective updates, these are the medications that the patient is on, this is what we do for his skin, this is what I'm seeing when he's off sedation, this happened today. He seemed satisfied with this approach, but I felt like it was a mess, overall.
>
> He seemed so hopeful, so sure that there would be a recovery. He would tell me "I know that this is in God's hand and God doesn't want my partner to go yet". It was really hard for the nurses to respect the partner's stance, and resentment started to build. Once it was established it just wasn't moving in terms of his code status, I just stopped trying with him. To try to um, it was just, it felt really surface, um, I think maybe I, I know I said things like, we are just trying to figure out what this patient wanted, I would say that I think it's important to keep an eye on what he would have wanted, or what he does want.
>
> The primary physician team just wasn't making any headway and they would get frustrated and the conversation would go kind of the same every time. "Well no, I've done my own research, I've Googled this, I've spoken on message boards with other people, um, I really believe that there is an outcome, he is going to come

back, that's my faith, this is what he would want," all these things. I just saw a kind of deterioration of the people being eager to be involved, they just were like, I can't do this anymore, like that situation has been going on so long and it seems so futile, like, rounds were very quick sometimes. They would pass by the room and say something to the tone of "ugh, same-same, same-same, same-same, let's go on to the next". Especially with no partner there to really check in with and the patient was not responsive. Um, I just wanted to speak up and you know, I maybe was a little passive aggressive and just like, "Hey, what's our plan?" Um, partially because I'm not privy to all the things that go on behind the scenes with the physicians and they don't often share a lot of that with the nurses. They don't feel like the nurses need to know. I would try to get everyone on the same page and sometimes I would get a "Oh yeah, thanks". So that is what I would get as a positive response with a return to "Oh yeah, here is our plan, this is what is happening". Everyone, like updated, everyone sort of snapped back to the idea that there is a patient that needs some focus and attention. And sometimes I would get pushback, sometimes a specific physician, who was very frustrated with this particular case, would be very, kind of abrupt, and reply "There's not a plan until we know more from the family".

After about a week of unproductive conversations, during which time the patient never responded to pain, never responded to really any stimulation but had constant myoclonic jerking, um, like slow organ shutdown, skin starting to react to like organ failure, um, just, like the futility of care was now just like the main issue. Every time a nurse took care of the patient they were just constantly like, what am I doing? What am I doing? It feels like torture! We struggled with the whole issue of when the patient was sedated, he looked so much more calm and comfortable, and um, the patient's partner would come in and think that everything is fine. And we would put a blanket on, so he wouldn't see all the terrible skin things that were going on. And like, he just felt like everything was fine and it started to work up a lot of resentment among the nursing staff that we were just working our tails off to try to manage an unresponsive patient, trying to protect the patient's partner from seeing what a really horrific sight. And then he would interpret that as, you know, that everything is fine and only stay an hour and then leave and it started to just make us resentful. So, what we started doing was turning off the sedation when he was there, so he could really get a full picture. This was hard for me to grapple with, that it was to grapple with like, forcing someone's face into a really terrible situation so that they can make a decision that is right? What's the right answer? Nobody knows! I felt like a huge ethical burden. Um, and I think it took the full three weeks for us to slowly, bit by bit by bit, bring the partner to a decision. I had to be so much more careful about the way I talked because I didn't want to imply that, you know, that I was biased in one direction or the other. It was just, it was kind of a mess.

Um, so as a nurse, trying to determine what your goals, what your plan is for the day, what your goals of care are for the day, it just becomes very tasky. Well, what are my goals? Well I guess I'm going to continue to try to like, beat back this infection that is happening, and try to like, continue to take three people to turn this patient to avoid skin breakdown and to try to continue to not think about the fact that this patient is probably not feeling any of this anyways. And it's so hard, um, so determining the goal of care becomes really difficult because I really felt the limits of, you know, my stamina as a nurse. Especially when you have another patient that is responsive and really, really, needs you as well. I was, after a while, I was, he was no longer a one-to-one patient and there were others, and like, he's so busy, coming in to get that three-nurse turn and do all that extensive skin care was frustrating in all the time it took.

It was hard to do things like take all the, once you've been taking care of a patient for so long, um to take all your feelings about it, to separate it out from your task at hand because you do start to ask, why am I doing this? Why am I doing this? And it's mixed in with, you know, it is a little bit of like, you know I did feel a little, um, I'm only human, I did feel a little bit like, this is so hard, and it's not doing anything, why am I doing this? It's… the patient is going to die, and he is not, ... you're just grappling with so many things. Is he feeling it? How do I know? Like, is it ethical to continue as though he is feeling everything and can hear everything? But you would catch yourself like, having a conversation with your people that are turning him, like over the patient because you assume he can't hear anything. You're just taught from day one that you never do that, for you know, and in the mix is like, am I just doing more harm than good? Like, imagine your own loved ones being cared for by strangers talking over them, or like, constant arterial sticks that are very painful, like, I'm just being there torturing this patient, suctioning all the way down, like, tons and tons of secretions, like, tons and tons of crazy wound care that just requires so many supplies, resources, money, time. There were so many things that go through your head and there is just this huge, … after a while you just walk in the room and you just have all of that in front of you so you have to like, push aside, in order for you to do your tasks, just do your tasks. Like I have a list, I have to check his blood sugar, and I have to suction him, and I have to crush up meds and give him his meds and then you know, why are we doing this? Why are we doing this? Turn that voice off, have to turn that voice off. And then you have another voice, like, should you be turning it off? <*laughs*> It's like a wheel spinning and because it was already just a really heated patient case, very emotional, also the judgements, like, it was just really fraught, it was really fraught. And I continued to do just very tasky, mundane nursing care, just, you know, some days I cut those wagon ties and some days I didn't. So, um, I felt like it just ebbed and flowed whether I went home feeling like I did a good job, going home feeling like I just

> didn’t have an idea if I did a good job, or I’d go home and say, yeah, I did alright today.

This lived experience description (LED) contains a vivid summary of what it was like for Cassi to take care of a patient that she knew would not survive but continued to receive aggressive medical care. This was a patient situation in which the patient was neurologically devastated, and his condition was deemed to be non-survivable by neurology and critical care teams. The critical care team provided the partner with the only treatment decision option, which was to withdraw supportive measures. The partner believed that the patient could recover and therefore pushed for a treatment goal of curative care and had the legal authority to enforce this decision. This resulted in a stalemate between the physicians and the patient’s partner that, in this situation, lasted for three weeks. As the physicians believed that functional recovery was not possible in this situation, they continued to readdress the goals of treatment for this patient with the patient’s partner and family. This discordance in opinions contributed to a polarized situation. Cassi tried to connect and engage with the partner and he told her that she had to remain optimistic and positive about the patient’s ability to recover. She struggled with concealing her concerns as she knew the condition was not survivable and tried to appease the partner by keeping discussions with him shallow. The manner in which the medical team discussed the patient and engaged with Cassi during rounds also deteriorated, same-same, no need to spend time here and she felt ignored and alone in the patient’s suffering. Cassi was able to speak and ask for validation, for a plan, recognition that it is a human being in that bed and the need to communicate, to connect with the team so that she was not alone in caring for this patient. At the same time, she found herself talking over the patient and having conversations with other nurses as the patient began to feel more like an object than a person. Most interesting was how everyday ICU care (turning, suctioning, and giving medications) became difficult when she did not believe that the patient could survive. Cassi explained her struggle with her inner voice and this dialogue shows what a nurse needs to juggle and balance in such a situation. Should she turn off the voice that asks why? And when she does, and takes a more distant approach, she asks if she should be turning it off. Cassi found meaning by remaining self-aware and balanced in her thought patterns and emotions while she completed the necessary tasks for this patient. With time, the patient's poor prognosis led her to question the purpose of her nursing actions and saw them as mundane and painful. While the goals of care decisions were focused on continuing or withdrawing care for this patient, Cassi maintained daily and hourly goals such as preventing infection, completing his wound care, engaging with the physicians and the patient's partner, and checking tasks off her worklist.

This experience illustrates a dynamic interplay of internal and external factors that affect the nurses' lived experience while caring for a patient that is unlikely to recover. The external factors included the family, in this case the patient's partner, the patient, the physicians, and other nurses. These people were connected in their responsibility for the patient, being there to provide supportive, medical and nursing care. A shift occurred as this patient could not speak for himself and the partner was the center of control and attention. Cassi's attention was divided between the patient requiring care and the partner who was in a position of increased influence with needs of his own. The internal factors included Cassi’s various judgments, an overall critical assessment of the situation, the inner voice asking for a sense of purpose, and a range of emotions. Thinking phenomenologically, these internal and external factors are part of consciousness and the embodiment of experience. Through this subjective account, Cassi shared her perceptions of what it was like to be involved in this unique patient situation and what she thought and felt throughout this experience.

There were several factors that influenced Cassi’s lived experience during the care of this patient. She first formed the opinion that the patient was not going to survive, developed a judgement based on the patient's physical symptoms and conversations with other nurses and physicians. She balanced her engagement based on the partner’s needs. Cassi tried to connect with him but struggled during the process as she felt that she had to conform to what the partner wanted to hear. During this time, the partner had a very difficult time accepting the prognosis of the patient and was in denial for much of this experience. Cassi worked hard to provide the care that the patient needed, to make sure the patient was seen by the physicians, and artistically described her emotional processing, her thinking throughout the process and the internal struggle that she faced. Her journey with this patient lasted for many shifts and she remained this patient’s primary nurse for most of the patient’s ICU stay. She described that a decision was finally made, that the patient’s partner and family, after three weeks, agreed to withdraw care and expressed sadness that she was not there for the final conversations and did not work on the day that the patient passed.

The LED exemplifies the themes that emerged in the analysis of the 30 stories described in the nurse interviews. The overarching theme is that goals of care decision-making is a process and covers a wide spectrum for people. This acknowledges that every story and situation in the ICU was unique and different and that many factors influenced a nurse's experience of caring for a patient in such a situation.

Overarching Theme: GOC DM Covers a Wide Spectrum

Nurses shared their experiences of this phenomena through stories involving patients in all stages of decision-making and in a wide range of situations. In only one of the 30 stories was the patient able to be involved in making the final decision regarding his treatment. It was usually the family, a significant other, parent or child, that made these decisions. A factor that unified these stories was the lack of advanced directives for these patients as most of the patients discussed did not appear to have one. Some patients were closer to death than others and the nurses' story evolved around the final discussion. Other nurses described what it was like in the day-to-day interactions with the patient and the family. As Jordan, a nurse with 10 years of critical experience described it: "Different, I mean it's a little different every time. You know, cause its, everyone has such, patients have, and their families have such different needs." A wide range of patient situations were described, and the lived experience of these situations varied widely for the nurse.

Several nurses provided examples of patients that were brain dead and described the difficulty that the family had accepting the death. Briana stated, "They had to face it, they were forced to, and that's hard". Briana and Emily felt that a diagnosis of brain death was the only circumstance that they, as nurses, could be 100% certain that a patient will die. Often in such situations, the decision focused on the timing of death as opposed to whether it would occur, so there was less of a decision for the family to make. Even in a brain death situation, Briana described an experience where the patient’s mother had difficulty providing consent to the withdrawal of support:

> She was stuck on the ventilator, seeing his chest rise and saying that he’s breathing. You guys are lying, he’s breathing, he’s breathing. You know, she’s shaking him saying wake up, wake up, show me, show them that you’re alive, show them that you can breathe, and she was totally refusing to um, understand what was going on.

The nurses described different patient situations when sharing their experiences with the proximity of death closer for some patients than others. Felicia described a patient that had coded several times over the past week and continued to receive aggressive treatment until he died. Some patients were acutely ill and had little time for decision-making due to rapid deterioration. Others were supported for weeks to months on medical equipment such as ventilators, continuous renal replacement therapy (CRRT) and vigilant medical and nursing care. Described by Grace as: “And then she was there for almost, like a little over a year, almost a year, um, rotated different rooms and stuff. But I remember, she just kind of, she almost became like a fixture <*laughs*> in the ICU”. In another situation shared by Briana, the focus was on the patient’s quality of life:

> Um, he was very sick, maxed out on vasopressors, and fluids and um, he did have, he had previously talked to his family about what he would want if anything would ever happen to him and he had said that he would never want to have sustaining interventions if he didn’t return to the way he was before, if he wasn’t

> able to work, he wasn't able to walk, talk, or eat. He wanted to return to however he was prior to living with his ADLs.

Nurses categorized differences within their narratives as they described them. Emily jogged her memory by recalling stories for patients that "Were going to die, and they didn't die, we said that they were going to die, and they did die, and I'm trying to think of like the one where we didn't think they were going to die, and they did". Several nurses categorized their stories as those that went well and those that did not: "So this one went well, alright because there are definitely some that don't go well. … I'm trying to think of one that had goals of care that just did not go well." Cassi, the nurse who provided the LED, explained that this experience was significant for her as it made a very strong impression on her. She considered it an important experience that she has drawn upon in her subsequent nursing practice.

Nurses described differences in their experiences based on the type of intensive care unit (ICU) that they work. As Emily reminisced:

> I've worked in other ICUs, neuro ICU, which is a little bit of a different animal, but, I've worked in the CICU (cardiac intensive care unit), where they have, they just need new hearts, or they need a balloon pump, or they need something where we can have a quick fix and then they get back on their feet and they're fine. They can have heart attacks, they can get, you know, all these types of surgical interventions or angios and they will be fine. In their medical ICU there, you'd see people that were so sick, so chronically ill.

Kelly shared a similar observation: "And that was, that was like, probably the first day I realized that in the MICU (medicine intensive care unit) there is a lot more death in the unit than from where I came from, which was the SICU (surgical intensive care unit) where people don't die that often". Along with unit differences, nurses also described differences among physicians in their ability to talk to family members.

Nurses described different family scenarios. Some family members were in the process of making a decision and were close to withdrawing medical interventions while other families wished to have every intervention possible, choosing the full care option. Many families were somewhere in between. Note the differences in the following two stories that Felicia shared:

> Well I think it went well because I got the sense, when I walked into the room, that the family knew, because the initial conversation started the day before. And so, by the time I had gotten in there, they had the night to think about it. They weren't okay with it by any means, but it wasn't as though, as if I walked in there giving them the news initially. Now, 24 hours prior it'd be a different story. But when I walked in there, um, they were already to the point to where they knew. And, she's on you know, pumps were all over the room, you know, clearly, they could see that this was not normal.

And this second story:

> And again, and um, the physician would try to talk to the wife about goals of care and nope, she wouldn't hear it. No, I don't, do whatever you need to do to save his life. Whatever it is. I don't care how many times we have to do this, save his life. And, the physicians did, I think, a good job approaching her. However, each time they would approach, she would completely shut down, wouldn't hear it, didn't want to hear it. Um, even the attending would say that this was a difficult case because she just does NOT WANT TO HEAR IT. So, I think we got to the point to where we finally ended up coding to where he wasn't coming back. So that was a tough one. And I don't think, none of us could have done anything better because, you know, she's gotta have the final say.

In the first story, the family was closing in on a decision and Felicia proceeded to help the family members finalize their decision to transition to comfort care and had what she described as a good experience. The second story differed as the physicians were negotiating decision-making and the wife wished for curative care. Felicia found the second situation to be difficult, and while the medical team worked hard caring for this patient and tried to change the wife's treatment decision, they were unable to change the trajectory of care. This situation required Felicia to participate in treatments and carry out orders and interventions that she knew were not beneficial. These two scenarios describe the wide spectrum of nurse experiences.

Some of the stories that the nurses shared occurred within the first six months of their ICU practice and was their first encounter with a challenging patient situation of goals of care decision-making. Other stories shared accounts of recent encounters with various patient situations that were fresh in the nurse's mind. Nurses described an evolution in their nursing practice and how they interacted in various situations. Kelly described that, as a new nurse, the family of a long-term ICU patient liked her because she did not know enough to question what was going on. With more experience, she explained that she "grew a spine", where she spoke her mind and was more willing to present a realistic picture to family members. Another nurse Jordan, who had more than 10 years of experience, described how her approach has shifted over the years:

> So, looking at this process, like, how do we make this process more efficient to where we get everyone on the same page earlier on? Or make it more efficient and then we're torturing people less, or, creating less suffering for people? And I guess my thinking has gotten less black and white as time goes on. And more, like understanding the grief and the letting go and the relationships and how, what a wide spectrum it is for people in that whole process. Not feeling like it has to happen in one sort of way.

Nurses described a wide range of patient situations and a wide variety of experiences. As Felicia, who had recently experienced a personal loss described it: “It is difficult having to let the person you love go and realizing the finality of that decision”. Cassi described this as “murky decisions based on murky situations”. The overarching theme that goals of care decision-making covers a wide spectrum was obvious in the scenarios that the nurses shared. It can therefore be anticipated that the factors affecting the nurses’ lived experience would vary. The nurses described fluctuating levels of engagement, energy, experience, and flexibility in the role they personified and the vibes they emitted in the stories that they shared.

This variation of factors linking the nurses’ experience will be examined more in depth to describe the spectrum of the nurses’ lived experience as it relates to the four subthemes of: 1) Judging that a patient will not recover and appraising the situation, 2) The family-nurse -patient relationship, 3) The nurses’ role in goals of care decision-making, and 4) The emotions encountered by the nurse.

Judging and Appraising the Patient Situation

In the LED, Cassi’s impression that the patient would not survive was based on feedback from physicians, the nurse’s neurological assessment of the patient, and visual cues such as myoclonus and skin deterioration. The research question asked the nurses to share stories of patients that were not expected to recover. A common theme from the interviews that affected how nurses embodied the experience was based on the nurse’s certainty of the patient’s prognosis and the judgements that resulted. It was interesting that there was such variability in the nurses' experience of how they appraised a patient's ability to recover.

Briana stated that the only way she could be certain that a patient would not survive was if the patient was declared brain dead:

> I had a patient who had been declared brain dead by neurology. For me, there is no denying when someone is brain dead, so that decision was so much easier to push for because at that point you are the patient advocate. And if you know that you are prolonging something against either someone's wishes, or you know, prolonging suffering, you have to advocate for the patient.

This anecdote described how important it was for Briana to be certain of the patient's prognosis before she moved the family towards a goals of care decision. Most of the stories shared by the nurses involved patients that were not brain dead, and nurses expressed concern about being certain in their evaluation of the patient's ability to survive or recover. Briana had a second experience with a critically ill middle-aged male patient who had advanced directives stating that he wished to maintain a high functional level. She described the concerns that she had:

> As for my opinion, I thought he would survive but I didn't think he'd return to what he wanted to be, like his wishes, which were to return to normal, working, like he could drive, he could eat, did not want to have any deficit. And I didn't think that was at all possible.

Nurses looked at the patient for signs of survival, laboratory values, assessment indicators, medical history, age, the amount of treatments received, length of stay in the hospital, and the patient's expressed wishes. Jordan looked for signs that the patient was improving:

> And the patient was still on continuous dialysis and still on the vent and still suffering through all these dressing changes. So like, we were able to look back and say she's in the same place that she was three months ago, then you know, we're not getting any better.

Nurses took cues from physicians and colleagues during patient handoff. Emily cared for a patient in which the physicians had previously talked to the family about the seriousness of her condition:

> This patient was young, in her 40's and had a severe infection. The physicians had already had several conversations with her family about the seriousness of her illness and they were waiting for a miracle. So, you know, this woman, I'm looking at this family, and I'm saying, well, you know, she's on four blood pressure agents, her blood pressure is barely maintaining, and I can only go up a little higher on the two of the four, and then there is nothing else that I can offer her.

These nurses recognized that the patient's condition was deteriorating and made judgements regarding the patient's ability to survive. Felicia appraised her patient's ability to survive by the number of organ systems that were affected.

> Um I took care of this lady with liver, kidney, and just complete multisystem organ failure. Complete organ failure. I took care of her several times because I loved taking care of her. She needed care, her skin was starting to slough, you know, you just, she was becoming more unresponsive.

Felicia judged this patient's ability to survive by the fact that the patient was in liver and renal failure, her skin had started breaking down and mental status was declining. Cassi, the nurse in the LED, described the condition of the patient's skin as one of the indicators of the patient's poor prognosis.

What factors affected how a nurse perceived a patient's ability to survive? Several of the nurses presented scenarios where the goals of care decision-making (GOC DM) process was at differing stages. Discussions with the family may have begun prior to the nurse entering the room for the first time. Grace described this experience:

> So, I came in on night shift, the conversations had happened on day shift. I received handoff from the dayshift nurse that, we're kind of been talking about this but we're not really sure, um, but we think that maybe they want to withdraw but maybe not. So, it was kind of this like, full code but, probably not, ask the family if and when the patient codes. Which I think as a nurse coming in you can see a little bit of anxiety, because you're like, I wasn't here for any of this conversation so, um, that's pretty scary.

Grace found it difficult to appraise this situation as the decisional outcome was unclear. She found it stressful to be in a situation where the patient was near cardiac arrest with an unclear decision. Irene describes a situation in which the decision-making process began and ended during the nurse's shift, resulting in a decision to transition to comfort care:

> When he coded, um, then we got him back and then there was a decision. Do we continue to code him? And that's ultimately when the family decided no, they wouldn't do anything else. I don't feel as though I was very involved because I was doing so many tasks for the patient um, I think it was more the physicians.

In other situations, the family requested curative care and the patient's condition continued to be poor, so the decision-making process continued for weeks to months. Grace describes a patient situation with a prolonged ICU stay where the medical and nursing staff were aware that the patient would not survive:

> I don't even remember what brought her in originally, but, um, probably by the time I took care of her or was doing like charge and following her care when she

> was at hospital day like, 150. Um, so, really just not making progress, had never even left the ICU because she was never stable enough to go.

The story of the patients and their evolving disease state was often described by the nurses as a diagnosis and as an age. Perhaps there was something more that informed these judgements and provided doubt in the patient's ability to survive.

> I had a patient with ARDS (adult respiratory distress syndrome) and this patient had been in the hospital for probably weeks and had been on the ventilator for two to three weeks. He was elderly, he had chronic conditions and so we knew that his prognosis was poor. But the family was not quite there yet.

Irene saw diagnosis, age, and underlying medical conditions to be indicators of prognosis. She did not say that "I" knew but that "we" knew that the patient's prognosis was poor. In this situation, this judgement was originating from the medical team and she aligned herself with that judgement.

One nursing judgement can lead to other judgements, such as what to tell a family member. Cassi described how judgments were an essential component of her nursing role and suggested that deciding what to tell family members was required:

> Um, because I felt like he needed to know. And he would call, and I'd be like, you know … I have learned that there is not, um, humans practicing what is expected to be an infallible art, like, I can't, I don't know, I can't … I have to make judgment calls. I have to sort of make an executive decision even though it isn't my family member and not really my call. So, it is just like, he needs to know. I'm the person taking care of him, and I want him to know.

Grace described the challenges of forming judgements and assisting family members with a decision because of the uncertainty in a patient's prognosis. She expressed her doubts in making sound judgements:

> I think in that moment, you feel, I felt, tremendously because I remember that situation too, and feeling like, did we come off a little bit too strong as a health care team? But like, you know, we really did strongly believe that this patient was not going to do well, um, or get out of the ICU. But we've seen people like, totally defy what it is that we think and so maybe this would have been one of those people? But it also wasn't, I don't know, you start to like question it within yourself …

Nurses struggled with the decisions of family members that were not in concordance with the nurse's judgement of the situation. The wife's desire to continue to resuscitate her dying husband led to judgmental feelings within Felicia:

> So, I will admit I came with a preconceived notion where you are just an awful, awful wife, just awful. Even though I had of course interacted, I, I will admit my prejudice did come in at that point where I'm just like, well everyone else has talked to you and it's not working, what's my two, three little words gonna make?

Felicia felt strongly that the treatments provided to the patient were not beneficial. The wife wanted all medical treatments, which conflicted with Felicia's value judgements. Felicia was aware that she was not going to be able to change the wife's mind by pursuing the end-of-life topic, the physicians had talked to the wife at length with no change in decision. Felicia interacted with the wife, although it was clear that there were emotions she restrained and topics that she avoided during their exchanges.

In the LED, Cassi explained that the neurologist and physicians strongly believed that the patient would not survive, and she believed that the prognosis was poor. Because she held that belief, she viewed her nursing tasks as mundane and painful and questioned why she was providing extensive care. Cassi struggled and pondered whether or not she should listen to her inner voice. Nurses in the interviews experienced this inner conflict in situations that were similar.

Several factors shaped the nurses' judgements and appraisal of the patient's ability to survive. Their considerations included variations based on the nurses' level of certainty, the patient's response to treatment, doubt about the value of various treatments and nursing interventions, and patient suffering. The judgement and appraisal of the patient's ability to survive was thus influential in the nurses' experience in such situations.

The Spectrum of Nurse – Family – Patient Relationship

The nurses' relationships with the family and patient affected the nurse's experience when caring for these patients. In the LED, Cassi perceived that she connected with the partner when she talked to him on the phone initially. A connection was important to her as she hoped it would help her learn more about the patient. Her relationship with the partner became more complicated when he visited and demanded that she remain positive about the patient's ability to survive his illness and in her communications with him.

Nurses discussed the importance of 'making a good' first impression on the family. Felicia described a routine she followed when meeting a patient's family at the beginning of her shift:

> So, when I walked in the room, the first thing I saw, the patient's husband was sitting to her left and in the chair. You could tell that he was just inwardly just kind of contemplating or thinking and sad. And then the mom was to the right of the patient holding her hand, you know, noticeably tearful, but you know, talking to her daughter. And so, when I first walked into the room, I just quietly, you know, introduced myself and when I introduce myself to the family, I also introduce myself to the patient. I talk to the patient, I look at the patient. I touch the patient's hand, because, you know, you never know if they can hear you. And also, it's my way of letting the family know that I am focused on her daughter and his wife. So, I'm in the room and I'll talk literally to the patient about what I'm doing for them for that day. And that's, and I think, I shouldn't say I think, I know, the family appreciates that. So that's one way that I initially establish rapport, is talking to the patient.

Felicia walked into the room and introduced herself, she touched the patient's hand, faced the patient and talked to the patient. Felicia knew that the family would be pleased by these actions. Thus, she established a line of communication and a relationship.

First impressions were not always positive. Grace encountered such a situation when she provided and update to the family of a long-term, critically-ill ICU patient:

> So, I started as I kind of always did, or as I was taught to, where I was explaining the devices and the room, and I think just making her a bit comfortable with, like, this is a ventilator, because her lungs aren't really working and so we're supporting her breathing. And these blood pressure medicines are supporting her blood pressure and without them she would not have a blood pressure, she would not have, you know, um, breathing support and she would die. So, I started with that and then we kind of talked about, we asked questions like what's your understanding of her condition, or her progress, or her status? And um, the response was pretty much, like, we've been told that she's been really sick, but I think that she'll pull through, type of thing. And so, it was a little bit defensive. It was the sense that I had gotten from there and I think it makes a lot of sense because I know a lot of people on the team were frustrated, myself included, with watching her, and um…, so…

Grace, in her first encounter with the family of this patient, was concerned about the patient's status as she emphasized that the patient was completely supported by the ventilator and by vasopressors. The family responded defensively, and Grace was not surprised by their response. She shared that she, along with other healthcare members, were frustrated by the patient's situation and this interaction confirmed that the family did not trust what she had to say. These two scenarios were on opposite ends of the spectrum of connection between the nurse and family members. Felicia and Grace described their initial interactions with the patient's family members with two different approaches in two different scenarios. Felicia developed her approach after years of experience and it is one that she uses repeatedly as it helps her form a connection with the family. Grace described an experience early in her career where she applied an approach that she was taught to deal with a challenging patient situation. The approach she used, as well as the family's defensive response, confirmed that there was distrust and distance between her and that family.

Family members, advocating for their loved one's survival, at times tried to micro-manage patient care which strained the nurse-family relationship. The following was a family situation as experienced by two of the nurses, Alexa and Felicia:

> The first day when I started was, um, he had a lot of questions about different nurses. Some of the nurses were already fired. Um, so the first day was kind of stagnation, as far as the trust, you know. The second day was better, um, because he trusted me more, and actually the third day was the best because he already knew what kind of a nurse I am and he trusted me, um, in what I had to say. And he just kind of liked me to be his wife's nurse.

Alexa described how long it took for this family member to trust her, which was important to her. She realized that this relationship was tenuous, and the trust was conditional. Alexa continued her story and explained how careful she was during her interactions with him:

> I really have to be careful in what I'm saying. Before I said it, I always thought about it, how to say it. He wants his wife to live, so um, I just don't want to make a mistake, um, so, um, from my, like, feelings. I was like, tip toeing all the time, um, but, then I got a little bit more comfortable with him.

Felicia described her experience with this same family member:

> I stopped taking care of her because of him. And she needed care, her skin was starting to slough, you know, you just, she was becoming more unresponsive. Basically, she just kind of mumbled things like that. And I wanted to take care of her because I thought, well you're dying and you're not going to get this kind of care when you go home. She's like, it's not possible. And you know her kids were strong and wonderful. So, I would include them and talked to them and you know ask about their life here, just to try to lighten things up. It never got light because the father just made it so unbearable. And to the point that when he'd come visit, I'd make it a point not to be in the room. I mean I'd be there to turn, and things like that, but I'd try to give all my scheduled meds before he got there 'cause he would, you know, (*altered her voice to sound demanding*) what'd you give her? What time? What is this? What is that? I tried to give all her scheduled meds before he got in there, you know, un, except some of the antibiotics that you'd have to give. Anything else I'd have to crush and I'm like, oh gosh, just give them all when I can give them before he walks through the door because he is going to be questioning every single thing we give, every … single … thing … we … give. It was awful.

These two nurses found the husband's vigilance challenging and felt that it was difficult to form a connection with him. The perceived lack of trust affected what and how the nurses communicated and interacted with him. Both Alexa and Felicia took a cautious and avoidant approach with this family member and they did not consider this to be a pleasant experience.

Goals of care discussions can take several days, Emily shared how difficult it was to enter into the middle of ongoing conversations with family members:

> They asked me how she was doing. Um, and that was the first thing that they had said. And I had asked, you've spoken to the doctors, correct? Do you understand what they told you? And they said, yes, we understand, but we still have faith and so, what do you, you know. So, then that was the first conversation and then you automatically have to launch into this talk with a family that, they don't know you, you don't know them, but you can only go on based on what you've heard from the other shift.

"How is she doing?" this appears to be a common question, one that is routinely asked when inquiring about a loved one's condition. It is a complicated question when one is "put on the spot" and there is not time to anticipate what the family wants to hear. Emily found it difficult to answer the question since she had not yet developed a relationship with the family. She did not give her opinion and only shared information from shift report about the family-physician meeting. Grace had a similar experience of accepting an assignment of a patient whose family was in the middle of making goals of care decisions. She was able to quickly integrate herself into the discussion through the following interaction:

> So, I asked them, tell me about the conversations that you had with the team today and tell me about what she was like and what you think she would have wanted. So, the conversation that I had was really led from what I had received from the day nurse simply because I hadn't had much time to establish any type of rapport with the patient. Um, and then I think in talking with them more, and saying, you know, look at how many days she's been on the ventilator, and, um, you know, we've been talking about, if the next day or the next couple of days, if we are going to do this, we'll have to trach her. But we have this kind of window because she could really take a turn for the worse and get much sicker. So, well you know, we don't know, even as a health care provider what to really advise to you about this. But typically, when we see this, it doesn't necessarily look great,

> but she's been in and out of the hospital before too so maybe? And I think coming to it with this humility in a way, of like, I honestly don't know, I have no idea, hum, but I do know based on what you told me about her that this is probably what our best outcome is. And if that is not what she would want, you know, we should really consider some other things.

Grace knew that the family had several difficult conversations with the physicians during the day. The family was working to make a decision. Based on this knowledge, Grace did not feel the need to push the family, but she remained curious and listened. Her approach allowed her to connect with the family during the decision-making process and to validate a few of their concerns.

Daphne shared a story where she felt that she had a good connection with the patient's family members:

> I had worked with them maybe a half-dozen times. Um, different shifts, days, nights, I'd admitted the patient initially, and so, I built a rapport with the adult children who were in their 20's maybe. And I identified with, connected with, um, and so they knew me and trusted me. And at the beginning of the day, the daughter was there alone, and the rest of the family had gone home an hour away. … I never knew her (the patient) awake or talking, she came from another hospital already on the ventilator, so she was moving some and had her eyes open, but never was truly herself. So, so, that helped with a little bit of emotional distance, but having known the family through the process, um, it made it more personal, as though I knew the patient better.

The rapport that Daphne had with this family built a connection and made this situation feel more personal for this nurse. Daphne noted that she was usually able to keep some emotional distance from a patient who was not awake and could not talk. A trusting relationship with the family fostered a sense of closeness in Daphne towards the family, and subsequently with the patient.

Emily discussed how knowing more about a patient made it difficult to maintain boundaries:

> Yeah, and sometimes it's better that I don't know their story, like, that I don't know the background because then it almost makes it harder to take care of somebody. If you know the, you know, parents have died recently or that they have a child in high school or something like that, that personifies the person more. I find that in critical care, I almost prefer to think that this is how they've always been, they've always been sick, they've never been healthy, so you don't have to reflect on the life that they are leaving behind. You can just objectively take care of somebody, I think that's the easiest thing.

Boundaries were sometimes broken. Emily shared another story where she felt very connected to a patient and his parent:

> I took care of him for a week straight. Yes, I chose to do that, I mean, I could have chosen somebody else, but I chose to do that because I knew that he needed to have continuous care and I knew that the mother more than anything else needed the support of the staff and of the nurse, because this was the hardest thing she will ever have to decide or live through. So, um, and I became rather close to him so when he got discharged she talked to me beforehand, but you know, it was one of those, it was tough, it was tough taking care of him, it was tough helping her because emotionally it's hard for you, you know, you try to stay separate, um, but sometimes you can't.

Both Daphne and Emily described how close connections with family members resulted in emotional attachment. Daphne felt very connected to this patient case because she felt that the family trusted her. Emily empathized with the mother of her patient and became strongly invested in this patient's care. Although both Daphne and Emily found these situations to be emotionally challenging, they were responsive to the family's needs for support and became connected to events within these scenarios. The connection that the nurses perceived with these family members allowed them to become emotionally vulnerable and strengthened their desire to help and support these family members.

Two of the nurses, Hannah and Irene, experienced situations where family members approached them and asked for advice. Hannah shared this story:

> I was with a family member that was asking, um, she kind of approached me and said, "I feel like, we are doing her harm, we're not really doing any good here, she's not getting better". So, we were able to have a discussion. She brought it up, so I felt that it was a safe conversation to have because she was asking.

Irene shared a similar story where she felt that the family member trusted her, and the family brought up concerns, so it made this nurse's role easier:

> Usually I rely on the physicians to do that, but I felt like she had more of a rapport with me and I felt like she would take it. Yes, I definitely felt like the family member trusted what I had to share with them. They asked, "What would you do if this was your family member" and that's when I took the initiative, or took the cue from them, that they were okay with me to share. Had they not asked, I probably, it just depends on the family, like, I think I would have tried to say, oh, I'm just really concerned, they are really sick, um, you know, what have the physicians said about the prognosis? But it really took the patient's family member coming to me and saying, "Oh I just don't know what to do, what do you think?" And so, that's when I took advantage of that opportunity.

A family member's reliance on a nurse for decision-making can be challenging. Briana had a close relationship with this patient's wife but found the dependence taxing:

> So, she kind of leaned on me to help make the decisions, which, the reason this sticks with me so much is because her dependency on me was very…stressful for me. And it is common because you're the one that is at her bedside, you know, taking care of her, taking care of the patient, and so she is reading every body language that I have, every facial expression. If I go in there and I see a temperature that is, you know, a little bit higher, I have to make sure that my face

> is completely stoic and not show anything or she'll say to me, "I saw that look, what does that look mean?" And I'm like, oh, great! <*short laugh*>

Briana was careful in what she shared with this patient's spouse and was aware that her body language communicated an influential message. Briana found it challenging to remain stoic and avoid emotional expression.

Sometimes it was difficult for the nurse when family members looked to God to heal their family member. Emily and Hannah described the challenges when families waited for miraculous healing while relying on medical technology to keep the patient alive. Emily shared:

> You know, it's tough to have these conversations because they don't really understand, and they've already decided that they are waiting for a miracle. I find it kind of a struggle sometimes because, you look at these families and they say, "Oh, I want God to heal them" or "It's in God's hands now", even though they are on multiple pressers and they are on the ventilator that is breathing for them. And you have a hard time because you look at them and you say, "God's already taken them, I'm keeping them alive, not God". And that is such a difficult thing to explain to someone, to grasp and to realize that, at what point does God's will end and our interventions begin?

Hannah found this situation frustrating:

> The other point of frustration that I sometimes have is that sometimes people will, like, I don't want to offend anyone with this statement, but sometimes people will like, use their faith in God as the reason that we are going to keep going. And sometimes that is very frustrating because it's sort of, I mean, I don't think, I think it's okay to believe in God and all that, but it's when you have all this data in front of you, it's like, this is very clear to everyone that this person is not going to get better, this person is dying. And so, it's frustrating to have that as the reason why.

These two nurses found it challenging to accept when religion was used as a reason to pursue aggressive treatment in an actively dying patient. Cassi, in the LED, experienced a similar situation where the partner did not want to hear what the healthcare providers were telling him because he strongly believed that God would heal his partner. In such instances, it appeared illogical to these nurses to see that patient family members used religion to validate decisions to continue painful treatments instead of a source of strength to accept what cannot be avoided. Hannah expressed frustration when she witnessed patient suffering because religion shielded the family from having to respond to the deterioration in the patient's condition.

Nurses found it difficult and frustrating when the family insisted on continued treatment for a patient who was suffering, especially when the nurses felt constrained in what could be discussed. Maintaining an open dialogue was important for nurses to establish trust and a connection with family members. In the LED, Cassi found her voice lessened when the partner told her that she had to be positive. Nurses who were afraid of upsetting family members described themselves as walking on eggshells or treading lightly in what they disclosed to family members. In those situations, the nurses tried to maintain civility but remained guarded in their interactions with the family. Nurses who experienced this situation described feeling more detached from family members.

To illustrate the importance of communication, Leslie shared a story in which a language barrier impaired her ability to connect with the patient's family. Leslie provided care for a patient whose brother spoke only Spanish, a language in which she was not fluent. She reported that speaking a different language affected her ability to communicate and connect with the patient's family member:

> You know what's funny is that I think that like, the language barrier and the cultural, like I still was sad and upset for the brother because every time he talked to the doctors and the translator, he was crying and upset and talking on the phone. But it's just kind of like too, because he was crying, upset, and talking on the phone in Spanish I couldn't help him because I don't speak Spanish. So, it was less, it was probably less heartfelt to me because I couldn't experience things with him and try to help him because we couldn't understand each other.

This nurse found it difficult to empathize with the family member since she could not understand what he was saying and was limited in her ability to communicate with him.

Nurses described experiences in which they cared for the patient for one shift and others took care of the patient for several shifts. Within these stories, nurses described situations where a functional connection and relationship with family members softened boundaries and improved engagement and therapeutic interactions. Situations of conflict, distrust or disagreement with the plan of care caused the nurses to have a poorer connection with family members. The family's openness to discuss the patient's condition and options for care allowed nurses to perceive meaningful contribution. Families who were consistent in their GOC decisions to continue treatment resulted in conflict. These factors affected the nurses lived experience because family members often stay with the patient in ICU, resulting in prolonged contact between the nurse and family members.

The Spectrum of Nurses' Actions

What actions do nurses take when caring for a patient that they believe will not survive? In the LED, it took three weeks for the partner to slowly come to the decision regarding the patient’s disposition. During that period, the decision was for the patient to receive standard ICU treatment which was curative focused. What was this nurse able or willing to say and do during this process? She planned and performed the patient’s care, she tried to update the significant other, she attended physician/family meetings, and she redirected the physicians when they were dismissive during physician rounds. Cassi perceived the experience with this patient to be an insightful learning experience due to the many challenges that she faced.

Nurses described their roles for the patients as: working hard, presenting reality, complementing the medical team, and supporting the patient and family. Their lived experiences and actions were context dependent and varied based on the nurse’s judgement of the situation and relationship with the family. Similarly, nurses’ involvement in the decision-making process was varied based on the family’s ability to make a decision.

Working Hard

In the LED, Cassi discussed the workload involved in caring for her critically ill patient with the wound care and neurological issues and balancing his needs with that of a second assigned patient. Several nurses discussed the workload involved in caring for critically ill patients, particularly those not expected to survive. Leslie described how busy she could be with a sick patient:

> If they make the decision to have things done full, like full strength, all hands-on deck, I kind of just don't, I just don't want you in the way then. You know, we're not going to be therapeutic and talk about things 'cause I'm going to have a whole slew of things to do now. Yeah, if you want everything done like you are saying you do, we don't have time to discuss things, I have a lot of tasks to do. I feel like it is up to the doctors to talk to the family members.

Leslie described that when curative goals were in place, critically ill patients required intense care and she focused on the tasks she was performing. This effort left minimal time for her to talk with family members. As Alexa explained:

> I worked really hard with her, constantly going from one side of the bed to the other. All day long you know, it wasn't like I wasn't there. Watching her and everything, watching numbers, sending labs, checking the numbers, you know, you know how it is…

Alexa shared how her tasks consumed her entire day. Irene shared:

> I was so very busy and just consumed with the patient that I didn't have time to talk to her. I don't know if the outcome would have been any different. It wasn't just me in the room, there was also another nurse there helping. And so, I don't even think I realized how serious it was at that time, so. I don't think anything, I would have changed anything, or done anything differently.

Irene was busy providing care and she did not have time to talk with the patient's parent. She continued her story:

> I'm trying to remember, when he coded, um, then we got him back and then there was a decision, do we continue to code him? And that's ultimately when the family decided no, they wouldn't do anything else. I don't feel as though I was very involved because I was doing so many tasks for the patient, um, I think it was more the physicians.

Irene was busy with tasks and providing nursing care resulting in the physicians talking to this patient's family members about treatment decisions. Jordan explained that, when a patient is decompensating very quickly, "it's almost like there is less of a decision, it's just happening and you're just along for the ride. And just not as many choices to make, you know".

Decision-making: Whose job is it? Cassi in the LED described how careful she was so that she did not appear biased in one direction or the other, particularly as the partner wanted full curative care for the patient. The decision-making process in that scenario took three weeks and many physicians were involved. The nurses who were interviewed presented various opinions of who should have the primary role of talking with family members about the patient's prognosis.

> I think the families look to the physician for that, like, as kind of the expert saying this is the end. And then I always think that my role is helping the family figure out how that is going to happen.

Jordan, an experienced nurse, observed that the families preferred to hear that treatment measures had been exhausted from the physician. She perceived her role as assisting the family to navigate events pertaining to the patient's death. Kelly explained her role:

> The doctors have a better understanding to the pathophysiology and like, how sick somebody is. Like, I have an idea, but the doctors are the ones who are like, "There are no options and she is not going to survive the week, likely". Um, whereas me, I can say like, "Her organs are shutting down, which is really bad", and I've had to say that. I feel like us nurses are kind of like, we just complement what the doctors are saying, like we have to reiterate, not dumb it down, but like, put it in lay persons terms because a lot of times the doctors just, it's just, and plus like, the first time they hear it, they may not have heard it. And then the second time they hear it, they still may not have heard all of it. So, sometimes you just

> have to keep saying it. I can be there to just kind of reiterate the reality, but I don't want to, I don't want the responsibility of having to make the decision or having to push them. I just, my job is to reorient to reality.

Kelly preferred that the physician make the GOC decisions. She perceived her role as reinforcing the physician's decision and assisting the family members understand the situation.

Some nurses found themselves in challenging situations where they did not wish to influence family members in their decisions. Briana did not wish to influence her patient's spouse:

> And in my opinion, I couldn't tell her to let him go because the same voice, the same concerns that she had were the same concerns I had. So, if I say, if I give her my opinion one way or the other, I don't know, that is outside my scope of practice. I've seen people come back from a lot of things that they should not have come back from. And so, I kept having to tell her she just had to take it day by day and see how he declared himself.

Briana preferred a wait and see approach, to wait until the patient declared a decision himself. Also, Grace was concerned about influencing the family members:

> I think I just kind of, I never want to feel like I've influenced somebody but at the same time I want to feel like I've informed them to make a decision. And, I don't know, it feels like, I think I struggle with saying too much, or leading too much sometimes.

Irene and Hannah shared stories in which they shared opinions and information with a family who asked for input. Irene shared:

> She had brought it up, so I felt that it was a safe conversation to have because she was asking. Um, and so we had that discussion about how we've done all these things and taking off the blood pressure medicine and taking away the ventilator

> doesn't mean that you're killing her. If she would, and I just like to be frank, I hope you won't be offended, but if we didn't have these blood pressure medicines and we didn't have this ventilator, she would have already died. You know, we're doing extraordinary life support to keep her alive, taking those things away isn't killing her. You know it's the disease process that would be the cause of her death. Yeah that was one of the few situations where I felt comfortable having that conversation because she was so open and honest with me and asked me these questions and participated and I can, you know, I just could tell that it was …(safe)

Hannah shared her situation:

> They asked, they said: what would you do if this was your family member? And that's when I took the initiative or took the cue from them that they were okay with me to share. Had they not asked, I probably, it just depends on the family, like, I think I would have um, tried to say, uh, I'm just really concerned, they are really sick, um, you know what have the physicians said about the prognosis. But it really took the patient's family member coming to me and saying "Oh I just don't know what to do, what do you think? And so, and that's when I took advantage of that opportunity. Yes. and so, then I went and said to the physicians, I really think that the family is ready for a talk about goals of care and um, they had the talk and then, either that day or the next day, I can't recall, they ended up transitioning the patient to comfort care.

Irene and Hannah felt comfortable sharing opinions and information with family members because families asked directly and appeared receptive to making a decision. If the family had not asked for input, both nurses admitted that they would have either avoided the discussion or they would have been very vague in what was shared with the family. Jordan summarizes this perception of nurses in GOC DM:

> I think that we've had very few instances that I've seen where I felt that a nurse went too far, I think most of the time, nurses don't go far enough in presenting that reality to family members and if the physician is not in agreement, I think they would go even less far to present that reality.

She observed that her nursing colleagues were generally cautious in what was discussed with family members. Nurses would share less information if the physician have not spoken with the family. While nurses perceived that physicians varied in the effectiveness in talking to families about end of life issues, the nurses in all of the scenarios perceived that the physicians were proactive in having discussions with patients and family members.

Two additional care modalities identified by the nurses as having a role in GOC decision-making were the palliative care and ethics teams. A palliative care physician was involved in the story that Cassi shared as the LED:

> We put in a palliative consult and the palliative doctor that came by was just amazing, just did a lot of education with the actual team and she met with the cardiac team and the neuro team separately, not in the patient's room and sort of, I think, what she has to do whenever she gets on a case, is she reexplains her role as this palliative doctor: "I'm just here to like, guide everyone, not here to convince anyone to turn the machines off. I'm here to assess what the patient wants, the patient needs, discuss with the patient and to just act as the lubricant for all the conversations that are happening." And then she did a really similar thing with the patient's partner and spent a ton of time with, like, the chaplain being in the room and the patient and the partner all together. Um, and really just filling in all the sensitive, she brought so much sensitivity, and like, also realism, to this situation. It was so helpful.

Cassi found it useful because the palliative care physician worked with the patients' partner, physicians, and nurses, and listened and provided a supportive role. Decisional capacity remained with the patients' partner and the palliative care physician provided guidance and support to everyone.

Ethics teams were consulted in three of the stories shared by the nurses. The ethics team was involved in Kelly's story of the patient that had a prolonged stay:

> They finally made her a DNR like after two months, thank the Lord she did not code because it was a long drawn out process with ethics and meanwhile every single nurse taking care of her was like, exhausted, just from the amount of care that she required and the amount of torture that we felt we were, um, putting her through.

In Kelly's story, the patient's wishes were not known, and the family had the legal authority to make treatment decisions. In another scenario, the ethics team supported the physicians in an argument that treatment was not in the best interest of the patient:

> And if it were up to the mother, she would have said we will do whatever it takes, we will send him to dialysis, we will do all this stuff. But in this case, the doctors, backed by ethics, opted not to offer any of the things and I think sometimes, that case, that is the best thing for people, not to give them that choice.

Jordan provided an overview of the nurses' perspective of the ethics team's involvement in the care of a long-term patient:

> I think oftentimes the distress that nurses feel, they have the feeling that if they ask for an ethics consult or if they get ethics involved, that there is going to be this group of people that are able to swoop in and just make the situation right or convince the family and make everything better and then that doesn't happen. So, it's not really the job of the ethics team. And I think they feel really disappointed that the ethics team was their hope of resolving this situation and then the situation doesn't get resolved and it continues to linger. So, what did we call the ethics team for if it didn't help resolve things?

The nurses described a variety of patient situations with different needs for GOC DM. Overall, nurses perceived that it was the physician's role to determine patient outcomes and to assist the family with goals of care decision making. After the physician had conversations with the family, the nurses described themselves as having a supportive role where they engaged with the patient's family in various capacities to assist with decision-making. The nurses reported that they would talk with family members about treatment options if there was trust and the nurse perceived the family was receptive.

Presenting Reality

In regard to decision-making, nurses preferred to provide factual information, or objective data about the patient's condition as opposed to personal opinions. Several nurses reported this type of communication as presenting reality or providing objective updates. A few of the stories have addressed this approach. Here is an example where Felicia shared and communicated with the patient's family member:

> So, when I walked in the room, you know, I knew the situation and I knew that the discussion had begun, but no decision had been made. So basically, I just say to them, what can I do for you today? And the mom said that I know that she's not doing well, and they started talking about maybe taking some of the medications off or slowing some of them down and they told me about what would happen, if, you know, how they say, if the heart stopped. You know, they discussed that. And so, I said, depending on what you decide to do, this is what would happen. Right now, she is full code, meaning we do everything. And so, if something does happen, this is my role. You know, I would come in, be in the room and immediately, depending on where I am, would start either compressions, or meds and this is what you would see. I explained that there is going to be, what feels like a dozen people in the room, there are going to be loud noises, but we're going to do our best to help her. However, I told her that I've never ever done compressions where I didn't break ribs, ever. And we're already at a risk for bleeding and it's going to be even worse and, but we can do that, we will do that if this is what your wishes are, and this is what you think she would want, we're all for it. And after I talked to her, I was like, "So if your daughter was just sitting here, walking past the room, you know, what would she want?" And she's like, "Oh, she wouldn't want that". Even her husband, he didn't say anything, he just kind of shook his head like, no, it's not, she would not want that. And so, I was like, okay, that's fine, you know we understand that but what I'll do is just have one of our physicians, you know, I'll be here, and we'll talk about things that we can do to keep her comfortable, you know, what your wishes would be, and we'll take it from there. And then the attending came in and talked about the withdrawal process and what we would do to keep her comfortable and I

> think, I think talking to them about what she would want helped, and I think that cemented it in their heads

Felicia sat down with this family and walked them, step by step, through the process that would occur if the patient coded. She described what the family would see and hear. Then, Felecia added another entity, the patient, and asked what the patient would want in this situation. The family did not believe that this was what the patient would want, and Felicia prepared them for the conversation with the physician. Felicia called the attending physician to the room so that the decision to withdraw support could be relayed between the family and physician and a new plan of care established. In this story, Felecia assisted the family members as they made GOC decisions, communicated the family's wishes to the physician and advocated to change the patient's treatment plan to comfort care.

Irene provided educational material to the patient's family pertaining to the disease process as a means of sharing information that assisted the family with a decision:

> I took a role in that I actually pulled up some information online and tried to educate the family on ARDs (Adult Respiratory Distress Syndrome) and tried to explain to her about it since the patient has been on the ventilator for this period of time.

Alexa shared laboratory data to allow the family member to recognize the decline in the patient's status:

> He was very hopeful, I also wanted him to be realistic, so I was supportive, but I also told him the honest truth that those labs were not getting better and because he was a physician, he accepted them, um, accepted all of those numbers, probably understood them very well. But still he was pushing to continue care.

Alexa communicated this laboratory data to provide this spouse an objective measure. The spouse appreciated the data but decided to continue treatment. In the next story, Leslie described to a spouse her assessment of the patient's overall condition:

> And I, at that time did tell, that's like one case where I did tell her, like, he's been here for so long, some things have just deteriorated so much. He's probably not going to recover, and if he were, it would take a really long time and he is in no place to start recovering right now. Like, we're not going to make that turn around in a week where he starts to do things on his own. Or like, he's atrophied so much and he's like all cachexic now and his kidneys aren't working, heart isn't working. Like all of these things aren't working and plus now his skin is all broken down and he's not, you know, able to absorb his protein and heal himself at this point. Probably isn't going to get better. But then I always throw in, because she's really religious, so I always throw in "But I hope they do but things probably aren't going to go well from here on out."

Leslie identified a list of patient conditions and issues and softened her delivery by ending it with "probably aren't going to get better … but I hope they do" to try to temper her message. Briana communicated what she observed at the current moment and was careful not to draw conclusions:

> So, my direction that I went was just based on what he was doing. That was how I remember to do it, like if he wasn't following commands, or he was still not breathing on his own, that is just what I was going to say. And you know, I can only go off what clinically he is doing. That is because it is the only thing I know for certain and the only thing I can say truthfully is what is happening, you know. Everything else is opinionated and, at best, a guess about prognosis. I can only, the only thing I can truthfully and honestly say is what is actually happening.

Briana was very careful not to share her personal or professional opinion and focused on what was occurring in the moment.

As a result of experience, Kelly emphasized the severity of the patient's condition:

> I guess I grew a spine and I don't have any qualms about it. Like, with the lady whose daughters were very religious and optimistic, I just kept telling them like, repetitively like, she's not doing well, she's really not, she might not even make it until tomorrow, you know, and you guys have to be prepared for that. So, and just kind of like, reinforcing, like, is this what they would want?

Kelly felt it was important for the children to be aware of the severity of the patient's condition. The nurse perceived the children's level of optimism was a barrier to coping and decision-making, so she reinforced the severity of the patient's status.

Cassi, in the LED, presented an example of how nurses would suspend the patient's sedation when the partner visited so the partner could see the patient without sedation. Grace employed this technique to convey to a patient's adult child what the mother endured while being repositioned in bed:

> It was one of those: "Okay, we're going to turn her, and it usually causes some pain for her but, you know, we gave her some medication." And the woman was like, "Okay, I don't want to be here, let me know when it's finished," and stepped out. And I think that just kind of like, floored me frustration-wise because it was one of those, we've been day in and day out with your mom who, we don't even really know except for how she is in this hospital. But what we do know of her is that she wouldn't want this, um, she was a nurse actually, the patient was, and it's like, I would never expect that anyone would want this to be continued on them.

Grace was convinced that the family member needed to see what the patient experienced and what the nurses observed when they were turning the patient. Grace's attempt was unsuccessful as the patient's adult child chose not to be present in the room during the procedure.

Working with and Complementing the Medical Team

The nurses described how they reinforced physician conversations with family members. Felicia shares:

> I knew when I walked into the room that we're going to have goals of care discussions, but it was almost things like, in report, where it was talked about by residents and interns to the family, but still the family wasn't quite there yet. And so, I knew that my job that day was to support them through it and also to, um, basically bring, because I knew who this attending was, bring this individual into the picture and say this is what's happening. And, you know, I really think coming from you, they will hear it better and hopefully we'll come to a decision that they can agree with as far as withdrawing care.

Felicia thought the family was close to a decision and was ready to discuss goals of care decisions with the physician. She approached the physician and requested he talk with the family. She was present for the discussion and confirmed to the family what the physician discussed.

The hospital where these nurses worked had open visitation in the ICU's, so the family members were encouraged to stay at the bedside with their loved ones 24 hours per day. Therefore, many of the conversations between family members occurred at the patient's bedside. This allowed nurses to hear conversations and observe behaviors. Hannah noticed that family members were misinterpreting the physician's intentions:

> But the daughters kept hearing what they wanted to hear. Like they just weren't getting it. And one of the daughters even got mad at one of the doctors who tried to um, reintroduce the DNR topic because this lady was a partial code and she thought that, what the patient's daughter thought was that the doctor wanted to give up and turn everything off. And that's not what I was told the conversation was. So, then I had to be a mediator, like, well, you know things aren't going well, and I don't know what was said in that meeting, but I'm sure that this is what she meant. And this is the reality and I even went to the attending who's

> great and just kind of gave her a heads up that there is a disconnect and she came in and talked to them.

Hannah observed that there were discrepancies in what the family was hearing and what the physicians were saying. She intervened to ensure everyone was clear about the patient's condition and plan of care.

The partnership between nurses and physicians was different when patients remained full curative care and differences existed between family and the physician team. Cassi, in the LED, observed that the physicians and medical team became more distant and rounds became shorter. The physicians would say "Same-same, same-same, no changes here until the family makes a decision". Emily shared a similar experience and how nurse involvement in goals of care decision-making differs from hospital to hospital:

> And I think that, well, I think it also depends on the hospital too. Because even when I'm there during the day, I don't participate in end of life conversations. I can talk to the families the same amount, it's not like I have a different dynamic with families during the day and during the night. I think that the real problem is that in our hospital we're not that engaged. It's not, we're not part of these conversations and some attendings and some residents and fellows don't want to hear what you have to say because there have been a lot of times when I've looked at them and I said, "Why are we doing this, what is the end goal here?" And they would just blow you off. And you know, I've unfortunately, I mean, not unfortunately, but fortunately, I've been a nurse for long enough where I can kind of throw my weight around and say, "No, no, no, you can't ignore this, you can't ignore me, you can't ignore this patient. What is your end goal? What is it that you hope to accomplish?" And sometimes that is what I ask the families too, I ask, "What would you consider to be successful, what would you consider to be a successful hospital stay?"

Briana found that her role in physician and family meetings was limited to supporting the family and confirming what the physicians discussed:

> As for my role, they really don't, they really didn't give me much of a say (during the conference), I kind of just sat there to support her and to be there with her and then if there were any questions about assessments, they would just look at me to confirm.

Support

Nurses discussed that their role was to support the family through the GOC DM process. Alexa shares her view on supporting the family:

> Yes, and I was supportive of that, although I kind of knew that her status declined too far to be able to pull her out of this. That is what I was thinking but even if, at this stage, she's got so many problems and even if we were going to give her this new liver, um, that would be like a miracle, to get her back. You know, seeing her body, her pressure sore, she did have a pressure sore, um, sores on her bottom, and seeing her skin, how fragile she was. I just don't think even a new liver will fix that. So, um, I always thought about this like, I always fight for the patients to the end, but like the old book says, you know, fight, fight and fight, but, there is a point where you have to say that it is not worth it any more, you know, like there is a point where you have to say, um, that's it. But I don't want to be the one, you know who …, they have to make this decision. I don't want to be the one to tell her this is it. You know, you're not gonna survive, why would I? As a nurse, I just don't tell family members bad news. It is not the nurse's job, it is the attending's job. I am there to support them, whatever they want to do.

For Alexa, supporting the family was respecting the family's decisions. For Briana, supporting the family was making sure the spouse took care of her own health.

> You just offer support, make sure that she is eating, she's, you know, taking breaks, make sure, despite her not wanting to leave that bedside that she had to go, she had to take care of herself. And so, it's hard because you have not just one patient, but you have two and you see the family members just withering away at the bedside because they can't physically leave and it's hard.

Kelly described her support role by ensuring the patient had no pain:

> To try my best, I mean, I always try my best to make the patient comfortable. I'm always, especially being a SICU nurse, I'm always for more pain medicine.

Kelly reported that it was easier to support the family when they made a decision that matched the patient's wishes:

> Even though it's not your decision and you don't get to make the right decision, like, you can tell that when a family member does decide to like, stop, almost torture, that they feel like a weight is lifted. Whereas when they feel like they should continue, you feel like they don't get any relief after because it's kind of just putting it off.

In an earlier quote, Jordan shared that she believed her role was to assist the family to understand what their decision would mean to the patient. Hannah stated that her supportive role intensified after goals of care decisions were made:

> I think after the decision was kind of made, I presented the options for what withdraw was because sometimes it is different for certain people. I discussed with him, like, we can turn off the blood pressure medications, we can take her off the ventilator and remove this endotracheal tube. We can kind of just, all those things. We can take her off some of this monitoring stuff. We can turn off the CRRT (continuous renal replacement therapy) and that's just the only, I guess, decision-making process that I've participated in was, how do you want this to go?

When Family Members are not Receptive to Decision-Making

In the LED, Cassi said that she had to be very careful in what she said to the partner and how she stated information. Nurses had less of a role in GOC DM in situations of irretractable decision-making as the family members were firm in their resolve to continue curative care.

Jordan had to be cautious in how she communicated with a patient's adult child:

> So, it was like, she was very healthy and made the decision to have this surgery which turned out being really disastrous, just really destroyed her life. I think that she (the patient's daughter) did not like hearing anything negative. So, she kind of viewed those kinds of interpretations as people just being negative or not having enough hope. Um you know, so she always came back to her religion and her feelings, like if she had enough hope and prayer that things would get better. I think it made me feel a little more guarded with the daughter. It made me feel more like, um, because I knew her perspective was just on a different page than mine, that it made me feel like I had to be more guarded as I tread those waters with her. Like that I had to be careful with what I said. So, I always thought about well, how, if I say this, how is she going to interpret it?

Kelly described a situation where a patient's family member's goals, desires and appraisal of the patient's condition differed from those of the nursing staff:

> They would argue with you when you would try to bring them back to reality. Like they would say, "Well she did this for me and she's nodding her head for me, you just, you guys don't see it". Like, okay. What do you say to that? They would be like, you can't put tape on her skin, and we'd be like, we have to. Um, like she has to have (EKG) leads on. Like, they just did not understand any of it. They were, they didn't understand nursing care, they didn't understand, like, why we do half the stuff and you could educate them until you turn blue in the face and they would still not get it. And then it made you wonder, like, did they hate their mother? Like, is that what was happening because she was grouchy? But I don't know, you just, it's, if it's me, I want to be like, this is the right decision, this is what you should do, but I can't do that. It's hard.

Felicia provided an experience with a patient that was being 'coded' frequently:

> It was just more, I knew 'cause I don't have a very good poker face, I think if I tried to be the nice nurse, that would show, would be perfunctory just sort of just doing it. And I was just like, I just know my, yeah, I would be like <*alters her voice to a sarcastic tone*>, "What would your husband want, is this really what he wants to do, but if he walks past the door, do you think this is something that he wants to see?" You know I couldn't even have the conversation because I knew my face would show really how I felt. I just don't have a poker face, I just don't

> have it. <*Laughs*> I just don't have it. So, yeah, yeah, exactly, because I knew I would stir up trouble. I thought, no, it's just better for me to keep my mouth shut, keep my mouth shut and just go into robot nurse mode.

Felicia described herself as working in robot nurse mode, where she suppressed how she felt about the situation and automatically performed the nursing tasks. Kelly described how she approached a challenging patient situation as a new nurse and implied that her approach has since changed with experience:

> I'd just reiterate what the doctors say. I think at that point in my nursing career I wasn't very good at it. Um, it's hard for me to not see the world through rose colored glasses and it was hard for me to not want to paint a nice picture, like, I'm much better at it now. Um, they complained about a lot of other nurses, they fired a lot of people from the room. They liked me, but this probably had something to do with me not being great at, like, really, making them face reality yet. I just kind of was like "okay yeah, uhhuh, like, whatever".

These accounts describe how the nurses' role in GOC DM for patients that they did not expect to survive was influenced by their relationship and connection with the patient's family members. In the situations where the family wished for continuing care, nurses found that there was little they could say to change the situation and felt that they had less of a role.

Nurses actions when caring for patients not expected to survive can be best described as a supportive role. The nurses provided families with objective updates describing the patient's status, provided education, and ensured that the family members were taking care of themselves. Nurses perceived a greater role when the families were in the deciding phase and were receptive to the nurses' updates. The nurses described how the role was different when families wanted to prolong curative care. Alexa described how she supported her patient’s spouse with his decision to continue care even though she knew the patient was dying. She, along with several other nurses, had to be careful what they told family members about the patient’s condition to avoid upsetting him. Nurses sympathized with the family as they understood the difficulty of these decisions, the uncertainty, the finality of the decision, and having to live with the consequences of these decisions. Nurses talked about how much care a critically ill patient required and the list of mundane tasks that had to be completed. Nurses described actions of being vigilant, of monitoring, of being concerned about what the patient and the family members were experiencing.

Many factors appeared to influence the nurses in their ability and willingness to be involved in goals of care decision-making. The nurses’ judgement and appraisal of the patient’s situation and the nurse-family-patient relationship factored into the nurses’ ability to act. The nurses communicated that many aspects of decision-making, such as delivering bad news, were the physician’s responsibility. Therefore, communication with family members depended on the physician’s level of initiative. Nurses described situations where they were busy with tasks and had less time for GOC DM and other situations in which they were able to contribute significantly. Nurses who perceived value and who listened found opportunities to contribute meaningfully in interactions with family members. If nurses felt that their contributions did not have value or would not make a difference, they were more reserved and worked in “robot nurse mode”. Within their stories, the nurses provided descriptions of their experiences of caring for patients within the ICU where options for treatment can seem limitless and life and death decisions are made every day.

The Emotional Spectrum

In the LED, Cassi described the level of frustration that she felt while participating in time-consuming treatments for a patient that she knew was neurologically devastated. She felt that she was inflicting pain on her patient during the daily care that she delivered. She struggled with her relationship with the patient's partner. He requested objective and circumstantial updates of a positive nature. Cassi engaged with him with caution and found it difficult that he did not see what the patient was enduring. All attempts she and the other nurses made to get the partner to see the direness of the situation were unsuccessful. Over time, Cassi found that her struggle with her emotions became more difficult as she questioned the purpose of her nursing tasks and interventions.

Too Busy to Feel Much

In some scenarios, the critically ill patients decompensated quickly, and the nurses were busy performing critical actions and lifesaving tasks. Jordan reported not having time to dwell on her emotions when caring for a patient with severe trauma:

> Yeah, and sometimes it just happens really fast, you know, like, especially with our trauma patients that are just, maybe like someone that was a young, healthy 19-year-old. They come in, it's all very shocking for the family but, over the course of, you know, however long we been working trying to make the patient survive, and then it becomes clear that it's not survivable. And you have to really sit down and tell the family about it, there isn't a lot of time to make that relationship and then you're just kind of, having to do it on the fly, you know, without much of a relationship to base anything on, or like, to even think about what would you want at this moment because it's just happening. Kind of just do

> your best. And sometimes you just have to rely on like a charge nurse or someone else to kind of help guide the family through it. I feel like I rely on the chaplain a lot just to like, because you don't have time to do all that. If you don't, it's just fast and you don't see it coming.

In Irene's story the events occurred equally fast:

> (The patient) just ended up crashing and we gave him multiple blood products, and he was on all kinds of pressers, and there came a time where he um, ended up passing and we ended up having to make him a full code, err, DNR. It was incredibly stressful because he was so young, and they expected him to do better with his diagnosis. This was really within one shift. And so, it wasn't that I took care of him over several days, it was really, well I take that back, I believe I took care of him two days, and the first day he was more stable, and the second day was when he decompensated, and we had to um… He ultimately passed at the end of the shift, after we coded him. I do remember, well, because I was so very busy, I do remember having conversations especially with the mother. The father had a hard time coming in because he was so very sick, and he was having such a hard time coping with it and because he was so young. Of course, their thought was yes, of course we want to do everything and being a parent, I could completely empathize with her. And so, um, but then towards the end, like I said, he was so sick, and he ended up, he did end of coding and we did code him but then there came a point where they said, you know, enough is enough. I guess initially um, we were obviously going to do everything that we could and then towards the …, I'm trying to remember, when he coded, um, then we got him back and then there was a decision do we continue to code him? And that's ultimately when the family decided no, they wouldn't do anything else.

This young patient also deteriorated very quickly, and Irene was providing lifesaving interventions for this patient. Irene empathized with the family, though she had minimal time to fully support them. Further, she did not have time to process her emotions.

Nurses' Emotions Related to Death

Daphne explained how death is hard for everyone, family members and health care providers. She discussed the conflict that nurses feel when curative care continues for a dying patient:

> It's hard to balance, they are charged, because, it's life and death, it's emotional, it's bringing up things for everyone, in different ways. It often I think, brings up feelings of inadequacy for physicians because they feel like they've let this family down, let this patient down. For us, we feel like we are letting them down by continuing, often, so there is conflict there. There is tension there. And you're also upset because you're watching the family grieve, it reminds you of your own family while you do, it's just hard and sad to watch someone die. Um, so it's charged, for me I put a lot of effort into remaining professional, in my discussions with my colleagues, in sharing my feelings.

Leslie discussed how she supported a patient's wife in the hours prior to the decision to withdraw support:

> I cried with her, and I cried like, outside of her room too thinking about it, yeah, and then when I left, we had like, a big hug and a cry. Yeah, yeah, it was just like someone slowly pulling the juices from you. I feel like that's true any time you talk to any patients that are like, just kind of like, giving a piece of yourself and listening to their problems just kind of, its, you have to have a lot to give to do it. <*laughs*> Yeah.

Emily felt that "death is hard, it is supposed to be" as she shared how difficult emotionally it was to experience the death of a patient. She explained the challenge she faced when dealing with feelings pertaining to death:

> Um, about the topic of a good death. And I think that as a new nurse I didn't understand that, you know. I talked to new nurses, these new grads. One of our coworkers who is a brand-new nurse, I've talked to her a couple of times about it, and she has had patients pass away, and she's like devastated about it. And of course, she should be, right? Because death is sad, and we should always be sad, it's always a loss of life. I had someone ask me: "Do you value life working in the MICU?" And I said, or like, um, is death okay for you? And I said, I value life, of course I do, anybody that works in health care values life. But, I have had these conversations with this new nurse and I've said, it's tough and you should be sad, it should be hard, but the best you can hope for them is to let them go peacefully and so, I think that takes time, that takes experience, and that takes a deeper a understanding and an ability to get in touch with your feelings. I think, which I feel like not everyone can.

When asked to explain what she meant about ‘getting in touch with her feelings’ and how that differs from suppressing her feelings, she continued to explain:

> I think it’s, you have to do both right? I think that you have to suppress your feelings in front of the families and become an objective person who is going to make good objective decisions for the person that you are caring for. But I think there has to be a degree of empathy that you have to instill in there where you have to give a portion of yourself where you can be sad for the family in a way, but you can’t, so it’s, it’s tough. It’s almost as if you are torn between two things, but that takes time. And it takes, and that’s not something they teach you in nursing school, right? And how can you teach that?

Emily emphasized the dual roles that nurses find themselves in when a patient is dying but continues to receive curative care. The nurses are expected to be objective and conceal any personal judgements or beliefs, which require the nurses to suppress their thoughts and feelings. Yet, empathizing with the family requires the nurses to be aware of their feelings so they can react to and support the patient’s family’s emotional needs. Emily was aware of the difficulty in empathizing with a family that was requesting care that the nurse did not agree with, although she felt that this was possible. Emily described that there were times when the nurse must conceal their own feelings of sadness about the patient’s situation from the family. Emily suggested that by valuing life and understanding what it means to provide a good death helps her remain in touch with her feelings.

Nursing Emotions During GOC DM

Kelly explained how the emotions she felt were different depending on the goal of care decisions made by family members:

> It makes you feel good if you can help people, kind of, come around to reality, um, you feel like you've helped carry that burden for them as much as you can. Um, but when they just don't want to hear it and they're not listening to you, it's just exhausting and frustrating. Um, and you just want to like, be like, what if you were her, think about what this all is like? People can't do that, they don't want to. I think it's like, it's not as much like they don't know, it's that they don't want to know. And that's frustrating. So, frustrating and exhausting but also can be gratifying when, especially when the family knows what the person wants, then it's like, thank God! But it's so rare, I feel like, when that happens, especially for a younger person.

Kelly provides an example where caring for a patient whose family was overly optimistic affected her level of energy:

> She didn't get mad at anything that I said, but I think hearing it from another person kept, started to chip away. But yeah, it was a little bit draining having to counter all the positivity with the negative.

Irene felt valued when she was able to help a family make an informed decision to withdraw support. She felt a sense of reward and satisfaction from this patient experience:

> But, ultimately, we ended up, or the family ended up, making the decision to make the patient comfortable and the patient passed peacefully. And I do remember feeling like I had, you know, had really helped that family because they really trusted me, and appreciated the time I spent with her. I felt really good about it. I felt like, valued by the patient, I felt like the physicians appreciated me stepping in and kind of bridging that gap. And so, yes, it was, um, a rewarding experience.

Hannah struggled with her emotions that were triggered by a patient's suffering. She tried to empathize with the family members as they were facing a difficult decision, but that did not reduce the intensity of the emotions that she felt:

> Um, but it was, I guess it was hard, it was just hard to see someone in such terrible shape. And you know, to be taking care of them knowing that they are suffering, and this is inevitable, he's going to die and his last months or weeks are this awful experience. It was just that it made me really angry that, you know, you're keeping this person alive for your own personal benefit while he is suffering and when he dies, I'm the one sitting there for him. Yes, I'm sorry. <*tears up*> Well, so that's hard. And that's, I think that's one of the biggest emotions that I felt when caring for people who are requesting aggressive measures, but I try to remember sometimes that it's, I try to remember that people are grieving and that this is a hard thing. Um, it's not always like that situation, I feel like this was an extreme, where the suffering was very obvious.

Hannah found it difficult to reconcile a situation in which the family prolonged the patient's life, but when it was the patient's time to die, no family was present. She as the nurse, was with the patient when he died, holding his hand so he did not die alone. Hannah became emotional and teared up during the interview because she felt sad for the patient and had difficulty seeing meaning in the situation.

Hannah struggled in another patient situation where the patient was suffering, and she was not able to give pain medication because of its effect on the patient's blood pressure.

> I just felt sad, just like nothing I do is going to help them. Like all I can do is try to make them comfortable, but I can't. Like, you can only give them so much pain medicine and she's critically ill, her blood pressure was not great. Um, she couldn't tell us what she wanted, you know, and you can tell that the family had to kind of, spend more time understanding that she really didn't want this, just kind of looking at her face, how uncomfortable she was. So, I don't, as much as I love taking care of sick patients, in that case it's like, you know that the inevitability is death and it's going to take the family a little bit too…, but while it takes them time to understand it, the patient is suffering. So, it's frustrating.

Hannah found it frustrating to observe suffering and to be unable to stop the suffering. She saw the suffering before and more often than the family. Hannah had provided two situations that where challenging and she was frustrated to witness what she judged to be meaningless suffering.

Felicia, while caring for the patient that was coding several times per week, reported a gamut of emotions while caring for this patient:

> My frustration was about what she was allowing us to do. It's just like, we're beating him up several times in a week. You know, so, why, why, this is someone you say you love! But again, it brings into my own personal beliefs. You know, again, I've never been married but I'd think I would never want to do that to my husband. I would think, but who knows, again, I don't know the history, maybe he told her one time, do everything you can for me. I don't care if they have to kick me through a wall. <*Laughs*> Do it! Maybe that was it. Exactly, maybe he was that person. But yeah, yeah, that was that. One of the rare times when I'm like, fine, I'm not going to try and fight this one. If she wants compressions, we'll just do compressions. I'm not … okay fine.

She understood that the situation was complex. She continued her story through a lens of compassion and shifted her perspective of the story:

> Again, it's a personal thing, I don't foresee it. But I think that gosh, you see us doing this every, several times in a week, this is the person you say you love. Oh my gosh. You know, if someone treated my cat the wrong way I'd be like, stop it! Like, how, how, how? But again, I've never been married, I don't know the situation that she was in, maybe he was the only support that she had, I have no idea. Maybe she had other people that we didn't know talking in her ear, people convincing her to do these things. Um, but it was, it was hard for me to see that, or watch that because I thought this is just plain cruel, this is just cruel, this is cruel.

Felicia was able to show compassion in this situation and was not in agreement with the treatment delivered.

Kelly explained the challenges she encountered when a family was determined in their decision to continue care for a patient with a prolonged critical illness:

> You almost resent them for their decision. You have to keep reminding yourself that it is their decision, but you are the patient advocate, and you almost resent them when they don't see, don't understand the suffering and it's like, they choose not to see it and it's kind of hard to like, get around that myself. It's like how could you not see your mother has skin tears and a wound vac, how do you not get that this is painful for her?

Kelly found meaning in serving as a patient advocate, although the power to make the decision was not hers but belonged to the patient's family. She explained how seeing the patient suffer as a result of the family's decision caused her to feel resentment towards this family. As this patient continued to live, nurses minimized their exposure and the nurse-family relationship deteriorated. Kelly continued with her story:

> She basically rotted away in a hospital bed and it was terrible, no one wanted to take care of her because they just couldn't handle that every day. You know, she had a new nurse every day, plus everyone was getting fired from the room. Um, for like tearing her skin or, one of the wound nurses even got fired from the room, it was just …. There were some nurses that didn't really have a filter and it was a good thing and they got fired and they were happy that they got fired, that's one of the cases where like, you almost don't want them to want you to take care of her <*short laugh*>.

Nurses alternated assignments to care for this patient to preserve the staff's emotional well-being. However, the family expressed preferences for who cared for the patient. Grace provided an example where the nurses expressed a similar need:

> And then it's just the same pattern, and it felt like a pattern day in and day out and we were, we felt like we were just kind of flogging this woman who was unable to speak. So, we were really relying on the family to kind of understand the brevity of the situation and maybe make some changes to her plan of care. And it never really happened. So, um, I think for us it was just, it was frustrating and sad and we'd waiver where we'd have to switch out staff members who would take care of her because she'd really, even if you'd just walk in the room, there was this like, like she wasn't there anymore, she was just this body of this person.

Nurses were aware of their emotional limits, and in this situation, the nurses recognized the need to rotate nurses assigned to the patient.

When a family member was hopeful that a patient would recover and requested continued curative care, it was stressful for the nurse when the patient abruptly declined. Alexa shared this experience:

> Well, there was one time where we were pulling a certain amount of fluid with CRRT that stood out because he lost it, and of course, I was in the room. Her blood pressure was very stable, very stable and then all of a sudden, her husband is in the room, and I see her next pressure was 70. So, I automatically went to the CRRT and I minimized her fluid removal to 10. I rechecked her blood pressure and it came back with the same number, so I called the doctors to the room. At that point, he lost it, he, he um, demanded a CVP (central venous pressure), he demanded, what is the fluid status of my wife? And you know, there was several doctors in the room, and he was basically yelling at the doctors that they were not watching her very closely. I kind of felt guilty because you know, maybe I should have had a CVP ready for her regardless of the doctor's order, you know. Like, you think about this fluid status, but everything is going well, you don't see anything wrong, so you just keep on removing the fluids. Until this one blood pressure comes back and is 70, you know. So, there was a discussion in the room, he was very upset at the doctors for not doing enough. They were not watching enough.
>
> And um, kind of, he made everyone feel guilty, despite how hard I was working with her um, he just kind of said that we were no good. He later apologized for being so abrupt and for raising his voice. He didn't apologize for what he said, he still believed whatever he said was right, and I think he was, you know. Um, but he just busted with all the, you know, accusations that wasn't very helpful in the room. You know, I don't want to feel pity for myself, but I worked really hard with her, constantly going from one side of the bed to the other, all day long you know, it wasn't like I wasn't there, watching her and everything, watching numbers, sending labs, checking the numbers, you know, you know how it is. So, I just didn't feel like I deserved that, you know, him putting us down like that.

The family member responded angrily when his wife's blood pressure dropped abruptly. While his outburst was directed at the physicians, Alexa felt guilty as the patient unexpectedly decompensated under her care. She had been working diligently to support the patient's spouse and to care for the patient. The outburst made her feel guilty, sad and mistreated.

The nurses in this study experienced an array of emotions while caring for patients that were not expected to recover. Some of these emotions were related to the impending death and other emotions were related to the struggle surrounding the goals of care decision-making process. The nurses found it gratifying when the family knew and honored the patient's wishes. The nurses caring for this patient group reported feeling that it was a gratifying experience, it felt good because they were able to help, and they considered it a rewarding experience. The nurses reported feelings of resentment and frustration towards family members when the decision was to pursue aggressive treatment for a dying patient. In different situations, nurses verbalized feeling emotions such as anger, fatigue, exhaustion, frustration, guilt, detachment and distress. As indicated by the overarching theme, goals of care decision-making covers a wide spectrum of experiences for the nurse as each patient situation is different. For the nurse, while providing care for such a patient, the emotions they experienced differed based on their experiences within the other three themes described in the previous sections.

Understanding this Phenomenon

The overarching theme that GOC DM covers a wide spectrum portrays the variation of situations that nurses encountered and shared in the interviews. The anecdotes described many different possibilities and factors that influenced how the nurse experienced the phenomenon in various patient situations. The themes allowed the stories to be sorted and organized by their commonalities so that they could be understood. To understand the entire picture of this phenomenon, it became clear that the characteristics of the nurse needed to be added as the owner of the experience. This study was about the lived experience of the nurse and it was therefore important to include the nurse as an active, influential participant within this phenomenon. The nurses who shared their stories for this study described themselves as having various levels of engagement depending on the patient situation. The nurses showed different levels of energy as they told their stories. The nurses described how they became more forthright with experience by knowing how to talk to family members and when to stay quiet. Even in difficult situations where the nurse was certain that the patient would not survive, the nurses were flexible by trying to understand the family's beliefs and motives.

Drawing the themes into a diagram provided a visual mechanism for organizing and illustrating the variables that were found to be influential to the nurses lived experience of this phenomenon. This drawing is captured in Figure 1.

Figure 1. Factors that Affect the Nurse's Lived Experience when Caring for a Patient that is not Expected to Survive and is in need of GOC DM

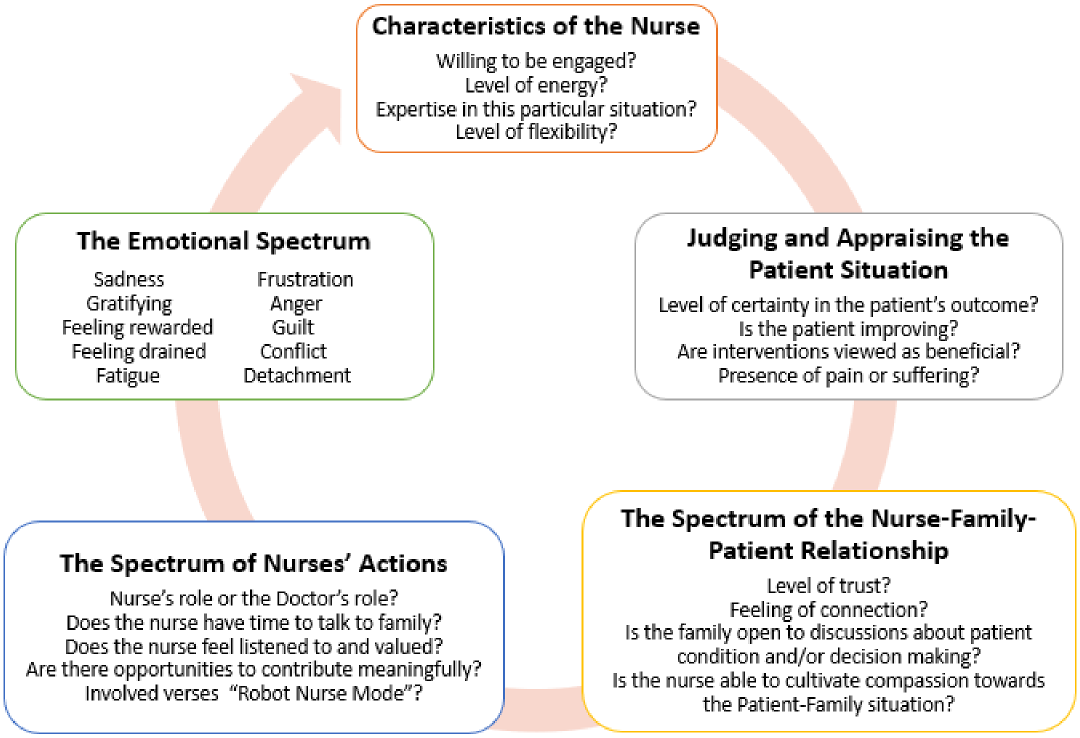

Figure 1 shows that the nurse's lived experience when caring for critically ill patients is cyclical in nature and depends on many variables that are dynamic and interrelated. These variables were identified in the stories that the nurses shared for this study. The purpose of this diagram is to understand this phenomenon, although it is important to refer to the nurses' anecdotes to understand this phenomenon in practice. For example, in the LED, Cassi was a new nurse, experiencing a difficult GOC DM situation for the first time. She judged with certainty that the patient would not survive based on her assessment and the physician's findings. The patient's partner wished for curative care and she tried to generate compassion for his situation. The partner was not receptive to Cassi’s interpretation of the patient’s condition and GOC DM was primarily physician driven. Cassi felt frustrated, conflicted, and fatigued while she cared for this patient, but remained engaged and flexible as she continued to take care of this patient for several shifts. Her experience was not static but changed over time.

The participants shared stories of patients that they believed would not recover and needed GOC DM. The nurses judged patient situations based on a variety of factors. Emily was certain that her patient with a severe infection would not survive because the patient remained hypotensive on four vasopressor infusions. Felicia saw her patient’s declining mental status as a sign of not improving. Cassi’s patient had extensive wound care that resulted from his severe illness and the dressing changes consumed copious amounts of her time. Leslie described a patient that was not getting better and had painful dressing changes. Nurses assessed patient’s ability to survive and level of suffering and made judgements about the patient’s outcome.

Findings from this study provides insight into the nurse-family relationship during the GOC DM process. The nurses’ interaction was affected by the type of relationship formed with the family. Feelings of trust, connection and an ability to discuss decision-making were found to be factors that weighed heavily on the nurses’ experience with GOC DM. Nurses shared experiences where family members did not want to discuss GOC DM. The partner in Cassi’s story told her she was not to say anything negative about the patient. This was evident when Felicia did not see a point in talking to a patient’s spouse about decision-making because she knew that it would not make a difference. Family members in other stories were open to discussion and asked the nurses for their opinions. Trust was also seen as important. When nurses perceived that family members trusted them, they were more willing to engage with them and share information. Felicia shared a story where the patient's spouse questioned her every action and took active measures so to avoid interacting with him. Nurses in some situations felt that they had to tread carefully in their interactions with family members as they found that trust was conditional based on their actions. Connection was seen as significant for it represented the bond that the nurses felt with the patient and family members. Daphne described how building a rapport with her patient's family members made her more emotionally attached to the patient's outcome. Felicia described how she fostered a feeling of connection with family members by looking at and talking directly to the patient. Some nurses described how the nurse-family relationship could become strained when there was disagreement about the patient's prognosis or when the families did not want to hear anything negative about the patients' prognosis. Nurses felt the need to be engaged with family members and found it challenging when family members did not trust them.

The current study examined the actions of the nurse and found various factors impacted nurses' roles and experiences in GOC DM. Nurses described situations where they felt that it was the physician's role to talk to family members about GOC DM. These included situations where the patient was declining rapidly, and the nurses were busy with tasks and unable to talk to family members due to time constraints. Most of the nurses preferred that physicians be the first one to tell the family members that treatment options have been exhausted. Nurses were willing to take action after the physicians talked to the family. In this study, the nurses shared how they presented reality, provided status updates, education, support and worked to complement the medical team.

The nurses' role was different based on the readiness of the family to make goals of care decisions. When family members were open to decision-making, nurses felt they could provide information and support. Nurses appreciated when family members listened to them for it provided them an opportunity to contribute meaningfully to goals of care discussions. When family members were entrenched in their decision to continue curative care, nurses reported less of a role in decision-making. Several nurses provided examples in which they would discuss or display the seriousness of the patient's condition to family members. Nurses in other situations knew that they could not influence the family. Felicia described going into robot nurse mode, where she focused on her tasks as she knew that the spouse would not change the patient's code status. She minimized her interactions with the spouse as she would be unable to conceal her feelings about the situation. Nurses described how challenging it was to remain emotionally responsive to family member's needs when they had to conceal their feelings and remain objective in their interactions.

The nurses identified, discussed and explained a wide variety of emotions. The emotions that nurses experienced were contingent on many factors. Nurses described how helping family members navigate GOC DM and accept death made them feel sad for the patient and family and took a great deal of energy. When they felt a connection with the patient's family and were able to contribute meaningfully, they felt rewarded and found the situation gratifying. Nurses provided various examples of feeling strong negative emotions. Situations where they tried to talk to non-responsive family members about the realities of the situations were draining and frustrating. Nurses expressed anger and frustration when delays in decision-making contributed to patient suffering. Nurses described distressing patient situations that caused them to feel emotionally overwhelmed, requiring them to rotate patient assignments. Nurses also reported feeling frustrated when they felt that their interventions contributed to patient suffering.

Based on this diagram, the nurse's experience of caring for a patient in need of goals of care decision-making can be different based on variations in the characteristics of the nurse and within the factors contained within the four themes. This diagram provides insight into these factors and can increase a nurse's level of self-awareness by serving as a roadmap to navigate situations and experiences encountered during GOC DM.

Finding Meaning within this Phenomenon

Several of the nurses shared how they found meaning within the experiences that they encountered during GOC DM. Nurses were keenly aware that the family controlled the decision in their SDM role and dictated the aggressiveness of care. Meaning was embedded in each situation that the nurses described and stories they shared. Several of the nurses wished to share additional reflections on the meaning of their experiences. These nurses found balance by generating compassion and understanding towards family members facing and end-of-life decisions. Jordan reflected on how she approached a challenging patient situation:

> My ideas for what needs to happen with this family are not important, like, that this family has needs and they are going to be different from the needs from any other family that I have taken care of, just, kind of figuring out what that family's needs were was more important than me trying to figure out how to get the family to where I wanted them to be.

Jordan found meaning by being flexible and worked to understand the needs of the patient's family. Grace reflected on her feelings of accountability when family members followed the advice of the medical team to withdraw support:

> And they had a goals of care conversation with the family and the family kind of expected and made the decision. But you always wonder based on when they leave, like, months, years, I don't know, decades down the road when they reflect on that experience, like, was it something made in the moment, was it something made … whatever, and I think with that emotion, it's just, even if you achieve, you're like, coming to terms with the fact that you helped someone make this decision, you've had some part in it, you think you've done right by the patient, but have you done right by the family member? I don't know. And you never really know. I don't know, it's hard to come to terms with that sometimes and I guess that is where the deeply emotional part goes where, when they do agree, like, it's almost like, when you get what you kind of wanted, what you think is best for the patient, and then you start to question, do I actually know what's best for the patient?

Grace felt that the goal of decision-making should be sensitive to the needs of the family members. She described the uncertainty involved in decision-making and how doubts can linger after a decision is made.

Felicia was able to view decision-making from the family's perspective. She understood the finality of the decision and she wanted to leave a good impression on the family:

> I would have to say, I do a really good job when it comes to end of life because I've had that experience before, where I know that it's not only about the patient,

> it's about their family members because, this is final, this is, you know, you're not coming back after this, this is, this is it, you know. You can make it as miserable as you want to or you can make it as, it's not pleasant, you can make it as bearable as you can because this is something that they will never, never ever forget and I don't want to be that face where they are like, oh yeah, that was THAT nurse, I want them to remember me as okay, she was caring and kind and patient.

After observing a patient in the ICU suffer for months, Grace sought advice from her father to help her cope with the situation. She found his perspective helpful and has since incorporated his advice into her nursing practice:

> It was a conversation that I had with my father, actually, who kind of changed how I perceived that and how, he had basically said, you know, if he needed to be tortured, essentially, to help his family members come to terms with the fact that he was dying, he would totally take that option. He would want that. And so, it's just weird because you think about the patient as this completely powerless entity and you know, we're supposed to be helping them and saving them but there is this kind of underlying resilience where if they, if they were looking in, they might actually, they might have a better understanding of it because they want to help their family members with the coping process. So, I guess in that way, as frustrated as I get with, like, okay, I see the end, I see that this is, we're just flogging this patient, I see that there is nothing in sight. I think hearing my father's words and then looking back on that situation when maybe I'm giving entertainment to the idea that maybe a patient wants, understands and is going through this because they know what needs to happen for their loved ones to go through the process of grieving is actually the way that we go. But then it's weird because you feel like an accomplice in this weird torture. Um, but it did really shed some light in terms of, yeah, you know, the relationship and the bonds and the things that people have before they come to the hospital, we have no ideas about, um, and maybe there is a family member that, err, the daughter for example in that story, where she's always had a really hard time with death and her mother knew that. And so maybe in some weird sense her mother was actually maybe okay with it? But you never know, and it leaves all these unknowns. But it has changed how I view, I think, I don't want to say, pushing goals of care, but how I view, okay, well, it's easy for me as a healthcare provider to say or see that we are doing this or not, um, but, it might not. Even so, and even if the family member saw that, it might not be the right thing for them because they need the time to reach that decision themselves. And that's actually kind of what's the better approach.

Grace described the moral nature of what critical care nurses are asked to do in a situation when the patient's family remained firmly committed to full care. She used strong words such as torture and flogging to describe what the patient was enduring and felt, as a nurse, to be an accomplice in these actions. Her father's advice injected the possibility that the patient was not a vulnerable entity in need of protection and was okay with such treatment if it helped the family cope. It helped her understand that family members needed time to make goals of care decisions. This thinking provided her a different perspective, a flexible mindset, in which it was not her moral imperative as a nurse to tell the family that they were wrong in their decision to continue care. This new perspective allowed Grace to view the situation from the family's perspective and to understand that there was always uncertainty and unknowns in every patient-family dynamic.

Emily shared this summary of goals of care decision-making and the importance of feeling emotions:

> And I say, the second I don't get upset about something like this is the day that I should not be a nurse anymore. But I think that, you know, we view death and dying as us making a mistake, or us being punished for some choice we've made, or us failing. I think that society views death as failure. And I think that we in healthcare also view death as failure, and so, there's a lot of things with the newer nurses trying to teach them, especially in the ICU, that like, you didn't do anything wrong, this was just their time. And so, I think that is just another kind of caveat that you have to look at is how you view death and how you view the whole dying process and, you know, things like that, to where it's just, you kind of have to teach others, you know, and this whole end of life topic. We're going to start seeing more and more with the rising health care costs, and just things like that. And when do we start having these conversations? Are we having them soon enough? And sometimes I don't think so. So, but other times I think we're having it too soon to where they're not ready to have these conversations. And the physicians are leading these conversations, but they don't have the type of relationship or type of caring for the family, to where the family believes that you are going to tell them the right thing.

Emily was able to be objective and summarize the challenges involved in decision-making. She explained why accepting death was difficult for both healthcare providers and family members. She pointed out the difficulty in the timing of these conversations and the challenges that physicians faced in helping family members believe and follow their recommendations. Relationships were described as important during the decision-making and dying process. Emily described that feeling upset, or feeling emotions, when witnessing death and dying was important to her and was necessary for her within her nursing practice.

Processing this Phenomenon for Context and Meaning

It is necessary to examine this phenomenon in the context of the life worlds to fully understand the lived experiences of nurses caring for patients that are not expected to survive and in need of goals of care decision-making. Spatiality (space), corporeality (embodiment), temporality (time) and relationships are important to consider when striving to understand the meaning of this phenomenon as these nurses experienced it. The goal is to understand what it is like to be a human being within this phenomenon.

Spatiality (Space)

Spatiality connects the experience to the participants, in this case critical care nurses, to their environment, which are intensive care units situated in academic medical institutions within the eastern United States. This study focused on nurses' experiences caring for patients that were not expected to survive and were in the need of goals of care decision-making. Thus, the stories that the nurses shared reflected their experiences with this subset of critically ill patients. The nurses in this study described the patients within this environment as critically ill and dependent on various forms of life support such as ventilators, continuous dialysis machines, medications to raise the patient’s blood pressure, and blood products. Felicia described what she saw as she walked into her patient’s room. She described the patient in bed with intravenous pumps and equipment all over the room. Felecia saw one family member sitting next to the bed, holding the patient’s hand, the other in the chair to her left. One was noticeably tearful, the other sitting quietly. The presence of family members was consistent in many of the stories, and when the family members visited infrequently, nurses expressed concern. These ICU’s had an open visitation policy, where patient family members were encouraged to visit and could stay at the bedside 24 hours per day if desired.

Nurses were one of many healthcare providers within the ICU, each having their own roles and responsibilities. Cassi’s stories involved consultants that weighed in on the patient’s ability to survive and the primary ICU team that managed the patient’s care. Most stories involved physicians from the primary ICU team with the attending physician directing treatment decisions. Members of the palliative care and ethics teams were described as available if needed and served in a consulting role. The nurses described how the environment in a patient’s room differed based on the patient’s status. Felicia described what a code would look like to a patient’s family, “There would be a dozen people in the room, there are loud noises, but we are going to do our very best to help her”. Jordan and Irene described situations where there were several nurses and physicians in the room to care for a critically ill patient that was rapidly declining. In

Cassi’s story, the family visited infrequently, and the physicians spent little time outside the patient’s room as they knew the situation was dire.

Accepting death was challenging for some in the ICU. As Alexa explained: “I always fight for the patients to the end, but like the old book says, you know, fight, fight and fight, but there is a point where you have to say that it is not worth it any more, you know, like there is a point where you have to say, that’s it. But I don’t want to be the one, you know, who… they have to make this decision.” Alexa summarized the environment in the ICU and how challenging it is to accept that a patient is dying, and the difficulty of making goals of care decisions. In the healthcare system in the United States, family members are responsible for goals of care decisions in situations where the patient is incapacitated and not expected to survive and does not have written advanced directives. As Felicia stated, referring to a patient’s wife, “she’s gotta have the final say”.

Corporeality (Embodiment)

These critical care nurses embodied their role as caretakers, which started when they accepted the assignment and received report on their patient at the beginning of a shift. Grace used of the term “handoff” to describe the procedure for transferring the weight of responsibility for patient care decisions from the previous nurse to the accepting nurse. She described a visceral feeling of anxiety and found it scary and stressful to accept an assignment where the code status was not clearly defined for a patient that was declining. This feeling prompted her to have a conversation with the patient’s family to clarify her understanding of their expectations about the plan of care.

The nurses explained that patient scenarios were unique and resulted in different experiences. Several nurses described caring for patients that were not expected to survive as routine and frequent occurrences. These nurses developed routines that they followed while they cared for such patients and interacted with the patient and family members. Felecia described how she walked into a patient's room and the actions she took to form a connection with a patient's family. Nurses described several challenging patient situations where the family members selected ongoing curative care for patients with prolonged ICU stays who were not expected to survive. Due to the qualitative nature of this study, the frequency of such occurrences cannot be estimated. The nurses described the many struggles they faced while caring for these patients and the strong emotions they encountered.

Frustration was the most common negative emotion that the nurses expressed in situations of ongoing curative care. Many of the nurses described feeling frustrated when they did not agree with the care and treatments that they were providing for the patient. Felecia described going into robot nurse mode as she did not feel that she could impact the patient's treatment trajectory and this mode provided some emotional safety. The nurses talked about not feeling safe talking to their patient's family about goals of care decisions because they were requested not to do so by the family. The nurses talked about situations where nurses were "fired" by family members and had to hand-off care to another nurse. Grace explained how nurses waivered as they cared for a long-term patient due to the emotional burden surrounding the situation and the nurses could only care for that patient for one shift at a time.

Suppressing emotions and remaining empathetic was described as challenging. Emily described how important it was for a nurse to stay balanced. She described the obligation of remaining objective and suppressing her feelings in front of the patient's family while at the same time remaining in touch with those feelings in order to have empathy. Obtaining this balance was described as difficult and took skill and self-awareness to maintain. Irene, Hannah and Felecia found it rewarding to help the family through the decision-making process. They each described a situation where they felt safe talking to the family about the patient's issues. Feeling safe gave them confidence to talk to the patient's family and to guide them through the decision-making process.

The nurses experienced many strong emotions as they cared for patients in stressful life and death situations. Nurses appeared to have different ways of coping with these emotions. Several nurses described actions that they took to understand the family's perspective and to generate compassion. The emotions that resulted from these situations lived on long after the nurse's experience with the patient ended. Several nurses became emotional and some cried as they described the details of these patient stories and the challenges they experienced.

Temporality (Time)

It is never the right time for a patient's family to lose a loved one. The nurses were aware that family members processed situations differently and needed time to come to a decision. Jordan described how her thinking had evolved to understand that "grief and the letting go and the relationship and how, what a wide spectrum it is for people in that whole process. Not feeling like it has to happen in one sort of way".

Nurses described feeling compassion for family members during this time, provided them with patient updates and clarified physician communication.

In the nurses’ stories, there was often a tipping point where the nurses’ experience of the situation changes. After a certain point, nurses appeared to perceive the care and treatments that they provided for their patients differently. These situations often occurred when the nurse was certain that the patient’s prognosis was poor, and the family members were not receptive to the nurse’s concerns. Nurses described having to “tip toe” and be guarded in their interactions with family members in these situations. The nurses had to be cautious and tread carefully in what they said to family members. Cassi experienced backlash from her patient’s partner who admonished her for not being positive in her assessment of the patient’s response. Cassi and several of the nurses described how everyday nursing interventions in such situations were viewed as painful to the patient. Nurses did not see purpose in the time that patients spent suffering. One aspect of time that nurses had control of was the decision to take the patient assignment back for another day. Some nurses chose to stay with a same patient assignment for a duration of several shifts. Other nurses found it necessary to switch to a different assignment after one shift.

Relationality (Relationships)

This principle incorporates the Ethics of Responsibility by the phenomenologist Lévinas (Lévinas & Lingis, 1969). Lévinas explored the phenomenon of human connection and the desire to help others. This principle sheds light on what occurs when nurses observe patients and family members in vulnerable situations. Applying Lévinas’s

Ethics of Responsibility as a philosophical thinking to these GOC DM situations, nurses in a caring role are called by the other, in this case, the patient and their family, to respond to their call for help in a difficult situation. This vulnerability calls on the nurse to act and to take personal responsibility and care for the other person. This act of caring makes the nurses feel emotions such as anxiety and worry which in turn strengthens their desire to feel responsible and care. If the nurses reach out and their offer to help is accepted, then a connection is formed between the nurse and the family. This connection can provide the nurses with opportunities to talk to family members about various clinical observations and concerns about the patient's condition. In doing so, the nurses must be careful because this connection can be broken if they push beyond the limits of what the family is willing to accept. It is within this relational-context that meaningful experiences occur.

Facilitating relationships with family members can be challenging but it is where critical care nurses developed their own art, their own techniques, for engaging family members and forming relationships. It took time, energy, skill and a willingness of the nurse to become engaged. When a close, trusting relationship was formed and nurses engaged with family members, it allowed the nurses to help in ways that were meaningful. It was in these situations where family members asked nurses for their professional opinions and were receptive to the nurses' judgements. Under those conditions, nurses felt that they could contribute by helping the family members see the realities of the patient's situation and contribute meaningfully during the decision-making process. Being able to help a person in a vulnerable state was therefore viewed as fulfilling. When the family rejected the nurses' willingness to help and the connection is either not formed or broken, the nurse felt conflicted and distressed because they were rejected and dismissed. Seeing a person in a vulnerable situation and not be able to help resulted in negative emotions. This affected the nurses' sense of value and ability to contribute meaningfully. Being disconnected from the family is this way and unable to help the patient was a source of frustration for the nurses in this study.

Nurses' experiences with family members who were open to discussions about the patient's goals of care were distinctly different from those where family members were not open. Thus, the meaning that this phenomenon for nurses also differ greatly between the two situations. When family members were open to receiving patient updates from the nurse, the nurses described close and meaningful connections. In these situations, the nurse was able to contribute more to GOC DM, and experienced more positive emotions. Nurses believed that maintaining a good relationship with family members was important as it sometimes allowed the nurse to tell the family more information about the patient's situation. Even with a good relationship with a patient's family, these nurses still preferred that physicians tell the family negative news and to prognosticate outcomes. Jordan and Grace described how they tried to avoid influencing family members with their opinions and preferred to inform them. The nurses in this study provided family updates about the patient's status and tried to portray the reality of the patient's situation. Sometimes with a vague approach using the terms that Irene shared: "I'm just really concerned"; "They are really sick"; "What have the physicians said about the prognosis?" And other times with a more direct approach to make sure that the family could make an informed decision.

When family members were resistant to hearing updates about the patient's declining status or were deeply entrenched in their resolve to continue curative care, nurses had less of a role in decision-making. In such situations, the nurses felt that it was the physician's role to have these conversations with the family to avoid conflict. The nurse-family relationship became strained in such situations due to a lack of trust and subsequently a lack of connection. The nurses described feeling more negative emotions such as frustration and anger, especially when they perceived that the patient was suffering. Felecia described a situation where she had to work in "robot nurse mode" where she kept quiet as she knew that the patient's spouse was firm in her resolve to continue curative care. Felecia performed her required tasks and checked them off her worklist. Working in such a mode was not a natural state for Felecia as she stated that this was "one of the rare times when I'm like, fine, I'm not going to try and fight this one. If she wants compressions, we'll just do compressions. I'm not … okay fine." She was frustrated by what the wife was allowing the medical team to do to the patient and found the treatment cruel and difficult to provide.

In situations where family members were deeply entrenched, the nurses felt that they had to make it until the end of their shift and the patient had a new nurse every day. Grace talked about nurses wavering and having difficulty with a challenging patient situation. Cassi provided an example of wavering, where she questioned her interventions as she completed them as she did not see purpose in her actions. Three of the stories shared by the nurses were extreme situations where patients, unable to recover, stayed in the ICU for months. These situations elicited negative experiences for the nurse, and they felt strong emotions such as distress, detachment, anger, and frustration. Nurses could only care for these patients for one shift at a time and even that was described as difficult. The meaning in such situations is much more challenging to describe because it would be easy to say that it is not meaningful to care for another human being is such a condition. Nurses may be told that the meaning in such situations is that they have a job to do and it is their responsibility to take care of this patient. In this case, the meaning would be for nurses to endure the patient assignment one shift at a time and to apply self-care practices to mitigate the distress that they were feeling. Perhaps the most constructive meaning to apply to such situations is to examine the morality of such cases. Nurses described how they were able to generate compassion for patient family members in these situations, although feeling compassion did not shield them from feelings of frustration and anger as they provided life-extending treatments to patients that were obviously dying.

Nurses in their stories described some situations where they felt that the patient was suffering greatly as a result of their interventions. In Cassi’s story, it took three weeks for a decision to be made to withdraw support on that patient. The physicians struggled with this patient situation as they did not see anything that was reversable, and they were not making progress in their discussions with the partner. It took an outside physician, a palliative care doctor, to act as a liaison to get the physicians, nurses, and the partner on the same page. This doctor was able to get everyone to work together and it was with her help and through their combined effort that they were able to come to a resolution. The meaning in such situations would be for healthcare providers to recognize challenging patient situations early and to put a plan in place before it escalates into conflict and frustration. Nurses in challenging patient care situations described strong emotions which made them vulnerable to distress. It is therefore important for health care providers to support each other and to support a healthy dialogue about these situations.

Summary

The critical care nurses in this study described a wide array of experiences that they encountered while caring for patients that they believed would not survive. Most of the emotions that the nurses experienced when caring for these patients were stressful. When the nurses were able to participate and have a positive impact on decision-making, they felt grateful that they were able to contribute, but also felt sadness, fatigue and grief. When the nurses experienced situations that ran counter to their beliefs of what was moral and ethical, they reported feeling frustration, anger, guilt, conflict, and distress.

The stories suggested that, when caring for this type of patient, it was impossible to avoid strong emotions that resulted from these encounters. The factors that affected the nurses' experience were complex and many appeared outside the nurses' control. There was meaning in every experience and this study exposed that meaning and subsequently a greater understanding of this phenomenon.

There were many parties involved in this phenomenon: patients, family members, nurses, physicians, and other healthcare providers. The meaning of this phenomena was reflected in the stories that the nurses shared. Felicia talked about a mother who had to make a difficult decision to withdraw her daughter’s life support on the daughter’s birthday and a wife of the patient who was not willing to give up on her husband even though he coded frequently and was near death. Alexa’s story of the husband who felt his wife slipping away from him and desperately tried to control the healthcare staff to ensure that she was being well cared for. Briana’s story of the mother that was convinced that her brain-dead son was alive because she saw his chest move. Meaning was reflected in every story, the struggle for life, the hope for survival, and in some cases, never wanting to give up. The overarching meaning of this phenomenon does not involve the nurse directly but revolves around the patient who does not want to die and the family members who are not ready to let their loved ones die. It involves making sure that medical options are explored and implemented to ensure that the patient received sufficient treatment and has had an adequate chance to recover. Everyone involved in the process must agree that withdrawing support is the best option available for that patient.

This overarching meaning affects nurses as they care for their critically ill patients and interact with the family members. Felicia, Jordan, and Leslie discussed challenging patient situations and reframed each of these stories to generate compassion and understanding towards the family. These nurses realized that the family was entrenched in their decision to continue curative care for reasons that the nurses were not privy to. Felicia found the need to go into “robot nurse mode” as she knew she would not be able to influence the situation, but she understood that there were various factors influencing her patient’s wife’s decision.

The nurses shared a wide variety of experiences and multiple stories describing what they encountered as they cared for patients that they believed were going to die and continued to receive full treatment. Every situation revealed a different aspect of the phenomenon and the nurses' lived experience. The stories provided an array of experiences which suggests that this is a broad phenomenon. Four subthemes within this phenomenon were identified that account for the variations in the nurses' experience. The rich experiential descriptions provided by these nurses provides an understanding of what a critical care nurse experiences in everyday practice while caring for these patients. These nurses looked for meaning in interactions and were aware that many layers of complexity were involved in the care of critically ill patients.

CHAPTER V

DISCUSSION

This study examined the stories of critical care nurses as they cared for patients receiving full-curative treatment, knowing that these patients would not survive and were in need of goals of care decision-making. The primary focus of this study was the nurses' experiences in such situations and what they felt, thought, and lived through within the context of the stories. This provided a rich description of the nurses' experiences within this phenomenon. This chapter provides a discussion of these findings.

An overarching theme that emerged in this study is that goals of care decision-making covers a wide spectrum. Four themes were found to contribute to the nurses' experience when caring for patients that they do not believe will survive. 1) Nurse judgement and appraisal of the patient situation, 2) The nurse-family-patient relationship, 3) The nurse's actions related to goals of care decision-making, and 4) The emotions experienced by the nurse.

Goals of Care Decision-Making Covers a Wide Spectrum

The nurses in this study described many different patient scenarios in which goals of care decision-making was required and emphasized that every situation was unique and thus affected them differently. Jezuit (2000) observed that nurses explained that every patient situation had subtle differences and noted that the nurses found the situations where there was conflict with family members most memorable. The same was true in this study. The nurses described several situations in which a young patient decompensated rapidly after a brief illness with little time for GOC DM. The nurses in Badger’s (2005) study shared that the death of young patients that died of an acute illness were difficult emotionally for a nurse to process. Stories that nurses shared for this study were memorable due to a close connection to the patient or family members and those where the nurse witnessed conflict and felt strong emotions. Still other experiences were significant to the nurses because the nurse faced a challenge and subsequently experienced personal growth either through increased self-awareness or through generating compassion for others within this human experience.

The nurses in this study carefully described their experiences within different patient stories that related to the process of goals of care decision-making. Figure 1 captures the thematic elements and the factors that impact the nurses experience as a means of understanding the complexity of this phenomenon. This framework can provide insight into GOC DM in a range of situations, from those where the patient deteriorates rapidly and to where family members request prolonged curative measures. The nurses in this study found meaning by being aware of the complexity of life and death decisions, by generating compassion and fostering trust and connection with patients and their family members.

Judging and Appraising the Patient Situation

When patients were declining rapidly, nurses in this study described being very busy and felt that there was less of a decision because the patient’s deteriorating status was taking the uncertainty out of the equation. McAndrew and Leske (2015) called this "crisis decision-making" that often resulted from not discussing code status early enough. When judging a patient situation, the nurses weighed their level of certainty in the patient's ability to recover, the patient's response to treatment, and perceived pain and suffering. These assessments allowed the nurses to appraise the appropriateness of their interventions based on how effective they judged them to be. Nursing in several other studies recognized that a patient would not survive before the family members did and used that knowledge to help prepare the family for the possibility of death and to encourage decision-making (Gutierrez, 2012c; King & Thomas, 2013; Popejoy et al., 2009). Gutierrez (2012c) found that nurses used this knowledge as a prompt to ask the physicians to talk to family members. In most of the scenarios shared for this study, the physicians were proactive, and goals of care discussions were already ongoing.   Badger (2005) found that nurses judged a patient's ability to recover by various indicators and recognized that patients had difficulty recovering from certain conditions. Nurses in this study talked about patients with trauma, organ failure, impaired circulation and respiratory failure. They looked at the patient's clinical parameters, length of stay, level of support and ability to recover to determine patient survivability.

In this study, Felicia described how difficult it was for the health care team to code a patient that they knew would not survive. The nurses discussed the difficulties they faced delivering care that they believed did not benefit the patient which is consistent with the finding in the literature (Badger, 2005; Espinosa et al., 2010; Popejoy et al., 2009; Robichaux & Clark, 2006). This study found that nurses viewed their interventions differently once they believed that a patient would not survive, especially if they believed that a patient was suffering. Thus, how the nurses' judged and appraised the patient situation impacted how they perceived the experience.

Nurse – Family – Patient Relationship

Findings from this study provided insight into the nurse-family relationship during the GOC DM process. Feelings of trust, connection and an ability to discuss decision-making were found to be factors that weighed heavily on the nurses' experience with GOC DM suggesting the importance of the nurse-family relationship. This study found noticeable differences in the nurse-family-patient relationship in situations where family members were open to discussions about the patient's condition and those where the family wished for full curative treatment options.

When family members were willing to listen to, trust and form a connection with the nurses, the nurses were more willing to engage with the family members and share information. Cypress (2011) found that patient family members often treated the critical care nurse as a member of their family. Connection was significant for the nurse as it represented the bond that the nurses developed with the patient and their family members. Family members in two of the patient stories in this study asked the nurses for their opinions and the nurses felt comfortable sharing. Many studies discussed the importance of nurse-family trust and the feeling of connection. Liaschenko et al. (2009) found trust important for it allowed nurses to learn more about the patient and their family members. Connection between the nurse and patient was necessary for an empathic understanding of the needs of the patient and the family (King & Thomas, 2013; McAndrew & Leske, 2015). Cassi in this study was hoping that a connection with her patient's partner would allow her to learn more about her unresponsive patient. Reinke et al. (2010) described how nurses facilitated a connection with family members by asking the family about their hopes regarding the patient's outcomes. Emily described the strong connection she felt with the parent of a young patient during the GOC DM process. Popejoy et al. (2009) confirmed that nurses were willing to become personally involved to meet the family's needs. Thus, several studies collaborated that trust and connection benefited both nurses and family members during the GOC DM process.

Nurses in this study found it difficult when family members insisted on continuing aggressive measures for a patient who does not have the ability to recover and were avoidant, overbearing, and not trusting. Lack of trust from family members was perceived as difficult and the nurses took a cautious and avoidant approach with such family members. Nurses tried to support and engage with family members and found it challenging when family members were distrustful. Two nurses described walking on tip toes around the family member with whom she felt conditional trust. Badger (2006) noted similar issues that nurses became frustrated when they were unable to develop close relationships with family members. In this study, the nurses generated compassion towards the family members in situations where aggressive treatments were requested as a means of coping and reframe the patient's situation. This mode of thinking helped the nurse contemplate the complexity of patient-family relationships in situations where full curative care progressed due to the inability of the surviving family members to accept that the patient was dying.

Nurses' Actions

The current study examined the actions of the nurse and found various factors impacted the nurses' role in GOC DM. Nurses described situations where they felt that it was the physician's role to talk to family members about GOC DM. These included situations where the patient was declining rapidly, and the nurses were busy with tasks and thus unable to talk to family members due to time constraints. Most of the nurses preferred that physicians tell the family members that the prognosis was poor, which was consistent with findings in the literature (Calvin et al., 2009; Gutierrez, 2012c; Slatore et al., 2012). In this study, the nurses felt that the physicians took a proactive approach in talking to patient family members about goals of treatment. Calvin et al. (2009) found nurses had to be careful about what they told family members out of fear of upsetting the physicians thus suggesting that in other institutional settings and perhaps different types of units, nurses were more constrained in their ability to provide updates to patient family members. In contrast, participants in this study were willing to take action and were still more likely to talk to family members after the physicians to explain and reinforce the patient's status. Badger (2006) described the process of goals of care decision-making as a team effort.

The nurse's ability to have a role in GOC DM was contingent on their relationship with the patient's family. When the nurses in this study felt a connection with family members and sensed that the family was receptive to their updates, nurses described having a greater role in GOC DM. The, nurses described their role as working hard, presenting reality, advocating for the patient, providing support and complementing the medical team. Nurses appreciated when family members listened to them as it provided them an opportunity to contribute meaningfully to goals of care discussions. Nurses were cognizant that family members had to make the decision and thus tried not to unduly influence family members but provided information so an informed decision can be made.

Studies in the literature identified various factors that influenced nurses' willingness and ability to have a role in GOC DM. Calvin et al. (2009) described that nurses had to "walk a fine line" because family members and physicians would get upset if they overstepped this role. Popejoy et al. (2009) noted that over time, nurses developed the skill to know when to have GOC discussions with family members and when not to intervene. Jordan in this study learned with experience that there were times for her to step back and try to understand the situation from the family member's perspective. Kelly talked about presenting reality to her patients. Nurses in several studies helped the family see and understand the patient's condition, which Gutierrez (2012) called painting the picture and Robichaux and Clark (2006) called presenting a realistic picture. Nurses in this study felt that they complemented the medical team, which Calvin et al. (2007), Gutierrez (2012) and Liaschenko et al (2009) described as being in the middle of the decision-making process. In this role, nurses worked as intermediaries between the family members and physicians and filled in information gaps in both directions. Popejoy, Brandt, Beck, & Antal (2009) called this acting as mediators and Jezuit (2000) as coordinators and Slatore et al. (2012) as intermediaries. In the current study, nurses supported the family, provided advice when solicited, and provided information, consistent with previous studies (Jezuit, 2000; McAndrew & Leske, 2015; Peden-McAlpine et al., 2015; Perrin, 2001; Popejoy et al., 2009).

When family members were firm in their decision to continue curative care and in a situation where there is conflict, nurses in this study reported having less of a role in decision-making. This was true in other studies as well. Several studies conveyed that these factors impeded the nurse's ability to intervene and made care difficult (Badger, 2005; Calvin et al., 2009; Espinosa et al., 2010; Jezuit, 2000; King & Thomas, 2013; Robichaux & Clark, 2006). Several nurses in this study provided examples in which they would present reality to convey the seriousness of the patient's condition to family members. Providing realistic updates was discussed in the literature and could result in conflicts with patient family members (Badger, 2005) or made them angry as they are not prepared to believe it (Calvin et al., 2007).

Nurses in other situations knew that they could not influence the family or change their mind and thus kept quiet. Nurses described how challenging it was to remain emotionally responsive to family members needs when they had to conceal their feelings and remain objective in their interactions. McAndrew and Leske (2015) called this emotional responsiveness, where nurses remained objective and still be able to empathize and be emotionally responsive to the patient condition. One nurse in this study described going into robot nurse mode where she did not try to talk to a family member of a dying patient about GOC DM. McAndrew and Leske (2015) discussed the importance of objectivity in situations where a nurse does not agree with the plan of care. The nurses in this study described the challenges of such situations and limited their exposure to such patient conditions.

Feeling Emotions

The nurses in the current study identified, discussed and explained a wide variety of emotions. Nurses described how helping family members navigate GOC DM and accept death made them feel sad for the patient and family and took a great deal of energy. They identified these emotions as normal, as one nurse in this study stated, “Because death is sad, and we should always be sad, it’s always a loss of life”.

The nurses emotional experience was different when the family was able to make a timely decision for a patient that was not expected to survive. The nurses who were able to assist a family with the decision-making process described having positive emotions as they felt a sense of reward because they were able to help. Also, the nurse-family-patient relationship influenced the emotions the nurse experienced. Having a trusting nurse-family relationship and sense of connection with the family made the nurse more emotionally vulnerable, but also provided the nurse with more opportunities to talk about the patient’s condition. Calvin (2007) provided a quote from a nurse who had helped a family with a decision:

> When you’ve expedited the family’s ability to make a decision, you feel good, because you facilitated some sort of forwardness or closure. As a nurse, you do that. You make a difference in the life of that patient (p. 148)

When family members wished for continuing curative care as their goal of care, nurses in this study were conflicted by their judgement of the situation and the appropriateness of their actions. Most described this as frustrating. Nurses' feelings of frustration was echoed in several other studies on this topic (Badger, 2005; Calvin et al., 2007; Jezuit, 2000; Popejoy et al., 2009; Robichaux & Clark, 2006). In this study, nurses found it draining to talk to patient family members about life and death decisions. Some of the nurses expressed anger when delays in decision-making contributed to patient suffering. Calvin, Kite-Powell and Hickey (2007) talked to 12 nurses and found that they too described feelings of frustration, confusion, helplessness and feeling emotionally drained during GOC DM.

A nurse in this study reported being in a difficult patient situation and felt that she had to retreat into robot nurse mode, do her job, and not discuss GOC DM as she knew she would not be able to conceal her real feelings. This nurse knew that this was a situation that she could not control and took an objective approach, as described by McAndrew and Leske (2015). Figure 1 illustrates the many factors that influence the emotions that the nurses experience which in turn affects their level of engagement and energy moving forward. Robichaux and Clark (2006) found that a nurse's exposure to prolonged suffering can cause them to withdraw or become detached in future interactions.

Nurses in this study generated feelings of compassion towards family members and worked to understand the family's relationships and motivations. This helped the nurses reframe their stories and empathize with the patient's family. Stepping back and viewing the situation with compassion helped the nurses find balance in their appraisal of the patient situation and their actions and interactions with the patient's family. It provided the nurses with opportunities to become involved differently and to establish a rapport with the family. An understanding of how the four themes interacted with the characteristics of the nurse placed emphasis on the importance of balance when participating in goals of care interactions. McAndrew and Leske (2015) emphasized the importance of remaining balanced by remaining emotionally responsive, to follow one's professional role and responsibilities in decision making, and for nurses and physicians to collaborate and communicate about GOC with intention. They found that a consequence of imbalance of any of these factors resulted in moral distress (McAndrew & Leske, 2015).

This study emphasizes the importance for nurses to be mindful when caring for patients in need of GOC DM. The questions under each theme in Figure 1 provides insight into this phenomenon and a greater understanding of what nurses' experience in various situations. This understanding will allow critical care nurses to reflect on their own experiences, to reframe situations they find challenging, and to recognize the source of their emotions.

Limitations

This study asked nurses to volunteer to share their experiences of what it was like to take care of critically ill patients who they did not expect to survive. Nurses discussed situations that were memorable to them and those that evoked various strong emotions. This method limited stories to those that the nurses perceived to be important and did not cover many interactions within this phenomenon that were considered routine practice. Sampling was one of convenience, which allowed participants to self-select and most likely attracted nurses who were interested in this phenomenon or had an experience that they wished to share. Nurses who were not willing to discuss their experiences and views on this topic did not volunteer to participate. Thus, their voices, which may have added a different perspective, were not captured. In volunteering for this study, nurses may have put additional thought into their stories and had time to reflect on them prior to sharing. The qualitative nature of this study increases our understating of what nurses' encounter in their everyday practice, but the results are not generalizable to all critical care nurses as that is not the goal of qualitative research. However, the stories shared by the participants offers a lived-through perspective that can increase one's understanding of this phenomenon.

Nurses who were interviewed felt that the ICU physicians were engaged and proactive in their conversations with family members about patient prognosis and potential outcomes. The experiences that the nurses shared for this study occurred at large academic medical centers located on the east coast of the United States and this may have contributed to the physician's proactive approach in GOC DM and thus impacted the experience of the nurse with this patient population. These academic institutions maintained an open visitation policy where family members could be at the bedside 24 hours per day. This impacts the nurses experience due to the prolonged exposure to the patient's family and can differ in institutions that maintain limited visitation.

Biases of the Researcher

This researcher has not had a personal experience of a close family member dying in the ICU but has years of professional experience caring for patients in such situations. The researcher, as an instrument of the research, was part of the life world and it is therefore important to provide some information about her positionings and experience with this phenomenon. With 25 years of experience in a medicine intensive care unit as a registered nurse, this researcher had witnessed many advances in the treatment of critically ill patients. She observed physicians becoming more proactive in addressing goals of care decisions while families and patients continued to struggle with life and death decisions. Over the years, the researcher enjoyed opportunities that allowed her to care for a wide variety of critically ill patients. Patient situations in which GOC DM was prolonged were found to be most challenging. Thus, the researcher embarked on a mission to understand the complexity of goals of care decisions and helping family members cope with the subsequent loss. To put her tenure in the ICU into perspective, it became important for this researcher to understand the complexity of the human experience surrounding death and goals of care decision-making. The researcher's familiarity with critical care nursing and desire to understand the GOC DM process potentially provided insider knowledge of the topic. The researcher attempted to reduce this bias by embracing a sense of curiosity and wonder into how other nurses experience situations involving goals of care decision-making as a primary mode of bracketing. This approach was incorporated into both the interviews and maintained throughout the analysis. The researcher collected stories from nurses who experienced this phenomenon and dwelled on the participants transcripts and reviewed them many times to understand what the nurses were describing and the nurses' experiences within this phenomenon. The researcher kept a journal detailing this analysis as well as a reflective journal that detailed the researcher's thoughts as she sought to understand the meaning of this phenomenon.

Another potential source of bias was that the literature was reviewed prior to conducting this research. The information allowed the researcher to step outside her own perspective and to understand the societal and cultural influences on decision-making as well as the perspectives of patients, family members, and physicians. The researcher continued to work in the ICU during the interview process and analysis period, which perhaps helped as she was able to recall the participants words as she encountered similar situations, but the challenge was to remain focused on the participant experiences. The dissertation committee assisted in identifying, clarifying and removing some of that bias in the analysis and interpretation of the data.

Reflection by the Researcher

Twelve nurses provided detailed accounts of their experiences as they cared for patients in need of GOC DM. The nurses thoughtfully shared stories to ensure that every aspect of this phenomenon was exposed. One of the challenges that I faced during the interviews was that I really wanted to hear about their actions, what they did to facilitate goals of care decision-making in the stories and situations that they described. I noted feeling disappointed as the nurses did not describe themselves as having much of a role. After reading and re-reading the interviews and labeling various portions of the nurses' experience, it became clear that the nurses' lived experience was not dictated by their actions, but by what they encountered. There were many factors that affected the nurses experience and actions and categorizing them into four thematic did not appear to adequately describe them. I followed the advice of a committee member and mapped out the variables into a drawing. This drawing (Figure 1) allowed me to capture the elements that I saw in the analysis and to illustrate the variation that I was seeing within this phenomenon. Figure 1 successfully captures the variability shared by the nurses and is consistent with the experiences that I have encountered while practicing at the bedside within a medical intensive care unit.

I found the insight that these nurses had into this phenomenon to be inspiring. These nurses provided a piece of themselves into the interviews and provided insight, solutions, and alternate viewpoints within challenging situations. I heard their voices in my head as I cared for my patients in situations like those that they described, and this helped me to reflect on situations with fresh eyes. Thinking phenomenologically during the conduct of this study has changed the way I view this phenomenon and it has softened my desire to insist family members make rapid GOC decisions. Also, immersion in this study reminded me of the importance of the nurse-family relationship and to be considerate of the lived experiences of others.

Significance to Research and Nursing

This study adds to the many studies available on the end-of-life and goals of care decision-making topic involving ICU nurses. Much of the literature focuses on the nurse's role and the emotional consequences from difficult situations. The voices of the nurses within this study taught us various ways of experiencing and finding meaning of this experience. The significance of this study to nursing practice and research addresses the complexity of this phenomenon and the understanding that these nurses have added to what is known.

The most significant contributions of this study are the lessons that the nurses incorporated into their stories. The nurses demonstrated a “lived-through” perspective of caring for patients in challenging situations. They portrayed a growth-mindset by describing what they learned and how they now practice differently as a result of that experience. The nurses shared examples in which they reframed the experience as they were living it to generate compassion, understanding, and curiosity. This study also illustrated how important trust and connection is between family members and nurses in these situations. It appears that the nurses entire experience within this phenomenon hinges on the amount of trust and connection that they feel with family members. Situations where they felt conflict can cause them to cluster their care to decrease their interactions with the family or patient situation and to change their patient assignment.

As a result of this inquiry, the research composed a preliminary drawing of the nurses’ interactions within this phenomenon (Figure 1). This figure reflects the overarching theme found in this study that every situation is different by illustrating the dynamics within this phenomenon. It is hoped that this drawing can help nurses reflect on their experience and to generate a deeper understanding of why situations and experiences vary greatly. It is important to note that not all experiences that the nurses shared can generate meaning in and of themselves, but to realize that when patient situations lead to profound negative emotions, professional and trained interventions are necessary.

Recommendations for Practice

Nurses' participation in goals of care decision-making is important to patients, their families and the healthcare team because of their ability to advocate for patients, to update and educate family members and to act as a go-between with family members and the health care team. With the continued emphasis on patient-family centered care within the United States, it is important that nurses have an increased role in goals of care decision-making. This study emphasized the importance that healthcare providers be engaged and work together as a team to facilitate GOC DM for the patients.

Advanced directives and the Patient Self Determination Act provides the opportunity for patients and families to make care decisions ("H.R.4449 - 101st Congress (1989-1990): Patient Self Determination Act of 1990 | Congress.gov | Library of Congress," n.d.). This law allows patients and their family members to make their own health care decisions and be informed of the risks and benefits of each procedure and provide informed consent. A shortcoming of advanced directives is that patients can choose the full treatment option and be subjected to painful treatments beyond the point of recovery. Programs to educate the general population about the need for and limits of advance directives should be led by nurses, bioethicists, and professional organizations with community groups.

The nurse can provide family members with the information and support to allow them to make informed decisions. Nurses can also facilitate relationships with family members to foster trust and connection with the health care team. The reality of the ICU is that, regardless of the technological advances, there will always be patients that cannot be saved. It is important to recognize patient care situations where there are concerns about the patient's outcome and family members wish for extraordinary measures. It is best to recognize these difficult situations early and work to reduce conflict and to preserve family trust. Healthcare providers should initiate efforts to develop and implement solutions to protect those involved in patient care situations where treatment is ongoing and patient suffering is evident.

Recommendations for Education

Nursing education programs must provide ethical principles and guidelines and provide student opportunities to solve practice dilemmas such as GOC DM. Role playing and simulation can be used effectively to allow practice and contemplation for actions and feelings surrounding death and dying. Educational programs designed for novice critical care nurses can also provide ICU-specific training opportunities using case study and more advanced role-playing exercises to practice and reflect on morally challenging practice situations. Inviting experienced nurses to share their stories can provide new nurses with the opportunity to reflect on the meaning of the human experience within real-life situations.

GOC DM requires a team approach. Interdisciplinary practice situations can be used to simulate the multilayered discussions and perspectives of physicians, nurses, pharmacist, social workers and others involved in GOC DM. Through this type of engagement, nurses can become more aware of the emotions, relationship building and difficulties in caring for patients not expected to survive. Helping nurses understand the moral complexities in patient cases requiring GOC DM can provide them with insight into the situation and understanding of the variables that are within their control. Educational programs and seminars reviewing and applying palliative care techniques and principles when caring for dying ICU patients can improve pain management and help health providers understand the concept of a good death. Continuing educational programs should focus on preventing nurse burnout and alleviating moral distress. Ongoing educational opportunities for practicing nurses on mindfulness, self-care, conflict management, communication and various end of life topics can help nurses understand the complexities that they encounter and provide them with insight into the situations, their emotions, and their nursing potential.

For patients and surrogate decision-makers, additional guidance and education is recommended on what qualifies as unrecoverable conditions or situations. For health care professionals, how to communicate those difficult conditions and who is responsible for the timing and content of those GOC DM discussions is necessary. Education should be provided on the ethical responsibilities of GOC DM and the role of the palliative care team and ethical consult team within each institution.

Recommendations for Policy

The ethical principle of patient autonomy guides the current law surrounding GOC DM in this state. When making health care decisions, it is important to consider the other ethical principles, such as doing no harm, benefiting others, and being just. This study provided three patient scenarios in which family members requested all treatments possible for patients for weeks to months causing healthcare providers significant moral distress. Hospitals should develop policies and procedures to follow in such situations to guide practice and to mitigate moral distress in health care providers. The occurrence of such situations should be closely evaluated and perhaps considered for possible change in health care policy or law to consider more compassionate decision-making for patients in such situations.

The nurses described an open-visitation policy which allowed family members to spend unlimited amounts of time at the patient's bedside. This policy appeared to work well in many of the stories that the nurses shared. The nurses described a few situations where nurses limited their time in the patient's room due to tensions with a family member. Having a visitation protocol in place that outlines appropriate family behaviors and an algorithm for resolving conflict between healthcare providers and family members is helpful when working with challenging patient situations.

Recommendations for Research

Future studies should include perspectives of other professionals involved in GOC DM processes using qualitative methodology. Research instruments for quantitative research should be developed that account for the wide spectrum of patient situations in need of GOC DM. This study gained valuable feedback as to the current state of nursing practice within an academic medical center. Additional studies should be conducted in less intense hospitals, as the technology and understanding of life and death may be different among nurses, physicians, patients and families. Also, conducting studies with various experience groups of nurses may provide an understanding of practice trajectories in dealing with GOC DM. Another research recommendation is to develop and test interventions to provide nurses with additional skills and strategies in dealing with GOC DM for patients who are not expected to survive. Studying the impact of peer support groups and institutional educational initiatives for nurses help to justify and improve such initiatives and programs. Implementing an evidenced-based policy to guide health care providers during GOC DM that provides guidance during both routine and challenging patient situations is recommended. Unique situations of GOC DM can be examined using a case study research approach. Nurses' experiences with chronically critically ill patients can also be examined using qualitative methodology. The final research recommendation is to focus nursing research efforts on the experiences and perceptions of patient and family members in various stages of goals of care decision-making to guide and inform nursing practice.

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APPENDIX A

INTERVIEW GUIDE

Begin Audio recording

Introduction to study: Thank you for participating in this study. I will be asking you about experiences you have had as a nurse regarding goals of care decision-making. I want to remind you before we start that there is not a correct way to respond, the stories of your experiences are your own and I am interested in your own meaning and your own personal experience. Please tell me all the details and describe them as though I am a lay person. I want to hear about your experiences fully. Remember, your participation is completely voluntary, and you can refuse to answer any question and stop the interview at any time. All identifying information will be removed from your answers when the audio is transcribed, including names, units, dates, and site information. Try not to state specific patient names but use Patient A or he/she when referring to any patient situations. Similarly, use Dr. Y or Nurse Y and not specific identification. I will remind you throughout the interview. If you accidently disclose a person's name, do not worry, I will delete it from this audio recording when I review it. Do you have any questions before I begin this interview?

Main question: Think of a time you took care of a critically ill patient(s) that was full code with continuing aggressive measures and not expected to recover and was in need of goals of care decision-making. Please share your story, your experience and what you encountered during the decision-making process for this patient.

Prompts:

- When exactly did this happen?
- What were you doing?
- What did you do/what was your role?
- What did you say?
- Who said that?
- And what did you say then?
- What happened next, how did it feel?
- How did you feel?
- What did you think?
- What happened?
- Who was involved?
- What was helpful?
- What else do you remember about the event?
- You are giving me a lot of good information, tell me what that experience was like for you.

- Can you tell me more about what it was like for you?
- Please go on, what are you thinking?
- Is there anything else you might like to add?

End statement:
Thank you very much for your time and for sharing your experiences with me!!