DELIVERING CULTURALLY SENSITIVE END-OF-LIFE CARE IN THE ICU

THE PERCEPTIONS OF ICU NURSES IN DELIVERING CULTURALLY SENSITIVE CARE AT THE END-OF-LIFE IN THE ADULT INTENSIVE CARE UNIT:

AN INTERPRETIVE DESCRIPTION STUDY

by

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LAY ABSTRACT

Patients in the Intensive Care Unit frequently die and the circumstances surrounding these deaths affects both family members' and nurses' wellbeing. Culture is an important influence on an individual's needs during the end-of-life period and on their views about a 'good death'. As such, when caring for dying patients, healthcare professionals need to be sensitive to the culture of each patient and family. In the Intensive Care Unit, nurses play an important role in making sure end-of-life care is culturally sensitive. The goal of this study was to learn more about nurses' perceptions and experiences of providing culturally sensitive end-of-life care within adult Intensive Care Units. This study found that nurses working in Intensive Care Units feel culturally sensitive end-of-life care mainly involves being truly person-centered and this requires staying open-minded and building strong relationships with patients and their families. Nurses in this study also indicated that they face many obstacles when trying to be culturally sensitivity during end-of-life care and some of these were created by their practice environment. This research shows that if nurses are to deliver culturally sensitive end-of-life care within critical care settings they need significant support in various forms, which likely includes a change in the unit culture.

ABSTRACT

Background: Death is a common occurrence in the Intensive Care Unit (ICU), and the circumstances surrounding a patient's death can have a lasting influence on the wellbeing of families and nursing staff alike. Culture is an important influence on an individual's perspective of end-of-life (EOL) care and a 'good death', and, as such, cultural sensitivity is an essential element of high quality EOL care in the ICU. Nurses are well situated to facilitate culturally sensitive EOL care within the ICU; however, there is a significant paucity of knowledge regarding ICU nurses' perceptions of a culturally sensitive EOL nursing practice and their experiences delivering this within an adult ICU.

Aims: The purpose of this study was to explore ICU nurses' perceptions of delivering culturally sensitive care within their current EOL practice, and thus better understand how culturally sensitive EOL care can be supported within adult ICUs.

Design and Methods: An Interpretive Description methodology was utilized to explore the perceptions of seven (n=7) Canadian ICU nurses regarding culturally sensitive EOL care. Maximum variation and theoretical sampling were used to recruit registered nurses from ICUs in two hospitals in Southern Ontario, Canada. Data were generated using semi-structured interviews and field notes and was concurrently analyzed using a constant comparative and reflexive approach. Study rigour was supported through the use of reflexive journaling/memoing, data triangulation, and peer debriefing.

Results: Analysis of the data led to the construction of three themes which described nurses' perceptions of providing EOL care within the ICU: 1) culturally sensitive EOL care is truly person-centered care, 2) dissonance between culturally sensitive EOL care and the biomedical model of care in the ICU, and 3) needing support to adopt a more relational approach to care in the ICU.

Conclusion and Implications: Study findings highlight that ICU nurses perceive that culturally sensitive EOL care primarily involves building a strong therapeutic relationship and being truly person-centered when delivering care. However, the context surrounding nursing practice in the ICU creates many barriers to adopting this relational approach to care; thus, multifaceted support is needed for culturally sensitive EOL nursing practice to be bolstered and sustained.

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LIST OF ABREVIATIONS

EOL = End-of-life

ICU = Intensive Care Unit

RN = Registered Nurse

DECLARATION OF ACADEMIC ACHIEVEMENT

This master's thesis is a report of original research that I conducted under the supervision of Drs. Sharon Kaasalainen, Patricia Strachan, and Olive Wahoush. I developed the study protocol with feedback from my committee members and completed the research ethics board submission with the assistance of Dr. Sharon Kaasalainen. I conducted all interviews and led data analysis and writing of the thesis with the assistance of my supervisory committee.

CHAPTER 1: INTRODUCTION

End-of-Life Care in the ICU

Despite significant advances in intensive care medicine, death is still a common occurrence within an ICU. In Canada, approximately 9% of all patients admitted to an ICU die, and this number jumps dramatically to roughly 19% for those who require mechanical ventilation, an increasingly frequent care process that is required by roughly 33% of ICU patients (Canadian Institute for Health Information [CIHI], 2016). In 2017, over half of all deaths (60%) occurred in a hospital setting, and of these, roughly 29% were in a specialized care unit such as an ICU or CCU (Statistics Canada, 2019; Wilson et al., 2018). While there is little Canadian data on the context of these deaths, according to European data, the majority of deaths within an ICU occur after the withdrawal or withholding of life-sustaining treatments (see Appendix A for definitions) (Orban et al., 2017). Death in the ICU is not always preceded by a de-escalation in treatment and literature suggests that these circumstances can be wrought with greater challenges during the delivery of care (Gelinas et al., 2012; Coombs et al., 2012; Orban et al., 2017).

With an aging population and the rate of ICU use increasing faster than the overall rate of acute hospitalization, it can be expected that death in Canadian ICUs will remain a frequent occurrence and possibly increase in frequency (CIHI, 2016). The care provided during the EOL period impacts the quality-of- life of patients, families, and clinicians. As such, the ability to provide quality end-of-life (EOL) care is important to the everyday practice of ICU clinicians. Understanding how to better provide this care

can help identify strategies to improve the delivery of care within an ICU, and, therefore, should be a priority.

Defining EOL in the ICU

Despite a general a lack of consensus regarding the definition of "End-of-Life", literature suggests it consists of three elements: 1) the presence of incurable illness, 2) acknowledgement that the patient will not recover, and 3) imminent death (Hui et al., 2015; CIHI, 2011; Canadian Association of Critical Care Nurses [CACCN], 2017). Within the critical care literature, EOL care is often linked to the withdrawal or withholding of life-sustaining treatments (Connolly et al., 2016; Gallagher et al., 2014; Sprung et al., 2014), indicating death is imminent. Considering this knowledge, this study defines the EOL period as the time after it is acknowledged that a patient will not recover from their illness, either because there has been a decision to withdraw life-sustaining treatment and/or death is perceived as inevitable, and death is imminent. EOL care is thus defined as the care delivered during the EOL period.

In the context of the ICU, the transition to EOL care can be murky due to logistical issues and high levels of uncertainty (Coombs et al., 2012); however, it usually centers around decisions by healthcare providers, patients and families members regarding what treatments will or will not be used (Aslakson et al., 2012; Coombs et al., 2012). Among the various parties involved in EOL decisions (i.e., patient, family, and the different health care providers involved in care), there is not always agreement on when a patient is or should be entering the EOL period and evidence suggests this can impact

care and be a source of conflict and distress (Aslakson et al., 2012; Coombs et al., 2012; Gallagher et al., 2015; Gelinas et al., 2012).

EOL Care within a Palliative Approach to Care

The Canadian Nurses Association (CNA) (2017) states that when caring for dying patients, nurses have an ethical (and enforceable) responsibility to:

> foster comfort, alleviate suffering, advocate for adequate relief of discomfort and pain, and assist people in meeting their goals of culturally and spiritually appropriate care. This includes providing a palliative approach to care for the people they interact with across the lifespan and the continuum of care, support for the family during and following the death, and care of the person's body after death. (p. 13)

Good EOL care is facilitated through incorporation of a palliative approach to care early in the trajectory of an illness, not just during the EOL period (Canadian Hospice Palliative Care Association [CHPCA], 2015; Touzel & Shadd, 2018; National Consensus Project for Quality Palliative Care [NCPQPC], 2018). According to the CNA (2015), CHPCA (2015), and Sawatzky et al. (2016), a palliative approach to care is a way of caring for patients with life-limiting illnesses that integrates the principles of palliative care into care at all stages of an illness and across sectors and disciplines, not just through specialized palliative services or in "palliative" or hospice settings. Drawing upon Sawatzky et al. (2016) and Stajduhar (2011), the CNA (2015) specifically states that a palliative approach "'does not link the provision of care too closely with prognosis'; rather, it focuses (more broadly) on 'conversations with [people] about their needs and

wishes.'" (p. 2). This care provides holistic and individualized care that minimizes suffering and meets the unique physical, emotional, psychological and spiritual needs of the patient and family from diagnosis of a life-limiting disease through bereavement (World Heath Organization [WHO], 2019). To do this, clinicians work to anticipate, prevent, and treat suffering; facilitates autonomy, access to information, and shared decision-making (NCPQPC, 2018); and ensure that care is truly patient- and family-centered (World Health Organization [WHO], 2019). Concepts central to this approach include dignity, hope, comfort, quality-of-life, knowing the patient, teamwork, suffering, care, and caring (CNA, 2015; Stajduhar, 2011).

When embedded within a palliative approach to care, quality EOL care in the ICU context stresses: 1) timely, effective, and empathetic communications by clinicians; 2) multifaceted support of patients and families, which includes facilitating spiritual support and help with practical matters; 3) effective and responsive symptom assessment and management; 4) facilitation of the patient's and family's desired level of participation in shared decision-making; and 5) emotional and psychological support for ICU clinicians (Baker et al., 2015; CHPCA, 2015; Hinkle et al., 2015; Nelson et al., 2010; NCPQPC, 2018; Registered Nurses Association of Ontario [RNAO], 2011; WHO, 2019). These characteristics align with the 13 quality standards for palliative care set out by Health Quality Ontario [HQO] (2018) which apply to all settings (home, community, hospital, long-term care, and hospice care) and direct assessment of needs, planning and delivery of care, and family, clinician, and system level supports for high-quality care (HQO,

2018). Aligning ICU care with a palliative approach and delivering high quality EOL care promotes a dignified death (CNA, 2017).

Culture and EOL Care in the ICU

Quality EOL care is influenced by many factors, one of which is culture (Fowler, & Hammer, 2013). Culture is the shared values, beliefs, and practices of a particular group which leads to a unique way of perceiving and evaluating the external environment and guides thinking, decisions, and actions in a patterned way (Giger, 2017; Srivastava, 2007). As international mobility increases and countries, including Canada, become progressively more diverse, ICU clinicians will be providing EOL care to an increasingly culturally diverse population. It is estimated that by 2036 up to 50% of the Canadian population will have been born outside Canada or have at least one parent born outside Canada; 26% to 31% will have a mother tongue other than French or English; 31% to 36% will identify as a visible minority[1]; and 6% will identify as Indigenous[2] (Statistics Canada, 2017; Statistics Canada, 2015a). Indigenous peoples, in particular, are a rapidly growing and culturally diverse group within Canada. Between 2006 and 2016, Canada's Indigenous populations grew by 43% and is expected to exceed 2.6 million persons by

[1] In Canada, "visible minority" refers to "persons, other than Aboriginal peoples, who are non-Caucasian in race or non-white in colour" and is as defined in the Employment Equity Act (Statistics Canada, 2015b)

[2] Indigenous peoples include First Nations, Métis, and Inuit. regardless of registration status (Statistics Canada, 2015a).

2036 (Statistics Canada, 2015a). While cultural diversity extends beyond ethnicity, these statistics emphasize the need for ICU clinicians to possess the knowledge, skills, and supports to both understand each patient's and family's culture-based EOL values, beliefs, and practices, and to deliver care that is respectful and responsive to these needs. It is imperative that EOL care be sensitive to the cultural needs of patients and families given the well documented variations and inequities associated with cultural differences, particularly for those from minority and/or vulnerable groups (Brooks et al., 2018; Cain et al., 2018; Muni et al., 2011). Embracing cultural differences during EOL care is vital as assisting patients and families through the dying process can accentuate cultural differences between patients/families and their healthcare providers who have been acculturated into the culture of modern healthcare (Krakauer et al., 2002)

It is important to note that in addition to ethnicity, cultural groups can be defined by a broad array of other social characteristics, including socio-economic status, age, occupation/profession, illness/ability, and/or sexual orientation, to name a few (Andrews & Boyle, 2016; De Beer & Chipps, 2014; HQO, 2018; NCPQPC, 2018; Ray, 2010). Individuals often belong to multiple groups and, while a person's culture may be characterized by the values, beliefs, and practices they share with these larger groups, their unique interpretation and expression of their culture is dynamic and shaped by personal experiences and interaction throughout their lifespan (Cain et al., 2018; Srivastava, 2007). It is thus vital that EOL care moves away from stereotyping and essentialism (Bosma et al., 2010) and assess and address each patient and family individually.

Culturally Sensitive Nursing Care at EOL

Culturally sensitive nursing care is important at the EOL in ICUs because of the pervasive, and sometimes subtle influence culture has on the diverse and nuanced EOL attitudes, values, beliefs, practices, and preferences which patients and families hold (Cain et al., 2018; Fang et al., 2016). Recognizing, respecting, and attempting to accommodate these variations is integral to providing high quality EOL nursing care, however, evidence suggests that families are not always cognizant of how to communicate their cultural EOL needs to clinicians (Brooks et al., 2018) and sometimes struggle to preserve their cultural belonging during an ICU stay (Høye & Severinsson, 2010a). Thus, culturally sensitive nursing care requires nurses to actively and consciously use their specific cultural knowledge and skills to understand a patient's/family's EOL needs, the nuances of their unique cultural expression, and ultimately advocate for and deliver care that is respectful of these needs.

The foundation of culturally sensitive care is the concept of cultural sensitivity, which is a term commonly used within the healthcare literature, but one often used ambiguously or within discussion of other culturally relevant concepts, such as cultural competence and cultural safety (Foronda, 2008). In an effort to return some of the term's meaning and clarity, Foronda (2008) conducted a concept analysis of "Cultural Sensitivity" within the healthcare literature and described it as both an internal and external process and as having five attributes: 1) knowledge, 2) consideration, 3) understanding, 4) respect, and 5) tailoring. This description by Foronda (2008) characterizes culturally sensitive care as care where a practitioner both: 1) seeks

awareness of their own cultural biases and assumptions in order to non-judgementally recognize and understand what is culturally important to the patient, and 2) reflects the unique cultural identity of the patient in the care they provide through assessment and implementation of care that is congruent with the patient's unique cultural needs and avoids stereotyping. This conceptualization is consistent with descriptions of cultural sensitivity by the NCQHP (2018), the World Federation of Critical Care Nurses (2016), and the RNAO (2007), which also suggests that cultural sensitivity emphasizes self-awareness and insight. Srivastava (2007) describes cultural sensitivity as the practitioner moving beyond cultural awareness to utilizing practical knowledge and skill gained from experience to provide quality care that is congruent with a patient's culture; in essence, going from "knowing what" to "knowing how". Based upon these sources this study defines culturally sensitive care as professional care that demonstrates due appreciation and respect for a patient's cultural context which arises from a practitioner's insight, experience, knowledge and awareness of self and other. The NCQHP (2018) suggests that to achieve culturally sensitive EOL care, first steps should involve assessing and respecting patients' and families' specific values, beliefs and traditions regarding health, illness, family caregiver roles, and decision-making, but that culturally sensitive resources and strategies are also needed for achieving culturally sensitive care.

This study has chosen to use the term culturally sensitive care because it appears to focus more strongly on a provider's self-awareness and on how they demonstrate and integrate knowledge, insight, and respect into individual care. For this reason, the term is appropriate both for studying clinician perceptions of culturally sensitive EOL care, and

for studying EOL care within the context of an ICU, where it is often difficult, or impossible, for patients to participate in decision making and/or express their wishes.

ICU Nurses' Roles in Culturally Sensitive Care at EOL

Nurses are well situated to facilitate culturally sensitive EOL care in ICUs as they are a continuous bedside presence during this time and frequently act as the chief point of contact between patients/families and the ICU care team (Gallagher et al., 2015). Additionally, ICU nurses enact advocacy and supportive roles and are often responsible for operationalizing decisions regarding EOL care (Arbour & Wigand, 2013; Gallagher et al., 2015). Because of these roles, ICU nurses are in a position to encourage, support, and deliver culturally sensitive EOL care. This is particularly important given that research suggests that high quality nursing care during this time improves bereaved family members' satisfaction with care in the ICU (DeSanto-Madeya & Safizadeh, 2017; Noome et al., 2015), and, in turn, may improve their long-term wellness and mental health (Davidson et al., 2012).

Cultural sensitivity is an element of high quality EOL nursing care in ICUs as, in the words of Madeline Leininger, "care and culture are inextricably linked and [can] not be separated in nursing care actions and decisions" (Leininger, 1988, p. 153). Many nursing theorists have addressed the concepts of culture, nursing, and environment and/or the role of a patient's culture in nursing care (Im & Lee, 2018; Shen, 2015). This has led to a plethora of terms describing care that is culturally respectful, responsive, and/or appropriate; in this study the term culturally sensitive care is used.

The Role of Relational Care in ICU Nurses Delivery of Culturally Sensitive Care at EOL

Nurses' roles in delivering culturally sensitive EOL care are grounded not just in what activities they complete (ie. what they do), but also the attitudes that inform these actions (ie. how they do it) and the broader context surrounding care delivery (Noome et al., 2016; Sekse et al., 2018). The premise of relational care is that compassionate and humane care is delivered when the interconnectedness of human beings is recognized and supported in ways that promote empathy, dignity, respect, partnership, person-centeredness, and an authentic healing presence (Hartrick Doane & Varcoe, 2015; Koloroutis & Trout, 2012). There are three essential relationships within relational practice, the nurse's relationship with the patient/family (the therapeutic or healing relationship), the nurse's relationship with self, and the relationships among colleagues (Koloroutis, 2004). It is through these relationships that nurses consciously engage with patients and families in ways which holistically examine and respond to the complex forces which shape individuals' unique needs and care experiences (Hartrick Doane & Varcoe, 2015; Koloroutis & Trout, 2012). In this context, culture becomes contextualized and inseparable within individuals' lived experience (Hartrick Doane & Varcoe, 2015; Zou, 2016), in turn, allowing for a more personalized and compassionate approach to cultural sensitivity during EOL care. Considering this, relational care frameworks, such as Relationship-Based Care or Relational Inquiry, could inform nurses' roles in delivering culturally sensitive EOL care.

Relationship-Based Care is a framework designed to support an authentic caring relationship between nurses and patients/families at all levels of an organization through six dimensions:1) leadership, 2) teamwork, 3) professional nursing practice, 4) patient care delivery, 5) resource driven practice, and 6) outcome measurement (Koloroutis, 2004; Koloroutis & Trout, 2012; Ledesma, 2011). In contrast, Relational Inquiry focuses on how to nurse in accord with the contextual complexities of individual experiences of health, illness, and care (Hartick Doane & Varcoe, 2007, 2015). Relational Inquiry promotes the use of reflexivity and the ontological capacities of compassion, self-compassion, curiosity, commitment, competence, and correspondence to engage during complex nursing situations purposefully and consciously (Hartick Doane & Varcoe, 2015; Younas, 2020; Zou, 2016). Both theories/frameworks are grounded in relational care and focus on becoming attuned to each patient/family, their unique needs and perspectives of care, and the relationships and contexts surrounding their experiences of caring. Attunement happens when a clinician's awareness of the patient and family becomes sufficient to ensure that care is delivered in harmony with what is meaningful to the patient/family, rather than what the clinician assumes is meaningful (Koloroutis & Trout, 2012).

Purpose Statement

The purpose of this study is to explore ICU nurses' perceptions of the delivery of culturally sensitive EOL care within the context of adult ICUs. This study aims to construct knowledge that: 1) provides healthcare professionals with evidence to better inform their individual practice; 2) helps decision-makers (administrators, policy makers,

and educators) better understand the experiences and needs of ICU staff and, thus, help improve policies, resources (such as spiritual care, ethics supports, and guidance documents), training (such as hospital and unit orientation), and education (such as in-hospital, continuing, undergraduate, and graduate levels); and 3) begin to develop the body of knowledge on culturally sensitive EOL care in ICUs.

In Canada, both the CNA (2017) and the College of Nurses of Ontario (CNO) (2019) have mandated that nurses seek to meet the cultural needs of dying patients and their families, however, there appears to be little research evidence on the perceptions of ICU nurses on providing this care. Considering the significant knowledge that can be gained from a nursing perspective on EOL care, it is important to develop a rich and in-depth understanding of their perceptions of culturally sensitive EOL care in adult ICUs. This study aims to begin to fill this knowledge gap and, in doing so, help ICU staff, administrators, educators, and policy makers improve EOL care within ICUs, work towards equity in care, and create a healthcare environment where all patients and families not only feel their values, beliefs, and practices are respected, but are empowered to integrate their individual culture into care.

Reflective Summary

Due to the nature of a qualitative research methodology, it is important for the researcher to explicitly locate their/her/his self within the study's context (Thorne, 2016). In this study, I will work in partnership with participants to construct knowledge from participants' words and experiences through social interactions. As a consequence, the participants and I, reciprocally influence one another and study outcomes (Thorne, 2016).

It is important that I account for the influences of my thoughts and actions and allow others to come to their own conclusions about my subjectivity and my potential influences on this study (Bradbury-Jones, 2007; Thorne, 2016). This reflection will share important and relevant information about the experiences and perspective I bring to the researcher role.

The idea for this research study originated from my work as an ICU nurse. I identify professionally as a critical care nurse and, since graduating from McMaster University in 2010 with a Bachelor of Science in Nursing, I have primarily worked in an adult level three medical surgical ICU in Hamilton, Ontario. One of my responsibilities as an ICU nurse has been to deliver nursing care to dying patients and their families and, in collaboration with the ICU care team, I have delivered EOL care in a variety of situations (including in the context of the withdrawal of life-sustaining treatments and in the context of a continuing escalation in care). These experiences, both the positive and the distressing, have cultivated within me a belief that EOL care is a critical competency for ICU staff, but that it is often inconsistently understood and executed. I have seen how excellent EOL care supports families during this consequential time, both as individuals and as a collective, and facilitates a dignified death. I have seen how excellent EOL care can help families say goodbye to their loved one, strengthen their bonds by overcoming differences, and begin healing the wounds left by their loved one's absence. I have also witnessed, and been party to, missed opportunities to provide EOL care that understands and meets the unique and nuanced needs of patients, families, and staff. Collectively,

these experiences have instilled in me a desire to understand how to promote and support quality EOL care in ICUs.

I am particularly interested in how to enhance cultural sensitivity during the delivery of EOL care. The impact of culture on health, illness, and healthcare is something I have been interested in since university and understanding how to deliver culturally sensitive EOL care is a natural extension of this. I have always had a desire to learn about unfamiliar ideas, perspective, and experiences of others. However, as a Caucasian woman whose childhood was spent surrounded by a homogenous community in an affluent area of Vancouver, I had limited exposure to different perspectives and/or cultures. In high school, I transferred out of this area, to a small school whose diverse student body came from across Vancouver. This school relished in its diversity and its students took pride in their egalitarian philosophical outlook. It was at this school that my curiosity about the experiences and perspectives of others was nourished and where my values and beliefs about justice and equity matured; it was at this school that my understanding of the world matured into a belief that every person is different and equitable and has the right to be treated as such.

The idea to focus this study on culturally sensitivity EOL care grew out of my personal experiences and discussions with fellow ICU nurses about their experiences and feelings regarding EOL care. It became apparent to me the subtle and often unrecognized influence that culture has on the EOL values, beliefs, and practices of both patients/families and nurses, and how this affects nurses' perceptions and attitudes towards the care they deliver. I felt that by exploring the nurses' delivery of culturally

sensitive EOL care I can help provide some clarity to the current enigma that is a palliative approach to care in the ICU and improve equity in EOL care.

CHAPTER 2: LITERATURE REVIEW

The purpose of this chapter is to explore the literature on the perceptions of ICU nurses of culturally sensitive EOL nursing care and identify of gaps in this knowledge. This literature review will be organized into four sections. The first section will provide an overview of my search strategy and results and will be followed by sections two, a discussion of issues associated with EOL care in the ICU, and three, a discussion and summary of findings on culturally sensitive EOL nursing care in the ICU. This chapter will conclude with the fourth section, a summary and critique of the body of knowledge on the perceptions of ICU nurses of culturally sensitive EOL nursing care, which, in addition to delineating important knowledge gaps within this body of literature, will outline this study's research questions.

Search Strategy

The databases MEDLINE, EMBASE, psycINFO, CINHAL, and Google Scholar were searched using terms relevant to *Nurses* (population), *ICU* (setting), *End-of-Life care* (phenomenon), and *Cultural Sensitivity* (context) (See Appendix B for search terms and strategy). To ensure relevancy, results were limited to those published in English within the last 10 years. In addition, the Transcultural Nursing Journal, critical care and palliative care nursing websites, medical association websites, and reference lists of relevant articles were hand-searched, along with articles by pertinent authors. Articles were included if they were original research or review articles about nurses or nursing in

an adult ICU. Articles were excluded if they: 1) had no findings relevant to culturally sensitive nursing care in ICUs (ex. compared practices between nurses from different countries, summarizing patient/family preferences in different countries, only discussed language barriers, etc.), 2) had no findings on palliative or EOL care, 3) focused on program, tool, or educational initiative evaluation, 4) studied students, or 5) had no (English) full-text accessible. Review articles which did not provide a search strategy were also excluded due to the inability to determine bias. Given the scarcity of literature on culturally sensitive EOL care in the ICU, all studies which fulfilled selection criteria were included, regardless of quality. Based upon these results, additional articles were found to provide contextual and background knowledge on key themes. See Appendix C for a list of key articles.

Search Results

In total, 319 abstracts were screened, of which 66 were selected for full-text review (See Appendix D for Prisma Flow Chart). After screening, a total of 12 articles met selection criteria (Aslakson et al., 2012; Bratcher, 2010; Borhani et al., 2014; Brooks et al., 2018; Brysiewicz & Bhengu, 2010; Crump et al., 2010; Endacott et al., 2016; Gallagher et al., 2015; Heidari & Norouzadeh, 2014; Mani & Ibrahim, 2017; McLouth-Kanacki & Winslow, 2017; Powazki et al., 2014; Van Keer et al., 2015); and of these, only Brooks et al. (2018) specifically focus on culturally sensitive EOL care. Due to the limited findings relevant to culturally sensitive EOL care, an additional five articles on nursing care for patients from diverse cultural backgrounds in the ICU were included (De Beer & Brysiewicz, 2016; Høye & Severinsson, 2010a; Høye & Severinsson, 2010b;

Listerfelt et al., 2019; Quindemil et al., 2013). All 17 key articles were assessed for quality using either the Critical Appraisal Skills Program checklist for qualitative studies (Critical Appraisal Skills Program, 2018a) or systematic reviews (Critical Appraisal Skills Programme, 2018b), Preferred Reporting Items for Systematic reviews and Meta-Analyses – extension for Scoping Reviews (PRISMA-ScR) Checklist (Tricco et al., 2018), or the AXIS tool for appraisal of cross-sectional studies (Downes et al., 2016)

The 17 articles which form the foundation of this review are primarily qualitative studies (n=14), however, two are literature reviews, two are cross-sectional qualitative survey studies, and one is a mixed methods survey study. Primary research articles (n= 15) are from the USA (5), South Africa (1), Norway (2), Belgium (1), Iran (2), Saudi Arabia (1), Sweden (1), England/Israel (1), and Brazil/England/Germany/Ireland/Palestine (1). No studies were found from Canada. The article specific to culturally sensitive EOL nursing care is a systematic review of culturally sensitive EOL communications in the ICU (Brooks et al., 2018) and synthesizes findings from several other studies included in this review. No primary research studies were found which focused on culturally sensitive EOL nursing care within ICUs that were published in English within the last 10 years.

Issues Associated with EOL in the ICU

Death in the ICU has always been a reality. However, there is increasing recognition that both the technologically complex environment and the traditionally curative focus of this setting are not well-suited to the EOL needs of patients and families (Baker et al., 2015; Gelinas et al., 2012; Stokes et al., 2019). Providers, patients, and

families all face challenges in achieving quality EOL care in this setting and a growing body of literature indicates that these challenges can have both immediate and lasting implications (Gelinas et al., 2012; Gries et al., 2010; Henrich et al., 2016; Mercadante et al., 2018; Pisani et al., 2009; Puntillo et al., 2010; Puntillo et al., 2012). This literature review found four articles describing culture-based barriers to quality EOL care (Aslakson et al., 2012; Brooks et al., 2017; Crump et al., 2010; Mani & Ibrahim, 2017). If we are to understand the literature on culturally sensitive EOL care in the ICU, it is necessary to first understand why quality EOL care is important as well as the broader context of the issues faced when providing culturally sensitive care.

Issues for Patients' and Families

Evidence shows that ICU patients at a high risk of dying may experience distressing and complex symptoms similar to all patients nearing death, such as anxiety, pain, thirst, sleep disturbances, delirium, fatigue, and generalized weakness (Mercadante et al., 2018; Puntillo et al., 2010; Rawal et al., 2017). Quality EOL care for patients requires effective assessment and management of these symptoms which is critical to minimizing suffering and recognizing imminent decline; however, ICU clinicians face barriers in providing this comfort (as discussed below) (Aslakson et al., 2012; Brooks et al., 2017; Crump et al., 2010; Mani & Ibrahim, 2017; RNAO, 2011). Due to the severity of their illness and treatment needs, patients dying in an ICU are often intubated and sedated, and therefore, unable to communicate their own needs and wishes or participate in care decisions (Montgomery et al., 2017; Orban et al., 2017; Pisani et al., 2009; Puntillo et al., 2010). In addition, many of the medications used in the ICU to treat

discomfort at the EOL, such as benzodiazepines and opioids, are associated with higher rates of delirium (Pisani et al., 2009). Clinicians must then rely upon their own experience and knowledge to accurately recognize and interpret symptom and/or rely on family proxies, both of which appear to respectively under- and over-estimate symptom distress (Puntillo et al., 2012). In addition, patients are unable to communicate their desired level of care or refuse treatments, and instead, must again rely on others, this time surrogate decision-makers who themselves are in a state of distress, to intuit their desires and wishes and carry the burden of making these decisions.

For family members of patients who are dying in an ICU, this time is often stressful and traumatic. Their experiences and the quality of care both they and the patient receive have been linked to high rates of psychological, emotional, and physical distress for family members both during ICU admission, and for months to years after their loved one's death (Courtright et al., 2017; Davidson et al., 2012; Imanipour et al., 2019; Mercadante et al., 2018; Rawal et al., 2017). Documented issues include sleep depravation, traumatic and post traumatic stress, complicated grief, and increased rates of anxiety and depression (Courtright et al., 2017; Mercadante et al., 2018; Rawal et al., 2017; Schmidt & Azoulay, 2012). While many of these symptoms and disorders are not limited to family members of deceased patients, having a family member who has died in the ICU is a major risk factor for developing these forms of suffering, as are: 1) poor communication, 2) being a caregiver, 3) having a decision-making role, and 3) discordance between a person's desired decision-making role and their actual decision-making role (Davidson et al., 2012; Gries et al., 2010; Rawal et al., 2017; Schmidt &

Azoulay, 2012). While literature supports that ICU care processes and clinician behaviours during EOL care influence the wellness and mental health of bereaved family members (Courtright et al., 2017; Hinkle et al., 2015), evaluating the effects of palliative care interventions on family-centered outcomes appears to remain difficult and findings are currently inconsistent (Courtright et al., 2017; Curtis et al., 2011; Wessman et al., 2017). This suggests that improving family-centred outcomes is complex and nuanced. However, characteristics of a palliative approach to care appear to be associated with family satisfaction with EOL care (Curtis et al., 2011; DeSanto-Madeya & Safizadeh, 2017; Wessman et al., 2017).

Barriers to Quality EOL Care

Barriers to EOL care was a significant theme within the studies in this literature review (Aslakson et al., 2012; Brooks et al., 2017; Crump et al., 2010; Mani & Ibrahim, 2017). Obstacles to quality EOL care appear to center around poor communication, conflict, inadequate clinician skill or training, and/or environmental factors, such as lack of privacy or time **(**Aslakson et al., 2012; Beckstrand et al., 2018; Brooks et al., 2017; Coombs et al., 2012; Crump et al., 2010; Kryworuchko et al., 2016; Mani & Ibrahim, 2017; Vanderspank-Wright et al., 2011). Difficult family behaviours were also identified by clinicians as barriers to high quality EOL care. These characteristics are influenced by an individual's values, beliefs, norms, and practices, both those of the patient and/or family and the clinician. Because no studies were located that capture patient or family perception of barriers to quality EOL care, this summary of barriers is exclusively from

the perspective of ICU clinician; thus, findings may not represent the complete phenomenon.

Culturally Sensitive EOL Care in the ICU

This literature review found only one article on culturally sensitive EOL care in the ICU, a systematic review by Brooks et al. (2018) on culturally sensitive EOL communications in the ICU. This article, which included literature relevant to both ICU nurses and/or physicians, found only nine studies published between 2007 and 2017 which met their selection criteria; six have been included within this literature review (Aslakson et al., 2012; Borhani et al., 2014; Crump et al., 2010; Gallagher et al., 2015; Powazki et al., 2014; Van Keer et al., 2015) and the remaining three either contain no information about nursing care, or were published before 2009. Using narrative synthesis, Brooks et al. (2018) combined findings and found two major themes emerged: communication barriers (n=8), and cultural and personal influences on culturally sensitive communication (n=8).

The theme of "communication barriers" describes challenges preventing effective communication between clinicians and patients/families. Specific barriers included: 1) nurses' limited scope in culturally sensitive communications, particularly around communication of prognosis and decision-making; 2) dependence of nurse involvement in EOL communications on physicians preferences; 3) system-related challenges, such as staff rotation (which affected the development of rapport between clinicians, patients and families) and inadequate access to resources, such as chaplains or guidance documents; and 4) knowledge deficits regarding culturally sensitive communication practices (Brooks

et al., 2018). Brooks et al. (2018) found nurses identified cultural assessment as part of enacting their role in EOL care. However, this appears to be limited to religion/spirituality. The theme "cultural and personal influences on culturally sensitive communication" describes both the influences of cultural differences on communications between clinicians and patients/families, and the characteristics of patients, families, and clinicians that appear to influence personal EOL communication preferences. Findings within this second theme almost exclusively related to physicians and/or physician-patient/family interactions. Findings about nurses were minimal, and data from nurses were focused primarily on physician-patient/family communications. Ultimately, Brooks et al. (2018) concluded that the findings of their systematic review suggest culturally sensitive communication is used in isolated circumstances during EOL care; however, it is wrought with multiple complexities which clinicians feel ill-prepared to manage. They also concluded that there is a significant paucity of literature on culturally sensitive EOL communication.

The review by Brooks et al. (2018) provides valuable knowledge on culturally sensitive EOL nursing care in the ICU. Culturally sensitive communication is essential for quality EOL care as cultural variations in how and what individuals communicate, both verbally and non-verbally, have been shown within the broader literature on healthcare delivery to lead to misunderstandings and/or misinterpretations when clinicians and patients/families come from different cultures (Degrie et al., 2017; Lorié et al., 2017; Rocque & Leanza, 2015; Suphanchaimat et al., 2015). Effective communication is critical to many facets of EOL care, such as decision making, symptom management,

and family support, which is represented in the breadth of the content covered by Brooks et al. (2018).

Despite synthesizing important knowledge, the review by Brooks et al. (2018) focuses on EOL communications, and thus may not accurately represent the culturally sensitive EOL nursing care in the ICU in its entirety. In addition, Brooks et al. (20018) also suffers from an overall paucity of literature. After a reasonably rigorous search, only nine studies were found that met well-described and appropriate screening criteria and these studies tend to focus more on outlining problems and barriers to care than on solutions to the issues. In addition, critical elements of culturally sensitive EOL care, as defined in this protocol, are absent from Brooks et al. (2018), namely: a) clinician self-awareness, b) ways in which clinicians gain knowledge and understanding of patient/family culture, and c) system or organizational level supports that clinician find helpful or desire during EOL delivery. Studies in Brooks et al. (2018) are almost entirely from the USA and Western European countries, thus skewing findings to a Western European context. No Canadian studies were included.

Seeking expert assistance and/or searching unpublished works or non-English publications may have revealed additional studies, thus increasing the robustness of findings. In particular, unpublished works could have been an important source of additional studies, considering that despite searching a 22-year period starting from 1995, over half the included studies were published within the last five years of the search period (2012 to 2017). The recentness of studies within this review suggests that

culturally sensitive EOL care within a critical care context is an emerging field of research.

Culturally Sensitivity EOL Nursing Care in the ICU

As Canada becomes progressively more diverse, it will become increasingly imperative that EOL care be culturally sensitive. An individual's cultural background influences many aspects of EOL care, from the reporting of symptom, to care expectations and engagement in EOL communications (Brooks et al., 2018; Høye & Severinsson, 2010a; Høye & Severinsson, 2010b; LoPresti et al., 2016; Van Keer et al., 2015; Wong et al., 2018).

Nurses play significant and important roles in the delivery of culturally sensitive EOL care and thus have a valuable perspective on its delivery. Culturally sensitive care is critical to delivering EOL care that is congruent with patients' and families' nuanced culture-based EOL practices, communication patterns, and ideologies about symptoms and EOL relevant concepts such as family, death, and dying (Cottrell & Duggleby, 2016). Clinician self-awareness and cultural assessment skills and knowledge, as well as system-related resources/supports, are important for delivering patient-and family-centred EOL care that is culturally sensitive (Foronda, 2008; NCQHP, 2018) and evidence suggests that without these elements, EOL care can fail to meet the needs of patients and families within the ICU (Brooks et al., 2018; Brysiewicz & Bhengu, 2010; Van Keer et al., 2015). Because clinician self-awareness and cultural assessment skills and knowledge are so vital to delivering culturally sensitive care, understanding ICU nurses' EOL perceptions, values, belief, and practices is important for properly grasping the context surrounding

culturally sensitive EOL nursing care. In the absence of culturally sensitive care, treatment decisions and care at the EOL may not accurately represent a patient's wishes or needs, thus undermining their dignity.

This literature review focuses on ICU nurses' perceptions of culturally sensitive EOL nursing care; however, no articles were located on this specific topic. Instead, this review found one article on culturally sensitive EOL care in the ICU (Brooks et al., 2018) and 11 articles capturing the perceptions of ICU nurses' about EOL care with findings relevant to culturally sensitive EOL nursing care (Aslakson et al., 2012; Borhani et al., 2014; Bratcher, 2010; Crump et al., 2010; Endacott et al., 2016; Gallagher et al. 2015; Heidari & Norouzadeh, 2014; Mani & Ibrahim, 2017; McLouth-Kanacki & Winslow, 2017; Powazki et al., 2014; Van Keer et al., 2015).

ICU Nurses' Perceptions of Their Roles in EOL Care

In general, ICU nurses appear to perceive their roles in EOL care as primarily supportive and as a patient and family advocate (Brooks et al., 2018; Crump et al., 2010; Gallagher et al. 2015; Heidari & Norouzadeh, 2014; McLouth-Kanacki & Winslow, 2017; Powazki et al., 2014). In Canada, ICU nurses have described their specific roles in EOL care as: a) encouraging and supporting family presence at the end-of-life; b) managing symptoms; c) being a patient and family advocate; d) maintaining and creating positive memories of the patient; e) providing necessary information; f) supporting family during the decision-making process; and g) providing encouragement, reassurance, and emotional support (Arbour & Wiegand, 2013; Bach et al., 2009; Stokes et al., 2019; Vanderspank-Wright et al., 2011; Wiegand et al., 2019). In order to be successful in their

roles, nurses have described orienting themselves to the values, beliefs and practices of patients and families regarding death, the process of dying (and associated symptoms), and support systems (Endacott et al., 2016; Gallagher et al., 2015; Heidari & Norouzadeh, 2014; McLouth-Kanacki & Winslow, 2017); all of which are shaped by cultural norms, beliefs, and values. Nurses have also described appealing to cultural and/or religious beliefs and practices in order to help families accept their loved one's death (Gallagher et al., 2015) and identified that attending to the cultural needs of patients and families is important in providing psychosocial support to families (Brysiewicz & Bhengu, 2010). This evidence suggests that ICU nurses are aware that tailoring EOL care to the culture of patients/families is essential for quality EOL care and this influences how nurses perform their roles at EOL.

Despite cultural assessment being essential for tailoring EOL care to a patient's/family's unique values, beliefs, and practices, there is little evidence specifically on how ICU nurses assess or acquire knowledge about a patient's/family's culture. The grounded theory study by Heidari and Norouzadeh (2014), which explores the experiences of Iranian ICU nurses in supporting families of dying patients, describes this knowledge as originating from nurses' perception and sensitivity, but does not elaborate upon this. Within the literature, assessment of culture is generally limited to open dialogue about religious/spiritual needs and supports for EOL care (Brysiewicz & Bhengu, 2010; Canfield et al., 2016; McLouth-Kanacki & Winslow, 2017); however, this may not be consistent with the needs of patients and families from cultures that avoid open discussion about death and dying (Høye & Severinsson, 2010a; Quindemil et al.,

2013). Taking a more comprehensive view of culture appears particularly important as Brooks et al. (2018) found culturally diverse families sometimes lacked awareness of how to communicate their cultural needs to clinicians and were less able to engage with clinicians in EOL communications. In addition, a patient's cultural background can influence their reporting of symptoms such as pain (Hanssen & Pedersen, 2013; Hsieh et al., 2011) and expression of emotions such as grief (Brysiewicz & Bhengu, 2010; Høye & Severinsson, 2010b; Listerfelt et al., 2019).

Important cultural differences have been noted in help-seeking behaviours, EOL communication practices, care expectations, and pain and symptom management (Cottrell & Duggleby, 2016; Degrie et al., 2017; Fang et al., 2016; Høye & Severinsson, 2010a; Krupić et al., 2019; Van Keer et al., 2015). Nurses, thus, require knowledge and awareness of cultural differences in order to provide effective and high quality EOL care. Nurses have described a sense of uncertainty regarding how to meet that family's needs when they feel they lack knowledge and experience with a family's culture and have expressed a desire for further training and education regarding culturally sensitive EOL care (Brooks et al., 2018; Crump et al., 2010; Canfield et al., 2016; Høye & Severinsson, 2010b; Listerfelt et al., 2019; McLouth-Kanacki & Winslow, 2017; Powazki et al., 2014). In addition, nurses' knowledge of cultural elements relevant to EOL care appears to be important given that an inability to recognize and/or accommodate the cultural needs of families can cause conflict between clinicians and families (Brooks et al., 2018; Høye & Severinsson, 2010b; Van Keer et al., 2015).

ICU Nurses' Beliefs about a *Good Death*

Providing a *good death* appears to be viewed by ICU nurses as the goal of quality EOL care. What constitutes a *good death*, however, is subjective and heavily influenced by cultural ideologies and practices and, thus, nurses may not share the same conceptualization of a *good death* as the patients and families they care for (Cottrell & Duggleby, 2016; Fowler, & Hammer, 2013; Hales et al., 2008). While the culture of ICU nurses is not a monolith, the studies within this review suggest ICU nurses hold a more biomedical and individualistic cultural perspective of patient autonomy, decision-making, truth telling, and the meaning of futile treatments, rather than a more relational or relationship-based perspective (Aslakson et al., 2012; Bratcher, 2010; Cottrell & Duggleby, 2016; Høye & Severinsson, 2010b; Listerfelt et al., 2019; Mani & Ibrahim, 2017; Van Keer et al., 2015). This in turn seems to colour their viewpoint on how to achieve a *good death* (Arbour & Wiegand, 2013; Aslakson et al., 2012; Bratcher, 2010; Crump et al., 2010; Endacott et al., 2016; Stokes et al., 2019). Elements of a *good death* found within the literature on ICU nurses' perceptions about EOL care include: 1) suffering is minimized though good symptom management (particularly pain), 2) the environment is calm and soothing, 3) death is accepted by the family, 4) the patient does not die alone (family is at the bedside), and 4) death and dying reflect the patient's wishes (Arbour & Wiegand, 2013; Bratcher, 2010; Endacott et al., 2016; Stokes et al., 2019).

This literature review located three studies, Bratcher (2010), Endacott et al. (2016), and Heidari and Norouzadeh (2014), in which nurses specify meeting the cultural or religious needs of patients/families as part of a *good death*. In the particularly rigorous

qualitative study by Endacott et al. (2016), ICU nurses in both England and Israel identified accommodating individual behaviours as part of providing a *good death* and described providing culturally sensitive care as an important element of this. Similarly, respecting a patient's/family's culture and orienting EOL care to reflect these cultural values was seen as essential for ensuring a dignified death by the 23 Iranian ICU nurses in the grounded theory study by Heidari and Norouzadeh (2014). Despite these two studies, ICU nurses may not always recognize the importance culture plays in the person-and family-centred care that is central to quality EOL care. Bratcher (2010) conducted a qualitative study looking at how nurses in one 12-bed medical/surgical ICU in the USA defined a *good death* and found only three out of 15 American ICU nurses interviewed expressed meeting the religious/spiritual/cultural needs of the patient as important. These nurses did however identify three characteristics, 1) acceptance of death by patient and/or family, 2) patient dies with dignity, and 3) patient's and/or family's wishes are honored, which other studies have linked to cultural needs (Aslakson et al., 2012; Gallagher et al., 2015; Heidari & Norouzadeh, 2014). It is unclear if this lack of awareness is due to the researchers' or participants' view of the phenomena, suggesting that further research is needed to clarify what nurses specifically identify as cultural needs, and whether this conceptualization is more narrow or broad. Further research is needed on nurses' awareness of the influence that culture, both their own and that of patients/families, has on beliefs and values about a *good death* and EOL care.

Nurse-Perceived Culture-Based Barriers to Quality EOL Care

Cultural differences have been identified as challenging during EOL care and cultural differences between ICU staff and patients/families are prominently featured sources of interpersonal and intrapersonal conflict within the studies in this literature review (Aslaskson et al., 2012; Brooks et al., 2018; Høye & Severinsson, 2010b; Listerfelt et al., 2019; Quindemil et al., 2013; and Van Keer et al., 2015). In particular, cultural differences concerning communication patterns and care expectations, both bedside care and treatment expectations, appear as frequent sources of conflict during ICU care (Aslaskson et al., 2012; Brooks et al., 2018; Van Keer et al., 2015). Racial and ethnic differences in the frequency of conflict during EOL care in ICU were noted by Muni et al. (2011), who found that clinician-family conflict was more frequently documented for African-American, Hispanic, and Asian families than for Caucasians, even after adjusting for socioeconomic status. In addition to interpersonal conflict, literature suggests that in situations where the cultural ideologies and norms of a patient/family oppose those of the ICU nurse, nurses struggle to balance their duty to provide culturally sensitive patient- and family-centered care with their own beliefs and values, particularly those regarding informed consent, patient autonomy, and what constitutes “good care” (Brysiewicz & Bhengu, 2010; Endacott et al., 2016; Høye & Severinsson, 2010b; Listerfelt et al., 2019). Findings on cultural sources of interpersonal and intrapersonal conflict, however, are not limited to EOL care, and thus may not accurately represent conflict during EOL care.

This literature review located three studies specifically on nurse-perceived barriers to quality EOL care which identify cultural differences between ICU clinicians and patients/families as potential obstacles (Aslakson et al., 2012; Crump et al., 2010; Mani & Ibrahim, 2017). In addition to a particularly comprehensive list of barriers to optimal EOL care, the 32 surgical ICU nurses in the qualitative description study by Aslakson et al. (2012) identify culture-based obstacles as: 1) discomfort discussing end-of-life care; 2) the perception that death is a defeat; 3) conflicting cultural beliefs between the patient/family and care provider, particularly regarding disclosure of prognosis, involvement of the patient in end-of-life discussions, and/or the meaning of "good quality of life"; and 4) lack of understanding of what constitutes extreme or futile measures or a natural death. Two other cross-sectional survey studies were located that describe ICU nurses' perception of cultural differences being a barrier to quality EOL care (Crump et al., 2010; Mani & Ibrahim, 2017). In both studies the same 29-item questionnaire was utilized, and this captured only one obstacle related to differences in culture, namely, cultural differences in how families grieve. Nurses in both studies ranked this barrier in the middle of the 29 items in terms of frequency and low in terms of intensity. Interestingly, in Crump et al. (2010) and Mani and Ibrahim (2017) barriers similar to those described as cultural barriers by the nurses in Aslakson et al. (2012) were rated both very high in frequency and intensity. However, Crump et al. (2010) and Mani and Ibrahim (2017) did not connect these barriers to cultural differences. This absence of linkage suggests that cultural differences may have a greater influence on nurse-perceived barriers to EOL care than is recognized within the literature and may highlight a general

lack of understanding and awareness of the impact culture has on the perception of a *good death*. While there is documentation that ICU nurses' perceived barriers to culturally sensitive EOL care, this literature review found no literature on how nurses manage or overcome these challenges, which represents a knowledge gap within the literature.

Impact of EOL Care on the Wellbeing of ICU Nurses

Caring for dying patients appears to significantly impact the overall wellbeing and job satisfaction of ICU nurses. Literature suggests that nurses derive satisfaction and meaning from facilitating a *good death*, successfully enacting their EOL roles, and connecting with patients and families during the EOL period (Arbour & Wiegand, 2013; Bratcher, 2010; Endacott et al., 2016; McLouth-Kanacki & Winslow, 2017; Stokes et al., 2019; Vanderspank-Wright et al., 2011; Wiegand et al., 2019). Canadian ICU nurses have described finding meaning and satisfaction from feeling that they had made a difference by creating a good death and by navigating and overcoming challenges (Stokes et al., 2019). Given that cultural ideologies and norms significantly impact perceptions of these actions, supporting the delivery of culturally sensitive care is important for maintain ICU nurses emotional and psychological wellbeing. Evidence suggests that actions which build supportive, trusting, and collaborative relationships appear to contribute to ICU nurses' perception of a death being *good* (Cottrell & Duggleby, 2016; Endacott et al., 2016; Stokes et al., 2019). Conversely, challenges or barriers to developing these relationships seem to result in a more negative impression and increased stress during EOL care (Gelinas et al., 2012; Henrich et al., 2016; Johnson-Coyle et al., 2016; Stokes et al., 2019).

ICU nurses' emotional and psychological wellbeing is also greatly impacted by distress during EOL, and this in turn, can lead to burnout (Epp, 2012). Burnout, according to Parola et al. (2022) and the RNAO (2011), is a state of high emotional exhaustion and depersonalization accompanied by the perception of low personal effectiveness or accomplishment. While stress is a significant contributor to burnout, as it leads to emotional exhaustion, other known causes of burnout for ICU nurses include role conflict, moral conflict or distress, and compassion fatigue (Epp, 2012; Gelinas et al., 2012; Henrich et al., 2016; Johnson-Coyle et al., 2016; Parola et al., 2022). In Canada, prominent sources of stress for ICU nurses during EOL care relate to conflict, communication difficulties, insufficient support, and/or a lack of consensus regarding goals of care, such as differing opinions on medical futility (Gelinas et al., 2012; Henrich et al., 2016). These findings are significant given the previously discussed culture-based challenges to quality EOL identified by ICU nurses (particularly differences in communication practices, treatment expectations, and desired goals-of-care) (Aslakson et al., 2012; Crump et al., 2010; Mani & Ibrahim, 2017), the conflict that can result from care not recognizing the cultural needs of patients and families (Høye & Severinsson, 2010b; Listerfelt et al., 2019; Quindemil et al., 2013; and Van Keer et al., 2015), and ICU nurses identified need for further education and/or training on culturally sensitive EOL care (Crump et al., 2010; Canfield et al., 2016; Høye & Severinsson, 2010b; Listerfelt et al., 2019; McLouth-Kanacki & Winslow, 2017; Powazki et al., 2014). Additionally, there is evidence that poor communication and conflict in EOL care, especially conflict related to the level of care and its perceived futility, are significant sources of moral distress for

ICU nurses in Canada (Johnson-Coyle et al., 2016). For ICU nurses, burnout continues to be a problem, both in Canada and internationally, and is linked to the decision to leave the nursing profession (Epp, 2012). Identifying strategies to support the delivery of culturally sensitive EOL care in the ICU thus may help mitigate some of the sources of distress nurses experience during delivery of EOL care.

Summary of Literature Review

This literature review provides an overview of what is known about ICU nurses' perceptions of culturally sensitive EOL nursing care. Nurses appear to recognize that the values, beliefs, and practices of patients and families play an important role in how EOL care should be delivered. Moreover, knowledge of a patient's/family's culture is necessary for nurses to fulfill their self-identified EOL care roles. Tailoring care to the cultural needs of patients and families is described by ICU nurses as an element of a *good death*; however, delivering culturally sensitive EOL care appears to be challenging for ICU nurses. Conflict, misunderstandings, and opposing beliefs and/or values appear as common barriers that have culture-based elements. While common themes within this literature included the need for EOL nursing care to be culturally sensitive and the experience of barriers or challenges to achieving this, there is little evidence on the specifics of how culturally sensitive EOL nursing care is delivered.

This literature review found a paucity of evidence exploring ICU nurses' perceptions of culturally sensitive EOL nursing care. What little evidence is available must be gleaned from studies focusing on various aspects of EOL nursing care in the ICU or on general ICU nursing care for culturally diverse patients and families. No original

research studies were found that explore culturally respectful, responsive, or congruent EOL nursing care within adult ICUs, and most studies within this review do not specifically discuss culturally sensitive care. Thus, studies may not accurately interpret the perceptions of ICU nurses of culturally sensitive EOL care, or its critical components. While this review deemed several included studies as high quality, most were of moderate to low quality and suffered from issues such as a lack of participant diversity, sampling from a single hospital/unit, poor description of recruitment or sampling, and/or use of un-validated questionnaires. These factors may limit the credibility of findings. In addition, the transferability of findings may be limited as most studies originate from the USA and Western Europe, settings which, when compared to Canada, have undeniably different contextual factors such as immigration policies, healthcare funding and infrastructure, and general attitudes towards cultural diversity. This review was unable to locate any studies on culturally sensitive nursing care in ICUs from a Canadian context. Finally, there is a lack of robustness within the literature relevant to culturally sensitive nursing EOL care. Given the role patient/family culture plays in the delivery of high quality EOL care, the consequences of poor EOL care in the ICU, and the documented challenges associated with delivering culturally sensitive nursing care within this setting, understanding how to navigate and overcome obstacles to culturally sensitive EOL care can provide useful knowledge. The considerable gaps in the literature highlights the need for significantly more research on this topic.

Research Questions

The following research questions have been informed by both this literature review and my professional practice. The primary research question is: What are the perceptions of ICU nurses related to delivering culturally sensitive EOL care in adult ICUs? Secondary research questions include: a) How do ICU nurses orient themselves to the unique values, beliefs, and practices of patients and families?; b) What influences do ICU nurses perceive to be important when delivering culturally sensitive EOL care?; and, c) How do ICU nurses reconcile their personal values and beliefs with those of culturally diverse patients and families at the end-of-life?

CHAPTER 3: METHODS

This chapter outlines the qualitative research design used for this study and discusses the study procedures used related to the study setting, sampling and recruitment, data generation, data analysis, and ethical considerations. As well, the strategies employed by this study to promote rigour and trustworthiness are also discussed.

Design

Interpretive Description (ID) was used for this study. ID is a qualitative research methodology designed to investigate and understand complex clinical experiences (Thorne, 2016). It aims to construct disciplinary knowledge that helps clinicians apply shared components of an experience to individual cases (Thorne et al., 1997). Coffey et al. (2013) recommends using qualitative methods when exploring nurses' preferences and perspectives on EOL care, making ID an excellent choice of methodology for this study. Additionally, the two-fold aim of ID can illuminate both universal knowledge and individual knowledge of how to personalize care. These aims are important in the context of delivering EOL nursing care in the ICU as this phenomenon is a highly intuitive and personalized experience (Noome et al., 2017). To interpret the shared experience from the constructed experiences of individuals, ID is both pragmatic in its methods, and uses the philosophical and theoretical foundations of Nursing as a lens through which to view phenomena (Hunt, 2009; Thorne et al., 1997).

In addition to its usefulness as a means for interpretation of a shared experience from the individual, ID is effective for small studies that draw upon the clinical experiences of the researcher (Thorne, 2016). My research topic arose out of my own

experiences as an ICU nurse and ID recognizes the value of this insight and provides a framework for acknowledging these influences while still maintaining rigour (Thorne et al., 1997; Thorne, 2016).

Study Setting

The setting for this study was Level 3 ICUs in Southern Ontario, Canada. I chose to recruit participants from ICUs classified to target patients with the highest acuity level in the ICU environment (Critical Care Services Ontario, 2020), and who in turn, have the highest risk of dying. Level 3 ICUs have the capacity to care for patients who require advanced and/or prolonged respiratory support and/or multi-organ support; and are the only ICUs that provide invasive mechanical ventilation beyond an interim period (Critical Care Services Ontario, 2020). As previously mentioned, invasive mechanical ventilation is a care process associated with a large percentage of ICU deaths (CIHI, 2016).

Sampling and Recruitment

Sampling in ID is done purposefully with the goal of selecting participants who can both provide information-rich accounts of phenomenal aspects that researchers deem desirable (Coyne, 1997; Gentles et al., 2015; Thorne, 2016) and "reveal elements that are to some degree shared by others" (Thorne et al., 1997, p. 174). Importantly, purposeful sampling evolves over the course of the study as the information needs of researchers change and is somewhat flexible (Gentles et al., 2015; Tuckett, 2004). Recruitment for the study followed two primary sampling techniques, maximum variation sampling and theoretical sampling. As well, specific inclusion criteria were used to ensure that recruited participants possessed sufficient experience providing EOL care to allow their

descriptions to have depth and richness (Morse, 1991). Only Registered Nurses (RNs) who had: 1) worked in an ICU for more than 12 months, and 2) provided EOL care within the last six months at the time of recruitment. It is important to note that, while sampling evolved as this study progressed, any changes remained congruent with the study's purpose and sampling aims (Coyne, 1997). Sampling, data generation, and data analysis occurred concurrently and, as themes and/or patterns emerged, sampling was adjusted to generate a robust understanding of the phenomena and to accommodate study needs (Thorne, 2016). For example, as data were analyzed and as a decision was made to re-interview some participants, sample size was adjusted.

Maximum Variation Sampling

This study used maximum variation sampling. In maximum variation sampling, participant selection is done to maximize opportunities for collecting data along the range of variations in relevant categories and their elements (Coyne, 1997; Thorne, 2016). Using this technique, participants were recruited with diverse experiences related to specific and critical characteristics, such as age, length of ICU experience, years of experience as a nurse, and country of birth. For example, participants in this study were born in different countries and their experiences interacting with different cultures was rich and varied. Similarly, my study sample consisted of nurses along the spectrum of age and level of experience, thus data represented the cultural perspective of more than one generation of nurses. Thorne (2016) suggests that researchers initially look to an easily accessible sample of appropriate participants and as patterns emerge, use maximum variation sampling to confirm hunches and develop theoretical variations/conceptual

categories. This suggestion guided sampling as I focused recruitment on participants who met demographic characteristics that appeared to be important in previous interviews, such as country of birth and which units they worked in.

Theoretical Sampling

Thorne (2016) explicitly states that, as an ID study progresses, sampling decision should be guided by the themes/patters that emerge during concurrent data analysis, and thus, theoretical sampling should be used to select participants who can deepen understanding of these developing themes/patterns. While theoretical sampling is strongly associated with grounded theory, it is also philosophically consistent with ID as these two methodologies share many symbolic interactionist beliefs (Handberg et al., 2015; Oliver, 2012). In this study, theoretical sampling was used to select already-recruited participants for second interviews. These participants were chosen based upon their capacity to focus more deeply on themes that emerged during their first interview (e.g. the intrinsic connection between culturally sensitive care and person-centered care, the tension caused by trying to deliver culturally sensitive EOL care within the ICU model of care/dominant mindset within the ICU, etc.).

Recruitment

Recruitment of participants was primarily done with the help of ICU managers and clinical educators from three ICUs in Southern Ontario. I initially contacted these individuals by email and then followed-up by phone to discuss the study and logistics, and to respond to their concerns or questions. These administrators were then provided with an email (see Appendix E) and flyer (see Appendix F) to distribute to their staff both

electronically, through email or the unit's online conference, and physically, by posting it in the staff lounge(s) and/or locker room(s). After an initial distribution of these recruitment materials, managers/educators were contacted two subsequent times and asked to re-distribute materials to increase recruitment. Both the email and flyer provided a short summary of the study's purpose, what was required of participants, and how to contact study personnel. It was also made clear that participation was entirely voluntary.

Two key informants (both staff nurses) were also identified based upon my knowledge of the different units and discussions with administrators and participants. Both staff nurses were viewed as nursing leaders regarding EOL care within their respective units and were responsible for the development of formal EOL initiatives within their units in the past. These individuals were asked, via email, to help promote the study among their co-workers, which they agreed to do.

Nurses who responded to the invitation to participate in the study were then provided with a more comprehensive description of the study in the form of this study's Information and Letter of Consent (see Appendix G) and given an opportunity to ask questions and seek clarification via email or phone. At this time, participants were also screened to ensure eligibility. Contact with potential participants was done via email (see Appendix H for telephone/email script) and information regarding confidentiality, consent, the use of participant data, and the voluntary nature of participation was clearly outlined (see section on Ethical Considerations for further information). Nurses who agreed to participate in the study were asked to review and sign the previously sent

Information and Consent Letter, and a date and time for the interview was mutually agreed upon.

It is important to note that recruitment for this study occurred between June 2020 and March 2021 and, therefore, was greatly impacted by the emergence of the COVID-19 pandemic, which limited access to units and strained resources. As such, it was not possible to employ additional in person recruitment methods to encourage participation.

Sample Size

The final sample size of this study was seven participants. Because of the inductive nature of an ID study, it is difficult to pinpoint *a priori* the precise sample size needed to make findings credible (Morse, 1995; Thorne, 2016). Sampling in qualitative research relies on relatively small numbers of participants to gather deep and detailed accounts of phenomena (Tuckett, 2004). While an initial estimated sample size of 15 to 20 participants was deemed credible at the start of recruitment (Tuckett, 2004; Thorne, 2016), due to recruitment issues related to COVID 19, it was agreed upon within my committee that a more in-depth exploration of the experiences and perceptions of a smaller number of participants was warranted; thus the option for a second interview was introduced into the study protocol part way through the study. This was seen as suitable considering the potential to revisit ideas and experiences which emerged as critical during analysis and the informational power of initial interviews, namely that participants were insightful, articulate, and open about their thoughts and experiences regarding culturally sensitive EOL care (Malterud et al., 2015; Thorne, 2016). This adaptation of the study protocol is consistent with an ID methodology, which supports re-engagement with data

sources, in this case through repeat interviews (Thorne, 2016). It is a way of clarifying and elaborating on developing relationships within the data and to allow interview strategies and observations to be informed by what has already occurred and the evolving data analysis (Thorne, 2016). The option of a second interview with selected participants was introduced into study procedures and received REB approval. After conducting and analyzing seven first interviews and four second interviews, it was determined by me and my committee that the phenomenon had been explored in sufficient depth and quality that new insights had been gleaned (Thorne et al., 2004).

Data Generation

ID does not prescribe the use of specific data generation methods. Rather, ID emphasizes selecting data generation methods that allow the researcher to get as close as possible to the subjective experience central to the study's purpose (Thorne, 2016). For this study, I chose in-depth semi-structured interviews as the primary method of data generation, with additional data being generated using a participant demographic form and interview field notes. All participants were offered the option of conducting interviews by either Zoom Video Conferencing or via telephone. Prior to any data generation, consent was first obtained from all participants. All data collected was stored electronically and/or as a hard copy in a manner that met Research Ethics Board (REB) the requirements.

Semi-Structured Interviews

In-depth, semi-structured interviews construct data though one-on-one interactions between an interviewer and an interviewee based upon a pre-determined set of open-

ended questions (DeJonckheere & Vaughn, 2019). In this way, a deep contextual account of the interviewee's experience of a phenomenon is generated and data is constructed (Doody & Noonan, 2013). Adopting this as the primary method of collecting data is congruent with my study purpose, namely, to understand the subjective experience and perceptions of ICU nurses in delivering culturally sensitive care at the EOL. In this study, all participants engaged in an initial interview, while four participants engaged in an additional secondary interview aimed at exploring emerging patterns and themes during analysis of the initial interviews.

All interviews were conducted online using Zoom Video Conferencing and held at a time and date requested by the interviewee. Participants were encouraged to conduct their side of an interview in a quiet and private place where they would not be interrupted or overheard, thus supporting privacy, confidentiality, and deep engagement in dialogue (Thorne, 2016; DeJonckheere & Vaughn, 2019). Interviews were an average of 64 minutes in length for first interviews (range: 51 – 88 min) and 76 min in length for second interviews (range: 61 – 98 min) and audio was recorded using both a digital recorder and Zoom's audio recording capabilities to ensure audio clarity (Thorne, 2016; Whiting, 2008). All video data associated with Zoom recordings were immediately deleted. Prior to initiating interviews, a copy of the Information and Consent Letter (which had previously been emailed to the participant to review) was verbally reviewed and verbal consent was obtained. This consent also included permission to record interview audio data and to contact participants at a later time if deemed necessary for interview content clarity. While one interview per participant had been originally planned, because of difficulty

with recruitment due to COVID-19, the option for second interviews with already recruited participants was introduced part way through the study. Four participants were contacted about participating in second interviews and all four consented. Verbal consent was again re-affirmed at the start of each secondary interview.

To construct data, a list of pre-determined, specifically-worded, open-ended questions was used to guide interviews. These questions were developed based upon feedback from my committee, relevant theoretical frameworks, study aims, findings from the literature review and, as the study progressed, patterns which emerged during concurrent data analysis (van den Hoonaard, 2012). Two interview guides were created, one for initial interviews and one for secondary interviews (See Appendix J for the First Interview Guide and Appendix K for the Second Interview Guide). The first interview guide was organized to initially capture contextual data and provide an easy entry into the interview before transitioning to more focused questions (Doody & Noonan, 2013; Thorne, 2016; van den Hoonaard, 2012). Questions required participants to: a) reflect upon and analyze their perceptions and experiences with understanding and appreciating the cultural perspective of patients and families at the EOL; b) explore how care was tailored to these individuals' culture-based EOL needs and wishes; and c) examine how participants dealt with distress caused by delivering care that opposed their personal values and beliefs. This guide was reviewed by my full supervisory committee and discussed with three nursing colleagues, two of whom had previous ICU experience. Additionally, a pilot interview was conducted with a research colleague who had significant experience conducting interviews. Through this process and the associated

feedback, the structure and wording of questions was refined, as was the list of probing questions which was distilled down to only those deemed essential.

The guide for secondary interviews was designed to explore themes and patterns which emerged during analysis of first interview data and delved deeper into specific topic areas (e.g. the intrinsic connection between culturally sensitive care and person-centered care, the tension caused by trying to deliver culturally sensitive EOL care within the model of care/dominant mindset within the ICU, etc.). Literature regarding Relationship-Based Care was also used to guide questioning in secondary interviews as emerging themes suggested that much of participants' approach to delivering culturally sensitive EOL care was grounded in the therapeutic relationship and capacity to encourage open and meaningful dialogue.

Importantly, these prepared guides were not rigid scripts, but rather, they provided structure to interviews while still allowing flexibility to explore perceptions, experiences, and/or ideas that arose during interviews which I deemed important to the study's purpose (Thorne, 2016; van den Hoonaard, 2019). Additionally, the guides were adapted and revised as data was analyzed to support better quality data generation, as is important for an ID study (Thorne, 2016; van den Hoonaard, 2019). Most notably, discussion of participants' definitions of culture and cultural sensitivity, along with an introduction of this study's definition of these two concepts, was moved to the beginning of first interviews when it became evident that participants were unsure and/or unclear of their personal understandings.

To support richer and deeper data generation, copies of these interview guides were sent to participants prior to interviews to ensure they were familiar with the content and had time for reflection (Doody & Noonan, 2013). In order to ensure timely transcription following interviews, recordings were transcribed by myself or a hired transcriptionist and these documents were re-checked against audio recordings to ensure accuracy. Audio recordings were kept after verification of transcripts and were used as another method of engaging with the data.

Participant Demographic Form

A participant demographic form was used to collect important and relevant contextual data about each participant (Appendix I). The form recorded participants' age, gender, ethnicity, highest level of education achieved, length of ICU experience, length of nursing experience, and whether they have had EOL or cultural sensitivity education or training. This data helped inform maximum variation sampling and enriched analysis of interview data.

Field Notes

Field notes are a record of researcher observations during field work, including the researcher's perceptions, ideas, and reflections, and can be used to improve rigor and trustworthiness (Given, 2008; Montgomery & Bailey, 2007; Phillippi & Lauderdale, 2018). While field notes are rooted in ethnographic anthropology, they have become an essential component of many qualitative methodologies as they can capture important contextual data and enhance analysis. This is because they help researchers notice and record important non-verbal data associated with the environment and interactions and

begin to stimulate researcher reflection and identification of biases (Phillippi & Lauderdale, 2018). The type and content of field notes should be dictated by the study's aim and methodology (Montgomery & Bailey, 2007; Phillippi & Lauderdale, 2018).

In this study, field notes recorded ideas and perceptions about my interpretation of what happened during interviews, including non-verbal communications and behaviours. Field notes were centered chiefly around ideas, patterns, and hunches which stood out as important during the interview, as well as my reactions to what was shared by participants. These data were particularly useful when critically reflecting upon my influences and biases during interviews and data analysis and helped me track my impressions of the interviews as a whole and keep focused on the bigger picture. While the process of writing field notes began during interviews, with brief jottings regarding my observations or ideas, they culminated in more comprehensive summary notes written immediate after each interview, which focused on what occurred during the interviews (Creswell & Poth, 2018; Montgomery & Bailey, 2007).

Data Analysis

In ID, data is inductively analyzed concurrently with data generation, thus enabling recruitment and data generation to be informed by what arises during analysis (Hunt, 2009; Thorne, 2016). In this study, ideas and patterns that emerged during data analysis were integrated back into data generation through adaptation of the first interview guide, creation of the second interview guide, and selection of participants for second interviews through theoretical sampling (as previously described).

Similar to data generation, data analysis in ID is more directive regarding the intentions and process of analysis, rather than prescriptive regarding specific techniques. Within an ID methodology, analytic techniques are viewed as simply tools to help expand thinking and open the mind to new possibilities. Their selection is driven by how well a technique can support both inductive analysis and critical examination of a researcher's interpretations of generated data (Thorne et al., 2004; Thorne, 2016). In an ID study, the intention and process of analysis is rooted in critical inquiry and symbolic interactionism and outlines that, since the meaning a researcher ascribes to each piece of data changes as new data are experienced, the researcher must constantly compare all pieces of data to one another, testing, examining, and re-assessing the relationships between pieces (Thorne, 2016). In this way, the researcher is able to ask questions, explore meanings, and thus refine patterns and themes to ultimately see the phenomenon as a cohesive whole and establish a coherent internal logic (Thorne et al., 2004; Thorne, 2016). As such, open coding and constant comparative analysis techniques were used in this study to interpret meanings from generated data and construct findings.

Coding

Coding commenced after the third interview. Prior to commencing the coding process, I immersed myself in initially generated data by listening to audio-recordings as least twice (at least three times for those transcribed by a transcriptionists) and twice reading transcripts and field notes. In this way, I was able to dwell within the data and allow myself time to both, absorb and learn the data and to begin to comprehend and synthesize data, forming initial ideas, thoughts, and hunches which were recorded as

reflexive memos. This approach is consistent with ID's emphasis on the researcher's relationship with the data and the avoidance of premature coding (Hunt, 2009; Thorne et al., 1997; Thorne, 2016), and laid the foundation for the development of initial codes and code refinement. This process was repeated for each subsequent interview.

In ID, the objective of coding is to sort and organize data into manageable forms which can illuminate thematic patterns and recurring ideas (Thorne, 2016). According to Thorne (2016), this is best done through the application of broad or generic codes which can group together potentially similar "data bits". These grouped bits are then continually compared and contrasted with one another, with other groupings, and with all other data bits, linking and deconstructing groupings to iteratively arrive at more and more subtle and refined themes and patterns (Thorne, 2016). Thorne (2016) advises that during this process it is critical to, "move beyond the self-evident and superficial in linking the groupings and patterns within your data" (p. 166). This is done by having deep knowledge of your data, recontextualizing this data within the broader context of the whole set, and ensuring coding is an active process which supports interpretive thinking and is not simply a process of categorizing and/or organizing (Thorne, 2016). Thorne et al. (1997) advises that this analytic process is best aided by asking questions such as, "'What is happening here?' and 'what am I learning about this?'" (p. 174) during repeated data immersion. This approach guided my data analysis.

To apply this inductive approach, transcripts of the first three interviews were openly coded and reflective notes were used to capture and highlight key ideas and/or concepts. This coding was then compared with that done by my supervisor on the same

three transcripts. After feedback from my committee and discussion of emerging patterns, initial broad codes were devised and used as the foundation for coding of subsequent transcripts. NVivo12 software was then used to store and organize data so that data bits could be more deeply compares. NVivo 12 is a qualitative data analysis software that, while helpful with handling or grouping data and maintaining study rigour, can hinder the creativity and inductive, holistic consideration of data that leads to a good, interpretive, and clinically relevant study product, particularly for newer researchers (Cypress, 2019; Thorne et al., 2004; Thorne, 2016). As such, during the analysis process, both whole transcripts in their original Word format and audio recordings were repeatedly reviewed as this helped keep an eye on the bigger picture, recontextualize data bits, and ultimately compare similarities and differences within the range of participant experiences (Thorne, 2016). Importantly, codes evolved over the course of data analysis as data were continuously compared and contrasted, and the underlying meaning of data bits and patterns became more apparent. This is consistent with an ID methodology, which warns against rigid adherence to analytic techniques, and indicates that data analysis should support creative thinking and focus on the overall picture that is emerging (Thorne, 2016).

Memoing

The creation of analytic and reflexive memos is an important part of data analysis within an ID study as they capture a researcher's internal dialogue related to the organization, conceptualization, and presentation of data during analysis (Thorne, 2016). Memoing, as outlined by Thorne (2016), encourages critical reflection and documentation

of how thinking evolves over the course of the study, helping to strengthen analytic conclusions. I engaged in this practice throughout the study, but most intensively during data analysis. This process began with the creation of a post interview memo (Birks et al., 2008; van den Hoonaard, 2019) and continued throughout analysis by recording thoughts, impressions, ideas, and reflections in an unlined bullet journal. Through journaling, I continually engaged in critical and interpretive discourse regarding the data and what was emerging, asking, and answering questions such as 'what does this mean?', 'what is really going on here?', and 'why is this important?'. Additionally, I recorded verbal memos when I felt analysis became particularly challenging or complex. By reviewing these memos, I was able to make cognitive leaps regarding relationships, themes, and patterns within the data, and better locate my perspective within my findings. This, in turn, helped open my mind to other interpretations of the data/avenues of enquiry (Thorne, 2016). For example, by reviewing memos I was able to recognize my tendency to focus on participants' actions and behaviours (i.e. focusing on what they are doing or how they are doing it), and thus I was able to open-up analysis to consider the broader implications which comments and accounts may have (i.e. why are they doing what they are doing?) when this had previously been overlooked. These memos also captured a paper trail of the analysis process.

Conceptualization

During analysis, I looked at emerging patterns and compared these with one another to construct and deconstruct data groupings, critically testing relationships and associations in the process by asking myself questions such as, 'does this idea belong

here?', 'where else does this idea fit?', and, 'why do I feel there is a relationship here?' (Thorne, 2016). The ultimate goal of this process was to deepen my understanding of the relationships within the data. A codebook was used to document tentative codes and help track their evolution as new data were generated and analyzed (Thorne, 2016). Techniques such as concept mapping, analytic memos, and reflexive practice were used to draw patterns and relationships out of the coded data and to critically assess these constructs (Hunt, 2009; Thorne, 2016). From this process, themes emerged which linked patterns and gave constructs an underlying meaning and structure. During initial analysis, two critical patterns emerged: 1) participants felt uncertain about the delivery of culturally sensitive EOL care; and 2) participants' conceptualization of culturally sensitive EOL care was blended with their understanding of patient-centered care. Considering these important patterns, analysis was enriched using two theories/frameworks: Relationship-Base Care (Koloroutis, 2004; Koloroutis & Trout, 2012; Ledesma, 2011) and Relational Inquiry (Hartick Doane & Varcoe, 2015). Both theories/frameworks focus on relational nursing practice and helped provide deeper understanding of the relational foundations within participants' perceptions of care delivery. This analytic process was undertaken with the help of my supervisor and committee and continued until a cohesive and sufficiently deep understanding of the phenomenon had been reached.

Strategies to Promote Rigour

Because ID uses an emergent design and disciplinary expertise to interpret the experiences of others, steps need to be taken to account for researcher influence (Thorne, 2016). Incorporation of strategies to improve study rigor and make researcher influence

explicit are necessary to maintain the trustworthiness of study findings (Morse, 2015; Thorne, 2004). To maintain the methodological rigor of this study, I engaged in the strategies of reflexive journaling and memoing, data triangulation, and peer debriefing and review. In this way I was able to improve the credibility, dependability, and confirmability of study findings (Morse, 2015). Additionally, to improve the dependability and transferability of findings (Morse, 2015), I have provided a detailed description of participant characteristics (Krefting, 1991) and study methods (Thorn, 2016), thus allowing others to make their own evaluation and judgements of findings.

Thorne (2016) emphasises that an ID study needs to explicate the subjectivity of the researcher and the influence this has on the ideas generated about the phenomenon being studied. It is suggested that reflexivity should be practiced throughout the study, from conception to knowledge translation, using strategies such as journaling and memoing (Hunt, 2009; Krefting, 1991; Thorne, 2016). Morse (2015) calls this practice, "clarifying researcher bias" (p. 1215), and stresses that it is necessary to assess and make explicit the influence the researcher has on study decisions and results. For this study, researcher bias was clarified through reflexive journaling and memoing. This practice let me explicate my theoretical allegiances, which are captured within this report's Reflective Summary, and both track the evolution of my perspective of the phenomenon and create a reportable account of the decisions I have made and why I have made them, which is also referred to as an audit trail (Cohen & Crabtree, 2008; Krefting, 1991). This process increases the confirmability of study findings.

In this study, data triangulation was used to increase the credibility and dependability of findings. Data triangulation is the comparing and contrasting of two or more data sets generated to answer a single question (Morse, 2015). These different sets of data can arise from the use of different generation methods, sources, or investigators (Morse, 2015). The use of multiple data sources and methods is also supported by Thorne (2016), who states that all data sources possess epistemological strengths and limitations and thus the use of multiple data sources produces a "richer and more complex data set" (p. 80). Ultimately, the idea of triangulation is to view the phenomenon from different perspectives or in different ways to deepen study results and to allow these different perspectives to corroborate one another (Cohen & Crabtree, 2008). In this study, triangulation was conducted using different data generationion methods (interview transcripts, and field notes) and, during analysis, using different coders (myself and my supervisor) and transcripts (looking for evidence to confirm or dispute the claims of one participant within the accounts of others).

Finally, peer debriefing and review was utilized to further increase the credibility, dependability, and confirmability of study findings. This strategy entails the presentation and subsequent analytic discussion of conceptualizations with peers (Morse, 2015). In this way, these conceptualizations are viewed with new eyes and the logic of conclusions can be fully fleshed out, assessed, and challenged (Cohen & Crabtree, 2008; Morse, 2015; Thorn et al., 2004). This analytic process also allows researcher influence to be brought to light, facilitating reflexivity, and thus the validity of conclusions can be better assessed (Cohen & Crabtree, 2008; Morse, 2015; Thorn et al., 2004). In this study, peer debriefing

and review consisted of consultation with my thesis committee throughout the study, from protocol development to dissemination of findings. It also involved informal dialogue with fellow staff nurses regarding conceptualizations or ideas that were emerging during analysis, as well as possible personal assumptions and biases.

Ethical Considerations

The Tri-Council Policy Statement on the Ethical Conduct for Research Involving Humans (TCPS2) requires that, "research involving humans be conducted in a manner that is sensitive to the inherent worth of all human beings and the respect and consideration that they are due" (Government of Canada, 2014). This respect for dignity informed my interactions with nurses, how I handled and used data, and decisions made about how this study was conducted.

Because of the nature of the study's purpose and the population of interest, the primary ethical concerns involved in study operation revolved around issues of privacy, confidentiality, and free, informed, and ongoing consent.

Privacy

The TCPS2 defines privacy as, "an individual's right to be free from intrusion or interference by others" (Government of Canada, 2014, p.57). In the context of this study, this right relates to the maintenance of participant privacy and of those individuals to which participants refer. While the purpose of this study was to capture the perceptions of nurses, these experiences do not occur in a social vacuum, and others, such as patients, families, and coworkers, are vital elements of participants' experiences and observations. These individuals also have a right to privacy. To uphold my legal obligation to maintain

privacy, I focused conversations on participants and their thoughts, opinions, and beliefs. Additionally, personally identifiable information (as defined by McMaster University (2015)) about individuals other than the participant was not transcribed. Rather, a random placeholder was inserted which included information only deemed critical to analysis, such as the individual's profession, when contextually relevant. Additionally, during analysis and reporting of findings, data was pooled and specific experiences or quotes that were shared beyond study personnel were de-contextualized. There were a few instances in which sufficient de-contextualization of data was not reasonably possible, and in these instances, this data was not included in the study report or shared beyond study personnel. After the completion and defence of this thesis, all identifiable data (e.g. name, phone number, address, email, etc.) will be shredded and all audio files will be deleted.

In this study, interviews were conducted online using Zoom Video Communication. This was seen as a potential source for a breach of privacy, as it is with all online video conferencing. To create a secure platform and protect the privacy of both participant and host, we used several of Zoom's multiple available security features. All meetings[3] hosted on Zoom were secured with end-to-end encryption and attendance was limited only to the host (researcher) and attendee (participants) through the use of a password and waiting room. Furthermore, in advance of the interview, the link for

[3] Within this protocol, when discussing interviews conducted via Zoom, the terms meeting and interview are used interchangeably.

McMaster's Zoom login page was provided, and it was strongly suggested that the participant use this to join the meeting. Zoom's marketing websites use third-party services, such as Google Analytics or Facebook, which track surfing habits for advertising purposes, however, McMaster University's Zoom login page does not use these.

Confidentiality

Another ethical consideration related to privacy is maintenance of confidentiality. The TCPS2 defines confidentiality as, "the obligation of an individual or organization to safeguard entrusted information" (Government of Canada, 2014, p. 58). To meet this obligation, all research data was protected from, "unauthorized access, use, disclosure, modification, loss or theft" (Government of Canada, 2014, p.58) by: 1) assigning participants an identification code which was used to identify documents and files such as demographic data, audio-recordings, and transcripts; 2) reordering all identifiable data on a (paper) master participant log linking participants to their unique code and storing this separately from all de-identified data in a locked drawer within my office; and 3) storing physical de-identified data (such as printed transcripts and USB storage device in a separate locked cabinet in my office (administrative safeguard), storing electronic de-identified data as encrypted password protected files (technical safeguard), and only accessing this data in a private place (physical safeguard) and by those involved in the study (administrative safeguard). Audio-recordings of all interviews were stored as de-identified digital files on an encrypted USB storage device which was kept locked in a cabinet within my office. While Zoom allows hosts to use cloud storage for recording

meetings, this study only recorded audio locally, which was then transferred to a USB storage device. All identifiable data will be confidentially destroyed at the end of this study, while all de-identified data will be kept for three years post-publication and then confidentially destroyed.

A breach in either privacy or confidentiality poses the only significant risk of harm for study participants. This risk is important as all healthcare professionals and organizations have an obligation to maintain confidentiality and protect the privacy of those they care for (CNO, 2017; College of Physicians and Surgeons, 2005). A breach of this trust can have significant and lasting legal, professional, and personal consequences for these individuals and organizations. The strategies for maintaining privacy and confidentiality described above should be sufficient to safeguard participants from a professional breach of trust and any harm this could cause.

Consent

As with all research studies, consent must be informed, given freely, and be an ongoing process (Government of Canada, 2014). To achieve this, I first made it clear during consent that the information participants shared would be used within my Master's thesis and any subsequent publications, conferences, or other knowledge translation activities. Further, my study consent forms contained information about the study, the potential risks (including the small risk of breach of privacy associated with using Zoom) and benefits of participation, how data will be stored, and how to withdraw from the study, which they can do at any point. During consent it was explained that if the participant chose to withdraw from the study, we cannot remove data that has already

been analyzed as it has already influenced our understanding of the phenomenon under study. However, we did promise that if the participant did choose to withdraw from the study, no quotes from their interview would be shared.

An electronic copy of the Letter of Information and Consent was emailed to all participants in advance of initial interviews and consent was obtained prior to data generation. Consent was reaffirmed at the commencement of second interviews. As all interviews were conducted on Zoom, consent was obtained verbally prior to data generation, and participants were asked to return a signed copy of the consent form to me by email.

In keeping with the principle of dignity, all participants were offered a $5.00 coffee card as a gift of appreciation for donating their time to the study. This will not be an incentive, but rather a token to recognize the time and effort required to participate.

CHAPTER 4: RESULTS

The purpose of this chapter is to report the key findings of this study. This chapter begins with a description of the characteristics of participants before proceeding to report the major patterns and themes which emerged during data analysis. Direct participant quotes are used to support these patterns and themes. This chapter concludes with a brief summary of the main study findings.

Participant Characteristics

Participants in this study were seven Registered Nurses (RNs) (See Table 1). Of these seven RNs, two participants were diploma-prepared (28.6%), four had a bachelor's degree (57.1%), and one a graduate degree (14.3%). The majority of participants identified as female (85.7%) and ages ranged from 28 to 56 years, with an average age of 39.4 years (SD = 11.5 years). Participants were primarily born outside of Canada (71.4%); however, only three participants identified as being able to speak a language other than English (42.9%). Participants were born in Africa (n=1), Eastern Europe (n=1), South Asia (n=1), the United Kingdom (n=1), and South America (n=1). Participants had spent an average of 8.6 years (SD = 4.2 years) working in an ICU, with a range of five to 16 year, but had worked as an RN for an average of 14.3 years (SD = 7.8 years), with a range of six to 28 years. All screened individuals met inclusion criteria and, thus, no potential participants were excluded.

Overall, the majority of participants identified as having had some form of EOL or Palliative Care training or education (71.4%); however, only one identified as having had formal education/training focused specifically on EOL or Palliative care. The remainder

identified training/education as being either informal (n=2), for example during mentorship or workplace orientation, or as part of a conference or university course (n=2). Less than half (42.9%) had some cultural sensitivity-related training or education (n=3), and this training/education was geared towards understanding other cultures.

Table 1

Characteristics of Participants (n = 7)

Variable	*n* (%)	*mean(sd)*
Age		39.4 (11.5)
25-35	3 (42.9)	
36-45	2 (28.6)	
46-55	1 (14.3)	
> 56	1 (14.3)	
Sex		
Female	6 (85.7)	
Male	1 (14.3)	
Highest Level of Education		
Diploma	2 (28.6)	
Bachelor's Degree	4 (57.1)	
Graduate Degree	1 (14.3)	
# of Years Working as an RN [mean(sd)]		14.3 (7.8)
5-10	3 (42.9)	
10-15	1 (14.3)	
16-20	2 (28.6)	
>21	1 (14.3)	
# of Years Working in an ICU [mean(sd)]		8.6 (4.2)
5-10	4 (57.1)	
11-15	2 (28.6)	
16-20	1 (14.3)	
Country of Birth		
Canada	2 (28.6)	
Not Canada	5 (71.4)	
Languages Spoken		
English only	4 (57.1)	
Other	3 (42.9)	
Cultural Sensitivity Training or Education		
Yes	3 (42.9)	
No	4 (57.1)	

End-of-Life or Palliative Care Training or Education	
Yes	5 (71.4)
No	2 (28.1)

Overview of Major Findings

Three key themes were constructed which capture participants' perceptions of delivering culturally sensitive EOL care within the context of an adult ICU. These themes are 1) *Culturally sensitive EOL care is truly person-centered care*, 2) *Dissonance between culturally sensitive EOL care and the biomedical model of care in the ICU*, and 3) *Needing support to integrate a relational approach to care within the ICU* (See Table 2). Each theme is comprised of four subthemes.

Table 2

Major Themes and Subthemes

Theme	Subtheme
1) Culturally Sensitive EOL Care is Truly Person-Centered Care	a) Defining culturally sensitive care: "*knowing what that actually involves is difficult to define because I think it changes from person to person.*"
	b) Learning about the patient as a person: "*I don't go at it from sort of a cultural perspective. It's far more general. If I'm trying to get the family—or build a rapport, I'll just ask about the patient*."
	c) Avoiding pigeonholing when using Cultural knowledge: "*I think the moment they box them in…it almost becomes a wall that they close, that they don't really, take the time, the extra time to listen or talk to the family or to the patient.*"
	d) Looking past assumptions and biases and being open during EOL care: "*Understanding is a big component because we may have biases, preconceived notions of what is important for the patient.*"
2) Dissonance Between Culturally Sensitive EOL	a) A need to reduce Culture to defined labels: "*You have to record surrogate decision maker as soon as someone's admitted, you could have ethnicity on there—although it's hard to say, because ethnicity doesn't always mean values.*"

	Nursing Care and the Biomedical Model of Care in the ICU	b) Task-oriented care in the ICU: "*Getting that dedicated time to have that discussion that's really open, it's actually getting lost…because they're so busy focusing on the tasks that are placed on them.*" c) A focus on physical care: "*I feel like it's* [values, beliefs, and cultural preferences] *extremely, extremely important and it's—it takes a huge backseat to the medical care we provide, but it should guide the medical care we provide."* d) An impersonal death and dying experience: "*We don't get to have that moment of going, ok, you know—this is a human being and we respect the life that is there."*
3)	Needing Support for Integrating a Relational Approach to Care in the ICU	a) Looking for tools rather than how to support a compassionate approach to care: "*Give us a tool or a framework; even that's less vague.*" b) Learning from and finding support among colleagues: "*I think it comes from colleagues, from working, experience of working.*" c) Needing support for reflexive practice to improve relational care: "*Oh my gosh! I think its part of that bias that I've been talking about. There's this implicit bias that I have, that a lot of us have, but we don't recognize it until we actually reflect on it.*" d) Emotional baggage prevents deeper connections with patients/families: "*It's easier to just shut off that side."*

Culturally Sensitive EOL Care is Truly Person-Centered Care

This theme describes the interdependent connection between culturally sensitive EOL care and person-centered care within participants' EOL practice. In general, this connection appears grounded in a belief that culture is an inseparable influence on an individual's worldview and who they are overall; in turn, making culturally sensitive care and truly person-centered care indistinguishable within participant's EOL practice. This theme contains four subthemes: a) defining culturally sensitive care, b) learning about the

patient as a person, 3) avoiding 'pigeonholing' when using cultural knowledge, and 4) looking past assumptions and biases and being open during EOL care.

Defining culturally sensitive care

Nurses in this study described culture as an expansive, foundational, and unpredictable influence on EOL needs and wishes. For instance, many participants suggested that culture has an expansive influence on core elements of a person, namely, their values, beliefs, personality, and perceptions about the world around them. They described culture as, "*a big component of your personality, of your humanity or everything in everyone*" (Nurse 4), "*what influences your beliefs, and where those beliefs sort of came from and were shaped*" (Nurse 3), and suggested, "C*ulture is the way you see the world*" (Nurse 5). Another nurse similarly expressed a view of culture as an inseparable part of an individual's worldview:

> *When it comes to culture, I find it more is how you feel about than just something—it's something obviously that you can be born into and then identify in it—but it's more where you feel like you belong…because you can be born in a culture and then not hold any of those traditions or beliefs and then really not be part of that culture. So, it's more of a personal, I guess, thing. (Nurse 7)*

This is an example of how nurses connected a person's culture to both their identity and how they function on a deeper, subconscious (emotional) level. It is representative of participants' shared perception that cultural expression is unpredictable and something personally meaningful.

Nurses in this study also indicated that their delivery of culturally sensitive EOL care was motivated by person-centered principles. When describing how they deliver culturally sensitive care at the EOL, participants made statements such as, "*it's all about*

the patient" (Nurse 4) and, "*it's not about what we think the person wants, it's about what those family members think they want or need*" (Nurse 2). One nurse suggested that culturally sensitive EOL care supports and respects an individual's personhood, commenting that, after some reflection, the most important thing for being sensitive to a patient's culture during EOL care is:

> *…listening to them* [the family and the patient]. *Asking them what they need and what is important to them and, most especially, what is important to that person…and, you know, that kind of gives me an idea of who the person is and to remember who they are as a person—and not only start a conversation, but treat them as such. (Nurse 1)*

Similarly, another nurse implied that culturally sensitive EOL care supports individual's autonomy and self-determination. This nurse reflected that:

> *Sometimes people have no choice, like, in terms—like in other places within the medical field. But, in this instance* [referring to EOL care], *this is where choice is important…It would be wrong for me, or for anybody, to take that away, to take away from that. Even if I think it's wrong or a mistake, it doesn't matter. That's life right. It's good that they have the ability to make that choice. (Nurse 7)*

This comment was made while Nurse 7 was reflecting upon an experience delivering culturally responsive EOL care which they felt had prolonged the patient's suffering. This comment is representative of how most participants drew upon a strong moral belief that EOL care should reflect the values, beliefs, and choices of the patient/family when trying to come to terms with EOL care decisions which they felt prolonged patient suffering. These findings illustrate that participants felt being culturally sensitive at EOL is about understanding and supporting the specific needs of patients/families as individuals. These findings also suggest that participants recognize

person-centered principles like autonomy, self-determination, and respect for human dignity, as defining features of a culturally sensitive EOL practice.

Cultural sensitivity and person-centeredness did not only seem indistinguishable at a moral level within participants EOL practice, it also seemed practical. For instance, Nurse 7 explained that shared decision-making is essential because the cultural values, beliefs, and practices an individual grows up around or is immersed in are unpredictable, rather than rigid, influences on that individual's perspective of EOL:

> *It is much easier and much more sensitive to go by what people need or express they need at a certain time than it is to make assumptions of what we think they do; because I've found that we could have learned a lot of cultures back in school, but that doesn't mean that the person in front of you holds those values, as you say, close and dear to their heart. Maybe they do, but maybe they don't. So, it's just easier to open up a conversation and to see what can be done to accommodate certain things. (Nurse 7)*

Despite participants' descriptions of cultural sensitivity and person-centredness being inseparable during EOL care, this connection did not always appear well-defined within their practice knowledge. For example, one nurse commented that:

> *It's easy to get carried away sometimes with the term culturally sensitive, but I think it's also important for us nurses, or for everybody, to know that knowing what each person wants ultimately is the—the way to provide better, good comfort, quality care. (Nurse 1)*

This comment seems to imply that the term cultural sensitivity is sometimes used in a narrow way that isolates culture from an individual's broader context. Another nurse suggested that a person-centered perspective was almost a reactionary response when considering cultural sensitivity during EOL care and expressed that cultural sensitivity was important at the EOL because, "*it's that commonly understood and well-established belief to see their* [patients' and families'] *values and beliefs, and truly incorporate it into*

this patient-centered mantra that we have" (Nurse 5). However, they prefaced this belief with statements such as, *"I don't know why it's—I think it's just engrained within me*" (Nurse 5), and, "*I haven't really explored that except that concept of empowerment*" (Nurse 5). Such comments highlight a deep-seated, almost unconscious recognition that at a practice level, being person-centered and culturally sensitive are entwined, while simultaneously suggesting that this connection is hazy within Nurse 5's practice knowledge. Similarly, another participant felt that culturally sensitive EOL care "*is a difficult subject to define and pull out*" (Nurse 6), and elaborated that the challenge with discussing it is:

> *…defining it. I think, I think defining it is going to be—because it's different for everybody. So, I think we all want to give our patients the best care that we possibly can as it pertains to them, but— that's our goal. So, we all want to be culturally sensitive, but knowing what that actually involves is difficult to define because I think it changes from person to person. And we don't have a lot of tools with which to do it, so we end up just being understanding and nice and that's our culturally sensitive care. So, yes, I think really understanding what it is the hard part.*

Nurse 6's lack of clarity regarding how to define culturally sensitive EOL care suggests that, while they understood cultural sensitivity and person-centeredness as interdependent, this knowledge is more intuitive than explicitly established within ICU nurses' broader body of knowledge.

Learning about the patient as a person

Participants described the importance of learning about the patient as a person when trying to deliver culturally sensitive EOL care. Most nurses in this study suggested that, when trying to become oriented to a patient's/family's culture at the EOL, they ask about and explore what is broadly meaningful to these individuals rather than focus on

culture per se. One nurse suggested that learning about patients/families as persons was vital since the diversity and individuality of cultural expression means everyone has different EOL needs and perspectives of "*what a good death looks like*" (Nurse 2). This nurse explained that, when trying to become oriented to their patient's/family's culture during EOL care:

> *I just try and ask questions like 'what do you they think that person would want?', 'do they want—you know music—is there a particular song they would like?', 'are there words or prayers that they would like?'. I don't know that it's specifically culturally-focused. I think it's just trying to focus on how to make it as pleasant as possible…because we all talk about a good death and what a good death looks like, but it's all very different for each person…because culture is such a diverse thing. So, there's so many different—I want to say there's just so many different cultural aspects of death and dying for people. I think each culture, even though you think you know, you may not know really what's going on—what that cultural sensitivity is for that person, because there's a personal aspect of it. Its not necessarily just—not necessarily just about someone who is different from you, because everyone is different from us. It's also about how they're different and recognizing that. (Nurse 2)*

Another nurse seemed to suggest that simply asking about culture can be too limiting for a culturally sensitive EOL practice. This nurse explained that, when trying to understand what is culturally meaningful to a patient/family at the EOL, they try to get a sense of who the patient is or was, reflecting:

> *I don't know if it's specifically culturally important, but I usually ask them to tell me about the patient. You know, what did they like to do? What did they do for a living? What memories do you have of that person? (Nurse 6)*

They explained later that taking this integrated and more holistic approach to culture was important because patients/families often don't view their needs as specifically cultural:

> *Sometimes families can't even explain it themselves—it's just what they believe. It's just, you know, this is just who we are. It's very difficult to—you know your*

> *first question, how do you define culture? It's actually hard to do. So, I think it's hard for families as well. (Nurse 6)*

These findings highlight the entwined nature of cultural sensitivity and a broader person-centered approach within participants' EOL nursing practice. They suggest that being culturally sensitive comes from understanding the patient/family holistically, as culture is "just who we are", and as such, separating culture from an individual's broader context creates artificial boundaries within ICU nursing practice.

Nurses in this study also highlighted that becoming oriented to a patient's/family's culture is not just about what questions they ask, but also about how they make the patient/family feel. For example, one nurse believed that when patients/families "*feel cared for*" (Nurse 1), they are more likely to share what is culturally important to them. This nurse explained that, when trying to understand what is spiritually meaningful to a patient/family, they try to stimulate dialogue by showing interest in understanding the patient as a person, stating:

> *It starts a little with something that isn't related, like, 'what did you use to do, as a—when you worked? What are some of your favourite things? Activities that you did?' So, it's made it seem like a conversation starter to get to know the person and then understand what was important to them. (Nurse 1)*

Nurse 1 further observed that their ability to demonstrate genuine caring is often what encourages families/patients to open-up and share what is culturally meaningful to them:

> *If the nurse provides care that aligns with the patient, I think that makes them feel that, 'Oh I'm loved, oh I'm cared for', and that makes them share…because there are so many times where I can say that because of what I'm doing—which it is just me. It is what I have to do, but I'm just being me. And those factors get patients talking about certain things that I never even asked them for. And it's all their personal life. (Nurse 1)*

Another nurse commented that, when working with culturally diverse patients/families, they do not specifically focus on culture, but rather, on developing rapport through showing genuine interest in understanding the patient as a person. They stated:

> *I don't go at it from sort of a cultural perspective. It's far more general. If I'm trying to get the family—or build a rapport, I'll just ask about the patient. 'What did _____ do for a living? What were his hobbies? What kind of guy was he?'. You know, then, after that it's more of a case of, 'Is there anything else that we can do to sort of make this easier for you?'. (Nurse 6)*

Nurse 6 further observed that with sufficient rapport, "*it usually comes out in the conversation, you know, if they have something specific that they would like*" (Nurse 6). Nurse 6 also observed that rapport was particularly important when individuals hesitate to open up and share their needs with staff:

> *As for more different cultures, they tend to be fairly self-sufficient I think. They tend to presume that we're not able to help them at all and so they kind of do their own thing. Unless—again unless you can sort of develop a rapport or chat with them to find out what we can do to help them—what is important to them…It's very private for a lot of people and a lot of people wouldn't even think to ask in a hospital because they wouldn't even anticipate that we can accommodate. So, it's—they save that for home later rather than expecting or anticipating that it could be provided in an ICU setting. (Nurse 6)*

These findings highlight the role of authentic caring and a strong therapeutic relationship in encouraging patients/families to open up and share their perspectives of EOL care, which are shaped by culture. This appears to be particularly important because some individuals presume staff can not or will not help them meet their cultural EOL needs within the ICU and, thus, hesitate to share their EOL needs and wishes.

Avoiding pigeonholing when using cultural knowledge

Participants indicated that a key role of cultural knowledge should be to support better person-centered communication rather than pigeonholing patients based upon their cultural background. One nurse illustrated this in their suggestion that knowledge regarding culture was good for, "*just asking those open-ended questions when I'm talking to them so that I'm not leading them to where I want them to go, but what they want"* (Nurse 2). With this comment, Nurse 2 seems to imply that knowledge about culture should be used to inform rather than replace their therapeutic communication skills, and to help individuals share what is specifically meaningful to them at the EOL. Another nurse explained that knowledge about culture/different cultures can be a useful tool when trying to explore a patient's/family's lived experience of culture, but added that this knowledge needs to be integrated into communications with humility and self-awareness, and in a manner that does not presume EOL values, beliefs, and needs. This nurse observed that knowledge about a person's cultural background:

> *…just provides that platform for me to create that commonality with the patient…But it—having more understanding about different cultures doesn't necessarily make me an expert in any way whatsoever. Right? Like the CNO teaches us the culture of the patient is their lived experience, so they're the expert of it at the end of the day. So, it just provides me that platform to ask them more questions and it's like more understanding from them. (Nurse 5)*

In general, when doing this, participants focused on elements of EOL care which they felt were universally influenced by culture (namely values, beliefs, religion/spirituality, music, sedation/pain management, and community/family), rather than on the beliefs/values/traditions of specific cultural groups. One nurse captured this in their comment:

> *I always encourage people to play music. I always ask them, 'Oh is there any music that your family member loved?'…to me that is a part of your culture, you know, even if it's not some kind of traditional music, like associated with our ethnicity or something. (Nurse 3)*

In contrast, one nurse observed that using knowledge about different cultures deterministically, or to pigeonhole patients, limits conversations and nurses' openness to really seeing the patient/family and understand their unique perspective, noting:

> *I've known that certain people, the moment they box them into, 'Oh! They're Italians' or 'Oh! They're Greeks' or 'Oh! They're, you know, this'— I think the moment they box them in to* [inaudible]*, it almost becomes a wall that they close, that they* [nurses] *don't really, take the time—the extra time—to listen or talk to the family or to the patient. (Nurse 1)*

Looking past assumptions and biases and being open during EOL care

Participants indicated that, when trying to learn about and provide care for patients/families as persons, it is critical to look past assumptions, biases, and personal perspective of EOL care and see the person as they truly are. For instance, most nurses in this study highlighted that maintaining an openness to the perspective of others is vital when trying to be culturally sensitive. One nurse described this openness as an active process of self-awareness and humility that is done consciously. This nurse expressed that what helped them to be culturally sensitive during EOL care was, "*just trying to be as open as I can when I'm talking to them* [patients and families] *and try and ask them those questions about what do they want or what do they need. See what I can do for them*" (Nurse 2). Nurse 2 later explained that this meant:

> *…just being open to that idea of that's what they want. You know, it's not about what I want. It's not about what I want for that person when they're dying, but it's about— I think it's just hearing them and referring back to them that this is what they want, I think is the most important piece.*

This comment emphasizes that openness is demonstrated by really *hearing* patients/families and validating their unique perspectives. Another participant emphasized humility as the core quality of this openness and suggested that being culturally sensitive involves approaching care from a place of humility. They reflected that, at its core, cultural sensitivity is:

> *…sort of acknowledging that other people may have beliefs and a culture other than your own. So, it's just understanding. You may not know all about their culture but at least accept the fact that not everybody has to think like you do. (Nurse 6)*

Most participants highlighted that a nurse's capacity to recognize and move past their biases and assumptions is what leads to understanding of, and appreciation for, patients/families culture during EOL care. One nurse captured this in their comment:

> *Understanding is a big component because we may have biases; preconceived notions of what is important for the patient. But at the end of the day, it's what the patient feels is important…Like the biggest thing for me is always the preconceived notions and trying to move past my biases as a person who is trained in Western medicine and the traditional bio-medical model. And trying to gain their* [patient'/family's] *understanding. (Nurse 5)*

Nurse 5 described self-awareness as something active and subsequently illustrated how this reflexivity helped them recognize an unconscious bias, thus enabling them to more broadly explore and understand a patient's/family's culturally influenced EOL needs. They identified the keystone of their experience as:

> *…being able to look past my preconceived notions. Because I would have just said, you know what, 'regular mainstream' - I hate to say 'white Canadians' - I would probably say 'they don't need all that care', but I was able to look past that and ask more. (Nurse 5)*

Dissonance Between Culturally Sensitive EOL Care and the Biomedical Model of Care in the ICU

This theme discusses the tension nurses in this study experienced between delivering culturally sensitive EOL care and the predominantly biomedical model of care within their ICUs. This tension appeared to stem mainly from trying to engage in the holistic and relational care of a culturally sensitive EOL practice within a reductionist, task-oriented model of care that privileged physical care and physiological health. This theme contains four subthemes: 1) needing to reduce culture to defined labels, 2) task-oriented care in the ICU, 3) a focus on physical care, and 4) an impersonal dying and death experience.

Needing to reduce culture to defined labels

Participants described tension between implementing a holistic view of culture and the systems and processes within their practice setting that required *Culture* to be simplified or categorized into defined and easily communicated ideas. For instance, one nurse observed that documentation requirements served to limit their practice in delivering culturally sensitive care, feeling that within their unit, culture is "*kind of directed to race and ethnicity*" (Nurse 1) in part because of "*the way we fill our forms*", and:

> *In the context of the workplace and health care, culture is related to religion and I feel like part of it is because in the admission, in emergency when you come in, the questions are 'what religion do you belong to?'*

Another nurse expressed a desire for a simple way of recording culture; wanting to approach the task in a "*systematic way*" (Nurse 3) and in a manner similar to the process for recording a patient's substitute decision maker or pain score, reflecting:

> *It's funny, you have to record surrogate decision maker as soon as someone's admitted. You could have ethnicity on there, although it's hard to say because ethnicity doesn't always mean values, like, you know, you may always go along with what your cultural beliefs are, or you may be the exact opposite. I don't know. It would be nice if there was that one phrase that every nurse was supposed to ask, like, you know, we all got really good at doing our vital signs for pain—like our pain is the 5th vital sign. There could be a way to add culture on there. (Nurse 3)*

This suggests that the documentation/communication practices within Nurse 3's ICU requires that a patient's culture fit within simple, clearly defined, and efficiently communicated categories. Since in Nurse 3's view this is not possible, they appear to be unsure of how to effectively communicate the patient's culture to colleagues. Nurse 3 further expressed that if culture could conform to their checkboxes, it would be assessed more frequently:

> *Maybe if it* [culture] *was on our end-of-life care standardized orders or something like that, that might be helpful. 'Cause we have all these checkboxes, you know, pain, sedation—if there was one even that said, like, end-of-life values or cultural preferences, that you had to fill out a one liner, even something like that might be helpful.*

These comments suggest that the emphasis on the standardization of processes within the ICU, using things like order sets, algorithms, or standardized forms, promotes a reductionist understanding of culture, where an individual's culture must conform to a checkbox or defined task. When attempting to describe culture in the context of EOL care within their ICU, one nurse captured the tension this reductionism created within their practice:

> *I don't really know how to define culture…if it is just ethnicity. But I think it is a whole bunch of pieces, like your ethnicity and your faith background and your — like I'm WASP, or Caucasian, or whatever. Like, those are all pieces of the culture, so it's—I don't think it's one thing, 'cause sometimes I think we just think of, 'oh, it's music' or it's how you're raised, or what—I think it's a much bigger, much bigger thing than what we label it to. 'Cause, culture is so hard to put—because the world is so diverse—to put it just into one little thing. (Nurse 2)*

Task oriented care in the ICU

Participants described nursing practice in the ICU as task-oriented and highlighted how this created challenges when trying to be culturally sensitive during EOL care. Many participants indicated that they experienced tension between the pressure to complete the tasks of ICU nursing care and the relational requirements of delivering culturally sensitive EOL care. This experience was captured by one nurse who explained that, to become oriented to their patients'/families' culturally influenced perspective of care:

> *I try to do everything I can first so that I can dedicate that time. I address the blood work, address all of the meds, but then really after all that's done and helping others—going down to talk with them* [the family]*. And that's often a barrier now-a-days because our workload is getting higher. (Nurse 5)*

Nurse 5 further observed that this struggle was a shared experience among staff and felt that because of this focus on tasks, quality communication skills were getting lost:

> *Getting that dedicated time to have that discussion that's really open, it's actually getting lost. And I'm seeing that especially among novice ICU nurses—mind you I'm just above novice—because they're so busy focusing on the tasks that are placed on them. Based on organizational needs, based on doctors' orders, based on what they believe they should do themselves. When really one of the best things you can do is just really have those discussions. And that's our—that really our communication is getting lost. That's unfortunate and I think that's one of the things I've found over the years. (Nurse 5)*

The pressure to complete specific tasks rather than engage in relational care appeared to be an important influence that shapes ICU nurses' conceptualization of EOL nursing practice and how they prioritize care. One nurse highlighted that this was a key reason why participants had difficulty discussing culturally sensitive EOL care, describing ICU nurses as "*doers*" (Nurse 1), and that, "*because everything is skills and tasks and things like that*" within the ICU, nurses feel cultural sensitivity is not tangible:

> *One of the issues I feel is that cultural sensitivity is not something that is tangible like skill-wise. Like, something you can do and then that's it. It makes it difficult, and I know even going back into nursing, you know, thinking about what nurses do? A lot of us can't answer that question because we just do—we just can't describe it or for some reason it's just so—it's not as fluid as you would with doing ABC and you get an E. (Nurse 1)*

This suggests that nurses in the ICU think of care in terms of concrete, linear tasks, and since culturally sensitive EOL care does not conform to these terms, they, as doers, are unsure of what to *do*. This perspective is illustrated by another nurse's request for practical guidance; some sort of plan they could follow:

> *Like honestly everyone just says provide culturally sensitive care. But what does that mean? I'm a very practical practitioner. I'd like to see it, you know—you can lay out the plans for me, but I'd like to see how it translates to what I'm doing for a day. And if we can do that, and we can make it more clear, then probably we can plan better in the front line. (Nurse 5)*

These findings highlight how participants exhibited a linear, task-oriented perspective of EOL nursing care and, as such, struggled with the amorphous and less concrete nature of culturally sensitive EOL care delivery.

A focus on physical care

Participants also identified that the prioritization of physical care and physiologic health within their practice setting is a challenge when trying to adopt a holistic approach

to cultural sensitivity during EOL care. Most nurses in this study felt that the prioritization of physical care within their ICU resulted in many psychosocial aspects of EOL needs (like values, beliefs, fears, and differences in the meaning of concepts such as health/disease/comfort) being overlooked or ignored, despite being important and culturally relevant to patients/families. This seemed to create a sense of dissatisfaction or discontentment among participants. For instance, one nurse observed that staff generally focus on the physical state of the patient and that "*personally, as an ICU nurse, we* [the participant and their colleagues] *don't do a good job assessing those fears that the patient has…I think that's the biggest prerequisite, as I would say, to providing culturally sensitive EOL care*" (Nurse 5). Another nurse was critical of the comparatively greater importance placed on physical assessment of the patient within their ICU compared to investigating important, culturally-relevant psychosocial elements like values and beliefs. They passionately observed:

> *Nobody ever assesses it…we admit people in crisis, we admit people when that's not important, or doesn't feel it is as important as understanding what's their comorbidities …I feel like it's* [values, beliefs, and cultural preferences] *extremely, extremely important and it's—it takes a huge backseat to the medical care we provide, but it should guide the medical care we provide. (Nurse 3)*

Other participants described the lack of support for a holistic view of patients and felt that cultural context was often not properly considered at the EOL, and thus ignored. One particular nurse's criticism illustrates this. They reflected that, when planning EOL care:

> *I would say overall our intensivists don't put much thought into it* [culture]. *Some nurses might consider it….but I don't think much thought goes into it…If a patient is at the end of life, the perception is that you hang your Versed and your fentanyl*

> *drips and away you go. It doesn't—the patient doesn't require anymore care. (Nurse 6)*

Nurse 6 further explained that this view of patients and EOL care influenced the training priorities within their unit, and as a result, they felt unsupported in delivering culturally sensitive EOL care, noting "*we can't get training on how to set up the level one* [infuser] *on a regular basis, so to get cultural training on how to interact with a different culture is not high on anybody's radar*". This nurse appeared dissatisfied and frustrated by this lack of support.

Another participant seemed similarly bothered by the focus on physical care and physiologic health within their practice setting and highlighted how this view made delivering culturally sensitive EOL care challenging since the patient's/family's perspective was often not well understood. This nurse explained that, in their practice setting, clinicians often consider "*only* [the patient's] *physical state*" (Nurse 5) during interactions and communications with patients/families and that this often led to a lack of awareness concerning differences in perspectives regarding health/illness/care, impairing communication. This nurse observed:

> *They* [patients and family members] *see that God will give them that miracle no matter what. There's that sense of grit that I read about in the Bible. Where, you know, if you stick through it and you persevere and you believe with your heart and you see with your mind, but you don't believe what's in front of you. You know that the patient will survive. And I think that's where culture comes to play with the disease model and there is an opportunity to actually look at the way culture looks at disease at the end of the day. Or, like, is it even called disease?...we don't approach it that way. We approach it the one way, which is, 'let's focus on their prognosis and the quality of life', as opposed to 'let's focus on prognosis, quality of life and how they see it based on their culture.' —and I think that's what is really lacking. (Nurse 5)*

Participants also described how the prioritization of physical care and physiologic health within their practice setting made it challenging to meet the emotional and psychosocial needs of patients and families. For instance, one nurse described how providing a patient/family with an appropriate physical environment at the EOL was challenging in a setting where the physical care of others was ever-present and often took priority, stating:

> *Privacy is a huge issue…We close the curtains, so, I think they* [family] *have the perception that they're by themselves. We know they're not because we can see everybody else in the room and we can hear what's going on and…you've got somebody doing chest physio, you know, in the next bed. (Nurse 6)*

Nurse 6 further observed that their busy workload impacted the quality of their presence because they focused on *doing* physical care rather than *being* with the patient/family during care:

> *So, you often end up being doubled and then you just don't have time. You're too busy looking after this patient that does need you, and then, providing care. You're still turning and bathing and that sort of thing. But, you know, there's not the time to spend with families then. (Nurse 6)*

These findings capture how time constraints and limited privacy impaired participants' capacity to be fully present and engaged when delivering care, something that was important to these nurses' overall approach to culturally sensitive EOL care. Additionally, these findings suggest that, in the context of workload pressures, physical care takes priority over psychosocial care.

An impersonal dying and death experience

The experiences of tension for many participants appeared to be fueled by a recognition that the model of care in their ICU can lead to an impersonal EOL experience

for both patients/families and staff. For instance, one nurse explained that culturally sensitive EOL care is important because, when care is sensitive and responsive to patients'/families' cultural-based needs, the experience becomes more personal and less sterile:

> *I think it makes it less—I want to say—less sterile. If I can connect with them on a cultural level, if I can find a way to make it so that the death is not feeling like it's in the hospital and with all the machines around and such, but it would be more like what would happen if they were at home. So, if you can connect with them that way, you can get an appreciation for making it less institutionalized. (Nurse 2)*

Nurse 2 further emphasized that the model of care in their ICU, in particular its focus on tasks and physical care, can result in staff not remembering to recognize a patient's humanity:

> *We don't get to have that moment of going, 'Ok, you know, this is a human being and we respect the life that is there.', whereas—'cause, we're so focused on doing the next thing, we don't get to do that. But in that situation with the smudging* [the patient's/family's Indigenous cultural practice] *you get to be sort of— there's that piece that you know that everybody is together and is ok, I guess.*

Nurse 2 appears to find satisfaction in the human connections they experience when attending to the culture-based needs of patients/families. Nurse 2's observations are reflected in another participant's account of working to facilitate a family's request to have their loved one's body reside undisturbed within their ICU bed for a prolonged time after death. This nurse explained that this practice was "*quite difficult to accommodate because most people are expected to leave a few hours after the death*" (Nurse 4). In this situation, Nurse 4 worked against the 'usual process' to deliver a more personalized and meaningful death experience for the family/patient despite pressure of *doing the next thing* and moving on to the next patient. Importantly, Nurse 4 also appeared to find

meaning and peace in being able to accommodate the cultural beliefs of the patient/family during EOL care, noting that what was meaningful was:

> *…the peace that came from the accommodation of cultural beliefs on the part of the family. The patient was not conscious, but I like to think that that really brought peace to the patient. And peace to myself. I was happy for the family that they were able to see things done the way they would have.*

Needing Support to Adopt a More Relational Approach to Care into the ICU

Despite participants' perceptions that culturally sensitive EOL care is person-centered, it was evident during analysis that ICU nurses still struggle to fully embrace the relational nature of how this care is delivered. This theme discusses key facets of participants' need for support with clarifying, developing, and honing the relational capacities and skills necessary for a person-centered approach to culturally sensitive EOL care. This theme has four subthemes: a) looking for tools rather than support for a compassionate approach to care, b) learning from and finding support among colleagues, c) needing support for reflexive practice to improve relational care, and d) emotional baggage can prevent deep connections with patients/families.

Looking for tools rather than ways to support a compassionate approach to care

In general, participants felt that, to adopt a more culturally sensitive EOL practice, they needed concrete or systematic instructions such as tools, frameworks, or facts, rather than guidance about how to develop the relational capacities which are the heart of a culturally sensitive EOL practice. For example, one nurse wanted concrete instructions about how to assess and/or respond to a patient's/family's culture during care, feeling that their ideas regarding culturally sensitive EOL care delivery were too abstract to be practical:

> *I guess in all of my palliative care education too, I've had a lot—they talk a lot about, you know, assessing people's values, assessing people's cultural background. Honestly, I'm not sure if I've really ever been given any good tools to do that. It's just been said, like, it is important to ask about this, but I don't always—but how to ask is hard—and, like, what specifically to ask and then what to do with that information, those things are all challenging. But I—in all of my palliative care education it's always in there, as in, this is an important part of end-of-life care—is cultural care, but it kind of ends there and it's kind of an abstract idea. (Nurse 3)*

Importantly, Nurse 3's lack of concrete tools left them feeling that, "*it's* [culturally sensitive EOL care] *uncomfortable, or I haven't been trained to do it*". This seems to suggest Nurse 3 feels that knowing what to *do* to be culturally responsive will help them be more culturally sensitive, and that without this knowledge they feel uncomfortable with or insecure about this facet of their professional role at the EOL. Another nurse conceptually understood the relational nature of culturally sensitive EOL care (describing culturally sensitive EOL care as *"this complex interaction between **the** culture of the family and the patient and **our** culture of the family and patient*" (Nurse 5)), but still described it as "*the vague commandments*" and struggled to ground this conceptual understanding within a task/action/activity-oriented practice, stating that:

> *I just don't know how it translates to what we do here except letting them be at the bedside. Holding their hand. Playing their music or involving the—a member of the spiritual community. That's all I know, but really, there's a lot more to it than what we're doing. We just need someone to actually come over to the front lines to talk to us and give us directions. And that's missing…give us a tool or a framework, even that's less vague.*

A possible reason for Nurse 5's feelings about culturally sensitive EOL care could be that they were unsure of how to develop the relational skills and capacities which support their theoretical understanding of culturally sensitive EOL care. This is something suggested by Nurse 5's advice to learners that to become more culturally sensitive during

EOL care they need to, "*gain that sense of empathy. And I personally don't know how to instill that upon them. But it's something that really needs to be considered*" (Nurse 5).

Another nurse desired knowledge about different cultures as a framework for their dialogue and suggested that a "*a cheat sheet or something*" (Nurse 2) regarding different cultural/religious beliefs would help support better conversations with patients/families about their cultural needs:

> *…if we just had a little—I don't know—and maybe it's not something you could do, but have a cheat sheet or something that let's you know these are things to think about in this—for this cultural perspective. Like, 'these are things that are important for someone who is Muslim', 'this is important for someone who is Buddhist', or whatever. Just so they can cue the nurse when they are having that conversation. That they know what to ask or what to say. You know? because I think maybe for some learners they don't—even like myself, I don't know every single thing out there. I sometimes I need cue's for me to help them to find where they are going. (Nurse 2)*

In this statement, rather than look for support with developing the skills or capacities that support mutually meaningful engagement and compassionate care, Nurse 2 appears to be looking to knowledge about different cultures as a way to streamline the process of unearthing cultural EOL needs and provide greater certainty about which questions they should ask.

Learning from and finding support among colleagues

Nurses in this study described having limited opportunities to expand their personal perspective of culturally sensitive EOL care delivery beyond the dominant perspective of their practice setting. Participants identified the primary sources of their knowledge as their workplace, colleagues (mentors), and on-the-job experiences. They described their relevant knowledge as coming "*just from experience…there's no formal*

training" (Nurse 6), "*from colleagues, from working, experience of working*" (Nurse 1), and also from, "*others who have done it before, others with experience; they're the ones that helped me grow the most in this area*" (Nurse 5). Participants also discussed how there was a limited influx of new ideas and perspectives regarding culturally sensitive EOL care delivery into their practice setting. One nurse identified that, since beginning to work on their unit, there had been little shift in their unit's culture regarding culturally sensitive EOL care delivery, observing that "*in the five years that I've been there I haven't really noticed much of a change*" (Nurse 2). Another nurse suggested that when it came to culturally sensitive EOL care, "*it's not something that anybody offers any training on. It's becoming more—you do hear about it a little more at conferences and stuff, but it's only fairly recently*" and added that, on their unit, culturally sensitive EOL care is a low training priority, noting:

> *It* [culture] *doesn't come up often enough for it to be high on anybody's radar. You know, there are so many other things that we are dealing with…so to get cultural training on how to interact with a different culture is not high on anybody's radar. (Nurse 6)*

These comments suggest that Nurse 6 has limited access to new ideas about culturally sensitive EOL care delivery and, as such, still believes that knowledge about different cultural groups is the foundation of their sensitivity. Another nurse described feeling unsure of how to handle systemic and social issues important to indigenous peoples (something that generally requires a relational approach to care), and felt they needed administration to step in and provide guidance, stating:

> *What does it mean when I have a specific conflict? Like there's a conflict between my view and their* [patient's or family's] *view…and it becomes even more muddier when we're trying to do TRC, the Truth and Reconciliation for Indigenous*

> *groups…We recognize and we acknowledge the treaty and we acknowledge the lands, which is great, but what does it mean when we are into specific situations that are difficult? I don't know and that's where we truly need the support. I think it comes from a top-down approach. (Nurse 5)*

This comment may indicate that there is limited knowledge and awareness among staff regarding the role of relational care in working with individuals whose experiences of historical trauma and discrimination are culturally important contextual factors.

Importantly, without the introduction of new or emerging ideas about culturally sensitive EOL care delivery, participants' practice settings became an echo chamber in which the dominant perspective was maintained. This was captured by one nurse in particular. They described how their focus on physical care at the EOL was reinforced by another nurse's validation and reassurance regarding a distressing EOL experiences:

> *I think the big thing was talking about it with people on the unit. People like* [Nurse 2's colleague] *was like really good in just saying that, 'You gave her a good death. You gave her drugs and kept her comfortable. She wasn't suffering when she died, you know, she wasn't in any pain.' (Nurse 2)*

Support from colleagues was participants' primary way of trying to work through their thoughts and feelings associated with distressing EOL situations, and as such, represents an important way that the dominant perspective of good EOL care was perpetuated. Nurse 2's comment also captures how most participants reconciled the care they delivered with their personal values and beliefs by trying to focus on elements of care which they felt were *good*.

Needing support for reflexive practice to improve relational care

It was evident during analysis that participants needed support with recognizing the assumptions and biases that influenced the EOL care they deliver. Most participants

discussed how the cultural biases within their unit influenced how staff interact with patients and families. One nurse described how ICU nurses' capacity to show compassion and respond to patients/families in ways that are meaningful to the patient/family was influenced by their ability to recognize the biases within their standard practices. This nurse observed:

> *I think we often make the mistake of comforting people by saying—people want to be so caring that they will want to say things like, 'Oh, you know, they are going to a better place', or 'God has a plan for them' or things like that and it's—for some people that's not what they believe at all. And, you know, you're really imposing your own beliefs on them. (Nurse 3)*

Another nurse observed that their ICU was still, "*very much a western society ICU*," adding that awareness of the "*white, Anglo-Saxon, Protestant whatever Catholic*" (Nurse 2) perspective varied among staff. They further explained that these biases limited nurses' openness to different cultural perspectives of EOL care, commenting, "*I think that limits it in some ways to how much. And I don't know how much then gets translated. Like, I don't know how much openness there is and some of that to culture, different cultures*" (Nurse 2). This was also illustrated by another nurse's comment:

> *It's distressing to us to see somebody be so demonstrative about their grief. Because we don't operate that way in our culture here…There was definitely a lot of that—you know? Not accepting, because that's not how we operate here. People don't like people who are behaving differently from them. (Nurse 6)*

These comments represent how an inability to recognize and/or move past personal biases promoted judgmental or adversarial attitudes towards patients/families which contributed to participants' feelings of distress during EOL care. Their comments also highlight how most nurses described *othering* (creating us vs. them) practices or attitudes within their units. For example, one nurse described singling out culturally

different patients and families by only actively exploring culture when they perceive the patient/family to be different from the cultural norm, commenting, "*I honestly don't ask everyone, 'Oh what's your culture like?', but only when I believe and I perceive and I see that they're of a different culture. That's when I say, 'Can we have a discussion? Let's talk about this*" (Nurse 5). When asked to reflect upon why this was the case, Nurse 5 explained that:

> *I actually haven't thought about it, but I just (laughs)— I can now. Oh my gosh! I think it's part of that bias that I've been talking about. There's this implicit bias that I have that a lot of us have, but we don't recognize it until we actually reflect on it, which is now.*

This comment suggests that Nurse 5's *othering* behaviour is a common practice within their unit which staff generally have not reflected upon or recognized as biased. Another nurse's comment expressed an *othering* attitude and demonstrates a need for better awareness of this issue when they stated, "*You know if you're doing something a little different for a family that has different needs from* ***our*** *own*" (Nurse 6).

Emotional baggage prevents deeper connections with patients/families

A few participants also highlighted how ICU nurses' repeated exposure to suffering can lead some to be unwilling or unable to emotionally engage with patients/families during EOL care and that this limits their ability to provide culturally sensitive EOL care. For example, when reflecting upon the delivery of culturally sensitive EOL care within their unit, one nurse felt that:

> *People are very insensitive, and they just don't care, because of what they see [patient suffering]…so, people get very jaded and they just get very insensitive, and they just don't care. It's easier to just shut off that side" (Nurse 7)*

Nurse 7 identified this as an important barrier to the provision of culturally sensitive EOL care. Another nurse further explicated how, for some, this was a protective measure, suggesting that the emotional toll of ICU nursing care may lead some nurses to feel unable to engage on a deeper level with patients and families at the EOL. They stated:

> *I realized what we do in the ICU is not normal. Like, this is not normal life. So, I think maybe some people just put up that wall so that they can protect themselves so they can continue to do the 'not normal' for their career. (Nurse 6)*

Summary of Main Findings

These findings reflect that within participants' current EOL practice, culturally sensitive care and person-centered care are entwined and inseparable from one another. Nurses in this study described culture as an expansive, foundational, and unpredictable influence on EOL needs and wishes, and described their understanding of cultural sensitivity as grounded in person-centered principles. Participants described being culturally sensitive by focusing on learning about the patient as a person, using cultural knowledge non-deterministically, and looking past assumptions and biases to properly see the patient as they truly are. However, while participants indicated that cultural sensitivity and person-centered care cannot be separated at a practice level, findings suggest that the nature of this connection does not appear well-established within their body of practice knowledge.

Study findings also reflect that participants experience tension between delivering culturally sensitive EOL care and the predominantly biomedical model of care of their ICUs. Participants described how the systems and processes within their practice setting

require that culture be reduced to labels, causing tension between a Gestalt view of culture and a need for culture to be categorized. Similarly, participants described how the model of care in their ICU leads to task-oriented EOL care (i.e. a checklist approach) and prioritizes physical care and physiologic health. These factors were incongruent with the holistic person-centered care that participants felt led to a culturally sensitive EOL practice, leading to tension within their current practice. Participants also discussed how these factors influence ICU nurses' conceptualization of EOL nursing care and that this resulted in culturally sensitive EOL care feeling *intangible*. For most participants, their experience of tension appeared fueled by a perception that the model of care in their ICU leads to an impersonal death and dying experience for both patients/families and staff, but that sensitively attending to cultural needs can create meaningful and satisfying experiences.

Finally, study findings reflect that participants need support with integrating a more relational approach to culturally sensitive EOL care within their current ICU practice. In general, key areas of support included: a) help with identifying ways to develop the relational capacities at the heart of a person-centered approach to culturally sensitive EOL care; b) increased exposure to new or emerging evidence-based approaches to culturally sensitive EOL care delivery; c) help with recognizing assumptions and biases and with improving reflexivity during practice; and d) emotional and psychological support to help cope with repeated exposure to others suffering.

CHAPTER 5: DISCUSSION

This chapter addresses the overarching findings of this study in relation to current literature and conceptual models/theory. The current study advances knowledge about nurses' experiences with trying to implement a culturally sensitive EOL practice within the ICU. Reflecting upon the study findings and previous work, including the broader body of literature and related theories, the following areas will be discussed: 1) reductionism in the ICU model of care; 2) relational inquiry to encourage culturally sensitive, high quality person-centered EOL nursing care in the ICU; and 3) ICU nurses' distress with EOL care. While previous studies have examined ICU nurses' experiences caring for culturally and linguistically diverse patients (Høye & Severinsson, 2010b; Listerfelt et al., 2019), this is the first known study which captures ICU nurses' understanding of how culturally sensitive care is delivered and their perceptions of cultural sensitivity within their current EOL practice.

Reductionism Within the ICU Model of Care

Participants discussed how they struggled to enact principles of culturally sensitive EOL care within their nursing practice in the ICU. These findings are not surprising considering that the underpinnings of these principles are grounded in a holistic approach to nursing care, which traditionally has not been fully realized in the ICU (Valizadeh et al., 2017). Other studies have reported similar findings; that is, nurses perceived that the ICU context creates significant obstacles to delivering holistic patient-centered care (Chen et al., 2020; Alshehri et al., 2020; Jakimowicz et al., 2017; Kiwanuka et al., 2019). Studies have documented issues related to time constraints/workload issues,

lack of physical space/privacy, restrictive visiting hours, a focus on physical health/lack of attention to psychosocial needs, and the technological complexity of the ICU as characteristics of the ICU model which hinder holistic caring within the ICU (Alshehri et al., 2020; Jakimowicz et al., 2017; Kiwanuka et al., 2019). This study adds that reductionism within the ICU model of care can be a significant challenge when trying to adopt a holistic approach to cultural sensitivity during EOL care.

The dissonance between delivering holistic, culturally sensitive care at the EOL in a largely reductionist setting like the ICU can cause a sense of tension for nurses. For example, nurses in this study discussed how assessment and documentation practices in the ICU take a standardized 'checkbox' approach that forces a patient's culture to fit within simple, clearly defined, and efficiently communicated categories. This practice does not address the complexity of cultural identity in today's modern society or the cultural diversity within "categories" of people (Barros & Albert, 2020; Fang et al., 2016). Canada has a multicultural society, with over one third of citizens identifying as having a multi-ethnic/cultural ancestry and over 450 different ethnic/cultural origins being represented in the 2021 Canadian Census (Statistics Canada, 2022). However, culture is not limited to ethnicity or religion and individuals hold allegiances to multiple cultural groups (belonging to groups associated with age/generation, socioeconomic bracket, ability/disability, etc.) (Fang et al., 2016; Hartrick Doane & Varcoe, 2015). Consequently, culture is dynamic and individuals and communities develop multicultural identities which do not align with the 'checkbox' approach to culture that nurses in this study indicated was favored within their ICU practice setting (Barros & Albert, 2020;

Hartrick Doane & Varcoe 2015; Hong & Khei, 2014). In this study, participants experienced cognitive tension when they were forced to reduce culture to specific labels or defined categories.

Current study findings appear consistent with a recent retrospective descriptive study by Brooks et al. (2022) which found that ICU nurses categorize their documentation of care and assessments by organ system or other defined categories like *psychosocial care*, and that culturally sensitive care is rarely effectively documented (Brooks et al., 2022). Venis and Dodec (2020) found a similar separation within ICU nurses' assessment and documentation of physical needs and psychosocial needs when investigating the feasibility and acceptability of a palliative approach screening tool within a Canadian ICU. While the findings of Venis and Dodec (2020) do not specifically address culture, they do suggest that assessment and documentation practices force a segregation and categorization of care elements. This study found that this categorization extends to culture and influenced how ICU nurses conceptualize culture within the EOL care they provide. Importantly, taking a reductionist or 'cookbook' approach to understanding cultural needs can promote issues such as stereotyping, othering, and stigmatization which are harmful to the therapeutic relationship and individuals' experiences of care (Claeys et al., 2022; Degrie et al., 2017; Schuster-Wallace et al., 2022). This raises the possibility that ICU assessment and documentation practices may impede culturally sensitive EOL care and highlights an area for future research.

This study found that participants' reductionist tendencies regarding culturally sensitive EOL care were highly influenced by the effect of the standardization of

processes within their ICU practice environment; using things like frameworks, algorithms, or standardized forms/order sets to improve EOL care. Literature indicates that this focus on standardization is aimed at improving deficiencies in EOL care (Alshehri et al., 2020; Jakimowicz et al., 2017; Kim et al., 2022; Kiwanuka et al., 2019; Mroz et al., 2021; Vuong et al., 2019). For instance, in response to a documented desire for guidance regarding EOL care delivery among Korean ICU nurses and staff, Kim et al. (2022) created a 25-item protocol to direct nursing care at the EOL which was divided into three phases of care. Studies by Vuong et al. (2019) and Mroz et al. (2021) represent how this protocolization can lead to a focus on defined tasks and a linear view of care. Both studies employed the same *Care and Communication Bundle* to assess and improve palliative person-centered care within American ICUs. This *Bundle* was a linear and systematic protocol designed around completing specific tasks at defined time points (at days 1, 3, or 5 post-admission) and was deemed to improve the overall quality and efficiency of care in their respective ICUs (Vuong et al., 2019; Mroz et al., 2021).

In contrast, the findings of the current study demonstrate that a focus on standardization and frameworks perpetuated a desire for culture to fit within predetermined categories or tasks and that this does not support a holistic view of culture or capture the relational nature of culturally sensitive EOL care. These findings suggests that, while standardization may help guide actions in the ICU towards a more palliative approach, it creates a simplified view of EOL care delivery which does not address foundational interpersonal capacities like compassion, empathy, humility, or effective communication; capacities that are central to participants' understanding of how

culturally sensitive EOL care is delivered. In fact, literature suggests that strict adherence to protocolized EOL care without development of effective communication skills or compassion may lead practitioners to feel more competent in delivering EOL care but may not translate to a person-centered approach or better experiences for patients and families (Borgstrom & Dekker, 2022; Jakimowicz et al., 2017; Parry et al., 2013). In the current study, ICU nurses seemed insecure about their ability to be culturally sensitive during EOL care without standardized frameworks, tools, or protocols. This may indicate that ICU nurses struggle to embrace the uncertainty associated with a more relationship-based practice (Hartrick Doane & Varcoe, 2015; Koloroutis & Trout, 2012) and require knowledge and training to help them feel more comfortable in doing so.

Overall, these findings of the current study suggest that an implicit reductionism within the ICU model of care can make implementing culturally sensitive EOL care challenging. However, there is a notable paucity of literature on the subject, indicating further research is needed to better understand this phenomenon and devise strategies to counteract it.

Relational Inquiry to Encourage Culturally Sensitivity, High-Quality Person-Centered EOL Nursing Care in the ICU

Participants in this study also discussed how culturally sensitive EOL care and person-centered care are interdependent within their current EOL practice. Considering that high quality EOL care in the ICU is person-centered (Aslakson et al., 2021; Bloomer et al., 2017; Noome et al., 2016), these study findings are not particularly surprising. However, they were unexpected. This study was initially undertaken with the intention of

focusing on patient/family culture in the context of EOL care delivery. However, over the course of the study, it became evident that this narrow focus created artificial boundaries within participants' nursing practice and that there was little difference between participants' approach to being sensitive to a patient's/family's culture during EOL care and their approach to being sensitive to these individuals as complex and unique human beings. As no other studies have explored ICU nurses' perceptions of how they are sensitive to the culture of a patient/family, this knowledge is new and significant.

Despite limited research on ICU nurses' perceptions of culturally sensitive EOL care delivery, study findings appear consistent with the current discourse regarding culturally sensitive EOL care within the broader healthcare literature. Previous literature has emphasized the need for a person-centered approach when addressing culture within one's practice (Claeys et al., 2022; Epner & Baile, 2012; Hartrick Doane & Varcoe, 2015; Lor et al., 2016; Narayan & Mallinson, 2022; Schuster-Wallace et al., 2022; Shepherd et al., 2019) and suggests that, because the influence of culture is felt in all aspects of life, cultural sensitivity and high-quality person-centered care are interchangeable at an individual practice level (Beach et al., 2006: Epner & Baile, 2012; Narayan & Mallinson, 2022; Schuster-Wallace et al., 2022). A recent qualitative descriptive study examining nine North American transcultural nurses' views of culturally sensitive/patient centered assessment and care planning also had similar findings to this study (Narayan & Mallinson, 2022); namely that participants: a) frequently did not differentiate clinically between culturally sensitive and person-centered care; b) understood a caring attitude and a strong nurse-patient relationship were the source of both cultural sensitivity and person-

centeredness; and, c) felt that needs assessments must be holistic if care is to be sensitive to individuals' unique expressions of culture (Narayan & Mallinson, 2022). While the study by Narayan and Mallinson (2022) was not set in an ICU context or at EOL, it does capture the opinions and beliefs of perceived experts and their findings align with that of the current study. Importantly, the study Narayan and Mallinson (2022) is the only other study found which captures nurses' perceptions of how they deliver culturally sensitive care. For this reason, there is a substantial need for further research in this area in order to either confirm or deny the claims of this study and more deeply understand this phenomenon in varied contexts.

A particularly significant finding of this study is that participants implemented a person-centered approach to cultural sensitivity during EOL care by building relationships. In particular, participants described how a culturally sensitive EOL practice comes from developing an open and supportive therapeutic relationship and learning about the patient/family holistically and as complex persons. In the current study, this came about through the intersection of person-centered communications, authentic caring, reflexivity/self-awareness, humility, and the use of cultural knowledge which helped them connect with patients/families on a personal level and helped patients/families articulate culturally influenced EOL needs and perspectives of care. These findings are valuable as previous literature has highlighted that healthcare professionals generally feel improving their capacity for a culturally sensitive and/or responsive practice comes from increased knowledge about diverse cultures (Ganz & Sapir, 2018; Gutysz-Wojnicka et al., 2022; Hart & Moreno, 2014; Shepherd et al., 2019). For instance, the qualitative study by Hart

and Moreno (2014) found American nurses perceived that having to learn the cultural preferences of a vast number of different cultures was a significant barrier to caring for culturally diverse patient populations. The study also found that nurses were overwhelmed by the overall diversity of preferences and values, not just across patient cultural groups, but within groups as well. These findings capture how a 'cookbook' approach to cultural sensitivity, where a nurse's capacity for a culturally sensitive practice is dependent on their knowledge about different cultural groups, is not feasible within modern nursing practice.

In contrast, the current study found that participants' approach to culturally sensitive EOL care was not reliant on their cultural knowledge, but grounded in universal relational skills (e.g. empathy, openness, caring, self-awareness, humility, etc.) and the development of a strong therapeutic relationship. This appears to be a more inclusive approach to cultural sensitivity as it encourages individuals to open up and share what is meaningful to them. Possible reasons for the differences in results between this study and that of Hart and Moreno (2014) could be the changing cultural climate of healthcare or differences in the cultural discourse within Canada and the United States.

A relational approach to cultural sensitivity during EOL care is important for several key reasons. First, relational capacities are essential for realizing a palliative approach within an ICU context (Aslakson et al., 2021). All patients/families, regardless of culture, are human beings deserving of compassionate care at the EOL and, as such, a relational approach to EOL care is universally important. Second, previous studies exploring patients' perceptions of intercultural care encounters have found that a

clinician's compassion during care and their ability to make a patient feel seen, heard, and valued as a unique human being can help overcoming cultural differences (Degrie et al., 2017; Nayfeh et al., 2021; Singh et al., 2020). This is particularly important in light of current plans to increase immigration over the next three years (Government of Canada, 2022). Thus, the cultural, ethnic, and religious diversity of Canadian society is set to increase and Canadian ICU nurses will need to be competent in delivering culturally responsive care with minimal prior knowledge about a patient's/family's cultural context. Finally, other studies on intercultural care have found that when critical care professionals do not value the perspectives and psychosocial needs of patients/families during communications, care is negatively impact and miscommunications and conflict can result (Yu et al., 2021; Van Keer et al., 2015). Better relational care may help overcome these issues as communications become person-centered within this approach, and emphasis is placed on understanding the perspective of the patient/family, even during conflict (Hartrick Doane & Varcoe, 2015; Koloroutis & Trout, 2012). Empathy and compassion are associated with behaviours intended to help others and have been shown to help with conflict resolution (Klimecki, 2019).

A key finding of this study is that, despite participants' descriptions of culturally sensitive EOL care being relational in nature, they appeared insecure about this understanding and expressed that they needed guidance regarding how culturally sensitive care should be delivered. This finding is unsurprising, given that other studies have similarly documented that ICU nurses feel they have significant knowledge and training gaps regarding EOL care (Karbasi et al., 2018), including aspects related to cultural

sensitivity (Gutysz-Wojnicka et al., 2022; Hart & Moreno, 2014; Jang et al., 2019; Shepherd et al/, 2019). Additionally, the shift to a holistic, multidimensional, and dynamic view of culture is relatively recent within the broader healthcare context (Hartrick Doane & Varcoe, 2015; Epner & Baile, 2012) and the concepts of cultural sensitivity and person-centered care have evolved separately (Beach et al., 2006; Epner & Baile, 2012; Lor et al., 2016), and are generally addressed separately within the literature (Lor et al., 2016; Schuster-Wallace et al., 2022). These factors suggest that ICU nurses need guidance regarding how culturally sensitive EOL care should be delivered and that this guidance should clearly establish the connections between relational care and sensitivity to an individual's culture. The findings of this study also add that this guidance needs to help ICU nurses understand how to develop the relational skills and capacities that are at the heart of a relational approach to culturally sensitive EOL care. This increased clarity may be important as it could help avoid role ambiguity in EOL care delivery, in turn decreasing stress and burnout and increasing compassion satisfaction and job satisfaction (Cengiz et al., 2021; Wells, 2021).

A possible solution to these knowledge needs could be education/training regarding Relational Inquiry (Hartrick Doane & Varcoe, 2005b). While there are other relational care theories and frameworks, Relational Inquiry may be particularly helpful in assisting ICU nurses with developing a more culturally sensitive EOL practice. Based upon these study results, ICU nurses could benefit from Relational Inquiry's: a) conceptualization of the individual and their culture and context as inseparable; b) emphasis on self-compassion and development of relational capacities and skills; and c)

guidance regarding how to develop reflexivity skills (Hartrick Doane & Varcoe, 2005a, 2015). The use of a post-structural lens to view caring situations (a component of a Relational Inquiry approach) may be particularly helpful with developing a more culturally sensitive practice. Nurses in this study seemed minimally aware of both the power dynamics within their nurse-patient/family interactions and their *othering* attitudes and behaviours. A post-structural lens critically examines power dynamics, inequalities, and the social structures which shape individuals' experiences and worldviews, and consequently, can help draw attention to these issues which influence nurse-patient/family interactions (Hartrick Doane & Varcoe, 2015).

Implementing a more relational approach to care within the ICU, however, will likely be challenging. Consistent with previous literature, the current study found that the circumstances surrounding nursing practice in the ICU interfere with the ability of nurses to be a compassionate presence at the bedside and/or meaningfully engage and connect with families during the EOL period (Jakimowicz et al., 2017; Karbasi et al., 2018; Noome et al., 2016; Vaughn & Salas, 2022). Previous studies have documented how it is challenging for ICU nurses to dedicate the necessary time and energy to build strong therapeutic relationships during care because of high workloads, time constraints, limited privacy/space, the cumulative impact of emotional demands, and a dominant biomedical culture within their practice setting (Basile et al., 2021; Jakimowicz et al., 2017; Karbasi et al., 2018; Noome et al., 2016; Slatore et al., 2012; Stokes et al., 2019; Vaughn & Salas, 2022). These obstacles are consistent with the findings of the current study. Moreover, the current study builds upon previous work to elaborate on how ICU nurses conceptualize

their practice around the tasks they complete, highlighting that when they are busy, ICU nurses tend to focus more on physical care rather than engaging in holistic support for patients/families. These characteristics are obstacles to implementing a relational approach to care (Hartrick Doane & Varcoe, 2015; Koloroutis & Trout, 2012) and indicate that supporting relational practice within an ICU is not only the responsibility of ICU nurses, but also needs to be prioritized at the organizational level. Similarly, a substantial shift in culture within the ICU needs to occur away from the predominant biomedical model of care to include more emphasis on psychosocial care to improve nurse-patient/family interactions within the ICU (Slatore et al., 2012).

Overall, the findings of the current study suggest that relational person-centered care is the path to culturally sensitive EOL practice within the ICU, but that ICU nurses will need support to embrace and implement this type of care. Findings indicate that this support will need to be multi-faceted as ICU nurses face complex obstacles to building strong therapeutic relationships with patients/families that are implicit within the ICU culture and model of care.

ICU Nurses' Distress with EOL Care

This section discusses study findings in relation to current literature regarding the emotional and psychological distress ICU nurses associate with EOL care delivery. With the emergence of COVID-19 and a recognition of the impact it has had on healthcare professionals' wellbeing, issues regarding distress associated with delivering EOL care have been placed in the spotlight (Galanis et al., 2021; Saravasan et al., 2022; Sullivan et

al., 2022). The current study adds that engaging in a culturally sensitive practice likely influences ICU nurses' experiences of distress with EOL care.

Previous studies have explored ICU nurses' experiences of emotional and moral distress during EOL care delivery (Atli Özbaş et al., 2021; Jackson et al., 2018; Jang et al., 2019; Lief et al., 2018; Omran & Callis, 2021; Ozga et al., 2020; Youn et al., 2022) and have documented how this contributes to compassion fatigue, emotional exhaustion, burnout, and an intention to leave the profession (Jackson et al., 2018; Saravasan et al., 2022). Studies have documented many causes of emotional or moral distress among ICU nurses, with many of these relating to nurses' perceptions of their patient's quality of death, the quality of care they provide during the EOL period, the overall strain of their workload, and feelings associated with grief and/or empathy with others' suffering (Betriana & Kongsuwan, 2020; Jang et al., 2019; Jones et al., 2016; Lief et al., 2018; Omran & Callis, 2021; Ozga et al., 2020).

In the current study, nurses discussed how their ability to engage in a culturally sensitive EOL practice impacted their emotional and psychological wellbeing. For example, participants described finding meaning and satisfaction in the human connections they made with patients/families when sensitively attending to culturally influenced EOL needs. Previous studies have had similar findings, namely that ICU nurses found meaning and satisfaction in connecting with patients/families on a human level during EOL care (Basile et al., 2021; Omran & Callis, 2021; Stokes et al., 2019). The interpretive phenomenological study by Stokes et al. (2019), found that ICU nurses derive satisfaction and meaning from getting to know a family on a personal level when

caring for dying patients. In doing so, ICU nurses felt they made a positive difference in the EOL experience of patients/families and helped lead to a ‘good death’ (Stokes et al., 2019). These findings are similar to findings from the current study, which add that a culturally sensitive EOL practice that is grounded in relational care can help facilitate these connections and improve satisfaction with EOL care delivery.

Other studies, however, have also documented how a deep connection during EOL care can heighten nurses’ emotional distress (Basile et al., 2021) and have found that a deep nurse-patient/family connection can increase ICU nurses’ grief, sadness, and emotional pain, both during and after caring for dying patients/families (Betriana & Kongsuwan, 2020; Mohamadi Asl et al., 2022; Omran & Callis, 2021). A phenomenological study by Omran and Callis (2021) exploring the bereavement needs of critical care nurses, found that connecting on a deep level with a patient/family heightens nurses’ emotional state and sometimes causes them to relive their own personal losses and grief. Similarly, the phenomenological study by Betriana and Kongsuwan (2020) found that ICU nurses’ feelings of grief are tied to their ability to empathize with the patient’s family and that ICU nurses feel the death of their patient as their own loss. In both studies ICU nurses described their emotions and experiences during EOL care as exhausting, which was intensified by a closer connection to the patient/family.

Within the literature, compassion satisfaction and compassion fatigue are depicted as opposing forces regarding the wellbeing of nurses. Compassion satisfaction is seen as a regenerative process where nurses derive pleasure, purpose, and gratification from delivering compassionate care (Sacco & Copel, 2017), while compassion fatigue is seen

as the cumulative draining of compassionate energy which ultimately leads to symptoms of physical exhaustion, lack of empathy, and feelings of detachment (Peters, 2018; Sacco & Copel, 2017). Compassion satisfaction is a documented protective influence against compassion fatigue (Sacco & Copel, 2017; Subih et al., 2023). This may indicate that the meaning and satisfaction nurses' experience when engaging in relational, culturally sensitive EOL care may help mitigate some of the psychological/emotional effects caused by negative and painful emotions felt during and after caring for dying patients. However, there are few current studies that explore the cumulative influence of a relationship-based, culturally sensitive EOL practice on healthcare professionals' wellbeing, indicating an area where further research is needed.

However, nurses in this study identified that ICU nurses carry emotional baggage from past experiences that can impact their ability to connect on a deep level with patients/families during EOL care. They described how colleagues who suffer from compassion fatigue (ie. those who are "insensitive" and "jaded" because of their repeated exposure to the suffering of others) do not seek to establish the interpersonal connections a culturally sensitive EOL practice requires. This could mean that, while these nurses may be spared some of the emotional distress associated with a deep nurse-patient/family connection, they also do not benefit from the emotional and psychological wellbeing which comes from the good caring relationship that providing a culturally sensitive practice involves (Basile et al., 2021; Omran & Callis, 2021; Stokes et al., 2019). Avoiding interpersonal connections may create a vicious cycle where nurses experience emotional exhaustion/compassion fatigue but are also unable to engage in the type of care

which may protect against worsening of compassion fatigue. As such, it is strongly recommended not only that self-care and self-compassion be an essential part of sustaining a culturally sensitive EOL practice, but that ICU nurses' emotional and psychological wellbeing be supported at an institutional level through the promotion of an optimal working environment, teamwork and collaboration during care, and peer support interventions (Bayuo & Agbenorku, 2022; Riegel et al., 2021; Zhang et al. 2018). Managing workplace adversity is beyond the capacity and responsibility of individual nurses, making organizational supports necessary (Jackson et al., 2018). It is also strongly recommended that bereavement support for ICU nurses be part of standard practice in the ICU (McAdam & Erikson, 2020; Omran & Callis, 2021) and that this support be studied and evaluated. Most studies regarding bereavement support within an ICU setting have focused on support for family members and loved ones of the deceased (Efstathiou et al., 2019), but there is also a need for knowledge about how to support nurses in processing and dealing with their EOL care experiences (Bateman et al., 2020).

Findings from the current study also suggest that the ability to engage in a culturally sensitive EOL practice may influence ICU nurses' experience of moral distress. Moral distress is a well documented issue for nurses delivering EOL care in critical care settings (Cooke et al., 2022; Hickey, 2022; Prompahakul et al., 2021; Sekse et al., 2017) and describes the emotional and psychological distress nurses experience when they are prevented from acting in accordance with what they feel is right (Cooke et al., 2022). In a concept analysis of moral distress in critical care nursing, Cooke et al. (2022) identified three antecedents of this phenomenon within the critical care literature: 1) *lack of*

resources, 2) *ethical dilemmas*, and 3) *perceptions of futile care*. This study found that that when nurses are able to engage in a culturally sensitive EOL practice, they: 1) have sufficient resources to provide attentive and supportive EOL care, 2) have a deeper understanding of the patient's/family's EOL values, belief, need, wishes etc. (thus ethical decisions may become clearer), and 3) are better able to move past their assumptions and biases about EOL care and thus appreciate the meaning and significance that care has for the family. The findings of the current study resonate with the antecedents of moral distress identified by Cooke et al. (2022) and suggest that, at the EOL, when nurses can care for patients/families in a manner that is culturally sensitive (and thus relational in nature), the drivers of moral distress are likely diminished. For example, a well-documented driver of moral distress among ICU nurses is the perception that care prolongs suffering or goes against the best interests of the patient (Bleacher et al., 2021; Cooke et al., 2022; De Brasi et al., 2021; Kovanci & Akyar, 2022; Lusignani et al., 2017). Findings of the current study suggest that a culturally sensitive EOL practice may help alleviate some distress caused by this belief. First, the ability to understand decisions and care from the perspective of the family/patient (which nurses in this study associated with a culturally sensitive EOL practice) may give others' suffering meaning and significance and may help ICU nurses overcome their perception that care is *futile*. Similarly, nurses in the current study expressed a strong moral and professional obligation to ensure EOL care reflects the values, beliefs and needs of the patient/family, and they drew upon this when trying to come to terms with EOL decisions which opposed their personal values and beliefs. A culturally sensitive EOL practice supports patients/families in articulating their

unique EOL values, beliefs, and needs, thus helping to make a patient's/family's values, belief and needs better known. Delivering culturally sensitive EOL care may help ICU nurses reconcile their personal values and beliefs with the care they deliver and help improve their certainty that care reflects the values and beliefs of patients/families, which previous literature indicates can help diminish moral distress (Cooke et al., 2022; Bleacher et al., 2021). Conversely, these findings suggest that when nurses feel unable to care for patients/families in a way that is culturally sensitive, it is likely that their moral distress is heightened as they feel prevented from delivering the type of care that patients/families should receive at the EOL.

Overall, the findings of this study suggest that a culturally sensitive EOL practice may help ICU nurses cope with the negative emotional and psychological consequences of delivering EOL care, but that they need support at an organizational level if this is to be realized. In particular, ICU nurses need a collaborative work environment which supports them in building strong therapeutic relationships and promotes peer support and self-care.

CHAPTER 6: STRENGTHS, LIMITATIONS, AND IMPLICATIONS

The purpose of this chapter is to discuss the strengths and limitations of this study, as well as implications of study findings for nursing practice, education, and research.

Study Strengths and Limitations

The strengths of this study include the diversity of participant characteristics. Participants in this study came from diverse ethnic and educational backgrounds, as well as a wide spectrum of ages and amount of nursing experience. Cultural awareness and

sensitivity are developed through exposure, interactions, and reflection (Hultsjö et al., 2019), making the varied experiences of participants in this study an important strength. As well, the focus on cultural sensitivity, rather than on caring for patients/families from diverse cultural backgrounds means that participants were asked to reflect on how they were broadly sensitive to patients'/families' varied cultures, rather than focusing on those patients/families seen as 'other' or having minority backgrounds (despite findings indicating that this is generally how participants did apply the term culturally sensitive EOL care within their practice).

This study does have a few key limitations. First, the majority of participants were female, with only one male participant being recruited. While this is fairly representative of the overall nursing workforce in Canada, with only 9% of nurses identifying as male in 2021 (CNA, 2023), it does reflect a skewed gendered perspective. Second, nurses were recruited from only two hospitals in a defined geographic area in southern Ontario, possibly limiting the transferability of findings to other areas with different contextual influences. Finally, an important limitation and ethical consideration regarding how this study was conducted is the inclusion of only one perspective, that of ICU nurses. Findings do not reflect the voice of patients/families on whether ICU nurses' actions/behaviours make individuals feel respected or that their culture was considered and valued during EOL nursing care. This inequality of perspectives also means that central concepts such as "quality care", "family", or "comfort", are seen through the dominant lens of the healthcare system. The intention of this study is to explore only a piece of the phenomenal puzzle, namely the experiences of ICU nurses in delivering culturally

sensitive EOL care. It is my hope that capturing this one piece will, in turn, stimulate and inform future research into different perspectives of culturally sensitive EOL care within critical care settings.

Implications for Practice, Education, and Research

Practice

Findings of this study have important practice implications, the most significant of which is that ICU nurses need to understand culturally sensitive EOL care as a way of *being with* individuals rather than as a collection of specific tasks. While education is likely an important element for shifting this perspective, study findings indicate that education alone will likely be insufficient as the culture and model of care within ICUs is a key factor driving task-oriented nursing care. As such, support also needs to come from within ICUs, both in the form of peer leadership and through organizational policies, decisions, and initiatives. In particular, nurses need assistance with developing and implementing the skills and capacities essential for developing the strong therapeutic relationships which are the heart of a culturally sensitive EOL practice. Relational care is how high quality EOL care is delivered in the ICU (Bloomer et al., 2017; Noome et al., 2016) and it is how nurses in this study understood and responded to the cultural EOL needs of patients/families in a sensitive manner.

To support better cultural sensitivity during EOL care, it is recommended that program leaders and decision makers ensure that unit staffing and workload reflect the time requirements needed for person-centered communication and the provision of emotional and psychological support to family members and patients. When

communicating in a person-centered way, nurses are fully present and explore patients'/families' unique perspectives by encouraging them to express their thoughts and feelings about the current situation and by showing that this perspective is valued (Kwame & Petrucka, 2021). This encouragement is both verbal and non-verbal and is aimed at creating meaningful, caring relationships as well as the mutual understanding of patients'/families' concerns, feelings, and needs using open-ended questions, active listening, silence (letting people just *be*), and other caring behaviours (Koloroutis & Trout, 2012; Kwame & Petrucka, 2021). This level of communication requires both time and the ability to be fully present during dialogue and, as such, nurses will need resource support in order not to feel rushed (Koloroutis & Trout, 2012). As well, nurses in this study described adopting a more task-/physical care-oriented mindset during care when they felt workload pressures, and evidence indicates that this mind-set is not conducive to person-centered communication (Kwame & Petrucka, 2021; Slatore et al., 2012).

Study findings also indicate that ICU nurses need support with engaging in a more reflexive practice. Reflexivity is the process of conscious engagement (Hartrick Doane & Varcoe, 2005a, 2015). When practicing reflexively a nurse: 1) observes their actions, feelings, thoughts, reactions, etc. in the here and now; 2) critically reflects upon these to see underlying assumptions and meanings; and then 3) chooses how they respond to individuals in ways that are consistent with the needs of the moment (Hartrick Doane & Varcoe, 2005a). ICU nurses predominantly learn about EOL care delivery through work experiences and from each other (Alshehri et al., 2020; Bloomer et al., 2016) and, as such, peer support and mentorship is likely the most beneficial way of sustaining

continued development of this skill. However, formal initiatives will likely be needed as these can help stimulate reflective practice and/or provide exposures which help ICU nurses recognize and explore the influence of their personal values, beliefs, and experiences on the EOL care they deliver. Similarly, formal initiatives will also likely be needed considering the normalization of cultural sensitivity and assistance with identifying 'othering' attitudes and behaviours implicit within the ICU culture and model of care need to be an important part of this supporting reflexive practice within ICUs.

Study findings also indicated that engaging in self-care is an important element of a culturally sensitive EOL practice. As such, this study strongly recommends that nurses have access to the supports they need to engage in emotional and psychological self-care. Support could be as simple as being allowed time and space to grieve after a patient has died (Pattison et al., 2020) or as involved as formal resiliency and/or mindfulness-based practice training (Pattison et al., 2020; Watts et al., 2021). Nurses should have a convenient and safe venue to express emotions associated with distressing situations (not just those associated with EOL) and process these experiences with the help of supportive peers, leaders, and administrators (Jackson et al., 2018; Pattison et al., 2020). Support for emotional and psychological self-care also involves sustaining heathy working relationships (both among staff and between staff and administration) and the creation of a cooperative practice environment that is conducive to a relational approach to culturally sensitive EOL care (Andrews et al., 2020; CNO, 2020). To this end, supporting self-care and an optimal environment for building strong relationships (therapeutic, professional, and personal) must be prioritized in all organizational/departmental decisions.

Education

This study also has implications for education. First, education for both current and future ICU nurses should support a view of culturally sensitive EOL care which focuses on how nurses relate to patients/families. In particular, education should explicitly link culturally sensitive EOL care to a relationship-based person-centered practice and the development of relation capacities like empathy, compassion, trust, person-centered communication, and reflexive/reflective practice. Discussion and training regarding cross-cutting, culturally relevant social issues (particularly those related to trauma and oppression) may deepen this education and help nurses understand how this education translates to their clinical practice (Hartrick Doane & Varcoe, 2015; Epner & Baile, 2012). At an undergraduate level, grounding discussion of culture within a relational inquiry approach may help students better understand the role of cultural knowledge in delivering high quality EOL care and help develop the relational skills and capacities associated with a culturally sensitive practice. Leadership and/or graduate education should include knowledge and training regarding what is needed for supporting and sustaining truly person-centered care at an organization level, as well as highlight the benefits of supporting this type of practice. It will be important to establish best practices and/or guidelines related to culturally sensitive EOL care and these should highlight the primacy of the nurse-patient relationship in unearthing and responding to culturally influenced EOL needs and wishes.

It is also recommended that both continuing education and undergraduate education include knowledge and training on reflexivity. At a basic level, this should

include clear guidance regarding what reflexivity involves. Education and training regarding the use of different theoretical lenses may be helpful in expanding perceptions of caring situations and self-awareness (Hartrick Doane & Varcoe, 2005a, 2015). In both continuing and undergraduate education, these activities could be done as group activities and involve dialogue. In this way, students/nurses could learn from one another. At an undergraduate level, these activities could be included as part of clinical practice courses and could provide students with mentorship and emotional support.

Education should also focus on developing relational skills through simulation, however, it is important that simulations actually reflect the complexity of nursing practice in the ICU and that scenarios do not perpetuate cultural stereotypes (Drevdahl, 2018). Accordingly, simulations should not seek 'token' cultural scenarios, but rather, work to subtly include diversity and equity throughout the program. Simulations should also promote self-reflection on personal biases, assumptions, and the influence of context on one's perspective of care. To do this, a component of simulation debriefing could require students to verbally reflect upon and share the influence of their background on their understanding of the simulated situation. In turn, this could help expand students' cultural awareness and help them learn from one another.

Finally, it is vitally important that education concerning a relational approach to culturally sensitive EOL care coincides with changes within the ICU practice environment. Education may help increase ICU nurses' understanding regarding their role in culturally sensitive EOL care delivery, in turn helping decrease role ambiguity; however, should those nurses be prevented from implementing what they are taught is

'good' nursing care for dying patients/families, this will likely exacerbate their negative emotions and distress (Cooke et al., 2022; Jang et al., 2018; Kisorio & Langely, 2016; Lamiani et al. 2017) and contribute to burnout and an intention to leave the profession (Cengiz et al., 2021; Lamiani et al. 2017).

Research

The findings of this study also have important implications for research concerning cultural sensitivity EOL care in the ICU. First, given the limited number of participants and ICUs in the current study, it is recommended that a larger study exploring ICU nurses' perceptions of EOL care be conducted. This would be valuable since a larger study that recruits from a greater number of ICUs could compare practices and experiences between different units. Similarly, a study with a larger sample size could find patterns associated with certain demographic characteristics or specific experiences that a smaller study, like the current one, may not capture. Future studies could also expand on the findings of the current study and explore ICU nurses' perceptions regarding current documentation practices regarding each patient's/family's values, beliefs, and cultural identity, and how these communication practices may be improved.

Second, this study focused on the perceptions of ICU nurses, however, the perceptions of patients/families are equally important in understanding culturally sensitive EOL care within critical care settings. Possible research studies in this area could include an exploration of family members' lived experiences of culturally sensitive care at the EOL in the ICU (phenomenology), or their perceptions of compassion during

this care (Interpretive Description). These studies would likely look to capture the experiences or perceptions of individuals who self-identify as belonging to a non-dominant cultural group, as this could emphasize cultural differences.

An important area of research regarding culturally sensitive EOL care highlighted by this study is relational person-centered EOL care in the ICU. This area of research could help inform policy development and training initiatives aimed at facilitating better culturally sensitive EOL care. In particular, a relational approach to EOL care can take a substantial emotional toll on practitioners (Basile et al., 2021; Betriana & Kongsuwan, 2020; Hickey, 2022; Mohamadi Asl et al., 2022; Omran & Callis, 2021: Prompahakul et al., 2021). As such, assessing the impact of relational care on emotional exhaustion as well as important factors which aggravate or alleviate this distress is important. This could be done quantitatively or through a mixed method study and could be used to inform initiatives geared towards supporting self-care and resiliency. Similarly, given the current body of literature on distress associated with EOL care, a literature review concerning the impact of relational care on ICU nurses' experiences of emotional distress would be valuable and may help identify areas in need of further research.

Finally, a key area for future research which was not highlighted within the findings of this study, but was important within study data, is understanding the specific resources ICU nurses use or find helpful in supporting culturally sensitive EOL care within their unit. Possible research studies in this area could explore ICU nurses' practices regarding resource use or ICU nurses' perceptions of what resources are helpful and why. Another possible avenue of research could be a mixed methods study which

maps resource use and patient characteristics, and then explores nurses' opinions or explanations for these findings.

Conclusions

This study deepens our understanding of how ICU nurses currently try to be sensitive to the culture of a patient/family during EOL care within the Canadian context. High quality EOL care in the ICU is tailored to each patient's/family's specific values, beliefs, and needs, all of which are highly influenced by culture. Canada has a multicultural society and, as such, ICU nurses often enter caring relationships with a limited understanding of a patient's/family's cultural context. Consequently, Canadian ICU nurses need to become oriented to their patients'/families' cultural values, beliefs, practices, and norms through strategies and skills. In this study, ICU nurses focused on being truly person-centered and on building strong therapeutic relationships when trying to become oriented to the cultural of a patient/family. This approach was grounded in interpersonal skills and self-knowledge and, therefore, may help prevent or limit the risk of stereotyping, othering, or stigmatization of patients/families based upon certain characteristics. Learning from the experiences and personal knowledge of the nurses in this study, it is likely that a relational approach to culturally sensitive EOL care is an important strategy to promote humanizing EOL care that is culturally respectful and responsive. However, the ICU setting creates significant barriers to adopting a relational approach to EOL care and thus ICU nurses will need multifaceted support in order to be successful in improving the cultural sensitivity of care in the ICU.

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APPENDIX A

Definitions

Culture: The shared system of values, beliefs, and practices of a particular group which leads to a unique way of perceiving and evaluating the external environment and guides thinking, decisions, and actions in a patterned way (Giger, 2017). This framework evolves through historical, political, and social forces and gives group members a sense of safety and identity, often operating on an unconscious level (Cain et al., 2018; Srivastava, 2007).

Cultural Awareness: being conscious of the different cultural values, beliefs, norms and lifeways of others by first being aware of one's own culture and biases (Cai, 2016).

Cultural Diversity: cultural variation between people resulting from the unique history, background, and experiences of each individual. This term emphasizes variation from the majority (Cain, 2018; CNA, 2010; RNAO, 2007).

Cultural Need: the beliefs, practices, and preferences that come from one's cultural identity, and may include linguistic needs, health beliefs and behaviours, traditions, rituals, or cultural barriers to accessing health care (HQO, 2018).

Cultural Sensitivity: an appreciation, respect, and awareness for another person's cultural context arising from awareness of self and others, insight, and experience (Foronda, 2008; RNAO, 2007)

End-of-Life Care: the care provided after it has been acknowledged that a patient will not recover from their illness (i.e. death is inevitable or the decision to withdraw

treatment has been made) and death is imminent (Hui et al., 2015; CIHI, 2011; Clarke et al., 2003; CACCN, 2017).

Ethnic Group: a group of people who identify with each other based on a common social, geographical, and/or cultural heritage. (Giger, 2017).

Ethnicity: the ethnic group an individual feels a sense of belonging to (Andrews & Boyle, 2016). Ethnicity is determined by the individual not by others and is separate from the construct of race.

Family: all individuals who are identified as family by the patient. These individuals can be related (biologically or legally) and/or have a close bond (friendships, commitments, shared households and child rearing responsibilities, and romantic attachments) with the patient (NCPQPC, 2018; RNAO, 2015)

Indigenous Ancestry: self-identifying as First Nations, Metis, or Inuit, regardless of registration status or band membership (Statistics Canada, 2015a).

Life-Sustaining Treatments: medical interventions (medications or devices) that sustain or replace organ function and require specialized staff and locations and involve significant resources. These are also referred to as “life-support”, and can include pharmacologic or mechanical hemodynamic support, mechanical ventilation, and/or renal replacement therapy/hemodialysis (Bandrauk et al., 2017)

Palliative Approach to Care: an approach to the care of patients with progressive illness that integrates the principles of palliative care across sectors and disciplines and links this care less to prognosis and more to the need to “reinforces personal

autonomy, the right for persons to be actively involved in their own care and a greater sense of control for individuals and families." (CNA, 2015, p. 2) (Bacon, 2012)

Palliative Care: the care of patients with life-threatening or life-limiting illness that is person- and family-centered and provides wholistic and individualized care which minimizes suffering and meets the unique physical, emotional, psychological and spiritual needs of the patient and family from diagnosis through bereavement (Bacon, 2012; World Heath Organization, 2019)

Patient- and Family-Centered Care: an approach by healthcare providers that partners with patients and families to place the whole patient (i.e. emotional, spiritual, psychological, physical, social, environmental, etc.) at the center of care and services, and recognises the importance of family in planning and decision-making (RNAO, 2015).

Personally Identifiable Information: "information about an identifiable individual, including: home address; phone number; email address; identifying numbers; sexual orientation; ethnic origin; race; religion; age; sex; Education, financial, employment, medical, psychiatric, psychological or criminal history; Personal opinions of, or about, an individual; Personal correspondence; name where it appears with or reveals other personal information." (McMaster University, 2019, What is personally identifiable information?)

Transcultural Nursing: nursing research, education, and practice which combines nursing knowledge with that of anthropology to focus on cultural similarities and

differences regarding care, well-being, and illness, and ultimately to lead to culturally congruent nursing care based upon a person's cultural values, beliefs, and practices (Andrews & Boyle, 2016; Giger, 2017).

APPENDIX B

Search Strategy

1) Nursing/ or Nurse/ or Critical Care Nursing/ or nursing.mp or nurse*.mp

   AND/OR

   Critical Care/ or Intensive Care Units/ or critical care.mp or intensive care.mp or ICU*.mp

   AND

2) Terminal Care/ or Palliative Care/ or Death/ or end-of-life care.mp or palliative.mp or dying.mp or death.mp

   AND/OR

3) Transcultural Nursing/ or Cultural Nursing/ or Cultural Competence/ or Cultural Diversity/ or Cultural Factor/ or transcultural.mp or trans-cultural.mp or intercultural.mp or cross cultur*.mp or multicultural.mp or cultural safety.mp or cultural* competen*.mp or cultural* sentistiv*.mp or cultural awareness.mp or cultural* congruen*.mp or

APPENDIX C

Summary of Key Articles

Citation	Methods	Key findings	Strengths and Limitations
1. Aslakson, R. A., Wyskiel, R., Thornton, I., Copley, C., Shaffer, D., Zyra, M., Nelson, J., & Pronovost, P. J. (2012). Nurse-perceived barriers to effective communication regarding prognosis and optimal end-of-life care for surgical ICU patients: a qualitative exploration. *Journal of Palliative Medicine, 15*(8), 910–915.	**Country**: USA **Methodology**: Qualitative **Participants**: 32 nurses from 3 different SICUs **Data Collection**: 4 focus groups in Sept. 2009 **Data Analysis**: Written notes were analyzed using content analysis	• EOL Care – barriers/challenges • Describes logistical, communication, cultural, clinician skill- or training-based barriers to EOL Care • Nurses' EOL Perceptions – culture-based barriers to EOL care • Cultural Barriers to EOL care: ○ Families uncomfortable with discussing end-of-life care ○ Death is seen as a defeat or giving up ○ Disagreement about if pt should be involved in discussion ○ Pt cultural beliefs contrast with those of the care provider ○ Unclear as to what "natural	<u>Strengths</u>: ▪ Justified use of qualitative/focus group methods to "facilitate unbiased and unrestricted discussion about these two topics across multiple focus groups" ▪ Good description of setting ▪ Used a clear and specific definition of "prognosis" within focus groups ▪ Member checking of domains ▪ Domains and barrier classification agreed upon through consensus of multiple team members <u>Limitations</u>: ▪ Possible power imbalance as moderator was known to staff (this helped with recruitment) and was a physician

		death" extreme measures" or "futile measures" are - supported by the findings of Mani & Ibrahim (2017 ○ Differences in beliefs about what is a good quality of life • Findings suggest a lack of self-awareness or awareness of cultural influences	▪ Focus groups were not audiotaped, only written notes were recorded
2. Borhani F., Hosseini S.H., & Abbaszadeh A. (2014). Commitment to care: A qualitative study of intensive care nurses' perspectives of end-of-life care in an Islamic context. *International Nursing Review*, *61*(1), 140–147. https://doi.org/10.1111/inr.12079	**Country**: Iran **Methodology**: descriptive exploratory qualitative **Participants**: 12 nurses from 3 ICUs affiliated with Kerman Univarsity; purposively sampled **Data Collection**: semi-structured interviews which were audiorecorded **Data Analysis**: Transcripts using an inductive coding approach by Redtke et al. (2012)	• Nurses' EOL Perceptions– nurses' roles and wellness • Nurses see their role as a support person • Nurses take into account pt religious beliefs/ practices into EOL care • See EOL care as a "valued opportunity" and can be deeply rewarding • Believe families have more needs then the dying pt and must be understood	Strengths: ▪ Justified use of methodology/ design Limitations: ▪ Unlike Canada family is not involved in treatment decisions ▪ Unable to confirm elements of rigor and trustworthiness – eg. Stated reflexivity was used, but no discussion of authors background or how/where reflexivity was used

		• Relationships are important	▪ No discussion of how sample was obtained or participant characteristics ▪ Purpose was to identify the perspectives of ICU nurses about EOL care in an Iranian/Islamic context – effects transferability
3. Bratcher, J.R. (2010). How do critical care nurses define a "good death" in the intensive care unit? *Critical Care Nursing Quarterly*, *33*(1), 87–99.	**Country**: USA **Methodology**: Qualitative (naturalistic exploratory) **Participants**:15 ICU Nurses **Data Collection**: Interviews **Data Analysis**: Interviews were audiotaped and transcribed verbatim. Data was analyzed using content analysis	• Nurses' EOL Perceptions - good death • Three nurses interviewed described a good death as meeting the patient's religious/spiritual/cultural needs. • In general, see a good death includes: ○ Does not die alone ○ Does not suffer; dies quickly and with dignity ○ Death is accepted ○ Wishes are honoured and religious/spiritual/ cultural needs are met	<u>Strengths</u>: ▪ Design selection was based upon lit review ▪ Pilot interviews conducted with 3 nurses ▪ Interviews conducted by only one person (maintains consistency) <u>Limitations</u>: ▪ Conducted in only one 12-bed med/surg ICU – limited to only one group of nurses ▪ Convenience sampling, but unsure how participants were selected – unsure if it was purposive

		○ Calm environment - nurse controls environment (no outcry from family, quiet environment, and everyone is calm)	
4. Brooks, L. A., Bloomer, M. J., & Manias, E. (2018). Culturally sensitive communication at the end-of-life in the intensive care unit: A systematic review. *Australian Critical Care: Official Journal of the Confederation of Australian Critical Care Nurses*, (bh0, 9207852). ** focus on patient and family centered care in pediatric ICU settings (with an emphasis on the child-parent/family bond and the role of family in care) means that	**Methodology**: Systematic Review **Databases**: CINAHL, MEDLINE, Embase, and PsycINFO; key journals on Transcultural nursing were hand searched **# of Studies**: n=9	• Culturally Sensitive EOL Care • ID's 2 main themes: ○ Communication barriers ○ Cultural and personal influence • Articles on nurses are also in my review • Limited research on culturally sensitive EOL communication • Culture (religion, race, and ethnicity) influence communication among clinicians, patients, and families	Strengths: ▪ Focused on adult patient population – like me ▪ 2 authors independently assessed for inclusion ▪ Narrative synthesis selected due to nature of included studies – justified use ▪ Articles appraised by 2 authors using Caldwell et al.'s framework to critique health research ▪ Date limitations (1995-2017) for included studies is reasonable (and justified) considering the limited number of studies Limitations:

communication practices in these settings are inherently different		• Nurses' Perceptions – nurses' roles and challenges • Nurses see their role in as primarily a support person (for families, prompting physicians to communicate, and facilitating family participation in decision-making) (Gallagher, Borhani, Crump) • Nurses' role involves cultural assessment of family religious needs (Gallagher) • When cultural and religious preferences were not identified and accommodated in care and communication, conflict sometimes occurred between the trifecta (Van Keer) • Culturally diverse families sometimes	▪ Did not seek out experts or non-English studies ▪ Small number of studies included and meta-analysis not possible due to heterogeneity ▪ Focus was on communication (interactions)

		lacked the awareness of how to communicate their cultural needs • Patient and families background impacted their ability to engage in communications with clinicians at the EOL • Clinician cultural background (including religion) impacts how clinicians' approach EOL communications and their preferences regarding EOL care	
5. Brysiewicz P., & Bhengu B.R. (2010). The experiences of nurses in providing psychosocial support to families of critically ill trauma patients in intensive care units: A study in the Durban metropolitan	**Country:** South Africa **Methodology:** Interpretive Phenomenology **Participants/ Setting**: 9 nurses from 2 private and 1 public SICU **Data Collection:** 2 semi-structured interviews per participant	• Nurses' EOL Perceptions – nurses' roles • Main Findings: o Cultural Awareness o Communication (problems) o Providing Assistance o Lack of training • Talk about awareness of family/patient	<u>Strength:</u> ▪ Good discussion/ description of setting, sampling, and sample ▪ While this does not focus specifically on EOL care <u>Limitations:</u> ▪ VERY limited description of

area. *Southern African Journal of Critical Care, 26*(2), 42–51.	**Data Analysis:** "manually analyzed to derive patterns and themes from recorded data" (cited Van Manen (2003) – which is relevant to phenomenology)	culture, not of own culture • Recognize that different groups deal with feelings in different ways • There needs to eb religions tolerance • Intrapersonal conflict - desire to provide culturally sensitive care vs. professional duty • Primarily gained skill in supporting families through experience not education or training	data collection and analysis ▪ While qualitative methods are appropriate, no discussion of why specific methodology was deemed best for the study ▪ Participation in family meetings appears different in South Africa compared to Canada
6. Canfield, C., Taylor, D., Nagy, K., Strauser, C., VanKerkhove, K., Wills, S., Sawicki, P., & Sorrell, J. (2016). Critical care nurses' perceived need for guidance in addressing spirituality in critically ill patients. *American Journal of Critical Care, 25*(3), 206–211.	**Country**: USA **Methodology**: Qualitative **Participants\ Setting**: 30 ICU nurses at one 25-bed medical ICU (Purposive sampling) **Data Collection**: Audio taped semi-structured interviews **Data Analysis**: Interpretive summaries, then themes and phenomena	• Nurses' EOL Perceptions – nurses' roles • Need further education on "multicultural considerations" • Nurses felt there were opportunities to address spirituality throughout an admission	<u>Strengths</u>: ▪ Good justification of methodology ▪ To minimize power imbalances interviews were conducted by bedside nurses on the research team (they acknowledged this also introduced challenges) ▪ Data was analyzed by all (8) team members, both

https://doi.org/10.4037/ajcc2016276			independently and collaboratively ▪ Listed interview questions Limitations: ▪ Participants predominantly white females (3% Hispanic; 7% male) ▪ Oddly large sample size for phenomenology ▪ No framework for data analysis given
7. Crump, S. K., Schaffer, M. A., & Schulte, E. (2010). Critical care nurses' perceptions of obstacles, supports, and knowledge needed in providing quality end-of-life care. *Dimensions of Critical Care Nursing : DCCN*, *29*(6), 297–306.	**Country**: USA **Methodology**: Cross-Sectional Survey (Pre-education implementation) **Participants**: 65 ICU nurses **Data Collection**: 2 surveys. Both had Linkert Scale items and open-ended questions **Data Analysis**: ▪ Quantitative data using SPSS to calculated Mean, SD, Rank, and Perceived Supportive Behaviour	• EOL Care - Barriers • Nurses ranked cultural aspects ("issues"), along with ethical issues and communication concerns, as the top knowledge needs • Describes western cultural values and ICU nursing culture • Nurses believe better education of families re: treatment consequences and prognosis is necessary to	Strengths: ▪ Used a previously studied/validated questionnaire (reported this internal consistency reliability) ▪ Intended as a pre-educational intervention implementation assessment of a specific unit, which is openly stated Limitations: ▪ Used an additional un-validated questionnaire which was

	Score calculated. ▪ Qualitative analysis to support and describe quantitative data	ensure families understand and can put suffering in context • obstacles relate to communication, families understanding of prognosis/aggressive LST, conflict, environment (ie. privacy and peacefulness) • Obstacles in study primarily relate to nurse-family interactions • Findings consistent with many other studies • Philosophy that values a cure is a problem	created by authors (based on ELNEC curriculum) ▪ No discussion of necessary sample size or unit demographics, and response rate was 31% (56/180) – non-response bias? Not representative? ▪ Appears to draw conclusions that are too broad ▪ Does not identify study limitations
8. Endacott, R., Boyer, C., Benbenishty, J., Ben Nunn, M., Ryan, H., Chamberlain, W., Boulanger, C., & Ganz, F. D. (2016). Perceptions of a good death: a qualitative study in intensive care units in England and Israel.	**Country**: England and Israel **Methodology**: Qualitative **Participants**: 55 RNs working in 3 ICUs in England and 4 ICUs in Israel **Data Collection**: 10 semi-structured interviews and 8 focus groups (n=45 RNs)	• Nurses' EOL Perceptions – good death • Found 4 themes which extended across countries: o Timing of communications o Accommodating individual behaviours	<u>Strengths:</u> ▪ Used principles of Kidd & Parshall (2000) to enhance trustworthiness of focus group data – linked design elements directly to principles ▪ Selected RNs that represented a broad range of ages, ICU

Intensive and Critical Care Nursing, 36, 8–16.	**Data Analysis**: Braun & Clark's 5 step process of thematic analysis and emotional content of individual patient stories was analyzed using Linguistic Inquiry and Word Count (software)	○ Appropriate care environment ○ Achieving closure • Nurses try to adjust care to be culturally sensitive (Culturally Sensitive EOL care not well described) • this is sometimes at odds with their professional duty (Intrapersonal conflict) • There are more similarities than differences in how nurses from UK and Israel describe a good death.	experience, and seniority <u>Limitations:</u> ▪ No discussion of researcher background or bias, or why England and Israel were the countries selected ▪ All interviews were conducted in English. Sometimes necessary to translate content in Hebrew. ▪ Lack of diversity in English cohort
9. Gallagher, A., Bousso, R. S., McCarthy, J., Kohlen, H., Andrews, T., Paganini, M. C., …& Padilha, K. G. (2015). Negotiated reorienting: a grounded theory of nurses' end-of-life decision-making in the	**Country**: Brazil, England, Germany, Ireland, and Palestine **Methodology**: Qualitative - Grounded Theory **Participants**: 51 experienced ICU nurses (10 Brazil, 9 England, 10,	• Nurses' Values and Beliefs – nursing role • See role as supportive • Nurses work to reorient others to the current situation and care needs • 2 core practices were: ○ Consensus seeking	<u>Strengths</u>: ▪ Clearly outlined legal context of EOL care in each country ▪ Triangulated data sources (between and across countries) ▪ Audio-recorded interviews ▪ Inter-coder reliability was checked

intensive care unit. *International Journal of Nursing Studies*, *52*(4), 794–803.	Germany, 10 Ireland, 12 Palestine) (Purposeful and Theoretical sampling) **Data Collection**: Semi-structured interviews **Data Analysis**: Constant comparative analysis	(getting everyone on the same page) ○ Emotional holding (emotional support and facilitate acceptance and closure – time and space for communal grieving) • ICU nurses ID relationships and dialogue as important in their EOL decision-making • Nurses act as enablers and facilitators of the decision process and support and guide the family through this • To enable family involvement • Nurses are well placed to establish needs and preferences of relatives and tailor information accordingly…this is regarding	throughout analysis ▪ The project teams in each country participated in analysis – seemed collaborative ▪ Good explanation for selection of methodology <u>Limitations</u>: ▪ Researcher backgrounds or other sources of researcher bias not discussed ▪ No evidence against argument (there may be none due to limited research)

		how much family wants to know and how much they already do know • Nurses act as a point of contact between the larger care team and the patient/family • Comfort giving is also done to avoid family distress • Nurses recognized that cultural norms influence who provided comfort • Nurses overall recognize that many families find comfort in religious beliefs and rituals and 'appeal' to help families accept death • Intrapersonal conflict - between their professional responsibilities and roles and their inclusion and participation in family cultural practices	

10. Heidari, M. R., & Norouzadeh, R. (2014). Supporting Families of Dying Patients in the intensive Care Units. *Holistic Nursing Practice*, *28*(5), 316–322.	**Country**: Iran **Methodology**: Qualitative - Grounded theory **Participants**: 23 critical care nurses **Data Collection**: Interviews – collected between Aug 2009 and Nov 2010 **Data Analysis**: Interviews were audiotaped and transcribed. Data analysis was done using a Constant Comparison method	• Nurses' Values and Beliefs – nurses' roles • Five categories of support aimed at providing comfort: ○ Death with dignify ○ Facilitated visitation ○ Value orientation ○ Preparing ○ Distress • Nurses described that dying with dignity is expected and requires the inclusion of patient's values – links to culture • Family support requires the nurses orient themselves to the values of the patient and family • Strategies for supporting families include understand the cultural and religious values of patients and families.	<u>Strengths</u>: ▪ Reported methods align with a Grounded Theory methodology ▪ Took steps to ensure data accuracy, such as member checking, but no details were provided ▪ Specifically detailed that interviews were to gather experiences and not theoretical knowledge <u>Limitations</u>: ▪ No discussion of researcher background or potential influences/bias' during collection and interpretation ▪ No discussion of recruitment or participant selection – may not be diverse enough ▪ Methods read like a textbook and does not outline how this was tailored to study (or why)

		(Awareness - Assessment) • Understanding of cultural and religious values come from the nurse's perception and sensitivity - not elaborated on (Awareness – Assessment) • Nurses tailor care to culture	
11. Høye, S., & Severinsson, E. (2010a). Multicultural family members' experiences with nurses and the intensive care context: A hermeneutic study. *Intensive and Critical Care Nursing*, *26*(1), 24–32.	**Country**: Norway **Methodology**: Gadamerian hermeneutic design (phenomenology) **Participants/Setting**: 5 family members with a non-western ethnic or cultural background (1st or 2nd gen migrants) recruited from 3 university and 1 regional hospitals **Data Collection**: In-depth interviews **Data Analysis**: "Inspired by" Lindseth and Norberg's phenomenological	• Provides Context • Main finding "Struggling to preserve the family's cultural belonging within the healthcare system" • The nurses incorporated both symbols and rituals, which were desired as expressions of religious behaviour • Communication practices were different from that of healthcare staff – filtering information to be culturally congruent -	Strengths: ▪ Discusses methodology and it's appropriateness for study ▪ Gave specifics of how certain principles were enacted in the study ▪ Variety of cultural backgrounds represented in sample ▪ Captured data from family members whose loved ones had died (did not specify if this was in ICU or not) Limitations: ▪ 5-6 other family members were also considered,

	hermeneutical method	often skewed the message and was not wholly truthful or accurate • Unique communication patterns via informal family networks • Family care preferences were different than the rules of the unit (visiting policies) • Concluded that it seems difficult for nurses to grasp the cultural range and diversity of the family members they interacted with	but declined shortly before data collection (reasons were provided) ▪ All interviews conducted in Norwegian only – thus only reflect this population
12. Høye, S., & Severinsson, E. (2010b). Professional and cultural conflicts for intensive care nurses. *Journal of Advanced Nursing, 66*(4), 858–867.	**Country**: Norway **Methodology**: Qualitative – descriptive and exploritory **Participants**:16 critical care nurses **Data Collection**: 3 multistage focus groups – total 8 meetings **Data Analysis**: Qualitative content analysis	• Provides Context • Inter- and Intrapersonal conflict • Main themes are conflict between: ○ professional nursing practice v. family cultural traditions ○ nurses' professional	<u>Strengths</u>: ▪ Accounted for and described variation in # of meetings of each focus group. ▪ Recruited from 3 different hospitals ▪ Extensive discussion of findings provides clarity and context.

		perception as total care providers v. families culturally based need to participate actively in care ○ professional obligation to provided comprehensive information vs. cultural communication practices and responses to illness ○ professional responsibility for the clinical environment v. family need for cultural norms and self-determination • Trying to maintain cultural and religions practices and norms (Tailoring care) • Issues interpreting symptom severity, in particular pain and grief, as the	▪ Clear description of contributions of findings ▪ Good description of participants and data collection process <u>Limitations</u>: ▪ Focuses on difficulties – thus may exclude supports and some positive experiences ▪ Primarily women – thus gender based cross-cultural differences may be exaggerated ▪ All participants had a Norwegian background and were either Christian, humanist, or non-religious/atheists – limited to this cross-cultural context ▪ Limited discussion of analysis process

		expression of these the nurse felt were cultural - some cultures seen as more expressive and extreme than others. (Awareness – Lack of knowledge and Assessment) • Intrapersonal conflict re: cultural traditions around the dissemination of information – re: pt autonomy, informed consent, and "truth telling" • Describe intrapersonal conflict - when professional culture conflicted with culturally sensitive care (ie. the culture-based needs of families). • needed to balance the patient/families need with the ICU culture/care/norms/ responsibilities	

		• Concluded nurses need increased competence in "assessment of diversity"	
13. McLouth-Kanacki L., & Winslow B.W. (2017). Listening to How Experienced Nurses Care for the Dying Husband and His Spouse. *Dimensions of Critical Care Nursing: DCCN*, *36*(3), 193–201.	**Country**: USA **Methodology**: Interpretive Description **Participants/ Setting**: 15 critical care nurses from one lg tertiary hospital **Data Collection**: Individual semi-structured interviews **Data Analysis**: Constant comparison (line by line coding)	• Nurses' EOL Perceptions – nursing roles • Primarily a support role • Role involved connecting spiritually with the wife and husband • Described sometimes feeling uncertain of what is appropriate spiritual care • Felt it is important to incorporate the patients/families spiritual (cultural) beliefs and incorporation of these enhances their experience of the care they provide. • Voiced that spiritual practices can be a difficult subject to discuss with family due to uncertainty	<u>Strengths</u>: ▪ Provided a summary of researchers' background and experience and theoretical influences related to topic ▪ Good amount of detail about sample, setting, and recruitment ▪ List of interview questions provided – which seemed consistent with study aims <u>Limitations</u>: ▪ Conducted in one faith-based hospital – thus spiritual aspects of EOL care (comfort, resources, clinician background) may not represent that of non-faith based hospitals. ▪ Participants religious/spiritual

		around family practices and background • Utilized other staff – needed SW or chaplain	beliefs/background not reported
14. Listerfelt, S., Fridh, I., & Lindahl, B. (in press). Facing the unfamiliar: Nurses' transcultural care in intensive care – A focus group study. *Intensive and Critical Care Nursing*, 102752. https://doi.org/10.1016/j.iccn.2019.08.002	**Country**: Sweden **Methodology**: Qualitative **Participants/ Setting**: 15 ICU nurses (8CCNs and 7 ENs) from general ICUs in two different hospitals **Data Collection**: 4 focus groups **Data Analysis**: Qualitative content analysis as per Graneheim and Lundman (2004)	• Provides Context • Relevant key themes: ○ Lg number of relatives is challenging (relatives wish to be near) ○ Communication is a challenge (mainly language based) ○ Crisis reactions cause drama (differences in cultural expression during crisis - unfamiliar reaction and the need to protect others) ○ Providing equal and personal adjusted care - level of care directed by	Strengths: **particularly good reporting of methods ▪ Clearly grounded findings in practice relevant implications ▪ Separated CCNs and ENs into different focus groups and described their different nursing roles in the ICU ▪ All authors involved in data analysis Limitations: ▪ Focused on challenges and conflict ▪ Did not identify how they defined or described "culturally diverse patients"

		medical needs	
15. Mani, Z. A. & Ibrahim, M. A. (2017). Intensive care unit nurses' perceptions of the obstacles to the end of life care in Saudi Arabia. *Saudi Medical Journal*, *38*(7), 715–720.	**Country**: Saudi Arabia **Methodology**: Cross-sectional survey **Participants/ Setting**: 77/140 ICU nurses from a 6 specialist ICUs (medical, hematological, oncological, surgical, and cardiac for a total of 129 beds) in a Lg Specialist hospital in Riyadh **Data Collection**: Modified version of the questionnaire developed by Beckstrand and Kirchoff (2005), which was first piloted **Data Analysis**: Microsoft Excel and SPSS – why 2?	• EOL Care – barriers • Nurse EOL Perceptions – culture based barriers • Cross cultural support for family to help them grieve was difficult, but only moderately frequent • Language barriers affected EOL care, and even translators were viewed as a primary barrier • Difficult to provide care when family beliefs/values opposed their own beliefs – ex. EOL care for brain-dead patients who were potential organ donors	<u>Strengths</u>: ▪ Used a similar analysis method as Beckstrand and Kirchoff (2005) – analyzed questions as they were intended to be analyzed ▪ Reported what was modified in the questionnaire - only demographic questions ▪ Investigators were not involved in recruitment – limits bias? <u>Limitations</u>: ▪ Conducted in English – limited to those how can read English ▪ Small sample size, 37% non-response rate, and only one hospital – may not be representative (non-response bias) ▪ Did not discuss measures to follow-up with non-responders

			▪ EOL care in KSA occurs within a vary different context from that in Canada – may not be generalizable to Canada ▪ Did not report significance
16. Powazki, R., Walsh, D., Cothren, B., Rybicki, L., Thomas, S., Morgan, G., Karius, D., Davis, M. P., & Shrotriya, S. (2014). The care of the actively dying in an academic medical center: a survey of registered nurses' professional capability and comfort. *The American Journal of Hospice & Palliative Care*, *31*(6), 619–627.	**Country**: USA **Methodology**: Cross-sectional survey, mixed methods **Participants**:123 nurses from 6 inpatient specialties (including ICU) **Data Collection**: Survey – 20 Linkert-type scale and one open-ended question **Data Analysis**: ▪ SAS software to analyze quantitative data – included association stats for association of participant characteristics and survey answers ▪ Qualitative data analyzed using thematic analysis	• Nurses' EOL Perceptions • More knowledge on cultural aspects of EOL care needed • Nurses needed further education and/or training regarding cultural aspects of prognosis and disclosure. • Domains of a concern for all respondents included religion and culture *Included in Brooks et al.	<u>Strengths</u>: ▪ Good description of questionnaire development, which was piloted with 2 different groups of nurses ▪ Justified sample size - 59% response rate resulted in larger sample size than estimated for desired power ▪ Described questionnaire development and provided example <u>Limitations</u>: ▪ 41% non-response rate – may not be representative sample due to self-selection ▪ Used a questionnaire developed specifically for

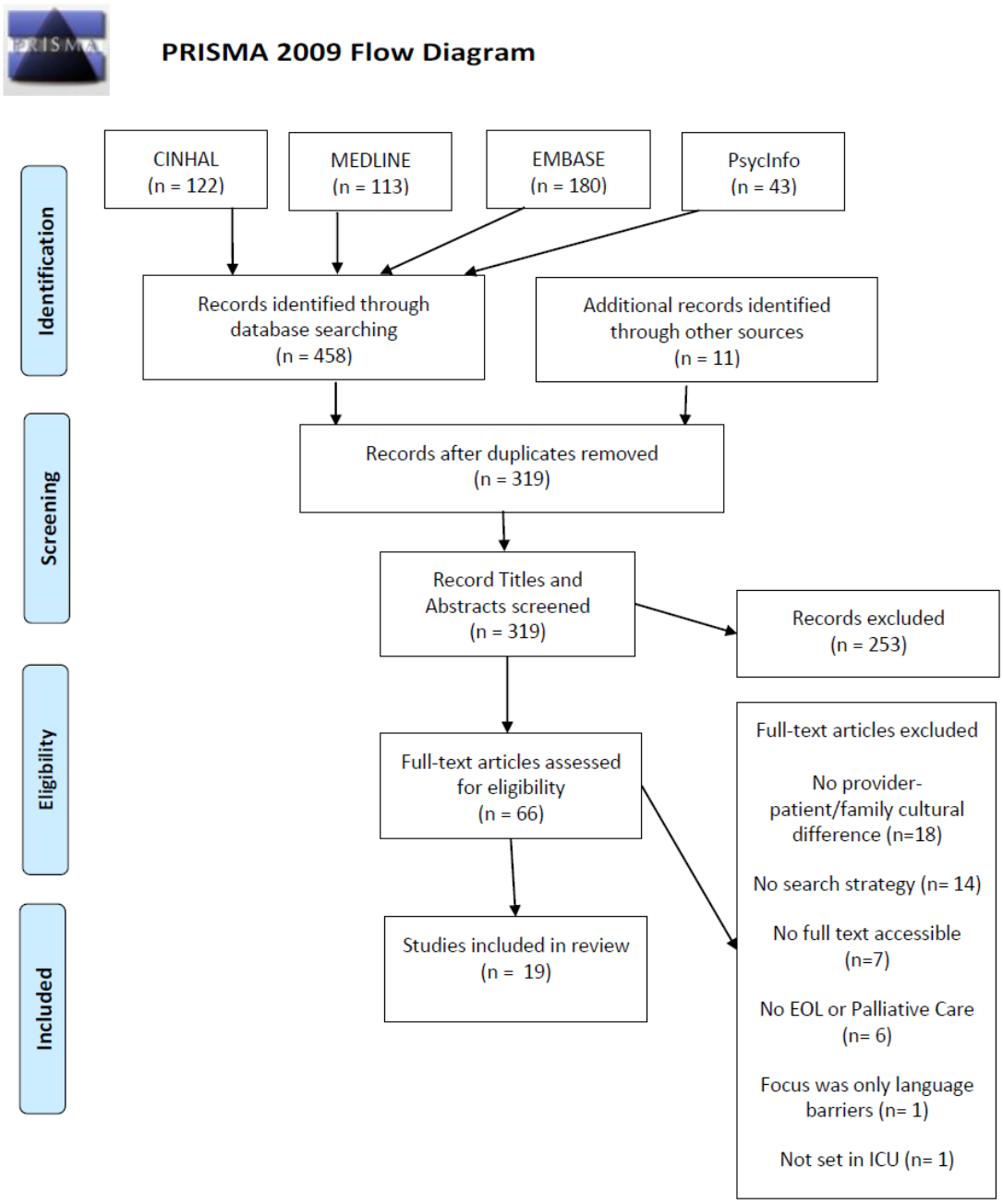
			the study – did pilot questionnaire, but overall internal and external unvalidated ▪ Grouped "Neutral" with "Disagree" and "Strongly Disagree" – may not inappropriate grouping and not accurately describe nurse beliefs
17. Quindemil, K., Nagl-Cupal, M., Anderson, K. H., & Mayer, H. (2013). Migrant and minority family members in the intensive care unit. A review of the literature. *HeilberufeScience, 4*(4), 128–135.	**Methodology**: Literature Review **Databases**: 3 (PubMed/ MEDLINE, CINHAL) **# of articles included**: 17	• Provides Context – pt/family perspective • Families described filtering information to the patient in an effort to minimize suffering and meet cultural norms, such as not directly talking about death or giving hope • Family members describe adjusting the information provided by healthcare professional in a	<u>Strengths</u>: ▪ Captures both patient and provider perspectives ▪ Wide selection of terms ▪ Articles in both English and German included ▪ Lit relevant to nursing well represented ▪ Does critique body of lit found <u>Limitations</u>: ▪ Limited search - # of databases, not reference lists, or other means (grey lit, experts, etc) ▪ Aim description seems consistent with a scoping review, but it is

		way that often skews the message and is not wholly truthful or accurate. • Predominantly western countries explored in research	not identified as such ▪ Attempted to focus on migrant populations from the Former Yugoslavia and Turkey – predominant migrant population not similar to Canada ▪ Includes lit on peds – may skew finding and not be representative of Adult ICUs
18. Van Keer, R.-L., Deschepper, R., Francke, A. L., Huyghens, L., & Bilsen, J. (2015). Conflicts between healthcare professionals and families of a multi-ethnic patient population during critical care: An ethnographic study. *Critical Care, 19.*	**Country**: Belgium **Methodology**: (Focused) Ethnographic Study **Setting/ Participants**: 10 patients, their family, and the staff who cared for them; interviews - 9 health professionals; 1 ICU with a high proportion of patients from ethnic minority backgrounds **Data Collection**: Negotiated interactive observation (432 informal conversations, 144 staff	• Nurses' EOL Perceptions – culture barriers and wellness • Interpersonal conflicts arose as a result of staff-patient/family cultural conflicts • Conflicts were related to families' and healthcare professionals' different expectations of: 1. care practices 2. emotional involvement, 3. information exchange 4. end-of-life decision	<u>Strengths</u>: ▪ Significant time spent in the field ▪ Multiple data collection methods used to triangulate data ▪ Did capture one case with no conflict ▪ Research team represented multiple professions, including anthropologists and a sociologist ▪ Expert reviewed results ▪ Interview guide piloted first ▪ Selected patients from a broad selection of cultural backgrounds

	meetings, 288 witnessed interactions between staff and families); In-depth interviews (9 staff – included nurses); Documents (medical records); Field notes **Data Analysis**: Coding appears informed by constant comparison (Grounded Theory Analysis?)	making (from MDs only) • Virtually all cases had one or more conflicts during field work period • Some of the quotes from nurses reflect a lack of cultural understanding • Many of the sources of conflict and staff stress described relate to obstacles identified in Crump et al. (2010)	<u>Limitations</u>: ▪ Only conducted at one site – limits generalizability ▪ No patient or family member interviews reported – data collection favored HCP perspective ▪ Almost all staff were white Caucasian (from dominant ethnic group?) ▪ Method of analysis does not appear consistent with ethnography

APPENDIX D

Prisma Flow Diagram



From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). *P*referred *R*eporting *I*tems for *S*ystematic Reviews and *M*eta-*A*nalyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

For more information, visit www.prisma-statement.org.

APPENDIX E

Recruitment Email

Subject: Seeking ICU nurses for study looking at culturally sensitive end-of-life care

Hello nurses of [redacted]

I am writing to invite you to participate in a research study on the perceptions of ICU nurses in delivering culturally sensitive care at the end-of-life in adult ICUs. I am seeking nurses who have worked in an ICU for more than 12 months and who have cared for dying patients within the last six months. If this describes you, I would love to speak with you about your experiences tailoring end-of-life care to your patient's culture.

Your participation in this study would involve a single one-on-one interview conducted outside of worktime at a location and time which is convenient for you. The interview will last approximately 60 minutes and during this time I will ask you to reflect upon your thoughts, opinions, and personal experiences delivering culturally sensitive end-of-life care in the ICU and discuss the knowledge and skills you use. Culture is the shared system of values, beliefs, and practices of a particular group which leads to a unique way of understanding and interacting with the world. As such, everyone has cultural end-of-life needs.

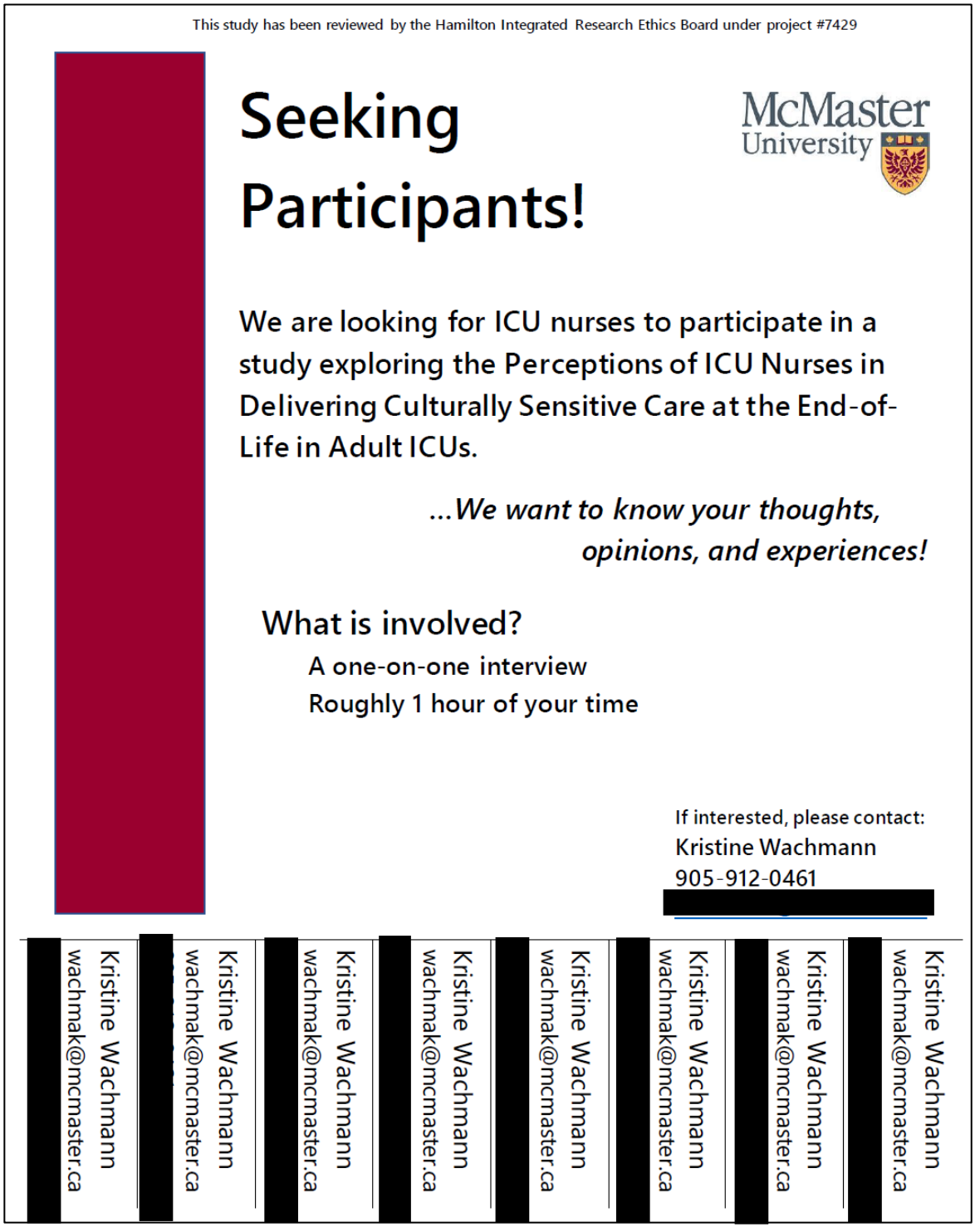
If you choose to be a part of this study, I assure you that your participation and all information you share will be kept strictly confidential, and that you have the right to withdraw from the study at any point. You will also be provided with a $5 coffee card as a gift of appreciation for the time you are volunteering. Your participation is entirely voluntary, but I do hope you can find the time to help develop this under-researched area of nursing.

Thank you,

Kristine Wachmann

APPENDIX F

Recruitment Flyer



APPENDIX G

LETTER OF INFORMATION/CONSENT

The Perceptions of ICU Nurses in Delivering Culturally Sensitive Care at the End-of-Life in the Adult Intensive Care Unit

Investigators:

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The following research study is being conducted to meet the requirements of the Student Investigator's Masters of Science degree. This Letter of Information provides the information that is needed to make an informed decision about participating in this study. Please do not sign the consent form at the end of this document until you are sure you understand everything in this letter. If you have any questions after you have read this form or at any point in the study, feel free to connect with the Student Investigator, Kristine Wachmann, using the provided contact information above.

Purpose of the Study

We are conducting this research study to better understand culturally sensitive end-of-life (EOL) nursing care in adult Intensive Care Units (ICUs). In the ICU, providers, patients, and families all face challenges during EOL care. A growing body of literature shows that these challenges have immediate and lasting effects on wellbeing. Culturally sensitive care shows appreciation, respect, and awareness for a patient's culture and is needed for EOL care to be great. Nurses play a vital role in delivering EOL care in ICUs and we are hoping to better understand their perceptions about delivering of culturally sensitive EOL nursing care.

You are being asked to participate in this study because we believe you can share valuable information about delivering culturally sensitive EOL nursing care in adult ICUs. In particular, we are also interested in: a) how you orient yourself to the cultural EOL needs of your patients and their families; b) what influences your delivery of culturally sensitive EOL care; and c) how do you reconcile your personal values and beliefs about EOL care with those of patients and families. We believe that this information will provide valuable and useful insight on how to promote and support excellent EOL care in the ICU.

Procedures Involved in the Research

Participation in this study is entirely voluntary. If you choose to participate, you will first be asked to fill out a short demographic questionnaire. This questionnaire will ask you to share some basic demographic information (such as your age, gender, work history, and ethnicity) and will help us describe our sample and provide context to what you share. You will then have a one-on-one interview with me, Kristine Wachmann. This interview will be conducted at a date, time, and location that is convenient for you and will last roughly one hour. Interviews can be done either face-to-face, in a location that is quiet, private, and safe, or, if you prefer, online through Zoom Video Communications. Zoom Video Communications is a remote video conferencing service that uses cloud computing to connect individuals in real-time. While all participants will have one interview, you may be asked for a second interview later in the study.

The purpose of these interviews is to explore your perceptions delivering culturally sensitive end-of-life nursing care in the ICU. Before each interview you will be provided with a copy of the interview guide. Interview questions will mainly focus on how you go about understanding and tailoring EOL care to your patients' and their families' culture. Some interview questions will ask you to share your knowledge, while others will ask you to reflect upon previous experiences or your own cultural influences. You are not obligated to share information you do not wish, and you are free to stop the interview at any point. Everyone involved in running this study is committed to respecting your privacy. Interviews will be audio-recorded, and these recordings will be transcribed into written documents**.**

While participation in this study involves a maximum of two interviews, we may need to contact you to clarify what you said during your interview.

Potential Harms, Risks, or Discomforts

Your participation in this study is unlikely to cause you harm or discomfort. We recognize that talking about your experiences delivering EOL care may cause you to experience distressing feelings and memories. If you feel you require the assistance of a health-care professional in dealing with distressing feelings/memories, we are ready to provide you with information about the resources and supports that are available to you as a hospital employee. We aim to create a safe space to share your knowledge, and as such, nothing that you say will be used to judge you or your practice. During your time in the study, you do not have to share information you do not wish to. In addition, every effort will be made to ensure information and details that could identify your, your patients, or co-workers will not be published.

You have the option to conduct your interview online using Zoom Video Conferencing, which is an externally hosted cloud-based service. Please note that whilst this service is approved for collecting data in this study by the Hamilton Integrated Research Ethics Board, there is a small risk with any platform such as this, of data collected on external servers falling outside the control of the research team. A link to their privacy policy is available here (https://zoom.us/privacy). If you are concerned about this, we would be happy to make alternative arrangements for you to participate, perhaps via telephone. Please talk to the researcher if you have any concerns.

Potential Benefits

It is unlikely that you will directly benefit from participating in this study. The information from this study will hopefully help improve supports and resources for ICU nurses when delivering EOL care and hopefully help to improve care for future patients dying in an ICU. You may indirectly benefit from this study by possibly finding sharing your stories cathartic, and, being an ICU nurse yourself, you could have some future nursing practice related benefit from the result of this study.

Reimbursement

We are offering a $5 coffee card as a gift of appreciate for your time and effort.

Confidentiality

Your participation in this study is entirely confidential. Only those involved in this study will know whether you participated and have access to your information, unless it is required by law. We will not use your name or any information that

would allow you to be identified. However, please keep in mind that despite our best efforts, others who know you may be able to identify you based on what you share. Please keep this in mind when deciding what to say and share. We also recognize that others such as patients and co-workers, may be a part of the experiences you share, and we will make every effort to ensure they are not identified. This will be done by combining the information you share with that of other participants (pooling data), ensuring no personal or contextual information that could identify others will be shared with those beyond study staff, and, if neither of these options are possible, your information will not be published. Additionally, the focus of this study is on your perception, and thus we will try to keep the conversation focused on you, thus limit the collection of information that could identify others.
All the data collected for this study will be kept in a secure location. Physical documents will be kept in a locked cabinet and electronic data/documents will be encrypted and only accessible to those running the study. Your interview transcript and demographic information will be de-identified using a unique identification code that will be assigned to you. All de-identified data will be kept for three years after publication, while all identifying data will be destroyed at the end of this study.

b) Legally Required Disclosure
If requested by legal authorities, I may be required to reveal the information you provide.

Participation and Withdrawal
Your participation in this study is entirely voluntary. If you do choose to participate, you can always change your mind, even after giving consent. You can withdraw from the study at anytime and for any reason. If you do choose to withdraw, you will suffer no consequences as a result of this. If you do withdraw, we will not contact you further, however we will be unable to remove already collected data from the study. What we can do is promise we will not use quotes from your interview and will remove any themes that are only supported by your data. To withdraw from the study please contact me, Kristine Wachmann, at wachmak@mcmaster.ca, or by phon[redacted]

Information about the Study Results
This study is scheduled to be complete by September 2020. If you would like a brief summary of the results, please let us know. You can contact me, Kristine

Wachmann, or fill out how you would like this to be sent in the space provided below.

Questions about the study
If you have any questions or want more information on this study, please contact me, Kristine Wachmann, at wachmak@mcmaster.ca, or by phone at [redacted].

This study has been reviewed by the Hamilton Integrated Research Ethics Board (HiREB). The HiREB is responsible for ensuring that participants are informed of the risks associated with the research, and that participants are free to decide if participation is right for them. If you have any questions about your rights as a research participant, please call the Office of the Chair, HiREB, at (905) 521-2100 ext. 42013.

CONSENT

I have read the information presented in this document about the study being conducted by Kristine Wachmann of McMaster University. By signing this form, I confirm that:

- The research study has been explained to me and my questions have been answered to my satisfaction.
- I have been informed of the alternatives to participating in this study. I have the right to withdraw from the study at any time for any reason.
- I am aware that my interview will be audio-recorded.
- The potential harms and benefits of participating in this research study have been explained to me. I have been told that I have not waived my legal rights nor released the investigators or involved institutions from their legal and professional responsibilities.
- I know that I may ask at any time, now or in the future, any questions I have about the study, and who to contact to do this.
- I have been given sufficient time to read the above information.
- I understand that I will receive a signed copy of this Letter of Information and Consent Form.

_____	_____	_____
Name of Participant (Printed)	Signature	Date

Consent form explained in person by:

_____	_____	_____
Name and Role (Printed)	Signature	Date

Verbal Consent Obtained ☐

_____	_____
Date	Time

I would like to receive a summary of the study's results.
Yes *No*

If yes, where would you like the results sent:

Email: _____

Mailing address: _____

_____

APPENDIX H

Telephone/E-Mail Recruitment Correspondence

Hi (*nurse's name*). Thank you so much for your interest in our research study. The purpose of this study is to better understand culturally sensitive end-of-life (EOL) nursing care in adult ICUs. There is a growing body of literature showing that the challenges patients, families, and providers face when delivering EOL care in an ICU has immediate and lasting effects on wellbeing. Culturally sensitive care shows appreciation, respect, and awareness for a patient's culture and is important for optimal EOL care. Because nurses play a vital role in delivering EOL care in ICUs, we want to better understand their perceptions about delivering culturally sensitive care at the EOL.

Participation in this study is entirely voluntary and you can withdraw at any time and for any reason. Participation involves the completion of a short demographic questionnaire and a (roughly) 1-hour one-on-one interview with myself. We are offering participants a$5 coffee care as a show of appreciation for their time and effort.

To be included during the COVID-19 pandemic:

For the time being, all study related activities will be conducted remotely because of the risk of COVID-19. This means that all interactions will be done online or by telephone, including interviews.

For email correspondence:

More information about the study is contained in the Letter of Information/Consent we have attached. If you are still interested in participating, please let me know and we can arrange a date and time for the interview. As well, I am also more than happy to answer any questions or concerns you have.

For telephone correspondence:

If you are still interested in participating, I will send you a copy of our consent letter, which contains more detailed information about the study. We can then arrange a date and time for the interview.

Do you have any questions?

Again, thank you so much for you interest.

Sincerely,

Kristine Wachmann BScN, RN, CNCC(C)

LETTER OF INFORMATION/CONSENT

The Perceptions of ICU Nurses in Delivering Culturally Sensitive Care at the End-of-Life in the Adult Intensive Care Unit

Investigators:

Local Principal Investigator:
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Department of Nursing
McMaster University
Hamilton, ON, Canada
Phone: [redacted]
E-mail: wachmak@mcmaster.ca

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This study is scheduled to be complete by September 2020. If you would like a brief summary of the results, please let us know. You can contact me, Kristine Wachmann, or fill out how you would like this to be sent in the space provided below.

Questions about the study

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- I have been given sufficient time to read the above information.
- I understand that I will receive a signed copy of this Letter of Information and Consent Form.

_____	_____	_____
Name of Participant (Printed)	Signature	Date

Consent form explained in person by:

_____	_____	_____
Name and Role (Printed)	Signature	Date

Verbal Consent Obtained ☐

_____	_____
Date	Time

APPENDIX I

Participant Demographic Form

Participant ID: _____

Date of Interview: _____

1. Age: _____ years old

2. Gender Identify: _____

3. What is the highest level of education you have completed?
   - ☐ College diploma
   - ☐ University degree
   - ☐ Graduate degree

5. How long have you worked as a nurse? _____ years

6. How long have you worked in an ICU? _____ years

7. Country of birth: _____

8. How do you describe your ethnicity? _____

9. What languages can you hold a conversation in?

   - ☐ English
   - ☐ French
   - ☐ Other(s): _____

10. Have you received any cultural sensitivity or cultural competence education or training?
    - ☐ No
    - ☐ Yes
      - what?_____ and
      - when?_____

11. Have you received any palliative care or end-of-life care training?

    - ☐ No
    - ☐ Yes

- what?_____ and
- when?_____

APPENDIX J

First Interview Guide

Hi (*participant name*). My name is Kristine Wachmann. I am a researcher and student in the Masters of Nursing program at McMaster University.

Thank you for taking the time to meet with me today. This interview will explore your perceptions about delivering culturally sensitive end-of-life nursing care in adult ICUs. To do this, we will explore your perceptions, including your thoughts, opinions, and beliefs about delivering this care and discuss the knowledge and skills you use. I will also ask you questions about caring for patients and families whose end-of-life beliefs or practices contradict what you believe is important for good end-of-life care. You should share only what you are comfortable sharing and you have the right to not answer any specific questions; however, I would like to assure you that what you do share will be kept confidential. You can choose to withdraw from the study at any point and for any reason. If you do withdraw, you will not be contacted further by this study and we will not use quotes from you interview in any publications; however, we will not be able to remove your data from the research study. This interview will take approximately an hour and will be audio-recorded. You can stop the interview at any time. Do you still wish to participate in this study?

Are you comfortable?

Before we start, do you have any questions about the study? During the interview, if you have any questions or are unclear about anything, please, feel free to ask.

I. People often identify with more than one cultural group. How would you describe your cultural influences?

Probes:

- How do you think this has influenced what you feel is important during end-of-life care in the ICU?

II. What do you feel is important for delivering end-of-life nursing care that is sensitive to a patient's and/or family's culture?

Probes:

- What do you think is important for learners (like students or new hires) to know about tailoring end-of-life care to a patient's or family's culture in the ICU?
- How do you find out what is culturally important to patients and families at the end-of-life?
- Are there any resource you have used to help provide culturally respectful and appropriate end-of-life care? Have any been helpful?

III. Can you describe for me a time when you felt you provided end-of-life care that was culturally sensitive? What about this situation makes it stand out to you?

Probes:

- What about this situation was meaningful to you?
- What factors do you think influenced your ability to meet the patient's or family's cultural needs?
- What do you think is similar to other situations?
- What do you think is different from other situations?

IV. Can you recall a time where you were required to provide end-of-life care to a patient and family where you feel their values or beliefs were inconsistent with your own? Can you describe this situation to me?

Probes:

- How did you feel about caring for the patient?
- What role do you think culture played in this situation? (explore the role of both the nurse's and patient's culture)
- How did you work through this situation?
- Where did you look for help dealing with this?

V. I really appreciate your willingness to be a part of this study. Before we finish, is there anything else you feel is important to share with me about culturally sensitive EOL care in the ICU?

APPENDIX K

Second Interview Guide

Hi (Participant Name)

Thank you for agreeing to a second interview. Your last interview was so great that I really wanted another chance to talk with you further about delivering culturally sensitive EOL care. I really think you can help us better understand some of the themes we've seen in the data so far.

A few things before we start. While we have talked about all these at the start of the last interview, it is important that we go over them again. First, your participation in this research study is still entirely voluntary. You are not obligated to share anything you do not wish to and can decline to answer any questions. Everything you share will be kept confidential and we are dedicated to maintaining your privacy. Second, while you can choose to with withdraw from the study at anytime and for any reason, if you do choose to withdraw, we can not remove the data we have collected up until that point…so, please consider this when answering questions. To withdraw from the study all you have to do is contact me using the information on the Letter of Information and consent form that was provided to you.

I just want to confirm that you received the updated Letter of Information and Consent.

I also want to verbally confirm that you still consent to being a part of this study and that you agree to this second interview.

Before we begin with questions, I think it is important to go over what I mean when I say culturally sensitive EOL care. When I use this term, I'm referring to the care of patients whom we know will imminently die that shows appreciation, respect, and awareness of that patient's cultural context. This care arises from the practitioner's self-awareness and their awareness of others, as well as their insight, and experience.

Do you have any questions or is there anything you want clarified?

Questions

I. In previous interviews, nurses spoke about how important cultural sensitivity is when caring for patients dying in the ICU. However they seemed to struggle with talking about this in practical terms. What do you think makes delivering culturally sensitive EOL care challenging to talk about?
   - In real life, how much consideration do you think is given to the patient's/family's culture when delivering EOL care? Why do you think this is?

II. What do you feel is your role in delivering culturally sensitive EOL care?

III. How do you feel your relationship with a patient and/or their family impacts your ability to deliver culturally sensitive EOL care?
   - What do you do to encourage families and patients to open up and share their cultural values, beliefs, and EOL needs?
   - What do you find helps you engage more meaningfully with patients and families from culturally diverse backgrounds?

IV. In previous interviews, when talking about the cultural needs of patients and families at the EOL, nurses often focused on religion and religious needs. Why do you think this is?

V. How supported do you feel in delivering culturally sensitive EOL care? Can you explain to me what makes you feel that way?
- How would you describe the EOL culture of your ICU? Have you ever thought about this?
- What impact do you think the culture of your ICU has on your ability to deliver culturally sensitive EOL care?
- How do you feel about the ability of your workplace resources to help you care for culturally diverse patients and families at the EOL?

VI. In the first part of this study nurses described turning to colleagues for advice and assistance in dealing with distress caused by having to deliver care that opposed what they feel is important at the EOL. For you, what characteristics make a colleague worth turning to for help in this situation?
- What is it about talking with colleagues that helps?
- Who do you think possesses these characteristics?

VII. What effect do you think understanding a patient's/family's culture has on how you come to terms with EOL care that didn't align your values and beliefs?
- What about at the time your delivering care?
- How important is understanding the motivation behind the patient's/family's decisions when you are trying to reconcile care with your own values and beliefs?
- In situations where a family's EOL decisions go against your values and beliefs, what kinds of things help you feel better about the care you delivered?