THE INFLUENCE OF THE PEDIATRIC CRITICAL CARE CULTURE ON END-OF-LIFE DECISION MAKING

by

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ABSTRACT

The primary goal of the pediatric intensive care unit (PICU) health care team is to make critically ill children better. In many instances, the professionals working within the PICU come to understand that this goal is unachievable. Shifting the focus of care away from cure and toward comfort and a good death within the context of high technology and a focus on cure can be exceedingly difficult. The purpose of this study was to investigate the nature of pediatric critical care culture in Canada and its influences on end-of-life decision making for children for whom the possibility of cure is remote or non-existent.

Guided by the qualitative method of ethnography, a rich and detailed description of the cultural influences of pediatric critical care on end-of-life decision making was obtained through semi-structured interviews with eleven PICU nurses and six PICU physicians from seven Canadian PICUs. Each of the participants had experience in caring for dying children and their families. Analysis focused on identifying cultural values and perspectives by comparing PICU cultures and the processes surrounding end-of-life decision making.

The findings from this study suggest that practitioners value a sense of control over the PICU environment and end-of-life decision making. This need to control is apparent in how the dying process is managed. Physicians and nurses endeavour to orchestrate and plan for a child’s death through the deliberate creation of a plan for managing the end of a child’s life. Additional values and beliefs which influence end-of-life decision making focus on protecting the family and staff from emotional pain and suffering, valuing a “good quality of life”, presenting a “united front”, and maintaining loyalty to “the plan”. Nurses describe experiencing emotional distress when requested to continue care aimed at cure when these efforts seemed futile. They describe feeling constrained within their practice to influence end-of-life decision making. Physicians describe a
less emotional and more analytical response to demands for ongoing treatment under “unrealistic expectations”. In essence, the unpredictability of death combined with the complexities of the pediatric critical care environment (e.g., technology, types and acuity of patient illnesses, access and flow issues, and nurse-family-physician relationship dynamics) create tremendous challenges for meeting the goals of a “planned death”.

This study is unique because it specifically addresses how the pediatric critical care culture influences end-of-life decision making. The findings of this study suggest a need to develop a deeper understanding of how the struggle to control dying in PICU impacts end-of-life decision making in order to improve upon the end-of-life experiences for dying children and their families. Further research and education are required that focus on: developing a better understanding of the concept, actualization and implications of control in a PICU; strategies to improve interdisciplinary end-of-life decision making within a family-centered care model; improving upon the current practices aimed at caring for dying children and their families in a non-hospice setting; developing strategies for individuals to explore their understanding and comfort with end-of-life care; and developing and sustaining collaborative relationships between health care professionals and families.
# TABLE OF CONTENTS

ABSTRACT .......................................................................................................................... ii

TABLE OF CONTENTS ...................................................................................................... iv

ACKNOWLEDGEMENT ...................................................................................................... vii

CHAPTER 1: INTRODUCTION ......................................................................................... 1

Background of the Study ................................................................................................. 1

Challenges of Caring for Dying Children ....................................................................... 1

Research Questions and Purpose ................................................................................... 3

Statement of the Problem ................................................................................................. 3

Purpose ............................................................................................................................... 3

Research Questions .......................................................................................................... 3

Significance of the Study ................................................................................................. 4

CHAPTER 2: LITERATURE REVIEW ............................................................................. 5

The Culture of Critical Care .............................................................................................. 6

Nurse-physician Collaboration and Decision Making in Critical Care ......................... 8

Dying in Critical Care ....................................................................................................... 13

Culture of Dying in Critical Care .................................................................................... 15

Ethical Issues Surrounding End-of-Life ......................................................................... 17

Euthanasia, the doctrine of double effect or simply alleviating suffering? ..................... 18

Patient autonomy versus proxy decision maker ............................................................ 19

Challenges of Providing End-of-Life Care in PICU ......................................................... 23

Effective Communication with Families Surrounding End-of-Life Decision Making ........ 24

Summary ............................................................................................................................ 28

CHAPTER 3: RESEARCH METHOD .............................................................................. 30

Research Design .............................................................................................................. 30

Ethnographic Research in Nursing ................................................................................. 30

Definition of Terms ......................................................................................................... 31

Sample ............................................................................................................................... 32

Participant Recruitment ................................................................................................. 32

Inclusion Criteria .............................................................................................................. 33

Data Collection ............................................................................................................... 33

Data Analysis .................................................................................................................. 34

Coding .............................................................................................................................. 35
CHAPTER 4: FINDINGS

The Sample

The Culture of PICU

PICUs in Canada

The Nature of the Work

Caring for the “whole” child

The Types of People Who Work in PICU

On top of their game

Experience definitely counts

No one understands but us

Parenting changes your perception

The emotional impact of caring

Dependent on Technology

Being Driven by Routines

Role Distinction

End-of-Life Decision Making in PICU

Values and Beliefs Regarding a “Good” Death

Protecting others

There is a right day and time to die

Some people are better at caring for the dying

Types of Deaths

Straight forward deaths

The “messy” death

Making the End-of-Life Decisions

Parents making end-of-life decisions

Making “the Plan” for a “Good” Death

Requesting a plan

Including the “best” people

Developing and Presenting “the Plan”

Loyalty to “the plan”

Presenting “the plan”

Location, location

Timeliness of the presentation

Parents need time to come to terms with “the plan”

Challenges for Providing a “Good” Death

People obstructing “the plan”

Medical-legal concerns regarding end-of-life decision making

What if we are wrong?

Technology as a barrier
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CHAPTER 1: INTRODUCTION

Background of the Study

The role of the pediatric intensive care unit (PICU) health care team is to offer the best care possible for critically ill children and their families within the complexities of the pediatric critical care environment. As the lines between life and death have blurred, largely due to increasing technology, end-of-life decision making in the PICU has become increasingly complex for families and caregivers (Reisman, 2001, p. 1).

Patients are generally admitted to PICU in a quest for recovery from illness or injury. However, in many instances, professionals working within this context come to understand that the possibility of recovery is remote, and begin making decisions about whether to continue treatment. Shifting the focus of care away from treatment aimed at recovery towards comfort and a good death can be exceedingly difficult; especially when the context within which the care is provided is one of high technology with a focus on recovery. The purpose of this study was to explore how the culture of pediatric critical care practice shaped end-of-life decision making when the possibility of full recovery is remote or non-existent.

Challenges of Caring for Dying Children

The adult critical care community continues to develop a scientific and theoretical knowledge base related to end-of-life care. Much of this work focuses on challenges such as decision making regarding withholding or withdrawal of treatment and how adults die in critical care (Cassell, Buchman, Streat, & Stewart, 2003; Fins et al., 1999; Hall & Rocker, 2000; Hawryluck, Harvey, Lemieux-Charles, & Singer, 2002; Heyland et al., 2003; Heyland, Lavery, Tranmer, Shortt, & Taylor, 2000; Kirchhoff & Beckstrand, 2000). Historically, pediatric critical care practitioners have drawn from the adult critical care literature to inform practice. While this has
provided some direction for practice, adult-based findings need to be cautiously applied to the pediatric population and their families.

Many health care professionals working in pediatric critical care speak about the challenges that members of the interdisciplinary PICU team face when working with dying children and their families. Yet few researchers have explored what it means to practice within the context of pediatric end-of-life care. The small body of pediatric critical care scientific literature reveals that the challenge of delivering quality care to dying children and their families is complicated by a lack of timely, honest communication between the family and PICU team regarding the predicted prognosis and a plan of care with regards to end-of-life decision making (Burns, Mitchell, Griffith, & Truog, 2001; Burns et al., 2000; Garros, Rosychuk, & Cox, 2003; Macnab, Northway, Ryall, Scott, & Straw, 2003; McCallum, Byrne, & Bruera, 2000; Meyer, Burns, Griffith, & Truog, 2002; Rashotte, Fothergill-Bourbannais, & Chamberlain, 1997). However, there is a dearth of scientific evidence that addresses the process of, or influences on, end-of-life decision making in pediatric critical care.

The available scientific literature addressing end-of-life care and decision making regarding critically ill children is primarily based on observational studies, retrospective reviews, and surveys of national regulatory bodies. Contributors to the pediatric end-of-life body of knowledge have called for further research into pediatric end-of-life care and the factors influencing the best outcomes for the child, family, and health care team members (Burns et al., 2001; Burns et al., 2000; Kenny, 2003; Levetown, 2002; Macnab et al., 2003; Masri, Farrell, Lacroix, Rocker, & Shemie, 2000; McCallum et al., 2000; Meyer et al., 2002; Mink & Pollack, 1992; Savage, 1997). Literature examining the context of decision making is lacking, especially regarding ways in which the culture of PICU effects this decision making.
Research Questions and Purpose

Statement of the Problem

While there is an emerging body of research literature related to end-of-life decision making for critically ill adults and children, the ways in which the PICU culture affects this decision making has not been explored. LeCompte and Schensul (1999) describe culture as consisting of the “beliefs, behaviours, norms, attitudes, social arrangements, and forms of expression that form describable patterns in the lives of members of a community or institution” (p. 48). Exploring a particular culture can result in a better understanding of how decisions are made and events unfold within that culture. A gap exists in our knowledge of the culture of pediatric critical care and how it influences end-of-life decision making. Exploration of this gap is needed, with a goal of contributing to end-of-life literature and providing direction for practice.

Purpose

The purpose of this study was to develop an understanding of the influence of the pediatric critical care culture on end-of-life decision making. While there are many health care professionals involved in delivery of care within the PICU, this study focused on the experiences of nurses and physicians. To gain a broad view of these experiences participants were recruited from PICUs across Canada.

Research Questions

The main research question to be addressed was: What influence(s) does the pediatric critical care culture have on end-of-life decision making? To answer this question I attended to what PICU nurses and physicians said regarding how daily decisions and end-of-life decisions were made in PICU, while holding in mind the multiple contextual factors that influence the efficient delivery of quality care within pediatric critical care and the complexities of decision making. To
facilitate this approach, the research project was guided by the following sub-questions: (a) How are decisions made in PICU? (b) What influences how staff members make decisions on a daily basis and when caring for dying children? (c) What values, assumptions, and beliefs underlie end-of-life decision making in PICU?

Significance of the Study

In our society, it is widely held that children are not supposed to die. When they do, the natural order of events is disrupted. Parents are not expected to outlive their children. Yet even in this miraculous age of modern technology, children die. Scientific evidence provides little direction to meet the needs of critically ill dying children, their families, and the health care providers. The intent of this study was to develop an understanding of the PICU culture and how it influences end-of-life decision making, thereby contributing valuable scientific information to inform end-of-life decision making and care.
CHAPTER 2: LITERATURE REVIEW

While there is a dearth of research literature specifically addressing the influences of the critical care culture on end-of-life decision making, a number of research and discussion papers address end-of-life decision making in adult and pediatric critical care. Much of the literature exploring end-of-life decision making focuses on identifying the challenges in providing a "good" death. Understanding the ways in which patients die in critical care is an important aspect of end-of-life inquiry. Equally important is knowing how the basic assumptions, values and norms of critical care practitioners influence their end-of-life practices and behaviours (Hagberg & Heifetz, 2000).

In an effort to elucidate the influence of PICU culture on end-of-life decision making, nursing and medical literature were searched. Business management and leadership references were also reviewed to explore the use of culture as applied to organizations and working groups. The literature search focused on end-of-life decision making, end-of-life care in critical care, critical care staff members' perspectives on end-of-life care, death in intensive care units, health care culture, critical care culture, corporate culture, organizational culture, nurse-physician collaboration, and decision making in critical care. Searches were duplicated to capture adult and pediatric critical care content. The literature reviewed consisted of scientific and theoretical articles and books, as well as discussion papers.

Throughout this review an attempt was made to identify relevant gaps in the current state of knowledge pertaining to the influence of PICU culture on end-of-life decision making. This chapter is organized into the following three sections: 1) the culture of critical care, 2) dying in critical care, 3) challenges of end-of-life care in pediatric critical care. The literature review concludes with a summary of the findings.
The Culture of Critical Care

In order to make sense of the influence that PICU culture has on end-of-life decision making in critical care I sought literature describing PICU culture. While some exploration has occurred regarding the impact of working in a critical care environment on nurses and physicians (Bunch, 2002; Burns et al., 2001; DePalma, Ozanich, Miller, & Yancich, 1999; Kirchhoff & Beckstrand, 2000; Miller, Forbes, & Boyle, 2001; Rashotte et al., 1997; Rodney, 1994), there is a gap in the literature explicitly exploring the cultures of pediatric and adult critical care. Little has been documented about the explicit or implicit values, norms, beliefs and assumptions held by team members; values, norms, beliefs and assumptions integral to the day to day running of critical care units. In an effort to develop an appreciation for how culture is used in reference to the workplace I sought information from the business world; a world which parallels the health care system with respect to teams of people working together for a common goal.

Culture within large organizations is neither universal nor consistent. Culture is dynamic; influenced by variables such as people and events. Within each organizational culture there may be varying degrees of integration due to the existence of subcultures (Deal, 1998; Hagberg & Heifetz, 2000; LaBarre, 2001). Subcultures are groups of people who work as departments, units, or teams and they may have unique values, norms, beliefs, and assumptions. Examples of subcultures co-existing in hospitals with different perspectives are palliative care and critical care units (Kaufman, 1999). The importance of identifying a culture and determining its strengths and areas for improvement is integral to the success of that organization or subculture (Hagberg & Heifetz).

A culture of critical care is implied but rarely explored in the literature. Curtis and Patrick (2001) identify ‘saving lives’ as the dominant culture of critical care. A health care culture that
emphasizes the saving of lives ill prepares nurses and physicians when they are faced with the reality of end-of-life decision making (Curtis & Patrick, 2001; Ferrand et al., 2003; Miller et al., 2001; Way, 2003). The most noted work regarding critical care culture and end-of-life care was published by Kaufman (1998). Results from Kaufman’s ethnography examining the approach to end-of-life decision making and care of the elderly in ICU are some of the first to describe cultural aspects in the ICU that influence end-of-life care. Four cultural forces were described: (1) biomedical knowledge as the driving force for understanding aging and death, (2) a heavy reliance on technology to determine events, (3) conflict between lay and medical knowledge, and (4) an indecisiveness about end-of-life goals. Kaufman’s findings have been utilized in adult critical care as a framework for articulating challenges and making recommendations for delivering quality end-of-life care (Miller et al., 2001). While many of the cultural forces described by Kaufman are alluded to in findings from studies that examine how children die in PICU (Burns et al., 2001; Burns et al., 2000; Feudtner et al., 2002; Garros et al., 2003; McCallum et al., 2000; Meyer et al., 2002), the culture of the PICU and its impact on end-of-life care has not been explicitly examined.

The way relationships are structured in health care organizations is informed by culture. It is important to consider these relationships due to the impact they have on health outcomes and experiences of health care for patients and their families. In turn, this has consequences for the overall satisfaction and quality of work life it has for health care workers (Canadian Council on Health Services Accreditation, 2004; Mallak, Lyth, Olson, Ulshafer, & Sardone, 2003; Miller et al., 2001; Varcoe, Rodney, & McCormick, 2003). In particular, collaboration, especially among nurses and physicians, has been explored in an effort to better understand the impact of health care relationships on the efficient and effective operation of critical care units (Baggs et al.,
Nurse-physician Collaboration and Decision Making in Critical Care

Nurse-physician collaboration is a positive component in the effective operation of a critical care unit. Researchers have reported that collaboration results in high levels of staff satisfaction demonstrated by retention (Rosenstein, 2002) and an increased ability to meet the families’ needs (Bowman, 2000; Curtis et al., 2001). There is also evidence that nurse-physician collaboration is associated with higher productivity and efficacy with a decrease in length of stay for patients and improved patient outcomes (e.g., Coombs, 2003; Coombs & Ersser, 2004; Surgenor, Blike, & Howard, 2003; Thomas et al.; 2003). Much of the research focusing on collaboration in healthcare has focused on nurse-physician collaboration and decision making in critical care. The overlap of physicians’ and nurses’ clinical responsibilities in a critical care unit is thought to lead to a higher level of collaboration as compared to other practice areas (Maureen Coombs, 2003; King, Lee, & Henneman, 1993; Taylor, 1996). However, as is described below, empirical evidence indicates collaboration in critical care is the exception rather than the rule.

Researchers have investigated the relationship between collaboration and levels of satisfaction with decision making. Baggs et al. (1997) conducted a longitudinal descriptive correlational study across three American ICUs to measure levels of collaboration and satisfaction with decision-making processes amongst nurses, attending physicians, and residents. The research team concluded that a statistically significant linear relationship existed between collaboration and satisfaction with decision making. Nurses perceived a slightly lower rate of collaboration compared to residents and attending physicians. Similarly, Thomas et al. (2003)
reported that of 320 participants surveyed (90 critical care physicians and 230 critical care nurses), 33% of the nurses compared to 73% of the physicians rated collaboration and effective communication as high or very high. Thomas et al. reported nurses were: dissatisfied with conflict resolution; experienced difficulty in communicating their opinions; felt discouraged from sharing their opinions; and expressed a desire to have greater input into clinical decision making. Baggs et al. and Thomas et al.'s findings are important because they identify the existence of differing perceptions of collaboration between critical care nurses and physicians. The reasons for these differences, however, are not explored.

An ethnographic study of physicians' and nurses' clinical decision making in three intensive care units (district, general, and university teaching hospitals) provided rich descriptions of what it is like to work in an ICU and be a part of the decision-making process (Coombs, 2003; Coombs & Ersser, 2004). By observing daily rounds and conducting in-depth interviews, Coombs (2003) was able to describe the relationships between physicians and nurses, including the power relations, subordination and frustrations exhibited by nurses and physicians involved in making everyday decisions pertaining to patient care in the ICU. Nurses modeled their behaviour and communication after medicine, the dominant culture, if they wished to contribute to clinical decision making (Coombs & Ersser). Coombs (2003) suggested there is a need for medicine and nursing to recognize the power of each profession and capitalize on the "complementary knowledge and roles held by each group" (p.134) without silencing one another's voices. An important finding from this study was the difference between the true workplace culture versus the stated institutional vision. The reality of nurse-physician relationships in critical care was not reflective of the visions espoused by the institutions where the studies occurred.
Manias and Street (2001) explored how nurses and doctors constructed their practices to inform their decision making in a critical care unit. In this critical ethnography, six adult critical care nurses were observed in an effort to examine how routine behaviours influence the decision-making process between nurses and physicians. The findings describe critical care nurses as having enabled clinical decision making, especially with resident physicians, through various strategies (e.g., nurse-doctor game, facilitator). The researchers suggest ways that nurses could contest the dominant culture of medicine in an effort to acknowledge the contributions that nurses bring to decision making. With respect to better understanding nurse-physician relationships and end-of-life decision making, a limitation was the restricted breadth of the decision making examined in these studies. End-of-life decision making did not appear as an aspect of decision making in either ethnography.

Dissatisfaction with nurse-physician relationships and decision making in critical care has implications for end-of-life care. Findings focusing on end-of-life care in critical care research reveal differences in values and beliefs, and communication difficulties between nurses and physicians as obstacles to collaboration (Bica, 1999; Burns et al., 2001; Burns et al., 2000; Kirchhoff & Beckstrand, 2000; Melia, 2001). In a survey of 300 American critical care nurses, Kirchoff and Beckstrand found that nurses ranked physicians who were overly optimistic of a patient’s outcome as the fifth highest obstacle (out of 25) to providing end-of-life care to dying patients and their families. In a prospective case study of 53 pediatric patients who died after withdrawal of treatment in three PICUs in a large city in the United States, medical and nursing staff completed anonymous questionnaires regarding why medications were given surrounding the time of death (Burns et al., 2000). Burns et al. reported that both PICU physicians and nurses indicated that they acted in agreement in providing care to dying patients. In contrast, in a cross-
sectional survey of 31 PICUs across the United States assessing the attitudes and practices of PICU physicians and nurses regarding end-of-life care, PICU nurses were found to be less likely to feel that care was optimal at end-of-life. The PICU nurses reported feeling disenfranchised in the decision-making process and disillusioned with the level of support given to the families (Burns et al., 2001).

In two phenomenological explorations of PICU nurses’ experiences in caring for dying children, Rashotte et al. (1997) and Way (2003) described the responsibility that PICU nurses felt in supporting families of dying children. In both studies, the burden of providing support for the family while caring for their dying child had a profound impact on the grief experiences of the nurses studied. In addition, Way reported the nurse participants wanted to care and develop relationships, and made every attempt to make sense of the situation of caring for a dying child and their family. A common thread in Burns et al.’s (2001), Kirchoff and Beckstrand’s (2000), Rashotte et al.’s and Way’s studies is the lack of support nurses perceive in providing end-of-life care.

This perception of a lack of support for PICU nurses is further supported by a growing body of knowledge concerning the moral distress that nurses experience when caring for dying patients (Burns et al., 2001; Masri et al., 2000; Mondor, 1999; Rodney, 1994; Varcoe et al., 2003). Rodney suggests that nurses are distressed by a combination of situational constraints (e.g., communication conflicts, questionable competence and excessive workloads) and patient/family ethical dilemmas (e.g., life-prolonging treatment, suffering, lack of communication). Critical care nurses are reported to feel constrained within the social structure of critical care. They describe feeling limited in their abilities to speak against popular medical decisions and advocate for patients and families (Burns et al., 2001; Corley, 1998; Ferrand et al.,
2003; Henneman, 1995; King et al., 1993; Miccolo & Spanier, 1993; Miller et al., 2001; Rodney, 1994; Surgenor, Blike, & Howard, 2003; Thomas et al., 2003; Varcoe et al., 2003). Professional associations have been responsive to the ethical dimensions of critical care by providing nurses with position statements to navigate through ethical dilemmas such as withholding or withdrawing life support (Canadian Association of Critical Care Nurses, 2001). Yet despite increasing awareness of these dilemmas and some practical tools to manage them, for some critical care nurses the end result of practicing within the critical care environment is often detachment or abandonment (Rodney, 1994).

In summary, recent empirical evidence suggests traditional hierarchies remain in critical care settings with nurses feeling undervalued and less satisfied than their physician colleagues with collaboration and decision making (Baggs et al., 1997; Maureen Coombs, 2003; Manias & Street, 2001a; Thomas et al., 2003). Frameworks for collaborative practice within a critical care environment provide direction for critical care managers and directors to replace a competitive environment with one in which sharing is valued (Corley, 1998; King et al., 1993; Miccolo & Spanier, 1993). Shared commitment to ensuring that collaboration is successful and maintained is a refreshing viewpoint in contrast to the historical 'us against them' exchange (Maureen Coombs, 2003; Henneman, 1995; Manias & Street, 2001a, 2001b; Miccolo & Spanier, 1993; Taylor, 1996). Applying the adult based findings to pediatric critical care, the literature suggests successful nurse-physician relationships (e.g., recognition and respect for roles, contributing to decisions together, trust and mutual respect) are essential to an efficient team, successful relationships with children and families, and a positive work environment, especially when working within the context of end-of-life decision making. However, while collaborative working relationships are valued, we have yet to develop a sound research-based understanding
of how to develop these relationships in pediatric critical care. The value of collaborative working relationships between nurses and physicians has resulted in positive outcomes for staff, patients, and families. With that knowledge, Taylor (1996) called for further research stating “concrete truths and pointers are needed rather than mere speculation or impossible directives” (p. 69) surrounding the phenomenon of collaborative practice within critical care. That request should include addressing the dearth of evidence that speaks to the effects of nurse-physician relationships and decision making in pediatric critical care, especially pertaining to end-of-life care.

Dying in Critical Care

Forty years ago, it was an accepted practice to wait for death to occur; wait for nature to take its course. Because limited heroic measures were available, the culture of dying was one of watching, waiting and supporting dying patients to the best of the caregiver’s ability (Kaufman, 1999). Our ability to support human life on both short-term and long-term bases has increased exponentially over the past few years. Technological advances in health care are making it increasingly difficult to distinguish life from death (Burns et al., 2000; Burns et al., 2001, Reisman, 2001). The media and internet appear to have influenced society’s expectations of an increased level of care and cure. Societal and technological pressures have influenced the level of care provided and altered how people die.

While adult critical care practitioners appear to have begun an earnest exploration of how dying occurs in critical care, literature pertaining to end-of-life care in the PICU is less developed. Current literature addressing how patients die in adult and pediatric critical care includes references to ‘withholding and withdrawing of life support or treatment’ in critically ill children as a means to end the suffering of the patient and/or their family (Balfour-Lynn &
Tasker, 1996; Canadian Association of Critical Care Nurses, 1999, 2001; Children's and Women's Health Center of British Columbia Ethics Committee, 2001; Fins et al., 1999; Garros et al., 2003; Levy, 2001a; Masri et al., 2000; McGee, Weinacker, & Raffin, 2000; Rocker, Shemie, & Lacroix, 2000; Vincent, 2001; Way, 2003). The incidence of patients dying from withholding and withdrawing of treatment is significant. For example, a recent Canadian study cites 37% of ventilated patients in 15 adult ICUs died after withholding or withdrawal of treatment (Cook et al., 2003). That figure has been estimated to be as high as 90% in adult ICUs in North America (Garros et al., 2003) and 70% in adult ICUs in the United Kingdom (Winter & Cohen, 1999). Garros et al. estimate that 30% to 60% of deaths in PICUs are post-withdrawal of treatment. The common practice in most intensive care units is to offer aggressive therapy for a period of time with the intent to review treatment within a short time frame. If improvement is not evident then discussions turn to withholding or withdrawing life support.

Terminology such as “withholding or withdrawing life support” is indicative of the perception of how patients die in critical care. Withholding or withdrawal of treatment in critical care is an indicator of medical futility; medical treatment is seen as non-beneficial to the patient as there is no hope for recovery or improvement (Storch, 2004). The patient dies because the adult or pediatric critical care team ceases to attempt to cure the patient. The description of how death occurs in critical care literature is frequently limited to the description of the support being withheld or withdrawn. The orchestration of death in critical care is more involved than simply limiting or withdrawing treatment. The implications for the patient, family and staff of the actual act of dying are deep and far reaching and include emotional, ethical, and sometimes legal perspectives.
Culture of Dying in Critical Care

The values, beliefs and norms regarding how children ought to die in pediatric critical care are not well understood. Literature exploring how children die in PICU has been mainly limited to retrospective chart reviews describing the circumstances under which children die in the technologically driven environment (Burns et al., 2000; Garros et al., 2003; McCallum et al., 2000). The culture of dying in critical care has been explored within the adult critical care environment (Harvey, 1997; Kaufman, 1998, 1999; Seymour, 1999, 2000). The findings illuminate values and beliefs held by families, critical care nurses and critical care physicians related to how death should occur in intensive care units.

Harvey (1997) conducted a comparative ethnography exploring the ‘natural’ death paradigm in critical care. Harvey compared the technological management and regulation of dying in critical care to that of the technological management and regulation of giving birth in hospital. Her findings focused on the attempts of critical care practitioners to mimic a ‘natural’ death by strategically withdrawing life support treatment. Harvey suggested that medical technology has allowed a greater control (e.g., surveillance and scheduling) over the birthing and dying trajectories. Because legislation was considered to be a significant influence in the regulation of birth and death, the medicalisation of birth and death was attributed to societal expectations as well as to a need to legally protect the physicians and nurses providing care (Harvey).

Seymour (1999, 2000) followed 13 individuals through their companion’s critical illness from admission to ICU to death or recovery. Seven of the participants’ companions died and six companions recovered. The focus of Seymour’s (1999) ethnography was to examine the expectations of death and technology. She questioned if a highly technological death was incongruent with ‘natural’ death. Seymour’s (1999) findings indicate that the concept of ‘natural’
death in ICU is specific to an individual’s understanding of the patient’s illness and their own meaning of technology. She discovered that the expectation of an individual regarding their companion’s prognosis and outcome was significant in determining how they viewed technology. For example, participants who had expected a companion to die viewed technology as a means of overcoming the illness or natural process. However, participants whose companions died, perceived technology as having an intricate role in realizing the best sequence of events; they viewed technological death as occurring before bodily death. Therefore, technology enabled critical care staff and participants to attend to the dying process in a manner that was reflective of the participants’ perception of a “good death” (Seymour, 1999).

In a secondary analysis of her original ethnography, Seymour (2000) explores two cases to better understand the way in which problems of definition between euthanasia, withdrawal of treatment and natural death are resolved during medical care in ICU. Seymour concludes that the relationship between ‘bodily’ death and the technologically negotiated death are constantly at risk of separating. She states that the successful negotiation of natural death in ICU is dependent upon four strategies. The first is the establishment of ‘technical’ death; achieved through tests and monitoring. The development of severity of illness scores is an example of an attempt by critical care practitioners to classify illness into predictable outcomes thereby erasing the uncertainty often introduced by different critical care physicians’ values and beliefs. The second strategy is to orchestrate the ‘technical’ and ‘bodily’ dying trajectories to coincide in an effort to dispel any concerns related to hurried or purposeful death on behalf of the critical care staff (e.g., euthanasia). The third strategy is often achieved through successfully balancing medical action with non-action or allowing the patient to declare himself. The fourth strategy addresses the role of the critical care team in achieving a natural death by negotiating with families.
Communication was viewed as key to negotiations between the family and critical care team, in particular with the physician group. Seymour’s analysis focused on the importance of finding a balance between current bioethical principles (e.g., autonomy, futility) in the face of advancing technology. This analysis is important because it questioned the importance of ethics in end-of-life decision making in critical care and begins to explore how ethics influences critical care culture.

Exploration into the culture of dying in critical care is important for developing a better understanding of the values and beliefs which drive the decision making that surrounds end-of-life. In this literature we see an emphasis on the medicalisation of death in Western society and the efforts made to make death as natural as possible in critical care within the ethical and legal constraints that currently exist (Harvey, 1997; Kaufman, 1998, 1999; Seymour, 1999, 2000). Attention to the futility of unnecessary treatment and death with dignity are emphasized. However, as previously discussed, there is often a tenuous balance between achieving death with dignity and the utilization and weaning of technology. This combined with physicians’ and nurses’ inability to accurately predict patient outcomes further complicates an already sensitive situation. Technological advances, the expectations that accompany these advances and variation amongst practitioners in communication surrounding end-of-life have magnified the complexity of end-of-life care, and have given rise to a number of difficult ethical issues.

*Ethical Issues Surrounding End-of-Life*

In exploring the relationship between ethics and dying in critical care it is important to gain an appreciation for how ethics informs values and influences the culture of critical care. Futility of care, euthanasia, and patient autonomy are significant ethical concerns associated with end-of-life care in critical care. As discussed in the preceding section, futility of care is related to the
concept of withholding or withdrawal of treatment. Reaching consensus regarding the futility of care is often a challenge in intensive care settings.

_Euthanasia, the doctrine of double effect or simply alleviating suffering?_ An ongoing debate in the literature focuses on the relationship between euthanasia and the doctrine of double effect (DDE). Euthanasia is viewed as a painless or mercy killing to end suffering (Storch, 2004). DDE is grounded in the philosophy that an act of good moral intent, regardless of potential evil consequences, is still viewed as morally good (Bica, 1999). This moral principle is used in modern day discussions predominately in the justification of murder by self-defence, death from pain relief, and the termination of pregnancy in an attempt to save the mother’s life (Bica, 1999; Botros, 1999; Boyle, 2001; Cohen-Almagor, 2000; Derse, 2000; Nuccetelli & Seay, 2000; Sanson et al., 1996; Vincent, 2001; Wolf, 2000). The ‘double-effect’ component of the doctrine lies in the acknowledgement that good actions may have negative consequences. Justification of these actions lies in the moral intent of the original action, not in the consequences. Burns et al. (2000) refer to DDE as “disingenuous hairsplitting, a form of rationalization for a practice that is surreptitious euthanasia” (p. 3063). Mitchell and Owens (2000) debate the legality and ethics of euthanasia in end-of-life care. American and Canadian authors appear to prefer the term DDE rather than euthanasia which appears to be a more controversial term in North America.

Nurses’ and physicians’ attitude towards, and practices about, administering analgesics, sedatives and neuromuscular blockers when withholding or withdrawing life support in PICUs has been examined (Burns et al., 2001; Burns et al., 2000; Garros et al., 2003). In a cross-sectional survey of 92 pediatric critical care nurses and 110 pediatric critical care physicians regarding attitudes and practices surrounding end-of-life care in PICU, two-thirds of the respondents reported being willing to increase or add analgesia and sedation to a patient’s end-
of-life treatment plan (Burns et al., 2001). In a retrospective chart review and nurse-physician questionnaire, Burns et al. (2000) examined both the type and amount of medications administered during end-of-life care and the agreement between nurses and physicians on the rationale for, and satisfaction with, the care provided. Physicians and nurses reported administering an increase in either the doses or dosage of analgesics and sedatives to 89% of the patients being reviewed. The reasons for doing so were recorded as pain management, to assist with anxiety, and to alleviate air hunger. Hastened death from an increased dose of analgesia and sedation was viewed as an acceptable, unintended side effect of end-of-life care by 91% of physician-nurse matched pairs. In an attempt to describe the circumstances surrounding end-of-life care, over an 8-month period Garros et al. (2003) surveyed pediatric critical care physicians after each of their patients died. Their findings regarding level of support and comfort measures indicate that analgesia was used in almost all end-of-life cases with less than 20% receiving an increase in analgesia. Only 13% were administered an anticipatory dose of sedatives at the time of death. In the three studies cited, the majority of physicians and nurses did not agree with administering neuromuscular blockades immediately prior to or at the time of treatment withdrawal (e.g., removal of the endotracheal tube). Recommendations were not made in the studies as to what dosage of analgesia or sedative should be administered for comfort and/or anxiety when withdrawing or withholding treatment. Findings from these studies provide data to support or validate current practice. The emphasis placed on alleviating suffering suggests that a component of the culture of dying in pediatric critical care is valuing patient comfort.

Patient autonomy versus proxy decision maker. Patient autonomy, the ability of an individual to make decisions about their own treatment, is often difficult to implement in critical care due to the patient’s physical and mental state (Winter & Cohen, 1999). The ability of
children to advocate for their own treatment is fraught with interpretive legislation and becomes even more complicated when the complexities of critical care are introduced. Because of their altered and limited capabilities to communicate their wishes, many adult critical care patients and almost all critically ill minors, are appointed a proxy. A proxy decision maker in health care refers to an individual whom health care professionals consult when decisions regarding treatment for a patient deemed incompetent need to be made. Common behaviours such as an ability to discuss, question, and demonstrate an understanding of the information as it pertains to their own health care are cited as indicators of an individual’s competence (Children's and Women's Health Center of British Columbia, 2002; Drane, 2000; Freedman, 2000). Unless a person is formally acknowledged as a proxy in writing, or through family consensus, the process of appointing a proxy decision maker risks becoming laborious and litigious. Parents, unless assumed to not hold their child’s best interest in mind, are routinely proxy decision makers.

‘Best interest’ is a term that appears in informed consent and discontinuation of treatment literature (Arnold & Kellum, 2003; Children's and Women's Health Center of British Columbia, 2002; Drane, 2000; Freedman, 2000; Leith, 1997, 1998). What is not clear is ‘best’ according to whom or what? Kluge (1995) suggested that medical, social and cultural standards should be examined when considering what is in a child’s best interest. One would hope the decision would be addressed from a holistic perspective while deciding treatment; keeping in mind that the complexities of these types of decisions often require ethical consultation.

The role of proxies in cessation of treatment decisions resulting in end-of-life within the adult context has been explored from a moral justification stance (Allen & Shuster, 2002; Arnold & Kellum, 2003) and through empirical inquiry (Emanuel & Emanuel, 1992; Heyland et al., 2003). There is a lack of evidence in pediatric critical care literature related to the role of parents as
proxy decision makers for their children. Perhaps, as previously discussed, the reason for this can be attributed to the position parents hold in society as decision makers for their children. The theoretical and empirical discussions surrounding proxy decision making in adult critical care are important because they identify staffbehaviours which may influence end-of-life decision making.

Few authors have captured the crux of the conflict surrounding proxy end-of-life decision making in critical care as succinctly as Arnold and Kellum (2003). In a discussion paper, the authors state that health care providers generally perceive a proxy as ignorant of medical knowledge and too emotionally involved with the patient. The proxy's relationship with the patient is believed to hinder the proxy from making unbiased decisions. Therefore, health care providers view proxies (who are usually family members) as being inappropriate choices as decision makers in critical care. Arnold and Kellum suggest that these viewpoints often lead health care providers to believe that proxies are pushing them to continue futile treatment. To this end, health care providers may exhibit avoidance, disapproval, or anger towards family or proxies as a result of the frustration and conflict the health care providers feel about having to provide care under what they may consider as futile conditions. Arnold and Kellum hypothesize the cycle of poor communication perpetuates a breakdown in communication and trust between proxies and the health care providers.

Arnold and Kellum (2003) provide suggestions for health care professionals when working with proxy decision makers to decide about treatment for patients within the critical care environment. They recommend allowing family members a fair amount of discretion in making decisions about other family members when those members cannot make the decisions for themselves. By doing so, health care providers are acknowledging that the position of family in
society and the position of family as proxy decision maker deserve the same freedom, respect and privacy. Their salient points are: to be mindful of the proxy decision maker's relationship with the patient while providing purposeful and meaningful communication; and, as with the findings in end-of-life empirical data, to ensure communication is timely. Although Arnold and Kellum's discussion was aimed at adult critical care, each of these points is likely to be relevant to end-of-life decision making in pediatric critical care.

Empirical evidence indicates that proxies are willing to participate and are satisfied with their experiences as proxy decision makers. In addition, proxies expressed a desire to collaborate with physicians in the actual decision-making process (Heyland et al., 2003). Emanuel and Emanuel (1992) reviewed 14 studies conducted with elderly adults and their family proxies in an attempt to ascertain: 1) the effectiveness of communication between family and patient regarding the patient's issues and values surrounding life-sustaining treatment, and 2) family members' perceptions of the patient's quality of life in comparison with the patient's perception. Emanuel and Emanuel concluded that empirical studies to date "suggest that proxies are not much better than chance at predicting patient's preferences during incompetence" (p. 2069).

There appears to be an assumption in health care that, under most circumstances, parents are, by virtue of being parents, the correct people to be making decisions for their children. Because parents are closer to their children than anyone else, it is usually assumed they would only have their child's best interest at heart (Shields, Kristensson-Hallstrom, Kristjansdottir, & Hunter, 2003). Kluge (1995) cites litigation which dissolves this assumption; disclosing that some parents are willing to have harm come to their children based on their personal beliefs and faith. Kluge states that in 1995, the Supreme Court of Canada deemed that incompetent children who have been placed in danger due to a refusal of medical treatment by their parent(s) can be
apprehended in order for treatment to be provided. This decision placed physicians in the role of patient advocate. However, the court cautioned the medical community that interference with a parent’s right to make decisions for their child must be justified (Kluge). In response to the national and provincial legislation, institutional and regulatory policies have been created that uphold current legislation.

There is evidence of debate surrounding the role of proxy decision makers; especially when it involves end-of-life decision making. In practice this debate seems to be the exception rather than the rule in pediatric critical care (Garros et al., 2003). Perhaps the relative silence in the pediatric critical care literature addressing the role of parent as proxy decision maker in end-of-life decision making is a reflection of the lack of problems surrounding the issue or it may simply be an unexplored domain of end-of-life care. Regardless, end-of-life decision making in PICU is typically set in a context of involving parents as proxy decision makers. Uncovering norms and practices related to the involvement of parents will provide direction for PICU nurses and physicians when communicating with parents on end-of-life issues.

Challenges of Providing End-of-Life Care in PICU

Consistent challenges of providing end-of-life care in PICU are described in the literature. These challenges are: effective communication with families and children; the process of dying within the PICU; working as a team to provide optimal care; and ethical issues in adult and pediatric critical care. An understanding of these challenges enables one to better appreciate the complexities and difficulties associated with end-of-life care which critical care health care providers are immersed in regularly. Some of these challenges have been addressed within the culture of critical care and dying in critical care section of this literature review. While this information is predominately adult based, cautiously applying aspects of it to pediatric critical
care practice continues to be a viable option due to the crossover in issues. Therefore, this section of the literature review will address effective communication with families surrounding end-of-life issues.

**Effective Communication with Families Surrounding End-of-Life Decision Making**

Studies exploring parental perceptions of their child’s death within the context of pediatric critical care (Macnab et al., 2003; Meyer et al., 2002; Votta et al., 2001) and retrospective reviews of pediatric critical care deaths (Burns et al., 2000; Garros et al., 2003; McCallum et al., 2000) have found that communication between physicians and families is a significant concern for family members. When a child is critically ill the possibility exists that they may reach a point where curative treatment is no longer an option. When that point is reached, families are usually approached by the PICU specialist to discuss withholding or withdrawal of life support. The dichotomy between end-of-life care and curative care has been identified as a key issue in critical care. Suggestions have been made that the two can work parallel to each other until the patient lives or dies, thus eliminating the need for a point in time or ‘line’ between curative and end-of-life care (Curtis & Patrick, 2001; Nelson & Meier, 1999). Rocker et al. (2000) suggest that a major difference between intensive care and end-of-life care could be related to the short time frame that exists before families are approached to discuss options for end-of-life care. For example, a family who has journeyed through a cancer diagnosis and treatment is likely to have had a period of time to realize the gravity of their child’s illness prior to discussing end-of-life care. In contrast, the family who has had a child stricken with an acute irreversible illness or injury may only have hours to experience this catastrophic assault to their world before being approached regarding end-of-life decisions. While Rocker’s suggestion is echoed in other adult and pediatric critical care discussion papers (Curtis et al., 2001; Fins & Solomon, 2001; Heyland,
Tranmer, & Feldman-Stewart, 2000; Miller et al., 2001), the scientific literature is inconclusive about the significance of the timing for end-of-life decision-making discussions (Macnab et al., 2003; McCallum et al., 2000; Meyer et al., 2002). The overwhelming theme in this literature is how the message is communicated.

An abundance of literature is available that addresses how to communicate with families regarding end-of-life decision making in pediatric critical care (Burns et al., 2000; Children's and Women's Health Center of British Columbia Ethics Committee, 2001; Cooley et al., 2000; B. Davies & Steele, 1996; R. Davies, Davis, & Sibert, 2003; Farrell, 1999; Fins & Solomon, 2001; Garros et al., 2003; Institute of Medicine of the National Academies, 2003; Kenny, 2003; Last Acts, 2002; Levetown, 1996; Levy, 2001a; Macnab et al., 2003; Masri et al., 2000; McCallum et al., 2000; Meyer et al., 2002; Rashotte et al., 1997; Robeznieks, 2002; Rushton & Catlin, 2002; Sahler, Frager, Levetown, Cohn, & Lipson, 2000; Savage, 1997; Simatovic, 1992; Tournay & Dickema, 2000; Votta et al., 2001) and ‘breaking bad news’ about health prognosis (Krahn, Hallum, & Kime, 1993; Simatovic, 1992; Wharton, Levine, Buka, & Emanuel, 1996). Adult and pediatric critical care authors agree that poor communication is a barrier to successful and fulfilling end-of-life discussions. Fins and Solomon (2001) state that “the success of these communications has a direct consequence for family trust and ultimately for the life and death decisions that families and health care professionals must make on behalf of patients” (p. N10).

End-of-life care discussions can lead to conflict amongst health care professional groups and family members. In a discussion paper regarding ethical decision making for children, Savage (1997) describes parents’ struggle with loss of control in their roles as provider and primary caregiver and cautions health care teams not to prejudge what a family’s reaction is based upon. She provides examples of health care team members assuming that families lack specific
knowledge when in actuality the families are experiencing a clash in values or beliefs with each
other or members of the health care team. She encourages exploring families’ values instead of
reacting with anger, defensiveness or legal apprehension. Vincent (2001) suggests the health care
team that end-of-life decision making has the potential to become further complicated when
cultural influences are involved. Masri et al. (2000) determined from their literature review of
end-of-life care and decision making regarding critically ill children that disagreements
regarding end-of-life decision making in PICU are usually resolved within five days. Garros et
al. (2003) reported consensus between family and staff regarding end-of-life decision making in
a Canadian PICU in 98 of 99 cases over an 8-month period.

Two key studies provide insight into parents’ experiences surrounding their child’s death in
PICU and how best to support parents through that process (Macnab et al., 2003; Meyer et al.,
2002). These studies are unique because they specifically address parents’ views of the adequacy
of pain management, decision making, and support during and after their child’s death. In both
studies questionnaires were distributed to parents who had had a child die in PICU. Macnab et al.
included a grief inventory and an interview by a grief counselor as additional forms of data
collection. Both authors identified their relatively small sample size (Meyer, et al., n=56 and
Macnab et al., n=24) and the homogeneity of the respondents as limitations to their studies.
Meyer et al. reported parents had a higher level of satisfaction with communication regarding
end-of-life decision making if the health care providers involved in their child’s care had
addressed factors identified as being most important to parents such as how their child would
behave post-illness or injury (e.g., a vegetative state), their child’s chance of getting better, the
amount of pain or discomfort their child was experiencing, and what was ‘the bottom line’. The
researchers concluded that discussions should not be focused on ventilator settings or
incremental changes in laboratory values but rather on issues that are identified as being important to parents. Macnab et al.'s findings indicated parent participants would have liked more information regarding updates on their child's status and what to expect during end-of-life care. In both studies, parents identified specific aspects of information they perceived as beneficial to assisting with end-of-life decision making and helpful in clarifying expectations surrounding what to expect during the dying process. These findings provide helpful guidance for pediatric critical care practitioners in communicating with families in ways that address their needs.

Exactly who should be delivering 'bad news' to families and children regarding end-of-life decision making has been questioned in the literature. As a result of their study findings, Macnab et al. (2003) recommended that physicians share the role of informing families of the futility of continued interventions and end-of-life options with other health care team members. There is evidence to support these findings; especially within the literature pertaining to disclosing diagnoses of life-limiting conditions (Baile, Lenzi, Parker, Buckman, & Cohen, 2002; Farrell, 1999; Ferrand et al., 2003; Sahler et al., 2000; Yardley, Davis, & Sheldon, 2001). Recent discussion papers emphasize a role for nursing in end-of-life communications because of the level of understanding, empathy, and sensitivity that nurses demonstrate with patients and families (Briggs & Colvin, 2002; Farrell, 1999; Miller et al., 2001; Puntillo, 2001). Farrell and Curtis et al. (2001) suggest that nurses could play a larger role in communicating with families by organizing and facilitating family conferences for the purpose of large group information sharing and planning.

The inclusion of nursing in formally facilitating end-of-life discussions is encouraging. Despite the existence of frameworks to assist health care providers in communicating with
families in complex situations (Farrell, 1999; Tracy & Ceronsky, 2001), further exploration backed up by education and support would be required to enable nurses to successfully engage in this aspect of end-of-life care. In addition, recommendations have been made for the education of health care providers to address the complexities of end-of-life care and encourage them to become self-reflective, able to identify prospective end-of-life cases and able to intervene accordingly (Fins & Solomon, 2001; Sahler et al., 2000). There is general agreement amongst the end-of-life authors that critical care nurses and physicians would benefit from end-of-life education (Burns et al., 2001; Garros et al., 2003; Levy, 2001a; Macnab et al., 2003).

The scientific evidence and discussion papers available provide some direction for pediatric critical care health care providers with regards to addressing the challenges of communicating effectively with families regarding end-of-life decision making. Specific parental needs and values have been identified pertaining to communication. However, evidence of the usefulness of the suggestions made for improving communication with families and children around end-of-life decision making is not evident in pediatric critical care literature and bears further investigation.

Summary

In this chapter, I have reviewed the literature pertinent to the influences of the pediatric critical care culture on end-of-life decision making. The literature reviewed provides limited insight into the culture of critical care and end-of-life decision making. The dominant cultural objective of critical care is to 'save lives'. This objective conflicts with providing end-of-life care. Achieving balance and working within this dichotomy is a challenge for anyone in critical care (e.g., nurse, physician, family member). Analysis of critical care and associated literature reflects this dichotomy; end-of-life care in critical care is a complex process.
Considering the impact that caring for dying children and their families has on health care professionals and their patients, the relative silence in all domains of the pediatric critical care literature regarding end-of-life decision making and pediatric critical care culture is noteworthy. There is little in the literature addressing the values, beliefs, and norms of PICU nurses and physicians. While retrospective chart reviews provide data on when and from what causes children die, they provide little information about the way we manage those deaths. Efforts to uncover richer data have begun (Meyer et al., 2002; Michon, Balkou, Hivon, & Cyr, 2003; Rashotte et al., 1997; Way, 2003) but the depth of research addressing the complexities of pediatric critical care remains lacking.

The implications of end-of-life care are far-reaching from an ethical and emotional perspective for families and health care team members. Explorations into how decisions evolve at end-of-life and how to achieve the best outcomes possible for all involved are important and needed contributions to the pediatric critical care literature. An understanding of what the culture of pediatric critical care is and how it influences end-of-life decision making will provide an important foundation for considerations in improving care.
CHAPTER 3: RESEARCH METHOD

A gap exists in nursing knowledge pertaining to how the culture of PICU affects end-of-life decision making. In an effort to reduce this knowledge gap I chose to explore the culture of PICU through qualitative research; more specifically through focused ethnography. The purpose of this chapter is to describe the rationale for choosing focused ethnography and to describe the study design including sampling, data collection, data analysis, protection of human rights, assumptions, and limitations.

Research Design

*Ethnographic Research in Nursing*

Nursing research and social science textbooks and articles describe ethnography in its simplest form as the study of cultural groups. Morse and Richards (2002) suggest that culture is responsive to change and is a way to describe the lens through which people view their world. Culture is described as consisting of “beliefs, behaviors, norms, attitudes, social arrangements, and forms of expression that form describable patterns in the lives of members of a community or institution” (Lecompte & Schensul, 1999, p. 48). LeCompte and Shensul’s definition of culture goes beyond the societal notions of culture that equate culture with ethnicity.

Ethnography has been described as a type of qualitative inquiry that provides a means of exploring a cultural group (Morse & Richards, 2002); “a picture of the ‘way of life’ of some identifiable group of people” (Wolcott as cited in Punch, 1998, p. 160); and a realistic, apolitical, and interpretive description of the culture being studied (Hammersley & Atkinson, 2001). Spradley (1979) and Polit and Hungler (1999) reinforce that ethnography is not about studying people; rather it is about learning from people to better understand their world as they view it. The group member’s or insider’s view is described as the emic perspective; whereas the view of
the researcher, presumed to be an outsider to the culture being studied, is considered to be the etic perspective. Tacit knowledge is described as “information about the culture that is so deeply embedded in cultural experiences that members do not talk about it or may not even be consciously aware of it” (Polit & Hungler, p. 245) and is, therefore, an important component of a culture. It is the goal of the ethnographer to gain an understanding of the emic perspective and to reveal tacit knowledge (Goodwin, Pope, Mort, & Smith, 2003; Platzer & James, 1997; Polit & Hungler).

Focused ethnography is referred to in anthropology as an applied form of ethnographic research (Wright, 2001). It enables the researcher to explore a particular topic or shared experience from a group’s emic perspective (Morse & Richards, 2002). Focused ethnography is often used to study sub-groups within a culture or to study institutions (Morse & Richards). In this study, the influences of PICU culture on end-of-life decision making were investigated. In this focused ethnography, PICU was the sub-culture; as opposed to the culture of health care providers, and the specific topic was end-of-life decision making in pediatric critical care.

Definition of Terms

End-of-life decision making and PICU culture were not pre-defined for this study because it was essential to elicit the participants’ definitions of these terms by exploring their values, beliefs, practices, and concerns surrounding end-of-life decision making in PICU. For the purpose of this study, a pediatric intensive care unit was defined as, “a hospital facility for provision of intensive nursing and medical care of critically ill [children], characterized by high quality and quantity of continuous nursing and medical supervision and by use of sophisticated monitoring and resuscitative equipment” (On-line Medical Dictionary, 2000).
Sample

Participant Recruitment

A purposive sample of nurses and physicians who work in PICU was sought. Participants were recruited from the 17 PICUs across Canada because the purpose of this study was to obtain data related to the general PICU culture and not a specific PICU’s culture. By studying nurses and physicians from PICUs across Canada the responses were more likely to reflect the general characteristics of the Canadian PICU culture (Biernacki & Waldorf, 1981).

Potential participants were divided into two groups. The differentiation for the groups was determined by which PICU the potential participants were employed in. Group A participants worked in the same PICU as the researcher and Group B participants worked in a different PICU than the researcher. Group A participants were informed of the study through discussion at the ICU Management Committee, announcements at PICU nursing education days, posting of the distribution of a ‘Participant Information Letter’ at the PICU front desk and coffee room and emailed distribution of a ‘Participant Information Letter’ to each PICU physician. Recruitment of Group B was achieved through emailing Canadian PICU nurse managers, nurse educators, and medical directors a ‘Participant Information Letter’ explaining the study and asking for their assistance in recruiting PICU nurses and physicians who fit the inclusion criteria. The email group was representative of the 17 PICUs across Canada. The email specifically addressed a request for the recipients to post the ‘Participant Information Letter’ in a location where PICU nurses and physicians will be able to see it and, if possible, approach participants that they feel have an interest in this particular topic and fit the inclusion criteria. In addition, potential participants were urged to contact the researcher if they had further questions. A copy of the participant information letter is included in Appendix A.
Inclusion Criteria

Participants were sought for the study who were registered nurses and pediatric critical care physicians currently working in a PICU in Canada with experience in caring for dying children and their families within the context of PICU. I avoided defining ‘experience’ as I did not wish to assume that experience with caring for a specific number of dying children and their families makes one more or less valuable of a participant. Interestingly, no one with less than four years of PICU experience expressed an interest in being in the study. A detailed description of the sample is described in the following chapter.

Data Collection

Data collection was achieved through one interview with each of the 17 participants. Four of these semi-structured interviews occurred in person. The remaining 13 interviews were conducted via telephone. The interviews were recorded via audiotape and digital recording. Fieldnotes were kept to enhance the recorded information with impressions and observations that I made about the interview process and content. This interpretive information aided in my analysis of the interview content by adding specific details about reactions, behaviours, or events occurring during the interview.

The interviews were conducted at a mutually convenient time for the participant and researcher. The length of the interviews varied from one-half to two hours. The average length of time per interview was one hour and ten minutes. The beginning of the ‘in-person’ interviews included a review and signing of the ‘Participant Consent Form’ and a collection of demographic data (see Appendices B & C). For the telephone interviews the consent forms and demographic data was received signed via fax or mail prior to commencement of the telephone interview. Confidentiality was reviewed with all participants prior to beginning their interviews.
The interviews were guided by an interview guide (see Appendix D). The questions were developed to probe the insider's view about providing end-of-life care in the PICU. Ideally ethnographic interviews are structured conversations in which topics are introduced and lines of inquiry are followed depending on what is shared by the participants. A better understanding of the participants' culture was achieved by: clarifying their 'natural language' (e.g., "I am unfamiliar with the term 'staff man'. Could you explain to me what their role is within your unit?"); probing any assumptions that the participant may state (e.g., the term "quality of life" required exploration to elicit the participants' perspectives and meanings associated with this concept); and encouraging the participant to share stories that described caring for dying children and their families and the end-of-life decision making involved in those experiences. Member checking occurred with select participants on an informal basis after preliminary analysis of all the data. Unlike a formal interview, these sessions were informal discussions which were held during a quiet time over the work day away from the bedside. This process proved to be a valuable approach for validating the credibility of the data (Polit & Hungler).

A staple of ethnographic research data collection tools has long been participant observation. The absence of participant observation in this study is addressed in the 'Limitations' section of Chapter 5. My role as nurse educator in BC's Children's Hospital PICU and the implications it presents in researching in my place of employment will also be addressed in the 'Limitations' section of Chapter 5.

Data Analysis

Morse and Richards (2002) describe the main goal of ethnographic research as creating narrative that richly, or thickly, describes a specific culture. I followed Morse and Richards' suggested approach for ethnographic analysis.
The first step in the analysis was aimed at developing an understanding of the cultural setting through data collection. The second analytic step was to develop thick descriptions through the following process of coding.

_Coding_

Following each interview I reviewed the tapes prior to sending them to a transcriptionist. I simultaneously updated my field notes while listening to the interview. On receipt of the completed transcripts, I reviewed each for accuracy in relation to content of the audiotape or digital recording. Once I had ensured that the transcripts were accurate, I coded each interview transcript by labeling beliefs, values and norms regarding routine decision making and end-of-life decision making in the participants’ PICUs. I coded using the QSR NVivo® qualitative analysis computer program.

QSR NVivo® enabled me to code the transcript using nodes. Much like colour coding or coding with labeled file folders, nodes are the electronic filing cabinets for coding with QSR NVivo®. I began the coding process by creating “free nodes” which were codes I applied to the values, beliefs, and norms in the interview data pertaining to routine and end-of-life decision making in PICU. Although my main goal was to analyse each interview independently, I looked for relationships and commonalities in the data as I worked through each transcript. After analyzing four interviews, I had a sense of some of the prevalent cultural themes. While this electronic approach to coding has its benefits, one of the risks I found was the tendency to over-code by creating too many “free nodes”. At one point I had over a hundred nodes and I was forced to rethink and recategorize my coding techniques by creating “tree nodes” which reflected the overall data and captured the themes. “Child nodes” were created from the “free nodes” and were sub-groups of data which supported the dominant cultural themes or “tree nodes”. This
coding enabled me to categorize the data to express relationships between the values, beliefs, and norms present in the transcripts.

The QSR NVivo® program has the ability to collate all the similarly coded sections. Another feature, the “node explorer”, is much like the file folder method of organizing data and enabled me to see which nodes reoccurred. By retrieving all data coded as a node, I was able to examine the commonalities and areas of divergence. For example, there were 11 passages for the node “unexpected deaths” from 8 participants that I was able to view by simply browsing the “tree node”.

Through the QSR NVivo® project manager I was able to file some adjunct data such as fieldnotes and a scanned participant’s decision-making chart. Throughout the analytical process I kept a journal of points of interest, my reflections on the process, and further areas I wished to explore. The keeping of a journal was an exercise I found challenging, therefore my “journal” exists in a project file box full of memos to myself and loose pieces of paper with notes about conversations or ideas for analysis. I found this a helpful way for me to make sense of the research process.

The third data analysis strategy focused on enhancing identification of cultural values and perspectives by comparing data collected from individuals working in different PICUs. Ideally there would have been equal representation of nurses and physicians from each PICU sampled. By including participants from more than one PICU, I was able to compare the participants’ descriptions of their PICU culture and develop an understanding of the overall PICU culture for the units they represented. As previously described, I was able to utilize the QSR NVivo® qualitative analysis program to sort through the values, beliefs and norms of PICU culture regarding end-of-life decision making and identify dominant cultural themes. A limitation I
experienced when moving towards analysis was how to make sense of my coding to create a rich description that presents a “comprehensive, consistent, and logical portrayal of the [PICU culture and its influence during end-of-life decision making] from the emic perspective” (Morse and Richards, p. 155). Once I had completed my coding process I switched to a non-electronic form of analysis by creating magnets for the “tree” and “child nodes” and, with the assistance of my thesis supervisor, rearranging the codes on a magnetic board into dominant cultural themes. This was an interesting and rewarding process as the ability to visualize the codes and group them together assisted me in my analysis process; something I was unable to accomplish at my novice stage with the QSR NVivo® qualitative analysis program.

Data collection and analysis occurred on an ongoing basis. By being reflective in my approach, my insider’s perspective benefited both the interview and analysis process as I was able to draw upon my experiences and theoretical knowledge to generate theoretical insights in the analysis process. The danger of being an insider was that some practices and assumptions could have been taken for granted. By involving my supervisor and committee members in the analysis I was challenged to consider alternative interpretations.

Assumptions

The fact that I am a PICU nurse who is considered an expert in my work environment regarding caring for dying children and their families, has led to the development of the following assumptions. These were developed at the beginning of this research process and have been revisited throughout the study. They were refined based on the literature review and influenced the design and implementation of this study.

1. End-of-life decision making and the death of a child is a traumatic event that should be effectively managed by PICU nurses and physicians.
2. Interprofessional health team members have a shared culture to be identified as the ‘PICU culture’.

3. PICU cultures across Canada are fluid and continually evolving, shaped by current trends in health care and society.

4. Some PICU nurses and physicians are interested in the relationship between their culture and end-of-life decision making. (This assumption was challenged by the findings of this study because all participants described being interested in the relationship between their culture and end-of-life decision making).

5. The PICU culture influences end-of-life decision making in some manner.

6. PICU nurses and physicians are interested in providing quality care to dying children and their families.

7. A power imbalance exists between PICU physicians and other members of the interprofessional health care team regarding decision making.

8. A power imbalance exists between PICU interprofessional health care team members and families regarding decision making.

9. PICU nurses believe that end-of-life decision making is not managed as expeditiously or sensitively as it could be by the PICU physicians.

10. PICU physicians believe that the PICU interprofessional health care team provides timely and efficient support regarding end-of-life decision making. (This assumption was challenged by the findings of this study because some of the physician participants provided examples describing their frustration in reaching consensus regarding end-of-life decision making and the detrimental effect this had on families).
Ethical Considerations

Approval for research with human subjects was obtained through both Children’s and Women’s Health Center of British Columbia’s Research Review Committee and the University of British Columbia’s Behavioural Research Ethics Board prior to approaching potential participants and commencing data collection. The ethical considerations focused on informed consent and confidentiality. The following processes were instituted:

1. Participation was confirmed with the participant once he/she contacted me by phone, email or in person.

2. Participants were informed about the purpose of the study and the potential use of the study findings (Appendix B).

3. Participants were informed that participation is voluntary and they have a right to refuse not to answer questions (Appendix B).

4. Each interview (whether in person or by telephone) was conducted in as private a setting as possible (e.g., a private room).

5. Access to the participants’ names is limited to my thesis supervisor and myself.

6. All audiotapes or digital recordings and their matching transcripts, field notes, consent forms, demographic data forms, and unit maps were given participant numbers and kept in a locked cabinet.

7. Specific details were altered to protect the identities of the individuals involved in these particular situations.

Summary

The complexities of the PICU culture in combination with end-of-life decision making are under explored topics. In an effort to uncover the cultural norms, values, and beliefs of the PICU
culture, a qualitative research approach of focused ethnography was chosen. Application of this methodology has resulted in rich descriptions of the influences the PICU culture has on end-of-life decision making. This study provides a starting point for research in this area and has uncovered questions for further research. The details of these findings are presented in the next chapter.
CHAPTER 4: FINDINGS

In this study, the nature of pediatric critical care culture in Canada and its influences on end-of-life decision making for critically ill children are explored. The findings suggest that PICU nurses and physicians endeavour to orchestrate death through a deliberate and conscious creation of a clear and unified approach to the end of the child’s life. End-of-life decision making is identified as a fluid process that continually shifts to meet the needs of the patient, family, staff, and the critical care environment. The unpredictability of death, in combination with the complexities and challenges of a critical care environment and the variety of health care professionals involved create barriers for the development of a clear and unified approach to end-of-life decision making.

To provide the reader with the context for this study, the chapter begins with a brief description of the participants. In the next section, the culture of PICU is described to enable the reader to appreciate the nature of the work and the values and beliefs of the types of people who work in PICU. Finally, how these cultural themes influence end-of-life decision making will be presented. In accordance with ethnographic principles, and in an effort to capture the meaning the participants shared, their own words have been used to exemplify key points.

The Sample

Seventeen participants, representing pediatric critical care nurses and physicians from across Canada, were interviewed for this study (Figure 4.1). The participants represented PICUs from British Columbia, Alberta, Saskatchewan, Manitoba, Ontario and Quebec. Even though many of the provinces have more than one PICU, only British Columbia and Ontario had more than one PICU represented in this study.
Figure 4.1: Distribution of participants by Canadian provinces (‘H’ hospital & ‘P’ participant)

The participant sample included 11 female nurses and 6 pediatric critical care physician specialists. There was an equal male/female split between the physicians. All of the physicians held another medical specialty certification (e.g., epidemiology, pediatrics, ethics, infectious diseases, and anaesthesiology). Of the 11 nurses, six held a specialty nursing certificate (e.g., neonatal ICU, pediatric critical care, critical care, and emergency nursing), four had an undergraduate nursing degree, and three held a graduate degree in nursing. The nurses represented four different nursing roles (e.g., 7 bedside nurses, 2 nurse educators, 1 clinical resource nurse, and 1 clinical nurse specialist). Ten of the participants have had experience working in another PICU in Canada or the United Kingdom. The age of the participants ranged from 25 to greater than 50 years. The number of years of experience in nursing or medicine ranged between 4 to 31 years (mean of 18 years), while the number of years in pediatric critical care ranged between 4 to 26 years (mean of 13 years). The last time the participants cared for a dying child was a median time of one month. The actual range was from ‘yesterday’ to three
years ago. Thirteen of the participants (all the physicians and seven of the nurses) reported being parents.

The Culture of PICU

_We’re not called critical care for no reason. We’re critical of ourselves and we do critical care work. And people feel bad when we can’t cure the kids. (Nurse participant)_

PICUs are different from other pediatric units in a hospital because they provide ongoing respiratory and cardiac support for the critically ill infant, child and adolescent (e.g., artificial airways, mechanical ventilation, invasive monitoring, cardiovascular support through continuous intravenous infusion of inotropic or vasoactive drugs). In addition, PICUs enable close monitoring of high risk patients in an environment where rapid access to highly specialized nursing and medical support can occur.

_PICUs in Canada_

To date there are approximately 17 PICUs in Canada. Eight of these PICUs are represented in this study. The smallest PICU represented in this study had a bed capacity of four and the largest was 36. The design of these spaces appears to be similar. With the exception of one unit, the participants indicated that the units were designed with approximately 25% of their capacity as isolation rooms and the remaining patient care areas were open to a central station. Curtains divide the patient care areas. To accommodate the varied age and size of the patients, patient care areas could contain bassinette, cribs, stretchers or beds. The spaces were described as relatively small with a standard setup of a worktable, assorted small supplies, a monitor, monitoring cables, intravenous infusion pumps, and a ventilator at each bedside. Depending on the size of the patient, the number of visitors, and the equipment required at the bedside, the patient care areas could be quite crowded.
The pediatric critical care delivered in these units primarily focused on close monitoring of high-risk children and invasive respiratory, cardiac, neurological and metabolic support for critically ill children. The support offered varied depending on the services available at each hospital. For example, the largest hospital represented in this study was not only a regional referral and teaching center but a facility that was nationally and internationally renowned for the specialized services provided. In comparison, the smallest unit provided basic critical care to critically ill children in its region. In this small unit, when the staff were unable to provide the support required, the critically ill child was transferred to the provincial children’s hospital.

The Nature of the Work

Simply describing the population served does little to describe the day-to-day nature of the work. The participants described treating children with a variety of illnesses and injuries. They emphasized how the unpredictability of their environment contributed to a sense of actual or potential disorder. Their environment included their work space, equipment, colleagues, patients, patients’ families, and the events which unfolded as a result of these components interacting. Discharging and attempting to admit planned and unplanned admissions was described as a stressor because of a shortage of nurses and limited bed spaces. Each of the participants worked within a hospital setting where the PICU members responded to pediatric cardiac and/or respiratory emergencies as part of the resuscitation team. While this role was viewed as important, it did contribute to the continuous sense of potential disorder. In addition, the critical nature of the patients themselves added to this sense of disorder as the participants described being vigilant in their assessment skills in an attempt to prevent a child’s condition from deteriorating.
There was consensus amongst the participants with respect to their goal of wanting to improve each child’s health. One physician stated, “It’s honestly our nature... we care for patients. We really want them to get better.” “Getting them better” was described as a complex process involving assessment, planning, and implementation of care within an unpredictable environment. Therefore, achieving this goal required trying to create order from the constant threat of disorder. One nurse described her conviction about the child being her focus: “It's the culture of the unit... the only thing that matters in that whole unit is the kid. And I don't really care about anybodies’ egos or feelings at that stage of the game. It really doesn't matter.”

*Caring for the “whole” child.* Nurses and physicians emphasized caring for the “whole” child; this included knowing the child physically and psychologically. The physician group tended to speak more about treating a whole body rather than a broken bone, damaged heart or failing kidney. One physician simply stated, “I think critical care physicians are probably the only physicians left that are still whole body doctors.” The nurses spoke of caring for the whole body and the person. For example, one nurse described the rationale for her practice in the following way:

Somebody asked me one day why I brought the colored blankets and the shampoos and stuff for the kids. It’s because I’ve been there for so long, I need to know that that’s a child. And if they’re just white on white on white, if they don’t smell like a child, if they don’t look like a child, I can be very clinical about it.... If you don’t use one of your five senses to say this is actually a child then it’s just too easy to forget that they’re children because no one’s looking at the child as a whole person.

For this nurse, valuing the child was essential to providing holistic care.
Interestingly, while the participants all emphasized knowing the patient, most admitted that this perspective was difficult to maintain. They described themselves as seeing limited “snapshots” of the children’s and families’ lives. This narrow perspective was in part due to the fact that the participants worked within a specific point in time of a child’s life and illness trajectory and therefore were unable to truly “know” the child. As one nurse explained below, not knowing the child prevented her from understanding treatment choices:

Oncology always has been, “If we can just get them through this…” And we see, we create, the suffering…. I think [oncologists] can be optimistic because they’ve seen the results. Whereas in ICU we tend to see such a limited picture…. We don’t see them after chemo and when they’ve been in remission for two or three years… All the suffering that we put them through, some of them do survive occasionally. So, in [the oncologists’] minds there is a 2% chance that they’re going to make it and they push for those limits, and all you want to do as a bedside nurse, all you seem to want to do is end the suffering sometimes. You put them through so much. They’ve been septic and on antibiotics, off for a week, and then back on again and extubated, reintubated, extubated, reintubated and you think enough is enough. But, I must say some kids that I thought we should have stopped treatment on they’ve come off [the ventilator] and gone home, so…

This nurse later described herself as “jaded”, as having lost perspective when caring for children she viewed as futile. She identified this as limiting her ability to care equally for all children. Another nurse emphatically summarized the nature of the work as “bizarre” and suggested the following about the nature of work in PICU:

The stuff you see in there and have to do and have to put kids through and put families through and put your colleagues through, is bizarre many, many of the times. When you think
of the burns, opening up kids' chests in the unit, it is not what you do on a day-to-day basis in an office job.

Therefore, in an effort to make sense of their perceived disorder, to make sense of working in a stressful environment, some of the participants withdrew emotionally or physically from the environment, some accepted the nature of the work, and some fought back.

*The Types of People Who Work in PICU*

Typically, the physicians and nurses used any combination of the following terms to describe themselves: "perfectionists", "control freaks", "Type A", "driven", "committed", "organized", "assertive", "opinionated", "caring", "compassionate", "responsive", "twisted", "intelligent", "a resource", "an adrenaline junkie", "looking for a challenge" and "a lifelong learner". How these characteristics played out in the work of the participants was personal. In an effort to control the potential or actual disorder, participants emphasized their sense of responsibility for providing the best care possible for the children within an interprofessional model of care. Nurses described themselves as the "gatekeepers", advocating for their patients and families. Critical care physicians described themselves as "ultimately responsible" for the care each child received. Often they were responsible for overseeing other physicians who were specializing in pediatric critical care or pediatrics.

*On top of their game.* To work in the PICU, the participants were required to have extensive education, both in the theory and practice of pediatric critical care. In the interviews, there was evidence of the value they placed upon their expertise. There was a sense of the PICU team viewing themselves as the ‘in’ or elite group within their institutions as evidenced by the ‘us and them’ mentality that pervaded their work.
As an elite group working in a fast-paced area, the participants described the need to be constantly honing their skills. They maintained that the ever-changing environment of critical care creates opportunities for continuous professional growth. The need to be ‘on top of your game’ at all times in order to provide the best care possible was identified.

Six of the seven PICUs represented in this study are located in pediatric teaching hospitals. In order to have a residency or fellowship program, the hospitals must meet certain academic and professional standards. Meeting this standard requires a commitment to ongoing learning and research, especially from the physician group. The physicians and masters-prepared nurses spoke of the value of qualitative and quantitative research in improving practice. One physician described how decision making is a balance of experience and scientific evidence. He stated that in the unit he works, “We tend to go by the gut feeling, our experience, and what the literature says.”

Because participants saw themselves as highly skilled and knowledgeable, those who did not work in PICU were perceived as not being able to understand the work or needs of PICU patients. The recommendations of specialists who continued to follow their patients following admission to PICU were particularly suspect. In particular, tension between the specialists in oncology, cardiology and cardiovascular surgery and the PICU doctors was apparent. Participants struggled with balancing their knowledge and experiences with the wishes of family and referring specialists, specifically when the participants perceived that the child had a limited prognosis. While some nurses perceived the PICU physicians’ and specialists’ struggles for control of a case as adversarial and detrimental to the progress of the child’s care, the PICU physicians spoke of these struggles as part of the process of planning the patient’s care. All participants verbalized frustration with trying to balance the needs of the patient, family and
specialist. The specialist was often viewed as “unrealistic” or thinking he/she was “never wrong”. Each participant cited one or more examples of how specialists had commented to family or staff that the physiologic system or organ they were responsible for was “fine” when in fact it was not. This created confusion for the family. When this occurred, the nurse assessed the family’s understanding of their child’s status and independently, or in conjunction with a physician colleague, attempted to provide the family with a clear picture of what was the current reality.

*Experience definitely counts.* The assumption that a nurse’s or physician’s years of experience in PICU equals expertise does not exist in the PICU culture. There was an expectation that individuals must prove their competence before they are valued for their experience. One nurse spoke of a physician from another country who was enrolled in the pediatric critical care fellowship program at her hospital. She described his previous work experience and his current performance:

> [He] is very much in over his head and things just don’t get done because he’s really not sure what to do, and he doesn’t want to make a mistake. I can’t fault him for that. But when I need something done for my child, I usually will just pass him because I know I’m not going to get the answer I need… a lot of us in here do that.

The need to prove competence related directly to the goal of the PICU “to make the child better”.

*No one understands but us.* The participants described the isolation they felt as a result of their work. They shared feelings of being disconnected from other health care professionals, their friends and family members. Many acknowledged that because the work done in PICU is not well known to the public and viewed as “sad” and “depressing” by many of their friends and
families, a “no one understands but us” attitude existed. One nurse explained her perspective of the need for colleagues to rely on one another for support because no one else understood:

But one thing you typically do hear from nurses is a lot of them don’t go home and vent. They vent with their peers… because family or friends at home that don’t have a medical or nursing background don’t understand.

*Parenting changes your perception.* When asked if having children had changed how they practice within the PICU, those who had children described themselves as being more sensitive to the needs of the families. One physician stated, “Having children has changed the way I see and empathize with the family. I don’t think before I had more or less difficulty in [end-of-life decision making] but I think now it hits home a little bit more”. Some of the participants described themselves as feeling more vulnerable since they had their own children. They described the ongoing fear they carry for their own children’s safety and health. For example, one nurse described how being a PICU nurse has altered her parenting:

It definitely makes a difference [being a parent and working in PICU]…. When there is a kid admitted who is the age of one of my children, that’s harder. And it’s also just harder in the fact that before you went into nursing you just kind of thought, “If I could only have a healthy baby, I’ll be fine. We’ll be through [the pregnancy] and life will be better.” And then you work in the PICU and it becomes, “Oh no, disasters can happen all the way till they’re eighteen years old.” And it’s like, “Oh my God, what have we gotten into? And will my kids …[still be] alive by the time they’re eighteen?”

The parent participants verbalized appreciation that their own children were healthy. While all participants implied that their work had helped them realize that life is fragile, the participants with children stated it made them really appreciate their children’s health and vitality.
The emotional impact of caring. The pressure of making a mistake and harming a child was alluded to by the participants. The emotional intensity was described as increasing when there was a sense that one had lost control and for some participants, this resulted in them withdrawing from the environment. In particular, one nurse had been severely impacted by some of her work experiences. A senior nursing leader in her workplace, she switched to casual work status. At the time of her interview, she continued to struggle with feelings of helplessness and an inability to make sense of what she termed “the chaos”. With great difficulty she shared the pain and anxiety she felt, and still carries with her, surrounding the care she provided for a dying adolescent. She believed that care should have been discontinued based upon the adolescent’s pre-operative wishes. The following is her story of how that one case has affected her:

[Participant asking interviewer] Did you not feel this unbelievable panic rising inside of you because things were going on that you felt shouldn't be going on and there's nothing that you could do about it? You had to go, you had to just go and keep [providing care].... The whole time I was on my vacation, every time I'd be [doing a sport her patient excelled in], I'd think of him and I'd just breakdown and I'd just go, "Jesus Christ, what did we do to him?" And even now... (Pause. Beginning to cry. Whispering.) I don't think I'm going to go back.... I cannot believe I feel responsible for allowing it to happen.

Her anguish over the decisions made for this adolescent paints a vivid picture of the impact of the work in PICU.

While the nurses discussed their feelings of loss and frustration at an emotional level, physicians articulated this loss in a more controlled and scientific manner. All of the physicians stated they “get pretty upset” at times when speaking with families about end-of-life. Many of them were able to estimate how many deaths they dealt with in a year or had experienced over
their careers. Yet none of the physicians spoke about the long-term impact this type of work has on them.

Interestingly, many of the participants were anxious about their interviews because they were worried about what I might ask or “dig up”. One nurse simply stated:

You know I fussed about it today. “Oh what’s she going to ask me? And how many memories am I going to dredge up? Am I going to be depressed tonight?” But I’m not. And this is good. We need to talk about these things more.

The participants verbalized the importance of the topic of caring for critically ill and dying children. They stated it was important for all PICU team members to address their beliefs and fears about caring for dying children and their families in order to survive the emotional impact of the work and provide quality, holistic care.

Dependent on Technology

Viewed as both a blessing and a curse, participants were influenced by the dependence on technology in critical care. Every child in PICU is connected to a cardio-respiratory monitor. The technology is endless with tubes for central intravenous infusions, catheters, infusion pumps, 24 hour dialysis machines, incubators, cooling/warming blankets, ventilators, medications and more. The role of the PICU team is to decide which technology the child should have, to put it in place, and to interpret the data to mark the child’s progress.

The unofficial motto of PICU practitioners as described by the participants was, ‘When in doubt, add a tube or line’. As one nurse explained, “In the heat of the moment, and when you’re faced with that reality you save the child”. Participants, however, lamented on how the “slippery slope” of technology often led to the difficult task of identifying when and how to discontinue it. “What have we done?” was a prevalent theme when faced with the realities of the situation after
certain resuscitations, such as full resuscitation on a child at the end-stage of a terminal illness. There was consensus amongst the participants that it is philosophically harder to remove a breathing tube than it is to put one in. However, all stood by the belief that in an emergency where there are no known wishes, the best choice was to treat. One physician stated:

I mean if the kid is crashing with hypoxia or bradycardia then that’s not the time to sit the parents down and say, “Well we should think very seriously about the type of support.” You provide the support and then worry about it after.

Despite being viewed as a blessing in many circumstances, technology was viewed as a curse when used to prolong life in cases deemed to be futile. Extracorporeal life support (ECLS) is a form of bedside heart-lung bypass. Many of the participants had this technology available and praised the technology for the lives it has helped saved. As one nurse laughingly declared, “We’ve seen some amazing things using technology which you wouldn’t actually think would ever happen. Heart transplant crashing onto ECLS. Whooeee. Aren’t we clever, and we are!” Yet, participants were quick to point out that ECLS is another technology that has complicated matters by adding one more dimension to care and with it altered expectations of what outcomes can be achieved. The participants viewed these expectations as unrealistic, especially when they felt pressured by families, society, and other health care professionals to be aggressive with treatment. One physician expressed his views on the subject of expectations:

I just think that families’ expectations are different. I don’t think it [end-of-life decision making] is any harder than it was when I first started [as a PICU physician]. I think what has happened is that expectations of what medical care can do has changed. And equally, expectations of what society can and should support has changed.... I also think that
traditional expectations of, or non-critical care physician expectations of, what critical care can do have also exceeded reality.

Not surprisingly there were reports of conflict between the health care team and family when viewpoints differed about what was and was not considered reasonable treatment.

*Being Driven by Routines*

When one considers the type of people who work in PICU, the nature of the work, the cluttered environment, and the stressed families present, it is not surprising that there is a need to control the environment and the people in it. The participants described how there is an attempt to provide structure to the work of the unit; to create a standard routine that symbolizes normalcy. They described efforts to create a predictable environment within one that is unpredictable.

In an effort to better understand each participant’s unit and their routines, nurses and physicians were asked to describe a typical day. There was little variation among the participants in this study. Nurses and physicians arrived on shift and obtained report from their peers. The nurses assessed their patient(s) and documented their findings. Each nurse then prepared her presentation for morning rounds. Participants felt that morning rounds were a medical teaching tool and necessary to create a plan for the next 24 hours. If family members were present at the bedside, the nurse might engage in conversation depending on the family’s wishes and the nurse’s busyness. The ICU physicians on call, respiratory therapist(s), residents and/or fellows would meet prior to rounds and view the night’s x-rays with a radiologist. Then the group of physicians and the respiratory therapist(s) would proceed to the first bedside for morning rounds. The PICU physician on call usually “collected” the charge nurse on their way. In most units the physician first provided a summary of the patient’s history, progress to date and current
problems. The bedside nurse and the remainder of the presenters (e.g., respiratory therapist, physiotherapist, pharmacist and social worker) then followed with their reports. A plan was created and the group moved to the next bedside.

Consistency in the implementation and communication of the plan was viewed as a key to good care, so much so that physician groups in various centers were reported to have changed their on-call schedule to allow for maximum consistency. One physician described what his physician group did to address consistency:

And the reason we do [one week on call] is for continuity of care. So that we become familiar and associated with the child’s clinical problems and also enter into discussions with the parents about whatever is going on with their child, or potential plan, etc. If we have particularly complex children who’ve been in for a longer period of time, longer than a few days, what we tend to try and do is to identify an individual staff physician who’ll remain the continuity or contact person from a physician level for that patient and their family. This is to try and get over the problem that one has with people conveying, or trying to convey, the same message and using different terminology and language which often leads to confusion in parents particularly given the multi-cultural nature of the population that we deal with.

As the PICU patient population was reported to be relatively transient with a less than three-day stay, maintaining consistency with long-term patients was described as challenging. In many of the centers, a once weekly round was conducted for the longer-term patients. Viewed as an opportunity to follow and make long-term plans for those children, this round was often reported to be inclusive of a wider range of staff such as the psychologist.

Until recently, the idea of anyone but the PICU team being present for morning rounds was unthinkable. With the evolution of family-centred care in pediatric centers many PICUs have
been encouraged to include families in all aspects of their child’s care. This includes participating in morning rounds and long-term rounds. While the participants spoke of family members’ rights to be included in reviewing and planning care, they were frustrated with the challenges it presented, especially the disruption parental presence posed for their routines. The limitations family presence placed on the rounds routine involved limiting teaching, affecting the “completeness” of the plan, and maintaining confidentiality. One physician complained about the inconveniences of parents’ presence during rounds for him but acknowledged the benefits to the parents:

The problem is that when we are discussing, the parents hear everything about the other family’s problems and the kid’s problems. Confidentiality [is an issue] and it inhibits our discussion regarding ethical issues at the bedside. Especially, when we talk about teaching.... You could say, “Well you should be open and talk about those topics anyway, with the family present”. Yeah sure, but after you have some kind of an understanding and agreement.... [Until that is established we move] to another bed that is hidden in the corner and we whisper about the case. So, I think that’s one of the disadvantages, but in terms of family-centred care, and that philosophy, having the parents present, I think it’s advantageous for them.

It is important to note that confidentiality was viewed as a privacy issue even though, as one nurse laughingly stated, “The families know more about each other from the waiting room than we do.”

Partnering with families was acknowledged as a primary value to successful family-centred care yet living the reality of partnering with families was identified as a challenge due to staff values, beliefs and ignorance. The physicians were open about their confusion regarding how to make this concept come to life in PICU without impacting care. Physicians claimed that the
nurses did not “like” the families at the bedside on rounds and that this was the reason they resisted family presence at morning rounds. The phenomenon of shifting blame away from themselves and onto the nurses was interesting because although nurses also spoke to challenges with parental presence during rounds, few believed it should be stopped. Rather, they spoke of trying to work within that particular context to create the best outcome for all.

The participants indicated that rounds, policies and procedures regulate and guide their practice. For example, in three of the units there was a formal policy on who a nurse should call first when needing assistance. Upon reflecting on these policies, the participants stated the policy in question was more of a guideline than a policy because they would “go above” a resident if he or she was deemed inexperienced.

As much as routines drive practice, the flexibility that is required of the PICU staff to respond to any situation was also evident. The participants described unique situations where they made decisions on the spot that subsequently led to an eventual practice change. One nurse recalled the conflict she felt when a mother refused to leave the room during her daughter’s resuscitation, “Up to that time I don’t know if we’d ever had a parent present when we were defibrillating. So that was new for us but I thought, ‘OK, if other centers can do it, we can too’.” Not surprisingly then, when there was a newer or difficult situation, there was a desire to create a policy in an effort to control the situation. One nurse described her desire to create a policy for nurses surrounding end-of-life care:

I would like to write the policy for the nurses on what to do in that case [caring for a dying child]; because I remember young nurses asking, "What is going to happen? What am I going to do?" Unfortunately, I have no recipe.
While routines appeared rigid at times, they provided guidelines and, more importantly, security for the participants who worked within an unpredictable work environment. Challenging those routines created disorder and the participants described being uncomfortable with someone else trying to control their environment by altering their routines.

**Role Distinction**

In an unpredictable environment driven by routines it is not surprising that the participants referred to defined roles and hierarchies. Each role had responsibilities attached to it. But in reality there was a fluid quality to tasks and decision making that was driven by necessity. One nurse spoke of what a nurse would do in a circumstance in which a child’s blood pressure and heart rate were dropping.

The nurse will up [the medications] and then go to the resident for the official order for it. Certainly if patients are deteriorating, the nurse would make changes. Medicine and nursing are quite blended; the line is quite grey. Officially, nurses don’t make a lot of medical decisions. But unofficially, they do.

The blurred line between nursing and medicine was reinforced throughout the participants’ stories. Legally, however, the responsibility of a patient’s health care was described as ultimately lying with PICU physicians. Care of the family was largely viewed as the nurse’s domain. Nurses were described as knowing more about the patient and family because they were physically with the child and family for longer periods of time. Nurses were described as patient and family advocates as evidenced by “badgering docs” to get the orders the nurse felt the patient needed or “going after them to sit down with the family again”. For example, one nurse described how nurses recognized patients as children by touching them and talking to them, “Nurses do it. Doctors don’t. Not even the good ones.” A “good” physician was described as
having advanced clinical skills, decisive decision making and compassion with children and families.

Participants agreed that the clinical boss in the PICU hierarchy was the PICU physician. Who was next in line was dependent on the personalities involved and what proven skill set and decision making capabilities they possessed. One nurse’s description of decision making in her PICU was typical:

The bedside nurse would take the concern to the charge nurse usually first. And then if it’s a medical concern, i.e., needing a drug order or a medical order, the charge nurse would take that to the resident and then if the resident wanted support or guidance on that they would take it to the [PICU physician].

In addition, the experience of the bedside nurse was believed to influence who he/she sought out to assist with a clinical problem. For example, an experienced nurse might bypass the resident based on the resident’s perceived competency or bypass the charge nurse and take a clinical problem to whomever would be best suited to answer it (e.g., ventilator problem would likely be directed to a respiratory therapist). One experienced nurse spoke of “passing something by” her more experienced colleagues before approaching a junior charge nurse. Many of the participants cited examples of working with residents or fellows who they felt were unsafe. Under those circumstances it was acceptable to break the policy and go straight to the PICU physician with a concern. All the participants reiterated that the patient’s safety came first.

The nurse-physician relationship in PICU was reported as being controlling in some centers. One nurse described the restrictive nature of the nursing role in her PICU: “The responsibility of the staff nurses is not as optimal as it should be. I would say that our pediatric intensivists are not very trusting about the responsibility of the staff nurse.” A physician participant from this same
PICU referred to the nurses as having a limited involvement in patient decision-making conversations. Other nurse participants described nurse-physician relationships as depending on the individuals involved. For example, one nurse described her relationship with her physician colleagues as depending on the physician:

Sometimes I don’t think (the physicians) listen to you at all and you could be saying, “The sky is purple and the sun was mauve” and they would still go “Mhmm, mhmm”. Sometimes they don’t hear you at all. Yet, sometimes I think that we do have physicians who are very respectful of the nurse and will say on a regular basis that “You guys are our eyes and we value you and we need to keep you here.” I think they really value our input. Some, more than others.

The evidence of hierarchy amongst the nurses was limited to the concept of experience being valued. There was great value placed on the competencies of a senior nurse versus a lesser experienced junior nurse. In one PICU the senior nurses worked the favoured shifts and the junior nurses worked the less desirable shifts with two senior nurses as resources. The nurse participants described themselves as working collaboratively with members of the PICU interdisciplinary team (e.g., physicians, respiratory therapists, occupational therapists, physiotherapists, pharmacists, social workers, spiritual care) and nursing colleagues from PICU and other areas of their hospital.

End-of-Life Decision Making in PICU

"End-of-life decision making is a very complex topic because it has many, many links with practice, also with individual values... what you value about life, about death, about nursing, about the medical profession, and I find that each case is unique. (Nurse participant)"
The complex nature of the PICU culture was a consistent theme across the interviews. As previously stated, paramount to any external forces was the desire to make children better. When that goal was threatened in any way the participants described their struggles in trying to make sense of and control the actual or potential disorder. They described their work as emotionally hard and they relied on each other to understand the daily stressors. It was not easy work and they strived to be ‘on top of their game’ and to model the best way to care for critically ill children. The nature of their work was clearly reflected when they faced the reality that further interventions were likely to be futile. The participants described how they reoriented their work towards creating a “good” death. Some participants were clear about when this reorientation should occur. For example, one nurse matter-of-factly stated, “If we all agree there is no hope for any meaningful life for the child; then we all agree that it's in the best interest that we allow a dignified end to all of this.” One of the physicians cautioned:

Making [end-of-life] decisions is never an urgent matter. Never. It should only be done with reflection, measurement of all the things you can measure, appropriate consultation with those that need to be consulted with. Only then should you move to that point.

Before discussing specific influences of the PICU culture on end-of-life decision making, it is important to understand what the participants meant by a “good” death.

Values and Beliefs Regarding a “Good” Death

The participants richly described their values and beliefs regarding a “good” death. Common themes from their stories included a need to control the environment, the people and ultimately the dying process as much as possible.

Protecting others. The need to provide a “good” death was infused with the need to protect the children and their families, co-workers and ultimately themselves from the pain and loss of
control associated with death and dying. In keeping with the need to protect, one of the first actions participants reported taking when death of a child was imminent was isolating the dying patient and family by placing them in a private room. This was done in an effort to maintain confidentiality, provide privacy for the family and to protect the other families from witnessing a child's death. In one nurse's anecdote, isolation of the dying also allowed the staff to bend the visiting rules:

siblings are not allowed to come in the unit if they are below sixteen. So, when we know that the outcome is moving towards death we will open visiting hours to anyone in the family; any friends and families, any siblings. But we will put them in a private room.

There is a right day and time to die. Controlling the manner in which children die was viewed as integral to a "good" death. The length of time it takes children to die, when they die and how they die are all aspects of the dying process that participants expressed a desire to control. The desire to control and protect seemed to be interrelated.

A "good" death occurred on certain days and at certain times because optimal care was available. Typically, patient deaths were orchestrated to occur on a dayshift when resources were available. For example, one physician described how "[We] try to make withdrawal of treatment on a dayshift, not on weekends. When everybody is there. When the psychologist, pastoral care, and most of the resources are there...to assist with families". Another nurse succinctly summarized and captured the challenge of planning death in an unpredictable environment:

How busy it is and the day of the week determines how well a child is allowed to die in there. That's a sad thing to say. That's the reality; whether we have a private room to put them in, otherwise they die out in the middle of the unit. If we had enough staff, then that nurse could sit there and help the family and be there for hours afterwards. If it's chaos, she's expected to
help someplace else. All of it depends on manpower and the timing. And I mean, is there such a thing as good timing with death?

There was an expressed desire to control the dying process and make it appear in a way that everyone felt was “neat”, “tidy” and “peaceful”. For example, one physician claimed:

No one likes to hear the gasping, and that’s a pretty natural part of death. I mean, gosh when people would die of whatever they would at home or... there would be a lot of gasping and the death rattle and all of that. We don’t like that. We don’t like kind of dirty ugly death, which is pretty natural. We like the sanitized, peaceful, slip away in your sleep, kind of death.

I think people don’t want to see suffering and we can relieve suffering.

Some people are better at caring for the dying. A final belief held by the participants about providing a “good” death was that some people are better at caring for dying children than others and those people should be the ones providing the care. One physician described how some of her colleagues will maintain a child over the weekend so when she arrives on-call on Monday she can begin the end-of-life care. Others described removing nurses from the care of dying patients because they are “too fragile” and “need a break”. One nurse’s approach to providing best care raised the question of “paternalism” rather than protection of her nursing colleagues:

Say we extubated a child and he’s sort of dragging on for an hour or so and I see that’s really bad for the nurse. I will send her away and I will be there when the kid takes his last breath.

So, that her coping doesn’t have to be that bad. And it helps and I find that my team members do the same thing.

This nurse made assumptions about her colleagues’ abilities and desires. She appeared to believe that she knew what was best for her colleagues. There was no indication that she considered what was best for the child and family.
In essence, the actions associated with a “good” death appeared to be motivated by a need to be ‘doing something’ to make things better. Understanding this need provides a context for appreciating the impact of end-of-life decision making on the PICU staff.

*Types of Deaths*

There were consistent reports that PICU nurses and physicians categorized deaths according to whether they were “straight forward” or “messy”. “Straight forward” deaths were preferred because there was no room for doubt. The outcome was clear. “Messy” deaths were less clear and often protracted. One nurse described her perspective of the difference between “straight forward” and “messy deaths” as:

I think probably those sudden [deaths] are obviously more traumatic but they tend to be a bit cleaner. Because [the families] do not have all the memories [of being in PICU]. One minute they’re well and the next minute they’re gone. You don’t have that protracted, long term... [with] parents stuck in the waiting room seeing their child like this.

*Straight forward deaths.* This type of death was described as inevitable and allowed for little questioning of the outcome. Examples of straight forward deaths were brain deaths and traumatic brain injuries with severe hypoxia. Often these deaths were unexpected and associated with a trauma. While the outcome is usually clear, the emotional trauma for the families was acknowledged sensitively by the participants. One nurse spoke of the suddenness as being “very hard for them to deal with”. “Shocked”, “traumatized”, and “devastated” were also used to capture the reactions of families when told of their child’s actual or impending death under unexpected circumstances.

Brain death in particular was seen as straight forward because of the clear set of criteria to guide diagnosis. One nurse participant emphatically said when asked about end-of-life decision
making and brain death, “There’s no discussion. That one’s easy.” Another nurse stated, 

“Obviously when it’s a head injury and there are brain death criteria to go through, the process is, it’s a little bit more straight forward I think. Because you either are or you aren’t.” Once brain death was confirmed and a child was legally dead, the pressure appeared to be taken off the participants and the families to decide what to do about treatment. While brain death was viewed as clear cut, approaching families about organ donation was viewed as a difficult but necessary task. Participants expressed their beliefs that the topic of organ donation should be presented in a sensitive manner. Approaching families about organ donation appeared to be primarily a physician’s role.

When recalling specific events or types of situations involving unexpected death, the pain and vulnerability that was felt by the participants was evident in their tone. The following quote by a physician illustrates the emotional difficulty of unexpected deaths:

Because I think often [death] is very upsetting. I get pretty emotional myself about it. Although you control it but you feel upset about it. Particularly in those that are completely unpredictable, like a motor vehicle accident where the child was fine three days ago and now is dead.

When asked to describe a death they felt went well, most participants described a “straight forward” death. One in which the participants described feeling as if the decision of an inevitable death was taken out of their hands, the family was informed and supported and the child died quickly and peacefully. They spoke of the family being in shock and how they were able to support the family through this horrible and usually unexpected crisis. While the participants were not immune to the tragedy that surrounded them at those times they appeared to take solace
in the fact that they had done the best they could and the decision had been made for them; they could offer no more than emotional support and a peaceful death.

*The “messy” death.* The reality of PICU is that it is often difficult to predict a child’s outcome. The participants talked about the ongoing discussions they have had regarding patient prognosis. They agreed that often the most difficult deaths involve those in which there are differing opinions or conflict surrounding goals of treatment (e.g., some believe that the child is dying and others believe the child can be “saved”). When these children did not die as expected it was often referred to as a “messy” death. This type of death caused the most distress for the participants.

The physicians were analytical and clinical in their discussions of their approach to children who are likely dying but active treatment had not stopped. The nurse participants described feelings of emotional distress more often than the physician participants regarding messy deaths. Messy deaths were described by the participants as: “unavoidable”, “necessary”, “protracted”, “futile”, “cruel”, “causing suffering”, “distressing” and “prolonged”. One nurse captured many of these descriptors when she recalled the death of a child who was a cardiac surgical patient.

There was a patient they tried everything on. The surgeon kind of got attached to that patient and didn't want to let go. He pushed it so hard and so far. The patient was basically dead in the bed. I remember her nurses saying, "Well you have to come and see her. I mean, you will understand why we cannot even go in the room." She was black. She was not perfused at all and she was really disgusting to look at. And I was thinking about my colleagues that were there in the room [for a full shift]. I thought about the family that was seeing the suffering. The surgeon was pushing it enough that even one day the mother came and said, "Well when, tell me when the surgeon will be ready to let my daughter go. Because, we cannot deal with
that anymore, any longer". And we all looked at each other and said, "Well that's it, I mean that's enough." And overnight the pediatric intensivist decided if something happened we were not going to resuscitate. So finally, [early] in the morning the patient died and the pediatric intensivist came and the family was there. But when the surgeon came in the morning, it was awful. [He kept saying], "You killed my patient!"

This excerpt summarizes the team dynamics and the distress the participants described throughout their stories. In one unit some of the surgeons co-managed care with the PICU physicians which automatically created a division at times because the surgeons, according to one physician participant, “can be quite organ-focused”. The participants focused much of their discussion on how “messy” deaths are dealt with in their units.

There was a myriad of feelings (e.g., acceptance, dissatisfaction, frustration, anger, and anxiety) expressed over protracted deaths. One nurse described deaths which accompany long-term admissions as protracted, “[When you] watch them slowly but surely go down hill, all of a sudden get better and then get septic and then go back down hill again. And come up and then go down again.” Participants shared their experiences in caring for children with long-term PICU stays and watching families become emotionally battered as they tried to make sense of what was happening. The participants expressed empathy for these families but stated the denial was often hard to understand, perhaps because they knew the inevitable outcome and wanted to protect themselves and the families from further hurt. One nurse recalled a time when a physician attempted to tell parents of a chronically ill child that the child was truly going to die.

It had been years since anybody had told them that she’s going to die. They had heard it so many times before that they looked at him and said, “Yeah. Well sure.” And you know that they were thinking, “Is it this time? Is it next time? Is it the time after that?” And so, for them
it must [have been] unbelievable…. And how devastated mom was when her daughter did die because she honestly didn’t believe it.

Many participants shared similar stories involving terminally ill children whom they cared for over the years, watching them deteriorate and waiting for them to die. While these types of deaths are different from other protracted deaths, in that they involve multiple admissions over a number of years, they were mentioned by the majority of the participants as “messy” because of the longstanding relationships they had with the family and child and the differences between the staff’s, family’s and child’s expectations, values, and beliefs about the quality and longevity of the child’s life.

Although “straight forward” deaths were primarily reflective of unexpected deaths, they seemed less distressing for the participants than “messy deaths”. There were usually more people involved in “messy” deaths (e.g., specialists, extended family members) which often led to conflict. The conflict primarily focused on differing opinions about continuing or withdrawing treatment. However, whether it was a “straight forward” or a “messy” death the consistent message from the participants was that it was difficult to watch children die and families grieve.

Making the End-of-Life Decisions

I’ve been doing this for a long time…. Nurses will often say to me and some of the junior doctors will say to me, “Why are we treating this child? He’s going to die.” I used to ask that same question. I’ve learned over time that the point that I will move toward limiting, withdrawing, well whatever you want to call it, end-of-life care, is now a different point from what I would have considered to be an appropriate point twenty years ago. Why? It’s because I’ve learned over time that there are some things that may look and seem abhorrent in what we do to kids but you need to go through that process to ensure that you have done everything
that you can that is possible and it’s only when you’ve reached a point beyond that, that you should move towards end-of-life care. And that’s why I consider once you’ve done those things then end-of-life care is the appropriate and best thing that you can be doing.

(Physician participant)

In an effort to understand how and why end-of-life decisions were made, it was important to uncover who was making the end-of-life decisions. When participants were asked who made the day-to-day decisions regarding patient care they identified the PICU physicians as the health care professionals responsible for medical treatment orders and nurses as responsible for deciding basic care and co-ordination of care for the child and family. One physician described her perspective on the difference between day-to-day and end-of-life decision making. She stated:

Day-to-day care is much more straightforward most of the time. It might have certain objectives and you’ve got medical ideas of how you want to achieve those objectives. We do chat with the family, but maybe not in so much detail, cause I kind of feel that some of the medical details are a little bit, not relevant. You know like they don’t care whether the Ventolin is 2.5 mg or 5 mg.... Some of that stuff, I guess I just don’t think that the parents really need to be drowned in all the details. But when it comes down to end-of-life decisions you know, you need to talk about kind of everything in as much detail as possible and talk about all kinds of more subjective things that the parents needs to tell us about, like quality-of-life and their perception of their child’s pain and illness.

There was a difference of opinion about who should and who was really making the end-of-life decisions. Each participant believed that families should be informed of what the PICU team felt was the likely outcome. Some strongly believed that it was wrong to ask parents to make decisions about withholding or withdrawing treatment and that the PICU physicians and
pediatric physician specialists should make these decisions. Others thought that parents must make the decision. It was notable that few discussed the ability of the child to decide about his/her treatment. Those who were asked stated that it was a rare occasion in their unit and that most of the children who would normally be competent to express their wishes could not because of their illness or injuries.

*Parents making end-of-life decisions.* One nurse spoke of the changes she had seen in the inclusion of families in end-of-life decision making since she began in PICU over 20 years ago, "Where years ago we didn’t ask parents how they wanted their child to die, now we do.” Many of the participants acknowledged the shock and suffering that parents and family members experienced while being faced with their child’s death and asked, “How can we really expect people to make decisions in a crisis?" Some were motivated to protect the families. For example, one nurse stated that it was not a family’s “job” to “pull the plug” on their child but rather it was “our job”. A physician colleague of that nurse presented a more inclusive viewpoint stating, “[End-of-life decision making] has to be done with the parents. We can’t do anything alone.” Another physician described how she structures her presentation to the family. Her belief that parents need protecting and her desire to do so are evident in her approach with families regarding withholding or withdrawal of treatment.

We make it very clear that it is our recommendation and our choice and that they’re not making the choice to pull the plug on their kid and end their life. It was the disease process that ended their life and not them and it was done by us in concordance with them, but they don’t make that decision. No parent can make the formal decision to actually kill their child…. I don’t personally give them that choice.
Participants spoke with conviction about their perspectives on asking parents to make the decision to officially end their child’s life. The language used during these discussions is of interest. The aggressive finality of the phrases used to describe expectations of parents in end-of-life decision making such as “kill(ing) their child” and “pull(ing) the plug” leaves no doubt as to where the participants stood with regards to asking parents to make decisions about withholding or withdrawing treatment. Asking parents to make the final decision without presenting the team’s perspective on withholding or withdrawal of treatment was viewed as unfair and unacceptable because a family might feel responsible for the remainder of their lives if forced to make that decision.

Overall, physicians and nurses saw themselves as responsible for “guiding” the families through the end-of-life decision-making process and were motivated by a desire to act in the child’s and family’s best interest. However, not all were convinced of the effectiveness of such actions. One nurse commented, “I think there is a fine line between guiding and influencing.” Her comment highlights the dissonance that existed amongst the participants regarding who should be making end-of-life decisions. Indeed, the “fine line” was evident throughout the participants’ stories.

Making “the Plan” for a “Good” Death

I think one of the hardest things that we have in PICU is to give up on the technology and the intensive part of it. And, to work intensively to make the death as good as possible, and as happy as possible. (Nurse participant)

If the PICU team believed they were unsuccessful in achieving their goal of making a child better, they focused on their next goal, creating a “good” death. There was consensus amongst the participants that caring for dying children was hard work. Providing a “good” death was
viewed as a way to decrease the difficulty of caring for dying children and their families. Participants described feeling better about themselves if they could support the family and child by orchestrating a “good” death. A “good” death consisted of preventing, or limiting, suffering.

Achieving success in negotiating and implementing a “good” death in a culture dominated by routines was a challenge. The participants valued a plan for death. In the instance of brain death the participants relied on the criteria and guidelines that were available to direct their planning. When presented with situations not supported by criteria, policies or routines (e.g., parents requesting to remain for a resuscitation), the participants described feelings of stress associated with a loss of control.

**Requesting a plan.** There was a distinct pattern in descriptions regarding how plans for death were developed and implemented. The process was described as structured in that it involved identification of the likely death of a child, development of a plan to present to the child’s family, presentation of “the plan” to the family, renegotiation of “the plan”, implementation of “the plan” and ongoing evaluation. Various people and circumstances had the potential to disrupt “the plan”. When disruptions occurred they were viewed as frustrating and often unacceptable by the participants.

“The plan” for a “good” death usually began when a family member or health care professional questioned a child’s likelihood of survival from a critical illness or condition. One physician described various ways in which a plan is requested:

When nurses at the bedside start saying, “Guys we’re going too far. This kid is going to die. Let’s do something. Let’s talk to them.”... The other trigger is where the family gives us hints... or when the social worker feels some vibes [from the family] as well. When the family is getting tired. They’re feeling that it’s been too long and there are no results...
"Where are we going from here? Is that true?" The other way when we start [questioning care] is when we feel that we have tried a lot of different things and the kid is in multi-organ dysfunction syndrome.

In other instances requests for a plan for death came from the nurses and physicians caring for chronically or terminally ill children whom they believed should have had end-of-life plans or advanced directives written prior to PICU admissions. One physician shared her frustration with exploring end-of-life decisions with parents of chronically ill children who were dying in PICU:

I guess I'm always a little surprised or taken aback by parents of chronically ill children who are absolutely stunned when you start talking about end-of-life issues. The kids are ten or twelve years old and they're obviously very impaired. They may have even been in hospital several times before, you know quite sick. I always find that kind of puzzling, that parents can be so taken aback by the idea that their child's life span is quite shortened and that the time is drawing closer where they might actually die. I don't know how to get around that... and I wonder if earlier discussions with their pediatricians or family doctors would be helpful....

And so as intensivists, we're often caught in that situation when you come down to the crunch [of discussing end-of-life decision making].

There was wide acknowledgement of the difficulty of aggressively caring for children who, from the participants' perspectives, had a poor quality of life. While quality of life was viewed as an ethical dilemma, each participant acknowledged they were operating from their own perspective of the child's life and recognized their perspective was limited and influenced by their past PICU experiences.
Some participants expressed anger about caring for patients in PICU when their quality of life was viewed as less than ideal; especially when it was believed to influence resource allocation. With a tone of disgust, one nurse stated:

I have personal values about how I think [end-of-life decisions] should be made, but you know I don’t see that in practice. Some of the kids I’ve seen coming in and out of here. Every winter you see the same kids coming in. Ventilated, oscillated, and I think there should be some sort of clear guidelines with the families, “Ok we’ll do this and this but we won’t go to this extreme”…. It’s a higher ethical decision…. Over the winter, we had quite a few sort of degenerative kids in that were ventilated for long terms [of time] and we’ve got acute kids needing beds and not getting beds. Surgeries getting cancelled for acute kids.

These frustrations surrounding resource allocation led some participants to push for discussions of end-of-life care plans.

While reference was made to “the team” making the decision, it was almost always the PICU physician who led “the team” and spoke with the family. Participants agreed that the PICU physician was the staff person most families looked to for information and the one who had the “ultimate responsibility” for decision making. A meeting between the PICU team and the specialists was usually held prior to meeting with the family. One nurse described how the process occurred in her unit: “Our [on-call PICU physician] would generally call the oncologist and meet with them and say, ‘We need to present this now to the family as the end’, and they would do it together.” The process in each unit appeared similar. The PICU physician would be aware or be made aware, of concerns regarding a child’s progress and potential death. Then the PICU physician would call a meeting requesting that the “best” people be involved in the plan. Once “the plan” was determined, the PICU team would go about orchestrating the plan.
Including the "best" people. There was an identified need to include the "best" people in the end-of-life decision-making process. The "best" people for the first meeting always included the PICU physician and any specialists currently involved in the child's care. The inclusion of 'invited guests', perceived as people who were not essential but might add something to the meetings or implementation of "the plan", varied between centers. Who was invited to the meetings appeared to be related to who was viewed as having the most influence for that particular decision or child. For example, social workers were involved in some of the units' initial meetings but more so in the meetings with the families. Nurses viewed themselves as 'invited guests'. The presence of a nurse at these initial and concurrent meetings was frequently referred to as problematic due to their workload and bedside commitments. One nurse described how it was difficult to release nurses to attend planning meetings because of a unit policy that prohibits leaving a patient unsupervised in a room. Even in end-of-life decision making, policy limited practice. One physician described how having to wait for a nurse did not fit with his schedule.

I usually invite the bedside nurse to significant interviews with the family.... I try to involve the nurses as much as possible and sometimes it's difficult if the nurse is on a break or if they're busy at the bedside doing lots of procedures.... If the nurse wants to be there, they'll usually find a way of getting there.

The purpose of the first meeting was to determine if a consensus that cure was unlikely could be reached. One physician described the purpose of the meeting and some of the challenges of reaching consensus:

The reason to have those meetings, it's not to sort of work out what you're going to say to the parents, but actually review the case in detail, to go through the medical management, all of
the feasible interventions and outcomes, and say, “What’s the most likely? What’s the best?”.... It should be a proper medical review. Not a, “This is my idea and I’m sticking to it.” It’s not a clash. It’s more a, “Review this in isolation. Try and look at it objectively. See what the options are.” The options will point towards saying we all think that this patient has no hope of a meaningful survival and that we should all stop major intervention care, and you agree that, that’s what you’re going to suggest to [the family].

Participants explained that consensus that a cure is remote precipitates discussions of available options for end-of-life care that could be offered to families. These options usually centered around withholding or withdrawal of treatment. The final objective of their meetings was usually to agree upon how to approach the family with the plan.

While information-sharing meetings, which occur with families in non-end-of-life situations, were described as requiring only the parents, or guardians, and the physician, the end-of-life family meetings were more inclusive of other health care team members and the family’s support group. Medical residents and PICU fellows were often invited to family meetings primarily for continuity of care and for teaching purposes. Family members also were given opportunities to invite others. One nurse explained, “Whoever the family wants there if it is possible to be pre-arranged. If they want grandparents, elders, their clergy or spiritual care people there, they decide who they want to bring.”

Developing and Presenting “the Plan”

The participants described a consistent approach across the PICUs when presenting “the plan” for end-of-life care to families. Themes in these descriptions were, loyalty to “the plan”, who presented “the plan”, where they presented it, and how often it was presented were constant across the participants’ stories.
Loyalty to “the plan”. Loyalty to “the plan”, and therefore the team, were key to successfully presenting and ultimately implementing end-of-life care. Presenting a united front, regularly presenting and sticking to “the plan”, and clearly communicating “the plan” were deemed integral to families “buying into the plan”.

As previously discussed, there was great emphasis placed on reaching consensus about end-of-life care between the PICU team and specialist(s) prior to the initial meeting with the family. One physician eloquently emphasized what many participants stated regarding consensus:

Any end-of-life decision making, you can only embark upon it once you’ve got all the caregivers on the same side. Until such time, it is pointless embarking upon it because all you’re going to lead to is confusion and conflict.

There was a sense that a united front persuaded families to trust the decision as it left little doubt in their minds that the experts agreed. The participants believed that the united front also decreased confusion about their child’s health status. There was agreement amongst the participants that confusion often led to conflict. Overwhelmingly, participants agreed that conflict and disagreement in end-of-life decision making and care should be avoided.

For an end-of-life plan to be successful, participants concluded there must be commitment to ensuring everyone (e.g., families and health care members) understood the plan. One nurse described her perspective on the benefits of ongoing communication to insure the success of the plan:

Our doctors are very good at keeping [families] updated and telling them that we’re trying this and that and this worked and this didn’t work. So, when we get to the point where there is nothing else we can do, then the parents are ready to say “Okay, you can stop”.
Therefore, regularly presenting “the plan” was important because it increased understanding, which decreased confusion and conflict, which maintained control over the situation.

Participants provided examples, however, of how one PICU physician could change a treatment plan based on personal preference or beliefs. PICU physician coverage was identified as being important to clear communication and integration of day-to-day and end-of-life plans. Participants described specific strategies they utilized in their units in an attempt to decrease changes in patient care plans and promote continuity of care, especially at end-of-life. One physician shared how her colleagues have embraced a philosophy of continuity of care within the context of end-of-life care.

If I have a child come in on a Tuesday and we anticipate that we may be withdrawing [treatment], or they may die on the Thursday, but I’m not on-service, I would make every effort to come and finish that and follow that through, even though I’m not the person on. We try not to hand that over to somebody who hasn’t been involved with the family. Sometimes it happens; it’s unavoidable. But for the most part we try to be consistent and have the same person involved. Unless it’s someone who’s been there for a month and has had care by every physician. But we try not to have a new person to come in just to be the Grim Reaper. I don’t think it’s good for that physician or the family.

While the majority of the discussions focused on physician management, nurses cited strategies they implemented to encourage continuity of care and to support ‘sticking to the plan’. One strategy was to move towards primary nursing, so that there was a consistent caregiver for the child and family. Another strategy was flexibility with scheduling to allow nurses to optimize coverage of care for a family and child. Nurses did not see a difference in their role whether it was day-to-day or end-of-life care.
The participants welcomed a clear plan for end-of-life care. The clearer the plan and the more obvious the outcome, the more the participants liked it and the easier it was to communicate to families. The “messy” deaths did not allow for such clarity. Therefore, “the plan” became less certain in its implementation and outcome. As a result, communication of “the plan” was more about possibilities and best guesses. The participants spoke about the difficulty and importance of communicating clearly when there is uncertainty.

You know I think in all fairness our physicians are actually fairly good at [communicating prognosis and “the plan” with families]…. Right now we have a little girl. It’s so sad she’s ten and she’s shot herself. I think it’s accidental but they’re really not sure. It’s not good. I think right from the get-go, our physician said, “I don’t know how this is going to go. I can’t tell you for certain, however, it doesn’t look very good.” They will say that right from the very beginning, and not give them any grandiose illusions. “Oh we’re going to save the day, and things will be wonderful and you’ll have a happy functioning ten year old.” You know that they will sort of say, “I don’t know, it could go either way, we’re trying everything we can right now. But you need to know that it doesn’t look very good.” So then, as the nurse, you can just sort of reinforce that. It’s sort of what I do anyway.

Others also focused on the importance of being as honest as possible in an effort to build the trust and manage the disorder.

*Presenting “the plan”*. The participants agreed that it was a physician’s responsibility to present “the plan” to the family. In the majority of situations, this task fell to the PICU physician but occasionally it might be the specialist with whom the family had the closest bond. However, as discussed earlier, representation from the PICU and involved specialist groups was thought to be important for the initial presentation to present a “united front”: 
We always meet with the consultants first and we nominate who's going to be the spokesman, who's going to run the meeting, and what our message is going to be. And even if we don’t all agree on the message, we agree not to disagree in front of the family. So we agree to only talk about the part that we agree [on], and if there are parts that are still controversial, whoever was nominated to be the spokesperson would present them as, “And this is something that we’re still discussing. We’re talking to further experts on the issue to help decide which way is better to go.” And we don’t let the people that actually disagree do the speaking. We always nominate a primary spokesperson. It’s amazing for the most part, even the people who I would say are on an individual basis a bit of a pain in the butt come together as a team.

Nurses’ opinions varied regarding the sensitivity of some of their physician colleagues in communicating end-of-life decisions to families but conceded that families looked to physicians for the “ultimate decision”. Nevertheless, nurses sometimes felt constrained in their communication with families.

My hesitation would be that I wouldn’t want to give them the wrong information. I wouldn’t want to sort of muddy the waters even more just by giving them what I think will happen, or what I’ve heard will happen. I sort of think that sometimes it’s best that the physician, or whoever is in that role, gives them that information and then you sort of reiterate that for them.

Nurses perceived their role to be restating “the plan” to families and interpreting and reinforcing physicians’ messages. One nurse described the importance of this type of communication with families:
I said to the doctor, "[Mom] didn’t hear you.” And the doctor said, “Oh well, I very matter of factly laid out all her son’s injuries and what his condition was.” And I said, “You may have said that, but this mother did not hear what you said. You need to go back to her and say it again.” I think just yesterday I was talking to this doctor and she said to me, “You know I think I told that family six times before they finally got what I was trying to say.”

PICU physicians appeared to have an overall strategy for presenting end-of-life information. They presented the child’s current status and suggested that treatment aimed at cure was no longer a reasonable option. Then they offered options for withholding or withdrawal of treatment. Interestingly, few of the physicians described using the words “dying” or “death” when explaining to a family that their child was going to “die”. Most of the physicians’ examples of their discussions with families included phrases such as, “We should withdraw treatment, because he’s had a severe hypoxic insult”, or “We’re concerned that we’re coming to the end of the road”. Each physician described adjusting their approach based on the child’s illness and the family’s perceived needs. One physician shared her “typical” end-of-life talk:

“Medical technology and knowledge has done everything that it can to divert the course of nature. If we let nature take its course, your child would be dead and wouldn’t be here right now. But we’ve tried everything we possibly can. We have been unable to divert the course of nature and I think it’s really important that we should respect your child as an individual. Not continue to apply technology, which is of no value, and allow nature to take its natural course. Allowing nature to take its course may not necessarily mean that your child will die. If your child has the will to continue to breathe then so be it and if your child stops breathing then so be that. In either case that is the outcome that we’ll accept.” But that’s how I do it. Obviously, you tailor every conversation to every individual but in general, that’s what I do.
This physician was the most experienced of the physician participants and was comfortable in sharing her successes and challenges in working towards a common understanding with families about end-of-life decision making. Another physician described his approach as one of setting limits and seeing how the child responds, thereby giving the family some time to “get used to the idea” their child may not survive:

[We usually start with], “Shouldn’t we start discussing when to put on some limits.” And that’s usually the way that we present [to families]. Obviously you don’t go straight to withdrawal [of treatment]. We tend to initially present, “Shouldn’t we put some limits from what we are doing [and explore] where we should go from here?”

None of the physicians described looking forward to these discussions but they acknowledged they were required to conduct them with sensitivity and accuracy because “parents remember what you tell them”.

Location, location. Nurses and physicians identified that, unless it was an emergency, end-of-life discussions with families occurred in a separate room away from the bedside. As one physician described there is a reason as to why these conversations occur away from the bedside:

Big discussions get moved away from the bedside... and it’s hard because you don’t want someone to think “Oh my God, they’re moving me to another room. They must be about to tell me something awful.” But at the same time it gets kind of distracting being at the bedside especially when the unit is busy. It’s hard to focus and kind of chat heart to heart and then there is the issue of confidentiality.... So we wouldn’t want to have a discussion like that in front of other parents.
One nurse commented about the irony of the situation of trying to pretend that it was just another update when the location of the meeting held such a significant cultural meaning for the acuity of the child.

For example, if we ever have a family conference or you went into the family meeting in the back room... and you never want to go there, right? But the meeting room? No nurse would be surprised at what was being said [in the meeting room] because she would have heard it before.

This nurse remarked at how quickly families learn the PICU culture and that they are never taken to “the back room” for good news.

Participants reported moving dying children and their families to isolation rooms to afford them the privacy they deserved in such stressful times. Many of the participants described not giving families an option and simply moving them as part of their end-of-life protocol. Dying children physically isolated from the rest of the unit in this way were ‘guarded’ by a nurse who sat near the door. Grieving was reported to occur behind closed doors and was considered a private event. The participants could be perceived as making an effort to manage the potential disorder by isolating the dying child and family.

Timeliness of the presentation. Almost as important as how end-of-life discussions occurred was when end-of-life discussions occurred. Participants emphasized that end-of-life discussions “should never be a surprise for parents”, unless the child’s deterioration is unexpected. Primarily the nurse participants expressed frustrations when there were delays in discussing end-of-life decision making with families. As described by one nurse:

When it seems very obvious to [the PICU nurse] that our treatment has not or is not working, then [the specialists] should say, “Okay, let’s stop.” And it usually takes [the specialists] a
good twenty-four to forty-eight hours after [the PICU physician and team has] decided that [the PICU team] will approach the family and go with [withholding or withdrawal of treatment].

However, others spoke of the responsiveness shown for urgent situations or unusual events. One nurse recalled how the PICU staff had been hesitant to approach a mother about end-of-life decision making for her toddler son until a sudden change in the child’s status prompted a need to discuss withholding of treatment: “It was about four in the morning and we had another bleed out episode. And we phoned his mom to advise her we needed to have a really good talk with her”.

Another nurse talked candidly about how some of her physician colleagues are better than others at approaching families about end-of-life in a timely manner. She suggested that parents “know it is coming”:

Not all [physicians], I find, are as comfortable at bringing forth [end-of-life] information, (laughter), ‘till it’s a bit late. But, I think in general, the families get a good taste of that kind of news through nursing…. I would say by the time everyone has come to an agreement on the medical side, usually the parents have seen so much, they’re kind of clued in at what’s coming… what news is heading their way…. It’s just a formalizing by that point; it’s just presenting all the information that you have and giving some choices.

Another aspect of the timeliness of presentation was the effect a delay had on the nurses in bedside conversations with the families. The nurse participants spoke of feeling conflicted and guilty because they “knew what was going to happen” and the parents were asking questions in such a way as to draw information from the nurses without having to ask, (e.g., “Is my child going to die?”). Most nurses felt compelled not to discuss the topic openly until the end-of-life
meeting had occurred with the PICU team and family. However, they described feeling obligated to address the families’ questions. Senior nurses would often begin the end-of-life preparation with families by answering questions in an honest and factual manner but none believed they should confirm a prognosis of impending death. One nurse described her general approach to families when being asked about their child’s deterioration:

Most nurses who have been in the unit for a while have seen enough to have a fairly good assessment of whether things are deteriorating or improving over time.... You may not say, “Oh I think he’s going die.” But I would feel comfortable saying, “I’m concerned that things aren’t going as well as they were yesterday and this is what I see that’s different.”

Most of the nurses avoided providing the family with a prognosis prior to physicians doing so. Once parents have been formally notified of the prognosis and a plan is in the process of being implemented, nurses expressed relief at not having to pretend anymore. One nurse described her relief in the following manner:

We’re cranking up the adrenaline and pumping in these antibiotics and going hell for leather and thinking in the back of our minds, “Shit this isn’t working”. This isn’t going to work. And at some point, the parents often catch up with you and then perhaps you do let out a big sigh of relief thinking, “Yeah! Phew! We can now be a bit more up-front about where we’re going with this.”

Another influence on the timeliness of the presentation of “the plan” was the ability to bring all the necessary people together. The actual date and time “the plan” was to be presented was described as having to be convenient for many people. Considering the size of the group (e.g., PICU team members, specialists, family and their supports), individual schedules (e.g., surgeon booked with surgeries all day or a parent having to work until early evening) and their
geographical location (e.g., many PICUs serve half of a province and arranging transport of a family member to be at a meeting could be difficult), arranging these meetings to meet everyone's needs was described as a challenge. Another aspect which influenced the timeliness was the perceived cultural aspect of time. One nurse, who worked with a large number of First Nations families, cited a difference in "cultural values" as reason for staff frustration around meetings being rescheduled:

There is a little bit of frustration with different approaches to time and meetings....[For example] if you’ve had something set out for two o’clock and nobody shows up and they show up at four o’clock most of the staff that were supposed to be there have gone home... Not everybody is as structured by the clock and sometimes that creates issues.

Some of the participants described ways in which their unit had problem-solved to insure that barriers to timeliness of the presentation of “the plan” were minimized.

Parents need time to come to terms with “the plan”. While the findings presented to this point may suggest that a plan was made, implemented and concluded, that was not the case. There was general recognition amongst the participants that the initial end-of-life discussion had the potential for a significant impact on families. Sensitivity to the family’s “acceptance” of the likely outcome directed the speed in which the PICU teams approached end-of-life care.

We got a heads up from the nurse on nights before that the family was not anywhere near accepting what had gone on. It was a very sudden diagnosis and a sudden admission through emergency to PICU. So the new staff person and I were able to talk about how sometimes families arrive at a place where they need to be in hours and some families take several days to get there.
Nurses described how their care took on an added dimension once a “good” death was the goal. They spoke of trying to keep the child alive until the time was chosen or the family was ready for discontinuing or withdrawing treatment. There was a desire to not want to “tip [the dying child] over the edge”. One nurse explained:

I still feel I have as many decisions to make and I have as much to do with these children. It’s just you’re going to be making different ones. Your thoughts and timing are going to be, “Is it really necessary to come and do that blood work right now?” It’s almost sometimes a protective way of nursing. You’re protecting the kids when you’re looking after them anyway from too much handling or only just what they can tolerate. And in this case it’s doing the same thing but for different reasons. That’s what I’m trying to say is that you’re often doing the same things but your reasons behind them are different.

Once the family had reached acceptance or had resigned themselves to the inevitable death of their child, implementation of withholding or withdrawing treatment began.

In keeping with PICU culture, there is great value placed upon creating and orchestrating a plan for death. Considering the emotional impact of caring for stressed and grieving families in combination with the acuity of their ever-changing patient population, it is perhaps not surprising that the participants described their need for order and direction in caring for dying children and their families.

Challenges for Providing a “Good” Death

While many of the challenges for providing a “good” death have been alluded to in the preceding sections, there is a benefit to explicating them further in the participants’ own words. Obstruction of “the plan” by others was viewed as a significant challenge to achieving a “good” death. Medical-legal concerns, fear of making the wrong decision, and technology were also
believed to create barriers to a “good” death and therefore negatively influence end-of-life decision making.

People obstructing “the plan”. Conflicting values and beliefs about treatment were identified potential causes of opposition. “The plan” naysayers included anyone who had influence on end-of-life decision making and did not agree with the PICU staff’s recommendation. One physician shared his experiences:

For the most part, opposition to the plan has been more physician against physician, but a few cases where we’ve had difficulty with it, it’s been where all the physicians and often all the nursing staff feel that, really this child is terminal and should be palliative and the family just won’t go there, no matter what we’ve done, no matter which channels, what... no matter how much communication that’s gone on and we’re still on opposing ends of the scale. That’s where I’ve found it to be very frustrating.

Perhaps the most striking finding was the frustration expressed towards pediatric specialists who tried to override “the plan” as suggested by the PICU physician. The struggle between the specialties was evident in every participant’s story. Interestingly, each physician identified themselves as the ultimate decision maker, or “the boss” of their patients’ care but they also acknowledged that they could “not work in isolation”. As one physician stated, “To successfully [care for children and make decision regarding treatment] you have to work in consultation with the other consultants in your profession”.

Some participants perceived that certain religious, ethnic, and cultural beliefs complicated planning for a good death in the PICU. Participants described how working within certain cultural social structures and beliefs had postponed end-of-life decision making due to a conflict between that culture’s spiritual perspective and Western medicine’s definition of death.
We do have families that prefer to call in the Medicine Man. Every once in a while there are conflicting decisions when we would like to say no more treatment or we say there is nothing else we can do. And the Medicine Man says, “Well you have to give me two weeks.” And we do. We ventilate the child for two more weeks or whatever time frame it is.

One physician described how her experiences with Muslim families has directed her approach to caring for a dying Muslim child:

I’ve learned over time that the people of a Muslim culture pretty much consistently [view withdrawal of treatment] as a non-concept in their culture. They don’t want to even hear about what the outcome is going to be because that’s not relevant to them. They will not withdraw. They will not hear of end-of-life, DNRs, any of that, regardless of what the outcome is going to be. That’s just not relevant to them. “Will he still have a pulse and a heart beat?” “Yes, he will.” Then they don’t care about the rest, and I’ve learned not to go down that road.

Participants described ways in which they tried to show respect for these beliefs by learning more about cultures and religious beliefs and meeting requests for ceremonial interventions and observance of religious rites. Some of these requests were reported to challenge hospital rules and regulations. For example, the burning of sweet grasses for First Nations people was an issue in some centers due to fire regulations. The introduction of First Nations’ Advocates assisted in implementing end-of-life rituals in these centers. However, despite the education provided, there were examples of generalizing cultures and religions. In addition, there were expressions of intolerance for certain cultural and religious practices which some participants interpreted as being problematic in enacting a “good” death.
Some participants identified the implementation of family-centred care as a barrier to a “good” death as well as a barrier to everyday care. As discussed earlier, a goal of family-centred care is development of a partnership between families and health care providers in order to provide children with the best care possible. Theoretically, the participants found the value of family-centred care difficult to argue, however, its implementation into practice was described as challenging. Within the context of end-of-life decision making, family-centred care created challenges for PICU nurses and physicians and families particularly when families and PICU staff disagreed about plans for end-of-life care. There was disagreement amongst the participants regarding what family-centred care meant in PICU and even if it was beneficial for the PICU environment. The participants did agree, however, that whether it was day-to-day or end-of-life care, family-centred care was contentious. Although the following excerpt is from one physician, it illustrates the uncertainty within which PICU participants approached family-centred care; in turn, that approach influenced day-to-day care and end-of-life decision making.

I think [family-centred care] is a major area of moral distress.... How do we deal with a situation where families have much more presence, much more to say, much more influence in our daily decisions? It’s not only end-of-life care, but it becomes much more problematic in end-of-life care. If you want to decide about different types of treatment then you can always discuss it.... When we talk about tracheotomy versus no tracheotomy on a kid that is like “totally vegetative”, to use a bad term, and the family is pushing for a tracheotomy, everybody gets upset. Everybody starts to get distressed. The nurses don’t want to go to that bedside. The RTs don’t want to change the tracheotomy.... [They want] the patient to die.... So, I think one topic that should come out of this study you are doing... I think [we need to
look at] the family driven end-of-life care and how we deal with it; when there’s conflict between the health care team and the families regarding the best decision.

The conflict that already existed surrounding family-centred care seemed to be accentuated in end-of-life care as staff and parents struggled to identify their roles and responsibilities within a contextual framework of death and a model of care they just did not quite understand.

*Medical-legal concerns regarding end-of-life decision making.* The impact of legalities related to end-of-life decision making was viewed as a complication to a “good” death by many of the participants. More so, the uncertainty of medical-legal requirements influenced how death could occur as evident in one physician’s description of her hospital’s attempt to rewrite their “do not resuscitate” (DNR) policy:

One of the major discussions that has been going on here is DNR against parent’s wishes. Because we had a draft DNR policy by the hospital that said that we ought to write a DNR order if we feel that is in the best interest for the patient. The best interest of the patient, despite what the family said. Oh! That made such a controversy. So the draft was removed and they did a full study for the last year. They wrote it again and but it only came out for the adult patient population. So, it is now again to the doctor’s discretion, which in one sense is good, but in another sense it’s bad because there is no hospital standard.

There was evidence from the physicians that they felt conflicted in resuscitative situations when they believed attempting resuscitation was not in the child’s best interest but there was no written DNR order. In those situations the physicians implied their decision making was influenced by the threat of litigation and a desire to protect themselves and their colleagues from litigation.

Some participants described the medical-legal and ethical aspects of withholding or withdrawal of treatment as vague, and they were uncertain about when treatment could legally be
discontinued. One nurse participant recalled a situation where continuation of care occurred despite the PICU staff recommending withdrawal of treatment “because it was hospital error that resulted in the incident that put [the patient] in that condition, [administration] preferred not to push withdrawing treatment”. Some worried these uncertainties led to continued use of prolonging the life of children in “vegetative” states who were, from the participants’ perspectives, burdens for the whole family. Another nurse shared her concerns regarding prolongation of treatment in a severely neurologically damaged child:

I would say my major concern in life when I care for a child who I know has significant neurological compromise, post arrest, be it whatever, I’m always afraid if we don’t discontinue treatment soon enough, they’ll breathe…. In my view, what the family goes for, nursing tends to support. Except when we believe [the injury will result in] a permanent vegetative state. And then we can’t [support the family’s decision]; then nurses find a real problem with that.

Many participants suggested that many children who went on to survive from devastating illnesses or injuries in “vegetative” states did so because their families insisted on treatment. Judging by the tone and language used to describe those children who were often repeat visitors to PICU, the participants suffered negatively from working within an environment that “saved” patients with a quality of life that did not reflect the participants’ views.

The balance between providing comfort and causing death when administering narcotics while withholding or withdrawing treatment was presented as a medical-legal challenge by some of the participants because they were unclear when this was considered euthanasia and when it was considered acceptable for comfort. However, the use of smooth muscle relaxants (pharmacological paralyzing agents) during withdrawal of treatment was viewed as a practice
both legally and ethically unacceptable. Two participants described situations in which smooth muscle relaxants (pharmacological paralyzing agents) were drawn-up with narcotics and administered intravenously to children prior to the breathing tube being removed. Both participants expressed discomfort with those situations and emphatically stated that they would remove themselves from the care of the child and report the physician should a physician attempt that again.

*What if we are wrong?* Feeling responsible for making the correct assessment (e.g., “This child will definitely not survive despite any treatments we can provide”) within the unpredictability of many prognoses was a prevalent theme amongst the participants. The participants were concerned about “giving up” too soon and “being wrong”. One nurse described her perspective on the hesitancy to make a definitive statement regarding a prognosis as, “There’s an element of, ‘Well, we’ve got to be sure!’ And if we leave it long enough we’ll all sort of be able to come to that, and acknowledge that that’s the way it is.” Many of the participants had experiences with “being wrong”; when they, and sometimes a family, believed a child was going to die and the child lived. One nurse recalled an incident of a baby who had had open-heart surgery and was not doing well:

Nobody except for one intensivist thought that this baby could possibly survive. His mom, said “That’s it. We can stop. I don’t want to go any further.” She stopped coming in. She wouldn’t come in the unit. She couldn’t bear to look at him. We were appalled…. “What are we doing? This is terrible”. Everybody, except this one, who happened to be on for the whole week. And he was right. It took for-bloody-ever but he was right.”
There were two responses to being wrong. One response was to ignore the fact that they were wrong and not discuss it further. The other was to celebrate the fact they were wrong and the child survived and to learn from this experience.

Technology as a barrier. Although there was general agreement that pediatric critical care is dependent upon technology in order to deliver the care it does, the participants described technology as a barrier to a “good” death when it was used to prolong life unnecessarily. The advancement of technology combined with “the expectations of parents” and other health care members regarding the usefulness and appropriateness of utilizing specific technologies was seen as presenting challenges for a “good” death because it occasionally caused the “boundaries [between life and death] to get blurred” leading to confusion for families and health care members. Despite the physician participants’ tendency to view technology as a treatment modality, one physician conceded, “The difficulty is limiting technological support in cases that are complex and there are unclear outcomes.”

Summary

The participants collectively provided helpful information about what it is like to care for critically ill and dying children and their families within a PICU in Canada. Although they worked hard to make children better, occasionally they failed and had to switch their focus to creating a “good” death. The nurses and physicians described the challenges and rewards of practicing within the paradox of life and death.

The participants valued control in order to handle the actual and potential disorder of their environments and the people within them. They valued learning, technology, experience, clear communication, plans, a “good” death, prevention of suffering and being correct. They accepted not being able to save each child’s life as part of their reality. The struggle to control the dying
process in an unpredictable environment and under unpredictable situations was a prominent theme. External forces such as: institutional values regarding family-centred care; the inclusion of specialists in the development and implementation of the end-of-life plan; the incorporation of cultural, spiritual and religious values and beliefs into end-of-life plans; and understanding medical-legal concerns were perceived as posing challenges to orchestrating a "good" death. The values and beliefs the participants described enabled them to function effectively in a stressful environment. These values and beliefs, while sometimes limiting in their perspectives, allowed the participants to deliver exceptional, genuine care to critically ill and dying children and their families.
CHAPTER 5: DISCUSSION

To date, limited research has been undertaken examining the influence of PICU culture on end-of-life decision-making. This study begins to address this gap by providing a description of the values and norms of PICU culture that underlie this decision making. The study was based on in-depth interviews with eleven nurses and six physicians from eight Canadian PICUs. While the results are not generalizable to all PICUs across Canada, they provide a starting point upon which further research can be conducted.

In this chapter, the most significant aspects of the findings are discussed in relation to the relevant research. Due to the lack of research available addressing PICU culture and its influence on end-of-life decision making, references to the literature include opinion papers and related research. The implications of the findings for nursing practice, nursing education, and nursing research are discussed. The methodology utilized to conduct this study is presented. In addition, the limitations of this study, particularly as they relate to my insider status, are considered and discussed. A summary of this study concludes this chapter.

The Struggle to Control the Dying Process in PICU

The study results clearly indicate that the participants value control. From daily management to end-of-life decision making, the participants described their efforts to develop and implement plans to achieve the goal of "making a child better" or ensuring a "good" death. Motivation for controlling the work environment could be partially attributed to national healthcare trends towards patient safety (Baker et al., 2004) and national standards for critical care accreditation requiring measurable outcomes (Canadian Council on Health Services Accreditation, 2004). A result of these trends is the demand for evidence-based critical care practices supported by standards, policies, procedures, practice guidelines, and protocols (Albarran, 2004); all of which
perpetuate the push to operate in a structured, controlled and predictable critical care environment. However, these trends and standards neglect ideas of human relationships as measures of quality in critical care practice. Therefore, it is not surprising that one of the most striking findings was the need for the participants to micro-manage situations, particularly people and the dying process, in an effort to elicit the responses they expected or thought they needed around end-of-life care. The findings from this study suggest that attempts to manage disorder in critical care may negatively influence relationships with colleagues, patients, and their families, particularly when dealing with end-of-life decision making.

*Influence of a Medical Model of Care on End-of Life Decision Making*

The medical model appeared to dominate the working dynamics between PICU nurses and physicians consequently playing an important role in end-of-life decision making. While the participants described themselves as members of the “PICU team”, there was little evidence to support that a team philosophy guided their practice or shaped their professional relationships. Despite their descriptions of a “team” approach, the nurse participants described themselves as having little input or influence in the actual planning of end-of-life care. Nurses outwardly supported physicians’ end-of-life decisions to families, even if they did not agree with them. Other researchers have reported a discrepancy between nurses’ and physicians’ perceptions of teamwork, with nurses perceiving less teamwork than physicians (Baggs et al., 1997; Sexton, Thomas, & Helmreich, 2000; Thomas et al., 2003). It would seem that ICUs remain strongholds of the medical model with nurses and physicians describing ICU physicians in a role of power over ICU nurses (Maureen Coombs, 2003; M. Coombs & Ersser, 2004).

A team approach to end-of-life care requires consensus regarding goals for patient care. Members of the PICU team who met with families were primarily physicians and “invited
guests” (e.g., social worker, spiritual care, nurse). Physicians were viewed as responsible for providing information to families. The role of the “invited guests” was to support the family. These findings are congruent with the literature that suggests it is the role of the PICU physician to approach a family regarding end-of-life decision making, to communicate to the family the futility of their child’s condition, and to recommend withdrawal or cessation of treatment (Garros et al., 2003; Macnab et al., 2003; McCallum et al., 2000).

PICU nurses’ conversations and behaviours with families of dying children are under-explored topics that could provide insight into how nurses support, or influence, families through the end-of-life decision-making process. Nursing’s professional codes of conduct identify the role of patient advocate as an important one for nurses (Canadian Association of Critical Care Nurses, 2001; Canadian Healthcare Association, Canadian Medical Association, Canadian Nurses Association, & Catholic Health Association of Canada, 1999; Canadian Nurses Association, 2000). The role of advocate places the nurse in a unique position of needing to know the child and family (Hayden, 1999; Tanner, Benner, Chesla, & Gordon, 1993). Certainly the critical care literature suggests there is room to build upon a nurse’s role with the family of a dying patient by having the nurse coordinate end-of-life care (Farrell, Ryan, & Langrick, 2001; Puntillo, 2001).

The insignificance many of the nurse participants applied to their role in end-of-life decision making could be a reflection of their beliefs regarding their placement within the hierarchical medical model in pediatric critical care. Or it could be that nurses are less confident of their roles as patient advocates because professional codes of conduct spell out duties, but do not give moral guidance. Both of these hypotheses limit the ability of the PICU nurse to realize his or her full potential as a nurse and can lead to role confusion. For example, critical care physicians are
primarily concerned with curing patients; only when all options have been exhausted do they actively focus on withdrawal or cessation of treatment. In contrast, critical care nurses focus on the impact of care on their patients and their families (Ferrand et al., 2003; Kelly, 2004). Critical care nurses have gradually absorbed more traditional medical duties as the specialty of critical care has developed. Kelly describes the conflict nurses feel in balancing their desires for being “maxi nurses” versus the ICU demands of being “mini doctors” in a highly technical environment as “nurses having lost their way” (p. 32). Kelly discussed how ICU nurses are forfeiting delivery of spiritual, holistic care in an effort to maintain the requirements for mechanistic care. When this occurs, the essence of nursing is lost and the rewards many nurses seek such as the development of meaningful relationships with children and their families are at risk (Kelly, 2004; Wheelan, Burchill, & Tilin, 2003).

The finding that there is little team involvement in end-of-life decision making in PICU has implications for nursing practice, education and research. Further evidence demonstrating how the medical model negatively impacts outcomes for families and staff could assist in developing curriculums to address resolving diverse opinions with a goal towards open discussion and exploration (Hawryluck, Espin, Garwood, Evans, & Lingard, 2002). Interprofessional education could be helpful in building collaborative practice environments at both academic and clinical venues (Shannon, 1997). Interprofessional education sessions and practice scenarios for communicating amongst each other and with families would be beneficial for professional development and building trust amongst the disciplines. Likely, it will take significant effort to shift the PICU culture toward a more collaborative state, but the consequences of failing to do so are great.
Belief that Physicians Break the "Bad News"

The participants in this study unquestionably supported the notion that the PICU physician was the primary communicator in end-of-life discussions with the family. The importance of initial discussions is widely acknowledged in the literature (Bowman, 2000; Brannack, 2001; Burns et al., 2001; Cohen-Almagor, 2000; Fins & Solomon, 2001; Garros et al., 2003; Meyer et al., 2002). Discussing end-of-life planning with, or "breaking bad news" to, patients and families has been widely researched in an effort to understand the best approach for effective communication (Ciccarello, 2003; Curtis & Patrick, 2001; Curtis et al., 2001; Heyland, Tranmer et al., 2000). How physicians approached a family, how they structured their conversations, and the language used were identified by the participants as important in successfully communicating the end-of-life plan.

Despite having a loose framework, the physician participants emphasized that the messages they delivered to families during end-of-life discussions were tailored to meet the families’ specific needs. They emphasized the importance of providing clear and consistent messages. Lilly, Sonna, Haley and Massaro (2003) found there was an increase in comfort, understanding, trust and acceptance by physicians, nurses and families when an “intensive communication” program (focusing on clear and consistent messages) was implemented in an adult ICU around end-of-life discussions. Lilly et al. attributed the success of the program to the participants feeling informed and aware of the limitations of technological care. While there was evidence of attempts in this study at “intensive communication”, the practice of presenting a “united front” when presenting “the plan” suggests that families were not hearing all perspectives when end-of-life discussions occurred. When there were differences of opinions, it appeared that “plan naysayers” were deterred from communicating their opinion to the family. In addition, as with
Burns et al.'s study (2001), nurses remained less satisfied with the quality of communication on end-of-life issues than physicians did. Nurse participants provided data to suggest that often the messages communicated in end-of-life decision-making discussions were not well understood by families, which required the nurse to interpret or reinforce the message.

The importance of the language physicians used when discussing end-of-life decision making was highlighted by Workman, McKeever, Harvey and Singer's (2003). In their study, a family was reported to have been approached numerous times by ICU physicians to withdraw treatment from their critically ill family member. The family allegedly became suspicious of staff and was litigiously resistant to withdrawal of care until they heard the word “dying” from one physician. After hearing the word “dying” they reportedly understood what was happening for their family member and consented to treatment withdrawal. This finding highlights the need to be sensitive to the words chosen to explain death. Findings from this study indicate that PICU nurses and physicians rarely use the “D-word” (dying) to describe the dying process. Instead, words or phrases which describe the dying process in clinical terms were used. The implications of being supportive, but indirect, when describing the clinical situation of a dying child to a family are far-reaching, especially in our multi-cultural society.

In terms of who is the best person to be “breaking bad news” to families, difficulties were identified within the current model of physicians being the ones to give the “bad news” to families. The current model created special difficulties for nurses and to some extent limited their communication with families at a time when communication appeared to be needed most. The nature and importance of the nurse-family relationship has been identified as a key theme in two phenomenological analyses of PICU nurses’ experiences in caring for dying children and their families (Rashotte et al., 1997; Way, 2003). In both of these studies, nurses placed great
value in establishing relationships with families and children and caring for them through involvement with decision making and withdrawal or withholding of care. Nurse participants in this study tended to share stories that involved them “knowing” the child and family and empathizing with them as decisions were made about treatment. Although the nurses defended their role as family experts in this study, they described feeling constrained in their end-of-life decision-making role and seemed helpless to identify strategies to improve their role.

In light of many of the physician participants identifying that end-of-life discussions were never “easy” and the nurses identifying not being consistently satisfied with the end-of-life discussions, there is an implication that further research is needed to understand the relational components of these complex interactions categorized as “breaking bad news”. As well, the desire to create a “united front” challenges the authenticity of end-of-life conversations and implies there are power dynamics within the physician-specialist group worthy of exploration. The power differential between critical care nurses and physicians (Maureen Coombs, 2003; M. Coombs & Ersser, 2004) might contribute to the inability of the PICU nurses and physicians to optimize child/family support and communication around end-of-life decision making. By identifying and consequently accepting each other’s strengths, PICU nurses and physicians could position themselves to work collaboratively in providing relatively seamless end-of-life care with nurses assuming a larger role in communicating plans with families (Briggs & Colvin, 2002; Farrell, 1999; Macnab et al., 2003; Miller et al., 2001; Puntillo, 2001).

The Enigma of Family-Centred Care and Its Influence on End-of-Life Decision Making

The theme of needing to control and/or protect family is identified in pediatric critical care literature (Jefferson & Paterson, 2001; McPherson & Thorne, 2000) and end-of-life literature (Burns et al., 2001; Mahon, Deatrick, McKnight, & Mohr, 2000; Puntillo, 2001; Way, Back, &
There is also an emerging trend in critical care which challenges critical care professionals to practice within a family-centred model by partnering and working with families through their children's critical illnesses (Board, 2000; Hill, 1996). In an ethnographic study exploring the context and nature of the interactions between registered nurses and parents in level II nurseries, Fenwick, Barclay and Schmied (1999) reported that the interactions were primarily aimed at teaching parents tasks aimed at caring for their infant (e.g., feeding) or reporting on the infant’s progress. Fenwick et al. suggested that nurses’ interactions were influenced by medically and technically focused care. The neonatal nurses in their study were noted to provide limited emotional care. Fenwick et al. hypothesized that family-centred care is a challenge in areas where the nurses’ professional identities remain strongly tied to technology. As with Fenwick et al.’s findings, actualization of the principles of family-centred care was sometimes difficult for the participants in this study. This difficulty appeared to be heightened when the participants were confronted with situations where their perspectives on what was best for the child conflicted with what the family perceived to be the best course of action for their dying child.

The ability to operationalize concepts of family-centred care into the clinical setting is recognized as a challenge and is often guided by best intentions and intuition with little empirical evidence to direct practice (Curley & Meyer, 2001). PICU policies and procedures create barriers to successful implementation of family-centred care because family presence and involvement in their child’s care is limited (Rushton, 1990). For example, Jefferson and Paterson (2001) described nurses and physicians referring to policies and procedures as rationale for excluding or limiting parental presence during procedures in PICU. These authors established that PICU nurses and physicians often interpreted policies and procedures to fit within their own value and
belief systems. In concurrence with Jefferson and Paterson’s findings, the nurses and physicians in this study articulated the value of family participation but viewed families as having a greater potential for hindering the professionals’ abilities to provide optimal care to dying children.

While there was no indication from the participants that families did not have a right to decide about withdrawal of treatment, many participants thought it was important to protect the family from the onus of bearing the final decision to “kill their child”. The language the participants used to describe their perspective of the position they believed they would be placing families in when asking them to withhold or withdraw treatment (e.g., “pulling the plug”) implies that their intentions to protect the family were honourable. However, it is important to note that the participants used different language when explaining death to families based on the circumstances surrounding the death and the family. For example, when describing brain death to a family the participants described going to great lengths to communicate that the child was clinically dead and just the machines were supporting them. The findings from this study corroborate Cassell, Buchman, Streat and Stewart’s (2003) findings that the “decision to withdraw therapy and shift to comfort care was made by the doctors, who then invited the family members to agree” (p. 1266). It is apparent that, for the participants in this study, the evolution of family-centred care, particularly around end-of-life decision making in a PICU, is hindered by the professionals’ attempts to control the environment and the dying process. Little research has addressed a family’s recollections of the dying process of their child and their preferred roles in end-of-life decision making and the dying process.

*Influence of the “Silent Voice” on End-of-Life Decision Making*

One of the more striking differences between adult and pediatric ICUs is the potential involvement of the patient in decision making. There was little evidence in this study of children
being consulted about their perspectives on end-of-life decision making. Indeed, the age of the child was cited as playing a significant role in the inability of a child to participate as a legally competent individual. In addition, the child’s medical status (e.g., unconscious versus conscious) was reported to contribute to the child’s inability to contribute to conversations directed at planning their future. Participants provided examples of adolescents who verbalized advanced directives to their family and surgeon only to have them ignored. This finding is disturbing but not unusual (Badzek & Kanowky, 2002).

Carnevale (2004) presents the argument that approaching health care decision making for children from an adult-based “best-interests model” of moral reasoning places the child at risk of not being heard. Carnevale purports that the moral agency of children is frequently ignored when decision makers do not fully appreciate the child’s ability for moral reasoning. This lack of awareness, combined with the adult-centred “best-interests model”, limits the inclusion of children in health care decision making. When this occurs the voice of a child is silenced.

Implications for not “listening authentically” to children’s voices results in adult-based moral reasoning taking precedence over children’s moral agency (Bluebond-Langner, 1978; Carnevale, 2004; McPherson, 1999). The participants described situations in which the road between the child’s moral agency, the adult-centred “best-interests model” and legislation frequently diverged; this divergence resulted in legislation taking precedence over the “best-interests model” which overrode the child’s moral agency. In a study exploring PICU nurses’ practice to preserve children’s personal integrity, McPherson (1999) found that ignoring a child’s moral agency leads to emotional and moral distress by those who believe that children’s expressions of wishes and intentions must be considered when decisions are made. There are many ethical questions that are only beginning to be addressed that have very important implications for how
we understand children as human beings (even as they die) as well as our responsibilities as health care professionals to elicit their views.

Beliefs about How Dying Should Occur

Levy (2001b) stated “good end-of-life care is like art: it is difficult to define but you know it when you see it” (p. 32). The participants appeared to agree that a “good” death was difficult to describe but they felt the dying process should be dignified, peaceful, pain and anxiety free, and quick. They provided rich, detailed descriptions of attempts to achieve a “good” death.

Protracted, loud, painful and aggressive (e.g., “technohysteria” or full cardiac resuscitation when considered futile) deaths were viewed as distressing and practice was focused on avoiding these types of “messy” deaths by controlling the dying process. The need to control the dying process has been noted by others. For example, in an ethnographic analysis exploring the ‘natural’ death paradigm in critical care, Harvey (1997) found that the deliberate practice of withdrawing technological support is done in an effort to control the process of dying and “mimic” natural death. Burns et al.’s (2000) exploration of end-of-life attitudes and practices of PICU nurses and physicians in providing analgesia and sedation to dying children as treatment is being withdrawn highlighted the escalated use of analgesia and sedation at end-of-life in an effort to control the dying process through hastening death and/or easing patient suffering.

The challenge of meeting the pain and sedation needs of dying children without hastening death is a finding from this study that is widely described in the literature (Burns et al., 2000; Cantor & Thomas, 1996; Chan et al., 2004; Garros et al., 2003; Hawryluck, Harvey et al., 2002; Nuccetelli & Seay, 2000). However, in comparison to the adult ICU literature (Chan et al., 2004; Foley, 2001), the “over-administration” of analgesia and sedation throughout the dying process was not viewed as a significant concern for the participants. This finding is consistent with other
pediatric critical care studies which examined administration of narcotics, sedation and neuromuscular blocking agents during the dying process in PICUs (Burns et al., 2000; Garros et al., 2003). Empirical studies comparing practices in adult ICUs with PICUs would provide interesting insights into this issue.

Findings from this study suggest that beliefs addressing how a child should die (e.g., quietly, privately and without pain) influence the approach to end-of-life care in PICU. For example, while isolation of the dying child and family in PICU was reportedly done out of respect for the family in order to provide a dignified death, there is little empirical evidence or theory to support this practice. The risk of someone losing control is minimized by isolating the dying child and his or her family from the rest of the unit therefore minimizing the risk of overt exposure to the distressing event for most staff and other families. The message is clearly conveyed that this is a sad, private and confidential event. The implications of this practice need to be examined including its influence on expectations about how dying should occur.

The way in which nurses and physicians behave and their attempts to keep interactions and unit practices “normal” with dying children and their families is documented in Bluebond-Langner’s (1978) classic ethnographic analysis of how children with cancer came to know they were dying and how they concealed their knowledge from their parents and the healthcare team. Similarly, the participants in this study provided examples of behaviours and practices which were attempts to normalize death in PICU. They describe policies and procedures they followed which supported structured care during the dying process. For example, in addition to isolating the child and family, the practice in many PICUs was to leave the dying child connected to the cardio-respiratory monitor so the staff knew when death (e.g., absence of heartbeat) had occurred. While this practice was normal for the PICU staff, some of the participants recognized
how this cultural norm of reliance on technology might limit a family’s ability to transition from cure to palliative care when little changed with regards to equipment and the monitoring aspect of the nurse’s work. Again, we lack knowledge regarding how family members experience their child’s death under these circumstances.

*Beliefs about Quality of Life and its Influence on End-of-Life Decision Making*

The participants richly described what it meant for them to care for critically ill children whom they felt had poor quality of life or whom they perceived were the recipients of futile treatment. These children were typically described as having a severe neurological impairment (e.g., permanent vegetative state) or being at the end-stage of a life-limiting illness. The participants shared their perspectives of how the ethically based concepts of quality of life and futility were linked and told of the conflict and distress they experienced and witnessed amongst the staff and families when facing quality of life or futility concerns. This finding is supported by others who have explored PICU staff members’ perspectives of families (Studdert et al., 2003; Workman et al., 2003) and specialists (Cassell et al., 2003) as having “unrealistic expectations” about potential outcomes and projected quality of life of the child.

The anticipated outcome for the child was described as being important to the participants. The significance of “saving” children’s lives with an anticipated reasonable outcome, especially neurological, was described by Albersheim (2004) in a study examining the perspectives of parents, nurses and physicians in a neonatal ICU. Albersheim reported that parents had an equal commitment to intensive care for a neonate with a mental handicap (35%) or physical handicap (40%). Neonatologists and neonatal nurses were less committed to providing care for a baby with a mental handicap (10%) than with a physical handicap (90%). Similarly, the participants in this study appeared to place value upon the child’s likelihood of being able to communicate
and function in a purposeful manner post-PICU. The nurses spoke of their concerns of being too aggressive with children who had suffered significant brain injuries. The suspected neurological outcome seemed to have more influence for PICU nurses than physicians in their beliefs about end-of-life decisions. In cases where children suffered significant neurological damage, many of the nurses expressed regret that treatment had not been stopped earlier because they believed the child would have died, freeing the family from the burden of caring for a severely mentally impaired child; a child unlike the one the family knew before their child’s illness or trauma. The distress they experienced in caring for these children was profound.

Little in the PICU literature describes the dissonance participants reported when caring for children who were repeatedly admitted to PICU for advanced medical support and were considered to have a “poor quality of life”. For example, tracheotomy and home ventilation for a child with neuro-muscular degenerative disease was considered too extreme by some PICU nurses and physicians due to the technical and staff resource requirements to manage a child’s health care needs at home.

The participants in this study appeared to struggle with the societal, family and legal expectations and perspectives surrounding quality of life and futility. They were reluctant to specifically define either concept from a global perspective but, as with Burns et al.’s (2001) findings, the participants suggested that quality of life should only be judged from the patient’s perspective, and not be influenced by the health care provider’s personal values and beliefs. Ironically, their stories of care seemed to suggest they did not enact these values. The language and tone used when describing these scenarios was enlightening. Death was juxtaposed against costs and quality of life. Many of the participants believed death would have been a better choice for some of the children they cared for on a regular basis.
Influence of Caregiver Distress in End-of-Life Decision Making

The profound distress expressed by some of the participants surrounding continuation of futile care has been described elsewhere (Curtis & Burt, 2003; Rashotte et al., 1997; Workman et al., 2003). For example, in an examination of adult ICU physicians’ and nurses’ experiences with providing life sustaining treatment at the family’s insistence, Workman et al. found some nurses and physicians experienced intense distress and frustration when they were made to provide patient care that the clinicians believed to be futile. The reason for their distress was related to the following: witnessing the suffering of dying patients, observing the marked distress of family members, and experiencing a breakdown in relationships with the family members. In this study, the PICU nurses were more likely than the physicians to report responding in these ways when they witnessed the suffering of a child and family.

The PICU nurses’ descriptions of feeling distressed when children died in a different way than the nurse felt he/she should has been described elsewhere (Rashotte et al., 1997; Way, 2003). For many of the nurses in this study, any plan which veered from their own expectations was viewed as ‘unrealistic’ or suspect. The literature supports the finding that not “sticking to the plan” can lead to feelings of frustration, anger, grief, a lack of fulfillment and decreased autonomy for the nurse participants (Curtis & Burt, 2003; Halcomb, Daly, Jackson, & Davidson, 2004; Rashotte et al., 1997; Way, 2003; Workman et al., 2003). McPherson (1999) identified the distress experienced by PICU nurses when prevented from acting in accordance with their own beliefs (e.g., a nurse being prevented from providing developmental care to a baby due to unit demands on her time). In this study the nurses expressed distress when not able to protect a child from threats to their personal integrity (e.g., prolongation of death). An inability to stop futile treatment was identified by the nurses in this study as failing to protect dying children.
In this study, the nurses’ views regarding the dying child were often grounded in their emotional responses. The use of emotions in end-of-life decision making has traditionally been frowned upon because emotional judgment is considered subjective (e.g., all about “me”) and therefore non-clinical. Nortvedt (2004) argues that emotional judgment plays an important part in moral agency and is reflective of one’s own emotional engagement to a situation. Emotional motivation is important for nurses because it makes us care about a person’s well-being and it helps us to care with the proper attitude. Thus, while emotional responses may be important they can also obstruct moral responses. Nortvedt cautions that, “Nurses are not saints, and in many situations our emotions do not comply with what we would consider morally acceptable behaviour” (p. 460). For example, the anger expressed by some nurses regarding decisions to continue aggressive care on children with a “poor quality of life” demonstrates the ways that emotions can clash with moral reasoning. Although the argument could be made that their anger was a valuable cue to the nurses’ moral orientation, it is important to remember family members were likely operating with a different moral orientation. It is difficult, and unnecessary, to label one response more morally acceptable than the other. In the examples provided by the participants, treatment decisions favoured the families’ wishes.

The findings from this study bring attention to the differences between the responses of PICU nurses and physicians when faced with demands for continuation of treatment. While Workman et al. (2003) found that physicians are significantly distressed with ongoing treatment requests by families when they perceived these treatments as futile, in this study physicians expressed frustration when specialists insisted on continuing care. The decision-making struggle between specialists and intensivists is documented in the literature as compromising patient care and
It has been established that end-of-life decision making in PICU is fraught with moral challenges. Nurses respond differently to demands for continuation of treatment than physicians. There is little evidence to explain why this occurs. Perhaps it is that a large component of nursing involves emotional caring. The focus for most physicians is to cure and base decisions on scientific evidence. Both require specialized skill sets. Making sense of end-of-life decisions was identified by Way (2003) as a major theme for PICU nurses when caring for dying children and their families. Possibly physicians make sense of the situation in different ways than nurses because of their educational training which demands a greater focus on scientific reasoning and less of a focus on ethical and relational reasoning. Or, maybe as one physician suggested, because physicians are directly involved with more deaths than nurses, they must find a way to cope with the magnitude of sadness they witness. In light of the distress associated with demands for continuation of treatment in the face of futility, further exploration into why PICU nurses and physicians have different responses to practicing under these circumstances would be beneficial for developing a better understanding of how they practice within contentious end-of-life decisions.

When nurses become distressed about delivering end-of-life care they react with emotion. It is important to note that a major reason nurses leave their areas of practice is due to dissatisfaction and feeling constrained in their practice (Corley, 1995; Melbourne & Glastonbury, 1992; Rushton, 1992). Within the context of PICU work the participants described experiencing many abnormal events. The tendency to normalize these abnormal events is not unique to healthcare (Jefferson & Northway, 1996) and is viewed as a means of coping. There is
a need to address the realities of working within a stress laden environment by creating accessible and accepted resources for exploring ethical issues or sensitive topics and addressing the impact of caring for critically ill children and their families (e.g., ethics rounds, grief counselors, critical incident stress management/debriefings). Although the topic of moral distress continues to be explored by researchers, a narrower focus, such as perceptions of quality of life amongst critical care nurses, may assist in understanding what contributes to nursing attitudes and delivery of care to patients with a "poor quality of life". Explorations of the lived experience of families who have children with life-limiting illnesses and their values and beliefs about parenting or being a sibling to a child who is labeled as having a "poor quality of life" would provide findings that could be used to educate PICU nurses and physicians about the everyday experiences of these families.

Beliefs Surrounding Protection in End-of-Life Decision Making

With the exception of wanting to protect families from feeling responsible for their child’s death by making end-of-life decisions, physicians did not express a strong motivation to protect the child. In contrast, the PICU nurses appeared to be strongly motivated to protect families and children from suffering and pain. This is a recurring theme in end-of-life research (Rashotte et al., 1997; Rushton, 1992; Way, 2003; Workman et al., 2003). “Best interest” was the motivation for the participants’ actions to protect others in PICU. Nurses described wanting to protect dying children and their families from further suffering, however, they rarely identified physical pain as a component of the suffering. Instead, the suffering appeared to be equated to physical deterioration.

A significant finding from this study suggests that PICU nurses take direct action to remove nurse co-workers from distressful end-of-life situations in order to protect them. This finding is
an unexplored aspect of the nursing literature. Their behaviours suggest that they are acting to
protect others in response to their own suffering from witnessing traumatic events repeatedly in
PICU. In addition, there is a possibility that working within a culture where their practice is
described as constrained influences nurses to control others they perceive as less powerful than
themselves. It would appear that further exploration of the aspect of moral sensitivity as it relates
to nurses and end-of-life decision making in PICU is warranted in an effort to better understand
the motivation and target of nurses’ protective instincts.

Summary

In their struggle to control the dying process in PICU nurses and physicians exhibit certain
behaviours based on their values and beliefs which direct how end-of-life decision making and
care should occur. The need to manage the actual or potential disorder has implications for
nurses and physicians because it influences the way in which PICU nurses and physicians
practice. Further exploration into the feasibility of consistently meeting the dying child and their
family’s needs in an open, supportive and holistic manner while balancing the environmental
demands of a critical care unit is warranted. Education for PICU nurses and physicians should
focus on celebrating the strengths of each profession through facilitating professional
collaborative growth regarding role expectations within a complex and uncertain environment.
Further exploration into how to partner with families and address their expectations could assist
in decreasing iatrogenic anxieties and conflicts. Further nursing research examining parents’
perspectives of end-of-life decision making and their preferred roles would be of value. In
addition, studies exploring the effects of end-of-life discussions with parents who have children
with life-limiting illness would provide insights into how to improve communication. Continuing
education addressing communication should occur on an ongoing basis with the interdisciplinary
team. Being aware of treatment limitations and respecting the parents' roles without being paternalistic are important concepts to reinforce in education sessions and daily practice. The challenge is creating a cultural shift in the PICU that will support these perspectives.

Discussion of the Method

This study utilized an ethnographic approach. In the following sections, the efforts taken to insure the approach was rigorous are described and the limitations of the study are discussed.

Rigor

Auditability, credibility, fittingness and confirmability address the four issues of rigor: consistency, neutrality, truth-value, and applicability (Szabo & Strang, 1997). Auditability was achieved through recording the investigative process, analysis and emerging theories in the form of detailed memos. These memos became a part of the audit trail and a record of my qualitative thinking and inductive work (Morse & Richards, 2002).

Triangulation and member checking were utilized to enhance credibility and fittingness (Morse & Richards, 2002). In order to challenge, illuminate or verify my findings, members of my thesis committee with expertise in nursing research and/or the subject content of my thesis provided consultation and advice throughout the research process. National and international research and content experts were contacted to critically review different components of the research process and findings. In addition, I reviewed the findings with participants and other non-participant PICU nurses and physicians for their perspectives on the authenticity of the findings.

Some participants wanted to only share positive stories, and seemed anxious to have their unit appear in a positive light. For instance, some nurse participants told of exceptional working relationships with critical care physician colleagues whom they described as "exemplary
communicators”. Having experienced different communication styles with physicians, I probed deeper to better understand what was exceptional about their work relationships and communication styles. After further questioning and reflection, many of those nurses voiced periods of dissatisfaction with their physician colleagues and their approach to interprofessional work relationships, particularly around support and collaboration. These discrepancies were described in the findings.

Validation of findings was also sought by presenting ideas from previous interviews to new participants. Participants confirmed validity by agreeing with and frequently building upon those ideas. For example, the first three participants referred to oncology specialists and cardiovascular surgeons as often obstructive or resistant with moving towards end-of-life discussions and decisions. When questioning the remaining participants, I explored if they had experienced disagreement about end-of-life decision making with specialist groups.

Confirmability was assured through consistency in the methodological approach to analyzing the data using reflexivity, being true to the research questions, appropriate coding and reporting of rich, descriptive narratives to support emerging cultural themes. Although all extremely important to the methodological integrity of this ethnographic inquiry, reflexivity was my primary concern because of my work experience and passion for the topic.

Reflexivity is viewed as an essential component of rigor (Morse & Richards, 2002). Being an ‘insider’ in ethnographic research implies that the researcher shares an identity with the participants thus making him/her part of the cultural group (Goodwin et al., 2003; Hammersley & Atkinson, 2001; Morse & Richards, 2002; Pellatt, 2003; Platzer & James, 1997; Wolcott, 1999). As a member of the PICU culture with a practice focus on end-of-life care in pediatric critical care, I entered into this study as an insider. Baillie (1995) cautions that while being an
insider has its advantages concerning the development of relationships with participants, the researcher must not make assumptions. Pellatt (1998) cautions that:

Researching in one's own culture can cause tension between strangeness and over-identification, and it has to be acknowledged that researchers who cannot stand back from obscure knowledge that they have obtained, and whose perspectives are identical to those of a host culture, are likely to face analytic problems (p. 31).

As a novice researcher, I was particularly sensitive to the influence my experience as a PICU nurse might pose. Fetterman (1998) described how researchers often begin the research process with assumptions and biases; I too was guilty of that. However, as Fetterman suggested, I spent a great deal of time reflecting upon those biases and assumptions in order to prevent my PICU nursing realities from influencing the quality of the study. In order to avoid making assumptions based on my knowledge and biases, and possibly miss data in both the collection and analysis phases of the research process, I recorded my thoughts and discussed my approach and findings with experts and my thesis committee members on an ongoing basis.

Polit and Hungler (1999) imply that tacit knowledge is an important component of understanding a culture. I consider that my being an insider was an advantage for understanding tacit knowledge; especially considering the fact I critically reflected on personal and professional values and beliefs on an ongoing basis. Insider status can be considered as beneficial in understanding the subtleties of an environment, thereby enhancing the credibility of the researcher with participants (Byrne, 2001). While my insider status posed potential problems with how I structured and implemented my inquiry, I believe it afforded me a level of trust with the participants because many of them spoke openly about their work culture and experiences in caring for dying children and their families.
My feelings of discomfort with being an insider and conducting research are substantiated in the literature (Pellatt, 2003). I had moments where I felt frustrated with or intimidated by some of the participants' responses or attitudes. For example, I was nervous interviewing one of the physicians who was extremely articulate and well versed in caring for dying children and their families because of his expertise and status within the national PICU community. At one point during the interview he politely asked me, “Can you speak English and not ‘nurse-speak’?” I was embarrassed but I apologized, collected my thoughts, rephrased the question and listened to his answer. After the interview, I reflected upon my use of language and wondered if my phrasing during previous interviews had influenced other participants’ answers. As a result, I became more sensitive to the way I was structuring my questions after that interview.

Because I had participants volunteer who were past and present colleagues of mine, I was sensitive about being too familiar with them. However, I was amazed at the depth of the information they shared and the personal investments they made regarding end-of-life decision making. Similarly, the participants I did not know were just as responsive. The benefits of partnering with the participants and being able to use my background while being reflective was constructive in uncovering valuable insights (Pellatt, 2003). Being a member of the PICU community created credibility for me that I could not otherwise have had and allowed me to explore a sensitive topic with relative ease. Therefore, I see the benefits to being an insider ethnographic researcher directly related to knowing the culture and being accepted as an insider by the participants.

Despite the criticisms and cautions surrounding an insider as researcher for ethnographic studies, I believe that my experience as a PICU nurse who has focused her committee work, staff education, and research on end-of-life care in the PICU was an asset. I acknowledged that I have
assumptions regarding how decisions are made in the PICU and end-of-life care that could have potentially influenced my research. By documenting my self-critique and discussing my ongoing reflexivity concerns with my thesis committee members, content experts and colleagues, I was able to create a "check and balance" approach to data collection and analysis.

Limitations

Limitations to this study are related to its limited scope, the absence of direct observation, and conducting the research from an insider’s perspective. As this study is my master’s thesis, it has a limited scope due to the time, size, and fiscal restraints placed upon the project. Ethnography is characteristically a lengthy endeavour primarily due to the time required for in-depth field observations, interviewing, and analysis (Hammersley & Atkinson, 2001; Wolcott, 1999). Wolcott cautions that alterations in ethnography, including rapidly performed ethnography (e.g., focused ethnography), should not imply that the approach and analysis have less integrity. He acknowledges that within the time restrictions placed upon many researchers today there is a need for ethnographers to work within flexible time frames.

There are opposing perspectives on the inclusion of direct observation in ethnographies. Wolcott (1999) emphasizes the importance of direct observation. Morse and Richards (2002) suggest that in focused ethnography using limited sources of data collection is permissible providing rigor is maintained. For the purpose of this study, I did not directly observe the participants for two reasons: logistics and the sensitivity of the topic.

Logistically, the scope and lack of funding for this study did not enable me to spend time observing participants working with dying children and their families in PICUs across Canada. The number of deaths in PICU is relatively small in comparison to adult PICU deaths. For example, 196 infants and children were reported to have died within a 30 month time frame in a
tertiary pediatric PICU in Western Canada (McCallum et al., 2000). In a retrospective study of adult deaths in a Canadian regional referral teaching hospital, 174 patients died within a 12 month time frame (Hall & Rocker, 2000). In order to observe PICU nurses and physicians involved in end-of-life decision making, research assistants would need to be available in each PICU for extended periods of time (e.g., 24-hours a day for seven days a week); such coverage was not logistically feasible for the scope of this research project. In addition, the sample includes participants from eight of the 17 PICUs from across Canada and is therefore, not representative of the broader PICU culture and PICU physician and nurse population.

Data was collected through semi-structured telephone or one-on-one interviews. While I believe I obtained rich descriptions through these approaches to data collection, the telephone interviews limited data collection in the following ways: a) the opportunity for non-verbal communication was eliminated; b) it was difficult to establish a rapport without being able to see the person and communicate with a smile or supportive gesturing; c) I was required to assess the participants' emotional status with limited feedback, and; d) it was difficult to communicate attentive listening without interrupting the participant. In comparing the two methods of data collection, I would have preferred to have conducted all interviews in-person based upon the ability to collect non-verbal communication as another data source.

Sensitive research is described as being “that which poses a threat to those involved in it, whether they are the researcher or the researched” (Platzer & James, 1997, p. 627). The authors caution that participants may feel threatened at any time during the research process. Feelings of vulnerability may resurface or develop during dissemination of the results. I found the following quote by Platzer and James particularly helpful in restructuring my questions based on my previous relationship with the participants and their responses and reactions to the questions.
Threat can come from intrusion into the private sphere and over matters which are highly emotional or sacred; it can arise where less powerful or oppressed groups are studied and where there are issues of social control over activities which are stigmatizing or incriminating (p. 627).

A component of the discussion surrounding sensitive research is the impact it could have on the participants and the researcher at any stage in the process. Because of the emotionally sensitive nature of this topic, I was aware of the threats participants could experience during the interviews and therefore, I was sensitive to changes in the participants' tone, phrasing and speech patterns. As a result of my experiences with critical incident stress management and being a member of a critical care team, I am aware that many health care professionals bury their emotions repeatedly in an attempt to cope with the ongoing emotional demands of their profession. While I am aware of the supports available for the staff at one of the study hospitals, I was not privileged to that information about other centers. I considered this knowledge deficit a limitation but addressed the issue by drawing upon my theoretical and experiential knowledge bases to support a participant who appeared distressed. For example, two nurses began openly crying when sharing their experiences in caring for dying children and their families. Both of them responded to a different way of acknowledging and honouring their grief. I found being genuine with the participants and using self-disclosure during the interviews assisted in building trust and encouraging the participants to share rich descriptive narratives.

Platzer and James (1997) discuss the perception of power influencing the participant-researcher relationship. I believe that my role as nurse educator in the PICU at BC Children's Hospital did not have an influence on the relationship that I had with the participants. I hold no supervisory power over any of the nurses currently practicing within the PICU and although I am
a member of the PICU Nursing Management Group, I am not a highly visible member because my office is not located in the unit and I play a small role in the day-to-day running of the PICU. Despite this, I was sensitive to the power dynamics in the researcher-participant relationship. Therefore, each participant was assured of confidentiality. In addition, they were informed that their participation and the information they shared would have no impact on their employment. I alleviated concerns any of the participants had regarding disclosure of information that could identify participants by informing them that I would be eliminating all identifiers, including their workplace and anecdotal details that could identify them.

Significance of the Study

This study provides some important insights into how the values and beliefs of a sample of Canadian PICU nurses and physicians influence end-of-life decision making. The PICU environment with its acuity and uncertainty play an important role in how the dying process occurs. End-of-life decision making in PICU is influenced by the desire to control potential and actual disorder through micromanaging care aimed at achieving the child’s, family’s and staff’s best interests. Often this endeavour creates challenges which lead to distress for the family and staff. This study has generated many questions for further study; primarily these questions investigate how the current culture could think of dying in another way.

Summary of the Study

There is no doubt that caring for critically ill children and their families presents many challenges. The intensity increases when all efforts fall short of being able to “cure” the child and the health care team is faced with the task of informing the family that options are limited. The purpose of this study was to explore how the PICU culture influences end-of-life decision
making. Within this study the beliefs, values, and practices of PICU nurses and physicians have been explored.

An ethnographic approach was chosen to gather descriptive data on how nurses and physicians work within their PICUs to deliver routine and end-of-life care. Due to logistical limitations, data was collected through telephone and in-person interviews. The interviews were recorded, transcribed and analyzed for common themes.

The findings describe the PICU culture including the shared values, beliefs and norms of the PICU nurses and physicians who participated in this study. The types of people who do this work are dedicated to the goal of helping children survive life threatening illness or injury with prospects for a “good quality of life”. In order to function within the actual or potential disorder of the PICU environment, the nurses and physicians developed routines to manage everyday and end-of-life disorder. The need for control was in direct response to needs to manage the unexpected and to decrease conflict. The participants described working under “emotionally stressful” situations, especially leading up to the diagnosis of dying. The desire to control continued into the dying process and was enacted through the development of an end-of-life plan to direct the dying process. Great value was placed upon this plan because it was designed with the intent of providing a “good death”. When “loyalty to the plan” was questioned, or the participants felt conflicted with the plan based on their beliefs and values, they described feelings of distress. The participants shared their desire to protect dying children, their families, and staff from unnecessary suffering. However, their behaviours appear to be related to a need to protect themselves from creating or witnessing further suffering.

The findings of this study suggest a need to develop a deeper understanding of how the struggle to control dying in PICU impacts end-of-life decision making. Further research and
education are required that focus on: developing a better understanding of the concept of control in PICU and its implications for end-of-life care; strategies to improve interdisciplinary end-of-life decision making within a family-centred model; improving upon the current practices aimed at caring for dying children and their families in a non-hospice setting; developing strategies for individuals to explore their understanding and comfort within end-of-life care; and developing and sustaining collaborative relationships between health care professionals and families.
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APPENDIX A: PARTICIPANT INFORMATION LETTER

University of British Columbia
SCHOOL OF NURSING

The influence of the pediatric intensive care unit (PICU) culture on end-of-life decision making

There is perhaps nothing so hard to accept as the fact that sometimes, despite even our best attempts to prevent it, children die ... The more technologically capable we have become as a society, the more we have been able to extend human life by mechanical and artificial means. While this has allowed us to save and cure patients never before possible, it has blurred the lines between life and death. For families and caregivers, end-of-life decisions have become more complicated than imaginable.

The purpose of this research study ‘The influence of the pediatric intensive care unit (PICU) culture on end-of-life decision making’ is to develop a better understanding of how health care providers in PICU work with families towards end-of-life decision making. This research study is being conducted by Dr. Joy Johnson, principal investigator and myself, Tracie Northway, a graduate student in the Master of Science in Nursing (MSN) program at the University of British Columbia. This research study is to meet partial fulfillment of the requirements for my MSN degree.

You are being asked to voluntarily participate in this study because you are a registered nurse or critical care physician currently working in a PICU and you have experience in caring for dying children and their families. Your time requirement would consist of one hour for an initial interview and no more than 30 minutes for a possible follow-up interview. The date and time of these interviews would be selected based upon your availability.

If you are interested in participating in this research study or you have any questions, please contact me at W. (xxx) xxx-xxxx or H. (xxx) xxx-xxxx or via email at xxxxx@xxxxx. Thank you for your consideration in participating in this study.

Sincerely;

Tracie Northway, RN, BScN
Graduate Student, UBC School of Nursing

APPENDIX B: PARTICIPANT CONSENT FORM

Study: The Influence of the Pediatric Intensive Care Unit (PICU) Culture on End-of-Life Decision Making

Principal Investigator: Dr. Joy Johnson
University of British Columbia
T159 -2211 Wesbrook Mall, Vancouver, BC
Telephone: (xxx) xxx-xxxx

Co-Investigator: Tracie Northway, UBC Graduate Nursing Student
Master of Science in Nursing (MSN) Program –Thesis
Telephone: W. (xxx) xxx-xxxx or H. (xxx) xxx-xxxx

Purpose:
The purpose of this study is to explore how the PICU culture influences end-of-life decision making in pediatric critical care. You have been invited to participate in the study based upon your expertise as a health care provider working with critically ill children who are dying and their families. It is believed that your contributions to this study will increase the understanding of how health care providers in PICUs work with families towards end-of-life decision making.

Study Procedure:
You will be asked to dedicate one hour of your time for an initial interview and no more than 30 minutes for a possible follow-up interview. The date and times of these audiotaped interviews will be selected based on your availability. You may ask questions of the researcher during the interview process. You are aware that the researcher’s interpretations of the data will be shared with you during the process of analysis and that you will have opportunity to clarify findings and may have input into the interpretation of the results.

Confidentiality/Risks:
Your identity will be protected by code naming of the tapes. The principal investigator and co-investigator will be the only people with access to the code naming. The tapes will be kept in a locked filing cabinet. A typist transcriber will have access to the anonymous tapes and transcripts. In addition, any persons you mention on the tapes will not have their identity revealed at any time. At any time during the process, you can refuse to answer questions, and/or request that the tape be turned off or erased. You can also end your involvement in this research project at any time. There is a possibility that you may find the content emotionally upsetting as you recall your experiences in caring for dying children and their families. If you require support you will be guided in how to seek assistance.
Contact for information about the study:

If you have any questions or desire further information with respect to this study, you may contact Tracie Northway at either W. (xxx) xxx-xxxx or H. (xxx) xxx-xxxx or via email at xxxxx@xxxx.

Contact for concerns about the rights of research subjects:

If you have any concerns about your treatment or rights as a research participant, you may contact the Research Subject Information Line in the University of British Columbia Office of Research services at (xxx) xxx-xxxx.

Consent:

Your participation in this study is entirely voluntary and you may refuse to participate or withdraw from the study at any time without jeopardy to your employment.

Your signature below indicates that you have received a copy of this consent form for your own records.

Your signature below indicates that you have had the opportunity to ask questions and that these questions have been answered to your satisfaction.

Your signature below indicates that you have given permission for the information you have provided on tape during the interviews to be used in teaching materials, research journals, books, or articles.

_________________________________________  ______________________________
Signature of Participant                  Date

_________________________________________  ______________________________
Signature of Researcher                   Date
The Influence of the Pediatric Intensive Care Unit (PICU) Culture on End-of-Life Decision Making: PARTICIPANT DEMOGRAPHICS

Participant #: 

Age:  
- ☐ < 25 years  ☐ 35 to 39 years ☐ > 50 years  
- ☐ 25 to 29 years  ☐ 40 to 45 years  
- ☐ 30 to 34 years  ☐ 46 to 50 years  

Sex:  ☐ Male  ☐ Female

Current position in your place of employment: 

Educational background: 

Other areas of your professional experience: 

Total years in practice: 
Total years in pediatric critical care: 

Employment in other PICUs (location and length of time): 

Experience as a parent:  ☐ No  ☐ Yes

No. of Children & their ages: 

When was the last time you provided care for a dying child and their family?
The individual interviews will focus on the following questions. Broad, open-ended questions are used to elicit the participants’ perspectives.

Guide to the first interview

1. I am interested in how your PICU works. Specifically, I am interested in how the culture of your unit, or how you work as a group of people, influences end-of-life decision making. However, in order to better understand your unit I would like you to walk me through a typical day for you in your workplace.

2. Tell me about decisions that you make when caring for patients and their families.

3. When do you consult others to assist you in your decision making?

4. From your descriptions so far would you agree that there is a process that is followed in your unit for patient care decision making? Please expand further upon this decision making tree so that I understand who decides what.

5. Tell me about an experience in caring for dying children and their families. (One in which you feel that the process was handled well and one in which it was not handled well).

6. How does decision making around caring for these patients differ from those who are not dying?

7. Is there anything else that you would like to share with me regarding what we have been discussing today?