Moral Distress in Pediatric Intensive Care Nurses: Experiences with the Death and Dying of Child Patients

by

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Abstract

Background: Moral distress has been commonly understood in the literature to be when one knows the right thing to do but being unable to realize it. Research has indicated the consequences of such an experience can deeply affect the individual. Critical care areas are fraught with ethical issues and end-of-life care has been associated with numerous incidences of moral distress among nurses. One such area, where the dichotomy of life and death can seem to be at its sharpest, is in the pediatric intensive care unit (PICU).

Purpose: The purpose of this dissertation was to understand nurses' experiences of moral distress in Canadian PICUs where advanced life-sustaining interventions are offered for complex medical and surgical cases. The intention was to better understand the moral distress experiences of PICU nurses related to the death and dying of their patients.

Methods: A content analysis was undertaken of seven transcripts from registered nurses from six PICUs across Canada. This secondary analysis uses data from a narrative inquiry reported in 2006 (Austin, Carnevale, Frank & Garros). The content analysis used open coding resulting in the emergence of nine dominant themes.

Findings: The developed themes, with associated sub-themes, denote the outer state of nursing in the PICU, the inner state of the individual nurse, the relationship dynamics between the nurse and others, and differing perspectives among individuals to clearly depict the experiences of moral distress. The outer state includes the two themes PICU context and nurse positioning. The inner state includes the two themes of feelings around dying and death and greatest nursing concerns for dying patients. Relationship dynamics include four themes of decision-making power, communication and messaging, stated support for nurses, and recommendations for change. The final theme of differing opinions, perspectives, and perceptions emerged as having tendrils woven throughout the others.

Discussion and Conclusions: Nurses are in a position to experience the burden of moral responsibilities intensely and with great effect to their inner state. This secondary analysis highlighted various feelings throughout the patient trajectory along with their reasonings; an additional notable contribution was the reimagination of distress related to decision-making in terms of the intention of treatment. Both of these findings have implications for practice in more precisely identifying reasons for moral distress and in tailoring prevention or intervention strategies. The findings of this secondary analysis show experiences of moral distress most often occur by being in some type of relation to others or to the environment. Indeed, this study demonstrates that a lack of communication is not simply a gap of exchanged knowledge; rather may indicate the underlying relationship health or status between the individuals. This indicates a need for interventions to be tailored less towards the sole individual but rather towards how relationships are being made and maintained with others and the organization.

Preface

This thesis is an original work by Michelle Gagnon. The research project, of which this thesis is a part, received research ethics approval from the University of Alberta Research Ethics Board, Project Name "Moral Distress in Pediatric Intensive Care Nurses: Experiences with the Death and Dying of Child Patients", Pro00095713, November 25, 2019.

This secondary analysis examined data from a narrative inquiry reported by Austin, Carnevale, Frank, and Garros (2006) in a CIHR funded research project of moral distress in the pediatric intensive care unit.

No part of this thesis has been previously published.

Dedication

This work is dedicated to those who are suffering.

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To my master's advisor and supervisor, Dr. Diane Kunyk. You have been an unwavering and incredible support since my entrance into the program. It has been an honour to study and learn from someone who is not only brilliant and wise but is also uniquely kind. You have been an outstanding mentor and I am far better for having adopted just a fraction of your qualities. Pursuing graduate school with you has been one of the best decisions I have made. Thank you for helping me regain meaning for the struggles we face collectively.

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of this dissertation and probably deserves authorship. As you know, nothing feels as good as being a part of a pride. With that, I will leave you here to read the rest while I go get some Aloe for this second degree.

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Chapter 1: Opening Introduction

Knowing the right thing to do but being unable to realize it is known as moral distress. First notably explored in the early 1980s by philosopher Andrew Jameton after hearing of bioethical dilemmas faced by nursing students, the phenomenon has received attention from researchers and clinicians alike, now having led to considerable findings within nursing and branch disciplines. While variation in definitions exist, common understandings of moral distress include internal (personal) and external (contextual) barriers that constrain an individual from acting on what they perceive to be right (McCarthy & Deady, 2008). Experiencing moral distress can have deeply impactful consequences to the individual's personal and professional wholeness. Psychological, physical, and emotional manifestations of moral distress include depression, anxiety, guilt, anger, nightmares, palpitations, migraines, diarrhea, self-blaming, withdrawal, decreased self-esteem, burnout, and loss of integrity (Austin, Lemermeyer, Goldberg, Bergum, & Johnson, 2005; Nathaniel, 2006; Hanna, 2004; Wilkinson, 1987). This overwhelming drainage of individual resources has shown to impact the context with whom the individual interacts, including attrition from their area of work or even profession.

Areas of critical care have often been cited as environments where ethical issues are common, and decisions can truly determine the life or death of patients. One such area, where the dichotomy of life and death can seem to be at its sharpest, is in the pediatric intensive care unit (PICU). This is an emotionally charged area with unique challenges of pediatric, parental, and healthcare team dynamics and can often be driven by the adage *what can be done should be done*. Common difficulties and ethical issues often surround communication between the medical team and parents or next-of-kin, parents refusing treatment, informed consent, and formal decision-making structures (Baek and Kang, 2018; Browning & Cruz, 2018; Cooper &

Kock, 1996; Foe, Hellmann & Greenberg, 2018; Gill, 2005; Mu et al., 2019; Rasoal, Kihlgren, James, & Svantesson, 2016; Studdert, et al. 2003). Less frequent themes can be tied to organ transplantation, use of innovative surgery, use of pain medications, allocation of resources, and mechanical support of brain-dead patients (Austin, Kelecevic, Goble, & Mekechuk, 2009; Mitchell and Truog (2000). Emergent research suggests that moral distress in nursing is pervasive, particularly in end-of-life care (Storch, Starzomski, & Rodney, 2013). With PICUs seeing the most pediatric inpatient deaths, investigating moral distress in cases of the death and dying of child patients could yield pertinent information on how the phenomena comes about, is lived, and how it is or may be mitigated.

What Compels Me

While working as a bedside registered nurse in the emergency department (ED) and adult intensive care unit (ICU), I often encountered situations of moral dilemma. The longer I worked, the more I began to see various responses in my peers, and myself, during and after such situations. I left the ED after burning out, four years into my nursing career. I truly thought I fell into the age-old mantra that I *just couldn't cut it*. I applied to work in the ICU, confident that a change of pace would be good. As time passed, I found myself with the same feelings of anxiety and dread becoming more profound, even though I was becoming more skilled at the ICU pace. I had confidence in my bedside skills, yet there were cases where I would distinctly think I was doing something *wrong* for the patient. Voicing "I feel like I'm torturing this patient" became more routine, and I finally had one crucial nightshift experience that I can clearly, retroactively identify as morally distressing. After this case, I withdrew personally and professionally. I was beginning graduate school soon anyway, so I thought I just needed a small break. I began meeting potential advisors in the summer before the fall term, discussing my interest in ethics, only to stumble over the notion of moral distress. I had somehow worked six years as a bedside nurse without coming across the term in a meaningful way; needless to say, this became a serious topic of interest for me in graduate school. This fueled my curiosity in studying moral distress.

Halfway through my Master of Nursing (MN) program, I began working casually with the Medical Assistance in Dying (MAiD) team. My role involves joining an NP/physician for the final meeting with the patient and family/loved one, where I initiate an intravenous line and witness the administration of medications to end this patients' life. I come in at the very last step of the MAiD process, often being given a small snapshot of the patients' medical journey before meeting them and discovering more throughout our interactions. It is difficult to express the feelings of witnessing a drawn-out in-hospital case, where people seem to be crashing into death, compared to a death that has been actively chosen by that patient. Witnessing these dichotomous journeys at the end-of-life have been profoundly impactful. Death will always have certain associated feelings, whether it be sadness, grief, loss, or hurt, yet some journeys seem extraordinarily fraught with pain. I am interested in rediscovering the process of death and dying; essentially, in the interest of all those involved in care, is our approach to death and dying in critical care how it ought to or could be? What is a good death?

Purpose

The purpose of the proposed study is to analyze nurses' experiences of moral distress in Canadian PICUs where advanced life-sustaining interventions are offered for complex medical and surgical cases. Futile care and end-of-life decision making are among the most common ethical issues in PICUs (Austin, Kelecevic, Goble, & Mekechuk, 2009). This analysis will take into account the dynamics of accessing certain exclusive resources, the situation of nurses within the healthcare team, and the unique Canadian environment of pediatric intensive care, where child inpatient death most often occurs.

The two research questions are: What are the moral distress experiences of PICU nurses caring for child patients who are at risk of death or who are dying, as revealed in their stories? And, what support systems/resources are in place, or are needed, to deal with such moral distress experiences? The proposed study is a secondary analysis of data collected from Austin, Carnevale, Frank, and Garros in 2006. At that time, narrative inquiry was used to interview various disciplines of frontline PICU healthcare providers from six hospitals across Canada. The hospitals chosen were based on PICUs that offered high levels of intensive care interventions, including extracorporeal life support (ECLS), organ transplantation, and complex heart surgeries. This proposed study will use a content analysis approach by reviewing transcripts and records of the original research.

Storch, Starzomski, and Rodney (2013) stated that the adage where if something *can* be done, it *should* be done contributes to the moral distress of patients, families, and health care providers (HCPs), particularly with the technological imperative of critical care settings. The proposed study will analyze data recruited from six Canadian PICUs where highly advanced intensive care interventions are offered to support complex patient cases. These technologies move beyond mechanical ventilation and inotropic circulatory support to include ECLS, organ transplantation, and complex heart surgeries. Garros, Rosychuk, and Cox (1993) found through retroactive studies that approximately 40% to 60% of all deaths in PICUs occur following the decision to forgo life-sustaining treatment.

In 2001, Corely, Elswick, Gorman, and Clor noted that in contemporary practice, nurses have more responsibility than they have authority; this persists to current day (Austin et al., 2005). The paradox of having little authority into care one is providing has made it, so moral distress is embedded into the structural and social makeup of the nursing profession (Austin et al., 2005; Wilkinson, 1987). In congruence with the research conducted on moral distress in critical care areas, Storch, Starzomski, and Rodney (2013) found that nurses frequently felt caught between maintaining the trust and best interest of the patients and families versus the physician's need to preserve life; this continues to raise troubling moral issues for nurses, along with their colleagues. Additionally, the authors identified that the phenomena of moral distress is likely not a linear process of cause (constraints) and effect (moral distress). Yet, regardless of its conceptualization, the cumulative effects of moral distress are a serious concern.

Given the advancements in technology, the research into team miscommunications, and the complexities in navigating care at the end-of-life (Mu, et al., 2019), the insights revealed in this analysis may provide meaning into understanding the context for Canadian nurses in PICUs related to death and dying and illuminate resources in place or needed to address this moral distress.

Significance for Nursing

The results of the proposed study will provide a unique perspective of the experiences nurses undergo when caring for dying patients in the PICU and will contribute to the existing pool of knowledge concerning moral distress specific to the Canadian context. The insights drawn from this study will give insight for nurses, nursing leaders, and researchers into perceptions of events that led up to, surrounded, and occurred after experiencing situations of moral distress. The rich descriptions and understandings garnered from this study illuminate a path for clinicians and future nursing research to channel tailored efforts into addressing moral distress strategically.

Rodney (2017) calls researchers to better understand how nurses can act with constructive moral agency within complex organizational structures and states the need for a better understanding of *how* to support nurses as individuals to move forward with meaningful change. This is precisely what this study has facilitated. Understanding the nursing experience informs support strategies to cultivate moral resilience and to enable nurses to continue providing sound ethical care.

"Before we start to investigate, let us try to realize what we do know, so as to make the most of it, and to separate the essential from the accidental." – Sir Arthur Conan Doyle, The Adventure of the Priory School

Chapter 2: Literature Review

This chapter provides a skeleton of the contemporary literature, beginning with a brief history of moral distress with a note to its consequences. The context and setting of PICUs will then be described and will include the role of the nurse. Following this, difficulties commonly seen in the pediatric patient milieu, ethical issues faced in PICUs, and death and dying, as seen in the PICU will be discussed. Chapter 2 will conclude with a synthesis of what is known and unknown in the literature reviewed.

Moral Distress

The concept of moral distress was first introduced into clinical ethics literature by philosopher Andrew Jameton in 1984. Envisioned in response to nursing student's stories and discussions of bioethical dilemmas, Jameton defined moral distress as "the psychological distress of being in a situation in which one is constrained from acting on what one knows to be right" (Jameton, 2017, p. 617). Alternately stated, when one knows the right thing to do yet is in a situation where it is nearly impossible to act it because of institutional barriers (Jameton, 1984). This pivotal work ignited an uptake in qualitative and quantitative research. Initially focused on the psychological dimensions of moral distress, particularly among critical care nurses, and has since found to be impactful to populations in healthcare beyond nursing, including physicians, respiratory therapists, psychologists, and social workers (Austin, Rankel, Kagan, Bergum, & Lemermeyer, 2005; Lev & Ayalon, 2018; Rodney, 2017; Thomas & McCullough, 2015). As McCarthy and Deady (2008) perceived, the growing literature on moral distress has several delineations from the original notion, including variations in definitions to adaptations in what constitutes as a constraint or attribute. For example, internal constraints have evolved to include personal failings (fear, doubt or lack of resolve) and external constraints as contextual or situational (hospital policy, hierarchical decision making or lack of resources) (Austin et al., 2005; McCarthy & Deady, 2008).

Research has primarily been conducted among the nursing population, with a focus in acute care or specialized areas of nursing (Pauly, Varcoe, Storch, & Newton, 2009). However, more recent literature reveals moral distress to be a critical problem that confronts multiple healthcare professionals, domestic and internationally and has significant implications for satisfaction, recruitment, and retention of professionals, as well as safe delivery and competent quality of care (Pauly, Varcoe, & Storch, 2012). Indeed, the breadth of research into moral distress has crossed boundaries beyond the health care arena. Through interviews, Svensson (2019) examined the challenges experienced by teachers of asylum-seeking pupils in Sweden and the strategies used to manage them. The author discovered institutional factors, lack of training, and insufficient support within the educational system constrained the work of the teachers. Tensions arose between the regime of care in providing education to the students and the power of the Swedish state's interest over controlling immigration, resulted in moral distress for the teachers, cited as ultimately stemming from a lack of control over the asylum decisions (Svensson, 2019).

Moreover, Papazoglou and Chopko (2017) explored research surrounding the role of moral suffering in police traumatization [compassion fatigue and post-traumatic stress disorder (PTSD)]. The authors noted that moral distress is one of two types of moral suffering that appear to lead to police traumatization; the second type is moral injury. With roots in soldier and veteran research, moral injury refers to unprecedented traumatic life events related to committing, failing to prevent, or bearing witness to actions that violate one's core moral beliefs and expectations, such as seen with violence and death-related incidents. The authors explained that while moral distress and moral injury emanate from different morally conflicted incidents, they both result in moral suffering where feelings of guilt, shame, and frustration are seen, and this suffering may contribute to compassion fatigue and PTSD (Papazoglou & Chopko, 2017).

In 2003, Lützén, Cronqvist, Magnusson, and Andersson described that focus had predominately been paid to the moral situations that give rise to ethical conflicts and morally distressing situations, with explorations into competing obligations for the nurse; the authors supposed that there appears to be a need for deeper understanding into the ethical component of moral distress. In more recent work, Lützén and Kvist (2012) stated that questions continue to lie in whether moral distress arises when there is a moral conflict between care and duty-bound or principled responsibility, or whether moral distress occurs when conflicting principles are at hand. Furthermore, Lützén & Kvist (2012) stated that much of moral thinking is personal and can be confusing for any individual to understand. Certainly, non moral based conflicts arise in practice, and there is, therefore, a question if nurses understand what is considered to be ‘moral' and if negative feelings resulting from conflict are being described as moral distress when an explanation of stress between individual – environment/ individual – individual is perhaps more appropriate (Lützén & Kvist, 2012). With unknowns and queries in mind, the proposed study of experiences of PICU nurses in caring for dying patients adds a unique perspective to the existing pool of moral distress knowledge.

Moral Distress – Implications and Consequences

In a 1987 study by Wilkinson, moral distress was found to be detrimental to nurses’ personal and professional wholeness; nurses cited loss of self-worth, effects on personal relationships, and various psychological and physical manifestations. Authors have noted these manifestations may include feelings of depression, anguish, sense of isolation, guilt, anger, nightmares, palpitations, migraines, and diarrhea (Hanna, 2004; Wilkinson, 1987). Furthermore, nurses who experience moral distress are at risk for decreased coping and self-blaming, which may lead to decreased self-esteem, sarcasm, withdrawal, avoidance behaviour, betrayal of values, burnout, and loss of nursing integrity, and is ultimately a powerful impediment to ethical practice (Austin et al., 2005; Rodney, 2017; Nathaniel, 2006). Overwhelming drainage of a nurse's resources often leads to burnout, which may result in deterioration of morale and teamwork, decreases in the quality of care, and attrition from the profession (Austin et al., 2005; Rodney, 2017). When moral distress occurs, the well-being of the nurse is threatened, and their integrity challenged. Unresolved moral distress can lead to moral comprise and subsequently moral residue, where one carries with them the knowledge of how they should have acted but were unable to do so (Rodney, et al., 2013).

Moral residue can be discussed in relation to the nonlinearity aspect of moral distress. The long-term "residue" an individual carries with them can have a cumulative effect, also known as the "crescendo effect" that may escalate increasingly over time (Rodney, 2017). In a similar vein, normalizing the disregard of ethical commitments can result in moral disengagement, in which a nurse becomes apathetic, sometimes to the point of being unkind, non-compassionate, or cruel to colleagues, patients, and families (Canadian Nurses Association, 2017). In an interesting exploration, Gini, Thomberg, and Pozzoli (2018) investigated the concept of moral disengagement to understand nonaggressive bystander behaviour in bullying with consideration to the role of moral distress. In this study, moral disengagement was approached through the social-cognitive framework, referring to a series of psychological mechanisms where individuals can morally justify their negative behaviour through reframing, thereby minimizing one's responsibility or distorting consequences of one's actions, or dehumanizing the victim (Bandura, 1990; Bandura, 2016). Through reframing techniques, the morally disengaged individual does not suffer consequences that would be evident with immoral conduct, such as guilt or shame, and makes failings to act morally more tolerable for the individual (Gini, Thomberg, & Pozzoli, 2018). The study found that students who endorsed moral disengagement were less likely to report moral distress when they acted as a passive bystander to bullying. Comparatively, moral distress was positively associated with actively intervening in a bullying scenario. Furthermore, students who had experienced moral distress in the past, when acting as passive bystanders, were more likely to anticipate moral distress if they did not intervene, suggesting that anticipated moral distress can act as a moral compass that guides decision-making. A final important finding described that individual moral disengagement and moral distress was significantly moderated by students' perceived collective moral disengagement. The findings of this study demonstrate that the perceived social-moral context can modulate and contribute to regulating individual moral agency, which may be important considerations and insight for the healthcare context for future research into addressing moral distress through the promotion of moral agency (Gini, Thomberg, & Pozzoli, 2018).

It is important to note that not all environments or situations will affect all individuals to the same extent or capacity; two nurses in the same situations may be impacted differently with only one experiencing moral distress. Factors that may influence the occurrence of moral distress can depend on the type of hospital unit, the nurse's individual moral sensitivity, or the individual belief framework of the nurse and its compatibility with that of their colleagues or institution (Austin 2005; Wilkinson, 1987). A final consideration is that level of education, age, and years of experience were not predictive of moral distress intensity (Corley, 1995; Corley, Minnick, Elswick, & Jacobs, 2005; Pauly, Varcoe, Storch, & Newton, 2009). Garros, Austin, and Carnevale (2015) discussed that moral distress presents as an individual response to a clinical circumstance; therefore resolution begins with acknowledgment within the individual themselves and with the important dialogue that follows. A critical piece to resolving moral distress requires an important paradigm shift in how it is understood today. It involves moving away from seeing the individual experiencing moral distress to be psychologically distressed toward viewing moral distress as an alarm for when a conscientious person is required to practice in challenging contexts. This is of importance as it recognizes that the practice setting can be triggering and compounds the individual's response, transferring the onus of change from the individual to the larger surrounding context (Garros, Austin, & Carnevale, 2015; Pauly, Varcoe, Storch, & Newton, 2009).

Pediatric Intensive Care – Context and Role of the Nurse

Canadian pediatric care medicine emerged in the 1980's with Toronto's Hospital for Sick Children being among the first pediatric critical care training programs in North American (The Hospital for Sick Children, 2019). The PICU is a relatively new context and it initially arose to support children with persistent and chronic lung disease after surviving infanthood in the neonatal intensive care units (NICUs), where child patients could receive complex postoperative monitoring and care unavailable on regular pediatric units. PICUs grew with technological advancements to support increasingly complex postoperative management, advances in medical and surgical subspecialties, and the development of sophisticated life-support treatments (Epstein & Brill, 2005). In current pediatric critical care research, a substantial portion of research attention is paid to challenging disease processes that have high rates of morbidity and mortality, namely those involving acute respiratory syndrome, septic shock, and traumatic brain injuries.

Since conception of the PICU, the nursing role has evolved with the sophisticated advancements in technologies and procedures. Carnevale and Dagenais (2014) described nursing care in PICUs as complex and multifaceted, often revolving around maintenance and anticipation of care. It was noted that the skillful nurse uses a kind of peripheral vision to act as a total system monitor, in which they continually examine all physiologic monitors, treatment devices, and the patient's body. The PICU nurses' peripheral vision is enacted by, using equipment in to be "tuned into" and "attentive to" the patient's status. In a similar vein, the nurse instantly evaluates the importance of any irregularities and initiates an appropriate response. Though irregularities are often attributed to normal patient functions, such as movement or coughing, the nurse immediately acts by scanning the child's body, equipment, and implementing interventions within their own scope (e.g., suctioning or manual ventilation) or notifies allied health care practitioners for assistance. Nursing plays a primary role in maintaining patient safety on a continual basis through vigilant monitoring and security measures to prevent adverse effects, including medication preparation procedures, infusion pump settings, and restraints. In addition to being attentive to physiological needs, the nurse has added responsibilities for fostering and maintaining a positive psychosocial bedside environment for the child and family. This involves addressing expressed needs while anticipating additional needs through the use of basic comforting skills or fundamental nursing skills, empathetic listening, and recognizing the extraordinary distress or lack of coping with critical illness. Finally, the nurse uses their unique position to integrate the vast body of bedside and laboratory information into a patient record that becomes a vital reference for allied healthcare practitioners and for subsequent shifts and reviews. The authors state that the nurses serve as a “live” patient data source by keeping up-to-date with the rapidly unfolding events to ensure integrated coordinated patient care (Carnevale & Dagenais, 2014).

Unique challenges continue to persist in this demanding context (Epstein & Brill, 2005). Sophisticated life-dependent technologies and interventions, anxious families, and diligent monitoring by staff is an everyday snapshot inside the PICU (Carnevale & Dagenais, 2014; Michelson & Siegel, 2014). Few health care areas are as emotionally charged (Studdert, et al., 2003). Many sources of emotional intensity for healthcare providers can be identified to constant exposure to death, disfigurement, and loss, with everyday activities being likened to participating in ‘active warfare’ (Woolston, 1994). Difficulties, ethical dilemmas, and feelings of moral distress are often related to caring for child patients with complex medical issues and unclear prognosis, most commonly stemming from resource utilization, patient suffering, and undue burden for outcomes that may be considered unacceptable (Ganesan & Hoehn, 2014).

Pediatric Intensive Care - Difficulties

“The starkest of alternatives – life and death of children – are focused into sharp relief in the PICU” (DeMaso & Meyer, 1996, p. 1411). The cost of providing critical care to children is enormous (Epstein & Brill, 2005), in various meanings of the word. Substantial ethical considerations arise when caring for children with a limited chance of survival or meaningful recovery. Ethical dilemmas involving life-sustaining treatment often hold significant emotional and psychological weight in which hospital ethics committees may be consulted; oftentimes, these dilemmas are tied to the considerations of allocating scarce or costly intensive care resources and services that are used appropriately and wisely (Epstein & Brill, 2005).

Rasoal, Kihlgren, James, and Svantesson (2016) explored ethically difficult situations in everyday clinical practice faced by healthcare teams during moral case deliberations in hospital and community care settings. The three themes that emerged include powerlessness over managing difficult interactions with patients and next-of-kin, unease over unsafe and unequal care, and uncertainty over who should have power over care decisions. The authors discussed that the nature of these situations contained a relational-orientated ethics, in which emotions were omnipresent and the described relationships were saturated by power aspects. Though the study did not capture what healthcare providers themselves perceived as ethical issues, the authors noted particularly challenging situations in which the team struggled to balance the emotional needs of the patients or family with their own needs.

In 2003, Studdert and colleagues conducted a study to determine the frequency, types, sources, and aspects of conflict surrounding the care in PICU patients with prolonged stays. Involving intensivist and nursing perspectives, the study prospectively detailed conflicts relating to team-family dynamics, often related to poor communication, unavailability of parents, and disagreements over the care plan. The authors noted that the complexity and profound nature of many disputes related to withdrawing care in PICUs was in no way a trivial undertaking.

Pediatric Intensive Care – Ethical Issues

With advancements in life-sustaining interventions, the patient trajectory has evolved; while mortality rates continue to decrease, child patients are experiencing higher comorbidity, chronicity of disease, and are at high-risk for sequelae after discharge, at times resulting in repeat PICU admissions with increased risk of mortality (Andrews, Rahman, & Pinto, 2018). Common ethical issues in the PICU include parents refusing treatment, informed consent for treatment, and formal decision-making structures (Austin, Kelecevic, Goble, & Mekechuk, 2009), along with futile care and end-of-life decision making to be discussed in the following section. In a review of consults of the Ethics Advisory Committee at Boston's Children's hospital, Mitchell and Truog (2000) identified additional less frequent themes of organ transplantation, use of innovative surgery, use of pain medications, allocation of resources, and mechanical support for brain-dead patients.

Gill’s (2005) observational research of a six-year-old patient in a PICU from the USA may shed light on parent involvement in decision-making. This patient had already endured a lengthy stay in hospital after undergoing liver transplant surgery, with notable complications. The author reported that unique factors of pediatric critical care suggest that parents exercise far less decision-making power than perhaps officially thought. In the study, the intensivists appeared less willing to allow parents to make what was perceived as a “wrong choice” for the child patient compared to an adult patient who may make such a choice for themselves. If an adult patient makes an “unwise” choice, the adult will be dealing with the consequences, whereas in pediatrics, there is a difference when the decider (the parent) will not live the same consequences themselves. Furthermore, the author states that some physicians believe the parents of acutely ill children are ill-equipped to take part in decision-making in a meaningful way; that hashing out decision-making details behind closed doors allows the parents to concentrate on personal matters without the added burden of medical issues. This was especially noted with patients who were critically ill, where the decision to discontinue treatment was based on an unambiguous medical statement of medical futility. The author reported that once this declaration had been conveyed, “allowing the child to die is no longer a judgment-call based in part on the value a parent place's on her child's life” (p. 266).

Zawistowski (2003) described the unique ethical challenges of informed consent in the PICU. Pediatric patients often lack legal authority, however, adolescents may be deemed to have adequate decisional capacity, where they understand the problem, the risks and benefits, and therefore can express a choice in determining their course of medical treatment. Although a pediatric patient may be deemed to have decisional capacity, their input is often not solicited by parents and physicians in medical decision-making. While parents shoulder social, emotional, and legal responsibilities, the medical team may question the parent's capacity for decision-making, namely in regards to issues with commitment to the child’s interest, adequate information and understanding, emotional stability, and the ability to make reasoned judgments. If these qualifications are unmet, a surrogate decision-maker may be required. This being said, it is the responsibility of the medical team and hospital to train and assist the parents in their understandings and knowledge in order to have the capacity to make ethically based medical decisions (Cooper & Kock, 1996). Given the number of key players to obtain informed consent, whether it be by the decisional capable adolescent, parent, or surrogate decision-maker, communication is of paramount importance.

In terms of decision-making structure, Gill’s (2005) observational research described the six year old child patient who was now being considered for a splenectomy. This author noted that there was a starkly inverse relationship between decision-making influence and the amount of time spent with the patient. The nurses, having spent the most time with the patient on a day-to-day basis, had no real active role in the decision. The PICU intensivists spent 2 to 3 hours a day with the case of this patient, and approximately 30 minutes in the room, face-to-face. While these physicians conducted the majority of the patient's decisions, the large-scale treatment strategies had to be approved by the transplant team, who spent approximately a few minutes in the “buffer room” reading charts. The final decision over the splenectomy resided with the transplant team, who explained to the parent what treatment would be. This example speaks to decisions being made behind closed doors where disagreements were hashed out and nurses followed the physician's lead as their institutional role dictated. This also exemplifies potential ethical issues that can arise with fragmented care. Multi-disciplinary approaches have obvious benefit. Providing state-of-the-art care for each of their medical problems, yet, at times, can fail to produce a single, coordinated view of a patient's case due to differing perspectives. When the team spoke to the mother, it was with one voice, yet pressure to stick to “the party line” also played a large role in shielding the mother from the grim view of the patient's status that the PICU staff harbored. As the author stated, none of the healthcare providers wanted to tell the mother the patient would likely die until all the players were willing to say so as well.

Foe, Hellmann, and Greenberg (2018) described a further consideration for ethical dilemmas with neonatal ICU patients, namely the moral distress and moral schism experienced by parents. The authors proposed that parents can also experience moral distress given their proximity and involvement in value-laden decision-making for their child; they differentiate moral distress and “moral schism”, the latter being a genuine uncertainty or internal struggle regarding a value-based decision that is accompanied by emotional distress and is unrelated to barriers as is found with moral distress. Importantly, the authors found contributing factors to both moral distress and moral schism include value conflict (clash of differing stakeholder values), communication shortcomings (setting, time, and amount of information given), and lack of trust. As an additional note on trust, parents may believe not enough time was given by HCPs to understand the parental views or that the HCPs were not transparent in communicating their prognostic thoughts. These perceived shortcomings can become a major source of moral distress as parents begin to see HCPs as external constraints, preventing them from their desired course of action; understanding the parental perspective had important influence for HCP approach and goings-on (Foe, Hellmann, & Greenberg, 2018). Establishing effective and consistent communication was noted to be essential for preventing fragmented care and increasing trust between parties. Trusting relationships allow for the contributing factors of moral schism and moral distress to be addressed through a mutual understanding of values and familiarity of expectations. As seen in the pool of research for HCPs, Foe, Hellmann, and Greenberg (2018) supposed that the occurrence of moral distress would not be eliminated in its entirety, yet a shared-decision making based in open and honest collaborative communication may decrease its intensity. This sentiment is shared by Austin and colleagues (2005) who stated that while the real suffering of those who experience moral distress should not be supported, moral distress can be an indicator of sensitivity to the moral domain of practice and therefore total elimination should not be a goal of interventions (Garros, Austin, & Carnevale, 2015).

Pediatric Intensive Care – Death and Dying

The growing research has shown that the experience of moral distress in nursing is pervasive, especially in end-of-life decision making (Storch, Starzomski, & Rodney, 2013). Furthermore, the PICU is the most common location for pediatric inpatient deaths (Mu, et al., 2019) and nurses are key actors in providing end-of-life care (Vanderspank-Wright, Efstathiou, & Vandyk, 2018). Particularly in PICUs, there exists a medical mission of saving lives, this is echoed through the adage of *what can be done should be done* or is referred to as the ‘rule of rescue’ (Garros, Austin, & Carnevale, 2015; Mu, et al., 2019; Jecker, 2017). These adages describe a compulsion and duty to act when seeing an individual in imminent peril, yet the notion of imminent peril, in and of itself, does not mean medical teams ought to intervene with live-saving measures, as with cases where the odds of success are virtually zero or the quality of outcome will be devastatingly low (Jecker, 2017). As Jecker (2017) stated, a bias toward action is embedded in the practice of medicine, which is often guided by the bioethical principle of beneficence; often times the emphasis from "doing good" is often placed on *doing* rather than *good.* This interpretation demeans inaction, regarding it as "doing nothing", where choosing not to act with all life-sustaining measures is an inherently lesser choice. The moments of continuing life-sustaining actions may feel good because the fear of death, failure, and losing the war against disease has been avoided, yet later moral distress will likely be suffered (Jecker, 2017). Given this foundation and that death often follows actions to withdraw life-sustaining treatment, PICU nurses are in a uniquely challenging position of facing their reluctance and sense of frustration when caring for pediatric patients who are dying (Mu, et al., 2019; Vanderspank-Wright, Efstathiou, & Vandyk, 2018).

A systematic review conducted by Mu et al. (2019) examined qualitative research in Australia, United States, and Brazil to describe the nature of experiences providing end-of-life care by nurses in the NICU and PICU. Of significant note, the themes of insufficient communication, emotional burden, and moral distress from medical futility were described, along with two further themes of strengthening resilience and taking steps towards hospice care. The authors found that the PICU nurses experienced a great degree of uncertainty when providing care, largely related to the changing course of the patient's disease and to the emergency care models of the unit. A main theme noted by the authors was insufficient communication. At times, the uncertainties of care were inevitable, where the prognosis is unknown for a certain amount of time, yet the different or inconsistent opinions between the medical team often made nurses feel helpless. Additionally, nurses unfamiliar with end-of-life care felt afraid and overwhelmingly challenged to assist the patients and families with facing the inevitability of death. While nurses empathized with the families over their despair and cared to support a peaceful death, the PICU nurses had limited time to sufficiently support the families and their involvement. In an interesting comparison to the adult ICU context, Vanderspank-Wright, Efstathiou, and Vandyk (2018) found that nurses sometimes disagreed with physician attempts to ‘over-involve' family members in decision-making, thereby creating additional tensions within the team, yet the nurses recognized and emphasized the importance of updating and sharing information with family members.

A second theme found by Mu et al. (2019) was emotional burden. At the approach of death, nurses were acutely aware of the family’s sense of hopelessness and the nurses felt that they had failed in a mission of saving the child. This struggle is reiterated by Vanderspank-Wright, Efstathiou, and Vandyk (2018), who describe that some nurses felt ineffectual their actions failed to relieve the family’s distress, further compounded by time requirements of treatment practicalities and of providing comfort when the nurses themselves were feeling upset. A further notable theme of Mu et al. (2019) depicted nurses’ moral distress from medical futility. A sense of hopelessness and anger were described when the autonomy and dignity of the child patients were ignored and when administration of ineffective medical treatments that impacted the child’s quality of life were continued. The nurses further questioned whether the care provided for the children and families was ethical. Ultimately, these feelings culminated into feelings of depression and anger regarding disrespect for the patient’s best interest and whole well-being. Moreover, the authors noted that nurses witnessed, and understood, families choosing to continue with invasive therapeutic treatment, likely inflicting unnecessary pain, to prolong life when the alternative is death. Though understanding the difficulty of making decisions for their child, the nurses continued to fulfill the family's expectation of aggressive treatment when the alternative is death, creating stress and a sense of guilt for nurses. A study performed by Hamric and Blackhall (2007) on nurse-physician perspectives on the care of dying patients in the ICU supported this assertion, finding that the highest morally distressing situations occurred where caregivers felt pressured to continue unwarranted aggressive treatment. While Vanderspank-Wright, Efstathiou, and Vandyk (2018) did not discuss moral distress specifically, they discussed similar sentiments with nurses caring for adult ICU patients; the nurses found it difficult or inappropriate to show their emotions, making it so they suffered alone, and also experienced impactful and lingering emotions for a considerable time following the death of the patient.

A study conducted by Baek and Kang (2018) measured 111 pediatric nurses' perceptions of obstacles and supportive behaviours related to end-of-life care. The highest perceived magnitude for supportive behaviours was found to be by physicians who are both compassionate and especially clear about patient prognosis. Comparatively, the greatest obstacles with the highest perceived magnitude involved initiating painful treatments in cases with no hope of recovery. Baek and Kang (2018) also noted statistically significant differences between nurses' perceptions of obstacles depending on the amount of education they received on end-of-life care. Furthermore, the turnover intention was positively correlated with the perception of obstacles in end-of-life care (Baek & Kang, 2018). In comparison to the adult context, Browning and Cruz (2018) conducted a pilot study to develop and test a protocol for alleviating moral distress through social work-facilitated debriefings with adult ICU nurses. The most frequent situations causing moral distress were related to the provision of nonbeneficial care. More specifically, the obstacles that generated the greatest intensity of moral distress were witnessing HCPs give “false hope” to the patient or family; following family wishes in continuing life support against the patient's best interest; witnessing diminished patient care quality due to poor team communication; and working with nursing colleagues or allied HCPs who were lacking competence for what the patient required.

Due to the complexities of end-of-life care, moral distress is neither uncommon nor unexpected (Mahon & Marker, 2018), especially in critical care contexts where nurses are often searching to provide a good death to pediatric patients (Mu, et al., 2019). Mu and colleagues (2019) stated the best way to achieve a good death is through consistent care by strong teamwork, globally proper communication, and maintaining the comfort and dignity of terminally ill child patients.

Synthesis

Prior to the work by Jameton, distress among clinicians was predominantly understood through a psychological lens, typically involving stress and burnout; in 1984, an ethical component was added to the study of distress (Rodney, 2017). As Jameton (1984) described, moral distress is not an abstract feeling, rather a feeling that is embedded within a specific occasion. Research has shown that said occasions, of feelings from being unable to fulfill one's perceived moral obligations, exist within many healthcare disciplines beyond nursing (medicine, respiratory therapists, psychologists, social workers) and outside of healthcare providers entirely (teachers, police, parents). While there has been an upsurge in moral distress research, there continues to be a lack of agreement in one universal definition. In 2005, McCarthy and Deady proposed viewing moral distress an umbrella concept, where a range of experiences are captured of individuals who are morally constrained; the authors described a lack of conceptual clarity of moral distress, where defining characteristics could be variable between researchers, and there existed inconsistencies in defining constraints as being either internal, external or both.

While there are some discrepancies in definition, the costs of moral distress for the individual and rippling impacts to patient care and the profession have been documented by many authors, with overlapping findings. Often, overwhelming physical, psychosocial, and emotional symptoms are ascribed as impacts of the individual, with a significant threat to the wholeness as a person and individual's integrity, which Webster and Baylis (2000) stated 'irreversibly alters the self' (p. 224). Added to initial feelings is the possibility of moral compromise, moral residue, and moral disengagement, which all indicate long-lasting effects indicating, as noted in police studies, that moral distress is truly a form of moral suffering that appears to have ties to traumatization (Papazoglou & Chopko, 2017). The influence of moral distress bleeds into the individuals surrounding context, where safe delivery and competent quality of care is negatively impacted, recruitment of professionals is decreased, and the overall number of individuals leaving their post or profession altogether is increased (Austin et al., 2005; Rodney, 2017).

Moral distress is understood as an individual response (Garros, 2015; Paul, 2009). Individuals facing similar environments or situations can have vastly different experiences; where one individual experiences feelings of moral distress, another may not (Austin 2005; Wilkinson, 1987). This being said, critical care areas have notably been found to yield high rates of moral distress, often related to general themes of medical futility, emotional burdens, and insufficient team communication (Mu, et al., 2019).

While the medical mission to ‘save lives’ is embedded in many healthcare contexts, the pediatric environment in particular lives the narratives of *what can be done should be done* and the ‘rule of rescue’ carries particularly heavy weight in the pediatric population (Garros, 2015; Mu, 2019; Jecker, 2017). Added to this weight is access to advanced technologies and capabilities for life-sustaining measures, resulting in an environment that understandably has a number of ethical issues. Common PICU issues surround parental decision-making and refusal of treatment, informed consent, and decision-making structures (Austin, Kelecevic, Goble, & Mekechuk, 2009). In nursing research, ethical issues often surround end-of-life scenarios (Storch, Starzomski, & Rodney, 2013) and the PICU is the most frequent location for pediatric inpatient deaths (Mu, et al., 2019).

PICU nurses are in a uniquely challenging position when caring for dying patients (Mu, et al., 2019; Vanderspank-Wright, Efstathiou, & Vandyk, 2018); though nurses are key actors in providing care at the end-of-life (Vanderspank-Wright, Efstathiou, & Vandyk, 2018), they are practitioners with high responsibility and low decision-making authority who spend the most time with the patients and families on a day-to-day basis (Gill, 2005). In a systematic review of nurses' experiences in end-of-life care in PICU, Mu and colleagues (2019) discovered themes of insufficient communication (uncertainties of care; avoiding discussing death), emotional burden (conflict between the idealized and the experienced), and moral distress from medical futility (depression and anger regarding disrespect of the child patient/family; knowing the difficulty in hoping for treatment). Additional themes included strengthening resilience (self-adjustment to obtain positive power; team support to relieve stress), and taking steps towards hospice care (balance and control between professionalism and humanness; supporting the parent-child relationship when moving toward good death).

Baek and Kang (2018) found that education on end-of-life care led nurses to perceive obstacle behaviours differently, unrelated to years of bedside experience, and a lack of targeted education for teachers was also found as a contributing factor to moral distress (Svensson, 2019). Interestingly, previous research involving moral distress intensity that found general level education, age, and years of experience were not predictive factors (Corley, 1995; Corley, Minnick, Elswick, & Jacobs, 2005; Pauly, Varcoe, Storch, & Newton, 2009) suggests that formal education targeted to specific occasions of potentially moral distressing situations is likelier a more effective strategy to mitigate feelings rather than relying solely on one's personal experience. This implies the need for systemic involvement in preparing nurses and for appropriate education to occur.

Common themes of moral distress for nurses found in both pediatric and adult intensive care settings included witnessing HCPs giving “false hope” or exercising unequal decision-making power, providing nonbeneficial care (or medical futility), or continuing with treatments against the patient’s best interests (Baek and Kang, 2018; Browning & Cruz, 2018; Gill, 2005; Hamric & Blackhall, 2007); of grave importance, establishing sufficient communication is pervasively cited throughout the literature related to varying healthcare disciplines and including parental perspectives (Baek and Kang, 2018; Browning & Cruz, 2018; Cooper & Kock, 1996; Foe, Hellmann & Greenberg, 2018; Gill, 2005; Mu et al., 2019; Studdert, et al. 2003).

In terms of moral distress at end-of-life care, recent research into PICU nurse's experiences is limited. In the systematic review by Mu, et al. (2019), moral distress was described only in relation to medical futility and the study was not inclusive of the Canadian context. Further noted in the adult context, the systematic review conducted by Vanderspank-Wright, Efstathiou, and Vandyk (2018) into critical care nurses' experiences with withdrawal of care, described experiences of moral dilemma and emotional distress in times of withdrawal, with moral dilemmas stemming from nurses' recognizing their own avoidance attempts to distance themselves from the process due to emotional drainage, failing to preserve life, or acting against religious beliefs.

'There is nothing like first-hand evidence.' – Sir Arthur Conan Doyle, A Study in Scarlet

Chapter 3: Methods

Chapters 1 and 2 have so far described moral distress as it currently appears in health care practice and research along with the contemporary context of PICUs. The purpose of this study was to analyze nurses' experiences of moral distress in Canadian PICUs where advanced life-sustaining interventions are offered for complex medical and surgical cases. To achieve this end, a systematic approach was employed to ensure researcher and research integrity. The current chapter will describe the research method with both a description of the original study and an explanation of my completed secondary analysis.

Research Questions

1. What are the moral distress experiences of PICU nurses caring for child patients who are at risk of death or who are dying, as revealed in their stories?
2. Supplementary question: What support systems/resources are in place, or are needed, to deal with such moral distress experiences?

Research Perspective

To address these research questions, a qualitative research method known as content analysis was proposed. A secondary analysis was carried out to analyze data previously collected by Austin and colleagues (2006). This original study was conducted through narrative inquiry with participatory action research (PAR) design. PAR allows researchers to actively collaborate with members of a group/community who seek to develop knowledge and to promote or impart positive change, with a specific action (Greenwood &, 1998; Reason, 1994). In terms of narrative inquiry, stories are how people relate meaning to their lives, through both living and telling stories about their lives; through narrative inquiry, these stories represent and gain an understanding of lived experience (Bruner, 2004; Connelly & Clandinin, 2006).

To complement the narrative inquiry style used by the original authors, I proposed a content analysis for this current study. Altheide (1987) indicated that content analysis is employed for the purposes of discovery and verification. It is a research technique that distinctively uses a reflexive and interactive process where the treatment of data is modified to accommodate new data, thereby allowing the researcher to make replicable and valid inferences from data to their context (Krippendorff, 1989; Sandelowski, 2000). The aim of this type of analysis goes beyond a literal description of the content, but rather presents aggregate accounts of inferences from bodies of data that reveal trends, patterns, and differences no longer obvious to the untrained eye (Krippendorff, 1989).

Codes are systematically applied and generated from the data themselves; the researcher rarely begins the process with pre-existing coding systems (Krippendorff, 1989; Sandelowski, 2000). Embedded in this approach is constant discovery and comparison of relevant settings, meanings, and situations, thereby allowing data to be coded conceptually so that one item may be pertinent for several purposes (Altheide, 1987). Krippendorff (1989) stated a content analysis ensures that all units of analysis receive equal treatment, regardless of when they are analyzed, and that the process permits the researcher to establish their own context for inquiry, allowing for social-scientific constructs to be revealed and for meaning to the texts to be shone in a different light.

Context

The conceptual design of this secondary analysis was to gain an understanding of the moral distress of nurses working in PICU related to their experiences of death and dying. Through this study, I wished to understand the similarities and differences between narratives, the nurse's attitudes described in their narratives (related to a perceived good death), what the nurses found as helpful or as barriers, what came after the death (nurse's feelings/actions/attitudes), and perceived effect on patient care. I was granted access to the recruited data transcripts from the original study's researchers Austin and colleagues (2006).

Participants

The original study conducted by Austin and colleagues (2006) included PICU professionals sharing their stories of moral distress in one-to-one interviews as well as PICU professionals participating in a "Stories of Moral Distress in PICU" workshop. Professionals with responsibilities for direct patient care in six Canadian PICUs were invited to participate in the research. These included dieticians, nurses, intensivists, medical residents/clinical fellows, respiratory therapists, and social workers. The PICUs were selected based on the range and complexity of intensive care interventions they offered, including the use of ECLS, organ transplantation, and complex heart surgeries. For the purpose of this content analysis, inclusion and exclusion criteria were as follows:

Inclusion criteria

1. Communications from registered nurses
2. All ranges of clinical experience, from new graduates to seasoned nurses
3. Communications that include one or more patient death experiences

4. Communications that include one or more dying patients, as identified or inferred by the nurse

Exclusion Criteria

1. Communications from non-nursing disciplines
2. Circumstances of critical illness where the nurse does not identify the trajectory as "dying"
3. Morally distressing incidences that involved a dying child, yet where the moral distress clearly arose from reasonings other than the dying or death process itself.

Sample size

A total of seven transcripts from individual one-to-one interviews were obtained and analyzed. Hard copies of three transcripts were obtained first (RN 1, 3, 5). The remaining four transcripts (RN 2, 4, 6, 7) were received as electronic copies (no hard copies were available). At that time, I requested and was granted to have the first three as electronic copies as well for consistency and security, allowing me to keep all seven together. While workshop discussions were conducted in the original study, the participants tended to include medical residents or other disciplines, and it was unclear how to distinguish nursing voices, therefore these transcripts were excluded. The documents were transferred by secured USB with each document having password protection. Documents included the original transcripts as well as the narratives created by the original authors. To analyze content from the direct sources and avoid predetermined interpretations, these narratives were set aside and only the transcripts were used for this analysis. The nursing positions were not stated outright by the primary researchers, but rather emerged through the stories each nurse told. The majority of stories occurred when the nurse was working in a bedside position, with an additional few mentions to being in an advanced practice nursing role. No included stories were from strictly a managerial perspective; oftentimes management was described in terms of their relationship to the bedside nurses.

Methods and Instruments

Authors Austin and colleagues (2006) conducted one to two 1-1.5-hour interviews with each professional. The interviews were audio-taped and transcribed verbatim. These transcripts were used for the content analysis.

Data Analysis

The procedure and steps of analyzing the data for content analysis was based on the four main stages outlined by Bengtsson (2016), beginning with decontextualization, followed by recontextualization and then categorization, finally ending with compilation. To begin, the decontextualization stage started with becoming familiar with the data. To gain a sense of *what is going on*, I meticulously read through each transcript in full, making notes in a hardcover notebook. These notes included lines, words or simple phrases from the transcripts that resonated meaning to the overall aim along with my own questions and reflections. Bengtsson (2016) stated the need for a table "where the researcher can make transparent the process from raw data to results is needed to ensure the quality of the analysis" (p. 11). For a structural and visual approach, I created a table using Microsoft Word, however after some frustrations with formatting, I created an Excel spreadsheet and used this for the remainder of my analysis (Table 1). This table included seven headings; *meaning units, condensed meaning units, codes, sub-categories, categories, sub-themes,* and *themes.* For the purpose of decontextualization, I first began by recording meaning units; these were the smallest units from the original text that contain insights into the research question, appearing as a collection of sentences or paragraphs. Meaning units were collected by the first three transcripts I had received (RN 1, 3, 5) and then with the remaining four (RN 2, 4, 6, 7). This was achieved by transcribing text from the transcript directly into the Excel table while indicating their corresponding line number to keep track of which text was included. These meaning units were then afforded a code, one that is understood in relation to the context. As Bengtsson (2016) described, this is often what literature recognizes as the “open coding process”. The codes were generated inductively and were used in identifying concepts wherein the data could then be assembled into blocks and patterns. As more data was analyzed, codes were reviewed and changed at times. Direct quotes from the transcripts were often included to serve as a guide and reasoning for the choice of certain codes and to minimize cognitive change during the process. Given my relative inexperience, the coding was reviewed on multiple occasions from an individual perspective as well as in discussion with Dr. Kunyk. This solidified my surety in the progress of the data and served to increase the stability and reliability of the analysis as a whole. I strongly considered using the qualitative program NVivo, and I received access to peruse its system; however, I decided to continue the analysis by hand, given my progress. While using such a program would likely have sped up a portion of the process, Bengtsson (2016) fittingly noted that “since computer programs are soulless software, and human creativity is of importance and needed, the human being is required” (p. 12); given this was my first ever dip into a solo-led analysis, doing it by hand felt right.

Following the identification of meaning units, stage two comprised recontextualization. This involved looking at the “negative space” of the transcripts to explore the remaining text not included as meaning units. I achieved this through a side-by-side comparison of the meaning units to the transcript and eliminating included text based on which line numbers were already recorded in the Excel table. The remaining (or unmarked) text was reviewed to consider whether it should remain excluded or be included as meaning units. The aim was to check whether all aspects of the content have been included in relation to the question. I admit that this process was difficult, as very close to all the data seemed important. At that point, I conferred with Dr. Kunyk for guidance on how to be most judicial with the overwhelming amount of information. Upon her suggestion, I created frozen cells atop the Excel table that listed the research question and elements of the overall aim (e.g. nurses' feelings, action, attitudes pre-/post-death; helps and barriers) so they could be continuously referred back to throughout analysis. This served as an effective reminder to allow information unimportant to this question fall to the side.

After completing the recontextualization, I moved to the third stage of categorization. Before creating categories, each extended meaning unit was collapsed into a condensed meaning unit. This is a commonly needed practice for interview-based data and involves reducing the number of words while maintaining the content of the unit (Bengtsson, 2016). Maintaining the depth of the meaning units allowed for a deeper level of analysis to be performed; this was achieved by dividing the coded data into broad groups based on the research question and aims. For example, groupings based on feelings related to experiences as a bedside nurse or witnessing decision-making dynamics. Following this, categories and themes were identified. Sub-categories were created first, as the smallest units based on the meaning units that could be sorted into broader categories. Categories then emerged and directed the development of themes, themes being the overall concept, and it answers the “how?” question. At that time, I created a second table, named “Themes Table”, in which the themes were listed as headings with pertinent category data listed underneath. Sub-themes were additionally included at times when the data gathered into obvious collections or aggregates within the theme, however, sub-themes were not needed for each theme. Bengtsson (2016) stated that while there is no consensus in the literature for which headings are to be used in a content analysis, all categories must be rooted in the data from which they arise. Categorization was completed once a reasonable explanation had been reached; after completing a rough draft of the analysis table and themes table, Dr. Kunyk reviewed both to ensure their sensibility and appropriateness for the overall aim. Listed below (Table 1) is an example of the coding process.

The final stage included the compilation in which the analysis and writing up process begins. Bengtsson (2016) stated that for a content analysis, the investigator must consider the data collected from a neutral perspective and consider their objectivity. Chapter 4 encompasses an in-depth presentation of the results from this content analysis. A condensed themes table is found in Appendix A. Additional information regarding each theme is found in Appendix B.

Table 1. Example of the Coding Process

Meaning Unit	**Condensed Meaning Unit**	**Code**	**Sub-categories**	**Categories**	**Sub-Themes**	**Themes**
45. Patient arrived for Berlin heart. At our institution "no-one gets turned away". Frontline workers often last to know. Decision are made up avove with usually CV surgery and powers much higher above us. They say it's informed consent. Second day postop her mother was beside herself. She said "I had no idea it would be this bad". She died six weeks later in PICU, never going home	Frontline often last to know of decisions. Decisions made by CV surgery and powers above. Questionable informed consent. Mother beside herself after surgery " I had no idea it would be this bad". Patient died	Decision makers: CV surgery and powers above Frontline often last to know Questionable informed consent Post surgery mother bedside herself: "I had no idea it would be this bad"	- Decision making CV surgery, "powers above" (front line last to know) - Reasonings for surgery - Communication and messagin (questionable informed consent "I had no idea it'd be this bad")	- Context (hierarichal, frontline last to know) - Reasonings (treatment) - Communication and messaging (questionable informed consent)	- (Hierarchy) - Intentions for treatment - Physican to family (? informed consent)	- PICU culture, reality - Decision making power -Communication, messaging

Validity and Reliability

In addition to the validity strategies mentioned previously, I employed further approaches guided by Creswell and Poth (2018). To begin, I corroborated evidence through the triangulation of multiple data sources, including multiple sources with varying methods and investigators. Secondly, I found, and will discuss, negative cases or “disconfirming evidence,” in which evidence that did not fit into the pattern of a code or theme reported; this was done with additional attention to uncovering what is not being said in the narratives. Finally, I engaged in reflexivity and clarification of my bias as a researcher, illuminating the “dark matter” by commenting on my past experiences, prejudices, and orientations that likely shaped my interpretation. From a participant lens of validation, I was not able to seek participant feedback, collaborate with participants, or become engaged with the participants/physical context given the length of time since the original study and the nature of the secondary analysis. From a reviewer's perspective, I sought external audits, through a committee meeting and oral defence.

Guided by Creswell and Poth (2018), reliability was addressed through an intercoder agreement based on the use of “multiple coders,” Dr. Diane Kunyk, in this case, to analyze the transcript data. Agreement in coding was achieved through creating and sharing the initial codebook in the form of the analysis tables, comparing the coding and assessing agreement, and finally revising and finalizing the codebook to inform further coding.

Ethical Considerations

As this was a secondary analysis of data involving human participants with identifiable information, I was required to obtain ethics approval to review and analyze the transcripts previously recruited. After approval of the proposed study was granted by my thesis committee following formal defence, an application for ethics approval was sent to the Human Research Ethics Board at the University of Alberta. The application was completed and granted through the Research Ethics and Management Online (REMO) system; Dr. Kunyk oversaw and officially submitted the application as the primary investigator, I was listed as co-investigator given my position as a graduate student.

Once I was granted access to the transcripts, privacy and confidentiality of the participants and data were safeguarded on my personal laptop via password protection. The original transcripts had been cleaned from identifiable information; yet, I continued to be attentive to potentially recognizable information, for example, when describing a rare disease or procedure that may only be attributable to a particular PICU or hospital. The first three hard copy transcripts were, and remain, securely locked in my personal office at home. The electronic versions of all transcripts were transferred via a secure USB key. In addition, each document on the USB was, and remains, password protected. The USB key is stored securely in a locked cabinet in my personal office at home. Data was not be uploaded to public servers or has not been, or intended to be, sent through email unless in a password-protected file. Identifiable information was not be included in the final write up of this study. Consent, past or future, from participants, was not required for the secondary analysis. I had no conflict of interest to declare the proposed study. I did not receive funding. My graduating from the MN program is dependent on completion and oral defence of the study and its findings.

"Data! Data! Data!" Holmes cried impatiently. "I can't make bricks without clay." – Sir Arthur Conan Doyle, The Adventure of the Speckled Band

Chapter 4: Findings

Presented in this chapter is an in-depth and detailed presentation of the results from this content analysis. Presented here are nine dominant themes, with associated subthemes, that emerged from the narratives. These themes denote four organizing categories to clearly depict the experiences of moral distress: the outer state of nursing in the PICU, the inner state of the individual nurse, the relationship dynamics between the nurse and others, and the differing perspectives among individuals. The first section begins with a description of the outer state of nursing in the PICU through the two themes of the PICU environment and reality as well as nurses positioning and role within this context. Following this, the inner state of the nurse is presented and depicts the individuals' feelings throughout the death and dying trajectory of their patients as well as their greatest nursing concerns, which speaks to quality of life, dignity, and best interest. The third section includes the four dominant themes of decision-making, communication, supports, and recommendations for changes to describe the relational dynamics between the nurse and others. Section four presents the ninth and final theme of differing opinions, perspectives, and perceptions. It is presented alone from the others as it has tendrils and ties into the previous eight themes described in section one through three.

As an overview, the characteristics of the participants were discovered throughout the narratives and are described here. At times participants did not clarify both their role and experience level at the outset of the interviews, rather glimmers of these descriptions were discovered throughout. Overall, this cohort seven nurses were generally very experienced and considered senior nurses with diverse roles and responsibilities. While Mieve had three and a half years of bedside experience in PICU, all other participants either stated to have between 11 and 30 years of bedside practice or indicated that they were working in an advanced role. Mieve, Genrah, and Oka appeared to work solely at the bedside at the time of the interview. With 11 years of experience, Genrah indicated being responsible for patients along the continuum of PICU care, yet most often caring for the very critical patients, as was also inferred by Oka who held 23 years of experience. While all nurses worked as bedside staff in PICU at some point, at the time of the interview four (Dara, Kethra, Lorella, and Morgana) stated they held advanced practice nurse roles or clinical instructor roles. Dara indicated the primary focus of their role was bedside clinical nursing along with responsibilities for education, training, and coaching or mentoring of nurses within the PICU for approximately 16 years. Kethra indicated that they held a clinical instructor role within PICU and described themselves as “a little bit more of a senior nurse”. With 30 years of experience, Lorella stated to be a part of the PICU transport team, a role that entails transporting critically ill children with a respiratory therapist. This is a role that required extra training and a higher level of skills, understanding, and responsibility than that of a newer nurse. Interestingly to the topic of this study, Morgana described their role as a clinical specialist, as one that manages the care of complex deaths and a resource nurse of children that have unanticipated deaths. This role also comprised an element of continuity of care where Morgana would coordinate care of long-term patients and act as the point person who is consistently in contact with these patients and families. With the aid of these descriptions, the following themes depicting the elements of moral distress experienced by PICU nurses caring for dying patients may be understood in context of years of experience and responsibility of role.

1. The Outer State of Nursing in PICU: PICU Context and the Nursing Profession

The PICU may have a physical structure similar to many hospital units. While the physical space itself can create issues with patient flow and care practices, most noteworthy and significant to the experience of moral distress are the happenings within this structure that make the PICU run. The two dominant themes included here are the PICU context and nurse positioning; both themes indicate the outer state of the nursing profession.

PICU Context

To begin, participants of this study described features of the PICU context in terms of the unit culture and reality along with the larger healthcare ethos in which it operates. All nurses described elements of the PICU context at the outset of the interview, for example in stating "the issue is as well we're short-staffed. Our unit is always short-staffed. Not a bed shortage, a nursing shortage". These elements primarily included the environment itself; resource shortages and busyness were most often cited as general PICU descriptors. Comparatively, context was also described in terms of ethos, for example as one experienced bedside nurse stated having to work working within a:

> ... mindset that they're children; we can't let them die, but death is terminal. We all die. And it might be in their best interests to let them die when they first decide they're ready rather than making things go on and on and on (Genrah).

Other common sentiments of the PICU were that it is a "very scary environment" for patients, families, and personnel. Nurses indicated that the structure within this environment led to having "no real sense of team anymore" or decisions being made by "higher powers". Normal PICU processes included giving the family time to resolve their feelings, pain control (managed well, but not entirely), and the use and availability of technology. Morgana and Lorella highlighted the use of technology: "we can pretty much keep children alive...sometimes that's good, and sometimes that's bad" and "I know what medicine and technology can do to a person". Notably, PICU culture was often described in term of mantras or dictums including “we’re supposed to save them all, but we can’t save them all” (Genrah) or “our beliefs are we need to try everything until there absolutely is no hope for anything else” (Mieve). Finally, given this study’s focus on death and dying, as well as the inclusion criteria of dying as identified or inferred by the nurse, specific topical terms included nurses’ descriptions of *palliation*, *rescued*, and alternatives for *dying*, such as “heading down” or “crummy, crummy, crummy”. One nurse noted their own discomfort using the word dying, saying, “that's probably my own comfort level” (Dara). Depicted here is the structure of the PICU with described elements of the environment, processes, and culture that lays the context through which nurses navigate.

Nurse Positioning

The positioning of nurses spotlights the unique situatedness of the profession as it is threaded and embedded within the PICU activities and context. Described here are experiences related to nursing roles as practitioners rather than the practices of the unit, which will be described further in the third section of navigating care for dying patients. Nurse positioning indicates how the role of the profession is situated in the larger PICU context and what elements are unique to itself. Participants described the nursing role through their various responsibilities.

One of these primary responsibilities were portrayed in terms of providing supportive care to the patients and families; this care addresses “more than technology, drip, and machines”. Rather, it was described as making difficult times for patients and families easier as well as remaining nonjudgmental, even when a family may “push the limit” and “threaten your role”. Support was achieved through many mechanisms that included: involving parents in providing care tasks to their child, explaining and translating physician messaging, and voicing concerns, even in cases when parents became angry. For example, when confronting such a situation, Dara gave the parents frank information on the patient's status “so that they themselves were not the first to give up on their child”. Ultimately, awareness of how to interact and gain trust with the family was a nursing trait reflective of those who are “highly-skilled, articulate, competent, and have confidence” (Dara). As a seasoned nurse recounted:

> I ended up going in with the little boy into the operating room while they removed his organs. Because this was the only way that [the siblings] would let their parents agree, was if somebody was there to hold his hand while he died. That's what I did. (Morgana)

Participants recounted times where they felt unable to provide enough support. For example, when recounting the events after informing a mother of her child's death:

> She was just totally hysterical. Totally hysterical, crying and screaming, we couldn't do anything with her, like all the comforting things that you have just hold somebody, give them a hug...talk about things, there was a big wall that you couldn't get through. (Oka)

Morgana described where support was lost by many, including by bystanders, during a nurse-patient interaction, which led to patient decompensation and a code in a shared common room. Oka additionally indicated an event where parental decision-making was judged by staff because of a perception that “they want[ed] the perfect child but the parents were thinking of the long-term outcomes”, ultimately indicating the need to be nonjudgmental in providing care.

An additional responsibility that participants described was facilitating and enabling communicating between physicians and families. Being a direct care provider, nurses explained that “parents can invest an incredible amount of confidence and comfort in the bedside nurse with whom they get close. And that’s a huge burden for that nurse to carry” (Dara). Participants further noted that there were difficulties for nurses who wanted to agree with the family but were compelled to maintain the physician's messaging. For example:

> We couldn't straight up tell the family we agree with them and go against the doctors for professional issues. But the ones that supported them [family], we definitely let them know we [heard] their story, and it was just a very hard situation to be in. And just told them that the doctors really thought that they were doing the best that they thought they could. (Mieve)

Genrah described the burden of knowledge of navigating a decision by the physician team that was misaligned with family wishes and expectations:

> I felt so guilty afterwards [the decision] because I would come back to the unit and see this child and know what was going to come. This person is going to exist in a bed somewhere for a very long time, and the family will have to go through untold suffering because they can't do what they would like to do for him because they don't have the tools to do it. And here we've given them the situation and left it as it is. (Genrah)

Genrah additionally described this need for teamwork and "we are we" collaboration by saying, "we need to all work towards the same goal, and that's to provide the best outcomes for the patients that we care for. And if the best outcome is to die, then that's what we need to provide them".

A final notable element of the nursing role the participants described is mentorship, being both a mentee or mentor depending on one's experience level. When coming into this role, novice nurses are "expected to just jump in and take on these very complex situations, not only from a nursing standpoint but from a psychological and spiritual side of it as well, and they're not being given the tools that they need" (Genrah). Newer nurses were described as having a hard time “letting go” of long-term patients because they have less experience, have established incredible rapport with the family, and struggle with not being heard when voicing concerns around the trajectory of care. Comparatively, Kethra indicated, “I'm a little bit more senior nurse, so I can handle an assignment that maybe someone else can't”. Further noted was that seasoned nurses helped to shift the focus for newer nurses from prolonging life to supporting the family, as explained:

> As I tell the new girls, “you guys have to toughen up”. It's a terrible thing to say, cause I've been working as a nurse for 30 years I said, “If you're going to stay in this field for a long time, you're going to see a lot of terrible things”. And more so [now], ten years ago, those kids wouldn't have suffered that long because we wouldn't be able to do what we can today. (Lorella)

Participants further explained that with experience, they become confident in knowing the patient may not survive, they grieve differently than when they first began nursing, yet still must navigate the parameters of the structure; “sometimes we're put in situations we shouldn't be. Often it comes down to staffing” (Kethra).

Interestingly, and similarly to novice voices, while seasoned nurses may be afforded more credibility, such as in mentoring residents and being heavily relied upon by intensivists, many participants stated that their opinions as an experienced practitioner still fell “on deaf ears”. One seasoned nurse indicated:

> I hate to say, I'm kind of mouthy, but I know which side of the bread that the butter goes on. I play along with their little games because it's a battle that you're never going to win. And I know that I'm not going to win because I don't have enough clout. I am just little,

> you know, in the big scheme of things. And I guess this is the frustration a lot of us feel we can't really change and make things better in many ways. (Lorella)

Signified herein are undertones of power and hierarchical dynamics enmeshed in the context and structure that surface throughout various themes of the findings.

2. The Inner State of the Individual Nurse: Feelings and Greatest Nursing Concerns

The following two dominant themes of this study are large and describe the inner state experiences that arose within the individual nurse during situations of moral distress. The first theme describes nurses' feelings around death and dying, including three subthemes of the milestone points during patient trajectories, the felt impacts post trajectory, and the reflections on bearing witness to suffering. The second dominant theme presents the greatest nursing concerns for dying patients, additionally comprised here are the subthemes of good death and "not good death" as well as right and wrong.

Feelings Around Dying and Death

Milestone Points. To begin, all nurses described feelings and thoughts throughout various points of the patient journey. Beginning at the time a decision was made to the time of death and beyond. Described here is the first subtheme of overall feelings, it is the feelings experienced at milestone points: at times of decision-making, withdrawal, and death as well as during nursing actions and when supporting others. To begin, at the times of decision-making, nurses described tension, concern, anger, and anxiousness. Upon witnessing decisions that they believed were not in the patient's or family's best interest, nurses stated, "the hair on the back of my neck goes up ... oh, this doesn't feel right" (Dara), "part of me is shrivelling up," and "I felt almost dishonest in fostering the ideas that this could go on indefinitely" (Genrah). At times of withdrawal of life-sustaining treatment, participants described having difficulty letting go, a great deal of guilt, and feeling extremely frustrated. At times of death, nurses conveyed, at times, widely varying feelings ranging from regret, to a sense of haunting, to relief. Upon witnessing a patient's final moments after a traumatic, sudden, and graphic death, Oka stated, "in all the years that I have been in PICU, that was the worst thing that I had ever seen and experienced". The reasonings for these feelings were vast and varying ranging including nurses not being heard by the decision-maker to nurses themselves not hearing the needs of the families and patients. For example:

> There was so much dissension in the unit, so much lack of understanding as to why we were taking so long to withdraw on this patient. And it didn't matter how many people I told that the physicians had had this conversation with the family. The family weren't there yet. She (the parent) needed the time to say goodbye, and we just kept pushing and pushing. The doctors were listening to the mom. The nurses weren't listening. (Morgana)

Comparatively, Genrah and Mieve described "I feel we failed the family by not perhaps tackling the physician and saying 'what are you doing?'" and "it gets harder to keep trying to defend the doctor's decisions especially if it's not something you believe in, it makes for a tense atmosphere".

Additional reasonings were related to decision-making from others, situations out of control of the bedside nurse, or feelings around not providing the best possible care. For example:

> They moved this dying boy from a single room into a four-patient room. The reason they had moved him was that the second child [I was assigned to] had to be isolated, so they

> felt that this boy, well, he's going to die anyway. The family whose son was dying had to fully gown, mask, and glove to come in to visit. (Kethra)

Oka also described a situation in which a procedure resulting in unanticipated patient death was unsafely initiated by a co-worker:

> A lot of things could have been prevented. I think that is what distressed me the most, but I still feel that the person who did that (initiated procedure), it was very un-responsible. Her reaction later, "well, the baby would have died anyways". Whether it is true or not, to me, that is not the issue. We are to provide the best care. (Oka)

Feelings of relief were often tied to the liberation of suffering, such "thank goodness for her she didn't suffer when she [died]" (Lorella). To be clear, nurses at times reiterated feelings of distress and profound sadness occur at times of death simply because it is death; that they are not always or inherently tied to feelings of moral angst or moral distress. What has been described above are feelings that arose from morally distressing situations, feelings that are woven into a larger picture of moral distress.

Two further milestone points involved feelings during nursing actions and when supporting others. During actions, varying feelings were also noted, with many participants expressing they felt that they were torturing patients. Whereas others stated they didn't feel they were contributing to patient suffering. For example, one nurse noted "yes, we do terrible things, yes, whatever we have to do it hurts them. But someone has to look after them, right? And you still give them exactly the same care. I guess I just kind of block that part out of my brain" (Lorella). Participants also reported compounding stresses from workload or busyness as well as from a sense of inability to act. For example:

> You've bundled them up, you've taken them to the morgue, and you're getting an admission. It's not even like you have time to sit down sometimes. Sometimes there is so much that you're picking something up right away. They don't give us time to resolve issues. (Kethra)

Or, as Genrah indicated, "... being powerless and feeling like I can't say what I'm feeling and what I know because it will be hurtful, but I still feel like I need to say it to someone". Comparatively, when supporting others, nurses reported feeling discomfort, in particular, when supporting other nurses who were not accepting of a decision or withdrawal of treatment. When supporting patients, families and members of the team, nurses use phrases such as "it breaks my heart ... it's not right to make them suffer so much" and "what have I done" when witnessing a surgeons' tears post quadruple amputation surgery (Lorella). These sentiments will be explored deeper in the following findings of bearing witness and right and wrong.

Impacts or Consequences Post Trajectory. Impacts and consequences were experienced first in terms of their psychological, emotional, or physical effects to the individual nurse and secondly, in terms of their professional effects. Post trajectory includes after a patient has died or after they have left the unit, most often discharged to another unit or facility. None included stories described a child being discharged home. In terms of the psychological, emotional, and physical impacts to the individual, participants cited lack of closure, resolution, or "ending". Statements included "[it] keeps me awake at night when I think about it because I was totally unable to resolve it" or "... it still haunts me. Had I stayed, would she had been alive another day?". Among many lasting effects, regret or anguish was frequently described through accounts of "often I wish I had done more or said more. Maybe if I'd stamped my feet and shouted and totally refused, then maybe something might have been done. I don't know"

(Kethra). Additional distress stemmed from knowing similar morally distressing situations could arise in the future:

> I was ready to quit. It’s the idea of continuing to do things that we know aren’t going to provide the result we want, knowing it from the beginning that this is going nowhere because that’s what we’re told to do, being powerless and feeling like I can’t say what I’m feeling. (Genrah)

Morgana stated, “the helplessness is that I just don’t know what more to do”. Most notably, the lasting effects were carried across work-life and home-life boundaries; many nurses “brought it home” and noticed the effects in their work life. For example, Oka stated, “that plays over and over again, and seeing the kid bleed out. Like being a puddle, that was what she was, a puddle of blood. That is just awful”. This nurse later reflected on an older case where they struggled to reconcile the manner in which their child patient sustained their injuries:

> ... I remember doing my job and doing everything that needed to be done. I pushed the rest away like I didn’t think about it until somebody came to the bedside and said, “how are you doing” and that put me totally over the edge because I wasn’t doing well at all. I remember that. (Oka)

In this time post trajectory, participants described the effects of patient trajectories or cases on other nurses or healthcare practitioners. For example, “anybody I've spoken to about it couldn't believe that we would do that to a family” (Kethra) or “people were upset because we didn't really debrief about it. There were people that were upset that were calling each other at night about what had happened and crying” (Oka). Dara indicated relying on these relational supports post traumatic death, having stated “they just told me ‘no, no. It (the cause of death) had nothing to do with that’. I needed that affirmation that I did not miss something or inadvertently contribute to the child’s death”.

The second notable finding of impacts and consequences are related to professional effects. It was often stated that feelings and concerns were not supported by some physicians and management. Participants reported concerns about approaching management, questioning, “if I say this, what will the repercussions on me be?”. Others noted the feelings of there being “a lot of hidden agendas and political connections” that drive decisions and create an environment where bedside nurses messaging “goes in one ear and out the other just to kind of shut us up” (Lorella). Ultimately, participants stated that with these impacts, they felt close to or considered quitting. Lorella stated many novices “have a very hard time, and I think that's why a lot of them leave PICU”; others echoed this, stating if they were in their first year in the PICU, “I would have quit”.

Bearing Witness. The final subtheme attributed to Feelings Around Dying and Death involves bearing witness to patient suffering, to parental suffering, and to frustrations of other nurses. In terms of describing the extent of patient suffering, nurses often additionally indicated the length of time as an important factor. Lorella recounted:

> I guess that's part of my moral distress, is that I know, like, which ones are not going to make it. Just from experience, you pretty well know which ones are not going to come out of that part. But that they've got about how many months of suffering? ... He suffered and suffered and suffered. He said numerous times he wanted to die; it's terrible what we've done. Some literally do rot away, and it's just horrific. I mean, if some people would see it, a layperson, you would think that you saw something out of a war, and yet

> every day we go there, and we look after these kids. It's not right to make them suffer so much. (Lorella)

Closely related to patient suffering is parental suffering. It often revolved around decision-making, for example, where parents were persuaded into a care pathway or around intended outcomes.

> I wish for them a best-case scenario, but so many of them don't get that. They get the persistent vegetative state, the moaning when you touch the child, crying when you suction them, and that's their existence. The burdens on the patients and on the family I don't think are worth it in some of these cases. (Genrah)

A final notable attribute of bearing witness is, somewhat interestingly, to the frustrations of other nurses. Morgana described witnessing cruel care practices and anger emerged from other nurses who were frustrated with the care pathway; for example, to a child with bilateral leg amputations, a bedside nurse stated, “no, you can't have pain medication. What are you going to do about it? Are you going to get up and walk over here?” At another instance, this nurse stated:

> People that I respect as colleagues and as nurses can be so very judgmental and quick to say “let her die. Why are we doing this? She is a burden on the health care system” ... they come to the bedside to do the sign over, and they would slam things down, and they would say, “Just tell me what I need to know. I don't want to be in this room”. And this young girl would hear them. She knew that she was going to be left to be cared for by these people, and she was basically at their mercy. It's not like I could go to the unit managers and say, “by the way”. (Morgana)

This nurse stated their difficulty in having understanding for their co-workers when they witnessed these behaviours: “it's a privilege to be giving the best of caring for children, it's an honour that parents trust you with the most precious little being in their life. And I have struggled because people don't feel that way about other people's children". This detailed theme of feelings experienced during important patient trajectory milestones, personal and professional consequences post trajectory, and bearing witness portrays important insights into the inner state of nurses felt during and after morally distressing situations.

Greatest Nursing Concerns for Dying Patients

Throughout the participant narratives, three of the greatest nursing concerns emerged as quality of life, dignity, and best interest. Additionally, two further subthemes of good death and "not good death" as well as right and wrong emerged and are described following the three greatest concerns. To begin, quality of life was most often expressed in terms of expected, potential or intended patient outcomes. Descriptors that involved quality of life included, "it's not high level but able to enjoy life and bring joy to others" (Dara) or to "get back to some semblance of what their life was like before" (Genrah). This nurse later stated:

> It's been almost two years, and he's still breathing, but has no connection to this world other than that he breathes. To me, saving someone means that when they go home, they will interact with their environment, they'll recognize the people that love them whether it's laughing at the TV or listening to music and enjoying that, that would be a quality to their life. (Genrah)

Lorella stated "there has to be some balance, so these kids don't have to finally rot away or blow an aneurism. They should have dignity, and they should have some quality of life, even if it's palliation. Even if that means their life is shorter, but they have quality".

Similarly, dignity was often described as a nursing concern leading up to and around times of death. For example:

> No-one just dies nicely in an ICU anymore, there should be dignity. This little guy did have a dignified death because his parents had been there for a long time, and the last few days of his life he spent laying, sleeping, with his mom in a bed, but that was because we made it happen for him. But some kids don't have a very nice death in there, and I think the kids deserve more than that. (Lorella)

During aggressive resuscitation effort of a child with catastrophic injuries, Genrah questioned, “should we allow him to have some dignity? Or do we continue to break his ribs? He's probably not feeling it, but we're not sure. And how much more of this can [the parents] take? Do [they] really want to watch us do this again and again and again and again?”.

Finally, best interest was expressed in relation to the patient, the family, and both. Best interest was noted, for example when Genrah stated “I feel that the five days that we kept his pulse visible on the screen was not in his best interest” or “for me, it's unethical if I were to prolong someone's life that I did not feel was in the patient's best interest; it would be unethical for me because it would not be true to what I believe” (Dara). Best interest was often described through statements about receiving the most appropriate care, however the path for making this determination was not always clear or agreed upon. For example, Mieve indicated a case where the parents lost decision-making power after wanting to discontinue aggressive treatment and voicing their beliefs of “we don't believe it's a bad thing when a child dies, he's going home to God, and we don't want him to suffer anymore”; here, Mieve stated that, while legal apprehensions can be helpful sometimes, “we didn't agree with the doctors on [this one]”.

Good Death and "Not Good Death". The narratives of this study highlighted how death happens in the PICU and how it can be perceived as good or "not good". Nurses described that a good death encompasses when the family themselves choose to withdraw care, when the death is peaceful for the patient, and with minimal suffering at the end as well as when the PICU space or "outer situation" is appropriately used, for example utilizing bereavement rooms and having appropriate staffing ratios. In contrast to "good death," nurses used the wording "not a good death". This was described by nurses to occur in situations where arriving at a unified decision "took too long" and where the child's death was not enabled by the team when the family was in "a horrifically horrible place" as well as patient suffering until the time of death.

Right and Wrong. While knowing what is "right" was stated clearly by some nurses, for example, "I know it's right to treat every patient and every family, no matter who they are, with the utmost respect" (Morgana), the notion of "wrong" was also described in terms of "not right" or "doesn't feel right". For example:

> I don't have a problem with doing things that hurt that are necessary if we will get this child back to some semblance of what their life was like before. But if we're just doing it because they're not ready to sign the death certificate, that's wrong. (Genrah)

Others stated: "you can't tell me that Medicine didn't know that she probably wasn't going to survive. And I'm sure that they did tell parents that. That is wrong, it's morally wrong" (Lorella), and "I think sometimes we don't give the care that we need to give. Sometimes that's not right" (Kethra). Described here is the inner state of the individual nurses throughout various times and dynamic experiences when navigating care for dying patients. The following section describes the relational dynamics at a greater depth.

3. The Relationship Dynamics Between the Nurse and Others: Decision-Making, Communication, Supports, and Recommendations for Changes

The following four dominant themes of this study are multifaceted and describe experiences stemming from relationship dynamics between nurses and others during situations of moral distress. The first theme is decision-making with discussion of who holds the deciding power and subthemes regarding the intention of treatments decided and nurses' decision-making influence. Communication and messaging are the second theme; described here is how messaging and information sharing occurred with participants recounting the standing of nurse's voices. The third theme indicates stated support for nurses, including non-supports. And, finally, the last theme presents changes, suggestions, and reflections of what is helpful, what would be helpful, and a subtheme of barriers.

Decision-Making Power

To begin, the most prevalent and often described elements by participants were found within the decision-making theme. Parents or families and physicians were the two groups to be described the most in regard to decision-making power. Dara described a commonly witnessed sentiment that, at some point, parents or families find it “impossible to consider that we would not do absolutely everything” and “often they’re thrown into it and even for the kids the parents know are going to die, they think they’re prepared. I don’t think you’re ever prepared for that last breath or when they’re not there. And what parent is ever going to say ‘stop?’” (Lorella). Lorella also remarked, “it's a whole new era now of healthcare with technology and family-centred care. We always say it's not family-centred care; it's the family calls the shots”.

When describing physicians as deciders, participants described situations where both the medical and surgical teams were not unified in their care plan or where they had reached an agreement through meetings to “find common peace,” with one participant noting that “even though he (lead intensivist) has power, he doesn't have ultimate power. He still has people he answers to, and there are situations that go on in the unit that he has no input into” (Genrah). From a nursing perspective, participants indicated the burden of knowledge in witnessing decisions made by physician teams, such as knowing the likely outcome of the patient, but would be reprimanded in some capacity when voicing concerns: physicians and management would “jump down our throats” (Genrah); witnessed decisions that were expressed included statements like “... the mom said ‘this isn't what I want for him, this isn't what he would want for himself. I think maybe we should stop’. And the doctor talked them out of it” or “they (physicians) aren't, for whatever reason, able to say to the family, ‘we can't keep doing this’. We have a couple of physicians who are comfortable with doing that, but we have a couple who aren't, and they seem to be the ones who set the tone” (Genrah). From a physician-based burden of knowledge perspective, Oka indicated, “often we think, you know what are we doing here? But, in the end, that is the way how I think, it is the physician that has to make the decision and they have to live with themselves too”.

As final thoughts, participants noted that through child apprehensions, legal involvement may restrict parental decision-making power, and at times, it is unclear who the decision-maker is or should be: “Part of me thinks I shouldn't say [this] and it's wrong to say, but did we waste on organ on somebody that would have been better ... and could be running around? And maybe that's not for me to say but then, who makes those decisions?” (Lorella). And, specific to frontline staff, participants stated, “the frontline workers are the last to know. Decisions are made up above" (Lorella) or "when decisions are made (for physicians to become unified), many of the discussions are not shared with other health care providers we may not be privy to all of the background of all of the perspectives or viewpoints" (Dara).

Nurses and Decision-Making Power. When further describing the experience of frontline staff, participants reported times when nurses possessed decision-making influence and when they did not. Influence was felt when parents or deciding health care providers afforded nurses credibility and, oftentimes, came with experience level; for example, as Dara described "parents knew that I was the advanced practice nurse in the ICU so, by virtue of title, I think they perhaps invested credibility with me" and "on rounds, the nurses will put forward their suggestions about treatment and the physicians will not respond to it until somebody's you know, 'Well you know, the evidence suggests...'. Now, do I have to have a randomized clinical control trial in my back-hip pocket to prove it's not? But if I have the languaging, I can almost elevate a nursing perspective to be appreciated. That sometimes brings me distress as well".

In an interesting paradox, seasoned nurses were shown to be mentors for nursing peers as well as for residents and were relied upon by physicians, "sometimes some of the doctors will say to some of the residents 'If she says so, then that's what needs to be done, right?' because we do have more specialized skills and knowledge," yet when voicing concerns regarding decisions being made they would say "I've been here for 30 years, you can say whatever you want, but it's falling on deaf ears" (Lorella). To further describe a lack of decision-making or influencing power, Genrah stated "we sometimes are invited to offer our opinions, but they never are taken into consideration when it comes down to actually making the choices" or when voicing concerns, "they (physicians or management) address the power angle, saying 'Well, you don't have that decision-making position: it's not your choice to make'". In an interesting contrast, Oka clarified, “there are nursing decisions, and there are medical decisions, I don't like it when they (physicians) get into nursing decisions ... I really don't need to hear that I need to turn a patient. That is nursing, I say that (laughs), but that doesn't help”.

Intention of Treatment. The intention of treatment is a detailed subtheme of decision-making where nurses described experiences of moral distress directly related to decisions being made. These decisions involved escalation or de-escalation of treatment, length of time for decisions, prolonged patient stay, expectations of prognosis, short-term or long-term patient outcomes, and reasonings behind the decisions. To begin, participants described experiences of witnessing and participating in escalating treatment as follows: “he'd sort of been failing for a few days, and it was a major cardiac arrest. Major. We did CPR for over 45 minutes, and they were going to cannulate him for ECMO, and we were all like, ‘you can't do this’. That kind of just finished me” (Lorella) and “she came out of heart surgery unstable, she was unstable for two days, and then she arrested. She went on ECMO, which was something that the parents were already like, whoa what is happening here? They did not consent” (Oka). Similar sentiments were noted around maintaining a level of care; for example, “he had brain tissue coming out of his nose and his ears, and he arrested several times. The family was not prepared to allow him to die. So, we had to do CPR on this poor body to get a heartbeat back for the family because they weren't ready to say goodbye. And I can understand that, and I feel for them, but at some point, somebody has to say, ‘We are not going ahead at this point’” (Genrah).

In a differing perspective, nurses described experiences involving de-escalation of treatment, whether it was intended or achieved: “there was significant difficulties and physicians wishing as a group being firm that we should withdraw treatment on this child. And families actually going to a lawyer to preclude us from doing that” (Dara) or “I participated in conversations with this family about him having care withdrawn. Every time the family was given all of the information, our physicians were very thorough, and every time the family said, "No. When God is willing to take him, then He will take him" (Morgana). Or, as Genrah stated:

> Palliative seems to be a bad word. We had a family whose baby was born with a syndrome that is incompatible with long-term survival the family was not ready to accept that their baby was going to die and they had a list of things that needed to be proven to them before they would consider withdrawal of treatment, we never actually got there with them. She [the mother] had this idea in her head that palliative care meant putting her baby in a room somewhere and starving her to death. It didn't matter what we said; we couldn't shake her of that opinion. (Genrah)

In terms of length of time for decisions to be made, occasionally nurses stated the team did not wait long enough, such as Mieve "I think that if they would have waited three or four days without doing the surgery, it would have been clearer to them that surgery wasn't going to produce the end goal that they expected," compared to many who vocalized decisions taking too long to make. For example, "I felt they were waiting for nephrology to be [the bad guys]. That they'll say, 'No, he can't have a kidney transplant', when they probably knew months ago that the chances of him getting, of being successful, were almost zero" (Lorella). Participants also reported experiences related to prolonged and protracted patient stays, both in terms of time and suffering: "she was with us for a very, very long time. She wasn't able to communicate and had extraordinary pain for long periods of time. It was very difficult for this patient" (Morgana) and "he continued to suffer, and we kept him alive" (Dara).

When describing expected prognosis, nurses indicated situations where life, death, and maintaining "connection to this world" were anticipated and times when this was not achieved;

these cases often included statements of “somebody needs to question the endpoint” or “the child they brought in is not the child they're going to be taking home” or “he never made it to the unit, that part of him was long gone before he got to us. All we were doing was caring for his body”. For example:

> The patient was a Do Not Resuscitate. The child very quickly reached the point where he was ready to die, and it was unexpected. We did end up giving this child some epinephrine to keep his heart beating until his family arrived. In those kinds of situations, I don't have a problem with doing that. We'll keep his heart beating until his parents get here. But I do have issues with “Okay, he's a Do Not Resuscitate, but we'll push up to 0.2”. That's a lot of epi. That's more than a code dose of epi, but we'll do it because we can. We've got it; we might as well use it, sort of thing. (Genrah)

On a similar note, nurses often described experiences where intention of treatment was focused on short-term outcomes and, sometimes, decisions more so based on long-term outcomes. Such as “there are things we do that hurt that are necessary, and I don't have a problem with doing those if the end result is going to be a good one. You know, we will get this child back to some semblance of what their life was like before. But if we're just doing it because they're not ready to sign the death certificate, that's wrong” (Genrah) and “it's terrible what we've done. He didn't want [the] transplant, and he said numerous times he wanted to just die. He will probably get out of PICU, but I would be very surprised if he survives because he probably will stop taking his meds or try to commit suicide” (Lorella) as well as “a lot of people judge these parents; you hear things in the hallway, ‘well, they want a perfect child’. Well, you know that is not really the case that they want a perfect child. They think about what has happened and do not just see the baby now. *Now* you can take care of her, but they also look at 5, 10 years down the road, and what is life going to be for her" (Oka).

Finally, participants described reasonings, given or interpreted, behind certain decisions that were made; these often revolved around aiding life or avoiding death, such as when patients state they want to live. Or, for example, in response to a de-escalation request from the parents, a physician responded, "well, this is really not an appropriate time right now because we don't know what is going to happen" (Oka) or, "sometimes they (the family) never resolves it, and then they end up traching the child and, you know, leaving them [like that] forever" (Kethra). Nurses further noted accessibility as the reasoning behind decisions, with resounding statements questioning "just because we can, or it's there, does that mean we should?"; Lorella recounted an adage of the context saying, "everywhere else had turned her down and said she was not a candidate for this ...but, of course at our institution, 'no one gets turned away'". Lastly, nurses often pointed to communication dynamics and pressures faced by physicians, such as pressure to let parents make decisions when they themselves know "the way it's going to go". Participants often reported feelings that "no one wants to be the bad guy" as a barrier or hindrance for decision making, yet all remarked that these cases were not "cut and dry", but rather involved many relation-based complexities. This detailed theme of decision-making highlights the complexities nurses encounter when witnessing, taking part in or responding to decisions as well as the notion of power and its implications for nursing practice.

Communication and Messaging

The act of communication and messaging is an important component to the dynamics of information sharing among individuals. This theme included messaging that occurs between the decision-makers, namely physicians and families, as well as information sharing among the team. Additionally, the subtheme of nurse voices described incidences of being heard, actions of nurses communicating, and reactions of that communication.

To begin, messaging between physicians and families was described in terms of clarity, tone, and goal orientation. Participants stated families seek definitive information from physicians and demonstrate anger and/or frustration when receiving inconsistent messaging. Perspectives and questions around obtaining parental informed consent was explained by some participants, for example, “they say it's informed consent, but they have no idea what's going to happen to them (the patient). It was probably second-day post-op and her mother was almost like beside herself. She said, ‘I had no idea it would be this bad’” (Lorella). Participants also indicated how physicians may “set the tone” of the conversation and message itself, such as when conveying prognosis or actions to inhibit or prolong treatment. For example, Genrah noted, “I think they have this image of the ones that turned out well, which supersedes the images of all the ones that didn't turn out so well. And that's their example. ‘Well, we had this other child, very similar to yours. This is what happened’. But they don't talk about the ten that didn't have that recovery”. Finally, nurses depicted scenarios in which messaging was used to achieve goals. For example, Mieve stated there was a sense of the physicians trying to show consensus with the family or parents while behind closed doors they may be arguing. Comparatively, Lorella stated, “but there's a way to tell them (parents) that you can get what you want”. Further still, Mieve described a situation in which a mediator was included to facilitate messaging between physician and the family “when it became clear that the family was not going to agree with the surgery, then there was a couple of meetings with ethics involved just [to] straight tell the family why they wanted to do the surgery”.

When considering information sharing among the team, participants noted that physician meetings to reach consensus and a unified physician voice were held behind closed doors and were, at times, held “a bit late” in the patient trajectory (Dara). Furthermore, this participant stated these conversations were not discussed or shared with nurses or other disciplines such as social work. In terms of information sharing, Mieve reported the unit does “rounds” every morning where “all the team, our ICU team, comes to the bedside. And it’s at that point in time that you kind of discuss like why are you doing this versus just letting them go?”. When asked how the physicians responded to such a question, Mieve stated, “oh, they have their textbook answers, as far as the states with this cardiac surgery, and move on to the next topic”. Informal discussions among the team most often did not involve the physician, occurred at the bedside if parents were not present: “between the RT and the nurse often we will share our perspectives like you know the comment of ‘why are we doing this?’ or ‘how much longer do you think this might go on?’. We may share. If the parents are there, you would not do that in front of them” (Dara). Additional informal conversations were stated to occur over coffee, such as for peer debriefing and coping, or in the nurses' lounge where other health care providers may congregate, such as RTs and dieticians.

Nurse Voices. The subtheme of nurse voices was described with regard to situations of being heard and not being heard in addition to actions taken by nurses when communicating as well as reactions of this communication from others. In regard to being heard, nurses remarked that families would invest credibility and merit into nurses’ insights; Dara commented this appeared to occur by holding the title of advanced practice nurse. Genrah described being heard by a particular physician as “I know he hears me when I speak my mind. I know that if he disagrees with me, he’s got a very good reason for it and will be able to tell me what his reasons are”. Participants additionally noted feeling heard by other nurses that resulted in both positive and negative impacts; positive impacts were described such as during mentorship, contrastingly one seasoned nurse described:

> ... this is a really good nurse most of the time ... this sort of information that was passed along that this boy is manipulative, and so she was acting on that premise – that he was manipulative. And so, she didn't believe that he was telling the truth and consequently when it all went to heck in a handbasket, she wasn't quite prepared for the emergency that ensued. (Morgana)

Comparatively, participants expressed times of not being heard by other nurses; Morgana recounted:

> I would come in in the morning, and she (the patient) would be almost hysterical because, at one point, she was unable to communicate. All she could do was click her tongue, and she was ventilated, she couldn't move her hands, and she was terrified of the dark – absolutely terrified. And the bedside nurse had said to her, “I am not coming in here anymore. I will come in when I need to check the numbers. I am closing the door, go to sleep”. And she closed the door and left this poor girl alone and terrified. And I have no recourse, you know? I said to the nurse, “Do you know she's afraid of the dark?” “Well, that doesn't matter to me. She won't be afraid of the dark if she's sleeping”. And you think, “Why are you in this profession? Why would you choose PICU?”. (Morgana)

Participants also remarked times of not being heard or not being able to be vocal when communicating with family. For example, Dara described a situation where, despite the same messaging, hierarchy was important to a family “it was his (intensivist) words that they were able to appreciate that things were not going to get better and not change” or, as Genrah stated:

> ... to know that perhaps if I would have been able to tell them (the parents) "this is what's happening this is his brain, and it's not in his head anymore, so it can't keep him alive anymore" and to know that if I would have said those sorts of things, that perhaps my job might have been in jeopardy. (Genrah)

A final important observation of not being heard or being vocal involved communication with physicians with many statements such as "falling on deaf ears" or not being heard in a meaningful way. For example, "he'll (physician) listen to what I have to say, and then he'll say, 'Thank you!' and turn and walk away" (Genrah). Comparatively, Kethra described:

> I honestly felt that we were not managing pain well on a particular [patient]. I was totally disagreed with. I had already gone over the top of the fellow and spoken directly to the Staff Manager. This didn't solve the issue. It wasn't of course, I was complaining about it all evening, all night, right through the night and it wasn't until the Staff Manager came back the following morning and actually spent some time in the room and saw what was happening that it was resolved. (Kethra)

The stated actions of nurses during communication were diverse. For example, translating inconsistent messaging between the physician team and families, in which Dara stated it "becomes very hard for me as a member of that team to try and explain to families no, they're saying the same thing, but they're saying it differently"; Genrah commented on interactions with that family to ensure that "everybody's feelings are respected". Comparatively, Oka described supporting families in alternative ways to policy necessarily:

> I am a little bit of a rebel (laughs). I was there for a year and a half, and this mother had different beliefs [requiring] that we burned a candle in the room, which was an absolute "no-no," it was a fire hazard, there was oxygen in the room. I turned the oxygen off, and

> of course, you try to take the precautions. Sometimes I say to parents, “I don't know about this” and pull the curtain. (Oka)

Mieve recounted actions of approaching the physician team once establishing mutual agreement among the nurses “we let the doctors know that we didn’t agree” or Morgana described approaching management “the unit manager and I had a conversation about the nurse telling him (the patient) to fuck off”. In a similar vein, aside from the various responses of “being disagreed with” or “being heard” by fellow nurses and others, a notable reaction to nurse-driven messaging was noted by Morgana when completing the previous story “[the unit manager] took offence at me telling it [witnessing a nurse tell a patient to fuck off], it's funny because it was at me telling it, not at the sense that the nurse said it”. Morgana later described this communication in general terms of support, or rather lack of support, in which “her (unit manager) and my relationship fell apart”. Stated supports and non-supports for nurses were found to be critical for future changes to practice and are discussed below. Described here in communication and messaging lies how, when, and between whom information is translated, highlighting the importance of both the message itself as well as the means of delivery.

Stated Supports for Nurses

The third dominant theme of stated supports for nurses highlights the dynamic relationship between nurses and others during the patient trajectory. Elements of this theme included professional and personal supports, at times, found within the PICU as well as non-supports. To begin, nurses supporting each other in a professional capacity was vastly noted in the PICU. This was shown through mentorship, whether formal or informal; for example, were seasoned nurse helped shift the focus of newer nurses to highlight different priorities and ways to approach care. When describing how nurses navigate team tensions, Mieve stated, “[the team does] nothing really. I mean, it really is just between us (nurses) once we start talking about it”. Further still, a seasoned nurse indicated:

> We have a dozen people who are identified as the go-to people. If you're struggling with anything, this is who you can go to. So that the new staff feel like they're being supported. It does make a big difference in how workflow goes and how the shifts go because they feel like, “Okay if I do get into trouble, I have some backup”. (Genrah)

Participants also indicated support from management and physicians. Dara stated noted, “I had the very good fortune to have X as my manager for 15 years. And she was an incredible support for me”, and Kethra stated, “I really have to give our people (physician team) credit. You know, they really do tend to address issues that when we bring them up”. Oka also noted, “if you need help there is help available. We have the ESP program; you can access at all times”. An interesting and likely sporadic support related to the PICU and nursing context revolved around nurses having “time to process” situations because of their schedule rotation, as Kethra noted, “it was fortunate that I actually had a few days off in between. That I found quite fortunate. After that child had died, I had a couple of days off”.

From a more personal note of supports for nurses, Dara described relationships among staff and colleagues:

> You know, the pub night, the showers, those types of things that are very supportive across all disciplines. So, if a social worker is having a baby, well, that baby shower is attended by nurses and RTs and social workers. So, there is a strong social network as well that is crucial in supporting practice and supporting working with difficult situations. (Dara)

Further still, personal supports included “reality checking” with coworkers or colleagues who may not work in the same area, perhaps asking them, “is this me or do you see this?”. Oka also described after an unresolved situation occurred “[people] were calling each other at night about what had happened and crying”. The family was often described as a support for individual nurses, in particular sharing a situation with a significant other, “I take my anger home, and I talk it out at home with my husband. Sharing my anger publicly is not supported, and I would not do it” (Dara). Contrastingly, some nurses reported “not bringing it home,” for example, Kethra said, “the effect is still there. And you address it later when you get home or whatever, and that's okay if you've got the opportunity to do that, but sometimes you don’t have that”. Oka furthered this, saying, “most things I don't take home. I try to deal with it and leave it”; when describing a certain situation, Oka went on to describe, “I did take this home because the whole of view of what had happened. That plays over and over again”. Nurses described individual coping techniques to include actions such as writing about their feelings or burning a candle for the patient. A senior nurse remarked, “you cope differently at every time in your life”.

In comparison, non-supports for nurses stemmed from various reasons surrounding difficulties in communication, fall out or repercussions when voicing concerns, and tensions arising from team dynamics. The following examples demonstrate nurses in various situations in which they encountered non-supportive actions or responses. Genrah stated:

> We don't feel like we're really comfortable a lot of times talking in front of them (management or physicians) about how we're feeling about things. There's quite a division between the direct caregivers and management and the physicians in certain cases, and we know that if we say something, it will come back at us in one form or

> another. They don't address feelings at all; they address the power angle. “Well, you don't have that decision-making position: that's not your choice to make”. (Genrah)

Genrah further stated addressing concerns with management can go “badly for you,” resulting in staff being hesitant to seek support from this avenue. As an interesting comparison, Oka reported situations where non-supports were found between bedside nurses:

> I don't think it is very accepted when you come into an ICU and you are new, and you have your opinion right away, you say things right away. You know, then it is, “well, who do you think you are”. Maybe the expectations are high of people that come in intensive care, you can't really expect that somebody can deal with parents the way I do, having been there for a long time, having kids myself. (Oka)

From a reporting and best care standpoint, Morgana was told to have crossed professional boundaries in a case where they had themselves brought to management concerns about the quality of care this patient had received:

> ... he would get really upset. And I would come into his room and stand very close to him, and I just sort of put my hand above his head, and I would talk to him very quietly. I just tried to talk and calm him down. And one of the unit managers said that I was acting inappropriately because I was hugging him, and I was talking quietly to him, and that's not appropriate; it's crossing professional boundaries. I was so angry. I was so angry, and I wasn't sure what to do with all that anger. I went to CARNA, pulled out the professional boundaries, highlighted, and I said, “you know if anybody ever wanted to take me to court and say, yes, Ma'am, you're right. I did talk quietly to this child. I stroked his head. I hugged him. And if you want to accuse me of crossing professional boundaries, then, yes, I did. But, by the way, this child has had pain medication denied to him, nurses have

> refused to care for him, he's not had dressings changed in days where they're covered in stool. He's been called a drug addict, and he's been told to get up and walk across the room (post bilateral leg amputation). That's fine; if you want me to stand up and say that I crossed my professional boundaries, I am more than willing to do that. But let's look at what professional boundaries are". (Morgana)

From a more context standpoint, Kethra noted, "I think a lot of issues are that we don't have the staffing, and you need to get people to stay, and you need to give them a reason to come. And if you're going to push them so hard that they have to talk away, then they will". Further to the context, Dara noted nurses being left out of important conversations:

> Even when it comes down to questions of withdrawal of life support, most of the physicians' groups have their little thing, so they're all together. Then nursing is a part of it with the family. It's relevant for me to hear the discussion from other perspectives so that I can feel comfortable in my own understanding. [A] part of moral distress for me is ... just our hierarchal nature at times. (Dara)

Further still, when consulting an external to the frontline team, such as the ethics committee, Mieve commented, "there's another situation that they were a definite help for the father ... [however] the general impression is that the ethics committee tends to agree with the doctors as far as what the doctors believe". Lorella echoed this by stating, "we never see the ethics committee ever come into PICU. If they do, we never hear about it". As Genrah stated, "there's no real sense of team anymore". Many of these supports and non-supports led to reflections of changes or recommendations to achieve resolutions, as discussed in the upcoming theme below.

Recommendations for Changes

Changes and recommendations to general practices are the final dominant theme to describe the relationship dynamics between nurses and others during and after situations of moral distress. Included here are suggestions and reflections in order to make change along with two subthemes of what is, was, or would be helpful and what acts as barriers or obstacles to achieving resolutions of morally distressing experiences. To make changes and achieve resolutions, participants reflected on suggestions that could occur both at a microstructure within nursing and at a more macro level, with emphasis on interdisciplinary relationships. At a micro level, Genrah suggested to say to management, "'walk in my shoes for a few shifts. Do what I do. Listen to the families say the things that they say to me, the questions that they ask me. Come and work at the bedside for a while because you have no idea'. They have lost connection with what it is we actually do". Kethra additionally noted, "sometimes we're put in situations that we shouldn't be. Often it comes down to staffing. Often it comes down to, you know, different peoples' opinions of how things should be done". In terms of nursing support from nurses, many participants echoed the "need to support the people there and those coming in". Morgana called for individual nurses to be respectful and "treat people with kindness", particularly when facing situations that are not fully understood or with which one does not agree.

From a greater macro-level perspective involving interdisciplinary dynamics, Kethra indicated:

> I don't feel bad about the system; the system is what it is. I think, if anything, we do need to make changes. I think we do try, but I don't blame the system for it. I don't even blame the people that put me in that situation; I don't know what would resolve [it]. I would say that other issues that I've had I've resolved them by working on them, by making a change

> so that it's not the same thing again [were] we can recognize that it's something that we're doing that's wrong, that we can make a change. Then when you make the change, it resolves the dilemma. I can't see a resolution [for some]. It's something that was done, and it can't be changed. (Kethra)

In terms of dynamics with physicians, Lorella indicated “I have worked there for a long time I said: ‘There's no way he's going to survive’. And I think Medicine knows, but I think also Medicine is torn, and I'm not saying that they're at fault, but I think that they are torn”. Participants indicated more specific changes in relation to decision-making as well as when communicating in general. For example, Mieve reflected that the team, in this specific case, should not have apprehended the child from their parents:

> The parents, they’ve lost; the parents have lost control literally like a couple of days before the end of his life, right? Instead of enjoying this time with them, with their son, we took over and took that time away from him and made him suffer even more. (Mieve)

In reflecting on their story, Lorella recalled “... palliative. Because that's what he was. I think he should not have been a candidate for a heart transplant, and he should have been made palliative at that time we have very good people that work in palliative care that specialize in pediatric palliative care, and I think that we shouldn’t have probably carried on for as long as we did with him”. This nurse further stated:

> I think that when you're 15, I think you have the right to say (whether he wanted a transplant). I think if he says “no”, I think it's a no. Because they're not the one laying in that bed suffering and being every day in pain like you would not believe like that boy suffered through. (Lorella)

Mieve noted, “we should [adopt] their (families) beliefs that it takes a community to raise a child; this clearly was the situation for them”.

In terms of communication, Oka succinctly voiced a sentiment shared overwhelmingly by all participants:

> People do not know why, and I think that is a problem in the units that not enough is being passed on. Like, when they make a decision to go on with the child, and other people are thinking, what are you doing? There is usually a reason behind why they decide that and that should be discussed. Staff should know that. (Oka)

As a final note, participants put forth a general call for change. One nurse questioned:

> When do we stop? But it's not just medicine, or it's not just surgery, it's very complex, and I guess the longer you work, the more you realize that I have no idea what the answer is. It's not just a blank simple solution. It's good that people are finally realizing that, yeah, we need to do a study about this kind of thing. We need to get some things out there and start questioning some of this. I don't think this is an easy fix. It may never be fixed, but I think that we do have to try to make things better. (Lorella)

These recommendations and calls for change indicate the complexities involved in interpersonal and interprofessional relationships and, ultimately, the need for more communication that is substantive and effective for all members.

Helpful. Participants described components of changes and recommendations, after experiencing moral distress or achieving resolution, through what was helpful and should be maintained as well as what would be helpful moving forward. In terms of what was found helpful, elements from procedural and context-based standpoints were noted. Mieve described an experience where feelings of distress were less strong because “they had good management of her pain and we had regular suctioning so we would pre-medicate her for that", indicating a degree of preparedness; this nurse also stated, "the good stories and the good endings help get through this kind of thing".

Participants also cited elements related to decision-making and communication. For example, consistent messaging from the physicians, including both where the information is delivered by one physician consistently and where physician teams have achieved a unified voice. Further, participants described mentorship or "talking with other nurses" as a key strategy and recommendation. Alternate to nursing, Genrah thoroughly described the qualities a physician held in which the nurse would have less experience of moral distress when working together that touch on many elements, including decision-making, communication, and nurse voices. This participant relayed:

> He's very detail-oriented, and he likes to leave his emotions out of it. He's purely looking at the facts, and when that was brought up, everybody was a little uncomfortable, because he did have a good point. He often will bring out, "Well, maybe you did this, and you shouldn't have. Maybe you dropped the ball". And it's really important having because he keeps us all honest when we're talking about what happened and how it happened. He is the voice of what really should be done, so it's good to have him there. And when he says something in a family meeting, I know that he has looked at it from every possible angle, and this is the right thing to do because he is probably the most ethical person on the unit. I respect his judgement. There're times I could slap him, but that has nothing to do with ethics. And everybody knows that when he opens his mouth, we're not going to like what comes out because he's going to point out our weaknesses in that setting. He's a wonderful persona, and I really enjoy working with him. There are other times when he is

> involved in a case where he's quite willing to look at his own errors in judgment and say, "Yeah, I really did mess that one up". It would be safe to point things out to him if you wanted. I know he hears me when I speak my mind. I know that if he disagrees with me, he's got very good reasons for it and will be able to tell me what his reasons are and that they're usually not emotionally fixed. That they're coming from a place where the best interest of the child is being examined. And I know that if he says, "This is what we have to do," that he really as looked at it from the best interests of the child and of the family as well. (Genrah)

Throughout the transcripts, participants cited strategies or actions that would be helpful throughout the patient trajectory and after death; these elements were primarily related to nurse voices, ethics committee involvement, and understanding decision-making rationales. As an example, for nurse voices, Genrah remarked, "perhaps if we (nurses) got that (opinions based on experience) out into the open at the beginning, the parents would make the choices that they would be most comfortable living with for the rest of their lives. Instead of being pushed into following suggestions and then having to cope with the after effect". Comparatively, for ethics involvement to be helpful, Lorella stated, "I think if we felt that ethics really could change things and that what we said was going to be listened to". Oka further indicated, "I think ethics should be more involved. I had been there once, and that was a long time ago, that [the ethicist] came to talk to parents. I know the child was dying; I don't remember what the ethical issue was. But, I remember thinking, wow, this is really good, what a wonderful man and the way he talks to parents, this is just so important and so good, and I think that doesn't happen enough". Finally, and notably, all nurses indicated it would be helpful to understand rationales and reasonings behind decisions; as Oka stated, "I think it would help if we have something like that (morbidity and mortality rounds) for the staff. So, they know why what has happened. We often say we treat our animals better than we do these children. So, more clarity on why and why".

Debriefings were a final suggestion and recommendation, with participants noting that they may be both helpful and unhelpful. Mieve recounted, "Most of the time, when there's a death within the unit, we do have a debriefing where the nurses who took care of the patients are invited to go. It's kind of like a round table and talk with the doctors and the social work and stuff about the situation. Those are useful for the most part". Contrastingly, Kethra noted, "sometimes it helps, sometimes it doesn't. When they leave it too long after, it doesn't work. If you're going to have a debriefing session within a couple of days, then that's okay. But if you have it a couple of weeks later, it's too late". Mieve described considerations with timing and organization:

> We're still waiting for the debriefing, you know (two months later). But I honestly just don't think it's going to happen cause the doctors don't want to, you know? It's only happened once in three and a half years that I've been there. But it would be nice if we could have regular meetings or whatever. (Mieve)

This nurse further described the importance of information sharing during the debriefings, stating, "I think some debriefings happen and we're not really given all the information, so you're still left walking out of there not really sure what happened". Dara suggested, "maybe the answer is you have them before the difficult situation, where everybody is allowed to share from their discipline, their mindset, and what it is that they're seeing and perceiving and bringing personal perspective to the situation as opposed to their professional perspective". As an additional comment to relational dynamics, Dara stated that "debriefings feel public. [People] tend to express regret or the fact that they felt disrespected. But they would not risk saying, 'I'm angry with you in relationship to this behaviour', they would say, 'I'm angry at the situation that happened'. I would suggest our culture doesn't encourage you to express anger. Tears are okay". Conversely, though not specific to formal debriefings, Oka stated, "I am not really one to talk in a group. I find in a group there are many people that are very judgmental, and I find that hard. I think a lot of the problems like I say I think this is everywhere, is communication".

Barriers. In a similar vein to what would be helpful, participants described general barriers to achieving resolutions encountered during experiences of moral distress: these were attributable elements of the PICU context as well as the dynamic elements of communication and repercussions or fallout. Barriers found in the PICU context often related to technology or flow of the unit. Lorella described the use of and subsequent removal of technology by questioning, "how can you ask a parent to withdraw [treatment]? It's like saying, 'kill your child'". Additionally, busyness and resource shortages (bed and nursing) were cited as compounding stresses for bedside nurses. The participants indicated that these stressors at play "don't give us time to resolve issues"; this speaks to resolving or addressing issues that arise within the patient's trajectory and personally afterwards. Lorella echoed this sentiment when recounting a story of having to care for young adults in the PICU:

> Every day we have five to seven people on overtime, but yet our unit is filled up with "kids" that really don't need to be there anymore; they need to go somewhere else. And I guess that's the other thing, that you feel that "Oh, well, there's another one". As I said, there's no rules anymore. (Lorella)

Kethra also noted, "we have ethics rounds in the unit, that's quite recently been brought up, but often the people at the bedside aren't able to get to it. Which is often the case for rounds".

In addition to barriers within the PICU context, dynamics of communication were often identified by participants as obstacles in finding resolutions. Communication and messaging, in particular the delivery of rationale behind decision-making as well as nurse voices not being heard or impactful, were among the most frequently stated barriers in experiences of moral distress. Most often, this was evidenced by statements of “why are we doing this” without resolution. Others included: “when every place in the region turns her down, there's a reason why. Just because the parents want a chance, it should have been a ‘no’” (Lorella) or “he hasn't recovered from the rest of our issues, so why are we going to open up his heart?” (Mieve). As Genrah summarized, “... a lot of people don't really understand all of the factors that go into the decision-making process in a situation like we might be facing. And they feel like the choices that are being made are wrong”. However, the notion of nurse voices not being heard or impactful included situations where nurses approached management regarding care practices of other nurses or during situations of nurses approaching nurses. Genrah stated, “my other role in the unit is identifying areas where we really need to support the staff and to act as a liaison between staff and management so that everybody is on the same page and working towards the same goal. I don't know if we're there yet, but we're working towards that”. Morgana described approaching a unit manager:

> I said, “You know, you have to accept that he's being abused by us. This is our own people that are abusing this child, and he is just so vulnerable, and you have to do something. You have to accept that it's happening”. So, her and my relationship fell apart. Completely fell apart. To a place where I couldn't even work with her. You know, it was so adversarial. (Morgana)

Oka indicated witnessing judgments from other nurses as a barrier:

> I try to get that across, it is not up to us to judge what parents should, or what physicians should do at the same time. I would like to hear her (physician) opinion, and that is what I did. I went up to her and said, “This is what I hear and what is exactly the case?” And then she tells me then I go with that, that is her decision, and I don't judge that at all. (Oka)

A final element of barriers was the perceived or real repercussions and fallout obstacles nurses faced when offering opinions or questioning care pathways. An example of a more perceived ramification is described by Lorella “you would just get the feeling from the staff guys and also from nursing management, from the manager and also higher up, that that was not the thing to do”. Comparatively, Genrah described when approaching management can go “badly for you”, recounting when a manager stated:

> “You need to come down to the office right now. We need to talk about this. You're being insubordinate”. That's happened. Or one of our managers actually used to stand in the middle of the unit and yell: “How dare you question my authority. I made this decision, and that is the way it's going to be. You will do what you're told”. Or it will be more subtle. You get the really nasty assignments for shift after shift after shift. And, you don't want to come into work anymore because you know what's going to be waiting for you for some people it's the chronic patients in an isolation room for other people it's the really sick patients that they get the same level of acuity shift after shift after shift and you don't get a chance to breathe, it really depends on the individual. Or you find yourself being passed over for new experiences and education and the chance to grow because you stepped on somebody's toes. (Genrah)

The basis of this theme, recommendations for practice changes, highlights the effects of relational dynamics as being helpful or as acting as barriers during experiences of or in achieving resolutions to morally distressing situations.

4. Differing Opinions, Perspectives, and Perceptions

Differing opinions, perspectives, and perceptions were included in and influenced all aspects found in situations of moral distress, with particular note to themes that discussed in the inner state experiences of individual nurses as well as the relationship dynamics between the nurse and others. While small, concise statements were noted by the participants, oftentimes, a great portion of a story included various perspectives and opinions while describing elements of other themes. For example, Genrah recounted:

> This particular incident happened on the same weekend when I had been involved in another discussion about end-of-life care, and it was dramatically different. In the first case, the family wanted everything done. It didn't matter that their child was not going to survive; we were still expected to everything that we humanly could do. In this case, the family decided that they really didn't want their child to continue on with the prognosis that they knew this child was to have with the degree of brain injury that they had. And the mom said, “This isn't what I want for him, this isn't what he would want for himself. I think maybe we should stop”. And the doctor talked them out of it. He said something to the effect that “Well, you know, maybe if we give him another day or so, we'll have a clearer idea of what is to come”. And the family agreed to that. And the outcome was that when we did withdraw care, he breathed. And it was not what the family wanted, but that's what they got. And he is still breathing. It's been almost two years, and he's still

> breathing, but he has no connection to this world other than that he breathes. And I feel that we failed the family by not perhaps tackling the physician and saying, "What are we doing"? (Genrah)

Upon analysis, a few dominant themes identified in this passage included decision-making power, with elements of intention of treatment and burden of knowledge, as well as communication and messaging, with a particular note to messaging between physicians and families, in addition to the theme of feelings around dying and death. Comparatively, this passage further indicated differing opinions and perspectives from the parents, physicians, and nurses. The nurse described witnessing to the communication of these differences between parents and physicians, the agreement in decision, and results; the ending being described by the nurses perspective of "I feel that we failed the family by not perhaps tackling the physician and saying, 'what are we doing?'" Therefore, this theme of differing opinions, perspectives, and perceptions is presented as an overarching theme that has ties and webbing throughout the previously noted dominant themes.

As noted, many instances of differing perspectives were found as streams throughout the stories; however, participants, at times, did indicate these differences outright. In particular, nurses indicated differences between personal perspectives and PICU perspectives as well as differences between individuals and groups. When describing personal perspectives, nurses voiced statements such as: "I believe what we each feel at that bedside is very much based on where we've been and who we are. It's the same way as how I grieve for children when they die and their families is different now in my experience in PICU than it was 20 years ago" (Dara), "I think you had to live [it] in order to be able to tell it from my point of view. They (others) wouldn't say it the same as I do, they wouldn't feel it the same as I did" (Kethra), and, when describing having had their own child as a patient in PICU and ICU, one nurse stated:

> I look at the ICU experience from so many views, so many angles. I'm able to tell the story at different levels. Maybe I just have to try and teach them (other nurses) my experiences. And maybe I have to appreciate that they haven't had the luxury of those experiences. (Morgana)

Further still, participants described navigating differing perspectives between their person and the PICU context from a relational standpoint. For example, Mieve stated:

> Everyone has their own beliefs. We recognize that. But in the grand scheme of things, the larger belief system around is that we need to do everything that we can for the children we couldn't straight up tell the family that we agree with them but, the ones who supported [their perspective], we definitely let them know what we definitely [heard] their story and it was just a very hard situation to be in. (Mieve)

In addition to acknowledging differences from a personal level, examples of differing opinions, perspectives, and perceptions were found among groups, including nurse and physician teams, respectively, as well as between the combinations of parents, nurses, and physicians. Evidence of differences among nurses included Dara, who stated, "when the day came when he died, I was not the bedside nurse but instead was trying to support staff nurses who themselves had not come to that point (accepting the withdrawal of care). And it was a very uncomfortable position to be in" who later remarked, "just as I believe surgeons and nurses and intensivists have different perspectives on the story, I believe that nurses in other areas, although we share the same nursing focus, it will come out differently". Or, when Lorella described, "I think that a lot of [newer staff] live with rose-coloured glasses". Comparatively, differing opinions among physicians were described in terms of nonunified voices or having achieved consensus; for example, Mieve noted, “they're trying to show consensus even though behind closed doors they may be arguing. You can definitely see that in their eyes on Wednesday rounds, all of our intensivists are in the unit that day, and you could see certain doctors looking back and forth between each other while one doctor's looking, while one doctor's talking”. When describing differing opinions or perceptions between parents and nurses, Dara described:

> Because of his neurologic, cognitive dysfunction related to cerebral and anoxic episodes; it was hard to perceive whether that was a grimace. But it did not appear to be a pleasurable response for him even just turning him every two hours to prevent pressure ulcers he would grimace with it. And that was my perception that it was uncomfortable. Parents felt that he was responding to my touch. So, a lot of it was in our perceptions. But I perceived it as a negative response. (Dara)

When considering differences between parents and physicians, Oka recounted, “the parents had asked to withdrawal while she was on ECMO, and the physicians have said, ‘well, that is really not an appropriate time right now because we don't know what is going to happen’”. Finally, when considering differing opinions, perspectives, and perceptions between nurses and physicians, Dara indicated a summary statement of differing opinions and perspectives that was echoed by many participants: “I believe we all have a different paradigm in how we look at it. And so, it’s relevant for me to hear the discussion from other perspectives so that I can feel comfortable in my own understanding. And I think that tends to make me feel less confused or less uneasy about something if I’m aware of what all the other conversations have been”.

In conclusion, these findings represent nine important themes that emerged throughout the narratives of nurses who experienced moral distress when caring for dying child patients.

Together, the outer state and inner state of nurses, the relation dynamics with others, and the differing opinions and perspectives among individuals describe this experience of moral distress and features important areas for discussion when considering our current understanding of this experience and future procedures and practices. Chapter 5: Discussion will explore these themes further in terms of novelty and their standing within the current literature as well as an in-depth exploration in their implications for practice.

“Come, Watson, come!’ he cried. ‘The game is afoot.” – Sir Arthur Conan Doyle, The Return of Sherlock Holmes

Chapter 5: Discussion

Moral distress has been commonly understood in the literature to be when one knows the right thing to do but being unable to realize it. Research has indicated the consequences of such an experience can deeply affect the individual. Critical care areas are fraught with ethical issues, and end-of-life care has been associated with numerous incidences of moral distress among nurses (Storch, Starzomski, & Rodney, 2013). Therefore, the primary research question proposed of this study was: what are the moral distress experiences of PICU nurses caring for child patients who are at risk of death or who are dying, as revealed in their stories? A content analysis was undertaken of seven transcripts from registered nurses in six PICUs across Canada. This data was previously collected through narrative inquiry by Austin et al. (2006). The content analysis used open coding where nine dominant themes emerged: the PICU context, nurse positioning, feelings around dying and death, greatest nursing concerns for dying patients, decision-making power, communication and messaging, stated support for nurses, recommendations for change. A final theme of differing opinions, perspectives, and perceptions emerged as having tendrils woven throughout the others.

It is important to note, as identified by a participant, that distress occurring at the time of death may not necessarily be from a position of moral angst but happens simply because it is a death and loss of a child. At times, the manner of the death itself can create characteristics and experiences of moral distress as seen with suicides or children dying from child abuse. This being said, a great deal of moral distress appears to occur in the events and on goings between nurses and other healthcare providers that involve the provision of end-of-life care. This study focused on the moral distress experiences of nurses when providing care to children.

To understand and make sense of this human experience, of the moral distress of nurses caring for dying children, I will draw upon concepts depicted by Canadian philosopher John Russon to guide this discussion. I begin this discussion by describing the *outer state* of the individual nurse. This includes the PICU and how the nursing profession hangs within this context. As Russon (2003) indicated, "the subject and the object are not different beings that might or might not come into relation: they are already involved, each having a grip on the other. We must reorientate our thinking and conceive of a subject who is intrinsically situated, or an environment that intrinsically calls for someone to resolve it" (p. 20).

Following this, the next section describes a form of *embodiment* that shapes the sense of one's experience. Russon (2003) stated terms such as trespass, pleasure, and shame name the terrain of embodiment and names ways that individual identities are sensitive to what is outside of themselves. The author stated, "being sensitive – being the possibility for experience – is the essence of the body" (p. 22). He stated, these feelings are layers of relation and are the way in which the body exists; "to be a body is to be open to noticing how we stand with others – to have others already influencing, already inside our experience". The embodiment of moral distress experiences of participants of this analysis is described as the *inner state* of the individual and will be examined through their stated feelings and reflections during and after patient trajectories, that either resulted in death or discharge from the PICU. An important notable finding from this analysis is the descriptions of feelings throughout the patient trajectory and the stated reasons for these feelings. This will be explored in detail.

The final concept to explore this human experience relies on an individual's *engagement* with others and ensuing social interactions. Russon (2003) stated, "other people ... are those others in whom I can have a shaping influence only by communication and cooperation, only by integrating my will ... with the other's will" (p. 54). Russon (2003) indicated here that cooperation does not necessarily mean friendly dealings, rather it would often include conflict, a feature which is pervasive within human experience; "to be a person is to be in the midst of other people" (p. 54). Therefore, this final chapter examines the relational dynamics between the nurse and others in terms of decision-making, communication, and recommendations for change. An additional notable finding of this analysis pertains to the intention of treatments and interventions made by decision-makers. This will be described further in the *relational dimensions of end-of-life care*. As indicated, findings that were notable and implications for future study are described throughout.

Outer State

When thinking of the outer state of nursing, it is important to consider the context in which the profession operates. The PICU has physical structures similar to other hospital units such as a certain limited number of beds, patient rooms, and family/conference rooms. Unique to higher acuity areas, the PICU houses extra equipment used for life-sustaining treatments. Further, the PICU culture often functions under the mantras or dictums of the 'rule of rescue.' In this analysis, participants indicated "we're supposed to save them all, but we can't save them all" and "we need to try everything until there absolutely is no hope for anything else". Interestingly, in an environment where death more frequently occurs, participants often used alternative terms to *dying* when describing their narratives such as "heading down" or "crummy, crummy, crummy." One participant indicated their own discomfort with using the word *dying*, stating "that's probably my own comfort level".

Participants in this study clearly indicated times when “nursing shortage” was a reason for moral distress while at the same time describing morally distressing experiences even when caring for a single patient. Participants also indicated that cases were assigned based on patient acuity and the seniority of the nurse, but also as a form a retaliation or punishment from upper nursing management resulting in receiving “nasty assignments,” including “really sick patients ... shift after shift after shift” eluding to the possibility of moral distress arising from a combination of caseload, acuity, and the extent of working with highly acute cases. In a systematic review of various countries, Lamiani, Borghi, and Argentero (2017) described relationships between moral distress and the organizational environment. These authors indicated that high caseloads were found to be directly associated with moral distress (Lamiani, Borghi, & Argentero, 2017). Comparatively, a national study of New Zealand nurses further supported the findings of this analysis, having indicated that the ‘system’ is not supportive of nursing endeavours as evidenced through staffing shortages and overall system and economically based needs outweighing those of the profession. This author also noted nurses leaving their position due to consequences of managers being perceived as unresponsive or indifferent to requests for change or improvements (Woods, 2020).

Further, nurses in this study often cited the use of technology in both a positive and negative light, saying “we can pretty much keep children alive ... sometimes that's good, and sometimes that's bad”. Participants also indicated part of their role as a seasoned PICU nurse involved mentoring newer staff, at times through relaying the message “10 years ago, those kids wouldn't have suffered that long because we wouldn't be able to do what we can today”. This finding aligns well with an earlier study. Schluter, Winch, Holzhauser, and Henderson (2008) found that sources of morally distressing experiences were attributable to the increasing acuity of patients, poor staff-patient ratios, and high technology availability and use. Similarly, Wall, Austin, and Garros (2016) indicated that adequacy of other resources aside from technology, including time and beds, can play a part in the rise of these distressing experiences.

In addition to these contextual factors, nurses indicated that part of their role and positioning involved being a direct care provider at the bedside. Participants indicated professional responsibilities extend far beyond managing “technology, drips, and machines” to include supporting patients and families alike as well as communicating between cohorts of individuals, demonstrating the diversity of the nursing role. Peter and Liaschenko (2004) described the necessity of framing nursing ethics socio-politically, with particular importance to nurses' position within the hierarchies of the larger health-care context and the neglected dimension of nurses' proximity to patients. These authors indicate that due to the spatiotemporal organization of nursing work demands persistent proximity, nurses experience “the burden of moral responsibility acutely” (p. 222). These authors indicated that others may 'walk away' knowing that the bedside nurse will remain at the bedside, thereby providing the others with an escape and avoidance of full responsibility and recognition of the consequences of decisions. The authors noted that decisions resulting in the suffering of the others are likely more easily made at a distance. Ultimately, Peter and Liaschenko (2004) stated that individuals who remain close to the bedside, such as the nurses described in the PICU, are not morally superior by experiencing this sharpness and intensity of moral responsibility, but rather it is their positioning within the healthcare system, both geographically and politically, and are even unable to flee if desired. Worded differently, nurses are made to bear witness to the consequences of decision made by others, even other nurses at times; this was a finding shared by all participants in this secondary analysis and will be more deeply explored in the following section of the inner state of nursing.

Inner State

This study uncovered feelings, psychological, emotional, and physical, at milestone points throughout the patient death and dying trajectory from decision-making to death as well when nurses took actions and were supporting others. At times, nurses indicated feelings of intense uneasiness and dishonesty about the patient care decisions being made and their implications for the patient or family. Nurses stated, “the hair on the back of my neck goes up ... oh, this doesn’t feel right” (Dara), “part of me is shrivelling up,” and “I felt almost dishonest in fostering the ... ideas that this could go on indefinitely” (Genrah). At times of withdrawal of life-sustaining interventions, nurses described having difficulty letting go, a great deal of guilt, and feeling extremely frustrated. At times of death, nurses conveyed varying feelings ranging from regret and a sense of haunting to being relieved; others indicated that what occurred was “very, very sad,” “extremely stressful,” and, as Oka described upon witnessing a patient’s final moments after a traumatic, sudden, and graphic death, “... in all the years that I have been in PICU, that was the worst thing that I had ever seen and experienced.” Importantly, the reasonings for these feelings were described by the participants, often in terms of not being heard by the decision-makers, having no influence of change, or, at times, witnessing other nurses not being supportive of family or patient requests. As Genrah described, “I feel we failed the family by not perhaps tackling the physician and saying, “what are you doing?”. Feelings of anguish and regret were most notably tied to regret that medicine and healthcare are unable to “fix everything”, that patients and family endured long protracted suffering, interventions within the last days were not pleasurable for that patient. Feelings of frustration were noted during situations that may have been prevented, when decisions impacted the quality of care delivered or when primary concerns of patient dignity, best interest, or quality of life were not realized. For example, as Kethra recounted

> ... they moved this dying boy from a single room into a four-patient room. The reason they had moved him was that the second child [I was assigned to] had to be isolated, so they felt that this boy, well, he’s going to die anyway. The family whose son was dying had to fully gown, mask, and glove to come in to visit. (Kethra)

This passage not only describes a frustrating or regretful situation that may have been circumvented but highlights the added barriers on the family for their last moments of interaction with their child. Feelings of relief were often tied to a release from patient or family suffering; as Lorella stated, “thank goodness for her she didn't suffer when she [died]”. At the time of performing nursing care, nurses indicated varying feelings, in particular around 'torturing' patients through painful interventions, a cited concern also confirmed in the literature (Austin, Kelecevic, Goble, & Mekechuk, 2009). Furthermore, a study by Fachini, Scrigni, and Lima (2017) conducted in the South of Brazil of PICU workers, feelings related to situations of moral distress to include: anguish, insecurity, powerlessness, embarrassment, tension, intolerance, indignation, regret, lack of autonomy, and pain in the face of death.

In this secondary analysis, many nurses indicated inflicting some form of 'torture' or suffering, whereas one nurse stated, “yes, we do terrible things, yes, whatever we have to do, it hurts them. But someone has to look after them, right? And you still give them exactly the same care. I guess I just kind of block that part out of my brain”. Nurses further cited feelings of distress and powerlessness through the 'inability' to perform nursing actions, often related to workload or busyness of tasks themselves or the unavailability of time during a shift to resolve issues within one's self or with others. A final interesting finding relates to nurses feelings when providing support at milestone points. Nurses indicated feeling discomfort when supporting other nurses who were not accepting of a decision or withdrawal of treatment. When supporting patients and families, nurses used phrases such as “it breaks my heart ... it's not right to make them suffer so much” and “what have I done” when witnessing a surgeons' tears post quadruple amputation surgery (Lorella). These findings offer a unique understanding of the feelings processed throughout various points of a patient’s trajectory. The following describes feelings arising as impacts and consequences after the morally distressing event has occurred.

Impacts and consequences to the individual (psychological, emotional, and physical) found in this study were similar to those of common definitions of moral distress that depict feelings as consequences of the experience; these include anguish, powerlessness, fear, anger, and guilt along with heart palpitations, diarrhea, migraines, and disturbed sleep patterns (Burton, Caswell, Porter, Mott, & DeGrazia, 2020; Deschenes, Gagnon, Park, & Kunyk, 2020). In addition, participants here indicated second-guessing their actions and regret for not saying more, as Kethra reflected, “maybe if I'd stamped my feet and shouted and totally refused, then maybe something might have been done. I don't know”. Additional distress stemmed from anticipating future morally distressing situations; “I was ready to quit ... it's the idea of continuing to do things that we know aren't going to provide the result we want, knowing it from the beginning that this is going nowhere because that's what we're told to do, being powerless and feeling like I can't say what I'm feeling ...” (Genrah) or “the helplessness is that I just don’t know what more to do” (Morgana). Importantly, the lasting effects were carried across work-life and homelife boundaries; many nurses “brought it home” and noticed the effects in their work life; Oka indicated a particular event “plays over and over again, and seeing the kid bleed out. Like being a puddle, that was what she was, a puddle of blood. That is just awful”. Other researchers have also remarked that symptoms of moral distress could carry into one's personal life (Corley, 2002). Lamiani, Borghi, and Argentero (2017) found moral distress was associated with a decreased job satisfaction as well; additionally, these authors reported a correlation between moral distress and intention to resign or actual job-leave and that moral distress was associated with burnout and low levels of work engagement. Additionally, Burton and colleagues (2020) indicated that nurses expressed the need to self-care through compartmentalization with still performing caregiving tasks at the bedside. A study by Wilson, Cutcliffe, Armitage, and Eaton (2020) of moral distress in critical care transport nurses also indicated a theme of “decreasing circles” which related to an individual's experience of following the same pattern of behaviour over and over, while obtaining worse results each time. A similar sentiment was expressed by a nurse in this secondary analysis who witnessed and was unable to address care practices among other nurses ranging from unkind to cruel. Wilson and colleagues (2020) indicated the experience of ever-decreasing circles is embodied by feeling numb, anesthetized or deadened. These findings in the literature were reflected by participants of this secondary analysis.

While the aim of the original study by Austin et al. (2006) was not of moral distress related to the death and dying of child patients per se, this secondary analysis uncovered meaning behind what participants indicated as a “good death”. Descriptors of a good death included such assertions as: when patients are peaceful and experience minimal suffering, when the family themselves chooses to withdraw care, and when appropriate use of the 'outer context' occurs, such as using bereavement rooms and ensuring minimum staffing ratios. The findings of this study are in alignment with other literature that describe indicators of a “good death.” For example, McAdam (2018) described in adult ICU, when an acutely ill patient who died suddenly, the family indicated it was still a “good death” because the patient did not suffer, despite the suddenness. Conversely, families viewed patient death associated with a prolonged hospital stay as a “bad death” due to an unanswered question regarding rationale behind the treatments and why their loved one suffered. In an interesting comparison to this secondary analysis, nurses oftentimes indicated “not a good death” as opposed to using the words “bad death”; however, they did echo these sentiments around prolonged decision-making and prolonged suffering. Wiegand and Petri (2010) indicated, “death occurs without dignity when treatments that the dying person would not want are continued and when basic comfort needs are not met” (p. 428). These authors described patients with life-limiting illnesses who indicated that a good death would mean dying while asleep, being free from discomfort, dying peacefully, and with family around or “being cared for”. Wiegand and Petri (2010) further described nurses' interpretations of a good death to mean in which patients and families are able to say goodbye, to die with integrity, to have open communication, and to achieve adequate symptom control. Conversely, a bad death included pain or other unrelieved symptoms, not being in accordance with patient or family wishes, prolonged death, a traumatic death, and patient suffering. Similar descriptions of what entails a good or bad death were also expressed through what is right or wrong by nurses in this analysis. For example, Lorella spoke themes of open communication and prolonged death when recounting, “... you can't tell me that Medicine didn't know what she probably wasn't going to survive. And I'm sure that they did tell parents that. That is wrong. It's morally wrong”.

Relational Dimensions of End-of-Life Care

This study uncovered that upholding patient dignity, best interest, and quality of life as the greatest nursing concerns for dying patients. Participants described various situations resulting in distress when they felt these concerns were not being appropriately addressed. Most often, these were evident during times of decision-making and communication of these decisions. For example, this was expressed by one nurse in particular who described a teenaged patient requesting to die after receiving an unwanted heart transplant and subsequent bilateral leg amputations; this nurse questioned the ethics of decision-making capacity for someone of this age and was perhaps describing a situation where seeking or broaching the status of a mature minor could have been warranted. In 2014, Ganesan and Hoehn also indicated ethical considerations in decision-making particular to the PICU includes ambiguity over parental permissions, informed consent, and assent with children who are older and are afforded for weight for their ideas about their own medical care (Ganesan & Hoehn, 2014). Furthermore, a recent 2020 study by Burton and colleagues supported quality of life as a major expressed concern by nurses working in neonatal and pediatric critical care.

In this study, physicians and parents were indicated to have the most decision-making power in relation to patient treatment, though who holds power may change at a given time. One nurse indicated, “we always say it's not family-centred care, it's family calls the shots” yet also stated that through communication styles and techniques “... there's a way to tell them (parents) that you can get what you want”. Corley, Minnick, Elswick, and Jacobs (2005) indicated that leeway for nurses in making patient care decisions and the resolution of moral distress could be affected by organizational cultures, including hierarchy. This hierarchal structure between professions, or even between those in the same category, effects and restrains how an individual can act out their own moral position (Kälvemark et al., 2004). This feature of decision-making restriction was noted in this secondary analysis from a physician and parental position alike, as indicated by the statements above, as well as from a nursing position. At times, nurses described when they had perceived decision-making power, most often when afforded credibility by virtue of a title (advanced practice nurse), however many stories indicated a lack of meaningful influence. One nurse stated “... if I have the languaging, I can almost elevate a nursing perspective to be appreciated,” and another indicated that, while afforded credibility in certain circumstances, it was not uniformly given by those in decision-making positions. In this analysis, statements nurses used to indicate ineffectual communication with physicians included: “falling on deaf ears” or “he'll listen to what I have to say and then he'll say ‘thank you!’ and walk away.” As Kälvemark and colleagues (2004) indicated, hierarchy and influence can occur with individuals in the same group.

This study further found that nurses actions, at times, were based on influences communicated to them from other nurses. For example, Morgana stated, “this is a really good nurse most of the time ... this sort of information that was passed along that this boy is manipulative, and so she was acting on that premise – that he was manipulative. And so, she didn't believe that he was telling the truth and consequently when it all went to heck in a handbasket, she wasn't quite prepared for the emergency that ensued”. As Gill (2005) indicated, there exists a stark inverse relationship between decision-making influence and the amount of time spent with the patient, which speaks to the role and positioning of the nurse. In this secondary analysis, Dara indicated the difficulties of navigating this positioning when interpreting physician messaging to the parents, having stated it “... becomes very hard for me as a member of that team to try and explain to families no, they're saying the same thing, but they're saying it differently”.

In addition to a substantial lack of influence in decision-making, participants indicated specific elements related to the intention of decided treatment that was morally distressing. This is a notable find in this study as it identifies and presents a slightly more detailed and categorical understanding behind distresses related to the decision-making process from a nursing perspective. This study uncovered situations related to the intention of treatment of a dying child as being involved in the experience or emergence of moral distress. These situations included: decisions of escalation or de-escalation of life-sustaining care, length of time for decisions, prolonged patient stays in PICU, expectations of prognosis, short-term and long-term patient outcomes, and uncovering the reasonings behind the decisions.

To explain the impact of escalating or maintaining high-level treatment, Lorella remarked, “he'd sort of been failing for a few days, and it was a major cardiac arrest. Major. We did CPR for over 45 minutes, and they were going to cannulate him for ECMO, and we were all like, ‘you can't do this’. That kind of just finished me”. In a time of quick decision-making, Oka indicated a failure to communicate with the parents, “she came out of heart surgery unstable, she was unstable for two days, and then she arrested. She went on ECMO, which was something that the parents were already like, whoa what is happening here? They did not consent.” From the alternate perspective, a time where de-escalation was intended included “very early on in his episode, there was significant difficulties and physicians wishing as a group [in] being firm that we should withdraw treatment on this child. And family's actually going to a lawyer to preclude us from doing that” (Dara).

The length of time for decisions to be made varied between waiting too long or not waiting long enough depending on the patient's condition. For example, “I think that if they had waited three or four days without doing the surgery, it would have been clearer to them that surgery wasn't going to produce the end goal that they expected” (Mieve) compared with “I felt they were waiting for nephrology to be [the bad guys]. That they'll say, ‘no, he can't have a kidney transplant', when they probably knew months ago that the chances of him getting, of being successful, were almost zero" (Lorella). In addition to reaching a decision, nurses indicated witnessing patient suffering during this time as a source of distress, ultimately pointing to an often-cited reason for moral distress: a prolonged stay.

Prolonged stays resulting in death have been discussed in the literature in terms of what onlookers and patients describe as a "good death" or a "bad death," with prolonged stays often indicating a bad death. The expected prognosis was mostly described by nurses in this study to be related to life, death or quality of life. Nurses described having a burden of knowledge, perhaps beyond the parents, of the quality of life a child may have during treatment as indicated by statements of: "the child they brought in is not the child they're going to be taking home" or "he never made it to the unit, that part of him was long gone before he got to us. All we were doing was caring for his body".

Similarly, questions arose around focusing on short-term outcomes or long-term outcomes. Genrah stated, "there are things we do that hurt are necessary, and I don't have a problem with doing those if the end result is going to be a good one. You know, we will get this child back to some semblance of what their life was like before. But if we're just doing it because they're not ready to sign the death certificate, that's wrong". Similarly, "they (parents) think about what has happened and do not just see the baby now. *Now* you can take care of her, but they also look at 5, 10 years down the road, and what is life going to be for her" (Oka).

Conclusively, participants indicated some reasonings (given, interpreted, or partial) behind certain decisions in an effort to understand the intention of treatment. Kethra stated, "sometimes they (the family) never resolves it, and then they end up traching the child and, you know, leaving them [like that] forever," and Lorella recounted, "everywhere else had turned her down and said she was not a candidate for this ...but, of course at our institution ‘no one gets turned away’”. Though these reasons certainly give guidance to understanding why decisions have been made, nurses here are perhaps indicating, for example, areas where best interests of the family and patient may be reconciled or a friction in the culture of “taking in” patients that have been refused care elsewhere due to the severity of their condition. Whereas reasonings such as “well this is really not an appropriate time right now because we don't know what is going to happen” (Oka) may point more to a communication of rationale between the physician and nurse. Uncovering and gaining insight into the reasons behind decisions that are involved in morally distressing situations may be an important key step for future mitigation techniques. This will be described further in the future research section.

Brown (2019) described decision-making as a form of ritual. This author stated that “while any one *decision* may conclude in a single moment for the patient – for instance, the moment in which the patient swallows a pill or a nurse administers an infusion – *decision-making*, like a ritual, is precisely the opposite. It is a process, one that naturally involves many people: a family and a health-care team coming together as a community” (p. 307). Brown further indicated that, while every end-of-life situation is unique in its own respects, most clinicians follow a similar script from experiences and influences of facilitating previous end-of-life discussions. This is a method of decision-making, one which involves the team and family as a community strikes significant similarities with what is being called for by the nurses in this secondary analysis. Indeed, Austin (2012) stated safe healthcare environments, ultimately moral communities, where ethical action is supported, and “messy” ethical questions can be discussed, is essential for creating a morally habitable environment and lowering the rising risk of moral distress. As Brown (2019) indicated, clinicians facilitating an end-of-life process possess previous experiences, experiences that nurses from this study are recommending be opened to the bedside nurses for help understanding reasonings and feel more connected with the decision-making process. Truly, what is being described here is a foundational element of relational ethics: relational engagement. Relational engagement indicates a shared moment in which individuals are able to find new ways of viewing something together; as Bergum and Dossetor (2005) stated: “there is power in the experience of people who have very different experiences coming to understand something together” (p. 103).

As a final note to this section, of relational dynamics with others, nurses in this secondary analysis indicated recommendations for change. As emerged from the transcripts, fundamental needs that would benefit from targeted change include valuing and increasing the weight of and openness to nursing voices from the physician team and nursing management alike, communicating rationales behind decision-making, and affording nurses an environment where ethical questions, stemming from all areas (including nurse-nurse dynamics) can be safely discussed. Indeed, Lamiani, Borghi, and Argentero (2017) found moral distress was correlated with low levels of autonomy both in terms of knowledge and action and was additionally associated with low levels of structural empowerment (the ability to access sources of power) and low levels of psychological empowerment. While supports for nurses in this secondary analysis were found in colleagues, friends, and family as well as individual-based coping strategies, such as writing or burning a candle, recommendations to mitigate moral distress were found through what would be helpful in the future or to maintain and what barriers existed to overcome for future change in the healthcare environment.

In terms of nurse-physician dynamics, the physician team achieving a unified voice was found as helpful for messaging with the family, in addition to being able to approach a decision-maker with questions or concerns, including rationale. A lack of a unified voice was also found as a challenge by Burton and colleagues (2020). One nurse in this secondary analysis indicated qualities of a physician with whom she experienced significantly less moral distress that summarizes many key helpful features including communication, nursing influence, approachability, and providing rationale; the nurse stated:

> He's very detail-oriented, and he likes to leave his emotions out of it. And when he says something in a family meeting, I know that he has looked at it from every possible angle, and this is the right thing to do because he is probably the most ethical person on the unit. I respect his judgement. There are other times when he is involved in a case where he's quite willing to look at his own errors in judgment and say, “yeah, I really did mess that one up”. It would be safe to point things out to him if you wanted. I know he hears me when I speak my mind. I know that if he disagrees with me, he's got very good reasons for it and will be able to tell me what his reasons are and that they're usually not emotionally fixed. That they're coming from a place where the best interest of the child is being examined. And I know that if he says, “this is what we have to do”, that he really as looked at it from the best interests of the child ... and of the family as well. (Genrah)

When considering changes related to management, one nurse stated, “walk in my shoes for a few shifts. Do what I do. Listen to the families say the things that they say to me, the questions that they ask me” (Genrah). Wall, Austin, and Garros (2016) noted that a well-functioning team can be an important source of support.

To achieve support, participants indicated strategies for change including mentorship programs for newer staff (formal or otherwise), ethics committee involvement, and access to morbidity and mortality (M&M) rounds where questions may be answered in full to avoid situations where “you're still left walking out of there, not really sure what happened”. Many nurses indicated debriefings sessions had been helpful; however, participants found they occurred too infrequently, if ever, or too far after the incident to be effective. Similar strategies were indicated by Burton and colleagues (2020), who also indicated clear areas of opportunity for understanding and change in terms of targeted informal and formal support and education.

In terms of preventing, mitigating, and resolving experiences of moral distress, barriers included the availability and use of technology in the PICU, busyness and resource shortages (bed and nursing), cultural hierarchal power structures impacting communication and decision-making capabilities, and the perceived or real repercussions to nurses presenting differing opinions or questions regarding care pathways. All nurses indicated a degree of potential fallout from physicians and nursing management. Lorella stated “you would just get the feeling from the staff guys and also from nursing management, from the manager and also higher up, that that was not the thing to do.” Comparatively, another seasoned nurse described approaching a unit manager:

> I said “you know, you have to accept that he's being abused by us. This is our own people that are abusing this child, and he is just so vulnerable, and you have to do something. You have to accept that it's happening”. So, her and my relationship fell apart. Completely fell apart. To a place where I couldn't even work with her. You know, it was so adversarial. (Morgana)

Similarly, Genrah summarized concern for professional repercussions, and when approaching administration can go “badly for you”, recounting when a manager stated:

> “... you need to come down to the office right now. We need to talk about this. You're being insubordinate”. Or one of our managers actually used to stand in the middle of the

> unit and yell “how dare you question my authority. I made this decision, and that is the way it's going to be. You will do what you're told”. Or it will be more subtle. You get the really nasty assignments for shift after shift after shift. And, you don't want to come into work anymore because you know what's going to be waiting for you for some people it's the chronic patients in an isolation room for other people it's the really sick patients that they get the same level of acuity shift after shift after shift and you don't get a chance to breathe, it really depends on the individual. Or you find yourself being passed over for new experiences and education and the chance to grow because you stepped on somebody's toes. (Genrah)

These findings align with a similar analysis pertaining to organizational influences on health professionals' experiences of moral distress in PICUs. In this 2016 study, necessities for ethical practice and the resolution of moral distress across various health disciplines were management support, adequate staffing and resources, inclusive and respectful teamwork, and support for debriefing and discussion, along with sound and flexible policies and procedures (Wall, Austin, & Garros, 2016).

Suggestions for Future Research

From this analysis, suggestions for future research revolve primarily around the inner state of nursing and the relational dynamics with others. This study has provided insight into two important areas of the experience of moral distress: the individuals’ feelings throughout patient trajectories with accompanied reasons as well as the intentions of treatment during decision-making. These two areas are described below in terms of their application for future study.

Inner State

Clearly delineating when the time feelings arise and the reasonings behind them will likely prove useful for prevention and intervention techniques of moral distress. For example, this analysis shows that feelings of regret can transpire from distinct reasons. While one nurse described regret because medicine and healthcare “can't fix everything”, another points to a lack of influence in decision-making or voice in communication when stating “often I wish I had done more or said more. Maybe if I'd stamped my feet and shouted and totally refused, then maybe something might have been done. I don't know”. When considering how to prevent or address these feelings, the underlying situation must be considered for the intervention to be as tailored and effective as possible. An intervention tailored to the first regret may surround the culture of the PICU's “rule of rescue” or how death is conceptualized among child patients. Conversely, the second regret could target strategies involving interpersonal dynamics and change how concerns can be effectively conveyed in real-time. Importantly, discussing feelings experienced in morally distressing situations is not for the purpose to consider these individuals as psychologically distressed or “in need of a break”, but rather to highlight these manifestations as an “expression of an alarm signal when a conscientious person is required to practice in challenging contexts” (p. 885); an important paradigm shift Garros, Austin, and Carnevale (2015) stated needs to be recognized.

Relational Dimensions of End-of-Life Care

As Ganesan and Hoehn (2014) indicated, the transition from heroic measures to withdraw or non-escalation of care is difficult to navigate. In this secondary analysis, the purpose of discussing the intentions of treatment during end-of-life care in such detail is not to minimize the conflicting pressures clinicians face or place blame; rather, it is to better understand the decision-making process from a nursing perspective, as indicated by patterns throughout their stories. The reason this is important since it highlights areas where there is likely a gap in conveying and understanding rationale. This understanding is perhaps an area of target for intervention strategies or future study: to explore why rationale may not be conveyed to nursing staff in a meaningful way, professionals who are indispensably involved in implementing these treatments, or how it may be improved.

In a study by Kälvemark and colleagues (2004), doctor and nurse value conflicts were explored. In end-of-life situations, a physician stated, “we have heard nurses, I think, quite often express that they think it happens too often that resuscitation is provided too long and that we don't decide early enough that this is not a thing we should do. I think we are keener on trying some more. We see the patients more as medical objects” conversely, the nurse stated, “you give intensive care to patients that are very old, they can be almost 100. And then you do everything. They can't be allowed to die, so to speak, a natural death, but you keep them alive as long as possible. And why?” (p. 1081). While this study was conducted in Sweden and did not necessarily focus on the pediatric population, it provides insight into the tensions surrounding intentions of treatment from both a nursing and physician perspective, a feature this secondary analysis does not offer. As seen with participants from this secondary analysis, substantial questions exist around practitioners understanding the reasons behind decisions as well as the rationales themselves. When reasons were effectively communicated, distress perhaps occurred more from a value difference position between the two professions, which may indicate different interventions beyond strengthening communication. Dara provided a summary statement that was echoed by many participants: “I believe we all have a different paradigm in how we look at it. And so, it’s relevant for me to hear the discussion from other perspectives so that I can feel comfortable in my own understanding. And I think that tends to make me feel less confused or less uneasy about something if I’m aware of what all the other conversations have been”.

In conclusion, considering the outer state, the inner state of embodiment, and the dynamics with others, nurses are in a position to experience the burden of moral responsibilities intensely and with great effect to their inner state. This secondary analysis highlighted various feelings throughout the patient trajectory along with their reasonings; an additional notable contribution was the reimagination of distress related to decision-making in terms of the intention of treatment. Both of these findings have implications for practice in more precisely identifying reasons for moral distress and in tailoring prevention or intervention strategies. Finally, the notion of individuals holding different opinions is one that has been discussed by many scholars from various disciplines and was found threaded throughout all narratives in this study. This will be discussed in the following section of implication for practice.

A significant limitation of this study is the time that has passed between this secondary analysis and the original study. Authors Austin et al. conducted this research in 2006, therefore technologies and processes may have since changed in the PICU. Promisingly, the results of this analysis are well aligned with current research, including systematic reviews of moral distress or experiences in NICU/PICU nurses completed in 2017, 2018, and 2019. Additionally, this analysis was limited to the Canadian context. As mentioned above, the study by Fachini, Scrigni, and Lima (2017) was conducted in the South of Brazil with PICU workers; while feelings related to situations of moral distress were well aligned with this secondary analysis, the access to technologies and use of processes were quite different. Therefore, expanding similar research beyond the Canadian borders may be a consideration in future studies. A final notable limitation of this study is the missed perspectives from other health disciplines. While the interpretation of others' roles holds great value in understanding individuals' perspectives, narratives directly given by others would also provide benefit.

Implications for Practice

The study highlighted that registered nurses navigate the care of dying children by guidance of their professional positioning within the PICU context as well as how they hang as an individual amongst others. The final and overarching theme emerged from this study is the notion of differing opinions, perceptions, and perspectives among the individuals who make up the healthcare team; evidence of this has been eluded to in the discussion section above. These differences were found evidently woven throughout dominant themes of decision-making and communication as well as threaded through others; for example, in considering the PICU context, nurses indicated times where the mantras and dictums of the "rule of rescue" clearly misaligned with their own perspectives. Further still, nurses commonly indicated "short staffing" as a source of moral distress and an area to target yet, perhaps from a system standpoint, short staffing may not be considered necessary to address if adequate care is still being provided. Kethra reflected this sentiment by noting, "... sometimes we're put in situations that we shouldn't be. Often it comes down to staffing. Often it comes down to, you know, different peoples' opinions of how things should be done". Ultimately, individuals holding differing opinions, perceptions, and perspectives from others shows to be a foundational feature associated to moral distress.

In essence, a significant portion of the moral distress experience related to the death and dying of children has emerged to be relational in nature. Richard Taylor (2000) described this relational nature between rational and conative beings to explain that all moral distinctions, including what is good and evil or right and wrong, are based entirely on facts concerning human nature. In his text, all beings are described as both rational and conative, meaning people have needs, desires, and goals; they pursue ends and satisfy wants by various means. Taylor (2000) argued against the notion that "some things are just naturally good and others bad, and some actions right and some wrong" (p. 164) and that the true nature of goodness and rightness simply needs discovering. He explained this by imaging a world that contained just one sentient being; the things that this being finds good are what satisfies their needs, whereas those that are frustrating are bad. This being, indeed, is the measure of all things good and bad. Taylor (2000) also argued here that there exists no moral obligation, that the distinction between right and wrong are not yet in the picture; the author questioned, "... by what standard, other than good and evil themselves, over which he is the sole judge, could any action of his be deemed right or wrong?"

This, however, changes, with the introduction of another being. With multiplicity and plurality of beings, wills, aims and purposes can conflict, resulting in subsequent evils, as well as coincide for cooperation, a consequent good. Importantly, Taylor (2000) stated that the modes of behaviour required for cooperation and conflict resolution become teachings passed on through generations that transform into rules embodied by a tradition or culture. Taylor (2000) declared that the notions of right and wrong absolutely presuppose the existence of rules. Plainly, a moral right is an adherence to rule, and a moral wrong is a violation of it. To be clear, the author indicated the term rule may not need to be formulated or embodied in code, rather it is simply a regular mode of behaviour. An example here is extending ones' forearm palm and hand exposed when approaching another being, thus indicating that they are unarmed. The obvious purpose is the avoidance of evil and advancement of good; this would be deceitfully violated if one being assaulted the other with a weapon concealed in the other hand, thereby “using the rule to promote the very evil the rule was meant to avoid” (p. 174).

This prelude is important for current practice because it shows that individuals have different conceptions around the fundamentals of right and wrong, indicating a much more profound “difference of opinion” than, for example, two individuals discussing the best technique to insert an intravenous line. In describing ethics in organizations, Lützén and Kvist (2012) stated the individualistic view of each person being morally responsible for their own behaviour is most often used. Thus, interventions focus on the individual health care provider. This, however, presupposes that individuals have complete control of relations that influence their behaviour and that their moral actions must, in a sense, align themselves to the “party line” of the organization without opportunity for raising “messy ethical questions,” as termed by Austin (2012). This additionally presupposes that the “rules” and culture of the organization do, in fact, aim for goodness and cooperation.

To better understand health professional behaviours and experiences within the organization, the current state of healthcare culture will be examined. Austin (2012) argued that the increase of moral distress experienced by said individuals results from a shift of focus from patients and families to the organization itself. Indeed, an ethnographic study by Rankin and Campbell (2006) found the primary commitment for nurses is now expected to be the healthcare organization and that the patients, families, and staff were found to have become objects for administrative handling towards achieving the best interests of the organization. Austin (2012) indicated this radical reframing has been occurring since the mid-'90s with the introduction of corporatism dominant strategies of rationing, streamlining, and efficiency measuring. Austin

(2012) noted, “it is particularly paradoxical that Canadian health care, a tax-based, publically-funded system is being restructured in the image of a marketplace and being *McDonaldized*” (p. 35).

From a different, albeit similarly bleak perspective, philosopher Ivan Illich described the state of modern medicine, or iatrogenesis (doctor-made), in his book Medical Nemesis: The Expropriation of Health (1976). In following Austin's (2012) described corporatization effects on the healthcare institution, Illich (1976) speaks of “social iatrogenesis,” meaning that health impairments result from the socio-economic transformations that the healthcare institution has taken. The author stated that social iatrogenesis is “at work” when healthcare becomes a standardized item. In this instance, suffering is “hospitalized” or when homes become inhospitable to sickness and death. To understand how the social implications of the current state of medical organization apply to this study, Illich (1976) poignantly stated “When cities are built around vehicles, they devalue human feet ... when hospitals draft all those who are in critical condition, they impose on society a new form of dying”. The distress indicated by the participants in this secondary analysis is likely tightly bound to the perils of navigating this new form of dying in a corporatizing system. And, as with any growing industry, products of the healthcare system are directed towards the often-sought demand of the defence against death. In considering a cultural orientation towards death, Illich (1976) noted that people believe hospitalization will reduce their pain or increase longevity, yet neither is likely to be true. The author indicated that each culture creates meaning of health and attitudes towards pain, disease, and death, thereby guiding behaviours towards what is known as “the art of suffering.” The standardization of health does not allow for individuals to behave by or experience the most traditional methods of healing, of suffering, and of dying as taught through their cultures.

Behaviour in dealing with pain, for example, could be culturally modelled through the Buddha, the warrior, or the victim, and draws attention from the sensation to the act of duty to suffer by this guise/model or to manage with dignity. However, medicalization deprives cultural integration in addressing pain and renders the “art of suffering” as an idea that has become shocking and incomprehensible.

In terms of death, Illich (1976) indicated a new (relatively) widespread value placed on a child's life with a disvalue of their death regardless of their bodily strength or abnormalities. This is echoed by current PICU mantras and dictums, including “the rule of rescue” and “do absolutely everything”. The author further considered the evolution of natural death and, ultimately, the medicalization and struggle against death throughout the ages. I will not delve into the grand history here, for the sake of my committee members. Most importantly, for this discussion, death under intensive care is the most recent and topical portion of history. Illich (1976) indicated that the practice of medicine, like all major rituals of industrial society, takes the form of a game in which the chief function of the physician becomes the umpire. With this duty, the physician ensures all players behave according to the rules, which include leaving the game and dying in any fashion that has not been specified. This example strikes significant parallels to Richard Taylor’s (2000) description and implication of rules in terms of what is morally right and wrong. While Illich’s (1976) example here may surfacely be read that the physician enforces the rules, I emphasize here the critically important institutional and healthcare organizational roles in determining what rules must be followed and how healthcare professionals may play the game.

By considering the healthcare culture and context, we may now return to the notion of individuals navigating such an environment where perspectives, practices, and mantras may differ from their own. The intention of exploring the current state of healthcare is in no way to demonize those who work within the higher institution; I understand the magnitude of time and effort needed to spark minute changes in societal and organizational direction. I point this out simply to help understand that the individuals inside the organization live and work amongst many influences that affect experiences and behaviours, influences that may not be taken into account or fully understood when considering how to prevent and address moral distress. What I believe may be the most clinically relevant findings of this study are the relationality of individuals, inclusive of their environment and the necessity for better communication of our differing needs, desires, and goals, as described by Taylor (2000). Indeed, in his descriptions about the human experience of communication Macke (2015) noted, “human relations do not occur in a context of ‘no context’” (p. 49).

Many participants in this study indicated times of failure to communicate, such as describing a lack of credibility or influence. For example, when a seasoned nurse recounted:

> I honestly felt that we were not managing pain well on a particular [patient]. I was totally disagreed with. I had already gone over the top of the fellow and spoken directly to the Staff Manager. This didn't solve the issue. It wasn't of course, I was complaining about it all evening, all night, right through the night and it wasn't until the Staff Manager came back the following morning and actually spent some time in the room and saw what was happening that it was resolved. (Kethra)

An important implication for practice is that communication involves both the manners in which individuals connect as well as the attachment to one another. Macke (2015) argued that the experience of human communication is fundamentally an embodied event of bonding, connecting, and holding. Most often, communication is solely understood as sending and receiving messages and is about creating intelligent points or influencing people. Macke (2015) argued that although communication does involve dynamics of talk and dialogue, disagreement and persuasion, the study of communication emphasizes that it is "the *relationship* that *defines* the participants *in their interaction*" (p. 210). He summarized, "the relationship is the *form* of human connection, and the form of human relationship is narrative" (p. 15). This author contended that it is in this relationship that connection resides and, regardless of what is said, importance lies in elements such as who has the last word and what is the status of the relationship before and after exchanges. What is being described here helps explain what participants had depicted as barriers of communication at a more profound level, notably that the lack of communication is not simply a gap of exchanged knowledge; rather may, in this instance, indicate the underlying relationship health or status between the individuals. Ultimately, to understand these barriers in communication, it is important to both explore what knowledge is being transferred and the relationship of the communicators.

As previously mentioned, ethics-based interventions originating from organizations are most often targeted toward the individual. The findings of this secondary analysis show experiences of moral distress most often occur by being in some type of relation to others or to the environment. This indicates a need for interventions to be tailored less towards the sole individual rather towards how relationships are being made and maintained with others and the organization along with an emphasis on communication. For example, interventions that simply call for nurses to be courageous in finding their voice discount the influences faced by any individual in a healthcare institution in addition to negating the relational engagement piece of communication. As an important note, Deschenes and colleagues (2020) stated that internal characteristics of the individual may predispose or contribute to the occurrence of moral distress, for example, with nurses who have lesser knowledge or experience facing certain situations that require a moral decision. What I am suggesting here is that while personal development may mitigate certain scenarios, a significant part of morally distressing experiences come from relationships with each other. Even with an example of a nurse having lesser knowledge, such as in PICU, as we have seen through this analysis, an appropriate intervention might include mentorship rather than waiting for the individual to "gain more knowledge" alone.

The general experiences and overall perspectives of the PICU nurses reported in this study align well with the existing body of literature on moral distress in high acuity areas, thereby contributing to the overall theoretical development and crystallization of knowledge in this area. Uniquely, this secondary analysis magnified elements specific to the end of life process to help understand the experiences of this often-cited reason for moral distress. This study has found that nurses caring for dying child patients in Canadian PICUs face varying challenges that have been shown to lead to experiences of moral distress. As one nurse indicated, "there's many sides to [moral distress]. There's not just one face; there are many faces". Going forward, it is imperative to create an ethical environment where collaboration can flourish, where rules of the "game" or context may be safely questioned, and where individuals, who hold varying needs, desires, and goals, can come together as a moral community based on a strong foundation of relational engagement and mutual respect.

"Nothing clears up a case so much as stating it to another person." – Sir Arthur Conan Doyle, The Memoirs of Sherlock Holmes: Silver Blaze

Glossary

Code: Code Blue. An emergency situation in which a patient is in cardiopulmonary arrest, requiring a team of providers to begin immediate resuscitative efforts.

ECLS: Extracorporeal Life Support. Life support that typically involves the continuous extracorporeal oxygenation of blood pumped from the body. It is the use of a modified heart-lung machine used when a patient is experiencing cardiac or pulmonary failure unresponsive to conventional therapies such as mechanical ventilation.

ECMO: Extracorporeal Membrane Oxygenator. A treatment that uses a pump to circulate blood through an artificial lung back into the bloodstream of a very ill baby. This system provides heart-lung bypass support outside of the baby's body. It may help support a child who is awaiting a heart or lung transplant.

Epi: Epinephrine. A medication used as emergency treatment to increase low blood pressure by causing direct vasoconstriction thereby improving perfusion pressure to the brain and heart. Is also used for life-threatening allergic reactions.

Moral Distress: “When one nurse knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action” (Jameton, 1984, p. 6)

Moral Dilemma: “Arise when there are equally compelling reasons for and against two or more possible courses of action, and where choosing one course of action means that something else is relinquished or let go. An ethical dilemma is a particular type of ethical problem.” (CNA, 2017, p. 6)

Moral Disengagement: “Can occur when nurses normalize the disregard of their ethical commitments. A nurse may then become apathetic or disengaged to the point of being unkind, non-compassionate or even cruel to other health-care providers and persons receiving care." (CNA, 2017, p. 6)

Moral Injury: Refers to unprecedented traumatic life events related to committing, failing to prevent, or bearing witness to actions that violate one's core moral beliefs and expectations, such as seen with violence and death-related incidents. (Papazoglou & Chopko, 2017)

Moral Responsibility: "Indicates that a person has some duty or obligation—some *responsibility*—to which that person is required, by some standard, to attend ... [and] a person bears the right relation to her own actions, and their consequences, so as to be properly held accountable for them." (Talbert, 2019)

Moral Sensitivity: "A process by which a person becomes aware of the existence of ethical problems, interprets a situation and decides what options are viable." (Lützén & Kvist, 2012, p. 20)

Moral Schism: A genuine uncertainty or internal struggle regarding a value-based decision that is accompanied by emotional distress and is unrelated to barriers as is found with moral distress. May be seen with parents of ill children. (Foe, Hellmann & Greenberg, 2018)

Moral Thinking: "The point of thinking in moral terms in the first place isn't to discover some facts about the universe, but to get ourselves to act in ways that allow us to live together and reap the benefits of cooperation" (Kauppinen, 2014)

Morbidity and Mortality (M&M) Rounds: Recurring conferences or meetings held by medical services at academic medical centers and most large private medical/surgical practices. The objectives of a well-run M&M conference are to identify adverse outcomes associated with medical error, to modify behavior and judgment based on previous experiences, and to prevent repetition of errors leading to complications.

They/Their: Used in the Methods section for descriptions of the participants. This pronoun was chosen as a singular pronoun since neither the gender nor how the participants personally identify was known.

Trached: Tracheostomy. A surgical procedure to create an opening through the neck into the trachea (windpipe). A tube is most often placed through this opening to provide an airway and to remove secretions from the lungs. This tube is called a tracheostomy tube or trach tube.

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Appendix A. Themes Table

PICU Context	Nurse Positioning	Feelings Around Dying and Death	Greatest Nursing Concerns for Dying Patients	Decision-Making Power	Communication and Messaging	Stated Supports for Nurses	Recommdenations for Changes	Differing Opinions, Perspectives, and Perceptions
Terminology	Experience Level	**During Patient Trajectory, Milestone Points**	Quality of Life	Decider	Messaging Between Physicians and Family	Non-Supports	To Make Change	Personal Perspective vs PICU Perspective
Pain Control	Burden of Knowledge	At Times of Decision Making	Best Interest	Burden of Knowledge	Information Sharing Among the Team	PICU Supports	**Helpful**	Amongst and Between Individuals and Groups
Technology	Direct Care Provider	At Time of Withdrawal	Dignity	**Intention of Treatment**	Where Converstaions Occur	Personal Supports/Coping	Debriefings	
Mantras/Adages/ Dictums	**Role**	At Time of Death	**Good Death and "Not Good Death"**	Escalation and De-escalation	Parents Who Revisit PICU Post Death		**Barriers**	
Structure	Supporting Patients and Families	During Actions	Good Death	Length of Time	**Nurse Voices**		Communication	
Environment	Attend Family Conferences	When Supporting Others	"Not Good Death"	Prolonged Stay	Being Heard		PICU Context and Relational Dynamics	
Normal Process	Professional Responsibilities	**Impacts or Consequences Post Trajectory**	**Right and Wrong**	Reasonings	Not Being Heard/Not Being Vocal		Repercussions and Fallout	
	Enable Good Death	Psychological, Emotional, Physical	Right	Expectations	Actions of Nurses Communicating			
	Mentoring	Professional	Wrong or "Not Right"	Short-term Outcomes and Long-term Outcomes	Reactions of Nurses Communicating			
		Bearing Witness	Unknown or Both	**Nurses and Decision-Making**				
		To Patient Suffering		Decision Making Influence				
		To Parental Suffering		No Decision Making Influence				
		To Frustrations of Other Nurses						

Appendix B. Detailed Themes Table

Moral Distress in PICU Nurses Related to Death and Dying

PICU Context
Culture/Reality/Healthcare Ethos

Terminology

- Nursing use: “I tend not to use the word dying, that's probably my own comfort level”
- Dying: “very, very sick; very, very ill; was not going to survive; heading down; lungs were horrible, horrible; he was crummy, crummy, crummy”
- Palliation: parental understanding that their child would be abandoned, starved, would receive poor quality of care; parent called palliative team member doctor death
- Rescued: implies some quality of life afterwards, not being in a vegetative state

Pain Control

- Manage well, but not totally; patient already in pain by the time we give extra drugs; unknown pain during resuscitations, but some believe it would hurt
- Type of diagnosis impacts pain control (hyperaesthesia)
- Patient management: good day was when there wasn't hurt; not good day was terrible amounts of pain, tried to keep patient drugged but they ached all over

Technology

- Advancements led to more treatment option, availability
- New era of decision making with technology
- PICU is more than drips and machines (is supportive family care)

Mantras/Adages/Dictums

- Not every child will live through PICU trajectory, medicine can't fix everything
- “Supposed to save them, but we can't save them all”
- Children: less comorbidities/less chronic, get well faster or they die; months long stays don't fit our PICU model of what should happen
- PICU: try everything until there is absolutely no hope for anything else
- “We work in the mindset that they're children and we can't let them die. We all die, and it

might be in the child's best interest

Structure (among staff/hierarchy)

- No real sense of team anymore (lost sense of team)
- Very much "us versus them"
- Decisions made by powers much higher than frontline
- Physicians have pressure to let parents make decisions even when they know how it will play out

Environment

- Nursing shortage and bed shortage
- Busyness/No Time: unit and individual assignments (including busy doubles); unit is so pushed, there is no time to resolve issues, reflect on what happened, to sit down (go from bundling up the child, to the morgue, and immediately receive an admission)
- No rules anymore: beds are filled with kids who do not need to be there anymore, need to go somewhere else; feelings of secret agendas and political connections (who is admitted/discharged)
- Very scary environment: for family and new staff (big hoses in little kids). We have skills and equipment here for emergency situations

Normal process

- Give family time to come around/resolve it
- Sometimes family never resolves it, "end up traching the child and leaving them there forever"

Nurse Positioning

Experience level

- Novice/new to PICU: have hard time letting go (less experience with length patient stays, established relationships with family); thrown into complex situations nursing, psychological, spiritual wise (not given tools needed); struggle with not being heard; newer staff seem to have rose coloured glasses (thinking patient might recover)

- Seasoned: helped shift focus for newer nurses from prolonging life to supporting family; “can handle an assignment that maybe someone else can't”; afforded credibility (mentoring nurses, residents, relied upon by intensivists); opinions still “fall on deaf ears”; confident in knowing the patient will not be okay, will not make it; grieves differently with experience and time

Power/hierarchy

- Dynamics: discussions (physician meetings) not shared with nurses or other HCPs; “I play along with their games because it's a battle that you're never going to win. I know I'm not going to win because I don't have enough clout, I'm down at the feeder level”
- Repercussions: if nurse calls ethics (from physicians and higher nursing), get the feeling that was not the thing to do

Burden of knowledge

- Suffering: diagnosis (hyperaesthesia) causes pain (parents believe patient simply responding to stimulus)
- Outcomes: knew “what was going to come” (“patient existing in bed, untold suffering for family”); felt patient would not survive surgery (legal apprehended patient from parents, surgery performed, patient died 2 days later); clear to nurses patient wasn't going to survive (being “at bedside for every failed ventilation trial”)

Direct care provider

- Burden/duty/strain: stated cause of moral distress; “parents can invest an incredible amount of confidence and comfort in bedside nurse (huge burden for nurse to carry); busyness - have to admit right after returning from morgue (no time to resolve/reflect), have to be “on top” of new admission, “if you don't give complete attention you're going to make a mistake, you're already stressed from what happened before” (death)
- Proximity: communicates the most with family (attachment); becomes very close with parents (mother - had child the same age)

Subtheme: Role

- Have a different role (than other HCPs), “people think they should have the same say and don't realize that it's a different position, not so much that they are higher or lower on the scale, it is a different position”

Supporting patients and families

- How: by voicing differing opinions (even if parents are angry so parents feel they aren't the first to give up); explain messaging of physicians; “tears and crying are seen as a genuine sharing of their pain and concern, is a wonderful expression of humaneness”; having an awareness of how to interact with the family; support even those “who really push the limit with nurses (threaten your role, have professional judgment questioned”; support family to support their other children (often forgotten, all energy and time spent with ill child); “encouraged family to take part in care as much as they could even though they didn't have legal decision making capacity”; parents afraid because patient was so sick and would need technology to survive (were tech naïve); supported patient (and decision to continue with treatment) when other nurses didn't, “felt like I was the only one who cared for her”; support family when deciding to leave unit or not (“very fine line if something happens “that is a decision I can't make for you”)”
- What is: “supportive family care is what pediatric intensive care is, it's more than technology, drips, and machines”; make patients and families time a little bit easier; support the patient and families to best of my ability and not to be judgmental
- Effects: nurses that create safety for parents are highly skilled, articulate, competent, and have confidence; adequate information sharing, everyone feels respected, everyone gets the same message; helping to support the psychological impacts of parents (“coming to terms with what's happening”); very hard not to get attached (12 hours a day with child and parents for months); “parents either trust you or they don't, when they trust you they leave easier, they know you will call when you say you will”
- Loss of support/unable to support: “we couldn't comfort the mother after the patient death, she was totally hysterical, screaming, we couldn't do anything to comfort her (hold, hug her), there was a big wall we couldn't get through, she was by herself”; lost parental support (after

witnessing interactions with nurse who assumed patient was “manipulative” which resulted in respiratory arrest), fall out with other parents, parents not wanting to come forward because their child needs care and anticipated readmissions to PICU; “parents were very distressed every single day because staff judged these parents for not wanting extraordinary measures (thought they “wanted a perfect child”), parents thinking of long term outcomes”

Attend family conferences

- Reasons: established relationship with family; information sharing in report (nurse to nurse); bedside nurse of the child that day is involved in the family meetings

Professional responsibilities (stated)

- Communication: messaging between physicians and families; “can't go against physician for professional issues” (tell family nurses agree with them)
- Professionalism: “can't show anger” (tailoring emotions)

Enable a good death

- “Need to work towards the same goal, that's to provide the best outcomes for the patients we care for. If best outcome is to die, then that's what we need to provide them”

Mentoring

- Who: new staff, residents, relief upon by intensivists (seasoned, advanced practice nurse)
- Actions: “tell novices to “toughen up”, it's a terrible thing to say, but with technology 10 years ago those kids wouldn't have suffered because we couldn't do what we can today”; help shift focus of newer nurses from prolonging life to supporting family

Feelings Around Dying and Death

Subtheme: During Patient Trajectory, Milestone Points

At times of decision making

- Descriptors: tension; concern; “hair on the back of my neck goes up”; “this doesn’t feel right"; "part of me is shriveling up"; "awful feeling"; felt dishonest (on nursing part), difficult to "buy in" to family; very difficult; felt weren't being heard; angry; anxious

- Reasonings: "feel we failed the family by not tackling the physician and saying "what are you doing""; overhearing physician speak to family, "parents are going to be stuck with a scenario they didn't want because they were persuaded"; "we did this to them because we weren't able to interfere with the path that the physician went along"; family wishes feels unethical at times (level of interventions, requesting dialysis during peri-arrest phase, keeping alive for visible pulse); "felt dishonest that treatment could go on indefinitely, difficult to "buy in", smile and talk knowing parent would hate them because we couldn't save their child"; "it felt like nobody wanted to be the bad guy" (to withdraw); "I thought "you (patient) are suffering for your parents""; "becomes very hard to defend physicians decisions if it's not something you believe in, makes for tense atmosphere"; felt like couldn't go to unit manager about behaviour of other nurses who disagreed with decisions because it felt like reporting someone; "so much dissension on the unit, so much lack of understanding as to why we were taking so long to withdraw, nurses felt they weren't being heard, I felt mother needed time to say goodbye (physicians were listening to mom, nurses weren't)"; distress from prognosis/diagnosis, especially with preventable situations (hangings, child abuse); felt that the decision was totally unacceptable (move patient into room with isolation patient, because the patient who was moved was "going to die anyway", unable to argue against it, no time or wherewithal; "told family we don't feel like they're bad people, everyone has their own beliefs, we recognize that, that we are working in the larger belief system that we need to do everything

<u>At time of withdrawal</u>

- Descriptors: hard time "letting go"; felt so guilty (for continuing on and, sometimes, for ending too soon); extremely frustrated
- Reasonings: "know what was going to come, patient will exist in bed for a very long time, family will go through untold suffering"; "why would I want to take away those last days, what I might be to the family"

<u>At time of Death</u>

- Descriptors: regret; distress (because it is a death, not moral distress); sadness (not moral angst); haunting; relief (no suffering at time of death); very hard; very, very sad; go home crying; extremely stressful; "worst thing I had ever seen and experienced"
- Reasonings: regret (1) medicine and healthcare can't fix everything (2) family went through long protracted piece of time (3) interventions in last days were not pleasurable for patient; "felt we didn't give the patient and family proper care (busyness, isolation room); thank goodness she didn't suffer at time of death; "very hard when you're attached to child and family"; "it's like knowing the end of the movie, knowing what's going to happen, you just think "okay, I just hope I'm not there when it happens""; "should never have taken child away from family (apprehension), instead of enjoying this time, we took over, took that time away and made him suffer"; "it was extremely stressful as it was my baby (patient) and I feel it was my responsibility, it was totally out of my hands what happened and how it happened"; "most distressing - it was very irresponsible and the person who initiated the event said "well the baby would have died anyway", that was the worst thing I had ever seen and experienced", "couldn't clean the child nicely for the family, she kept bleeding no matter what we did"; feel the people I work with need to have a quick end and equate prolonging death with discomfort, agony, anything "esthetically unattractive is more difficult"

<u>During Actions</u>

- Descriptors: torturing patient; not giving proper care; wanted to say something (didn't have time or wherewithal); *don't feel that I'm contributing to their suffering; compounding stresses; -- Inability to act?: "feeling like I can't say what I'm feeling or what I know to the family" (torn about who to tell); difficult to "buy in" with parents, felt dishonest;
- Reasonings: didn't have time or wherewithal (to say something); *"yes, we do terrible things and whatever we do hurts them, but someone has to look after them"; by diagnosis (hyperaesthesia) touch and movement will cause pain and discomfort, will always be noxious; have to give complete attention to new admission right after returning from morgue (no time to resolve/reflect), already stressed from what's happened before, no time before you're starting with another; "can't say what I'm feeling to the family because it will be hurtful to family but I still feel I need to say it to someone; difficult to "buy in" with parents, fostering

moms idea that patient would survive a syndrome that is incompatible with long-term survival; feeling that “nurses can't call in ethics” (not the thing to do)

When Supporting Others

- Other nurses: discomfort (with other nurses not accepting decision to/time of withdrawal); charge nurse “felt really badly” for putting bedside nurse and family in a bad position; “tell novices to “toughen up”, it's a terrible thing to say, but with technology 10 years ago those kids wouldn't have suffered because we couldn't do what we can today”
- Patient: “I feel so bad for the patient, he (teenager) suffered, suffered, suffered, he's said numerous times he just wants to die, no one stands up for him, it's terrible what we’ve done, he has no more will to live you can tell in his eyes, it breaks my heart. It's just torture for that boy, parts of his body literally did rot away, it's not right to make them suffer so much”; when admitting patient after surgery, bedside had to leave room, surgeon had tears that looked like “what have I done” (gangrene, quadruple amputation - feelings from intervention)
- Family/parent: “as a novice, I would put myself in the position of the mother, now I know that what I imagine cannot be anything like what a parent must feel”; “difficult to be tactful and supportive when you're feeling threatened in your role (professional judgment); “told family their story was a very hard situation to be in and the physicians really thought they were doing the best that they thought they could; very hard to care for a patient and supervise parental visit when what happened could've been prevented “your kid doesn't need to be here, you did this”, had to be in room anyway but felt like a totally different situation

Subtheme: Impacts or Consequences Post Trajectory

Psychological, Emotional, Physical

- Closure/resolution: no sense of closure or ending once patient is transferred/off the unit; keeps me awake at night (unable to resolve it); I needed closure (it still haunts me); not given time to resolve or reflect on what happened (the effect is still there but can't always address it after the fact)
- Support (relational)/coping (relational, individual): not safe, unsupported to get angry afterwards (people will think you've become very emotional and can no longer be part of the conversation); second guessing self, questioning if something was missed or could have

prevented decline (think of what actions I could've done - shouted, stamped my feet, totally refused); “feeling powerless and like I can't say what I'm feeling, but still feel like I need to say it to someone”; “nurses involved who heard the story were horrified, couldn't believe we would do that to a family”; many people were upset, crying, calling each other at night about what happened and crying

- Regret?/anguish: I often wish I had done more; anguish over “the idea of continuing to do things that we know aren't going to provide the result we want”; part of me feels wrong for saying this but did we waste an organ on somebody that would have been better? Who had less issues, could be running around?;
- Lasting effects: keeps me awake at night; it still haunts me; impact probably less difficult than it was (1.5 years later); the effect is still there; sleep is affected; the helplessness is that I don't know what to do anymore (maybe try to teach other nurses about my experiences); bring it home (“plays over and over again, seeing the kid bleed out, like being in a puddle, that was what she was, she was a puddle of blood. That was just awful”); I remember doing my job and pushing the rest away until someone came to bedside and said “how are you doing” and that totally put me over the edge, “don’t talk to me right now” because it will make me cry and it doesn't go anywhere”

Professional

- Relationally (consequences): feelings and concerns not supported by some physicians and management; what made me want to quit (1) powerlessness to make influence felt by decision makers and management (2) powerlessness to be frank with the family; always concern that “if I say this, what will the repercussions be”; repercussions if nurse call in ethics (from higher nursing and medicine); it feels like there's secret agendas and political connections (about who is admitted to unit) (power structures/dynamics)
- Personally (impacts): felt close to quitting; new staff have very hard time with patients that die who they've become attached to, reason why many leave PICU; “that was the worst thing I had ever seen and experienced, if I was a newer nurse I would have quit”

Subtheme: Bearing Witness

To patient suffering

- Patient: known and unknown suffering; knowing patient outcomes but having to watch them suffer for months (“rot to death”); “teen suffered, suffered, and suffered. It's terrible what we've done, I feel so bad for him, it breaks my heart. It's just torture for that boy, parts of his body literally did rot away, it's not right to make them suffer so much”; “the boy held on for parents”; patient absolutely suffered, would turn red during suctioning/slight tube movements (heart rate would drop), lots of bagging and suctioning. So uncomfortable, already in pain by the time we give extra drugs”; “they tortured that boy because his parents could not let him go, it should have ended”

To parental suffering

- Decision making: parents being persuaded into something I know they didn't want, patient is still alive, which matters, but isn't what they signed up for (no connection to the world); unsafe, unprecedented, ultimately lethal event initiated by other staff member when nurse was supposed to be present, very frustrated because the death could've been prevented
- Intended outcome: the burden to the family; “burdens on the patient and family I don't think are worth it in some cases” (persistent vegetative states); “continuing to do things we know aren't going to provide the result we want” (unable to say what I'm feeling)

To frustrations of other nurses

- Care practices (lack of respect): cruel care practices (overheard anger come out from nurses, to bilateral leg amputee child “no you can't have pain medication, what are you going to do, are you going to get up and walk over here? (said by charge nurse, supposed leader on the unit); knowing patient could hear them say “let her die, she's a burden on the system” (she was at their mercy), struggled watching them leave her in the dark when she was terrified of the dark (hysterical in the morning), felt like I was the only one who care for her, others were judgmental); nurses refusing to care for patient because bilateral leg amputation (didn't feel they could stay in and care for a boy with legs like that, esthetically)
- Decisions made/pathway: seeing frustrations, anger from nurses who didn't agree with decision making plan, so judgmental, quick to hear them say “let her die, she's a burden on the system” knowing the patient could hear them; saw anger, frustration from nurses not comfortable with interventions, physicians decisions to not end care (even when patient

wanted to live); I felt moral distress in witnessing situations that caused moral distress to others

- Personal coping: it's really hard for me to be understanding of my co-workers need when I witness the behaviours; “I just want to scream if I hear one more time how tough their job is, be more respectful, be the kid in the bed, treat people with kindness and maybe your job won’t be so damn tough”; “I know it's right to treat every patient and family, no matter who they are, with the utmost respect. It's a privilege to be giving the best of caring for their children, it's an honour they trust you with the precious little being in their life. I struggle because people don't feel that way about people's children

Greatest Nursing Concerns for Dying Patients

<u>Quality of Life</u>

- Descriptors of quality of life: “not high level but able to enjoy life and bring joy to others” (did not believe patient would get that); connection to this world other than that he breathes; more than “existing in a bed; having connection to this world; some semblance of what their life was like before; there's a difference between a child breathing and a child living; he was loved and recognized his parents and brother; persistent vegetative state (now/low quality of life) - moaning when they're touched, crying during suctioning, that's their existence. How is that fair?; patients shouldn't have to declare themselves, should have dignity and some quality of life (even if it's palliation and shorter life, even if technology is available, patients and families deserve that

<u>Dignity</u>

- PICU interplay (rule of rescue)/avoiding death: during aggressive resuscitation of catastrophic injuries, patient probably not feeling ribs breaking/pain, but not sure. Thinking to family “how much more of this can you take? Do you really want to watch us do this again and again and again”; no one dies nicely in an ICU anymore, there should be dignity; patients shouldn't have to declare themselves, should have dignity and some quality of life (even if it's palliation and short life, even if technology is available)

Best Interest

Best interest (patient, family)

- Of patient: felt patient discomfort, pain, and anxiety was not in best interest of patient (parents felt differently); felt the 5 days we kept his pulse visible was not in his (patients best interest); “what distressed me most, the person who initiated the unsafe (and ultimately lethal event) was irresponsible and their reaction was “well the baby would have died anyways”, it doesn't matter, we are here to provide best care”
- Of family: need to give proper care (“horrified we would do that to a family”); involving legal (apprehensions) can be helpful, in this case it was not
- Both: true for (taken into account by) physicians when making decisions

Subtheme: Good Death and “Not Good Death”

Good Death

- Family: family choice to withdrawal (avoid prolonging discomfort)
- Patient: peaceful death (not so much suffering at the end)
- PICU interplay: appropriate physical environment and space (bereavement room); appropriate staffing ratios

“Not Good Death”

- Team planning/dynamics: unified decision (physician team) took too long; when child's death is not orchestrated (not enabled by team)
- Family: when family is in a horrible place; when “we've been unable to help the family”; family didn't get the support they wanted
- Patient: suffering until the end; no dignity
- PICU interplay: unnecessary physical barrier for parents (nursing shortage - child moved into room with isolated patient), parents having to wear PPE, limited number of visitors in room; no one dies nicely in an ICU anymore, we can make it happen but some kids don't have a very nice death in there, the kids deserve more than that

Subtheme: Right and Wrong

Right

- I know it's right to treat every patient and family, no matter who they are, with the utmost respect. It's a privilege to be giving the best of caring for their children, it's an honour they trust you with the most precious little being in their life

Wrong or “Not Right”

- Wrong: aggressive resuscitation is not a problem if will get back some semblance of life they had before, but if we're doing it because they're not ready to sign the death certificate, that's wrong; “I'm sure parents were told the patient would survive when she probably wasn't, that's wrong, morally wrong”; I think it's wrong, she should not have been a candidate for specific treatment/surgery (co-morbidities, pathologies, turned down by other health centers); part of me feels wrong for saying this but did we waste an organ on somebody that would have been better? Who had less issues, could be running around?; he was crummy, crummy, crummy, we thought what we did was so wrong
- Not right: “this doesn't feel right” (in a moral distressing situation); sometimes we don't give the care that we need to give, sometimes that's not right; they don't give us enough time to resolve issues to reflect what's happened (bundled to morgue to admission, not enough time to sit down, so pushed you're picking something up right away); it's just torture for that boy, parts of his body literally did rot away, it's not right to make them suffer so much; it wasn't right that they took away the child from the parents

Unknown or Both

- We've come far with technology, sometimes that's good, sometimes bad. I don't know right or wrong. Sometimes it's really not the best to save but how do I know which one is right or wrong? I don't know; just because we can with the technology, is it really the right thing to do?

Decision-Making Power

Decider (Who is?)

- Families/parents: sometimes “find it impossible to consider that we would not do absolutely everything”; parents want something, are they the best advocate? I'm a parent, we don't own our children; often in the throes of it, aren't prepared for last breath, what parent is ever going to say stop unless the child's brain is gone
- Physicians: nonunified physician team (intensivist versus surgery team); unified physician team (meetings to find common peace); “talked them (family) out of it (stopping care)”; some physicians aren't able to stop (to say “we can't keep doing this”); physicians feel MD because they don't have ultimate power (must answer to people, don't always have input)
- Frontline: often last to know decisions; “part of me is shriveling up” because the parents have been persuaded by the physician and will be stuck with that I know they didn't want
- Health care team: no team-based decision making anymore (no real sense of team, we need to work towards the same goal, if best outcome is to die, that's what we need to provide them)
- Health care ethos: hierarchy of medical care very important to some families; whole new era now with technology and parents calling the shots
- Legal involvement: apprehension from parents, parents left with no decision-making power
- Unknown: part of me feels wrong for saying this but did we waste an organ on somebody that would have been better? Who had less issues, could be running around? Maybe not for me to say or judge, but who makes those decisions?

Burden of knowledge (Nursing perspective)

- Same messaging being delivered by nursing, yet family only appreciating words of intensivist
- Wanting to give parents best case scenario, but knowing many don't get that, they get persistent vegetative state
- Knowing outcomes: when remarking these concerns, physicians and management “jump down our throats”; having to watch patients suffer for months (“rot to death”)

Subtheme: Intention of Treatment

Escalation and de-escalation

- De-escalation: family wanting to withdraw/stop, physician “talked them out of it”; parents not accepting palliative care (thinking child would be abandoned, starved); problem with technology, “how do you ask a parent to withdraw treatment? It's like saying “kill you child”, problem is no one in medicine wants to step up and say “we've done everything we can do, we are withdrawing”“; for the parents, only small improvements were made, surgery was kind of a last straw, enough is enough (then patient was apprehended by legal)
- Maintaining level of care: family not wanting to stop aggressive resuscitation of catastrophic injury (team continued CPR on “this poor body”); “continue to do things we know aren't going to provide the result we want”
- Escalation: plan to escalate care on crashing patient (massive brain infarct), patient kept alive for 1.5 months to give parents time; “we have these wonderful machines to keep us alive, but to what end?”; physicians felt strongly that surgery was needed despite patients current state (horrible, horrible lungs); parents were surprised by ECMO being initiated (not consented), they didn't want extraordinary measures

Length of time (for decision)

- Waited too long: to reach unified decision among physicians; parents don't understand the reality of outcomes until they don't have any further choices; “have to resuscitate children time after time after time because nobody has really explained to the family that your child is not coming back”; waited months for surgery to decline transplant when intensivists knew patients outcome was likely zero anyway; so much dissension on unit, so much lack of understanding as to why we were taking so long to withdraw, the mother needed time to say goodbye (physicians were listening to the mother, nurses were not)
- Not waited long enough: had they waited 3-4 days, we would've seen that it wasn't right to go ahead with surgery or apprehend child from parents

Prolonged stay

- Time: very, very long protracted piece of time; many, many, many months of almost futility; patient was sick for many weeks, only small improvements (1 step forward, 2 steps back), hadn't recovered from the rest (of his issues) so why more surgery?”

- Suffering: patient “continued to suffer and we kept them alive”; “they come here and they will rot to death”; boy held on for this parents, “they tortured that boy because his parents could not let him go, it should have ended”; patient was with us for very long time, had extraordinary pain for long periods of time and was really afraid

Reasonings

- Image of outcomes: “perhaps physicians have the image of the ones that turned out well, that superseded the ones that didn't turn out so well, but they don't talk about the ten that didn't have that recovery”; moved dying patient into a room with an isolation patient because “they felt ...well he's going to die anyway”
- Aid life: patient wanted to live (continued with prolonged care); “it is the physician that has to make the decision and they have to live with themselves too” (physician in response to de-escalation request: “well that is really not an appropriate time right now because we don't know what will happen”)
- Avoid death: parents sometimes can't resolve it, end up traching patient (and staying there forever); not easy for the physicians to make tough decisions when they know the bottom line

- Accessibility (to technology?): it's wrong, she shouldn't have been a candidate for surgery; at our hospital, “no one gets turned away” (cardiovascular surgery runs the department
- Pressure dynamics: physicians get a lot of pressure to let parents make decisions that they know the way it's going to go; potentially based in secret agendas, political connections (feeling of this on the unit); no one wants to be the bad guy (for family, parents), this case was not cut and dry

Expectation (of prognosis or outcome)

- Life: have to “resuscitate children time after time after time because nobody has really explained to the family that your child is not coming back”; “we had to do CPR on this poor body to get a heart beat back for the family because they weren't ready to say goodbye”, somebody needs to question the endpoint and give dignity to the patient; DNR means no intubation and compressions but decisions made still include resuscitation interventions with medications and fluids

- "Who is coming back"/connection to the world: physician "holds the end of the rainbow in front of them: we can do this, we can do that, but he doesn't tell them that the child they brought in is not the child they're going to be taking home. The child that they knew is no more"; unrealistic expectations from parents regarding recovery of devastating injuries, unwilling to consent to imaging that would show extent of injuries
- Death: withdraw of care resulted in the patient breathing, but no connection to the world (still after 2 years); pushing Epi to keep a patient alive while waiting for parents to arrive to PICU is different than doing it "because we can"

Short term outcomes and long-term outcomes

- Types of case: no expectation of good outcomes by looking at physiological evidence and reports; "every complication"; hangings tend to have the worst outcomes
- Short term outcomes: aggressive resuscitations of catastrophic injuries "I feel for the family, but we should afford the patient dignity"; DNR decision still includes some escalating interventions "we've already got this Epi infusion going, turn it up"; okay to have painful interventions if the end result will give quality of life, it's wrong if they are done because people are not ready to sign the death certificate;
- Long term outcomes: "parents were judged for not wanting extraordinary measures, but they were thinking about 5, 10 years down the road not just immediate short term outcomes"; prolonged suffering with poor outcomes "they come here and they're just going to rot to death"; teen with double amputation stated numerous times his desire to die "he will probably get out of PICU but I would be very surprised if he survives because he will stop taking his meds or try to commit suicide"

Subtheme: Nurses and Decision-Making Power

- Decision making influence (possessed credibility): by parents (parents knew nurse was advanced practice nurse, invested credibility, felt what the nurse said had merit); seasoned nurse (in a role of responsibility) mentors residents and is relied upon by physicians, intensivist says "if she says so, then that's what needs to be done"; languaging can almost elevate a nursing perspective to be appreciated (ex: discussing recent study results)

- No decision making influence (did not possess credibility?): paradox - seasoned nurse relied upon by intensivist also not given decision making power “I've been here 30 years, you can say whatever you want but it's falling on deaf ears (no clout even with credibility and experience); “I play along with their games because it's a battle that you're never going to win, I know I'm not going to win because I don't have enough clout, I'm down at the feeder level”; sometimes invited to share opinions, but are never taken into consideration when choice is finally made; when voicing concerns, being reminded that nursing role has no decision making power and that it's not the nurses choice to make; “can't advocate”, decision “came from above, no negotiation”; part of me feels wrong for saying this but did we waste an organ on somebody that would have been better? Who had less issues, could be running around? Maybe not for me to say or judge, but who makes those decisions?

Communication and Messaging

<u>Messaging between physicians and family</u>

- Unclear/miscommunications: anger and frustration with inconsistent messaging from physicians, families are looking for definitive information; questionable informed consent, “they say it's informed consent, but afterwards parents said “I had no idea it would be this bad”“;
- Tone: physician presents best case scenario and uses a hopeful lens, but doesn’t talk about the ten that didn't have that recovery; physicians set the tone (when conveying prognosis, actions to stop treatment); there's a way to tell patients, families that you can get what you want (nurse was sure the parents were told that the patient would survive even with their poor prognostic condition)
- To achieve care goal: after controversy over patient being apprehended from the parents, many formal family meetings were held with the team, ethics, social work, and elders; “once it became clear the family wouldn't consent to surgery, ethics was involved to straight up tell the family why the team wanted to do surgery”; physician team tried to show consensus though likely disagreement behind closed doors (non-verbal communication between physicians who

agreed/disagreed during rounds)

Information sharing among the team

- Among physicians: the meeting to achieve a “unified physician voice was a bit late”
- Physicians and nurses: discussions involving the physicians only were not shared with nurses or other disciplines (social work); information sharing was one directional (nurse brought up concern, physician responded with “textbook answer” around statistics of outcomes), no discussion

Where conversations occur

- Physician team: behind closed doors
- Family conferences: conference room within PICU (helps focus on the conversation, 5-6 people); at night (quieter); in quiet room
- Informal conversations: at bedside if parents aren't present (ex: RN, RT discussing “why are we doing this?”); over coffee (debriefing/coping); nurses lounge (including RTs, dieticians)
- Team: bedside rounds

Parents who revisit PICU post death

- Reason: to thank and see staff
- Impact: reaffirming for the family; “for staff, there's nothing better than to see the families whom we've cared for”

Subtheme: Nurse Voices

Being heard

- Families: parents invested credibility into nurse’s insight, felt parents thought that they had merit (advanced practice nurse)
- Other nurses: can be impactful to other nurses – positive during mentoring/negative - (a really good nurse acting on premise that patient is manipulative, did not act quick on patients request, which resulted in respiratory arrest)

Not being heard/not being vocal

- Families: family only appreciated words of intensivist despite same messaging; can't be frank with family (feels dishonest)
- Physicians/management: seasoned nurse opinions still “fall on deaf ears”; not being heard by physician on multiple occasions; invited to share opinions, but not taken into account in decision making; physician acknowledges what nurse has to say, “then says thank you!” and turns and walks away” (not being heard in a meaningful way); powerlessness - influence not felt by physicians and management; can't advocate for patients (decisions “came from above, no negotiation”, hierarchy); at rounds physicians would give “textbook answers” to nursing concerns (statistics of outcomes) and “discussion would move to other topics”; nurse voices are discouraged from sharing their own opinions with family, “it might not reflect what the physician's is at that point in time”
- Other nurses: child who was afraid of the dark was left alone at night, RN clarified this worry to the bedside nurse who said “Well, it doesn’t matter to me. She won’t be afraid of the dark if she’s sleeping”

<u>Actions of nurses communicating</u>

- Toward family: “my hands would sweat” when stating personal opinion to family
- For care: translating inconsistent physician messaging to families, it was “very hard for me as a member of that team”; attend family conferences (to share information in report); establish awareness to create relationship with the family for (1) information sharing (2) so everyone feels respected (3) for consistent messaging
- Toward other nurses: tell novice nurses to “toughen up”, “it's a terrible thing to say, but with technology 10 years ago those kids wouldn't have suffered because we couldn't do what we can today”; scope out nurses who feel similarly (when giving report, can read nurses faces as far as whether they agree or disagree with course of treatment)
- Toward physician team: approached physician team once knowing there was some mutual agreement among a few nurses; vocalized concerns; vocalized discomfort supervising parental visits (had to be in room anyway, but felt like a totally different situation)
- Toward management: vocalized concerns; vocalized discomfort of supervising parental visits; reported cruel care practices to management (after witnessing charge nurse say to patient with bilateral leg amputations: “no you can't have pain meds, are you going to get up

and walk over here”)

- Inaction: felt “we did this to them” because “we didn't interfere with the path the physician was going along”

<u>Reactions of nurses communicating</u>

- Parents: anger, saying “you've given up on our child” (nurse still felt it was necessary to say so parents didn't feel like they were the first to give up)
- Physicians: give “textbook answers” (statistical outcomes), say “thank you!” and walk away
- Management: offended by the nurse who reported witnessing cruel care practices rather than by the nurse who performed the practices
- Nurses: annoyed when professional judgment is questioned (when truly feel it's in best interest of patient)

Stated Support for Nurses

<u>PICU Supports</u>

- Other nurses (in professional capacity): seasoned nurses help shift focus for novice nurses from prolonging life to supporting family; colleagues are important supports because they know the context and the PICU world; I told “anyone who would listen”; stated cause of moral distress was from witnessing and supporting others in moral distress
- Management/physicians: shared story with manager (felt supported); will go straight to management or physician if they feel like they can “this helps”

<u>Non-Supports</u>

- Communication (voicing concerns): they don't address our feelings at all, they address the power angle “you don't have that decision making position”; felt unheard by management (didn't receive an answer for what happened “there is no answer for that”); felt like couldn't go to management to discuss behaviour of nurses who didn't support the decision; personalities of management can be very abrasive, a lot of little power struggles and micromanagement “I think a lot of the problem is communication”

- Fallout/repercussions: if we say something it will come back to us in one way or another; make remark in front of certain people and they jump down our throats; repercussions if nurse calls ethics (from higher nursing and medicine), get the feeling that was not the thing to do; unit manager took offense at nurse who was reporting another nurse for telling a patient to “fuck off”, not with the nurse who said it
- Structure: no given enough time to resolve issues (go from bundling patient to the morgue straight to a new admission), no time to sit down sometimes
- Team dynamics: division with physicians and management staff (if we say something it will come back to us); not a lot is done about the tension between the team; ethics committee tends to agree with physicians as far as what the physicians believe; struggle with the judgment peers can hold of these patients

<u>Personal Supports/Coping</u>

- Family: family support is important; brings it home (replays over and over in mind); sometimes can't always cope at home or bring it home (have to switch gears, can't be crying over what happened at work)
- Other nurses (personal capacity)/social network: talk to coworkers in different areas who are removed from the situation (reality checking “is this me or do you see this...” and to reduce tension); discuss with PICU nurses over coffee too (brainstorm, support each other); tends not to involve physicians or management staff (quite a division, things come back on us); calling each other at night about what happened and crying
- Personal techniques: write about feelings, “block that out of my brain” (patient suffering, performing interventions that cause harm”; burn a candle for the patient; “I used to be very judgmental, I remember doing my job and pushing the rest away until some came to bedside and said “how are you doing” and that totally put me over the edge, “don't talk to me right now” because it will make me cry and it doesn't go anywhere. You cope differently at every time in your life”

Recommendations for Changes
To Make Change (Suggestions, Reflections, Achieving Resolutions) - PICU micro structure (nursing bedside/management): say to management “walk in my shoes for a few shifts”; “sometimes we're put in positions we shouldn't be in, often comes down to staffing and different people’s opinions of how things should be done”; need people to stay but need to give them a reason to stay, “if you're going to push so hard that they walk away, then they will”; - Support: need to support the people there and those coming in; be the kid in the bed, be more respectful. Treat people with kindness and maybe your job won't be so damn tough (maybe teach the other nurses about my experiences, appreciate that they don't have the luxury of experiencing a child in PICU); enable family support for the patient - Macro structure (interdisciplinary): I don't feel bad about the system, it is what it is. I don't blame the people that put me in that situation, I don't what would resolve it (“something that was done that can't be unchanged”); not saying it's medicines fault, but I think they are torn (they want to do good and not have babies die, but a lot of transplant is still experimental and takes practice); never see ethics committees come into PICU, if they do we never hear about it (no direct contact with bedside nurses), we don't know their background (if there's contact with nurses, they see the distress of nurses about prolonging death, the “why are we” questions, not often the distress from the behaviours of those nurses); - Decision making: should never have taken the child away from the family, instead of enjoying this time we took over, took that time away and made him suffer more; should adopt families beliefs that it takes a community to raise a child; use palliation measures and appropriate treatment for patient conditions (not being candidate for surgery); adolescents having the right to say no and that being the final decision - Communication: voiced concerns - seems like it goes in one ear and out the other (higher nursing, medicine), maybe their hands are tied; no place to deal with upset (and there was a great deal of upset), no debriefing; information is not being shared, we think “what are you doing”, there is usually a reason behind it, staff should know that (not necessarily everything, know what we should know); need better communication, hear why decisions are made - General call for change: “when do we stop? It's not just medicine or surgery, it's very

complex. The longer you work the more you realize that I have no idea what the answer is"; need to start questioning some of this, it may never be fixed but I think that we do have to try to make things better

<u>Subtheme: Helpful</u>

<u>Is Helpful</u>

- Consistent messaging: information coming from the same intensivist; physician team (intensivists, surgeons) met to find common peace/unified voice
- Team collaboration: talking to others, mentorship (nurse to nurse)
- Good stories, good endings
- Qualities of decision maker: (experienced LESS moral distress with physician) is detail orientated, leaves out emotions, is very ethical, looks at own errors in judgment; listens to nurses concerns, if disagrees has valid reasonings, communicates those reasons effectively, reasons are not emotionally fixated, come from the best interest of the child
- Pain/suffering management: good pain management; predict situations (premedicate)

<u>Would Be Helpful</u>

- Nurse voices: perhaps if nurses can state opinions to the team, family at the beginning "the parents would make choices they would be most comfortable living with for the rest of their lives instead of being pushed into following suggestions and having to cope with the after effect"
- Ethics/ethics committee: if we felt ethics really could change things and that we are going to be listened to; ethics should be involved more, it was just so important and so good, I don't think it happens enough
- Understanding rationales: "M&M rounds for staff to understand why and how we treat our animals better than we do these children", some clarity

<u>Debriefings</u>

- Helpful: can be, sometimes not; before difficult decisions as well as afterwards; include all disciplines; bring personal perspectives as opposed to professional perspective (role specific tasks); round table with physicians (information sharing)

- Not helpful: if left too long it doesn't work (should be within a couple days, a couple weeks later is too late); one hasn't occurred (2 months later) and is unlikely to happen because physicians don't want to, nurses don't set it up; debriefing happened once in 3.5 years of working in PICU; not helpful when we're not really given information and you're left walking out not really sure what happened; did not happen after a case where there was a great deal of upset among staff
- Dynamics: it's not safe or supported to get angry (people think you've become very emotional and can no longer be part of the conversation); they feel public, can express regret or frustration and can say “I'm angry at the situation that happened” but not “I'm angry with you in relationship to this behaviour”; tears are okay; group conversations (group dynamics) can be very judgmental

<u>Subtheme: Barriers</u>

<u>PICU Context</u>

- Technology: how do you ask a parent to withdraw treatment? It's like saying “kill your child”
- Busyness: no time given after death to resolve issues, reflect what's just happened (so pushed, from morgue to new admission), compounding stresses
- Unit is very short on beds and nurses
- Beds are filled with “kids” that really don't need to be there anymore and need to go elsewhere, there's no rules anymore (secret agendas, political connections)

<u>Communication</u>

- Deciders not sharing information for basis of their decision (rationale)
- No one in medicine wants to step up and say “we've done everything we can do, we are withdrawing”
- Feels like there are secret agendas and political connections

<u>Repercussions and Fallout</u>

- Offering opinion: always concerned with repercussions
- Asking questions: if you question a decision “it goes very badly for you, being told you're

insubordinate, how dare you question my authority, you will do as you're told"; receive difficult assignments shift after shift after shift, being passed over for new experiences and education and the chances to grow (speaks to hierarchy, power, divisive management; actual harm from confronting/fall out)

Differing Opinions, Perspectives, and Perceptions

Guides and influences all aspects found in situations of moral distress, in particular decision making, communication/messaging, feelings, support, what nurse deems most morally distressing. This section, while the examples listed are not many, holds an enormous weight and is threaded throughout the other themes.

<u>Personal perspective vs PICU perspective</u>

- Personal: "what we each feel is very much based on where we've been and who we are"; "I think you had to live it in order to be able to tell it from my point of view"; "look at ICU experience through many views and angles, as a mother of a PICU child and adult ICU child, as PICU nurse and advanced practice nurse"
- Relational to PICU context: PICU beliefs (do everything) don't always align with family beliefs (that a child dying is not inherently a bad thing)

<u>Differing opinions between individuals and groups</u>

- Amongst medical team: not always unified opinions; often intensivists have broader perspective of patient in decision making (compared to surgeons); often ask "what are we doing", child suffering (nursing perspective) but physicians have to make the decision and have to live with themselves too
- Between bedside nurse and parents: nurse felt discomfort, pain, and anxiety were not in patients best interest (parents thought they were for life); nurses perceptions of patients response to pain compared for parents perception of it being a response to touch; communicating differing opinion with parents was difficult (hands would sweat); parents thought nurses believed they were bad people for their belief system (child is going back to

god), not the case from nursing side, “we don't think it's a bad thing, just a difference in beliefs”; it's not what I would choose for this patient, but it's what they chose, it's not my job to judge them

- Between nurse and nurse: discomforts with other nurses accepting decision to withdraw care; different perspectives with nurses from other areas, “although we share the same nursing focus, it will come out differently”
- Between nurse and physician team: “we all have different paradigms in how we look at it, it's relevant for me to hear the discussion (physician meeting) so that I can be comfortable with my own understanding”