PHYSICIAN-PARENT INTERACTIONS IN PEDIATRIC END-OF-LIFE CARE:
IMPLICATIONS FOR INTEGRATIVE COMMUNICATION,
DECISION-MAKING AND ETHICS TRAINING*

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MEDICAL SOCIOLOGY

ABSTRACT

In this dissertation, I utilized a primarily qualitative mixed methods longitudinal process to explore physician-parent pediatric end-of-life communication. Between August 2011 and March 2012, participant pediatric physicians (N=21) from emergency medicine (PEM) and critical care (PCC) were presented with a standardized case of an 8 year-old child in respiratory distress who had a degenerative neurological disorder and was nearing the end-of-life. Participants were observed in a timed simulation experience and given a physician-parent participatory communication score. All simulations were followed by a post-simulation debriefing interview. Then, between March and October 2012, a total of 17 of the original 21 participants then took part in Phase II individual narrative interviews to discuss how their stories informed their approaches to pediatric EOL communication. Finally, between April and June of 2013, all 17 participants from Phase II took part in Phase III narrative interviews, to discuss topics generated out of the data from Phase II.

Phase I quantitative results show that women (as opposed to men), fellows (as opposed to attendings), PEM physicians (as opposed to PCC physicians), and parents (as opposed to non-parents) scored higher on the measure of physician-parent participatory communication. Simulation sessions were longer for participants who were male (as opposed to female), PEM physicians (as opposed to PCC physicians), attendings (as opposed to fellows), and parents (as opposed to non-parents).
opposed to fellows), and parents (as opposed to non-parents). Qualitative data was analyzed using Atlas.ti version 7, according to the guidelines of grounded theory.

Qualitative findings indicate that individual physician characteristics emerging from their narratives, particularly those related to religion, parental status, experience level and early experience with death, influence physician-parent EOL interactions. As physicians struggle to find strategies to improve EOL interactions, they realize that their own stories affect their approaches. I propose that a communicative ethic could serve as a foundation for training pediatric physicians to be more effective communicators to promote better care for patients and more positive interactions with caregivers, as well as diminish their own emotional and moral distress.
DEDICATION

To Mark
ACKNOWLEDGEMENTS

There have been many people without whom I could not have completed this work. I first want to thank my family—my husband, Mark, whose support, sacrifice and love encouraged me to pursue this degree and see it through to completion; my children, Katy Grace, Sara and Anna-Li whose love and playfulness helped balance my stress; and my parents who nurtured an intellectual curiosity in me and whose life-long encouragement and support continued in full force through this time.

I have been incredibly fortunate to have had Jeffrey Clair serve as my mentor and am grateful for the time and energy he invested in my work. Jeffrey’s expertise in doctor-patient communication and qualitative methods, in addition to his acute sociological imagination, was invaluable to the work presented here and my future direction as a sociologist. I am also grateful to Belinda Needham, whose inspiration initially led to me into the field of Medical Sociology and whose work ethic, expertise, and insight instilled in me an understanding and appreciation of the field and my own place within it. I also very much appreciate the other members of my committee. Nancy Tofil and Marjorie Lee White provided tremendous clinical expertise and support. Irena Stepanikova and Ria Hearld are both wonderful teachers and professional role models from whom I have learned a great deal.

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<tr>
<td>AND</td>
<td>allow natural death</td>
</tr>
<tr>
<td>CPR</td>
<td>cardiopulmonary resuscitation</td>
</tr>
<tr>
<td>DCD</td>
<td>donation after cardiac death</td>
</tr>
<tr>
<td>DNAR</td>
<td>do-not-attempt-resuscitation</td>
</tr>
<tr>
<td>DNR</td>
<td>do-not-resuscitate</td>
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<tr>
<td>EOL</td>
<td>end-of-Life</td>
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<tr>
<td>PCC</td>
<td>pediatric critical care</td>
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<tr>
<td>PED</td>
<td>pediatric emergency department</td>
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<td>PEM</td>
<td>pediatric emergency medicine</td>
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<td>PICU</td>
<td>pediatric intensive care unit</td>
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<td>RCC</td>
<td>relationship-centered care</td>
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CHAPTER 1
INTRODUCTION

On an icy winter night, a second year pediatric physician in training, or resident, working at the regional children’s hospital in a large Midwestern city was part of a team called to pick up a sick infant who needed a higher level of care than could be provided at the local rural hospital. After a difficult journey, the ambulance arrived and the resident found an infant with a rare genetic disorder, trisomy 18, which he knew to be universally fatal by age 1 (at that time). The resident, knowing the child’s life expectancy, explained to the parents that although the child had just been resuscitated, the condition was terminal. Did they want to continue life-sustaining measures or did they want to stop? He assured them that stopping was a laudable option. Not one of the physicians they had seen previously had suggested it was okay not to pursue the most aggressive treatments available. Not one had said that allowing their precious infant to die a peaceful death might be the most loving act they could choose. They were left meeting a stranger, a trainee for that matter, at an overwhelmingly stressful moment, who exonerated them of the responsibility of saving the dying child. But, they were tired, and they were relieved.

Dying Children in a Death Denying Society

This vignette, shared by one of the physician participants in this study, begs the question, why had none of their regular physicians discussed the imminence of the child’s
death with the parents and suggested that comfort measures as opposed to life-sustaining medical technology may be most appropriate? Perhaps the absence of these conversations reflects the fact that talking about end-of-life (EOL) issues tends to be universally difficult for physicians, whether in the context of discussing the prognosis and treatment options of a patient or presenting the news of a loved one’s death. EOL conversations are especially challenging for physicians whose patients are children. The emotion that these types of discussions elicit in parents of dying children coupled with a physician’s sense of failure from their inability to heal complicates the physician-caregiver relationship. Throw in cultural assumptions about the ability of medical technology to protect against death with the breaking news of an impending death of a child, and indeed physician credibility with parents can be compromised (Meert et al. 2008).

Training for the delivery of difficult news to patients and caregivers about both imminent and actual death represents a gap in medical education (Ahrens and Hart 1997; Baker et al. 2007; Fallowfield and Jenkins 2004; Khaneja and Milrod 1998; Sullivan, Lakoma and Block 2003). What we do know is that the ability of physicians to communicate both realistically and compassionately about the prognosis, treatment options and the death event itself is crucial for enabling parents and/or patients to make the most appropriate EOL decisions as well as being able to cope post-death. Because EOL interactions affect the well-being of everyone involved, in this study I aim to collect and examine understudied physician narratives on the difficulties they face with information-giving about EOL issues. My focus is on how their approach to EOL communication has been shaped and how interactions about death have affected them professionally and personally. Ultimately I aim to offer insight into interventions that could improve interac-
tions between physicians and parents of dying children and therefore alleviate some of
the suffering experienced during the terminal care process.

In our American society, death is something that seems misplaced, invasive and
unnatural. The most striking characteristic of the current "American way of death"
(Mitford 1963) is that a majority of people do not die at home, surrounded by loved ones
and familiar sights, scents and sounds. Instead death has been moved to the impersonal,
technological environment of the hospital, where the resources exist to fight to the very
end. The modern project left its cultural mark on society by proclaiming that through the
continuous march of progress not only would peace and security ensue, but also even
death could be held at bay or controlled. And, indeed, scientific innovations in the 20th
century vastly advanced the technological capability of physicians to heal patients and
prolong life. The average life expectancy increased from 47 in 1900 to 78.7 for a baby
born in 2010 (Murphy, Xu and Kochanek 2012).

While the awareness of death has been present among members of all societies
throughout human history, our modern day cultural narrative tells us that we can work
hard, and through exercise and diet and other health practices, we can delay, which sub-
consciously translates as “avoid,” death. People go to great lengths to avoid thinking
about death. Multi-billion dollar industries sell us products to keep us from appearing to
age. When death does occur, it is kept sterile and separate from life. We use euphemisms
like “passed away”, “no longer with us”, “went on to a better place” to avoid the “d”
words—die, dead, death. We spend small fortunes on funerals so everything possible can
be done to make the body look alive and then it is put in an airtight container in a con-
crete vault—all to try to prevent the ancient idea of “ashes to ashes, dust to dust.”
As several observers of the contemporary social scene have noted, “experts” dominate the behaviors of persons in today’s “postindustrial” society. Experts advise us on virtually every aspect of our lives. Today, experts follow us throughout the life course. They are there when we are born and follow us each step along the way, through death. Nearly all aspects of the life cycle--birth, puberty, menopause, old age, and death--are conceived of as problems requiring medical intervention. Just as we have turned other features of our lives over to experts, we have given the responsibilities for the management of death to health care providers, nursing home personnel, and funeral directors.

In earlier historical periods the situation was different. Individuals greatly feared a sudden death that would rob them of the opportunity to author this "last chapter" of their lives. In contrast, today, with medicine's capacity to prolong the life of chronically ill persons, it is a long, drawn out, often painful death that is feared. Now, an increasingly larger proportion of persons eventually die after a "lingering death trajectory". Death has shifted from being a moral, religious event to a technological event. In North America, most notably, death is seen as a failure of technology in rescuing the body. This historical transformation has been described by Ivan Illich (1976).

Illich describes six historical stages corresponding to changes in the imageries held of dying. The first stage, which he labels the dance-of-the-dead image, appeared during the fifteenth century. During this stage, death was an occasion to celebrate life, often by dancing on the tomb as an affirmation of the joy of life. Later, during the Renaissance, this image was replaced by one which saw the end of life as marking the beginning of eternity. According to Illich, one indication of the switch to the stage he labels the “danse macabre” (taken from the title of a sixteenth century Hans Holbein picture book on death)
was the proliferation of clocks symbolizing a new time-bound consciousness. Bourgeoisie death, the third stage, emerges with the appearance of a bourgeoisie class that could begin to pay physicians to delay or to keep death away. This image, in turn, set the stage for physicians' promulgation of a clinical image of death based on the idea that death resulted from a disease that could be fought. By the 1900s, the image of clinical death had been further transformed into the notion of natural death in which doctors were expected to prevent any deaths occurring from disease. Finally, our imagery of death evolved to the current view that "unnecessary" deaths are to be prevented at any cost through a vast armament of medical technology. This Illich (1976:201) terms "death under intensive care."

In sum, Illich finds that our image of death has been changed from death as part of nature to death as a force of nature that makes the event untimely and finally to an image of "unnatural" death against which total war must be waged. Although a natural and inevitable part of the living process, death is viewed today as an evil adversary that must be defeated regardless of how heroic the technological measures required. The contemporary treatment of death has created a range of new bioethical questions about prolonging life beyond its "normal" course with a range of technical devices.

In the battle against death, patients seek out the latest medical technology that experts have to offer. Our physicians assist with this, because not only is death an unwelcomed intruder for patients, physicians view death as contrary to the goals of medicine. William May (2000) suggests that the two dominant images of physicians in contemporary society are that of a parent who protects and a fighter who battles against the onslaught of disease and death. The physician as parent comforts his or her patients and
shields them from destructive, deadly forces, while the physician as fighter musters all the technological weapons available in the all-out war against death. In this climate, people die in the hospital with the doctor present so their physicians can assure the survivors that everything that could have been done was done to prevent death.

John Lantos (1997) has described cardiopulmonary resuscitation (CPR) as a modern death ritual. Although few dying patients are actually brought back through basic life support, its implementation serves as a sort of last rites. However, CPR is often antithetical to last rites, in that instead of preparing the dying soul for death and providing prayers for the relief of suffering, the administration of CPR refuses to admit that death is an option until it becomes reality, and it often imposes violence and pain on the dying in the last moments of life.

If death feels unnatural in general, the death of children is viewed as abhorrent. In contemporary U.S. society, children are not supposed to die. Advances in medical technology and immunizations have saved most families the unbearable pain that accompanies the death of a child. In 1900 almost 1 in 10 children died between the ages of 1 and 15. In 2007, almost all children (99.7%) survived. Our infant mortality rate has decreased dramatically as well, from 146 deaths per 1000 in 1900 to less than 6 per thousand in 2012 (Central Intelligence Agency 2013).

Although the death of a child is more rare, it has gained a different status. It has become a “bureaucratic event” that is controlled by experts, both clinical and legal specialists (Lantos 1997). Since there are very few dying children in U.S. society, it’s not surprising that most physicians do not often encounter dying children in their practices. Even for the physician, the death of a child inevitably causes the emergence of challeng-
ing questions about the meaning of life. Treating children who have terminal illnesses may cause unique difficulties for physicians. Because children are supposed to live a full biography, physicians may not be able to see the futility of life-sustaining treatment in their dying patients (Sahler et al. 2000).

Ethical Considerations in Caring For Dying Children

Medical technology has led to tremendous advances in the ability to save children, thereby reducing a great deal of pain and suffering. But, how best do we care for children who have life-limiting terminal conditions? Should the quantity of life, extending the months or years of survival, trump quality of life? The field of bioethics has provided clinicians guidance on difficult decisions since the mid-20th century through the establishment of principles on which to base their decision-making. Principles theoretically provide a common set of general comprehensive norms that can be applied in diverse medical situations when patients and providers have differing orientations.

The principles of autonomy, beneficence, nonmaleficence, and justice are foundational in American bioethics. However, bioethical paradigms do not always apply neatly to pediatrics (Lantos 1997). Parents serve as the surrogate for their child’s autonomy and the best interests standard typically applies in decision making, meaning that the parents decide the best course of action for the child. Beauchamp and Childress (2013:228) describe the best interests standard this way: “…a surrogate decision maker must determine the highest net benefit among the available options, assigning different weights to interests the patient has in each option and discounting or subtracting inherent risks or costs.”
We need to consider the confusion parents experience in trying to make rational, calculated decisions when they are crushed with the reality that their child is dying. Of course, they will be at the core of such discussions, but their ability to make informed decisions will be based on the quality of the information they receive. For pediatricians, the legal and moral obligations are disparate. They may be legally obligated to the parents or legal guardians, but they are morally obligated to the patient (Lantos 1997). And, what happens when these obligations conflict? In other countries, physicians rather than parents are responsible for making EOL decisions in children. Bioethicists argue that parents do not have the medical expertise and should be protected from having to make a decision regarding their own child’s death (Baines 2008; Carnevale et al. 2006). Poor communication could be considered a breach of the moral obligations physicians have to both patients and their parents in that it may adversely affect the EOL decisions.

Physician Discomfort and Distress in Their Care for Dying Children

Many aspects of EOL care that are related to communication can generate difficulties for physicians of dying children. Their inadequate training in EOL discussions, the moral distress they feel when parents’ decisions conflict with their beliefs about what is best for a particular patient, and the grief they experience from their patients’ deaths all have the potential to affect the patient care process as well as physician well-being.

It is peculiar that since patient death is likely the most difficult experience in pediatric medicine there is not more adequate training provided (Ahrens and Hart 1997). Due to the relative brevity of their medical education and the paucity of child deaths, training programs typically do not allot a significant amount of time to training in com-
municating with patients and their caregivers about death. In fact, one survey found that only 14% of physicians had any training in informing loved ones about the death of their child (Ahrens and Hart 1997). Some become masters at death and dying communication by muddling through the awkwardness of triadic doctor-patient-caregiver encounters, but many never do. And, there are consequences of poor communication for patients, parents of patients, and physicians themselves. For example, EOL patients may not receive optimal palliative care if their parents do not understand that their prognosis is terminal despite the presence of life-sustaining technology. Poor communication can magnify the extreme pain and frustration that parents are already experiencing as their child is dying. And, physicians too are susceptible to stressors, with awkward encounters with parents contributing to moral and emotional distress. There are few formal mechanisms in place to help physicians of any rank deal with personal grief or moral distress, and continuous exposure can lead to physician burnout and personal pain (Brazil et al. 2010; Burns et al. 2001; Sahler et al. 2000). An Institute of Medicine (2003) report, *When Children Die: Improving Palliative and End-of-Life Care for Children and their Families*, suggests that strategies must be developed to support clinicians who deal with pediatric death in order for them to continue to provide quality care.

Although EOL communication between physicians and parents is of paramount importance, it remains understudied, and is particularly devoid of any in-depth inquiry into the physician’s communication strategies (Cramm and Dowd 2008; Knapp, Mulligan-Smith and American Academy of Pediatrics Committee on Pediatric Emergency 2005). In this research, by exploring physicians’ perspectives on EOL communication I aim to:
(1) Explore how physicians’ approaches to EOL communication are shaped,

(2) Examine the difficulties physicians experience in talking about EOL issues with parents of pediatric patients who are dying or who have died,

(3) Investigate how interactions about death affect them personally and professionally, and

(4) Explore physicians’ insight into how to improve EOL physician-parent communication.

This study used a primarily qualitative mixed methods approach to gain deeper insight into this topic. A sample of 21 participant physicians, fellows and attendings, males and females, from the specialties of pediatric emergency medicine (PEM) and pediatric critical care (PCC) initially took part in the study. Each participant completed an experience in a high-fidelity simulation setting that involved their treatment of a standardized EOL 8 year-old patient and their communication with an actor-parent. Following the simulation, participants completed a questionnaire. The specialties of PEM and PCC were chosen because they both deal with children at the EOL, but in dissimilar environments and under generally different circumstances.

A series of three one-on-one semi-structured interviews were conducted to discuss their approach to and feelings about EOL care and how their narrative backgrounds, both personal and professional, have shaped their care of dying children and how their interactions with dying children affect them personally. Each round of interviews led to further topics for discussion in the following round.

Through analysis of both the quantitative and qualitative data and presentation of the findings, I ultimately propose a training structure for physicians based on the tenets of
communicative ethics. Through this research, I hope to provide insight into how communication may be improved to promote better care for dying children, more positive interactions between physicians and caregivers, and less moral distress and burn-out in physicians. In the next chapter, I will discuss the context of EOL communication between physicians and parents, the factors related to medical culture and the individual physician that shapes this context, and finally, the impact that EOL communication has on the personal and professional lives of physicians.
CHAPTER 2

REVIEW OF LITERATURE

Life is a journey. The passage from birth to death is manifest with companionship and loneliness, work and rest, and health and illness. Although we joyfully anticipate the birth of children with baby showers, gift registries, and birth announcements, in our culture we do not want to face the fact that death also is a natural part of the life cycle. We reluctantly realize that when people become old and frail that death is nearing. However, we seem to continuously refuse to acknowledge that unwelcomed life-limiting disease and injury may appear at any point during an individual’s journey, even in youth. As discussed in Chapter 1, the idea of death is difficult for most people, but when the person at the end of life is a child, the pain is magnified (Sahler et al. 2000).

Research indicates that physicians even have difficulty facing the death of children (De Graves and Aranda 2005; Lee and Dupree 2008; Papadatou et al. 2002; Papadatou 2000; Williams 2010). This struggle has disparate sources including our societal disdain of death, a culture of medicine that relegates education and training in EOL issues to a low priority, and varying characteristics inherent to individual physicians. Physicians’ struggles with child deaths may generate significant problems in the patient care process, a starting point being with the physician-parent relationship. In pediatric EOL care, the partnership between physicians and parents is principally centered on communication and the parents’ decision-making role about the patient’s impending or actual death. Research indicates that this communication is often poor (Aschenbrenner,
In comparison to all aspects of medical care, communication has been historically ranked at the bottom of the list in terms of patient satisfaction (Bertakis 1977), and when asked to comment about the communication of bad news and overall care provided, parents of children who have died directed the least number of positive comments and most number of negative comments towards physicians (Jurkovich et al. 2000). However, because parents are charged with EOL decision-making for their children, physicians are morally responsible to ensure that prognoses and treatment options are communicated to parents in a comprehensible way. Information-giving that is clear, truthful, and timely encourages parents to choose optimal care for their child, which often is palliative care over life-sustaining measures (Institute of Medicine 2003).

Parents who have endured the unthinkable pain of seeing their child die want desperately to know that their child was given the highest quality medical care and that suffering was minimized (Institute of Medicine 2003). It is only through effective communication with their physicians that parents are assured of these needs. The pain can be unbearable for parents left wondering about these issues after their child’s death (Masera et al. 1999).

In the decade since the Institute of Medicine (2003) issued a pressing call for descriptive research on clinical communication with the parents of dying children, many studies have examined parents’ perspectives (Aschenbrenner et al. 2012; Hendricks-Ferguson 2007; Weidner et al. 2011; Widger and Picot 2008). Few have examined physician-parent communication from the point of view of the physician. In order to under-
stand the phenomenon of physician-parent communication, its weaknesses and strengths and potential for improvement, further research is necessary.

Pediatric EOL Communication: Definitions

Pediatric patients at the EOL present unique challenges. They are young and most cannot speak for themselves. Their prognoses often are difficult to determine. A child’s death generates unique challenges and distress for everyone involved (Basu 2013; Sahler et al. 2000). Although relatively rare, the number of children facing death each year is not insignificant. In 2009, 48,073 children (ages 19 and under) died in the U.S. (Kochanek et al. 2012) and approximately 500,000 children in the US have life-limiting conditions (Himelstein et al. 2004). An estimated 20% of children who die each year are pronounced dead in outpatient sites, primarily the pediatric emergency department (PED) (Knapp et al. 2005). After a decision has been made to withdraw life-sustaining technology, the pediatric intensive care unit (PICU) represents another location where children die (Garros, Rosychuk and Cox 2003; Meert et al. 2008; Moore et al. 2008; Sands et al. 2009).

Effective communication between parents and physicians is associated with higher quality medical care for patients (Committee on Bioethics and Committee on Hospital Care 2000; Jurkovich et al. 2000) and less suffering by parents whose child has died (Bertakis and Azari 2012; Contro et al. 2002). To begin the discussion on EOL communication between physicians and parents, this section will examine definitions germane to the topic that will be utilized in this study.
End of life

In health care, the “end of life” refers to the situation of a patient who has a life-limiting condition. According to an NIH “State-of-the-Science Conference Statement on Improving End-of-Life Care” (2004), a clear-cut definition for the phrase end-of-life (abbreviated EOL here) does not exist, although two components are described in the literature. First, a patient who is at the EOL has the presence of one or more chronic diseases, persistent symptoms and/or functional impairment. And, second, the resulting symptoms from this chronic, irreversible condition require both formal or informal care and will likely lead to death (National Institutes of Health 2004). The goals of EOL care include preparing for a probable death, such as discussing limitations of life-sustaining technologies, and managing the end stage of a terminal disease or condition (Institute of Medicine 2003). Determining when a child has reached the EOL is more difficult than for adult patients due to greater prognostic uncertainty that exists in children with life-limiting conditions (Basu 2013; De Graves and Aranda 2008; Mack and Wolfe 2006; Sahler et al. 2000), and therefore determining when to initiate EOL discussions with parents often is problematic for physicians.

Palliative Care

EOL care often involves palliative care, the goals of which include, “…to prevent or relieve the physical or emotional distress produced by a life-threatening medical condition or its treatment, to help patients with such conditions and their families live as normally as possible, and to provide them with timely and accurate information and support in decision-making.” (IOM 2003:2). Although the American Academy of Pediatrics
(2000) has stated that high-quality palliative care is expected in all children with life-limiting conditions, most do not receive adequate palliative care (Carter et al. 2004; Durall, Zurakowski and Wolfe 2012). Ideally, EOL care and palliative care should work together to “promote clear, culturally sensitive communication that assists patients and families in understanding the diagnosis, prognosis, and treatment options, including their potential benefits and burdens” (Institute of Medicine 2003:2). Clearly, effective communication between physicians and patients is crucial to proper EOL care. Because of the prognostic uncertainty that accompanies children diagnosed with life-limiting conditions, some have suggested that integrating palliative care with life-sustaining technology is an important goal for these children and medicine as a whole (Basu 2013; Institute of Medicine 2003; Lindley 2011).

**EOL Conversations**

Pediatric EOL communication refers to interactions between the physician and the patients’ parents about an impending or actual death. There are two basic types of EOL conversations between physicians and parents. The first type occurs when an infant or child has a life-limiting prognosis, such as a birth-related congenital condition or a terminal cancer that has been resistant to all available medical treatment. In this case, the communication focuses on EOL issues and/or palliative care. Often these children have never led healthy lives and never will. EOL discussions address the parents’ questions about determining the best course of treatment for their child by evaluating the child’s quality of life (Basu 2013; Sahler et al. 2000). EOL conversations also occur when a previously healthy child has been involved in some type of accident or experienced an
acute disease state that results in a life-limiting prognosis for the child. Parents of these children may feel guilt which may make the EOL decision-making process even more complex (Sahler et al. 2000).

The second type of EOL conversation is known as “death notification” (Ahrens and Hart 1997; Olsen, Buenefe and Falco 1998). In this situation, which commonly occurs in the PED and the pediatric intensive care unit (PICU), the physician must tell the parents that their child is dying or has died. This is considered by many to be the most difficult task for any pediatric physician (Ahrens and Hart 1997). Families will never forget the conversation where they were told that their child was dead, and thus this conversation has the potential to begin the process of healing or to be permanently damaging (Ahrens, Hart and Maruyama 1997; Contro et al. 2002; Institute of Medicine 2003). During both of these types of conversations, parents expect physicians to not only provide factual information but to serve as a counselor attending to their emotional needs (Ahrens et al. 1997; DeLemos et al. 2010; Jurkovich et al. 2000; Knapp et al. 2005; Meyer et al. 2006; Meyer, Snelling and Myren-Manbeck 1998). Because most pediatric physicians receive little training in general communication strategies and EOL issues, their ability to meet parents’ expectations may be compromised (Baker et al. 2007; Khaneja and Milrod 1998; Levetown 2008; Sullivan et al. 2003; Wittenberg-Lyles et al. 2008).

**Physician-Parent Communication**

This study focusses on physicians’ perceptions of their individual interactions with families of dying children, called here *physician-parent communication*. Although there is debate in the bioethics literature about when a child is old enough to have a voice
in his or her own care (Beauchamp and Childress 2013; Levetown 2008; Morrison and Berkowitz 2007), this research will focus primarily on communication between physicians and parents. Further, the term *parent* will be used, although *guardian* could be substituted if appropriate. *Parent* was chosen over *surrogate* because *surrogate* could mean someone who has minimal emotional connection to the child, such as a social worker given power of attorney to make decisions for a child who is no longer in the parents’ custody. This relationship is quite different than that which exists within the parent-child bond and thus the emerging issues are disparate as well.

**The Physician-Parent Relationship in Pediatric EOL Communication**

The components of physician-parent communication are foundational for other facets of care, including appropriate medical treatment for the patient, emotional support for the parents, and a healthy work environment for physicians. These aspects work together to affect the functioning of the larger health care system. The importance of one-on-one interactions between individuals in determining social structures is echoed in Goffman (1983:8) who claims that, “social structures are dependent on, and vulnerable to, what occurs in face-to-face contacts.” The hospital setting can be envisioned as a social structure where the functions and expectations of individuals are both interrelated and crucial to the overall functioning of the system (Clair 1990). Clair (1990:60) describes the oncology unit as “a place of activity where role performers find much of their identity from indigenous values, norms and artifacts.” And, this is true of hospital and clinic settings where EOL physician-parent communication occurs. The setting influences the way that role performers present themselves (Goffman 1959). Physicians and
other health care professionals are socialized to feel comfortable in the hospital setting, whereas patients and parents are often entering a strange land and quickly must internalize the values and norms presented (Clair 1990). Meert et al. (2009) has described the environment of the PICU and its effect on parents of dying children. Parents desire privacy and quiet. PICUs, however, are designed so that patients can be constantly monitored by health care professionals which makes the setting rather loud and hectic. Parents also desire more time to process and make decisions and this may come into conflict with the staff’s lack of time (Meert et al. 2009).

Through immersion into the hospital setting, patients and parents quickly learn that their behaviors must be directed to the clinical values of their health care providers (Clair 1990). For example, often parents are ready to discuss EOL issues before physicians broach the subject with them, because although parents fear death for their child, they also do not want their child to suffer (Institute of Medicine 2003; Levetown 2008). Researchers in one study found that 45% of the parents of critically ill children thought about limiting life-sustaining technology before the physician brought it up (Meyer et al. 2002). Results from another study found that in 24% of cases, the family initiated the EOL conversation (Garros et al. 2003). Parents may not initiate EOL conversations because they have been socialized into the values of biomedicine, which include the preference of life-sustaining technology. Further, they may have learned that despite patient autonomy, their role is one of submission and compliance (Clair 1990).

As the above example illustrates, both parties in the physician-parent interaction have reasons for controlling their presentations of self. Physicians do not want to admit that they cannot heal, and through impression management (Goffman 1959) they may
avoid or temper the discussion of EOL issues. Even in the age of patient autonomy, physicians still report censoring information they share with patients as they want to appear that they can heal and they feel providing less knowledge of difficult information may be better for families and patients (Fallowfield, Jenkins and Beveridge 2002). Parents also practice impression management in their efforts to be advocates for their child and have the best care available provided. They want to solicit truthful, comprehensive, understandable and timely communication about their child’s prognosis and treatment options (DeLemos et al. 2010; Meert et al. 2008; Meyer et al. 2002; Meyer et al. 2006; Meyer, Snelling and Myren-Manbeck 1998).

Effective Physician–Parent EOL Communication

In order for children at the EOL to receive optimal care, which is often palliative care as opposed to life-sustaining measures (2000; Hinkka et al. 2002), advanced planning is crucial (Durall et al. 2012; 2004). Physicians must talk with parents about the prognosis and that technology cannot prevent an untimely death (Durall et al. 2012). Although research is sparse on what constitutes good EOL communication in pediatric care, some insight is available on effective EOL communication for dying children from parents, physicians and the general clinical communication literature.

Parents’ Perspectives

Appropriate EOL physician-parent communication is crucial to the well-being of both the patient and the family. Parents want to be assured that everything possible was done to save their child and that their child’s suffering was relieved. Poor EOL commu-
communication has the potential to leave families with regret about their child’s care and memories of painful interactions with clinicians about their child’s impending death (Institute of Medicine 2003). Parents indicate that both cognitive and emotional needs should be addressed and they look to physicians for both information-giving and reassurance (Contro et al. 2002; DeLemos et al. 2010; Jurkovich et al. 2000; Meert et al. 2008; Meyer et al. 2006).

Meeting cognitive needs means ensuring that that parents are kept abreast of all information related to their child’s diagnosis and prognosis and that this information is presented in a clear and understandable way. First and foremost, parents desire truthfulness. Withholding news about a child’s prognosis can lead to false hopes, anger and then distrust (Fallowfield et al. 2002; Meert et al. 2008). Although physicians may resist telling patients painful news out of respect for the principle of beneficence, not being truthful may lead to greater pain (DeLemos et al. 2010; Mack and Wolfe 2006). Parents also cite availability, the use of clear and comprehensible lay language, and being attentive to their informational needs as being crucial to good physician-parent communication (DeLemos et al. 2010; Meert et al. 2008; Meyer et al. 2002; Meyer et al. 2006; Meyer et al. 1998).

In addition to cognitive needs, studies have indicated that parents want their physicians to address a wide range of their emotional needs, such as providing empathy. They want physicians to allow them to freely express emotions (Davies, Davis and Sibert 2003; Jurkovich et al. 2000; Levetown 2008), permit them to preserve their role as parents in taking care of their children (Meyer et al. 2006), and acknowledge their faith (Cadge, Ecklund and Short 2009; Meyer et al. 2006). However, addressing emotional
needs at this level may be unreasonable to expect of physicians who have had little training in psychosocial issues such as communication.

**Physicians’ Perspectives**

Physicians’ orientations differ from parents’ regarding EOL care (Berlinger, Barfield and Fleischman 2013). Although there is a dearth of studies that examine physician-parent interactions from the physician’s perspective, researchers do report that physicians may have difficulty accommodating parents’ desires for communication. First, prognostic uncertainty often accompanies diagnoses of childhood life-limiting conditions (De Graves and Aranda 2005; Mack and Wolfe 2006). Determining the best time to shift from life-sustaining treatment to palliative care often is difficult. Further, the recollection of cases where children have survived unexpectedly influences the timing of physicians’ decisions to instigate EOL conversations. And, finally, physicians do not want to take hope away from parents and patients (De Graves and Aranda 2005).

In one study examining in-depth interviews of health care providers, hope was identified as the most significant coping mechanism for families of children diagnosed with cancer (De Graves and Aranda 2005). By initiating EOL discussions, physicians fear that families will lose hope (De Graves and Aranda 2005), although families report that honesty does not take away hope (Mack and Wolfe 2006). Prognostic uncertainty and fear of taking away hope are among factors that most likely lead to the anxiety that physicians report (De Graves and Aranda 2005; Hilden et al. 2001). This anxiety can lead in turn to compromised care plans and poor communication with parents (Institute of Medicine 2003).
Patient-centered communication could be improved by training physicians in patient-centered communication. Although not specific to pediatric EOL care, patient-centered communication has been widely discussed as foundational to quality health care (Bertakis and Azari 2012; Bertakis, Franks and Epstein 2009; Epstein et al. 2005; Roter and Hall 2004) and is seen as distinctly different from biomedical or technology centered health care (Mead and Bower 2000). The principles of patient-centered communication may provide insight into effective physician-parent communication. According to Epstein (2005:1517), an operational definition of patient-centered communication includes:

1. Eliciting and understanding the patient’s perspective—concerns, ideas, expectations, needs, feelings and functioning;
2. Understanding the patient within his or her unique psychosocial context;
3. Reaching a shared understanding of the problem and its treatment with the patient that is concordant with the patient’s values;
4. Helping patients to share power and responsibility by involving them in the choices to the degree that they wish.

Adapting this definition to the parent as surrogate, a similar picture emerges as the literature examining parents’ perspectives presents. The importance of communicating with honesty, empathy, and understanding and helping parents make difficult EOL decisions based on the principles above could be seen as effective physician-parent communication. Patient-centered communication has been associated with decreased health care expenditures (Bertakis 2009) and higher rates of patient satisfaction (Bertakis 2009; Christen, Alder and Bitzer 2008).¹
Consequences of Poor Physician-Parent EOL Communication

Research indicates that EOL conversations do not happen early or frequently enough and that when they do happen they are often of poor quality (Aschenbrenner et al. 2012; Brooten et al. 2013; Cherlin et al. 2005; Contro et al. 2004; Contro et al. 2002; Davies and Connaughty 2002; Gilmer et al. 2013; Maynard et al. 2005). A landmark study in adult EOL patients indicated that whether or not to instigate (CPR) was only discussed in 41% of the patients and the patients’ wishes were misunderstood 80% of the time (Support Principle Investigators 1995). Evidence indicates that poor communication occurs in pediatric EOL patients as well. In one survey, 71% of pediatric physicians and nurses reported that they believed advanced care planning discussions happened too late in the course of a child’s treatment (Durall et al. 2012). For children who are at the end of life, often the most appropriate care involves withholding or withdrawing life-sustaining technology and focusing on the quality of the child’s remaining time (American Academy of Pediatrics 2000; Basu 2013). EOL discussions between physicians and parents often lead to limitations placed on life-sustaining technology. For example, in a study that examined the medical charts of 236 children who had died, findings indicated that 60% had a documented EOL care discussion. Eighty-seven percent of those with a documented EOL discussion had a documented limiting of care order (Tan et al. 2006). However, when physicians fail to discuss the child’s prognosis with the parents, this kind of appropriate care may not occur.

Cherlin (2005) found in a mixed methods study of adults that 20% of the caregivers of patients enrolled in hospice reported that the physician never told them that loved
one’s illness was terminal and did not provide life-expectancy information, and 33% reported that they were never told about hospice by their physician. Of the caregivers who were informed that there was no cure, they were often told late in the course of the illness. Findings indicate that the gap of information resulted from both the physicians’ lack of communication and caregivers’ lack of understanding due to difficulty absorbing the information (Cherlin et al. 2005). A qualitative study examining parents of child EOL patients found that 33% of the parents had not been told that their child was dying despite being at the EOL (Gilmer et al. 2013). However, what parents hear and what physicians feel they have told them may be not match. For example, physicians have been found to use an EOL communication style that may be confusing for patients. Physicians tend to use cautious optimism in EOL communication, meaning that they attempt to provide some hope even while simultaneously trying to deemphasize the chance of recovery (Clair 1990). Since patients and surrogates tend to hear more optimism than caution (Clair 1990), it may be that physicians believe they have been honest about the patient’s terminal prognosis, but the parents did not comprehend it.

Although determining the appropriate time to initiate EOL conversations is difficult for physicians for the reasons mentioned earlier, inadequate preparation for their child’s death may lead to more suffering for parents. Research indicates that parents of children who have died wanted more preparation for their child’s death (Davies and Connaughty 2002; Midson and Carter 2010). In addition to intensifying parental grief, delaying EOL conversations may compromise the patient’s care by not initiating palliative care in a timely manner and thus missing opportunities to improve on the child’s quality of life (Mack and Wolfe 2006).
Physician-Parent EOL Communication as a Moral Enterprise

Poor communication could be considered a breach of the moral obligation that physicians have to both patients and their parents in that it may adversely affect the EOL decisions made by the dying child’s parents. Studies repeatedly show that one poorly handled EOL conversation can affect families for years in the future as they ruminate over the hurtful words that are associated with their loved one’s death (Ahrens et al. 1997; Contro et al. 2002; Jurkovich et al. 2000). In order to promote patient autonomy, physicians have a moral obligation to provide clear, comprehensible and honest information in a way that takes their emotional state into consideration. Good communication between physicians and parents is crucial to reaching the goals of EOL care that often includes palliative care. In fact, clinical communication has been called a *moral enterprise* because it has the potential to ensure parent/patient autonomy in decision-making while also upholding the principle of beneficence in providing honest information about prognosis and the plausibility of available treatments. It also implies being empathetic to the patient and family’s emotional needs (Levetown 2008; Salmon and Young 2009).

As discussed in Chapter 1, as an extension of the bioethical principle of autonomy, parents in the US have been given the decision-making capacity for their dying children. What is known as the *best interests standard* typically applies in decision making, meaning that the parents decide the best course of action for the child by weighing the benefits versus the risks (Beauchamp and Childress 2013). But, ethicists question whether or not parents should be ultimately responsible for making these decisions (Baines 2008; Levy 2001). Not only do parents not have the medical expertise for make medical decisions, their emotional bond with their parent may cloud their decision-making ability
Furthermore, parents report feeling abandoned by their physicians when they need their advice and counsel the most (Levy 2001). Some have suggested that a shared-decision making model in which physicians and parents work together to plan EOL care would be more appropriate (Levetown 2008; Truog, Meyer and Burns 2006).

There are two ways that a child-patient’s best interests could be compromised at the EOL. Physicians may have difficulty implementing parents’ wishes to limit life-sustaining care due to paternalism (Fallowfield and Jenkins 2004), difficulties in communication (Einav et al. 2006), and the discomfort physicians feel addressing EOL issues (Sulmasy et al. 2008). Alternatively, the patient’s best interests may be compromised as the result of pressure from families to treat patients with life-sustaining technology that is deemed futile by the physician (Sorlie et al. 2001; Sorlie et al. 2000). The American Academy of Pediatrics Committee on Bioethics and Committee on Hospital Care (2000) has given physicians the moral responsibility of ensuring that life-sustaining medical technology is only utilized in EOL patients when the benefits outweigh the burdens. In both of the instances described above, more effective communication could promote more appropriate care and thus, the child’s best interests.

Although physicians fear compromising beneficence by taking away hope if they tell parents of the impending death of their child, an equally significant ethical concern is the lack of integration of palliative and EOL care into treatment plans. EOL conversations are necessary in order to instigate this kind of care which not only improves the child’s quality of life but provides the parents with the hope that their child’s suffering will be relieved (Basu 2013; De Graves and Aranda 2008).
Determinants of Physician-Parent Communication

How do physicians become effective EOL communicators? Some no doubt are born as good conversationalists while others receive exceptional training. What we do know is that effective communication may be influenced by characteristics inherent to the medical culture as well as those of individual physicians. The next section will examine each of these areas in relation to EOL physician-parent communication.

The Medical Culture and EOL Physician-Parent Communication.

The medical culture may itself be detrimental to efficacious EOL communication. Because of a lack of protocols for pediatric EOL care and communication, inadequate education and training of physicians, unclear EOL terminology, difficulty with cross-cultural communication² and issues related to physician specialty and rank, it is no surprise that EOL communication problems are common.

Lack of Guidelines

A significant reason for the difficulty in EOL communication is that even though consensus statements have been instituted by various organizations, no comprehensive guidelines exist that address ethical and clinical care for the medical treatment of dying children (Contro et al. 2002; Knapp et al. 2005; Levy 2001; Tan et al. 2006). In order to provide appropriate EOL care, some have suggested that clear standards for education and certification in EOL care be established as they are for medical procedures such as surgical techniques, allowing for the assessment of students and trainees ensuring they
are competent (Levy 2001). EOL communication would be a crucial component to this care.

*Lack of training*

Since no comprehensive guidelines for training and assessment in either EOL care or communication are in place, there continues to be a dearth of education and training in EOL issues in medical education. Therefore some have called the inclusion of training in EOL communication in pediatric training a “moral imperative” (Levetown 2008).

Unfortunately, communication is not a high priority in medical education and training, despite the fact that it has an important effect on medical care beyond clinical competence. Delvecchio et al. (2002:595) describe the power of the medical culture in training students: “…the ‘medical gaze’ soon becomes the dominant knowledge frame through medical school, that time and efficiency are highly prized, and that students and their attendings are most caring of patients who are willing to become part of the medical story they wish to tell and the therapeutic activities they hope to pursue.”

Because pediatric physicians are taught to heal, dying patients may threaten their medical identity, which likely affects how they approach EOL care. Physicians also may experience guilt and inadequacy when the child cannot be cured and may want to avoid facing these feelings (Meert et al. 2008). Physicians at all ranks and levels of experience report feeling uncomfortable with their ability to give bad news and express a desire for more training in the area (Contro et al. 2004; Kolarik, Walker and Arnold 2006; Sullivan et al. 2003), which is not surprising because medical training is focused on biomedical facts and procedures as opposed to effective interactions and continuity of care.
Physicians are not typically trained in medical school in EOL communication with patients and families (Wittenberg-Lyles et al. 2008). Further, according to the American Medical Association, only 26% of primary care residency programs include components in the care of terminally ill patients (Khaneja and Milrod 1998). Khaneja and Milrod (1998) found that 13% of residents, 56% of fellows and 71% attending physicians responded that they felt adequately trained to deal with EOL issues. Findings from another large study of a random sample of students, residents and faculty from US medical schools indicate that fewer than 15% of medical students and residents receive formal EOL care education. Further, almost 40% of students felt unprepared to address patients’ fears and close to half felt unprepared to deal with grieving families (Sullivan et al. 2003).

Evidence indicates that medical school faculty may not be properly equipped to teach EOL communication skills. A survey of medical directors of residency programs found that 1 in 3 directors said that their residents were not exposed to EOL care and 1 in 3 reported that they had no faculty to teach in this area (Baker et al. 2007). Another study found 30-50% of attending physicians report feeling uncomfortable with discussing palliative care with their patients (Contro et al. 2004). Therefore, students and trainees may lack good role models and may be left to learn to communicate with patients through a process of trial and error (Levetown 2008).

Related to role models is the presence of the hidden and informal curriculums. Hafferty (1998) suggested that most of what is learned in medical school does not come from formal course offerings and experiences, but within both the informal and hidden curriculums. The informal curriculum refers to what trainees learn through interactions...
outside the formal learning environments, like in the cafeteria, hallways and elevators, and the hidden curriculum consists of the assumptions, norms, and customs of the medical culture. Haidet and Stein (2006:S16) explain the informal and hidden curriculum as such: “…much of allopathic medical care is informed and directed by a set of premises that go undetected in professional oaths, mission statements, course syllabi and other artifacts of the explicit medical curriculum.” For example, studies have indicated that although the importance of cultural competency is taught in the classroom in medical schools, this material may conflict with what students learn from interactions with their attending physicians (Paul, Ewen and Jones 2014; Phillips and Clarke 2012; Roberts et al. 2010). Phillips and Clarke (2012) found in a qualitative study of medical students that although trainees learned in their coursework about the importance of being non-discriminatory, interactions with role models taught them that patients, who were obese, used drugs, had mental illness, or were poor possessed moral failings or individual weaknesses. And, when students disagreed with their superior's assessments, they felt they had to stay silent and conform to those values in order to be part of the powerful medical culture themselves. The hidden curriculum also can play a positive role in training as in the case of exceptional role models (Karnieli-Miller et al. 2010; Lempp and Seale 2004), but addressing it is imperative when discussing training in the social sciences (Lempp and Seale 2004).

Terminology

The medical terminology typically used to discuss EOL issues may contribute to the difficulty of the communication and may limit discussions and decisions about EOL care. For example, there are suggestions that “do-not-resuscitate” (DNR), “do not intu-
bate” (DNI) or “comfort measures only” may be interpreted by families negatively, as heartless and uncaring (Wittmann-Price and Celia 2010). For parents, who feel obligated to do everything possible to save their child, this terminology may be particularly difficult and they may resist discussions about implementing these kinds of orders. Some have suggested that we look for other terminology, such as “allow natural death” (AND). This phrase may help humanize the dying process by implying that care would continue as opposed to being withheld or withdrawn (Wittmann-Price and Celia 2010). Others, however, have argued that death is difficult and terminology such as DNR is necessary in order to confront and work through the pain associated with human mortality (Chen and Youngner 2008).

Another problem with DNR, however, is that it implies that resuscitation is probable, which typically is not the case (Clark and Dudzinski 2013). A review of 41 studies found only a 13% survival rate in pediatric patients after cardiac arrest and attempted (CPR), and in only 65% of the cases was a good neurological outcome reported (Young and Seidel 1999). Berkowitz and Morrison (2007) suggest that DNAR (“do not attempt resuscitation”) is a more appropriate term because it implies that resuscitation is not guaranteed even if the procedure is done. Using the term DNAR in EOL conversations may be more comfortable than DNR for patients and their families because a DNAR order clearly states that CPR would only be an attempt at resuscitation and therefore refusing it is not a choice of death over life.

Physician Specialty

Physician specialty may also play a role in communication in pediatric EOL care. In this research, the specialties of PEM and PCC are examined because they both deal
will children at the EOL but in dissimilar environments and under generally different circumstances. In both settings, the PED and the PICU, patients almost always present with the goal of recovery (Michelson and Steinhorn 2007; Schears 1999; Truog et al. 2006). Establishing a relationship with the child and parents is important in engendering a climate of trust in which fruitful EOL discussions can happen. The problem in both the PICU and the PED is that there often is not time to establish trust and strangers must tell parents that their child is dying or dead (Meert et al. 2008; Truog et al. 2006).

Research shows that PEM physicians may not discuss advanced directives or appropriate EOL care as death in the emergency room may be seen as contrary to the goals of emergency medicine and thus be considered a failure by PEM physicians (Michelson and Steinhorn 2007; Schears 1999). Also, since PEM physicians must make decisions quickly, they often have limited time to discuss complex medical issues, such as options related to the limiting of care in EOL patients (Michelson and Steinhorn 2007). Death in the PED is often sudden and tragic and the traditional doctor-patient relationship has not been established (Baren and Mahon 2003; Knapp et al. 2005). Because patients and parents do not have an existing relationship with the PED physician, discussions about EOL issues may seem inappropriate (Baren and Mahon 2003) and ideal communication constrained. However, it has been suggested that in some situations PED physicians should discuss a patient’s impending death with the patient and family and suggest that comfort measures may be the most appropriate form of care (Michelson and Steinhorn 2007; Schears 1999).

In contrast, PCC physicians are faced with the decision to withhold or withdraw life support perhaps more often than other pediatric physicians. Research has shown that
the most common reason for death in the PICU is the withdrawal of treatment (Garros et al. 2003; Sands et al. 2009), and most children die after the decision to withhold or withdraw treatment is implemented (Devictor, Latour and Tissieres 2008). Because PCC physicians are often faced with the decisions to withdraw or withhold life-sustaining therapy it would seem that these physicians would feel more comfortable discussing EOL issues with their patients. But, research shows that physicians’ EOL communication may need to be improved. For example, one study found that, compared to physicians, nurses were significantly less likely to report that families of children in the PICU were adequately informed about EOL issues related to their child (Burns et al. 2001). In another study by Meyer et al. (2002), 56 households who had a child who died in the PICU were surveyed about their experiences. Fifty-five percent reported that they felt they had little or no control over their child’s care during his or her final days and 25% reported that they would have made decisions differently (Meyer et al. 2002).

Physician Experience/Rank.

Physician experience and rank also most likely play a role in physician-parent EOL communication; however, the nature of the relationship is unclear. Physicians who have been practicing for less time may be more hesitant to withdraw life-sustaining treatment in their pediatric patients, while those who have been in practice longer may offer life-sustaining care less often (Burns et al. 2001; Cook et al. 1995) although this may depend on specialty. For example, one study found a correlation between fewer years of experience and a hesitancy to withdraw life-sustaining treatment in PCC physicians (Burns et al. 2001). A Canadian study found similar results in that the greater the length of time since graduation the lower the chance that intensive care physicians and
nurses would offer aggressive care (Cook et al. 1995). However, research indicates that internists may be more likely to withdraw life support if they are younger (Christakis and Asch 1995). More research is needed in the area of experience and willingness to withdraw life support as well as how all of this relates to EOL physician-parent communication.

Physician Characteristics and EOL Physician-Parent Communication

Besides factors related to the culture of medicine as described above, individual characteristics associated with physicians themselves may affect physician-parent communication. Physicians are trained to be objective, but they do not practice in a vacuum, and their family background, socialization, and personal beliefs likely shape who they become professionally (Hinkka et al. 2002). It has been reported that physician characteristics may influence patient care decisions more than the symptoms of their patients (Christakis and Asch 1995; McKinlay et al. 2002). One study found that even when withdrawing life support is indicated by the patient’s previously stated goals, almost half of internists of adult patients were either neutral or unwilling to withdraw (Christakis et al. 2000). The physician characteristics of gender, socioeconomic status³, race/ethnicity⁴ and religion may each interact with EOL communication.

Gender

Physician gender may affect care of EOL pediatric patients. Studies examining physician gender have found distinct practice differences between male and female physicians (Bertakis 2009; Bertakis and Azari 2012; Hall and Roter 1995; Hall and Roter
1998; Hall and Roter 2002; Roter and Hall 2004; Roter, Hall and Aoki 2002; Weisman and Teitelbaum 1985). Because there is a dearth of research on how physician gender may affect pediatric EOL treatment specifically, the following comments attempt to extrapolate results from other areas of study. Female physicians have been found to exhibit communication styles that are more participatory than male physicians (Zandbelt et al. 2006). While male physicians tend to focus more on technical practice behaviors, female physicians spend more time discussing the patient’s psychosocial and emotional status (Bertakis 2009). Female physicians also tend to spend more time overall with patients, engage in more positive communication, and treat their patients in a more egalitarian manner (Cooper-Patrick et al. 1999; Roter, Hall and Aoki 2002). Regarding EOL care, one study found that female oncologists were more comfortable than their male counterparts with discussing hospice as an option and were less likely to withhold prognoses from adult patients at the family’s request (Baile et al. 2002).

In terms of ethical decision-making, some researchers have suggested that women tend to focus on relationships and care over justice and rights in their treatment of EOL patients. Female physicians may have greater difficulty discontinuing life-sustaining therapies and be more influenced by families’ desires that everything be done (Hinkka et al. 2002). They may also be less likely to instigate EOL discussions than their male counterparts in adult patients (Mortier et al. 2000). It has been posited that women’s notions of autonomy may be seen through the lens of childrearing rather than through the more established lens of property (Raymond 1999), which would imply that women might in fact practice more paternalism in EOL decisions.
Although gender differences in the physician-patient encounter can significantly affect communication processes and outcomes, it is has been suggested that gender is not the only factor that can impact communication (Street et al. 2003). It may not be physician gender specifically, but gender-related communication styles that influences patient satisfaction (Christen et al. 2008). It may also be that gender concordance is what leads to better encounters (Bertakis and Azari 2012; Bertakis et al. 2009; Sandhu et al. 2009); for example, role taking accuracy, or the ability to perceive the other’s perspective, appears to be better when the physician and patient are the same gender (Yoels et al. 1993). In general, however, it appears that female physicians have the potential to engage in more effective EOL discussions with patients and families.

Religion

In addition to gender, physician religion has the potential to influence EOL physician-parent communication. As represented in primeval religious healers, religion is the most ancient form of medical practice (Sulmasy 2009). And, although religion has been separated from Western medical science, it continues to influence the worldview of both physicians and patients. Although much has been written about how the worldviews of patients affect their illness journeys, physicians have traditionally been assumed to be immune to the subjective effects of their own life stories, including their class habitus, their worldview, and their religion. Medical training stresses evidence-based medicine, and physicians are assumed to be objective interpreters of data (Curlin 2008; Curlin et al. 2005). However, if medicine is a “moral enterprise”, religious beliefs no doubt effect physicians' decisions in conscious and unconscious ways. Although there is not a signifi-
cant body of research on how the religious orientation of physicians shapes their clinical practice, this area is recently beginning to be explored in the literature (Curlin 2008).

Recent studies indicate that religious differences among physicians may account for much of the variation in medical care in controversial issues, including EOL care, and may be stronger influences than other socio-demographic variables (Christakis and Asch 1995; Curlin 2008; Wenger and Carmel 2004). Curlin et al. (2008:1119) claims that physicians function as “practical philosophers” in their practices and as such take scientific evidence, patient’s wishes, but also their own religious and moral views into consideration when making clinical decisions.

Religions provide guidelines about EOL care for their followers, who could be physicians, patients, or families, especially in the area of withdrawing and withholding care (Sulmasy 2009). For example, Catholicism holds that the withdrawal of extraordinary measures is acceptable, whereas some eastern religions emphasize the endurance of suffering, and Judaism upholds the sustenance of life even in the midst of great suffering (Curlin et al. 2008).

Although physicians may not be as religious as their patients, the majority of physicians report practicing a specific faith tradition. For example, in one survey of academic pediatricians, 88% reported being raised in a religious tradition and 67% identified themselves currently with a religious tradition (Catlin et al. 2008). Although some studies find patients more religious than physicians, others have found physicians to be more likely than the general population to attend religious services weekly, but less likely to try to apply their religious beliefs to other aspects of their lives (Curlin et al. 2005; Sulmasy 2009). Even so, surveys have found that more than half of physicians say their religious
beliefs influence their medical practice (Catlin et al. 2008; Curlin et al. 2005; Ecklund et al. 2007). With regard to EOL care, it is particularly poignant to note that the withholding and withdrawing of treatment has been found to be more common in non-religious physicians than those who claim to be religious (Seale 2010; Wenger and Carmel 2004).

Although one study found that EOL communication was not strongly related to physicians’ religiosity (Wenger and Carmel 2004), it seems that if physicians’ religious beliefs affect their willingness to engage in certain EOL practices, such as the withholding or withdrawal of life-sustaining treatments, their communication with parents about these options may be influenced as well. More study in the relationship between physicians’ religious beliefs and EOL physician-parent communication is needed (Curlin 2008; Seale 2010).

The Impact of Poor EOL Communication on Physicians: Moral and Emotional Distress

Up to this point, the focus of this literature review has been on the factors that may contribute to difficulties in communication about EOL care in children. A lack of communication skills and the experience of poor communication with parents of dying children can cause significant difficulty for physicians as well as families. And, these difficulties may affect their personal well-being and practice of medicine (Ahrens and Hart 1997; Graham et al. 1996; Levetown 2008; Sahler et al. 2000). Physicians may experience two types of distress in pediatric EOL care, both of which are associated with communication. First, they may experience “moral distress”, which is when they feel they are prevented from doing what is morally correct (Jameton 1993; Jameton 1984). They also may experience emotional distress resulting from the grief that ensues while dealing with
dying or dead patients (Lee and Dupree 2008; Papadatou et al. 2002; Papadatou 2000; Williams 2010).

*Moral distress*

Moral distress, the inability to do what one considers morally correct due to external or internal obstacles (Jameton 1993; Jameton 1984), is experienced by physicians in EOL care (Hamric and Blackhall 2007; Kalvemark et al. 2004; Schwenzer and Wang 2006; Ulrich, Hamric and Grady 2010) and specifically pediatric EOL care (Sahler et al. 2000; Solomon et al. 2005). One study found that over half of physicians who cared for children with life-limiting conditions experience “moral distress” (Solomon et al. 2005). Situations which cause the most moral distress for physicians involve the continuance of aggressive care they feel is unwarranted (Hamric and Blackhall 2007; Solomon et al. 2005; Sorlie et al. 2001; Sorlie et al. 2000; Ulrich et al. 2010). For example, in a qualitative study that examined the narratives of pediatric physicians as they reflected on ethically difficult care situations, the authors concluded that because physicians were more concerned with the parents’ perspective then the patient’s, the child may be submitted to futile treatment and, thus, unnecessary suffering (Hamric and Blackhall 2007).

Poor communication may be related to “moral distress” in two ways. First, inadequate information-giving by the physician may result in improper EOL decisions made by parents on behalf of their children. In some cases, physicians may feel they have discussed the terminal prognosis of the child, but the parents may not have been able to hear and comprehend the discussion either because of poor communication, the practice of cautious optimism on the part of the physician (Clair 1990), or because of the emotional state of the parent (Cherlin et al. 2005). Either way, the parents may push for life-
sustaining technology if they do not fully understand the situation or that alternative measures, like comfort care, are available. Second, open conversations with parents may alleviate the distress physicians feel when they perceive ethical issues that they cannot change (Ulrich et al. 2010). The simple act of having an honest conversation with parents may decrease the feelings of “moral distress”.

**Emotional Distress**

Besides “moral distress,” personal emotional distress is a common response in physicians to the care of EOL pediatric patients (Lee and Dupree 2008; Papadatou et al. 2002; Papadatou 2000; Williams 2010). In a survey drawn from a random sample of US medical schools, close to one half of students felt unprepared to deal with their own feelings about patients’ deaths (Sullivan et al. 2003). While moral distress is primarily an ethical issue, emotional distress is a social psychological challenge (Epstein and Hamric 2009). Emotional distress in physicians may result from feelings of powerlessness and vulnerability that emerge from patients’ deaths (Ahrens and Hart 1997; Papadatou et al. 2002). The relative rarity of children’s deaths and our cultural aversion to death may be difficult for physicians and lead to feelings of grief and helplessness.

Further, because physicians may be seen as being immune to emotional attachments to their patients, they may experience disenfranchised grief. Disenfranchised grief, as described by Doka (1989; 1999; 2002) ensues when the one who mourns stands outside the accepted grieving rules of society. Although society determines who has a legitimate right to grieve (mainly those who are kin to the deceased) and which losses are significant (such as spouses and children), often societal expectations do not correspond
with real life attachments. Disenfranchised grief, because it is not socially sanctioned, leaves the mourner with a lack of social support which may further intensify the grief. Physicians may deal privately with the grief associated with deaths of their patients for days, weeks or months, and feelings of anger, detachment, and depression may spill into their personal lives (Jellinek et al. 1993).

Emotional distress also has the potential to affect an individual physician’s practice of medicine. For example, physicians report that the stress they experience in preparation and during the delivery of bad news often carries over to future patient interactions (Orlander et al. 2002; Ptacek, Ptacek and Ellison 2001). Effective communication with parents has the potential to alleviate some of the grief experienced by physicians as it may help eliminate ambiguities associated with EOL care (Fallowfield and Jenkins 2004; Lee and Dupree 2008; Sahler et al. 2000).

Another aspect of emotional distress is the potential it has to enrich physician-patient/parent relationship, if addressed properly. Narrative medicine tells us that both clinicians’ and patients’ stories are important in the therapeutic relationship. And, physicians can be better caregivers by understanding their own backgrounds with illness and death, including the deaths of their patients. The concept of the wounded healer, which dates back to ancient Greece, was introduced in the 1970s by theologian Henri Nouwen (1972) and examined in the context of medicine more recently (Charon 1993; Kleinman 1988). The idea surrounding the wounded healer is that those in a healing role can perform their duties more authentically by recognizing their own suffering. Charon (1993:158) states with regard to physicians, “As we get more skilled in our work, we learn not to dodge reminders of personal suffering, but to allow our own injuries to in-
crease the potency of our care of patients, to allow our personal experiences to strengthen the empathetic bond with others who suffer.” However, in order for personal grief to translate into more effective practice, the pain must be dealt with in constructive ways.

Although the American Academy of Pediatrics (2000) recommends institutional support for clinicians dealing with their patients’ deaths, such as paid funeral leave and routine counseling, there are few formal mechanisms in place to help physicians of any rank deal with personal grief or moral distress (Ahrens and Hart 1997). However, in order to decrease physician burnout and personal pain, appropriately addressing personal grief and moral distress is crucial (Burns and Rushton 2004; Graham et al. 1996; Hamric and Blackhall 2007; Sahler et al. 2000; Taubman-Ben-Ari and Weintroub 2008; Ulrich et al. 2010). The IOM (2003) suggests that strategies must be developed to support clinicians who deal with pediatric death in order for them to continue to provide quality care. In fact, one study found that 100% of residents, 83% of fellows and 90% of attending physicians desired more support in dealing with the death of their pediatric patients (Khaneja and Milrod 1998). Research also indicates that physician burnout is more prevalent among those physicians in palliative care who feel inadequately trained in communication skills (Graham et al. 1996). In addition to promoting better patient care, more education and training in communication and EOL issues may prevent physician moral distress and emotional distress which can decrease physician burnout and ensure more efficacious humane patient care.
Conclusion

In conclusion, we find that literature supports the significance of physician-parent EOL communication. The quality of the timing, comprehensiveness, and sensitivity of communication has the potential to begin emotional healing or be permanently detrimental to parents of children who are dying or who have died. Effective physician-parent communication also may have a significant effect on physician performance and well-being. Therefore, this study has four specific aims: (1) To explore the difficulties physicians experience in talking about EOL issues with parents of pediatric patients who are dying or who have died, (2) To examine how physicians’ approach to EOL communication is shaped, (3) To investigate how interactions about death affect them personally and professionally, and (4) To explore physicians’ insight into how to improve EOL physician-parent communication. This investigation has the potential to provide significant insight into interventions that could promote better care for dying children, more positive interactions between physicians and caregivers, and less moral distress and burn-out in physicians.

Notes

1. However, one study found that a significant proportion of adult patients preferred a more biomedical oriented communication to PCC, indicating that the quality of medical information is important (Swenson et al. 2004).

2. Cross-cultural communication could be an individual-level issue or an issue inherent in medical culture, but one that we will not be able to address in our study. Studies indicate that cultural differences exist in EOL attitudes towards
honesty, use of life-sustaining technology, and decision-making (Kagawa-Singer and Blackhall 2001). These cultural differences can cause problems in racial/ethnic non-concordant physician-patient relationships. EOL communication may be particularly poor between African-American parents and their child’s physicians, who are typically white (Cooper-Patrick et al. 1999; Gordon et al. 2006; Kaplan et al. 1995). One study found nonwhite parents to be more likely than white parents to report that they felt that their physicians did not listen to them in the PICU (DeLemos et al. 2010). Research indicates that blacks receive more life-sustaining care at the EOL than whites (Mack et al. 2010). In addition to communication difficulties, this may be due to inadequate knowledge about advanced directives on the part of black patients and their surrogates, a lack of trust that black patients have in their white physicians or particular values held by black patients (Linton and Feudtner 2008; Mack et al. 2010).

3. Physician socioeconomic status (SES) likely plays a role in EOL patient care as physicians are born into a specific SES, which no doubt has some effect on their practice of medicine. The powerful influence of class on individual behaviors is seen in Bourdieu’s work. For Bourdieu the *habitus*, as a product of the history of a particular class, underlies individuals’ propensities to think, act and feel in ways determined by their history and structure. Bourdieu described the *habitus* as being embodied history, “structuring structures” (1990:53), shaped by the social conditions in which it was formed and internalized by individuals from the day they are born. The *habitus*, then, produces unconscious disposi-
tions and practices to act in certain ways that are more powerful than any overt rules and norms. Thus, embodied history leads to the generating of new history, “the active presence of past experiences” (1990:54), and the replication of class and of moral character within that class.

Although entry into medical school is more egalitarian then in the past, physicians overwhelmingly come from higher SES backgrounds. Their interactions with patients with different class habituses may not be as positive as with those of similar SES backgrounds. And, their habitus certainly influences their treatment of all their patients. The physician’s specialized knowledge as well as his or her higher SES sets up the power differential in the physician-patient relationship. With physician as superordinate and patient/parent as subordinate, an organizational hierarchy is established (Clair 1990). Those patients/families in higher SES groups are more likely to pay for health care services in private settings, more likely to share a similar cultural framework as the physician (Starr 1982), and are more likely to have a positive interaction with the physician. On the other hand, the poor and racial/ethnic minorities may not share the same cultural assumptions, may have difficulty in communicating with physicians and may not have the financial means to choose where their care is provided (Starr 1982). Although we are not able to deal with SES in our study, more research is needed to understand the relationship between physician SES and physician-parent EOL communication.

4. Since our sample was primarily white, we are not going to be able to look at how the race of the physician effects EOL communication. Few studies have
examined the effect of physician race on communication with patients, and none have looked at physician-parent communication in pediatric EOL care (Linton and Feudtner 2008). One study found no differences between physicians that were racial/ethnic minorities and those who were white in whether or not the physician used a participatory decision-making style (Cooper-Patrick 1999). This is in contrast to another study that showed that physicians of racial/ethnic minorities were less participatory than white physicians (Kaplan et al. 1996). Studies have shown that African American physicians are less positive towards advance care planning in EOL patients (Mebane et al. 1999). Further, black physicians have been found to desire more aggressive treatments for themselves as well as their patients (Mebane et al. 1999). More research is clearly needed in this area.
CHAPTER 3

METHODS

Although a significant literature exists that examines parental perspectives on physician EOL communication (Aschenbrenner et al. 2012; Contro et al. 2002; Gilmer et al. 2013; Jurkovich et al. 2000; Meyer et al. 2002; Weidner et al. 2011; Widger and Picot 2008), far fewer studies have examined the topic from the physicians’ point of view. This is a gap in the literature; qualitative studies that delve deeply into the attitudes and orientations of physicians who treat EOL pediatric patients and facilitate family care decisions are lacking. The qualitative approach used here is particularly important to “get below the surface of social and subjective life” (Charmaz 2006:13). By using a mixed methods approach that is primarily qualitative, I aim to gain insight into the perspectives of pediatric physicians.

Participants and Procedures

I ultimately used a three phase approach in this study of PEM and PCC physicians. These specialties were examined because they both deal with children at the EOL, but in dissimilar environments and under generally different circumstances. In both settings, the PED and the PICU, patients almost always present with the goal of recovery (Michelson and Steinhorn 2007; Schears 1999; Truog et al. 2006). And, in both the PICU and the PED there is often not time to establish trust between physicians and parents and strangers must tell parents that their child is dying or dead (Meert et al. 2008; Truog et al.
The first phase of this study examined the participants’ communication with an actor-mother in a simulation experience. The second and third phases employed narrative interviews with the participants from Phase I to examine how physicians’ stories underlie their approach to EOL communication with parents of pediatric patients. Each subsequent phase grew naturally out of the previous phase as the data generated more topics that I wanted to discuss with the participants. Because the simulation portion of the study provides insight into the way participants may actually communicate with parents of dying patients, this information is combined with the participants’ narrative responses to paint a more detailed picture of the social processes under study than interviews alone.

Phase I

There were 21 participants in Phase I, who were PEM attendings or fellows (n=9) and PCC attending or fellows (n=12). Fellows have completed college, medical school and three years of pediatric-specific residency and are now within a three year subspecialty training phase of education specifically in either PEM or PCC. Attendings have completed all of the above training and have completed their fellowship training. There were 9 fellows (6 in PCC and 3 in PEM) and 12 attendings (3 in PCC and 9 in PEM). For a complete breakdown of participant demographics, see Figure 1. All participants were located at the same hospital, a 380-bed not-for-profit, regional children’s hospital in the southeast. These advanced practitioners were chosen because this level of discussion is almost always done by more senior doctors and not by medical students or residents. Examining fellows and attending physicians provided data as to whether or not there
were differences in communication based on experience in practice. The demographic breakdown of the participants is presented in Table 1.

Participants were recruited by email to take part in an exercise utilizing high-fidelity simulation involving an 8 year-old simulated patient, with a fictional, chronic degenerative disease in respiratory distress. This portion of the study examined the participants’ communication with an actor-mother. Phase I took place between August of 2011 and March of 2012 as part of a study examining overtreatment in pediatric critical care. This phase of the study utilized high-fidelity simulation in its design. High fidelity simulation has become a common tool for both the education and evaluation of clinical providers during all levels of practice (Cook et al. 2011; Deutsch 2008; Peckler, Schocken and Paula 2009; Stewart, Kennedy and Cuene-Grandier 2010; Yager, Lok and Klig 2011), and it is increasingly being used in pediatric emergency medicine and critical care. Originally introduced in the 1950s, simulation in medical education offers opportunities to practice skills in standardized formats while eliminating the possibility of harm to patients (Brooks-Buza, Fernandez and Stenger 2011; Chikotas, Parks and Olszewski 2012; Teherani, Hauer and O'Sullivan 2008). In high-fidelity simulations, a mannequin takes the place of a patient and a simulation operator controls the mannequin’s clinical signs and symptoms, such as vocal, heart, and lung sounds, observable and palpable signs, and physiological changes through a computer connection (Donoghue et al. 2010; Okuda et al. 2009). Studies indicate that simulation can be a reliable and valid method for evaluating clinical competence (Cook et al. 2011; Tsai et al. 2003; Yager et al. 2011) and that in addition to clinical skills, physician-patient communication also can be observed and evaluated (Cook et al. 2011; Okuda et al. 2009; Teherani et al. 2008; Volk et al. 2011).
Although the literature documenting pediatric simulation outcomes is limited at present (Yager et al. 2011), literature on adult simulated patients suggests that while participants in some studies question the realism of simulation (Gordon et al. 2001; Peckler et al. 2009), others have reported it as being quite realistic (Donoghue et al. 2010). Further, most studies have found that participants rate the simulation experience positively (Gordon et al. 2001; Peckler et al. 2009).

A decade ago, the Institute of Medicine (IOM) called on researchers to “combine creativity, flexibility, and sensitivity both to patient and family burdens and anxiety” in efforts to examine EOL communication with parents (Institute of Medicine 2003:358). Simulation may be a particularly useful tool in examining this type of communication, because utilizing real life settings can be difficult. First, the emotional milieu of the PICU and PED makes gaining access problematic. Parents in these settings are fraught with fear and uncertainty and requesting consent for observation may appear cold and insensitive. Further, EOL communication occurs in situations that are rare in both the PICU and the PED as discussed in Chapter 2. In addition to the rarity of child deaths, research indicates that EOL communication happens infrequently and late in the progression of life-limiting illnesses in pediatrics (Durall et al. 2012), so the probability that the researcher would be able to observe all the participants engaged in EOL communication is low. Finally, because each patient’s prognosis is unique, comparing the quality and appropriateness of participants’ interactions with actual parents and patients would be more difficult than comparing their performances with a simulated patient/parent.
**Procedures**

Experts from the facility’s Simulation Center developed a standardized case, complete with written medical history and current vital signs (Appendix A). The case was designed to represent a chronically ill patient who presented urgently in a clinical state that would allow for flexibility in EOL decision-making. The participants were blinded to the subject of the simulation. Each participant was given a written medical history of the 8 year-old patient which indicated the patient was nearing the end of life. Each session included an actress-mother who followed a script which also contained the medical history of the child (Appendix B). To improve the reproducibility of the scenario, two plot sessions were done with graduating PCC and PEM fellows. To determine the extent to which life-sustaining care, intubation in this case, was offered and implemented at the expense of alternative options such as comfort care, two members of the research team independently reviewed the video recordings and assigned scores on the measure of participatory physician-parent communication (see Methods and Materials section for a description of these measures). After the first 8 sessions, the research team realized that recording the sessions would provide useful information for analysis. Therefore, the IRB protocol was revised and approved and sessions #13 through #21 were audio and video recorded. I will call this portion of the simulation study Phase IB and the earlier portion, in which we do not have simulation recordings, Phase IA. If the scores assigned by the two research team members for a given participant did not match, they were averaged. Inter-rater reliability was calculated to be .761 utilizing Cohen’s Kappa. In addition to assessing a score of physician-parent participatory communication, simulations in Phase IB were timed and transcripts were examined to determine whether or not participants
asked the actor-parent if she had a previous EOL discussion with a health care provider, whether the physician discussed EOL issues with the actor-parent, and whether or not alternatives to life-sustaining technology (intubation in this case) were offered. All simulations were followed by a post-simulation debriefing interview. The demographic breakdown of the sample in each phase are presented in Table 1.

Table 1. Demographics of Participants

<table>
<thead>
<tr>
<th></th>
<th>Phase IA</th>
<th>Phase IB</th>
<th>Phases II &amp; III</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>N</strong></td>
<td>21</td>
<td>13</td>
<td>17</td>
</tr>
<tr>
<td><strong>Female</strong></td>
<td>7</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td><strong>Male</strong></td>
<td>14</td>
<td>8</td>
<td>11</td>
</tr>
<tr>
<td><strong>PEM</strong></td>
<td>12</td>
<td>7</td>
<td>8</td>
</tr>
<tr>
<td><strong>PCC</strong></td>
<td>9</td>
<td>6</td>
<td>9</td>
</tr>
<tr>
<td><strong>Fellows</strong></td>
<td>9</td>
<td>4</td>
<td>6</td>
</tr>
<tr>
<td><strong>Attendings</strong></td>
<td>12</td>
<td>9</td>
<td>11</td>
</tr>
<tr>
<td><em>Non-white</em></td>
<td>3</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td><em>White</em></td>
<td>18</td>
<td>11</td>
<td>15</td>
</tr>
<tr>
<td><strong>Age (mean yrs)</strong></td>
<td>39.7</td>
<td>40.2</td>
<td>40.9</td>
</tr>
</tbody>
</table>

*Because there were only 3 non-white participants (1 African-American, 2 white Hispanics) in Phase 1A and only 2 non-white participants (1 African-American and 1 white Hispanic) in Phases IB, III, and III, I decided not to explore differences based on race/ethnicity in this research.

Each simulation session was followed by a post-simulation, semi-structured interview which addressed the following questions:

- Why did you decide to (or not to) intubate the patient?
- Can you describe any cases similar to this that you have had in real life?
- Thinking back to the case that was similar, how might that case have influenced your treatment decision today?
- How likely are you to seek assistance when making a treatment decision?
- In what kinds of cases have you found yourself seeking assistance?
- Describe for us the kind(s) of assistance you have sought in the past?
- Why do you (or why don’t you) seek assistance?
- What would you want for your child if he or she had this disease?

The above questions were selected by the research team in order to examine the phenomenon of physician EOL decision-making. After the interview, the participant was
asked to complete a post-simulation questionnaire in order to obtain socio-demographic data as well as the physician’s fatigue level, parental status, assessment of the realism of the simulation, fear of malpractice, level of empathy, and confidence in addressing DNR orders with patients and families (Appendix B). The post-simulation interviews were audio recorded, transcribed and coded (see the Qualitative Analysis Strategy section for an explanation of the coding process).

Phase II

Phase Two of this project naturally grew out of Phase I in order to attend to more and deeper questions related to EOL communication. As the Phase I post-simulation interviews progressed, it became clear that participants’ decision-making was based on more than the questions encompassed. Many participants brought up topics that deserved further attention. Our participants seemed genuinely interested in the project and provided insightful responses in the post-simulation interviews. As Phase I continued, I expanded the questioning focus and designed Phase II. Phase II took place between March and October of 2012, and consisted of conducting narrative interviews with the participants from Phase I. All participants from Phase I were recruited to take part in 30-45 minute, Phase II individual narrative interviews. To help them find time in their busy schedules, each participant was offered an incentive of a $50 gift card. An e-mail invitation was sent to each participant from Phase I inviting her or him to join Phase II of the study. If the participant did not respond, up to 3 additional e-mails were sent. A total of 17 of the original 21 participants agreed to take part in Phase II. The demographic breakdown of the Phase II participants (illustrated in Figure 1 is as follows: PICU physicians (n=9) and ED physicians (n=8); fellows (n=6) and attendings (n=11); males (n=11), females
(n=6). Three interviews took place by phone as the participants had taken other positions and moved out of state.

**Narrative Interviews**

Because it was becoming clear that participants’ perspectives as well as their communication styles were shaped by socio-demographic variables as well as their life experiences, I chose the narrative interview technique to structure the Phase II interviews. Polkinghorne (1988:1) claims that, “Experience is meaningful and human behavior is generated from and informed by this meaningfulness.” Because narratives are the key way people make meaning out of their experiences, studying narratives are an important way to gain insight into social phenomena. Physician narratives are important ways to gain in-depth insight into EOL care experiences. The term narrative typically refers to stories that describe events in a specific order, where a participant’s story becomes the object of analysis (Riessman 1993). Narratives, however, are not limited to stories per se, but also include “habitual” narratives that discuss events that happen recurrently over time, hypothetical narratives that describe events that never occurred, and topic-centered narratives that describe events that happened in the past but are connected by themes (Riessman 1993). According to Riessman (1993: 3), “Respondents narrativize particular experiences in their lives, often where there has been a breach between ideal and real, self and society”. Because the primary tool for the collection of data in narrative inquiry is the interview, interviews with the purpose of facilitating the discussion of personal narratives as they relate to the pediatric EOL care experiences were conducted in this study (Marshall and Rossman 2011). Another tenet of narrative research is the importance of
doing follow-up interviews to ask about details previously provided, to complete missing information and to check the interviewers’ initial coding interpretations (Duffy 2012).

The Technique of Grounded Theory

The technique that informs the analysis of the interview data in this study is grounded theory. According to Charmaz (2006:28), grounded theory and interviewing go well together because both methods are, “open-ended yet directed, shaped yet emergent, and paced yet unrestricted.” Interviewing is a dynamic, not a linear, process. Wasserman, Clair and Wilson (2009) claim that grounded theory represents more than a specific scheme of analysis, and is more appropriately called an “epistemic frame of mind.”

Grounded theory was introduced by Glaser and Strauss (1967) in the late 1960’s and aims to, “…to generate theory that accounts for a pattern of behavior which is relevant and problematic for those involved”. Fundamentally, grounded theory is a systematic approach to collecting and analyzing data with the purpose of building theory that emerges directly from the data (Charmaz 2006). This approach contrasts with hypothesis testing which consists of beginning with hypotheses and then testing them through collecting and analyzing data. Grounded theory begins with the data and proceeds to develop theoretical models from the analysis of the data (Wasserman et al. 2009). Data is examined and analyzed throughout the study through the process of qualitative coding. Through coding, names are attached to concepts derived from the data. These codes provide a way to organize, compare and analyze data (Charmaz 2006). Codes are organized into concepts hierarchically, ideally paving the way for the emergence of theoretical propositions and ultimately theoretical models (Wasserman et al. 2009). Grounded theory has been re-
vised and expanded since Glaser and Straus’s seminal work (1967) as a technique that is flexible and applicable to a variety of qualitative studies (Charmaz 2006). As such, methods inherent in grounded theory can be utilized in studies that do not use grounded theory exclusively (Charmaz 2006), such as this research.

A particular tenet of grounded theory, utilized in the design of Phases II and III of this study, is the idea that emergent conceptual themes are pursued intentionally by asking new questions in subsequent interviews (Wasserman et al 2009). According to Charmaz (2006:17), “Grounded theorists evaluate the fit between their initial research interests and their emerging data. We do not force preconceived ideas and theories directly upon our data. Rather, we follow leads that we define in the data, or design another way of collecting data to pursue our initial interests.” Researchers doing grounded theory aim to observe what is happening in the data from the beginning of the research. Therefore, as new themes emerge in interviews, those themes can be immediately pursued with that particular participant and subsequent participants. Returning to the field to re-interview participants based on emerging concepts also is an important part of building theory (Charmaz 2006). In this study the emerging data from Phase I led to proposing Phase II, narrative interviews with participants, to further explore concepts derived from Phase I. Concepts that emerged from the data collected in Phase II, in turn, led to proposing Phase III, another round of narrative interviews, in order to further expand and refine those concepts.

In designing interview questions, grounded theorists consider questions that are general enough to cover the experiences of the participants, yet narrow enough to get to the issues being explored from the participant’s perspective. Interview questions only are
used as a guide; veering off the guide is acceptable in order to explore concepts emerging from the participants’ responses. Given that the interview is meant to be more conversational than structured, some grounded theorists choose not to take the questions with them into the interviewing process (Charmaz 2006).

In Phase II, the overarching interview question was: *How has your background influenced the way you care for dying children and their families?* This question was designed in order to explore, from the participants’ perspectives, what facets of their life story have influenced their care of dying children and in what ways that care has been influenced.

Follow-up questions were formulated based on data collected in the Phase I post-simulation interviews. Justification for the inclusion of each question is provided in the Table 2 below, including the interviews from Phase I from which the concept emerged. The interviews are referenced using a Roman numeral which indicates the phase number of the study and the participant identifier number (1 through 21). So, for example the Phase II interview with participate 20 would be cited as (II:20). References to simulation transcripts use an “S” in place of the phase number.

**Table 2. Phase II Questions**

<table>
<thead>
<tr>
<th>Question</th>
<th>Topic</th>
<th>Justification</th>
</tr>
</thead>
<tbody>
<tr>
<td>Where did you do undergraduate, medical school, residency training?</td>
<td>Training/Experience</td>
<td>I added this question after my first Phase II interview when I found out the participant had completed a unique undergraduate program of study (focused on the Western intellectual tradition) in a university where I was teaching at that time. I wondered how differences in education, even at the undergraduate level might effect...</td>
</tr>
</tbody>
</table>
How have mentors shaped you?

Training/Experience

Some of the participants mentioned the importance of mentors in Phase I (I:17, I:20).

What kinds of training and experiences were helpful to you or would have been helpful to you in dealing with pediatric EOL patients and their families? What kind of training might be helpful to current medical students, residents, and fellows?

Training/Experience

The literature mentions that training in EOL care, including communication, to be a gap in medical education (see Chapter 2). I wanted to explore the insight of these participants in order to find out how medical education and training may be improved. This was also mentioned by I:17 and I:20.

Have you ever felt that the best interests of the EOL patient might be different than the best interests of the family? If yes, please elaborate.

Patient vs. parental best interests

Question emerged from my own education in ethics (see Lantos 1997) and examples given by 2 of the participants in the Phase I interviews (I:8, I:16).

How has your own role as a parent (if participant is a parent) shaped the way you deal with children and parents at the end of life?

Participant’s role as parent

This question was added to the interview guide after almost all of the first participants I interviewed in Phase II (II:2, II:12, II:14) mentioned the significance of their role as a parent in their response to the main interview question (see above).

Have you noticed differences in the ways male and female physicians interact with EOL patients? If so, please describe the differences.

Gender Differences

I noticed from observing the simulation sessions that there appeared to be gender differences in communication patterns with the actor-parent. I wanted to get the participants’ insight into this phenomenon.

Please describe an ethically difficult situation you’ve been involved in related to a pediatric patient at the end of life.

Ethics

In the phase I interviews some participants alluded to ethically difficult situations (I:8, I:16) and I wanted to further explore this concept with all participants.

Not every question was asked of each participant as some already addressed the specific topics in the Phase I interviews. In keeping with the tenets of grounded theory
and narrative interviewing, the questions above served as a guide in order to maintain a conversational style.

### Phase III

The data generated from the interviews in Phase II, led to additional questions and topics for exploration, and I wanted to go back into the field to re-interview the participants in order to clarify their responses from the Phase II interviews and to ask them about emergent topics. Therefore, I proposed Phase III. The 17 participants (out of the original 21 from Phase I) who consented to be interviewed in Phase II were asked to complete a third narrative interview, between April and June of 2013. The interview guide for Phase III was developed from topics that arose in Phase II that I felt needed further exploration. Some of these topics were mentioned directly by the participants, while others emerged indirectly from my background in bioethics and the reading I was doing for the literature review portion of my dissertation proposal. The questions below, in Table 3, which focus on the topics of moral distress, emotional distress, comfort with EOL communication, and religion, served as basis for these semi-structured interviews. Justifications for their inclusion are listed below. Not every question was asked to every participant as some participants addressed these topics in Phase II. All 17 participants from Phase II consented to participate in Phase III. Five interviews took place by phone as the participants had taken other positions out of state.

Table 3. Phase III Questions:

<table>
<thead>
<tr>
<th>Question</th>
<th>Topic</th>
<th>Justification</th>
</tr>
</thead>
<tbody>
<tr>
<td>Moral distress occurs when health care providers feel that they cannot</td>
<td>Moral Distress (moral convictions)</td>
<td>This phenomenon was described by many of the participants, although not</td>
</tr>
</tbody>
</table>
act in accordance with their moral convictions (Jameton 1993; Jameton 1984). Please describe moral distress that you have encountered specifically in your experiences with children who are at the EOL.

<table>
<thead>
<tr>
<th>Question</th>
<th>Topic</th>
<th>Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td>How does moral distress affect you personally and professionally?</td>
<td>Moral Distress (communication strategies)</td>
<td>I am interested in how moral distress affects their communication with parents and care of children at the EOL (II:1, II:8).</td>
</tr>
<tr>
<td>How do you deal with moral distress?</td>
<td>Moral Distress (coping strategies)</td>
<td>I am interested in strategies they use to deal with moral distress.</td>
</tr>
<tr>
<td>What changes could be made to alleviate moral distress felt by physicians in your position?</td>
<td>Moral Distress (organizational support)</td>
<td>I am interested in how organizations could help physicians deal with moral distress (II:1).</td>
</tr>
<tr>
<td>How could medical education and training be altered to help physicians deal more effectively with moral distress?</td>
<td>Moral Distress (education and training)</td>
<td>I am interested in how medical education could better prepare physicians to deal with moral distress (II:1).</td>
</tr>
<tr>
<td>How do your patients’ deaths affect you?</td>
<td>Emotional Distress (coping)</td>
<td>In Phase II some of the participants described the difficulty they had dealing with their patients’ deaths (II:8, II:10, II:12, II:21). I wanted to explore this with all the participants.</td>
</tr>
<tr>
<td>How do you deal with the effects of patient deaths?</td>
<td>Emotional Distress (job performance)</td>
<td>In writing the literature review I found that research indicated that patients’ deaths could affect the performance of physicians if not dealt with properly (II:1, II:21).</td>
</tr>
<tr>
<td>Please describe your communication style in EOL conversations with parents.</td>
<td>EOL Communication Comfort (reflexivity)</td>
<td>Included at the suggestion of one of my committee members, to assess the degree to which physicians are self-reflective and whether the reflective</td>
</tr>
</tbody>
</table>
and not-so-reflective physicians differ in their perceptions of moral hazards.

<table>
<thead>
<tr>
<th>Question</th>
<th>EOL Communication Comfort</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>How comfortable do you feel discussing life-limiting conditions with parents?</td>
<td>Several participants mentioned that doctors don’t like discussing EOL issues (I:8, II:8, II:20, I:21). I wanted to follow-up on that. Communication issues were mentioned in almost all of the Phase II interviews, so I designed questions that would allow me to explore EOL communication from many aspects.</td>
<td></td>
</tr>
<tr>
<td>How comfortable do you feel discussing withholding and withdrawing treatment?</td>
<td>Mentioned by II:18 specifically. The answer to this will be particularly interesting when looking at it in light of the physician’s religious beliefs.</td>
<td></td>
</tr>
<tr>
<td>How comfortable do you feel addressing the emotions that emerge in patients and families in EOL situations?</td>
<td>Many discussed dealing with family emotions, especially II:4 and II:8.</td>
<td></td>
</tr>
<tr>
<td>Research indicates that parents expect physicians to deliver empathy, tend to social psychological issues, and to comfort torn emotions. Do you think these are reasonable expectations?</td>
<td>I would like to get the participant’s perspectives on this question in light of the literature.</td>
<td></td>
</tr>
<tr>
<td>Can you describe any particularly bad or good situations that you’ve had in EOL communication with parents?</td>
<td>The literature mentions examples of bad communication from the parent’s perspective and I would like to explore the physician’s perspective.</td>
<td></td>
</tr>
<tr>
<td>Do you feel that you have had adequate education and training in EOL</td>
<td>Most participants discussed education and training in Phase II, but</td>
<td></td>
</tr>
</tbody>
</table>
communication? Please explain.

<table>
<thead>
<tr>
<th>What could have made that training better?</th>
<th>EOL Communication Comfort (training)</th>
<th>Again, many discussed this already, but I would like to probe this further with a few participants.</th>
</tr>
</thead>
<tbody>
<tr>
<td>What do you think about the term <em>Allow Natural Death</em> (AND) as opposed to DNR?</td>
<td>EOL Communication Comfort (terminology)</td>
<td>The difficulty discussing EOL issues using the term “DNR” was mentioned by II:8 and some researchers are suggesting that AND is a better term (Wittmann-Price and Celia 2010). I would like to get the participants’ views on that.</td>
</tr>
<tr>
<td>How do you think your religious commitments or worldview affects your treatment of EOL patients and communication with their parents?</td>
<td>Religion</td>
<td>In response to the main interview question in Phase II, several physicians brought up the importance of religion (II:2, II:10, II:11, II:12, II:13, II:14) in their patient care. Religion questions were adapted from a study that used in-depth interviews to explore the perceptions of pediatricians (Cadge et al. 2009).</td>
</tr>
<tr>
<td>Do your religious beliefs affect your willingness to discuss withholding or withdrawing treatment?</td>
<td>Religion</td>
<td>Exploring the participants’ views on this question would be important in assessing the relationship between religion and EOL care. It has been explored to a limited extent in the literature (see Chapter 2).</td>
</tr>
<tr>
<td>Do you feel that full disclosure of a patient’s illness may take away hope from the family? If so, how does this affect your communication with</td>
<td>Religion</td>
<td>Many participants addressed the importance of hope (II:8, II:13, II:21) and I would like to explore this with the others as it is discussed in the</td>
</tr>
</tbody>
</table>
families?

<table>
<thead>
<tr>
<th>How were issues related to spirituality/religion addressed in your medical school, residency, or fellowship training, if at all?</th>
<th>Religion/Training/Education</th>
<th>Literature (see Chapter 2). Responses to this question would add to our understanding about medical education and training.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Would you feel comfortable commenting on your own spiritual/religious background, such as explaining whether or not you are affiliated with a particular tradition and if consider yourself a religious or spiritual person?</td>
<td>Religion</td>
<td>Many have volunteered this information already (II:2, II:10, II:11, II:12, II:13, II:14, II:16) and it would be helpful to have from all.</td>
</tr>
<tr>
<td>How many EOL pediatric patients have you treated (total or monthly)? How many of those included an EOL conversation?</td>
<td>Background information</td>
<td>Suggested by one of my dissertation committee members. This information may be useful in interpreting results.</td>
</tr>
</tbody>
</table>

Measurement and Materials

*Quantitative Measurement*

*Participatory Physician-Parent Communication*

In Phase I, two members of the research team independently reviewed the video recordings and assigned a score on the measure of Participatory Physician-Parent Communication. If the scores for a given participant did not match, the scores were averaged. The scores were determined as follows: (1) the participant made a treatment decision after extensive discussion of available options (e.g. asked numerous open-ended questions; offered alternative therapies; discussed hospice and/or pain management), (2) the participant made a treatment decision after moderate discussion of available options (e.g. asked...*
some open-ended questions; offered alternative therapies), (3) the participant made a
treatment decision after minimal discussion of available options (e.g. asked yes/no ques-
tions), (4) the participant made a treatment decision without discussing available options.
This variable was reverse coded for analysis.

Potential Correlates of Physician-Parent Communication

Realism of the High-Fidelity Simulation Experience. To measure the extent to
which the participant experiences the simulation exercise as realistic, the following item
was included in the post-simulation questionnaire (Appendix C): “During this simulation
I forgot I wasn’t dealing with a real child” (Stewart et al. 2010). Participants responded
on a scale from 1 to 7, strongly disagree to strongly agree.

Fear of Malpractice. To assess fear of malpractice, three questions were asked
from the Fear of Malpractice Litigation Scale (Benbassat, Pilpel and Schor 2001) (Ap-
pendix C). Participants were asked whether they frequently worry about the legal conse-
quences of medical errors, whether they think a malpractice claim harms the reputation of
a physician, and whether a malpractice claim harms the self-esteem of a physician. Re-
sponses range from strongly disagree (1) to strongly agree (7). In addition, participants
were asked they had ever been named in a malpractice suit (0=no, 1=yes).

Physician Empathy. Next, the first ten items from the Jefferson Scale of Physi-
cian Empathy (Hojat et al. 2002) was utilized to assess empathy (Appendix C). Examples
of items in this scale include “I believe that empathy is an important therapeutic factor in
medical treatment,” “My patients feel better when I understand their feelings,” and “I try to think like my patients in order to render better care.” Responses range from strongly disagree (1) to strongly agree (7).

**Confidence in Addressing EOL Issues.** To measure confidence in addressing EOL issues with patients, a 4-item questionnaire was utilized from Sulmasy et al. (2006). The questionnaire items focus on perceived self-efficacy and are as follows: (1) I feel confident in my ability to talk with patients or their surrogates about consent for medical procedures about which I am knowledgeable, (2) I feel confident in my ability to talk with patients or their surrogates about DNR orders, (3) I find talking to patients about DNR orders difficult, and (4) When patients cannot speak for themselves, I find talking to patients’ surrogates about DNR orders difficult.

These were scored on a 7-point scale with responses ranging from “strongly disagree” to “strongly agree” and were included on the post-simulation questionnaire (Appendix C).

**Other Potential Correlates to Physician-Parent Participatory Communication.** Participants were also asked to record the number of hours worked in the past week, level of fatigue (on a scale from 1 to 7) and parental status (1=participant has children; 2=participant has no children).

**Physician Demographic Characteristics.** A demographic questionnaire was used in Phase I (see Appendix B) to assess physician demographic characteristics. The questionnaire includes questions about sex (0=female; 1=male), age (in years), race/ethnicity
(0=non-Hispanic white, 1=non-Hispanic black, 2=Latino, 3=American Indian or Alaska native, 4=Asian or Pacific Islander, 5=Other), specialty (0=pediatric emergency medicine, 1=pediatric critical care), seniority (1=fellow, 2=attending physician).

Length of Visit. Results of previous studies examining primary care physicians have found that that length of visit is correlated with higher patient satisfaction (Gross et al. 1998) and fewer malpractice claims (Levinson et al. 1997). A longer session could indicate that the physician spent more time interacting with an actor mother in reaching a decision, suggesting that more participatory communication was practiced by the physician. A longer visit could also suggest that the physician spent more time assessing whether or not to intubate the patient by exploring alternative EOL options with the actor mother, such as suggesting comfort measures. The length of visit has important implications for practice as those physicians who spend more time with patients could foreseeably be significantly behind their colleagues in terms of numbers of patients seen in a given day (Roter and Hall 2004). However, a longer visit might lead to more positive clinical and psychosocial outcomes in EOL care, which could be examined in further studies.

Length of each visit was measured in seconds from the time the participant enters the simulation room to the time that the facilitator stops the simulation, which is determined by the participant indicating whether or not he or she would intubate.

Quantitative Analysis Strategy

The main focus of this research is qualitative, but the quantitative data serves to (1) provide background information about the socio-demographic and professional characteristics of the sample, (2) show the distribution of physician-parent participatory
communication as well as fear of malpractice, empathy, and confidence addressing EOL issues among the participants, and (3) conduct preliminary analysis of the relationships between physician-parent participatory communication and gender, age, specialty, rank, parental status, level of fatigue, hours worked. Length of visit was examined in relation to the physician characteristics of gender, seniority, specialty and parental status. Because of the small sample size, quantitative analysis was limited to univariate statistics and bivariate tests. Caution was used in interpreting inferential statistics because of the small sample.

*Qualitative Measurement and Analysis Strategy*

In the simulation session recordings in Phase IB, post-simulation interview portion of Phase I and in the narrative interviews of Phases II and III, participants’ responses were analyzed using Atlas.ti version 7. All recorded data was transcribed and then coded according to the guidelines of grounded theory. The coding process of grounded theory proceeds in a hierarchical fashion beginning with narrative data, which for this project mainly consisted of interview transcripts. According to Charmaz (2006:43) “Qualitative coding, the process of defining what the data are all about,…means naming segments of data with a label that simultaneously categorizes, and accounts for each piece of data.”

In the initial coding phase, I went through the data, line-by-line and assigned a code that described the data and stuck closely to the data. This initial coding not only functioned to make concepts logistically manageable, the line by line coding process helped to crystallize key concepts that otherwise would have remained diffuse in the ex-
tensive narrative text. These initial codes were used to start illuminating potential conceptual categories.

Through analyzing these codes, social processes began to emerge in the data, and to record my observations, I wrote theoretical memos throughout the coding process. Memo-writing allowed me to elevate codes to categories that could be expanded upon. Through the memo-writing process of continuously comparing data and making connections between data, I was able to explore emerging concepts and processes while building linkages between concepts (Charmaz 2006).

Next, through focused coding, I arranged recurrent concepts into codes that were more “directive, selective, and conceptual” (Charmaz 2006:57) than initial coding. These codes classified the data according emerging themes. Throughout the coding processes, working with my faculty mentor, I deleted, trimmed, renamed, and merged codes into larger categories that corresponded to themes in the data. This coding process was not a simple grouping procedure. By using the technique of constant comparison, a dynamic between codes, categories, and themes was generated, where new gaps were identified and concepts were further refined throughout the analytic process (Wasserman et al. 2009). This means that statements within an interview were compared with each other and with other interviews (within phases), new data were compared with older data (between phases), and so on.

Unlike typical hypothesis testing, which begins with the development of hypotheses that are then subsequently tested with the collected data, with a grounded theory approach everything begins with the data. This means data was collected and then analyzed, and then more data was collected and analyzed in order to pursue emerging themes from
the first wave of analysis and each subsequent wave. Therefore, rather than employing the standard order of data collection then data analysis, in the grounded theory approach used here, data collection and analysis was simultaneous and dynamic. Conceptual themes eventually were pursued intentionally by focusing or altering questions in subsequent interviews (Phases I, II, and III). Therefore, as broader concepts emerged, they were not treated as a priori concepts for subsequently collected data. Instead, I dealt with discrepancies between new data and previous concepts by modifying the conceptual scheme with synthesis, rather than forcing a fit or trying to explain away non-fitting data (Glaser 1992). Concepts were constantly improved by synthesizing new data or new analysis of older data. This allowed for eventual theoretical explication.

Human Subjects Protection

This study was approved by the Institutional Review Board for Human Use at the University of Alabama at Birmingham, Protocol #E120130002. In lieu of obtaining a signed Informed Consent form, the participants received an information sheet in the form of an e-mail. Given that the interviews are audio-recorded, there is a potential risk of loss of confidentiality. In order to diminish the risk of loss of confidentiality, the interviews took place in private locations and were strictly confidential. Participants are known only by a study number and are linked to that number by a single key kept by the PI and destroyed after recruitment has ceased. Audio tapes of interviews are stored in a locked drawer in the PI’s office and interviews were transcribed within 3 weeks. Tapes were immediately erased after they have been transcribed and rechecked for accuracy. All electronic documents were stored on a password protected UAB computer.
CHAPTER 4

FINDINGS

In this dissertation, I utilized a primarily qualitative mixed methods approach to (1) Explore how physicians’ approaches to EOL communication are shaped, (2) Examine the difficulties physicians experience in talking about end-of-life (EOL) issues with parents of pediatric patients who are dying or who have died, (3) Investigate how interactions about death affect them personally and professionally, and (4) Explore physicians’ insight into how to improve EOL physician-parent communication.

In order to address the research aims sufficiently, a longitudinal process was utilized which provided both quantitative and qualitative data. The purpose of Phase I was to examine physician-parent communication in pediatric EOL care utilizing high-fidelity simulation coupled with a debriefing interview. In the second phase, participants from Phase I were invited to participate in a narrative interview to discuss how their stories informed their approaches to pediatric EOL care and communication. Finally, in Phase III participants from Phase II participated in a final narrative interview to discuss topics generated out of the emergent data.

Throughout the course of the study, participants shared cases of good and poor communication. Many cases were remembered positively by physicians. Families gathered together and sang to create an atmosphere of peace as life-sustaining technology was removed from their loved one. Parents sent thank you notes and photos to the attending physician in appreciation for their hard work and skill. And, where the parents and physi-
cians had a shared faith, they talked about scripture verses and heaven. Even though pa-
tients ended up dying in these cases, physicians felt they were met with a good death in
large part because of the effective communication that occurred.

But, then there were cases that, as one physician put it, “…literally destroyed me”
(II:21). Cases of poor communication included those where parents did not comprehend
that their child was dying and when they finally did realize it they felt that they had been
deceived. Other cases of poor communication were where parents felt the physician, by
bringing up EOL issues, had given up on their child or “wanted to kill their child.”

What determines whether a physician-parent EOL interaction is going to be good
or bad? Certainly extant circumstances play a role. Some cases are so horrific and so
heartbreaking that no amount of effective communication can bring a positive outcome to
the experience for the parents or for the physician. But the thesis of this study is that
communication is powerful and the quality of the communication has much to do with
EOL outcomes for patients, families and physicians.

The findings will be presented in three sections in this chapter before concluding
with a conceptual model. The first section will examine how characteristics arising from
participants’ narratives influence physician-parent EOL communication. The following
section will examine ethical decision-making related to physician-parent EOL communi-
cation. Then, the focus will turn to how physicians struggle to find strategies to approach
EOL communication with parents, yet how they still often feel inadequate in their com-
munication. Finally, a conceptual model for physician-parent EOL communication,
based on the findings, will be presented.
Physician Narrative and Pediatric EOL Communication

*Phase I Quantitative Results*

Although the results from Phase I are limited due to the small sample size, interesting trends emerged that set the stage for the later phases of the study. In Phase IA, using the simulated case described in the methods section, mean physician-parent participatory communication scores were higher, but not significantly higher, for women (as opposed to men), fellows (as opposed to attending physicians), PEM physicians (as opposed to PCC physicians), and parents (as opposed to non-parents).

Table 4. Mean Participatory Physician-Parent Communication Score by demographic variable (N=21; Phase IA).

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean Communication Score (t-test)</th>
<th>t-test result (p-value)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td>Male = 2.64</td>
<td>2.64</td>
</tr>
<tr>
<td></td>
<td>Female = 3.21</td>
<td>.22</td>
</tr>
<tr>
<td>Age (median split)</td>
<td>Younger = 3.05</td>
<td>3.05</td>
</tr>
<tr>
<td></td>
<td>Older = 2.64</td>
<td>.37</td>
</tr>
<tr>
<td>Race (white v. nonwhite)</td>
<td>Nonwhite = 2.33</td>
<td>2.33</td>
</tr>
<tr>
<td></td>
<td>White = 2.92</td>
<td>.35</td>
</tr>
<tr>
<td>Hours worked</td>
<td>Fewer hours = 2.90</td>
<td>2.90</td>
</tr>
<tr>
<td></td>
<td>More hours = 2.77</td>
<td>.77</td>
</tr>
<tr>
<td>Specialty</td>
<td>PEM = 2.92</td>
<td>2.92</td>
</tr>
<tr>
<td></td>
<td>PCC = 2.72</td>
<td>.66</td>
</tr>
<tr>
<td>Seniority</td>
<td>Attending = 2.71</td>
<td>2.71</td>
</tr>
<tr>
<td></td>
<td>Fellow = 3.00</td>
<td>.51</td>
</tr>
<tr>
<td>Fatigue (median split)</td>
<td>Less fatigued = 2.50</td>
<td>2.50</td>
</tr>
<tr>
<td></td>
<td>More fatigued = 3.00</td>
<td>.34</td>
</tr>
<tr>
<td>Parental status</td>
<td>Yes = 3.09</td>
<td>3.09</td>
</tr>
<tr>
<td></td>
<td>No = 2.50</td>
<td>.18</td>
</tr>
<tr>
<td>Malpractice Fear (median split)</td>
<td>Less Fear = 3.28</td>
<td>3.28</td>
</tr>
<tr>
<td></td>
<td>More Fear = 2.50</td>
<td>.07</td>
</tr>
<tr>
<td>DNR Scale (median split)</td>
<td>More comfortable with = 2.85</td>
<td>2.85</td>
</tr>
<tr>
<td></td>
<td>Less comfortable with = 2.75</td>
<td>.86</td>
</tr>
<tr>
<td>Emptpy (median split)</td>
<td>Less empathy = 2.95</td>
<td>2.95</td>
</tr>
<tr>
<td></td>
<td>More empathy = 2.73</td>
<td>.62</td>
</tr>
<tr>
<td>Tolerance for uncertainty (median split)</td>
<td>Less tolerant for unc = 2.83</td>
<td>2.83</td>
</tr>
<tr>
<td></td>
<td>More tolerant for unc = 1.00</td>
<td>1.00</td>
</tr>
<tr>
<td>Actor</td>
<td>white actor = 3.04</td>
<td>3.04</td>
</tr>
<tr>
<td></td>
<td>black actor = 2.50</td>
<td>.23</td>
</tr>
</tbody>
</table>

Mean age: 39.67 years
In Phase IB, simulation times also were recorded, from the time the participant walked into the simulation room until the facilitator stopped the simulation indicating that the participant made a decision about whether or not to intubate the patient. According to the literature, length of visit is correlated with higher patient satisfaction (Gross et al. 1998) and fewer malpractice claims (Levinson et al. 1997) in primary care visits. Results are reported in Table 3 and suggest that simulation sessions were longer for participants who were males (as opposed to females), PEM physicians (as opposed to PCC physicians), attendings (as opposed to fellows), and parents (as opposed to non-parents) even though only the parent-non-parent difference reached statistical significance.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean Simulation Time (seconds)</th>
<th>t-test result (p-value)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>551</td>
<td>.40</td>
</tr>
<tr>
<td>Female</td>
<td>467.8</td>
<td></td>
</tr>
<tr>
<td>Specialty</td>
<td></td>
<td></td>
</tr>
<tr>
<td>ER</td>
<td>579.9</td>
<td>.15</td>
</tr>
<tr>
<td>PCC</td>
<td>448.0</td>
<td></td>
</tr>
<tr>
<td>Seniority</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Attending</td>
<td>546.3</td>
<td>.39</td>
</tr>
<tr>
<td>Fellow</td>
<td>457.5</td>
<td></td>
</tr>
<tr>
<td>Parental status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>612.0</td>
<td>.02</td>
</tr>
<tr>
<td>No</td>
<td>410.5</td>
<td></td>
</tr>
</tbody>
</table>

**Physician Individual Characteristics and EOL Communication**

These quantitative results, although preliminary and in no way definitive, suggest that physicians may vary in their communication patterns with parents of children at the end of life due to their individual-level characteristics. Results from Phases II and III provide deeper, more definitive insight into the question of how physicians’ own narratives affect their communication with parents of dying children. A note about interview citations: quotations will be identified as (phase number: participant number). If the
quotation comes from the simulation, the phase number will be referred to as “S”. For example, (II:9) would mean the quotation came from Phase II, participant 9.

Qualitative interview data reveals that participants were overwhelmingly in agreement that their own background and experiences influenced the way they cared for patients and interacted with parents. They were aware that these effects were subtle, but present to varying degrees and although they tried to be objective, personal emotions were often indicators of a compromised objectivity. The participants talked about the fact that they were assumed to be objective interpreters of information, but they innately knew that they were not. A male PCC attending stated this idea well: “But, I’m just saying, you like to think that you’re always very logical, that you make your decisions in a very rational way and you always use the same methods and you bring the same quality of care to every patient. And, the fact is that that can’t possibly be true” (II:14).

Results from Phase I suggest that physician gender, parental status, specialty, and seniority may influence the way physicians interact with parents of dying children. These findings were explored further in Phases II and III, and the theme of physicians’ religious beliefs and early experience with death emerged as an additional narrative characteristics that may influence physician-parent EOL communication. In taking account the study as a whole, the most salient themes that emerged as being influential in the processes related to communicating with parents of dying children were physician parental status and physician religious beliefs. The following sections will examine how characteristics arising out of physicians’ stories have the potential to impact the objectivity that they bring to their care of children at the EOL.
First, we will examine narrative characteristics arising from physicians’ professional practice: specialty and seniority. Perhaps the most interesting finding related to these characteristics is that they are the attributes for which the least differences were seen in this study. Whereas interview data suggests that substantial differences exist related to EOL physician-parent communication based on gender, parental status, and religion, differences based on specialty seemed minimal except in the details of professional duties. Seniority, as defined here by experience level, did appear to affect EOL communication to some extent.

The literature indicates that characteristics inherent in each specialty may play a role in pediatric EOL physician-parent communication and some of these differences emerged in this study. Pediatric critical care and pediatric emergency medicine were chosen specifically because they are similar in that they see patients for relatively short periods of time and patients almost always present with the goal of recovery. They, unlike general pediatricians, do not practice with the expectation that they will follow patients from just after birth through adolescence. Further, their encounters with patients are generally not scheduled. Results in the Phase I quantitative portion suggest that PEM physicians score on communication higher, but not significantly higher compared to PCC physicians (PEM = 2.92 vs. PCC = 2.72); Mean simulation times were higher, but not significantly, in PEM than PCC physicians, (PEM = 580 seconds vs. PCC= 448 seconds). This trend in the data is the reverse of what was expected. It would seem that since PEM physicians are used to having more time constraints than PCC physicians, they would gather histories and make decisions faster. However, because PCC physicians are more com-
fortable seeing EOL patients perhaps they were able to assess the situation and make a decision about treatment in less time.

Although the consensus of the participants was that pediatrics “draws a certain type of people…more relationship oriented, family oriented, touchy-feely emotionally driven people” (III:10), differences in EOL practices between the specialties emerged. A main subspecialty difference between PEM and PCC is in time allotted for each patient. A hallmark of PEM is the pressure to see as many patients as possible in a limited amount of time. In this study, time was an important theme voiced by PEM physicians. They see patients at “one instant in time” (I:20) and for such a “short period of time” (II:10) that assessing whether or not to address EOL issues with the family is not really an issue. If too much time is spent with each patient, “there’s going to be a lot of people stuck in the waiting room” (II:20). An EOL conversation requires time, and if no DNR order is readily apparent in the chart, most PEM physicians err on the side of treating them, including resuscitating them, and deferring EOL conversations to a specialist later in the chain, like in the pediatric intensive care unit (PICU).

Time was not mentioned by all of the PCC physicians, and for those who mentioned it, contrasting ideas emerged. Two of the attendings said they felt that time was not a limiting factor in their ability to address EOL issues with families. Although time was limited in some circumstances, “…in the span of a week…we have time in the bigger scheme of things” (II:9). “Well, we have time. They [PED patients] are exactly the kind of patient that I told you was the most difficult one. Because you have no relationship whatsoever with them and all of a sudden you’re there and you have to tell them that their child died. Their job is harder than mine. I have the luxury of being able to talk to the
family for days if I want to” (II:9). This physician claimed that it meant that his work sometimes cut into his personal life, but this was an important sacrifice for him to make in the care of his patients and families. In contrast, others felt that time was limited because of the number of patients in the unit and you had to “pawn it off”, referring to emotional discussions with families (III:17), but this was not a prevailing theme.

In the PED, EOL conversations are avoided because there is no relationship with the parents. As one PEM attending put it, “EOL discussions in the acute setting are much more disastrous” (II:1) due to the shock the parents are typically experiencing and the fact that there is no time to establish a relationship. Although there are a few chronically ill patients known because they are brought in regularly, most families are unknown to the PED staff. This makes it even more difficult when EOL conversations must happen, “…because we’re going down quickly and so I need to know whether I need to intervene or not…” (III:1). Interestingly one PCC attending stated that, “I’m not the first line in seeing the kid, so the PED…has probably already had the discussion” (I:9), indicating that PCC physicians may be assuming that PED physicians are having EOL discussions when in reality they are not.

The ultimate goal of PEM is to save the life of the child. Several PEM physicians of varying levels of practice mentioned that they had never had a parent in the PED say not to provide life-saving measures, even for those children obviously at the EOL. In the PED, the philosophy is to save the child and then ask questions later. Even parents who have consented to a DNR order, or whose child is receiving hospice care at home, often get scared when their child appears to be at the terminal moment, and so they come to the PED for life-sustaining care. Sometimes when that happens, physicians are able to stabi-
lize the child enough to get them to a private room with their long-term physicians, who it is perceived have already developed relationships and are better equipped to engage in EOL conversations. One female PEM attending stated that, “I think it was about planning on their supervising doctor’s part, but sometimes it was just the way the parents felt, that they just couldn’t watch their child die at home, that they wanted the nurses and doctors around, to let them know that things were okay, that it was okay to die” (II:8). Perhaps with better planning and communication from their long term specialists, parents could be better prepared when faced with their child’s terminal moment and avoid the discomfort of the PED.

One PCC physician also explained that “relationships are short-term” like “a new trach may come in who’s on an otherwise healthy kid who spends 5 or 6 days with you. But you know he’s going to leave you and you’re probably not going to see him again” (II:18). The way that the practice of pediatric critical care is organized also limits interactions. Physicians work at intervals, being on service in the PICU for a fixed number of days and then rotating off. Most admissions are only a few days, “So you’re not looking at people who want a relationship or a patient interaction that goes on for days, for weeks, for years. That’s just not what we do” (II:18). However, even though relationships are short-term and most patients “get better” sometimes EOL discussions must happen.

So, in the specialties examined in this study, very few differences were found in the way they relate to physician-parent EOL communication. Although time is shorter in the PED and patients are more likely to be unknown to the staff, time is also relatively short in the PICU. The PICU staff does have more time to establish a relationship with families; however these are typically not long term relationships.
Seniority

This research suggests that fellows were more likely to engage in physician-parent participatory communication than attending physicians. This finding is substantiated by some research studies and conflicts with others. Fellows in this study reported having more structured training in communication than their attendings, indicating a generational shift in training. However, the main reason for the finding in Phase I could be that in this particular facility high-fidelity simulation was used for the training of fellows. Therefore, they would have been exposed to the method more frequently than attendings, and thus be more comfortable with it. Fellows were in agreement that high-fidelity simulation was a valuable training method and many suggested that it could be used more widely to help train physicians in communication. Attendings, on the other hand, viewed simulation more negatively. Several voiced that they disliked, even “despised” participating in simulation. It may be that they were not happy about the idea of being evaluated, but they also claimed that the simulation setting does not seem like a natural situation to them. For example, they find it difficult to use their intuition in assessing the patients’ condition when the patient is a mannequin. Further, a male PEM attending explained that in his experience high-fidelity simulation was used to assess procedural skills. Therefore, evaluating him based on his communication performance was not appropriate because he was only thinking of the clinical aspects of the case. If fellows were more familiar with the versatility of high-fidelity simulation, it is not surprising that they would have treated it more as a real-life encounter and would have spent more effort
communicating with the parent as opposed to simply performing the medically appropriate, life-saving procedure.

**Seniority and comfort with EOL communication.** In Phase IB, attendings had longer (but not significantly longer) simulation times than fellows (546 seconds vs. 458 seconds). The qualitative interview data reveals that, not surprisingly, experience leads to more comfortable EOL interactions with parents and that could have resulted in longer discussions with the actor parent. Preparedness was an important subtheme related to experience level and this will be discussed in detail in a later section of this chapter. Even though most participants said that they did not think they could ever be truly comfortable talking with parents about EOL issues, experiences had enabled them to feel prepared. Many, such as the following male PCC attending said EOL conversations that went badly motivated them to do a better job the next time, “And you can get better with time, because you’ve screwed up before” (II:9). Older attendings claimed that it “took years” (III:10) to get the point of feeling competent to discuss EOL issues with parents and admitted “…telling a family member that their child has died…will always bring anxiety for me” (II:10) as stated by a female PEM attending. A male PCC attending stated, “But, it’s never, easy. It’s always…a little awkward and you feel unsure of yourself” (III:14). Experience may help “build up a little bit harder shell,” (II:18), which may make communication less painful for the physician.

**Seniority and emotional distress.** Indeed, experience emerged as an important factor in determining the level of emotional distress that physicians felt as a result of the
EOL interactions. One male PEM attending described a case that affected him immensely early in his career in which an infant died. He said, “I think over time I learned to handle it,” but, at first it was, “Very difficult. Very, very difficult” (II:21). And after practicing for several years, he says that he does not “take a lot of it home anymore…You have to survive” (II:21). With experience, participants gain a longer view and can hold examples of lives saved along with those of lives lost. Feeling the satisfaction of knowing that because of one’s actions, a child was saved can help balance the pain of losing children. For example, a PEM male attending stated that when people ask him how he can deal with something so difficult as child deaths, he says, “…the opportunity to occasionally save someone and help the families and the kids that I do, outweighs the bad side of it” (III:7).

Although experience seems to moderate the effects of patient deaths, it does not diminish it completely. Attendings who had been practicing for decades teared up when they described their pain, “Sometimes the tears are really close ” remarked a male PEM attending (II:7). A female PEM attending described her interaction with a male colleague the previous week, who was struggling with difficult resuscitation. Both of them had been in practice about 20 years. “I don’t know if people understand that we do carry it with us. You don’t put in on a shelf…You don’t walk away from it and pull your gloves off and go, ‘Well, I’m on to see the next kid with the sore throat or the stubbed toe or the broken arm’” (II:8). In addition to level of experience, emotional distress occurring as a result of EOL interactions also was related to gender, parental status and religion, and this will be addressed below.
Gender

Physician gender differences in practice and communication have been clearly established in the literature. Female physicians tend to engage in more participatory communication styles with patients (Zandbelt et al. 2006), spend more time discussing patients’ psychosocial and emotional status (Bertakis 2009), and spend more time overall with patients (Bernzweig et al. 1997; Hall and Roter 2002; van Dulmen and Bensing 2000). Phase IA mean physician-parent participatory communication scores suggest that the participants in this study did not differ significantly by gender, with male physicians receiving slightly higher scores. Male physicians also spent slightly longer in the simulation than female physicians in Phase IB, but this difference was not statistically significant. These trends are contrary to what was expected based on the literature. For example, Roter and Hall (2004) reported in a review article that visits with female physicians were on average 10% longer than with male physician in primary care. As will be discussed in the next section, it may be that parental status moderated the influence of gender in this study. More male physicians were parents and qualitative results suggest that parental status may be a larger influence than gender in pediatric EOL communication.

Gender and emotional distress. The main differences that emerged with regards to gender and physician-parent EOL communication were related to emotional distress. Clear gender lines were drawn among participants in relation to the way with which emotional pain resulting from EOL interactions was experienced and managed. Although all acknowledged some difficulty in facing pediatric death, women physicians on the whole felt pain more intensely, had longer lingering effects of EOL interactions and patient deaths, and in general had more difficulty detaching pain experienced at work from their
lives outside of work. On the other hand their male colleagues were more likely to say that they could remain objective in order to do their work and live their lives.

Men claimed they could detach from their dying patients in order to protect themselves emotionally. Two male participants said point blank that “no” their patients’ deaths did not affect them emotionally. None of the female physicians admitted this. Being able to detach from patients who are dying is important because, “you have to see more patients and you have to live your life,” described a male PEM attending (II:12). A male PCC fellow stated that the job has “calloused me some,” and even though he still gets emotional when working on critically ill children, “I can see them as an object and do what I’m trained to do…when I’m talking to families” (II:17). A male PEM attending said that although he has learned to detach, “I hope, hope that it’s not because I am numb…I don’t want to be insensitive and I don’t want never to be sad” (II:21). Although one of the female participants talked about the importance of trying to be objective, none of the women described seeing their patients as “objects”.

With regards to taking their work “home” with them in terms of the lingering effects of interactions surrounding patients’ dying or deaths, male physicians claimed they rarely did that. Women, on the other hand, almost universally claimed that that they ruminated over painful cases while not at work and their own pain affected their personal lives. One female PEM attending stated, “I mean we go home and it takes days or weeks to get over it. You remember the families, the situation” (I:8).

_Differing views on the influence of gender._ Participants were divided along gender lines about whether or not they believed gender influenced pediatric EOL care, including
physician-parent communication. The consensus of the female participants was that physician gender did play a significant role in their care of EOL patients. Female participants believed men think and respond differently than women and this is reflected in their patient care. For example, a female PEM fellow stated, “The males would probably be more likely to do, to jump in,” but women physicians “for the most part…would be able to talk with the parents, empathize with the parents” (II:11). Similarly, a female PCC fellow explained that her male colleagues “just back off” when parents get emotional and are therefore “more prone to do everything” (II:19). Female physicians, on the other hand, “…take a stand more in what they want and they try their best to convey that to the families” (II:19).

One female PEM attending noted that she learned more from female physicians than male physicians and early in her career she recognized that her male colleagues “didn’t have the sincerity, the genuineness” that she saw in women physicians (II:16). Female participants in both critical care and emergency medicine pointed out that they spent more time with patients and families than their male colleagues and felt that they bonded to them more, “and if someone else saw them, they’d be upset, because you know you get attached to them” (II:19).

Male physicians, on the other hand, were quick to point out that pediatrics is a gendered specialty, with more women practitioners than men, and more men with “big hearts” who “act like girls” entering pediatrics than other medical specialties (III:21). Therefore, they believed observed gender differences in care and communication are not as great in pediatrics. Males agreed that there were probably slight expected gender differences, but noted that they could give plenty of examples where they had observed fe-
male physicians being more objective and males being more emotional. For example, one male PEM attending stated, “I don’t think it’s a fixed difference. I think there’s a crossover…And, so there’s probably something to it but I think the individual characteristics of the people involved probably override some of that…” (III:20). Of all the narrative and demographic differences in physicians, male physicians tended to feel that gender was the smallest influence. As one male PCC attending explained, “I think it’s more background related, and how you grew up, and how long you’ve been doing it” (II:18).

Therefore, this study found an interesting contrast between male and female physicians. Whereas female physicians in general believed significant differences in practice existed between them and their male colleagues, with women having an advantage in compassionate EOL communication, males felt gender differences were minimal and that other narrative and demographic variables influence patient care to a greater extent. One female PEM attending summed up her feeling, when asked whether or not she thought gender affected her care of children at the EOL by responding, “1000%, 1000%. Probably there is a gender difference that is measurable and exists, definitely, but I would probably compound that to say the bigger difference is whether you’re a mother or not” (III:16). Of the physician variables that may affect pediatric EOL care and physician-parent communication, physicians indicated that parental status was one of the most salient, even more so than gender.

**Parental Status**

A recent commentary in the *New England Journal of Medicine* discussed the question that pediatricians often hear from parents, “What would you do if it were your
kid?” (Korones 2013). Parents may ask this, the author hypothesized, for two reasons: one, because they believe that the option the physician would choose for his or her own child must be the best choice or, two, they may ask it in an attempt to make the physician’s involvement in the care of their child more personal (Korones 2013). Regardless, the question of “What would you do?” can be daunting for physicians, especially those with children, because it forces them to be more personal and less objective, chipping away at their own coping mechanisms in place. Participants in this study who had children overwhelmingly felt that their status as parents changed their practice of pediatrics and this can be seen through the quantitative and qualitative findings.

Results of the Phase IA quantitative portion of the study revealed a trend toward differences in physician communication by parental status. Mean physician-parent participatory communication scores were higher (though not significantly higher) in physicians who were parents than in those who were not, suggesting that parents may have practiced somewhat more effective communication strategies than non-parents. Further, simulation sessions (Phase IB) of the participant physicians who were parents were 33.3% longer than those of nonparents (p<.05), indicating that participants who were parents spent significantly more time talking to an actor mother. Interestingly, contrary to what was expected based on the literature, no significant differences were found in length of visit between male and female participants. However, in the sample of physicians in Phase IB, 75% of the male physicians were parents, whereas only 20% of the female physicians were parents, which could suggest a moderating effect of parental status on physician gender and length of visit.
Parental status, EOL decision-making, and communication. All of the participants, both those who were parents and those who were not, felt that physicians’ parental status influenced their care of dying children. In the Phase II interviews, when asked the question, how has your background influenced the way you take care of dying children and their families?, parental status was the factor most often discussed by those who were parents. Physicians who began having children during their medical training had difficulty determining precisely how parental status changed their practices, but they were sure it had. Words like “absolutely” and “definitely” were used by multiple participants in relation to the effect that parenthood had on practice. For example, a male PEM attending stated, “I think that really paints your experiences and your decision-making in a way that you can’t really quantify or understand until you’ve been through it” (II:12). Others were able to explain clearly how they thought it impacted their care of children who were dying; they claimed that the influence was not so much on decision-making as it was in their interactions with families. One male PCC attending explained the complexity of becoming a parent, “… it became a lot more difficult once I had children…It actually became easier to empathize with families once I had children too. The pain was bigger, because you feel like, ‘Whoa, that could have been my child.’ But… at the same time it prepares you better because you understood the love they have for their children” (II:9). Although they experienced more emotional distress in dealing with dying patients after they became parents, participants who were parents also felt that they were better able to show empathy to parents of their patients.
Parental status and emotional distress. Many parent participants, both male and female, discussed the increased emotional distress they experienced as a result of caring for EOL patients and their families after they became parents. And, non-parent participants observed this phenomenon in their colleagues. One attending, although not a parent, noted that her fellows who were parents seemed to struggle the most (II:10). For example, a female PEM fellow who became a parent during the course of this study was able to clearly elucidate her feelings. In fact the theme of her Phase II interview was her experience of becoming a parent, which happened between Phases I and II. “… before I had my baby, they would affect me a little bit and I wouldn’t really take that much home with me. But I feel like now, sometimes, I’ll just keep thinking about the case and thinking about the parents and... I do, I take it home with me now. I definitely do” (II:11). She went on to explain that as a new parent, EOL conversations with parents were “much harder now” (I:11). She said that she heard from colleagues that it does get better. However, the attendings in the study who were parents did not tend to reflect this idea.

No matter how many years they were in practice or how old the physician’s children were (all parents had children who were 18 or younger at the beginning of the study), participant parents commented that the more they identified with the children they were treating and the more their patients reminded them of their own children, the more difficult the cases were. One female PCC attending physician stated, “The things that could happen to your own children are harder than the things that couldn’t is what it boils down to” (III:2). A male PCC attending explained how this played out, “I mean you’re taking care of a 2 year-old, who had drown or something, and you have a 2 year-old, or especially if you have a child the same age, same gender… It still gets me now” (II:14).
One male PEM attending explained that now that his children had reached driving age, automobile trauma cases are more difficult, “I think of my perspective…having a kid driving… and all of a sudden the vulnerability level that you have is much, much higher” (II:21).

During the Phase III interview, a participant with young children discussed a case that he experienced since his Phase II interview of an elite high school athlete who collapsed while competing. After an unsuccessful resuscitation, he had to pronounce the child dead, and this affected him at a deeper level than any other case he had up until that point. He stated, “You know, I wasn't sure if I saw my own child laying there. Or, if it was just the loss to the community…Also, witnessing the interaction between the father grieving his son, just kind of the father-son dynamic which I participate in with my own son” (II:1). He believed a significant reason for the pain he felt was his own status as a father.

*Parental status and increased empathy.* But, through the exaggerated pain, participants across the board felt that when they became parents they could better empathize with the parents of their patients. By becoming a parent, a PEM attending male said he had a “significantly deeper understanding” of what parents go though (III:20). One PEM attending physician described how a critical incident that brought his infant daughter to the PED, left him better able to interact with the parents he encounters in his work, “…and I didn’t contemplate her death long, thankfully, but of course it crossed my mind and so it, I think it made it absolutely more personal to me. And since then, when I’ve encountered families in the same situation. I can feel for them as a parent, but also I think
I can counsel them better as a doctor” (II:1). Related to empathy, one male PEM attending explained how he understood the importance of parental autonomy better:

I think that understanding the parents’ perspective just from relating to them a little bit, helps understand the autonomy that’s important for them to hold to. It’s important for them to feel a sense of understanding of what’s going on and somewhat a sense of control. And, I say that not with a negative connotation but in a positive sense. That they have some control over the situation and are being enabled to share in decision-making” (II:12).

Clearly parent physicians felt that they could relate better to parents than non-parents and this improves communication with them.

**Observations from non-parent physicians.** From observations of their colleagues who were parents, non-parent physicians felt that physicians who were parents were affected more emotionally by child deaths, “because they could picture their own child being there” (III:19). One female PCC fellow who was not a parent suggested that being a parent may impact her colleagues’ care for their patients, “And then it makes them really want to push more, especially if it’s a child who’s the same age or kind of looks a little bit like their own kid” (III:19). So, she indicated that because of their bias they may be less willing to withhold or withdraw care. In general, but with notable exceptions, non-parents indicated that not only did they not feel as much emotional distress over their patient deaths, but they were able to remain more objective in the decision-making process. One male PCC attending explained how the objectivity he had as a non-parent was beneficial to him: “…so I don’t get quite some of the emotional attachment…as I would if I had to project back on my child” (I:18). He went on in the next interview to say, “I wouldn’t want to do this work I don’t think if…I had to take that home after a busy day
and a hard day and I had kids; it would just be very difficult for me to do this. But, since I
don’t have that, it’s never been that hard for me” (II:18).

Clearly, certain features of cases interact with physicians’ own narratives and elu-
cidate emotional responses. For parents, whether or not the identification of patients with
their own children leads to improved or compromised care is unknown. Identifying with
families could play out in positive but also negative ways. When asked if being a parent
was helpful to his work as a physician, a PCC attending was not sure, “I think so. I have
to think so. But, I don’t know. The other way to look at it is it a harmful situation when I
don’t have someone at every age. I think what it speaks to is that you don’t fully identify
with every family in the same way. Which is another type of disparity...” (II:14). Bias,
no matter the source, has the potential to be harmful, but it also has the potential to be
beneficial depending on if and how it is dealt addressed.

Religious Beliefs

Physician religion was not addressed in the Phase I high-fidelity simulation proto-
col nor did it emerge as a theme during the simulations or the post-simulation interviews.
However, from the first interview in Phase II, religion emerged as a salient theme and
continued to be woven throughout the study. When asked the question in the Phase II
interview, how has your background influenced the way you take care of dying children
and their families? many brought up their religious beliefs. This led me to ask in Phase
III specifically how their religious beliefs affected their interactions with parents of chil-
dren at the EOL. The method of using open-ended questions posed a problem when I
tried to classify participants based on their religiosity, as their answers did not fit neatly
into a preconceived box. For example, although frequency of church attendance is commonly used to quantitatively measure religiosity, such a measure did not seem to capture these participants’ level of religiosity in relation to patient care. As an illustration, one participant stated that even though he was brought up Catholic and attends church regularly with his family, he was “cynical” about religion. Another participant also said that he grew up Catholic, still attends church with his wife, but would classify himself as “probably closer to agnostic or atheist”. Because I did not have enough information to categorize participants based on their religiosity, I ultimately determined that in exploring physician communication, the best way to categorize participants was to examine the language they used in their interview responses. Therefore I classified them based on the extent to which religious language was infused into their responses to moral and ethical questions. When I use the word religiosity in the remainder of this paper, I am referring to religiosity as expressed in their language used.

Participants were classified as follows:

- Religiously Rich Responders (RRR)
- Moderately Religious Responders (MRR)
- Low Religious Responders (LRR)

Table 4. Religiosity Based on Richness of Religious Language Used

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<thead>
<tr>
<th></th>
<th>Religiously Rich Responders (RRR) (n=7)</th>
<th>Moderately Religious Responders (MRR) (n=5)</th>
<th>Low Religious Responders (LRR) (n=5)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interactions with patients</td>
<td>Faith affects interactions</td>
<td>Faith does not affect interactions</td>
<td>Faith does not affect interactions</td>
</tr>
<tr>
<td>Identification with a faith perspective</td>
<td>Identifies with a faith perspective</td>
<td>Identifies with a faith perspective</td>
<td>Claims to be atheist, agnostic or non-religious</td>
</tr>
<tr>
<td>Use of religious language in responses</td>
<td>Infused religious language freely</td>
<td>Used a limited amount of religious language</td>
<td>Did not use religious language</td>
</tr>
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</table>
As a group, these participants can be considered religious. Twelve of the 17 were classified into the religiously rich respondent (RRR) or religiously moderate respondent (RMR) groups, meaning that these physicians practiced some kind of faith tradition and infused religious language to some extent into their responses. This sample, with 70% of participants in the RRR or RMR groups, was similar to, who found that 67% of academic pediatricians identified with a faith perspective. Participants in the RRR group used extensive religious language to describe their faith. For example, one male attending stated, “I would call myself a feeble follower of Christ, you know, one who is saved by him and knows that as hard as I try I won’t live up to the standard that’s expected of me but I understand that by his grace and his work I am saved”. (II:12). Another male fellow described his beliefs as, “Well for one thing… I spent 2 years doing missionary work in Mississippi and Louisiana and sharing my faith. So I think a lot of what helps me with my perspective is my faith that there is a purpose that, you know, that we’re not here alone.” (II:13). These participants had clear religious beliefs and freely shared them with me and to a great extent with their patients and patients’ families. They reflected in-depth about how these beliefs were integrated in to their roles as physicians including interactions with patients and families, decision-making, and their own mental and emotional responses to their work.

Those participants in the MRR group identified with a faith perspective, but used a limited amount of religious language in their responses. For example one participant stated, “Yeah, so I am Catholic. And, I’m not extremely religious but we do occasionally go to church” (III:11). And, another explained, “I was born and raised Catholic. I do not practice Catholicism anymore because I do not believe a lot of things that I was taught.
But that's my basic belief system. What do they say? Once a Catholic, always a Catholic.” (III:10). I neglected to ask one participant about his faith, but categorized him here because he did not clearly fit in either of the other two groups and used limited religious language. These participants claimed that their religious beliefs were separate from their practice of medicine and used minimal religious language when discussing patient care. For example, one participant, who identified as Catholic, stated that she “never let my religion interfere” in medical decisions.

Of the five participants placed in the LRR group, identifying themselves as atheist, agnostic or non-religious, all were attendings over the age of 40. Three claimed that they were raised in a particular faith tradition and one said that he still attended Catholic Church with his wife. For example one participant stated, “I guess I do believe in a supreme being that is responsible for maintaining hopefully a balance in the world and the universe of good and evil. But, like I said, it's not specifically Catholicism, there's not a pope” (III:18). Each of these participants specifically mentioned that even though they did not have a particular faith, they respected patients and families who did. For example, one participant upheld his objectivity, “I think I can distance my feelings from what other people may feel. And I can respect theirs whether they may or may not have a religious preference. And to me that's their choice and their decision” (III:4). Further, their experience taught them that religion could be helpful to families struggling with EOL issues. For example, another stated, “Personally…I'm not religious, and yet I can certainly understand its value for the family” (III:7).
Physician religion and medical practice. The majority of the physicians in this study suggested that religion played a role in their practice of medicine in a myriad of ways and to varying degrees. This finding is similar to survey studies that have shown that more than half of physicians surveyed (varying specialties) indicated that their religion impacted patient care in some way (Curlin et al. 2005; Ecklund et al. 2007). Not surprisingly, those in the RRR group felt strongest about the influence of their faith on their practice. For example, one attending claimed, “I think anybody who says it doesn't play a role would lie… who you are and what you believe filter out some” (III:9). And, a fellow, when discussing about whether he thought a physicians’ religious beliefs affected his or her practice, stated, “Yeah. I think they do. Because I really think your belief system, if you really believe it, is going to influence everything you do in your life.” (III:13)

For many in the RRR category, their faith appeared to be the primary lens through which they viewed their practice of medicine, especially when it came to taking care of children at the end of life. A male attending explained, “I think, you know, that Christ longs for me to empathize with the parents and longs for there to be a just outcome for the child. That longs for me to think about the child as an individual and ensure minimal suffering and at the same time thinking what’s best for him or her or family” (III:12). This participant’s ethical duty as physician to provide optimal care, as he saw it, was based in his Christian faith.

However, for these physicians, their faith was private and was not a topic that they talked about often with colleagues. Some mentioned that they did not know the religious persuasions of those with whom they worked and, likewise thought that observers may not recognize their religious commitments. Further, those in the RRR group pointed
out that outside observers would most likely not be able to notice a difference between the way they practiced medicine and their colleagues who did not have the same depth of faith. Two participants in the RRR group, both male attendings, felt that their colleagues and the families of their patients may not recognize that their actions stemmed from their faith because basic moral beliefs of people of faith were not that different than cultural norms. For example, one participant felt that faith did not affect his practice in a way noticeable by others.

I have to tell you that it certainly does affect the way I do my work and everything in my life. But I can't say that a lot of the core values, beliefs, and practices that most of us hold to in terms of EOL care aren't germane just to what most would consider humane care…the way that looks, if a third party were to look, would ultimately be similar to my colleagues who are atheistic or you know or whatever. (II:12)

The other participant related his ideas to EOL communication, “I think religions are so holistic, usually, and the moral codes are not that terribly different. They are but I don't know if I'm, say, a Christian, and I'm talking to someone who is not a Christian, that I necessarily come at these particular issues with some kind of moral absolute that varies much from what they're already feeling…I like to think my religious beliefs have kind of shaped my habits and my ethics and the things that precede that conversation” (III:14)

By being diligent and doing his work well, all which is motivated by his faith, this participant would be able to have better EOL conversations with families because they would trust him, although he did not think his patients or their families could detect his underlying faith. However, others, notably those in the LRR group, did notice that their colleagues who were more religious (‘hyper-religious’ as stated by one female attending) used religious language with patients and families, and made EOL decisions differently. The overwhelming theme that emerged from the perspective of these physicians was that
a physician’s religion plays a role in their care of their patients, in both implicit and explicit ways.

Asked whether or not their religious commitments affected their EOL decision-making with families, including those related to withdrawing or withholding treatment, the physicians, no matter what their level of religiosity, said that personally it did not. One male attending participant in the RRR group suggested that his religious beliefs may have played more of a role earlier in his career than they did now with regard to limiting care, “I think I would say that my default position as a younger man was always you do everything to save every life. So, that’s kind of where my religious background was centered on the sanctity of human life…” (II:14). But as he practiced for a while he realized that the complexity of cases led to these decisions being less black and white, “because you don’t know all the areas you’re going to encounter. And I think people who hold those views don’t imagine scenarios where it gets more complicated than that” (14:II).

Although physicians said their religious commitments did not interfere with their own ability to be objective, some, notably female participants in all groups, felt that their colleagues’ religions did play a role in their practices related to EOL decisions. For example, one female fellow in RRR group explained the differences she observed in her attendings’ proclivity to withdraw care,

I haven't figured that part out yet...if it's religious-based. There are some people in this practice who will not withdraw for anything.... if there's just a glimmer of anything they will not discuss that with the family. And, then there are others who have done this a lot longer and think about what's ahead and say, you know, think about this from a different perspective...You have to help the family make these decisions and not just continue to prolong things and continue to give them hope that may not be there (P19:III).
Clearly this participant felt that physicians’ religious beliefs, as well as experience level, might play a role in EOL communication with families by not discussing life limiting/comfort-measure only options with families. Another participant, in the LRR category mentioned how faith might affect a physicians’ decision to resuscitate, “They don’t want it to be on their hands; they want it to be in God's hands so they will just willy nilly continue to offer resuscitation to a corpse” (III:8). The third participant, in the MRR group explained her experience of observing physicians work to prolong life at all costs as a medical student in a Catholic hospital, “There was no child that they let, no matter how young that baby was… I saw babies that had no hope of viability, being resuscitated which came from, I feel like came from, religious convictions of those individuals” (III:10). Because of the particular religious beliefs of the physicians practicing at the Catholic hospital, this physician felt that inappropriate life-sustaining care was provided to EOL infants.

Another physician, in the RRR category, who went from being a fellow to an attending in the course of this study, agreed that experience played a role in physicians’ feelings and practices about withholding treatment and withdrawal. When asked whether or not a physician’s religion influenced the decision, he said, “I do. I mean especially when…you start. We kind of really fear the term physician assisted suicide. ..Their religious beliefs will definitely affect people's perception of withholding care” (III:1). He went on to explain how he felt as an attending, “For me… I am the physical hands of what God wants me to do, uh, and there's some things that I can't fix and I'm okay with that” (III:1). He was putting his practice into God’s hands, but that included letting patients die if they were clearly at the end of their natural life.
Physician religion and communication. Many participants described the significance of religion in EOL communication. Catlin et al. (2008) found that 58.6% of academic pediatricians believe that their religious/spiritual beliefs influenced their interactions with patients. The participants in this study who were classified in the RRR group noted that their ability to interact with families using religious language improved their communication because they could discuss issues on a deeper level. Because the research was done in the southeast, most families in the hospital under study were from the Judeo-Christian tradition as were all the participants who identified with a religion. For example, one attending affirmed, “Here in Alabama most people are religious, so you can always go into the religion part and say like, "You guys should pray and you know, maybe we'll get what we want" (III:9). Another stated about his faith, “I don't really see it as much of a liability. It depends on what your beliefs are but to me it's an asset and it's not something I wear on my sleeve. If families ask me, they usually don't, but if they did, I would tell them what my beliefs are” (III:14).

Those in the LRR group agreed that faith concordance could help with physician-parent communication. For example, one male attending, when asked if a physician’s faith affects EOL communication with families, stated: “I'm sure it does and for some families that makes a difference I've noticed…And, I've seen or heard descriptions of physicians who use the spiritual or religious part of their lives to share with the families and that's, depending on the family, very well received” (III:7). However, others in the LRR group expressed concern that religious language might appear to be disingenuous and was perhaps inappropriate, as explained by a male attending: “I've heard other nurs-
es and other people kind of use very religious terms and when counseling or talking to somebody who has child has died to and to me it kind of felt like it was a little inappropri-ate at times like they sort of overstepped” (III:4). Some tried to examine the complexi-
ty of bringing religion into their EOL conversations: One participant called having a sim-
ilar faith perspective of patients and families a “mixed bag.”

It really is… It's good because to me I know [3 sec pause] I know the truth and I know the ultimate hope and I also know that medicine is a great tool for physical healing but medicine is not the end all be all for the ultimate healing that's needed for people's souls… And, when it's clear that those things aren't held to I struggle because it's…almost disingenuous in itself in a way. And again, not as a judgmental kind of thing at all, and it's hard because I really don't know these people (III:12).

This participant’s understanding of the wide spectrum of spiritual beliefs, even for two parties both identifying with the same faith perspective, led him to a feeling of frustration that was exaggerated by trying to connect on a spiritual level at a time of crisis. The situa-
tion is made worse when physicians are just meeting families, such as in the emergency room setting.

Several of the physicians in the RRR group described strategies they developed for determining whether or not they should engage in religious language in their commu-
ication. And, once they heard certain triggers they feel comfortable infusing religious language into the interaction. For example, a male attending stated,

I think it's easier when…your beliefs are aligned with the ones of the patient…I try to stay as generic as I can with religion and I get more specific if I hear them talk and align my words to whatever they talk about. So, if they don't talk about religion, I try not to talk about religion. If they talk about religion, I may allow myself to be a little more religious with them (III:9).

One fellow explained how she integrated her own faith into her communication with fam-
ilies, “Yeah. I do. Especially if I get any clues from the family that they are Christian, I am not afraid to share scripture, talk about prayer …” (III:2). These physicians integrated
their faith into their EOL conversations and to do so seemed like a natural part of their practice.

Although the physicians expressed toleration for families with different religious beliefs, some in the RRR group implied that a family having non-concordant religious beliefs did not preclude them from bringing their own faith into EOL conversations. For example, one of the attendings in the RRR group said that he might bring in his Christian faith, even if the family was of a different faith background, “If people seem to have a common faith background then we can have those conversations. Less commonly if they seem to have a different faith background, I also will talk about Christ” (III:12). Another attending in RRR group seemed to question his hesitancy to bring his faith into EOL discussions with families of non-concordant faiths, “But, if I get a sense that they don't have a [unintelligible] for God or they say no to a chaplain, no we don't go to church, we don't believe in God, then I don't talk to them about God. Maybe I should. I feel like I should. But, I generally reserve, you know, I generally pull back and I don't” (III:1). Finally, another fellow in the RRR category expressed her belief in conversion in her conversations in the PICU, “I am not trying to convert the entire patient population that comes, although I do believe in the urgency of eternity…” (II:2). These attending physicians in the RRR category all openly stated a tolerance for the differing beliefs of their patients and families, but their deeply held beliefs about conversion and salvation may be affecting the way that they approach EOL conversations with families as their responses indicated that they could be imposing their faith on those who have different beliefs.
Nurturing families’ spirituality. Virtually all participants felt that religious beliefs could be beneficial to families coping with the horrific experience of having a terminally ill child. Therefore, participants felt it was their role to nurture the family’s spirituality, which could be done through their own EOL conversations with families or through connecting families with chaplain services. One physician in the LRR group was influenced by his experience working on an Indian reservation. In seeing the meaning of the medicine men to his patient population, how his patients often stopped to see them on the way to the emergency room and how the hospitals on the reservation had a room for the medicine men, he realized that even though he was not religious himself, nurturing spirituality in his patients and families was valuable.

This idea was echoed by another physician who described himself as “cynical” in terms of religion. “Because I think if somebody is really, really spiritual, it’s important not to lose that spirituality in a moment of weakness and if God is the source of strength for the family…so they don’t start doubting their own spirituality at the moment when they need it the most probably” (II:9). He went on in the next interview to state, “You can help them. Guide their spirituality toward like understanding there's a likelihood of death here but we can stay hopeful with prayer” (III:9).

Physicians who did not feel that they could connect with families on a spiritual level offered chaplain services. One attending explained, “For some of my colleagues who are …what I consider to be a little bit of a hyper-religious type, I don't know kind of how they handle that. I think they do defer to God in their conversations. And I just tend not to but I do offer them those services because I feel like it's absolutely what they need” (III:8). Likewise, another commented, “I know that we have a chaplain here that is fan-
tastic that I'm always happy to get the chaplains involved. Not because they're of my specific belief system but because they are there to offer support” (III:13).

Although one of the RRR attendings explained that if a family appears to not be religious she would not use religious language.

However, she may call in a chaplain to be with them, “I try to be respectful and sometimes when there’s a difficult situation…I would not sit down with a family who has expressed that they are atheist…I would not push anything on them, and create a point of tension between us, although I’ve had those patients before that our chaplains have spent time with and they’ve actually accepted prayer and stuff like that (II:2).

Although she clearly felt that she should not impose her beliefs on those who are not Christian, she also subtly indicated satisfaction that non-religious families had accepted prayer from the chaplains.

**Hope.** Upholding hope was seen by the participants universally as crucial to nurturing a family’s faith through the tragedy of watching their child die. This is not surprising given that hope, as throughout history, remains a significant concept in bioethics. But, as with many ethical concepts, hope can be both a virtue and vice. Providing too little hope on the part of the physician could lead to despair in families; however conveying too much hope could lead to unrealistic expectations and discourage parents from considering comfort measures over life-sustaining technology (Miller 2012). Physicians have difficulty reaching the golden mean of the appropriate amount of hope to be offered. Physicians have been found to use cautious optimism in EOL communication, meaning that they attempt to provide some hope even while simultaneously trying to deemphasize the chance of recovery (Clair 1990). Patients and surrogates tend to hear more optimism
than caution (Clair 1990), while physicians feel the information given was clear, patients and caregivers end up not clearly understanding the terminal prognosis.

Many of the physicians mentioned hope in the first round of interviews, so in the second round I explored this concept in more detail. In particular I asked if they felt that full disclosure of a patient’s illness might take hope away from a family and if so, if that affected their communication. Upholding hope was an important theme for all of the participants. They also tended to feel frustration about parents wanting to continue life-sustaining technology. Although discussed more in a later section, it may be that parents have latched on to the hopefulness inherent in conversations with their physicians while not hearing the more realistic information.

Many participants specifically mentioned that not taking hope away was critically important in EOL communication. Even those in the LRR group described hope with terms like “sacred”. One male attending in the LRR group stated its importance, “I’ve developed a philosophy at some point… that you never take away hope if there ever is truly any hope, no matter how small it is (II:21). A female attending, also in the LRR group agreed, stating that she never wanted to cause a family to give up hope, “because when you give up hope, you’ve taken away something sacred from someone. And that’s not ever really taught to you, but you learn it… It’s okay, even when you in your own mind feel zero hope, I think it’s okay to say, “Let’s take this one day at a time, and let’s see what happens” (II:8).

Most participants acknowledged that they have observed what they deemed “miracles”, in their work with kids at the EOL, when their patients survived and recovered against the grimmest of circumstances. Many admitted that observing these anomalies
influenced them to speak in less pessimistic terms and uphold hope in EOL conversations. For example, one highly religious fellow stated, “So that’s something all of us run into. Some kids make it, despite everything, so you can’t totally take hope away” (III:13). A female PEM attending in the LRR group explained her view of miracles and that they exist, “…we all know we're not God but we don't know everything and there are sometimes things on the cusp, developing techniques and procedures and treatments that maybe are out there and for some family members who don't feel comfortable letting their child die, maybe they're right (III:8).

However, although upholding hope was crucial, most felt strongly that hope had to be balanced with realism and that providing accurate, timely information was critical even if the news was negative. One male attending in the RRR category stated, “…I don't think that the ideas of hope or faith, anything interrelated, should preclude the exploration of data or the things that are reasonably well known scientifically” (III:12). Providing accurate information was seen as a moral imperative in many cases given the best interests standard. The physicians saw it as their responsibility to be truthful so parents could make the most appropriate EOL decisions for the child. For example, the participant mentioned above stated that, “giving people the facts that I know hopefully will again arm them with the ability to make decisions but I don’t worry about taking away their hope” (III:12). Another male attending in the RRR group stated, “I usually feel like my highest responsibility besides caring for the child, when I'm talking to the family, my highest responsibility is accuracy in what I tell them. Because they're in the difficult situation of kind of being the ultimate decision-maker” (III:14).
Physicians worried that too much hope could work negatively for families. One male PEM attending physician stated that, “I use the D word for death rather than ‘they might deteriorate’…And I use the C word for cancer rather than ‘We've got a little growth here’” (III:20). Further, participants expressed frustration at what they interpreted as patients’ families using religion as a crutch to stay in denial about their child’s grave terminal condition. Notably, it was physicians in the RRR category who seemed most concerned about families who were too hopeful based on their religious beliefs. For example, one male attending in the RRR category expressed, “I worry about some of the families…whose views of God won't let them acknowledge the possibility that the child might die…Every time I come in the room they will only say positive things or only want me to say positive things” (III:14). Here EOL communication is most certainly impeded by the parents’ religion. This was also expressed by one female PCC fellow who explained the frustration she feels: “They say if God wants to take them, God will take them no matter what you do. And the problem with that is when they want you to do everything, when honestly when you do everything you’re making the child suffer” (II:19). Further, one male attending in the LRR spoke in more cynical terms, “They want to have hope no matter what. Because that's all they have left. And, they want a miracle. I mean every time we resuscitate somebody it's a miracle that happened and I'm like, ‘Not really’” (III:7). He felt that families were too quick to believe that miracles occurred, when in reality sustaining a heartbeat was easy with medical technology, but the prospects for a productive life after resuscitation for children were grim.

Physicians in the RRR group discussed how they used language to help parents become more realistic about their hope while simultaneously working to sustain their
faith. For example, one attending described how he framed his discussions with families who were hoping for a miracle when the prognosis was bleak: “I don’t think you guys understand. I know your spirituality is very strong, but sometimes God doesn't give us the miracle we want. God sometimes gives us…something that we don't think we want but it's supposed to be what he thinks we need” (III:9). The same participant explained how he tried to sustain the family’s faith in the midst of unwelcomed news by using words such as, “‘I prayed for you and I understand God's plan is different from our own plan and provision’” (III:9).

Finally, a male attending in the low religiosity group explained that hope changes for families as they go through the journey of their child dying.

People's hope kind of changes, what they hope or wish for, kind of changes with the spectrum of their illness. So what they hope for at the beginning of an illness is not the same as what they hope for in the end. So, um, yeah I think as long as you tell them that we're going to do everything we can and I usually tell people that, your child is in exactly the right place they need to be because we have lots of people who know a lot about this and they'll do what they need to do. So probably provide realistic hope, you know (III:4).

The participants emphasized their role to nurture the appropriate amount of hope in families as a child progresses to the EOL, but as can be seen from the quote above (III:4), cautious optimism is present in his thoughts which may translate into his communication with patients.

Prayer. Physicians in the RRR said they prayed for their patients and participated with families in their prayers as a way to uphold hope. One male attending explained how he prayed as his patients were dying during resuscitation,

My residents and fellows are sort of doing hands on stuff and I'm just supervising all of it. I just sort of put my hand on their foot and then I'll just either keep my
eyes open or close my eyes and pray for them. I kind of feel like I'm ushering them into a different place and I feel that different place is heaven. And so yeah, it completely affects the way that I deal with this. And, I don't feel that I'm giving up… it's a disease process that's taking them and I'm unable to intervene in it with the medicine that I have available to me (III:1).

This participant was voicing his understanding of the limitations of medicine, and how he still continues to participate in patient care through supernatural means. Another attending in the LRR group says she participates in prayers for patients, “Even though it's not my personal belief… I think it comforts them to see me bow my head and listen to their prayer. And, I do and I take it into my heart for what it is; it’s a heartfelt hope for the best” (III:8). Several physicians tell families that they are praying for them and one female attending said then when asked by families what they could pray for, she would tell them, “…absolutely pray for us. Pray that our therapies work” (III:2). In EOL care, when physicians are reaching a limit of their power as clinicians, prayer and the hope for miracles become significant topics in communication. Physicians are taught to heal, and want desperately to heal these children who they care deeply about. And, if they cannot heal through medical knowledge and technology, some turn to supernatural means.

*Religion and physician emotional distress.* Besides playing a role in EOL communication, religiosity also may be influential in helping physicians deal with the grief they feel from interacting with dying children and their families. Participants said their faith helped them by feeling like they did all they could to help their patients, feeling certain that since their patients were children that once they died they would be in heaven, and by providing comfort in the midst of the pain they experienced because of their patients’ deaths.
As described above in the section on prayer, physicians in the RRR group prayed for wisdom and for their patients’ healing. By praying they felt that they were doing the best they could, which may ease their own suffering later. Further, two physicians in the RRR group explained that they believed in age of accountability and since their patients were children they were assured that once the child died he or she would be in heaven. This seemed to diminish the pain they felt for the dying child. A female fellow who became an attending during the course of the study claimed:

I believe in life after death. Specifically, I'm a Christian so I believe that Christ is sovereign over death and it might make it easier for me being in a pediatric ICU where there are children where if you believe in an age of accountability, then I, you know, I believe that there are children that die and are with Christ and there's no experience that is better than being in the presence of Christ (III:2).

Similarly, a male PCC fellow explained,

So, I realize that one, they’re probably in a lot better place. And, two, I remember that they’re not responsible for what they did. And most of our kids, haven’t been smoking, haven’t been drinking, they didn’t get themselves into anything, but it’s just something that happened to them. So when you focus on that, it’s a lot cleaner. I’m really just here to help them. I really don’t have to worry about what they did, or whether they got themselves into this (II:13).

These physicians seemed to be comforted by believing that child-patients who died were in heaven, an artifact of how deeply their religious beliefs were integrated into their work as physicians.

Finally, several participants in both the RRR and MRR groups relied on their faith to help them deal with the pain of children dying by bringing them comfort in the midst of the anguish they were feeling. Some described the support they felt from having a church group to rely on and others explained that their inner faith brought them personal comfort. For example, a male fellow suggested that his faith helped him continue to do the work of caring for children at the EOL, “Yeah… I think it helps me keep going”
(II:13). Others suggested it was their belief that God is in control that eased the suffering they experienced, as stated by one female PCC attending,

I use my religious beliefs to help me with a lot of that. To believe that God is in control. That we are in a fallen world and that these horrible things happen and there’s a bunch of horrible things that I don’t even know about…. But to say that God is sovereign and the children who die are definitely not missing out (II:2).

One female fellow explained that her belief that all things had a reason behind them helped her, “So I’ll end up talking with my mom about it or somebody and say this happened today. And they’ll say, ‘Oh, that’s just so sad.’ And it is, I said but in the end there’s reasons for everything...” (III:19). Finally, one female PEM fellow in the MRR anticipated that becoming more involved in her religion would help her deal with the pain of having patients die: “I’ve always been, my parents have been very religious. But, I do think that…I’m going to probably start going to church a lot more frequently with my family and I think that will probably help me deal with some of the harder situations” (III:11).

Early Experience with Death

When asked in the opening of the Phase II interviews how their personal stories contributed to their interactions with dying children and their families, parental status and religious beliefs were the most frequently mentioned influences. Other factors such as family of origin, experience in the military, and hobbies were mentioned but not frequently. However, one other influence, experiencing the death or disability of a loved one at a young age, emerged as a significant influence. Even though it was only mentioned by 4 of the 17 participants, its potential for shaping these physicians’ approaches to EOL
physician-parent communication is great and it serves as an illustration of the power of narrative in forming one’s medical practice.

In this section I will use two cases studies as examples of the potential that the early experience of the death and/or disability of a loved one has to shape practice. What is interesting is that these two participants are different in every other narrative characteristic we have explored, except for having an early experience with death or disability. One is a male PCC fellow who is a parent and in the MRR religion group and the other is a female PEM attending who is not a parent and in the LRR religion group. It is notable that these particular participants are two of the three (out of 21) who did not ultimately intubate the patient in the Phase I simulation. In both cases, tragic situations in their early personal lives led these participants to deal with the reality of death and delve into personal growth, which ultimately influenced their EOL interactions with parents.

Case 1. The first case we will examine is of a male PCC fellow, who became an attending during the course of this study. When asked at the opening of his Phase II interview, a week before completing his fellowship, what influences shaped his ability to deal with children at the EOL, his first words were, “The biggest thing is that I unfortunately had to deal with death in my adolescent years. My dad died when I was 13. All my grandparents were already dead by that point. And, I just had a lot of friends and stuff that died, but my dad was the biggest one” (II:17). After the death of his father, he explained how he felt anger and hatred towards others but as he emerged from the initial shock and grief he began a journey of discovering how death affected his life. Since then he has been through many periods of trying to understand how his father’s death affected
him, during which he consulted numerous books and supportive individuals. For example, after years of reflecting on harmful words spoken to him after his father died, he read one particular book that outlined things not to say to people after they experienced death. He feels this information combined with his own experiences has helped in the EOL interactions he faces with parents in his practice.

Given that he was one of three participants who did not make the decision to intubate the simulated patient in Phase I, perhaps his experience did play a role. When asked why he did not intubate, he explained that the actor-mother seemed tired and, “With everything that has happened in the last 4 months, she seemed ready to let go, but she needed someone to say ‘It’s OK’” (I:17). Whereas many of the other participants were afraid of offending the mother since she indicated that she had not had an EOL conversation with a health care provider previously, he did not worry about that. He went on to say, “You could just tell that from her personality. Other ones would be more defiant… ‘I want everything done’, and there’s not even a discussion really. She seemed more, ‘I need someone to help me with the decision; I can’t make it on my own.’ And she was on her own” (I:17).

In contrast to other participants who seemed to defer to parents on EOL decisions almost as a way to wash their hands of them, as will be discussed later, he pointed out that no parent wants to say, “‘Let’s kill my child. I’m ready. Let’s do it. It’s my decision.’ So it has to be you” (I:17). He confidently offered his advice to the actor-mother in the simulation:

I think if it was my child and again I have not spent any time with her at all, that if I felt that I had had a great quality of life with her, I’d be very happy with my daughter, I love her very much and I’d just take this time and see what happens right now and not do the breathing tube and the long ICU stay (S:17).
He was also the only participant in Phase IB to clearly explain to the actor-mother what he meant by comfort measures, “She will be comfortable and we have an IV in her so we can always give her a little bit of sedation to make sure with this happening, with her CO2 going up is a very peaceful way to pass away. It is the way that your body naturally does it itself” (S:17). He did not push his recommendations and clearly asked if she needed to consult with family members, her regular physicians or other support staff, such as chaplains. He further discussed the importance of relying on where families are in their process of grieving and realizing sometimes there was no choice but to intubate an EOL patient.

When asked what he would do if he had a child in the situation that was represented in the simulation, he said that he would do what he advised the actor mother, “…I would bring everybody home …I like hospice, so I like everyone at home with family and friends. It’s a bias I have” (I:17). Because, as he later said in his Phase II interview, “You can stave it off if you want to. It may be personal opinion, but death is not always the worse thing. And it might be stand back from everybody dying and you learn that it’s not that bad. It’s worse for us. Cause we’re here” (II:17). For him, quality of life is more important that avoiding death and he unequivocally demonstrated that through his experience in the simulation.

Case 2. The second case, that of a female PEM attending, is one where the participant also valued quality of life over absolute existence. She did not wait until her Phase II interview to share her personal story, but freely offered what she saw as a significant
narrative influence on her approach to EOL communication in the simulation debriefing interview,

But I tell you that I have a profoundly retarded sister and I’m the legal guardian, and I had both parents die before I finished medical school, so I had some personal life experiences that maybe made me a little bit more in tune with death and dying with a family member and watch someone slowly dying and watch someone rapidly dying (I:8).

She later explained that although her father lived until she was in her 20s, she was aware of his life limiting condition since as early as she can remember, and he was able to talk about the fact he was dying. Her mother also died when she was a young adult and the participant took a leave from medical school to care for her toward the end of her life. Her experiences amassed during her parents’ dying processes, along with the additional life-long experience of having a special needs sister, almost certainly influences the way she interacts in EOL communication with parents.

Unfortunately, the participant took part in the study before we added the recording of the simulations, so no transcript is available of the actual experience. However, we know from her post-simulation interview that she decided not to intubate. She explained her decision,

If you look at her CO2 it was horrendous …I felt that we had time to make decisions that we could incorporate. Get to know the family and parent a little bit better. I felt like she has an end-stage disease and the need to be tremendously aggressive may or may not be there…sometimes in the middle of the night I might go ahead and intubate but I thought …83 and getting worse (I:8).

She, as the Case 1 participant above, described using her intuition to assess the actor-mothers’ state,

Most parents are more intense and more frightened than you [the actor-mother] were but she made it easier for me. I think I make an effort when I’m seeing EOL patients to present some options going from least to more aggressive. And in fact, I
try to explain to them that...this may be a temporary measure and you may be faced with a more difficult decision down the road (I:8).

She claimed that her views surrounding quality of life had much to do with growing up with her sister and experiencing the deaths of her parents, and these experiences made her better able to accept death and view it as not the worse outcome. She described her sister, “...who is profoundly retarded, and quality of life for her, although she has no physical ailments, her quality of life in my opinion is very impoverished” (II:8).

Her experience with her sister influenced her specialty choice. When she was being heavily recruited into the specialty of neonatology, she had to explain to the director of the program that, “I did not feel like I wanted to contribute to creating more children surviving with significant special needs that impacted on their family to a huge degree” (II:8).

As in Case 1, this participant put considerable effort into trying to understand the grieving process. She, like him, discussed Kubler-Ross’s stages of grief (the only two participants who mentioned that theory or any other theory about grief). She combed the literature for insight on how she could improve her interactions with families and was frustrated when she realized that EOL communication represented a research gap. She explained how she consulted her colleagues to solicit feedback on her EOL interactions with families. For example, she said she would, “go to the charge nurse and say, ‘What went wrong about that conversation and what did I do that I could do better?’ because they're a bystander and a lot of them were older than me” (III:8). She, like the participant in Case I, also discussed the importance of giving the family time to grieve, doing more aggressive treatments than she felt were appropriate given the patient’s EOL status, but
knowing that if the family has more time, and more interactions they will eventually come to the point of letting go of the life-sustaining technology.

Where this participant differed from Case 1 was that she described significant emotional distress over children’s deaths and moral distress from family members who insisted on life-sustaining care when she felt their child was suffering. This may be due to their differences in gender. She explained how it took sometimes extended time periods to get over a difficult case and that she carried some of them with her, and how she can remember every patient who died over an extended period of time. Although she is not a parent, she asserted that her experience with grief contributed to her empathy for parents, “And while I've never had a child and I've never had a child that died, I think there are some things that are universal about losing” (III:8). For example, from the experience of her mother dying, and believing her mother suffered at the end, she developed the practice of always telling parents that their child did not feel any pain as he or she died. She feels this is so important that she tells them this even if she is not sure it is true to save them additional angst. She also spends time talking to the parents about the grief process. She sees her mission as helping them to “begin their journey of grieving” (III:8).

From these case studies, and the quantitative and qualitative findings discussed above, physician narratives clearly may play a role in physicians’ EOL interactions with parents of dying children. As seen above EOL interactions are often about decision-making and as such they involve ethics. Often the ethics of physicians clash with the ethics of parents as each have very different perspectives. The next section will examine significant themes related to the ethics of pediatric EOL communication that emerged in this study.
Best Interests, Decision-Making, and the Aftermath:

The Ethics of Pediatric End-of-Life Communication

Poor communication, as discussed in Chapter 2 can be considered a breach of the moral obligation that physicians have to both patients and their parents in that poor communication may adversely affect the EOL decisions made by parents for the dying children. The best interests standard expects parents to make unbiased, objective decisions about their child’s care. But, is this possible? Parents’ emotions—guilt, fear, uncertainty, excruciating pain—coupled with the filial bond that exists between parent and child—surely clouds their reasonable judgment. Further, parents must understand their child’s case medically to make the best decision, and can we expect lay people to do this? But physicians are also biased. The biomedical principle of patient autonomy emerged as one way to protect patients from physician bias, and physician bias may be one reason for the importance of the best interests standard. But do parents really want to this protection in all cases, especially when they would be responsible for ending their child’s life?

So far the findings reported have suggested that physicians often feel ill-prepared to enter into EOL conversations with parents, and therefore communication with parents about their dying children may often be awkward or completely avoided. And, physician communication may be influenced by the physicians’ narrative characteristics. This section will examine physician-parent communication from an ethical perspective. What ethical dilemmas related to physician-parent EOL communication do physicians experience and how do they deal with the moral struggles they face as a result of taking care of dying children?
As discussed in Chapter 2, in the US parents have been given the decision-making capacity for their dying children. The best interests standard was established to uphold autonomy and means that the parents decide the best course of action for the child by weighing the benefits versus the risks (Beauchamp and Childress 2013). But, in order to appropriately evaluate benefits and risks, parents must have understandable, honest information. In this research, physicians claim that they have biased ideas about futility and quality of life issues. The question becomes, could physician biases shape their EOL communication with parents and limit parents’ ability to act in their child’s best interests?

For the most part, physicians respected the best interests standard, believing that parents were in the best position to make EOL decisions for their children. One attending summed up the general feeling of the participants well, “So, I think the way the system works in pediatrics is that we all agree, that parents aren’t perfectly positioned, but they’re in the best position to make those decisions” (II:14). One attending PEM attending commented that he did not feel torn between the child and parents’ best interests because parents, “… almost always have the best interest of the child and the family’s best interest at heart. So I respect their wishes” (II:4). It is interesting how “the family’s” best interests are woven into his response as well.

Participants see their role as caring for their child patient as well as the child’s family and in many cases the participants’ words indicated ambiguity as to whose best interests were at stake, the parents or the child’s. For example, one physician explained how he talked to parents about making decisions, “You just have to do what you think is
best for you and what you think is best in the interest of the child” (I:18). What is best for the parents was given as the first criteria. This may be because physicians not only view the parents as patients, but in some cases may give precedence to parents’ well-being over what’s best for the child-patient. Further, often quality of life was viewed from the family’s, not the child’s perspective. One PCC fellow suggested that she counseled parents of EOL patients to continue with life-sustaining measures as such, “If this child gives you quality of life then your quality of life is improved by that then why not go ahead go through that portion of things” (I:19). It is interesting how the decision to use life-sustaining treatment is based on the parents’ quality of life, not the child’s.

In pediatrics, unlike other medical specialties, training is focused on treating the family unit and it begins as soon as the patient presents for care. Families have to provide medical information in the place of infants and small children and so the physician-parent relationship becomes a key therapeutic relationship. In general, outcomes are seen in terms of the family as well, not just the patient. Part of taking care of parents was seen as honoring their wishes as the party responsible for making EOL decisions for their child. The literature indicates that parents often have difficulty making EOL decisions on their child’s behalf, based on the best interests standard, and the participants confirmed that. Choosing to limit care is a decision that parents feel is akin to killing their child. They therefore push for “everything” to be done. However, for children at the EOL, the most appropriate care is often comfort measures. This way, the child’s pain can be minimized and quality of life maximized during the remaining life. When life-sustaining measures are chosen by parents, the child may not experience the highest quality of life possible and could be left to endure painful and/or uncomfortable treatments.
Several physicians discussed the concern that painful or uncomfortable, yet futile treatments, were done to kids at the EOL at parents’ requests. Others however, affirmed that they felt like they could usually be reasonably certain that the child was not suffering thanks to the medications they had at their hands. For example, one PCC attending stated, “In the setting where I work I can usually ensure that the child isn’t suffering in the way that we usually mean by suffering…But basically every patient I take care of in the cardiac ICU is a little baby who has to go through a decent amount of suffering to survive” (II:14). Best interests of the child-patients could potentially be compromised when parents can’t make up their mind, when parents needed time to deal with their grief, and when parents are simply putting their own desires ahead of the child. Physician-parent communication plays a role in each of these areas.

The participants in this study agreed that sometimes the best interests of the patient were compromised when parents cannot come to a decision. For example, one female PEM attending stated, “I’ve had some parents that have said “I can’t make up my mind, I can’t make up my mind and we do what we can medically aggressive whether that’s in the child’s best interest or not.” (I:15). And, similarly, a male, PCC attending stated, “If they can’t make that decision …I just provide what they’re asking me to provide, up until you reach that point when you can’t continue things or you can push any further” (II:18). It seems that effective physician-parent communication could potentially help parents in the EOL decision-making they are doing on behalf of their child.

Related to the discussion earlier in this chapter on the importance of giving parents time, several physicians talked about potentially compromising the best interests of child to give parents time, and in most cases physicians understood that parents needed
time to make EOL decisions that would involve limiting care to their children. For example, one male fellow suggested that, “So sometimes you do have to do what they want to do and just know that to give them more time they’ll come around and say, ‘This is probably not what my child would want done to them’” (II:17). Another PCC fellow stated, “I think especially at first, when the parents first find out that they have a really sick child, it takes them sometimes a long time to get to the point where they realize, ‘I’m doing this for me and not for my child’” (II:13). A PEM attending conveyed a similar sentiment, even acknowledging that a child may be suffering, stating, “And, so I realize that a parent may want me to continue to resuscitate their child when I don’t feel like there’s long term hope for this child and the child may actually be suffering, but I also know perhaps if I can get the child to the ICU then perhaps with time the parents can make better decisions” (II:10).

Whether they agreed with the parents’ decisions or not, all physicians affirmed that they honored their legal ability to make the decision and followed through with their wishes. Some physicians felt conflicted about the duality between the parents’ and the child’s best interests; others felt no conflict existed between the two because they fully trusted the parents to make those EOL decisions. And, physicians seemed to have two approaches to parents whom they felt were not making decisions in their child’s best interests. They either felt anger and frustration over their own inability to provide what they felt was optimal care to their patients or they stood firmly behind the best interests standard believing it was not their place to judge the parents’ intentions.

Frustration ensued from physicians feeling like parents were ignoring the child’s best interests in a selfish way as expressed by a female PCC fellow, “You know that’s
frustrating because you’re like, “What are you doing to this child. You’re keeping this child alive for yourselves” (II:19). A male PEM attending expressed a similar thought,

…but there are also many, many times when it is very clear to everyone, at least on the medical side, what's going to happen. And it's those cases when the physicians really need to make the decision and it's, it's difficult to know how, you want to involve a parent in the decision making, um, but when … From your perspective it's against the child's best interest… that's a dilemma that is created that is difficult for us to figure out what's the right thing to do (II:7).

This physician is expressing the concept of moral distress, when internal or external obstacles keep providers from doing what they feel is ethically correct.

Although some physicians expressed frustration over the best interests standard, others relied on it to help them in their practice of medicine. One male PCC attending claimed the parents were the in the best position to make decisions for their child, and “I console myself in that and that way I can do my work” (II:14). Another stated that, “As they take care of this kid, they’re responsible for this kid, they live with this kid. If they’re satisfied with things, who am I to say that it’s not in the child’s best interests or the family’s best interests. That’s not my call” (II:18). He went on to say, “So, if that means… that you’re going to end up with a kid that’s only going to lay in bed… and be non-interactive for the rest of his life, that’s fine with me if that’s what you want” (II:18). By punting the decision to the parents, these physicians did not struggle ethically with the decisions the parents made even if they were against their medical judgment. To do this, they talked of divorcing themselves from thinking about quality of life issues.

Quality of Life: Differing Perspectives

Perhaps, as pointed out by a PCC fellow, a benefit of the best interests standard was that it was important to keep physicians, who hold biases, from imposing their will
on patients as stated by a PCC fellow, “I think that in some cases it’s good, because that stops us from imposing our will on the questionable cases” (III:13). Physicians discussed the dichotomy that existed between themselves and parents on beliefs about quality of life. A preeminent question for this study is how do physician biases related to quality of life influence their EOL communication with parents? This study cannot answer that question, but through the data presented here we can see that biases do exist and we can speculate that this may effect EOL interactions with parents.

Because of training that is dominated by examining clinical signs and symptoms in scientific, objective ways, physicians “don’t see the potential for things to happen outside of our scientific understanding …” (II:12). Further, because of their clinical experiences watching the difficulties experienced by patients and their families at the EOL, they see prolonging what, from their perspective, is a low quality existence, as futility. A male PEM attending summed this idea well, “And, so I think sometimes we’re too quick to say there is minimal interaction with the outside world and so…even though I don’t think we would profess that we’re making a logical jump, we’re saying the life is worth less...And, I think a lot of people would be afraid to say that that’s what they’re saying… I think it’s in our subconscious a little bit” (II:12).

Since PCC and PEM physicians often see patients when they are at their sickest, they may not relate to the patient as a child. For example, a male PCC attending explained this, “…a lot of times the child has been through so much and in a way by the time they get to me, intubated with lines, sedated, a lot of times that's the first time I've seen the child, they're sort of dehumanized” (III:9). Whereas, according to a female PCC fellow, parents are, “looking at that child that they knew and then an hour before and then
2 weeks before and not looking at the child that they're going to have 10 years from then” (II:19). One female PEM attending described how she considered neonatology, but because she saw them as “creating children who were not too dissimilar from my own sister [who is mentally challenged] in that they often had tracheotomy tubes and gastrostomy tubes, and they didn’t eat, and they couldn’t speak, and they sat in a wheelchair and went to special ed class and sat there like zoned-out creatures all day long” (II:8), she chose PEM. Physicians find it difficult to understand the perspectives of parents who have chronically ill children. A male PEM attending, who had seen cases throughout his several years of practice stated, “I really don’t know how people do what they do, taking care of these kids. I don’t know how they survive doing it” (II:7).

In the post-simulation debriefing interview of Phase I of this study, the question of “What would you do if it was your kid?” was posed to the participants. Several qualified their answers by saying that they could not give an unbiased response. They admitted that their work had jaded them and they had a very different perspective from the child’s parents who see him or her every day at home. Of course, whether or not to intubate their child would depend on where the child was in his or her disease process and how the participant viewed their quality of life. Five of the simulation participants (all parents except one) suggested that if the child had any amount of quality in her life, since her present condition (pneumonia) was treatable, then they would intubate to provide them a bit more time. The majority of participants, almost twice as many as said they would intubate and a mix between parents and nonparents, said they would not have intubated if it were their own child given the diagnosis of a progressive neuromuscular degenerative disease. One female non-parent PEM attending stated, “I probably…would
have let my child die early in the course of their illness from natural causes” (I:15). A PEM attending parent said he would not “want an intervention done that interfered with what otherwise would have been a natural terminal event” (I:21). Another male PCC fellow who was a parent suggested that he would bring the child home and utilize hospice services. Of these, all except three ultimately intubated the patient in the simulation indicating that they did something different than what they believed to be the best course of action for their own family given what they knew about this case.

Participants for the most part believed that although they wanted to provide their patients the best quality of life that they could, they were in no position to judge quality of life issues. Responses did not seem to vary based on gender, parental status, specialty or rank. However, responses about quality of life issues varied in some ways by religiosity as examined in this study on the basis of the richness of the religious language used.

Several of those in the RRR group seemed to approach the determination of quality of life with humility. They expressed the feeling that the parents may see something different than they as a practitioner observe when the child is hospitalized. For example, a PCC male fellow stated, “And that’s really mom’s job. Because I’m not around her. Mom’s around” (I:13). Another female PCC attending stated that a patient’s life may seem of low quality to her, but she does not see its determination as her role. “And, one would be prolonging care for a child that you don't really see the quality of life. And the way that I deal with it is that I try to divorce myself from determining quality of life, which can be very difficult….You know what I mean? Like I don't get to decide what the quality of life is” (III:2). One male PEM attending expressed his belief that quality of life is not something that he could determine, “There may be some kind of immeasurable ex-
perience that has value to that child even though they may not be able to be cognitively aware of that if that makes sense, just like an 8 month-old enjoys shaking a rattle” (II:12).

Interestingly, those in the group that claimed the least religiosity spoke the most about death not being the greatest evil. For them, “quality of life is much more important to me than absolute existence” (II:18) as one male PCC attending stated. A male PEM attending expressed his concern about trying to preserve life at all costs, when quality of life is low, “Total vegetative existence to me is not worth living. Other people disagree with that. Any life is precious, etcetera, and while I understand that I see it destroying families” (II:7). To him and others in the LRR category, they were worried about the harms of preserving a low quality existence at the expense of the family. These physicians elevated quality of life for not only the patient but the family as their primary goal in EOL care. How this bias of quality over quantity of life plays out was alluded to by participants.

Most participants mentioned the idea of seeing preventing suffering as a more significant goal than prolonging life with futile treatments. One PEM fellow explained her preference for preventing suffering, “… but I probably lean more towards preventing the suffering because I feel like sometimes, I mean we just had a drowning case the other day. They restarted her heart but that was it. She just had a heartbeat. So, I don’t know, I feel like I’m more… I would love to save a life, but if it’s going to be a really poor outcome and the child is going to be paying for us bringing them back to life, I feel like letting them die is better” (II:11).

The participants acknowledged that they only see patients when they are at the sickest. They cannot determine what the patient’s quality of life is away from the hospi-
tal nor can they judge how the child is imbedded within the family dynamics. As stated by a male PCC attending, “So, a lot of times…it’s hard because we’re taking care of a child and you know you wish you say, if I was this child I would like my parents to stop. This is crazy. But the parents want to continue either because they believe a miracle is possible or because they know the quality of life of the child at home when they’re good is better. And, I have not seen that” (II:9). But the same participant went on to say that it was still the physician’s duty, “It doesn’t matter what you think. Now, it is our job sometimes to tell them that maybe and just maybe what’s going to happen after this critical illness will no longer be worth living and that’s when we make prognosis and we talk to families” (II:9). However, participants were also concerned that parents had a difficult time seeing the long term results of life-sustaining care. “And, there's really not much you can do about it. The family, the parents want that, that's what they want. But, they don't see what their life is going to be like when they go home” (III:19). Although physicians maintained that they were biased in their perceptions, they claimed that they did their best to not let it interfere with their communication with parents.

**Futility**

Related to quality of life determinations are beliefs about futility. Many participants reported feeling negative emotions such as frustration or annoyance when parents prolonged treatment in their dying children and insisted on therapies that physicians deemed futile or even harmful to their patients. However, despite negative feelings, most felt that it was indeed the parents’ prerogative to make these calls about their child. One physician made the distinction between futile treatments and futile cases, “So, I always
tell, remind myself, and tell my fellows that we can only judge the futility of medical care, we cannot judge the futility of a life. If the parents tell you that this patient’s life is worth living, then you go with that” (II:9). Although futile and in their opinion, not in the best interests of the child, some of the physicians were not distressed by life-sustaining medical care as they felt that it was the parent’s decision. “The futility portion is deferential as the patient is. Would you subject somebody to this? No, maybe not, but it’s not my call” (II:18).

More than half of the participants discussed the fact that even if treatments were futile for their EOL patients, they were acceptable if it was helpful for the parents. Many of those discussed cases where the child had been kept alive for the parents’ benefit. One female attending admitted, “And, I have done more aggressive things than I would have thought might have been in the patient’s best interest knowing that it is going to take the family time and multiple interactions with probably multiple doctors or doctors that know them better…” (I:8). She mentioned the necessity of multiple EOL conversations with the family in order to help them fully comprehend that their child is dying and that life-sustaining measures are counterproductive. However, if hope is infused in this discussion, the parents may not hear the more negative news, as mentioned earlier, and push for maximum life-sustaining technology. Another attending highlighted the fact that sometimes it may be most appropriate to let the child die a natural death instead of discussing the idea of withdrawing care with parents,

…but it’s better to just be patient and wait for the child to actually progress to brain death instead of going and asking the family to withdraw. Because it’s way easier for the family to live the rest of their life with the child died then potentially having the mixed feeling of, ‘I was the one who told the doctors to stop.’…If they’re not in the right place they might not take it as a loving decision (II:9).
Undoubtedly, the best interests standard that puts the decision making capacity squarely in the hands of the parents may have an unintended consequence of children at the EOL not getting the most appropriate care because of parents’ views that limiting technology would be in effect killing their child (Levy 2001). The difficulty of discussing ceasing life-sustaining treatments and difficulties families face in making EOL decisions is highlighted here.

*Ethically Challenging Decisions*

Parental decision making in EOL issues is ultimately linked to the interactions they have with their child’s physicians. Even though parents ultimately make EOL decisions on behalf of the child, these decisions may be altered by the tone and information-giving provided in EOL conversations with physicians. In the section on physician religion earlier in this chapter, findings were presented to indicate that communication could potentially be altered by a physician who was hesitant to withdraw treatment based on religious beliefs. This finding is consistent with quantitative research that indicates that more than half of physicians say their religious beliefs influence their medical practice (Catlin et al. 2008; Curlin et al. 2005; Ecklund et al. 2007), particularly in controversial areas such as the withholding and withdrawing of treatment (Seale 2010; Wenger and Carmel 2004). Substantive differences were not found in responses based on gender, parental status, specialty or rank. However, participants reported that experience moderates the effect of religion on EOL decision-making.
The Aftermath

Moral Distress

Although most physicians felt that EOL decisions were the families’ decisions, the physicians also described experiencing moral distress in EOL cases, especially when they felt they were forced to put the parents’ prerogatives over the child-patients’ best interests. Moral distress, the inability to do what one considers morally correct due to external or internal obstacles (Jameton 1993; Jameton 1984) was described by several participants and their responses varied by religiosity. Moral distress ensued from observing other physicians withdrawing life-sustaining care too soon, from parents prolonging care against what these physicians thought were the child best interests, and issues surrounding resuscitation and organ donation. It cannot be determined in this study the extent to which moral distress may influence physician-parent EOL communication, but understanding the significance of moral distress will hopefully lead to studies that can examine its role.

Withdrawing care too soon. Two physicians, mentioned the difficulties they had in observing EOL decisions as trainees in children born with anomalies. When asked whether or not he experienced moral distress, one male PEM attending in the MRR group stated,

Yeah. I think so… “I kind of grew up at the end of the era where certain diagnoses had a self-fulfilling prophecy of being terminal. So Down's Syndrome was probably an example and I saw um some of my teachers basically say that Down's Syndrome is incompatible with life and we are not going to do anything about this child's Down's Syndrome's birth defects... And I never personally believed that...I basically told people that there's people who believe differently about this and you would be better served to get a second opinion elsewhere (III:20)
The other participant, a female PCC fellow in the RRR category described a case of an infant that was not genetically normal, and her attending made the decision to extubate the patient when his mother was not in the unit. The baby died and she stated that, “… I struggled with the perception that …if he’s genetically abnormal then we’re not going to try too hard” (II:2).

_Prolonging care/overtreatment._ Contrary to the above cases, most moral distress ensued from parents who wanted to continue life-sustaining care against what these physicians felt was in the best interests of their children. Although they may feel stressed about parental decisions regarding EOL care for their child, physicians almost always did what the parents wanted.

Many of those in the low religiosity category described moral distress when it came to prolonging life in EOL patients. Interestingly none of those in the highly religious category described this level of moral distress at prolonging presumed futile treatments and three of the moderately religious physicians did. One male attending, in the LRR group, expressed the idea of moral distress well,

> I don't know if there's a way to deal with it when there is no option for me as a physician. I just have to go through the motions and do what the parent wishes….But there's many times when it's not that clear and we see patients every day, and…that the child is absolutely vegetative, there's no level of interaction whatsoever, and we're keeping them alive for 10-15 years... (III:7).

This same participant in an earlier interview expressed his concern that the issue of overtreatment was not addressed more in pediatrics, “How do you make them comfortable through that versus put them through hell, more hell, you know? I don’t pretend to have to answers to that, but it’s a question we should be asking and no one is (II:7).
female attending in the LRR category expressed moral distress about following through with the parents’ wishes against her better judgment,

But there have been times when children with terminal diseases have come in, whose family members have a different idea about what medical care should be administered than I do, and I do what they ask, but I get quite upset by it. And it flavors my month. Like, it’s not something that I easily shed and get rid of… So I think I carry it with me maybe longer while I kind of slowly process it, and try to understand what their thoughts are, although really all I see is that the child is suffering (II:8).

Likewise, a female RRR group was frustrated when families used their faith to demand life-sustaining treatments,

They always say that. They say if God wants to take them, God will take them no matter what you do. And, the problem with that is when they want you to do everything, when honestly when you do everything you’re making the child suffer, and you’re thinking OK, do everything and God will take them anyway, but we’ve done all this stuff and made this child suffer for God to do what he was going to do in the first place. But, in a critical way, you say we weren’t able to make that decision for your child because you were selfish (II:19).

The word “selfish” suggests this participant’s frustration with parents who could not limit life-sustaining technology in their child who was suffering.

Some of the physicians expressed frustration at the cost of treatments they deemed futile. One male attending stated, “And, the child is vegetative and we have resuscitated him from death 6 or 7 times now. And that's an example of when I react that this makes no sense. Not only putting the child through that, but the cost associated with that care is phenomenal… (III:7). Another female attending in the moderate religiosity group stated, although she always follows parents’ wishes, “I do have a lot of conversations about really the waste of resources like this is really not worth it to go down this road, this predictable road, leading a child to long intensive care unit stay of someone who is clearly not having a high quality of life. I do feel conflicted. (II:16).
Two physicians said they did not experience moral distress when parents were asking for life-sustaining care that they deemed inappropriate because they believed parents were in the place to make the best decisions for their child. For example, one PCC attending in the LRR group stated, “And if they decide something that's contrary... you know is something that I think is not something that I would do, well that's fine. I can live with that. They're the ones who are ultimately going to have to live with whatever happens or doesn't happen…” (III:18). And he went on to say that he would respect their wishes up to the point that medically there were no decisions to be made. Another male PCC attending, this one in the RRR category described that he rarely felt moral distress because he felt the parents should be able to make EOL decisions, “I don’t have to have perfect knowledge and so I think somehow this idea, well I’ll speak about it religiously. God gave this child to this family. If he had wanted me to make all the decisions for everything about them, he would have given them to me” (II:14).

Resuscitation. The PEM physicians, no matter what their gender and level of experience, spoke at length about the ethics related to resuscitations and the moral distress that emerged from the associated ambiguities. Unlike the other themes related to EOL ethical decision-making and moral distress, no differences emerged based on religiosity related to resuscitation. PEM physicians described cases where it was very difficult for them to stop resuscitation, even though they knew continuing was futile. These were cases where they related to the patients or the families on a personal level or where the situation was sudden and traumatic. Unlike in adults, the outcome of resuscitation is “dismal” (II:21) in pediatric full arrest and the chance of an intact survivability is small.
A male PEM attending stated, “And, the more I saw sick kids and resuscitated kids and pronounced kids dead, the more I realized that most of the kids who come that need resuscitation are already dead” (II:7). If resuscitation is successful, the child is likely to have suffered neurological damage. And, the longer the resuscitation takes to get a heartbeat, the more severe the damage is likely to be. The same PEM attending expressed his frustration, “If we resuscitate someone that is, that we didn’t know was a no code or we spent longer than we should have or for teaching purposes we let a resident do a procedure in part of the resuscitation and they ended up coming back unexpectedly….knowing full well that the child is going to die. And, um, they consume significant resources and some of those incur significant debt…” (II:7).

Although the prognosis is poor, resuscitations are continued for a variety of reasons, according to the participants. They may be continued so that the patient may be an organ donor or for training purposes. However, primarily, they are continued because the staff is waiting for the parents to arrive. Because the child often arrives in the PED in the ambulance before the parents, physicians feel that they need to continue resuscitation until the family arrives because, “the family needs to see that you’ve done and are doing everything. Because they will never forget this moment…and need to know that you did everything that you possibly could to save their child” (II:1). Physicians felt it was important for parents to witness the resuscitation and if that is too difficult, to at least give the parents a chance to say “good-bye” before the resuscitation is ceased.

The ethical question for the physician becomes, how long do I continue resuscitating? Several PEM physicians mentioned conventions that they had determined over their
time in practice in terms of number of rounds of CPR and doses of epinephrine. But dificulties ensued from parents.

…you don’t want to give up, because the mom is screaming at you, ‘Please, do everything, do everything! Don’t give up!’ And yet, you know, at 20 minutes, at 30 minutes, at 40 minutes out from the heart stopping that the outcome is very bad…You could potentially get a kid back and put a family through the life-long change because their child is now debilitated and requires 24-hour care…And nobody knows the right answer (II:1).

This participant described that when he continues resuscitation too long and does get a heartbeat back the family celebrates, yet the staff “feels sick to our stomachs” because of the prognosis of the child.

To attempt to resolve the ambiguities related to resuscitations, the idea of drawing wisdom from the community emerged. A female PEM attending stated that, “You need people that don’t feel comfortable pronouncing children dead, and you need people who do feel okay with it, and realize that we’re not in control of when the human body dies” (II:8). A male PEM attending summed up the feelings of the PEM participants saying, “…the ethics for me is making sure the whole team is comfortable with the decision.” (II:21). And, it is often through the consensus of the team that attendings decide when to cease the resuscitation.

Organ donation. Six of the participants mentioned distress over ethical issues surrounding organ donation. Three main subthemes emerged related to organ donation: communication with families about organ donation, whether or not it was ethical to keep a child alive only for the possibility of he or she becoming an organ donor, and the ambiguities related to procedure of donation after cardiac death (DCD). The difficulty of dis-
cussing organ donation with families can be seen in this extended response from a male PCC attending,

I had a family that, we had just pronounced the child and...the dad said, ‘I want her disconnected now.’ And, I told them, why don’t we just take some time? Let’s wait and be patient with this. And, he just out of the blue said, ‘So, what for, so you can harvest her organs?’ No, no, no, no. And, yes. She was a potential candidate and we need to think about it, but it’s...a difficult decision because you know that child is dead and there is nothing you can do for that child, but there is another child somewhere in the country who might benefit from the organ. But, at the same time you don’t want to insult the family or go against their wishes. But, you sort of have to bring it up. And, all the literature related to organ donation says that almost unequivocally, most families, after the donation feel very fulfilled by it. In a way the literature backs up the idea that it’s a good thing to try to convince them” (II:9).

The participant explained the distress he felt by knowing that organ donation can be a potentially healing decision for families, yet in the heat of the moment of death mentioning it by the physician can be insulting to families in shock.

Participants also felt moral distress about whether it was ethical to delay death in acute cases for the sole purpose of the patient potentially being an organ donor. For example, one attending summed up the ambiguities, “We sometimes have patients that we know have a fatal situation and everything is futile, but we may be able to delay it for a very short period of time. Should we delay it with the intention that we try to get an organ donor out of this? Try to have something good to come out of this? Or, is that, pushing the limits?” (II:20).

Two participants, both in the RRR group, were genuinely troubled by donation after cardiac death (DCD). In DCD an organ donor has suffered an irreversible brain injury, but does not meet formal brain death criteria. Moral distress ensued from the ambiguity surrounding the DCD procedure: the lack of guidelines related to the length of time after cardiac death before organs are removed, whether or not the patient can still feel
pain given that no anesthesia is given, and the fact that families may not have adequate time to mourn in the presence of the body before the body is whisked off to have the organs removed. The participants clearly desired more evidence-based guidelines for the DCD procedure, ethical guidance about organ donation in general, and more training in communication about organ donation. One attending stated,

I just kind of worry that one of my cases is going to be promoted for DCD, because I'm not sure how I'm going to feel about it. And you can argue either way. You can argue that it's immoral to have a patient pass away and have their organs not be available for someone else to survive. It's wrong. Or, you can argue that it's wrong to take organs from somebody who, the circumstances are a little sketchy under which they were taken (III:14).

And the issue of hurriedly taking the child away from grieving parents is difficult for others, “It feels like you're ripping the child out of mom's arms and they can't just sit there and grieve and hold their child” (III:2). With few evidence-based guidelines and ethical confusion these physicians felt uneasy about DCD.

_Dealing with moral distress._ By definition, moral distress ensues when health care providers cannot act in accordance with their moral beliefs because of either internal or external obstacles. Perhaps moral distress is par for the course in a culture where we value patient autonomy above all else. But, if moral distress is inherent in practice and results from the inability to do what one thinks is right, how can a physician deal with the distress so that he or she does not experience emotional exhaustion? Some participants could not think of a way to deal with it, such as the male PEM attending, “I don't know if there's a way to deal with it when there is no option for me as a physician. I just have to go through the motions and do what the parent wishes” (III:7). Most agreed that moral distress was just something one has to deal with as part of being a physician who treats
dying children. Some said that they divorce themselves from quality of life issues or “compartmentalize that off”. Others said that taking time away provided some benefit. A male PCC fellow claimed that he, “…put some distance between me and that. I mean cause you go home and sleep on it. Things are a little bit better the next day. The situation hasn't changed but you feel a little bit better when you have a little bit more distance I think” (III:13). And, as discussed in the section on preparing parents, often families eventually come around to the physicians’ viewpoint if given time. A few discussed seeking support from spouses and colleagues, but finding support from others may be more difficult with moral distress than with the emotional distress which will be discussed later. As a female PEM attending shared, “The majority of the time, this is something that no one wants to hear about, and you can’t easily talk about this kind of thing. So I think I carry it with me maybe longer while I kind of slowly process it, and try to understand what their thoughts are, although really all I see is that the child is suffering” (III:8).

In addition to evidence-based guidelines that might reduce ambiguities associated with resuscitation and organ donation, one wonders whether moral distress in general could be reduced if physicians understood better how their language, such as the unintended use of cautious optimism, could potentially lead to families’ refusing to limit care. Families have difficulty limiting life-sustaining measures because of their natural inclination to do everything to keep their child alive. This underlying feeling, coupled with cautious optimism (Clair 1990) on the part of the physician could conceivably limit the parents’ ability to reject life-sustaining measures, even if the child may be suffering. Physicians may be unknowingly contributing to families’ unwillingness to let their child
go. Perhaps training in EOL communication could lead to a decreased occurrence of
moral distress by helping them truly balance hope with information-giving in ways that
facilitated ensuring that parents were clear on their child’s prognosis and were not hold-
ing on to unrealistic hope. Finally, the simple act of having open, truthful conversations
with families may alleviate the distress physicians feel when they perceive ethical issues
that they cannot change (Ulrich, Hamric and Grady 2010). However, conversations
around difficult issues, such as the impending death of the child-patient are rarely simple.
The final section will explore the difficulties physicians have in communicating with par-
ents of dying children by examining awkward communication, reasons for avoiding EOL
communication, the disconnect between physician and parent perspectives, and how phy-
sicians have learned to communicate more effectively.

Physicians’ Pediatric EOL Communication: The Struggle for Strategies

Up to this point, the findings have focused in large part on individual characteris-
tics of physicians and how these influence EOL interactions with parents. However, all
participants share one primary characteristic—they are physicians and have been accul-
turated into their medical practice in significant ways that gives them a narrow perspec-
tive. A medical model born in modernity expects all players to be objective. Medical
training is almost 100% clinical and physicians are expected to be rational, dispassionate
providers of knowledge. Similarly, patients and families are supposed to be able to make
rational decisions; the best interests standard is one illustration of this. Further, evidence-
based medicine may take the art out of medicine and expect healing and dying to be a
rational process. Although physician biases come from many sources in their narrative
backgrounds, the participants seemed to agree: As physicians, because of what we’ve experienced and how we have been trained, we are biased.

*Awkward Communication: Simulation Findings*

The simulation portion of Phase I of this research provided a unique dimension: the ability to observe the participants engaged in EOL interactions. Each participant was given a simulated case of an 8 year-old patient in respiratory distress and had to interact with an actor-parent in determining the best course of treatment. Since the patient was unknown to the participant, he or she had to gather a significant amount of information from the mother, as well as clinical information from the simulation, in order to decide whether or not to implement life-sustaining technology even though the child was clearly nearing the end of her life. Interestingly, only three participants out of study made clear decisions not to intubate the simulation patient, even though the patient was nearing the EOL.

One of the ways physicians assess whether or not there have been previous decisions made with regards to withholding life-sustaining technology in dying patients is to ask whether or not the parents have had an EOL discussion with a health care provider in the past. In this way, they can probe the parents about what has been discussed previously and whether or not that would affect the decision to make at hand. Of the 13 participants from Phase IB, 5 did not ask the actor-parent whether she had had an EOL discussion previously with a health care provider that addressed limiting life-sustaining technology and 8 did ask if she had a prior discussion. Most of the participants initiated some form of an EOL discussion with the parent; only two did not address EOL issues.
However, the form of that discussion varied between participants, with some participants’ communication about EOL issues appearing awkward, closed, and arguably coercive. Perhaps most surprising is that even though the simulated pediatric patient was clearly at the end of her life, only 3 participants offered clear alternatives to life-sustaining care to the actor-mother, while 10 did not offer viable alternatives.

Although most, but not all, asked the actor-parent about the implementation of life-sustaining technology (intubation in this case) before they proceeded with the simulation, the words were often vague and confusing. Questions such as, can we “do everything to take care of her” (asked in similar ways by 6 participants) may be interpreted by parents that if they decide against life-sustaining technology, they are not adequately taking care of their child. For example, one attending physician inquired, “In other words, you want us to take care of her, as much as we need to, up to the maximum things we need to do for her?” (S:18). And, a female PEM attending physician likewise asked the actor-parent, “And if she gets sick like that again do you want us to go ahead and intubate her and do everything we can for her” (S:16). And, a male PCC attending physician also asked, “Uh, has she uh, can we do everything that we need to do to take care of her? Are there any limitations on what we can do to take care of her? (S:14)”. What parent would refuse a doctor “taking care” or his or her child?

Since palliative care is the most appropriate care for children at the EOL, and comfort measures are considered the optimal treatment in palliative care (American Academy of Pediatrics 2000; Jurkovich et al. 2000; Tan et al. 2006), it is interesting that only 3 of the 13 participants suggested alternative, comfort measures, and only one of those was clear in what he was offering. Two reasons likely exist for the lack of discus-
sion. First, this scenario was set up in the PED setting and the participant had no previous contact with the patient. Since the actor-parent indicated that she had not had a previous EOL discussion with a health care provider about limiting life-sustaining measures, the general feeling among participants in the post-simulation interviews was that it would be inappropriate for someone who had not had previous contact with the patient to instigate an EOL discussion with the parent. After a male PCC attending physician learned that the actor-parent had not talked to another health care provider in the past about limiting technology, he stated, “If you haven’t, I’m just going to go ahead and intubate her and not have a long discussion about it” (S:9). Second, the simulation progressed in such a way that the participant had to make a decision about intubation in a relatively short time. Therefore, several of the participants advised the parent that the best course of action was intubation as it would give them time to make EOL decisions about limiting treatment later. Three of the participants used the term “buy time” in their interaction with the actor-parent.

Analysis of the post-simulation interviews confirms that many of the physicians felt that they did not have adequate familiarity with the simulated patient’s case to begin discussing EOL issues and alternatives to life-sustaining technology with the actor mother, despite recognizing that the patient appeared to be nearing the end of life. For example, one PEM male attending respondent said, “It’s very difficult to be a new face making potentially life-changing decisions,” while a male PEM attending remarked, “…it’s difficult in the emergency room because you’re just seeing them in one instant in time and it’s pretty hard to find out where you are on that spectrum [of quality of life]” (I:20). However, it has been suggested in the literature that in some emergency situations physicians
should discuss a patient’s impending death with the patient and family and suggest that comfort measures may be the most appropriate form of care (Michelson and Steinhorn 2007; Schears 1999).

Physicians practice patient-centered communication when they elicit the patient’s perspective, seek to understand the unique situation of the patient and reach a shared understanding of the problem and treatment, helping the patient share power (Epstein 2005). In the case examined in this study, these principles can be extrapolated to the physician’s interaction with the patient’s parent (as opposed to the patient herself) because the parent is expected to act in the child’s best interests in making health care decisions for her. The actor-parent was trained to respond that she did not remember a previous EOL discussion with a health care provider, and when asked about her wishes she only asked for the participant physician’s opinion. The actor-parent never said outright that she preferred intubation. But, if the physician suggested that as the best option she was trained to agree.

Although the participants generally asked the actor-parent for her input, often their communication was closed and coercive, which may make reaching a shared understanding of the problem and treatment difficult. For example, a male PEM attending physician stated that, “…if you’ve not discussed with the regular doctor if this is beneficial or not [intubation], then that is the right thing for you to do at this point. Are you okay with me doing that?” (S:21). It would be difficult for a parent to object to what the physician said was the “right thing”. Another example of a closed inquiry into the parent’s agreement of the physician’s decision to intubate is given by male PCC attending physician: “Let’s just go ahead and get her situated [by intubating], okay?” (S:9).
There also were examples of honest EOL communication. For example, a female PEM fellow who did not ultimately intubate the patient stated, “there is a strong possibility that we may never get the tube out [if the patient is intubated]” (S:11). Another of the three participants who ultimately decided not to intubate the patient, the male PCC fellow described in the section above as one who experienced the death of his father as a young adolescent, exhibited clear communication about the patient’s situation and recommended alternative measures to intubation. He asked, “Mom, has anyone ever talked to you about this disorder and the progressiveness of it and what you want to do when it comes to the time when she needs to have a tube down her throat?” Then, he followed with “…it’s always kind of nice to have a plan in motion but with her progressive disease, everything we do as medical professionals would just be a Band-Aid. I mean her lungs will get so sick that she will never come off the breathing machine. I can never say when that time is.” And, finally offered his opinion, that his advice would be to forego the breathing tube and the PICU and provide her child with comfort measures.

Although this participant was clear in his preference for comfort measures over intubation, some might argue that given this was the first time meeting this patient he overstepped his bounds. In the post-simulation interview he claimed that the actress-mother looked “tired” and he intuitively felt that this suggestion might ease her mind. The case that opened Chapter 1 was similar in that even though the PEM resident was just meeting the parents, they expressed relief at being able to stop painful resuscitations that were simply prolonging the inevitable death of their baby.

Honest, comprehensive and understandable communication by the physician about the child’s condition and prognosis and treatment options is imperative in order for
parents to make the most appropriate EOL decisions on behalf of their children. As suggested above, the communication observed in this pilot study was, in many cases, awkward and confusing. For example, a male PEM attending physician explained to the actor-mother, “… different people have different feelings about whether or not to do certain interventions in difficult cases and I didn’t know if you thought about that before, been thinking about that today” (S:20). And a female PEM attending physician asked,

Have you discussed with your primary doctor her condition in terms of, how it relates to her future and what to expect in terms of the level of sickness that she gets that maybe [unintelligible word] due to her conditions and how, how you feel and what these thoughts are in terms of how much you would like the medical professional to do in terms of her resuscitation or the tools that we used such as the intubation and other medicines that are part of what we call resuscitation … (S:16).

In both of these examples, the physician is attempting to elicit the actor-parent’s perspective, but the language is awkward and confusing and may limit the parents’ ability to make informed decisions.

The findings from the simulation transcripts indicate that adequate physician-parent communication may not consistently occur in EOL pediatric care. In fact, more examples of awkward communication were observed than clear communication. Analysis of the interview data from all phases of the study provides insight as to why communication was so awkward.

**Reasons for EOL Communication Difficulties/Avoidance**

Initiating a conversation with a parent about his or her child’s impending or actual death is not easy or comfortable for any physician. And, this difficulty has the potential to translate into both the avoidance of conversations by physicians and awkward communication when discussions do occur. Particular difficulties based on specialty, seniority,
gender, parental status, religion, and early experience death and disability have already been examined, but here we are looking at EOL communication more generally. Multiple themes emerged that explained reasons for difficulties that physicians have with EOL communication with parents. These centered on their concern with the families’ emotions, their own discomfort with their patients’ deaths, and their lack of training in EOL communication.

_Fear of Alienating the Family_

In the simulations, 10 of the 13 participants did not offer comfort measures as a valid alternative to life-sustaining technology (intubation in this case). Many of the physicians indicated that this was not their place due to their lack of history with the patient and the fact that the actor-mother indicated that she could not recall having had an EOL discussion about limiting life-sustaining treatment. If a physician who does not have a history with the family broaches the subject of limiting life-sustaining technology prematurely, serious damage can be done to the physician-parent relationship. Physicians described cases where they had asked the family whether or not they wanted “everything done” and the families were insulted or angry because no one had ever discussed limiting life-sustaining technology. These memories caused physicians to exercise great caution when bringing up EOL topics with families. Many concluded that the PED was not an appropriate setting to discuss EOL issues, except when death was imminent after an acute incident.

Avoiding EOL discussions causes particular difficulties for PEM physicians when children with apparent life-limiting conditions present for care, although both PCC and
PEM physicians felt frustration over cases of terminally ill patients whose families had not had EOL conversations earlier with their long-term physicians. PEM physicians discussed the fact they were frustrated with their patients’ primary care physicians for delaying EOL discussions, describing it as a failure in the system. “And you just wonder how they fall through the cracks. Obviously there is not a meter you can use to tell there is an uncomfortable physician or that’s a physician who just didn’t want to put the time into it, or that physician actually did it but it didn’t get actualized by the family…” (II:20). Another male PEM attending summed up the idea,

And I still find that we find ourselves in the emergency department seeing patients just like that, where if they get the emergency department, to me that means that the rest of the system is failing these families, because that conversation… should happen many times between the family and the specialists and the primary care provider… But, often people will come to the emergency department never having had that discussion or having really, really unrealistic expectations of the child’s potential (II:7).

Whereas, PEM participants saw it as a system failure when EOL conversations had not been had or documented with families of children with apparent life-limiting conditions, PCC participants saw themselves as last in line to have the discussion. One male PCC fellow summed up the feeling of his colleagues,

I think that we, the medical profession, sometimes doesn't do that good of job as preparing the families for EOL, especially when the patients are chronic. That's a little bit more frustrating, but you feel that there have been plenty of opportunities to prepare the family for this and we are at the end and everybody else that's taking care of the child says there is nothing else to do. But, I'm the last one in the chain because I’m the one in the critical care unit and the family is not ready to give up and so the child gets worse and ends up in my unit and I know that everything that I'm doing is not going to change the ultimate outcome (III:9).

Perhaps if parents were informed earlier in the course of their child’s illness about its terminal nature, they would have had time to prepare once their child reaches the PICU
and thus be more ready to accept the need to limit technology and institute comfort measures.

Uncertainty

Many of the participants discussed uncertainty as an inhibiting factor in initiating EOL conversations. Interestingly, findings from Phase I of this study suggest that tolerance for uncertainty does not have a statistically significant effect on participatory physician-parent communication, although due to the small sample size these results are preliminary. It is difficult to be certain that a child is at the EOL as one male PEM attending stated, “I think another dimension is that there's a lot of uncertainty in some of these things. And if you… are off the mark, that can create harm and problems as well” (III:20). Therefore, many would rather err on the side of not discussing EOL issues so as to not upset parents unnecessarily. Some participants explained that past experience with observed “miracles” has taught them to be humble in their assessments: “There are some circumstances that are sometimes very difficult to do on your own. Traumatic brain injury…we’ve had several kids to improve dramatically from their traumatic brain injuries and so you do get surprised sometimes, like, ‘Wow, we were talking about withdrawing care on this kid,’ and then they come back in a year later and say, ‘How ya doing.’ And you’re, like crap, glad I didn’t do that” (II:17). But as one male PEM attending asserted, there are times, even in the PED, when the child is clearly at the EOL and this needs to be addressed with the parents: “And there are certainly times when there is not enough known, within a high degree of certainty to know what the prognosis is going to be, um, but there also are many, many times when it is very clear to everyone, at least on the
medical side, what's going to happen” (III:7). It’s those cases that cause the most frustration, even moral distress, for physicians.

**Fear of Malpractice**

An interesting topic that was universally left out of participants’ responses in this study is the fear of malpractice and the effect it might have on EOL communication with parents. In Phase I a scale was used to assess malpractice fear; mean physician-parent communication scores suggest that those physicians with less fear of malpractice may communicate better than those with more fear. And, this trend approached statistical significance (p<.07). Interestingly, none of the participants talked about the issue of malpractice in their interviews. Fear of malpractice and its relation to EOL physician-parent communication is clearly an area of further study.

**Difficulty with Children’s Deaths**

Further, physicians have been acculturated in a society that fears death and in which the death of children is unnatural. It is not surprising then, that they avoid thinking about and talking to parents about their children’s life limiting prognosis. “It’s not supposed to happen,” stated one male PCC fellow in the context of his discussing the death of children (II:17). According to a male PEM physician, “…there is a bunch of reasons why it doesn’t, probably the most, this is just my bias I guess, but um, that people just aren’t comfortable talking about death and physicians are about saving lives, not letting people die and so, and it’s uncomfortable, especially say that it’s okay to expect death and to provide whatever comfort care for when that happens” (II:7).
Children are not supposed to die and definitely not on their watch. Physicians are trained to cure and death is seen as a failure. For example, a male PEM attending stated, “…in pediatrics we hold out hope for an extended period of time that we’ll be able to turn things around…and…we refuse to give up” (II:1). He later went on to say that, “We don’t want to bring up a lot of pain for them (the family)”. A male PCC attending, “I think pediatrics is a completely different field than the others. If you think about what’s driving your thinking. Just that the whole, the level of emotion is higher because death is uncommon and it’s viewed as being unnatural in children and so the emotional stakes are higher for everyone involved” (II:14).

*Lack of Training*

Participants spoke almost universally about not feeling like they had enough training to prepare them to effectively interact with parents of dying children. When asked to describe the type of training they had in EOL physician-parent communication, attendings responded with phrases such as “None” (III:8), “I definitely did not have it (III:21), and “…limited. I probably had no training” (II:10). As mentioned in the earlier section on seniority, fellows reported having some structured education in communication with patients, indicating a generational difference in training methods. But, when asked how they learned to communicate with parents of children who were dying or have died in the absence of intensive training, phrases like this emerged from attendings and fellows alike: “kind of just on the fly” (II:4), “trial by fire,” (II:17), “riding by the seat of my pants (II:16), and “pulled myself up by my bootstraps” (II:20). I was planning to classify the participants based on the amount of training they had to see if that influenced their
approach to EOL communication, but I was not able to do this because they mostly all said they had inadequate training.

When EOL communication was addressed in their training, it was mostly mentioned only briefly. Since they were not graded on their performance in communication as they were on technical skills, its value was diminished. Several methods of training in EOL communication were described by the participants. Three mentioned that they remembered formal lectures of the topic of EOL communication. Two the participants engaged in hospice rotations in their training, which made a significant impact on their ability to interact with families. Some even mentioned doing research on their own to improve their EOL communication skills and coming up short, “There is very little experience about how to break bad news. I mean I’ve done research and there seems to be very little out there. I don’t know what would make people better (I:8). A male PCC attending reflected an emergent idea among some participants that communication is an innate ability and it therefore cannot be taught: “Because we don’t know what works. I mean I know what works for me, what works with my personality, but I don’t know if my personality would work with everybody” (II:9).

Many questioned the way physicians were trained, focusing primarily the biomedical aspects of care and neglecting other important aspects like communication skills. One male PEM attending stated, ‘But, medical school and residency isn’t always real good at teaching art or giving people artful experience in all this” (I:20). Another male PEM attending, agreed, “I think all of us…want to be very scientific in the way that we approach patient care because from the ground up that’s sort of how we learned it. We learn basic science and then we learn clinical science and then we sort of learn the way to
apply it in the milieu of caring for humans” (II:12). Another male PEM attending actually felt that the way physicians are trained causes their psychosocial skills to diminish, “…just stuffing all the knowledge in that doesn't stick anyway. And, forcing them to work hours that are, that don't allow you to have a life outside of training, really neglects the aspects of what ends up being predictive of how you are a physician… The most valuable skill you have as a physician is your ability to interact with people, you know?” (III:7).

The participants were in agreement that experience is the best training. Some even felt that it was the only legitimate training for EOL physician-parent communication. For example, one male PCC attending stated, “I don’t think you can train people to do it. That’s more of an art or an absorption process than it is a learning process” (II:18). Further, a PEM attending stated, “Nothing can train you for the experience of telling a parent that their child has died. No amount of training can prepare you for the emotional and overwhelming news that you’re delivering and the emotional responses that you get back” (II:1). A female PCC attending expressed her feelings about experience, “… over and over again and see the more experiences you have, the more variety… You’d have the families that were just distraught. Sometimes you'd have a family that actually made you really uncomfortable and really was just angry. And, I think you've got to have that experience too (III:2).

In addition to experience, all participants discussed the importance of observing mentors in EOL conversations with parents in their own training. For example, a female PEM attending stated, “I think that it helps the fellows to have training because often the first time they may not ever [have] had an opportunity to model anybody and so they're
going into this cold and it's a really sensitive area” (III:10). Many described how they modeled good communication techniques they observed in their attendings. However, mentors were not always good communicators themselves. One attending described how he believed some of his mentors directed their trainees to engage parents in EOL conversations because they never got comfortable with it, “And I think some of that is that people never experienced it enough or never had enough positive experiences and they never got comfortable with it and so they always viewed it as a burden or a discomforting experience. And so you get this possibly self-fulfilling state, where nobody’s comfortable so everybody flees for the exits…” (I:20). In the next interview he followed with, “And so nobody really learns and the few people that are comfortable or masterful at it are too few to be able to get a critical mass of people trained or built up....” (II:20).

Fellows described that they, even as medical students, had sometimes felt the responsibility to soften the impact of their attendings’ EOL discussions. One male PCC attending described it this way:

Oh yeah, you see the whole gamut. You see the physicians who are the real poor English speaking and you’re just like, “Oh God” and the family’s kind of looking at you, like what is he saying. And, you kind of have to fill it in as a med student or a resident. Or, you see somebody who’s just very abrupt and quick and then they’re gone. And you don’t see the aftermath ...And then you see people who have developed a relationship with the family, the patient and family, it’s much easier give it, then versus the acute and they’re dead (II:17).

Another female PCC attending stated, “There’s some people who are better at it than others and there are some that I specifically, like I will go in and watch, partly so I can go back in and do a little bit of damage control. It’s just maybe a little bit too blunt or didn’t quite use the right language” (II:2). Others described attendings as being manipulative. For example, one male PCC attending described,
But, yeah there were people who I thought didn’t engage families at all. There were doctors who were good people, but were pretty pushy. And I didn’t feel comfortable with their style of interacting with families. And there were doctors I worked with that gave more or less information or just enough information to lead the family in the direction they wanted to go. And they wouldn’t have said that they were trying to be manipulative but it seemed manipulative to me (II:14).

But, participants talked about how they took the good with the bad and used those experiences to develop their own communication style. A male PEM attending explained how he became a “conglomeration” of his experiences, “They were mostly good. I mean I think we all take pieces of certain people, you know, under whom we train, and we try to take the good and the bad and probably interject some of our own bad and some of the good that we’ve learned as well.” (II:12). So, it is interesting that fellows have had more structured training in EOL communication than their attendings, attesting to a generation-al shift in medical training, but they are still more influenced by mentors than anything else attesting to the “hidden curriculum” in medical education described in Chapter 2. If their mentors did not have training, they may not fully benefit from their own structured training.

Finding Effective Practices

Many participants discussed their own dearth of training as well as the lack of general parent-physician EOL conversation guidelines as reasons for their discomfort with and subsequent avoidance of these types of interactions. Although PEM physicians face the death of their patients less often than PCC physicians, they appeared equally likely to feel uncomfortable with EOL conversations. What seems to make the most difference in comfort with EOL conversations is experience. One female PEM attending described the difficulty faced by young trainees, “I think it’s harder when you are twenty
something and all your family members are living and …you’ve not been around death and dying … there is a horrifying thought that now I’m in charge and oh my God, what do I do and how do I make this better for these parents?” (I:8).

Many said that they thought they could never be truly comfortable telling a parent that their child is dead or dying, but that experience has given them a feeling of preparedness. Physicians discussed how they developed their own EOL conversation style, primarily from watching mentors and from trial and error. At first young physicians are “trying to find some kind of algorithm, pattern to apply to the situation. And they kind of get a little further on and they recognize when the algorithm needs to be adapted or doesn’t apply. And then I think they kind of get to the masterful stage when there isn’t an algorithm but they can come up with something that applies…” (III:20). And, one female PCC attending discussed taking “bits and pieces of everybody’s style and make it your own” (III:2).

Interestingly, even though many participants discussed the discomfort they had with EOL physician-parent conversations, most did not mention seeking assistance in these conversations by calling in hospice or palliative care. In fact, hospice was mentioned only one time by a male PCC fellow who explained how it was important to “plant the seeds of hospice” in parents with children at the EOL (II:17). Palliative care was mentioned only once as well by a female PEM attending who explained that the palliative care team was more equipped to manage emotional issues with parents (III:10). Assistance in EOL interactions was most likely to be sought from chaplains, and less likely to be sought from nurses or social workers.
Participants developed their own styles of communication through their experiences, and they identified practices they felt were important when interacting with parents of dying children. The themes of building rapport, establishing a relationship, addressing parents’ emotions, and preparing parents for the death of their child emerged and together formed a cohesive interactional structure for effective EOL communication. The length of time this process may take could vary from minutes, as in an acute PED case, to days, weeks or months, as in a more chronic PICU situation. But, the data here suggest that EOL communication is a process as much as a practice. It must proceed in defined stages in order to be effective and where stages are missed, communication will surely suffer.

*From Rapport to Relationship*

The first task at hand in physician-parent EOL communication is establishing rapport with the parents. In order to broach EOL issues, having a relationship is imperative and building rapport can lead to eventual trust. This is true in the acute crises in PED, where physicians only have a matter of minutes to establish rapport, as well as in chronic cases seen in the PICU where patients may be there for days or weeks. In order to genuinely build trust, spending time with families getting to know them and their child is needed. In this way medicine becomes a narrative practice.

When a mortally injured or ill child, who was previously healthy, enters the PED, participants discussed the importance of meeting the family before a pronouncement of death is made. For example, a male PED attending explained, “I at least try to build a little rapport in those few minutes while we’re providing resuscitation so that when I do
have to tell someone that we can’t bring their child back that it’s not the first time that we’ve laid eyes on each other” (II:1). A female PEM attending described the importance of preparing “them for the next talk that’s about to come” (III:10) when they tell the parent that their child has died. Spending even a small amount of time to get acquainted with the family can indicate the physician cares about the patient which can establish trust early. As one PEM attending stated, “And the level of trust that people have with physicians who they feel care about them, is different than those who don’t” (III:7).

In cases where children are chronically ill, effective communication is more likely to occur in the context of relationship and the PCC physicians spoke of the importance of going beyond rapport to a trusting relationship with the family. Because time is short in the PED, there are differing opinions on whether such a setting is appropriate for EOL. Although most felt, like this female PEM attending, that with regard to initiating EOL discussions in chronically ill children: “I am not the person to do that” (III:16). Others felt, “…you don’t necessarily need a relationship to have EOL discussions with them” (II:1). Most, no matter what specialty, felt that if possible, establishing a relationship with parents went a long way in improving EOL conversations.

The importance of narrative practice in EOL physician-parent communication can be observed in this extended quotation from a male PCC attending. He describes the critical importance of going beyond building rapport to truly getting to know the families of the patients.

And I think that helped me if/when the time comes and they don’t do good then it’s not just a professional relationship of making logical decisions…I know these people, I know their story and it’s easier for them to trust me and so it becomes a two-way street where the time spent with them before it happens kind of pays off. It’s…easier to find words that will suit that family because it’s not just a random family X…. you have a gut feeling and you create that gut feeling by actually
knowing somebody. It’s like a friend. I encourage people to do what I do which it to talk to families. Ahh, again I think there are two things that go along with talking to families. One is that you get to know them, like I said and I think if you know somebody then you’re, you’ll be better to know the words to use. But the other thing that happens is if you’ve a built a relationship with the families and they’ve seen your work, they trust you… And then they become a little bit more forgiving about a maybe a poor choice of words (II:9).

Effective communication is not contrived but emerges through time and effort on the part of the physician.

Addressing Parents' Emotions

In order for EOL communication to be productive, physicians have to be sensitive to the parents’ wishes and where they are in the grief process. By taking the time to get to know families, physician can effectively take the next step in EOL communication, addressing parents’ emotions. One male PCC fellow explained that even when he thought the best decision for the child was to cease life-sustaining technology and “let nature take its course”, he also felt it was important “… to rely on families, where they are in the grieving process and take things slowly.” (I:17). Others suggest that it is important to get a “gauge for their comfort level” in terms of approaching EOL issues (II:12). In order to truly understand where parents are coming from, it seems there is no way of getting around simply taking the time to get to know them.

The physicians agreed that showing the family empathy was vitally important, but not all were equipped to provide empathy and the family may not always be able to “perceive the empathy that is there” (III:20). And, although training has the potential to help physicians develop their capacity to show empathy, it is not usually addressed. Some physicians discussed calling in other members of the health care team to do the emotional
work of showing empathy, such as chaplains and social workers: “So you address it, but you don’t do it personally. Well some physicians probably do. The ones who are really good at it” (III:17). Because families are in such a difficult situation during EOL conversations, physicians may be trying to provide empathy, but they may not see it. One female PCC attending stated that when giving bad news, “I’m more likely to have tears in my eyes. But then I have colleagues…that I know have a lot of empathy and compassion…but they might not just show it at the bedside” (III:2). A female PEM attending explained that families, “…might think that doctor was cold and uncaring because she didn't sit down…When in fact sometimes you feel like if you sit you won't be able to stand up [ laugh] you're so tired” (III:8)

Research indicates that parents want to have their emotions addressed by their health care providers (Aschenbrenner et al. 2012; Gilmer et al. 2013; Meert et al. 2009; Meert et al. 2008). But, is this fair? Are physicians trained in this way? And, is it too much to expect for physicians to be physical healers as well as therapists? When asked this question directly, participants generally felt that it was indeed fair for parents to expect that their child’s physician be human and therefore sensitive to their emotional state, but many also felt that they were not always prepared to deal with families’ emotions. Most agreed that there was no or very little formal training in addressing families’ emotions, although it is one of the “intangible things you learn as a trainee” (III:12).

Others emphasized that being sensitive to emotions is simply something expected as part of being human. As a male PEM attending stated, “…they want a professional, but they want a human too.” Another male PEM attending mentioned that “I think it should be expected just as I would expect anyone in any kind of business you know to under-
stand my position and to empathize with me” (III:12). In fact, “the human element,” is critical in order to practice the “art of medicine”. Practicing the art of medicine, dealing with patients and families on an emotional level leads to greater satisfaction: “It’s a huge part of why I became a doctor for kids….so I think it’s essential to our practice and I think it’s only fair for that to be expected” (III:12).

Five of the 17 participants said that it was not fair for parents to expect their emotions to be addressed by their physicians. For those physicians, the lack of time stands out as the main theme. Interestingly, it was mostly PICU physicians who mentioned this problem with time in relation to addressing parents’ emotions, whereas only one PEM physician, a female attending, mentioned it: “You would have to be so emotionally invested in the family to be able to do that. And you have one physician taking care of your patient population. You can't, to be devoted that much to each family, to really have that, and even if it's just the one or two families that are so critical at that time then does that diminish the other children?” (III:10). Her frustration is clear. The demands placed on her left her unable to fully address emotions. She and the PCC physicians suggested that physicians must refer to those who can help, such as the palliative care team, social workers and chaplains. One male PCC fellow stated, “…you’ve got to pawn it off. You ask all the right questions and you kind of do it quickly because you don’t have two hours to sit there with the family” (III:17).

The four PCC physicians who explained the lack of time prevented them from addressing parents’ emotions explained that with multiple critically ill children on a unit, they were simply spread too thin to provide full emotional support to families. One male PCC fellow stated: “…from the families’ perspective there is one, their child is the pa-
tient. Unfortunately, from the physicians’ standpoint there can be 20 patients” (III:13). And, even though the physician is there to support each family as much as he/she can, they “can’t necessarily do the kind of thing that a chaplain would do…because that…becomes outside of a medical situation and more a psychological…or religious support system” (III:18). This male PCC attending had more clearly drawn lines practice than others did. Another PCC physician, a female fellow, stated that she was not a “touchy feely” person and that her personality did not permit her to address emotions to the extent of others in her practice. Further, she felt that if one was too emotional, they wouldn’t last long in the field (III:19).

However, others who addressed the importance of building relationships over a period of time seemed to dismiss the notion that limited time was a deterrent in addressing families’ emotions. A male PCC attending explained how he tried to give parents the time they needed from him: “We have time in the bigger scheme of things. Does that make you sometimes get stuck in the unit a little bit longer and affects your family life, yes. And that’s why… I tell my wife, ‘You know there is only one way I know how to do this and it’s all the way.’ And, yes, the schedule gets horrible and but if it was my child I would want the doctor to care” (II:9).

Although, some male doctors talked about the importance of being objective in their interactions with parents, far more discussed the importance allowing themselves to be emotional and show their personal side with the families. One female PCC fellow described it as “liberating” for her to be given permission by her attendings to express her emotions in a “professional way” after an attending earlier in her training had told her never to cry in front of patients and families. A male PEM attending stated that “showing
your own grief or sharing it with them” is “usually well-received by families” (III:7) and he went on to say that, “…I think physicians who…are stoic and cold in their interactions are not very well liked” (III:7). Others discussed how they sometimes share personal stories with families. One male PEM attending stated, “…it makes me a little more human” to share experiences he had with his own children with parents and helps him establish rapport in a short period of time. (II:1).

Preparing Parents

After establishing rapport with parents and addressing their emotional states, discussing EOL issues becomes less awkward and physicians can more effectively prepare parents for the possible death of their child. In order to prepare parents, physicians must make sure parents understand what they are communicating, and the ability to do this will no doubt vary with each physician. How well parents are informed about their child’s prognosis and options “depends on who’s talking to them,” (III:19) observed a female PCC fellow. Because they often are overcome with emotion, even well-educated parents may not hear or comprehend what their health care providers are telling them. And, there is a higher likelihood of misunderstanding when health care providers use vague and unclear language because of their own lack of knowledge, discomfort, or uncertainty. Cases where parents did not comprehend what was being stated remained etched in these physician’ memories.

The use of factual, understandable and unambiguous language and the avoidance of technical lingo was a clear subtheme that emerged in relation to preparing parents. As mentioned earlier in this section, the simulation transcripts contain numerous examples of
ambiguous language, especially related to the idea of “doing everything.” Although they used awkward language, most participants did not use technical language with the actor-parent. In the interviews, no participant admitted using technical language and all said they tried to speak in lay terms when talking to parents. Although they claimed to use clear and unambiguous language themselves, participants reported observing colleagues who “sugarcoat things or dance around things or use euphemisms or whatever” (III:20) or who “cannot use 5th grade language” (III:2). Participants talked about the importance of using words like “brain dead”, died, “cancer” so families immediately understand the seriousness of the situation.

Participants were aware that technical lingo could easily create misunderstandings for patients and families, which could lead to them being unprepared for their child’s death. An example that was brought up often was CPR. Because the positive outcomes of CPR are misrepresented in the media, families have unrealistic expectations about the probability of their child coming back intact from cardiac event. This belief may underlie some parents’ hesitancies to consider do-not-resuscitate (DNR) orders for their children at the EOL. Participants said they tried to avoid using the term DNR with parents. Instead they claimed to spell out what it means in lay terminology. The terms DNAR (do-not-attempt-resuscitation) and AND (allow natural death) were discussed as being favorable to DNR, since DNR implies that resuscitation, if attempted, is going to be successful, when in reality in children it almost never is. DNAR implies that resuscitation is merely an attempt, and probably not a great one. AND was seen as being favorable to DNR because it is “gentler” and more “patient-centered”, but one male PEM attending
said he felt that AND would not work for children because “a parent could say, ‘A natural death? My kid’s 4. You know there’s nothing natural about this.’” (III:1).

However, more important than always using unambiguous language is to fit the language to the situation, and the idea of tailoring language to meet the needs of the family was another subtheme. Clearly, it takes building rapport and getting to truly know families to understand the nuances of the situation and use language appropriately. A PCC female attending explained, “I shy away on that very first conversation from using ‘dying’ or ‘death’ if I’m not certain…especially if there’s a conflict between family members” (III:2). She went on to cite an example of a case where she intuited that one parent was blaming the other and after sensing the critical tenseness and seeking to diffuse the situation, she avoided using the word “death” to describe the possible outcome. “It’s sort of like when you get into a pool and you think it might be cold or hot, you get your little toe first and see what the water is like and then you go slowly to get used to it” (III:9). By being in tune with the situation, physicians can also comprehend non-verbal clues, “like this is not going right and then you have to back track and change the topic or change the language right away so you don’t lose them” (II:9).

In order to prepare parents appropriately, the physician must be in tune with the parents’ emotional state, where they are in the grieving process, their level of understanding and religious influences (discussed earlier), all of which may affect EOL decision-making they will do on behalf of their child. This can be difficult, especially in the PED where time is short. It can also be difficult in the PICU, unless significant time and attention is given to getting to know the parents. A female PCC attending described how she tried to be in tune with when the parents had reached their limits of comprehension:
“...you have to have more than one conversation...sometimes I feel like you get to say a few words and there’s just so much shock, the family just has to stop and process and they’re not going to hear anything else that you say” (III:2).

Therefore, the participants of both specialties emphasized the importance of several conversations over time by multiple health care providers in chronic situations. But this implies the importance of careful planning and teamwork, and this is done with varying degrees of competence. A female PEM attending explained: “So there are different levels of preparation that parents have had, and there are different groups in [town] that were either good, poor, or crappy at preparing families for the EOL problem” (II:8). In addition to multiple conversations, timing is also important. In Phase I of this study, many of the participants stated that they did not feel the timing was appropriate to initiate an EOL conversation, if the parent had not been exposed to one before. For example, one male PCC attending stated, “Well I think in the specific instant, when you’ve got to make the decision ... there is a lot of stress and a lot of tension. This isn’t when you have a reasoned conversation when you say, what do you really want?” (II:13). He went on to explain, “…if they have time to prepare themselves, it’s a lot easier for everybody.” The importance of timing the EOL conversation before a crisis, if at all possible, was emphasized by many of the participants. The same male PCC attending illustrated how having an EOL conversation in a crisis might sound to a parent, “I’ve never met you. Your child will probably die if I don’t do this [intubation] right now. Have you considered EOL care? You have 5 minutes to make this decision” (I:13).

Time was a salient theme related to EOL conversations as families need to get used to the idea that their child is dying. Parents may ask for life-sustaining technology
to be continued, although their child’s physicians may feel it’s time to stop, because they need time to grieve and get used to the idea. The decision may be compounded by the parents’ religious beliefs, as discussed earlier; they may be waiting for a miracle. As one male PCC fellow explained, “A lot of times what it is is giving them time. So you say, “Okay, we’ll do it. And you have to…[assess] where are they in the process of letting their child go” (II:17). Another male PCC attending confirmed, “And they get there in their own time. And there’s not much you can do to either hurry them or rush them” (II:18). A further PCC attending stated that if, “… you push too hard your lose them. Because they distrust you. They think you want to quit. That you don’t have the best interest of the child at hand.” (II:9). But, having a relationship is the most effective way “to feel out families and figure out where you are” (III:14). One of the three participants who ultimately did not intubate the patient in the Phase I simulation, explained that even a small amount of time was important in helping parents forego life-sustaining technology, And if the parent’s unsure and we have a little bit of time then we might as well take our time to evaluate and see if we really need to do this because we do certain things, maybe not intubate, to have time to talk. I would just prefer not to intubate a completely, disabled, debilitated EOL thing where you know it’s going to happen no matter what” II:17.

Even in acute cases, sometimes time can help a family let their child go. A female PCC attending described a drowning case where she “billed like 7 hours of critical care time that I was at her bedside” because she was “trying to keep her alive…until the family was able to process that I was not going to be able to keep her alive anymore” (III:2).

Telling a parent that their child is dying or dead are the most difficult types of conversation that a physician ever has with families. The potential for disaster is great, but so is the potential for the healing process to begin. Effective EOL interactions with
parents do not typically happen without great effort on the part of the physician. As the most difficult kinds of conversations physicians will ever encounter, they have the potential to leave deep wounds or feelings of satisfaction that a good death was accomplished. By assiduously doing one’s work every day through taking the time to build rapport and establish a relationship where trust is built and parents’ emotions are addressed, the physicians can ensure that all has been done to prepare for an effective EOL discussion, which is crucial to preparing parents appropriately for their child’s death. A male PCC attending summed this idea,

So that by the time I go to speak with them I know that I've been diligent in my work and I've been honest with them… So there's the conversation and there's everything that comes before it. And if you go… to a conversation with a family and you've been lazy and slack in your work and you've missed 10 opportunities to help their kid, because you just didn't care, then you'd really have to be a good actor…to have a conversation with them and be good experience for you guys…I know that I've been diligent in my work and I've been honest with them… So there's the conversation and there's everything that comes before it. And if you go… to a conversation with a family and you've been lazy and slack in your work and you've missed 10 opportunities to help their kid, because you just didn't care, then you'd really have to be a good actor…to have a conversation with them and be good experience for you guys…(III:14).

By spending the time to get to know families before approaching EOL issues, the conversation is much more likely to go well. As stated by another male PCC attending regarding the initiation of conversations that include limiting life-sustaining technology, “And so if they know that comes from, that not only comes as a professional opinion but comes as a sincere opinion from somebody who cares about the child as a human being, it’s easier for them to trust you” (II:9).

Parents as Patients: Post-Death

The idea of treating both the family and the patient was discussed by several of the participants, but as the child became progressively sicker and near death, both PEM and PCC physicians believed that taking care of the families took precedence over the
child. For example, one PEM attending stated, “And, so you know I realized again, I'm shifting my attention. I'm not really caring for this patient right now because there is nothing I can do. We're beating on the chest and we're pushing drugs but there's nothing else I can do to comfort the family” (III:1). He went on to say, “Because really when you’re dealing with critical care and you think the outcome is dismal, the patient is not really the patient anymore” (III:1). Two PEM attendings explained that after a child’s death, even more important than being completely truthful was telling parents things they needed to hear such as, your child did not suffer, everything was done to save your child, and it’s not your fault.

The process of effective physician-parent EOL communication that emerged from the participants’ responses is illustrated in Figure 1. As described in detail above, the themes of building rapport, establishing a relationship, addressing parents’ emotions, and preparing parents for the death of their child emerged and together formed a cohesive interactional structure for effective EOL communication.

Figure 1. Stages in Effective Physician-Parent EOL Communication
Emotional Distress

The emotional labor that inherently goes into EOL conversations has the potential to affect physicians, and personal grief is a common response in physicians to the care of EOL pediatric patients (Basu 2013; Williams 2010). Research in palliative care indicates that physician burnout is more prevalent among those physicians who feel inadequately trained in communication skills (Graham et al. 1996). As a male PEM attending stated, “even the coldest physician can’t separate themselves” from the emotional anguish of experiencing life-limiting diagnoses and deaths in their child patients and having to communicate this information to parents (II:1). Physicians are emotionally affected by child death no matter what their gender, specialty, rank, age, parental status or religiosity.

However, as already discussed in this chapter, some characteristics lead to more emotional distress than others. Being female, less experienced, less religious, and a parent seems to increase the emotional distress experienced as the result of dealing with dying children and their deaths.

In addition to certain characteristics, certain cases, those that involve deaths that are sudden, accidental, traumatic and more personal, affect physicians more than others. Even physicians who say they can detach, can be affected by particular cases. One young PEM male attending who claimed he never shed a tear in the PED described a case that affected him deeply, where a young athlete came in after collapsing during a game and subsequently died (this case was referred to earlier). Several participants described cases such as this that were exceptionally painful, “cases that never leave you” (II:19) such as an infant who died after being left in a hot car by an uncle on drugs, a toddler who
climbed through the dog door and drowned in the pool on his aunt’s watch, a girl who drowned on her property after trying get her dog unstuck from a pond. The deaths of chronically ill children seem to affect physicians less than acute ones, “not that they’re any less of a person but there’s the expectation that the end is coming and they kind of reach their expectation or even exceed it of what we kind of thought based on their illness” (III:1).

Emotional distress also emerges from empathy for the parents and having to interact with them about their child’s grave condition. In fact, for some physicians, dealing with grieving parents causes more emotional pain than caring for their dying children. One female PEM fellow explained, “…I can take care of the patients and be fine, but it’s more when you have to talk with the parents about what’s going on that’s very, I don’t know, heartbreaking…” (II:11). Another female PEM attending stated, “…it’s distressing to me when they’re so distressed” (III:16). When children present to the PED or PICU after trauma, it is easier for the physicians to dehumanize them because they do not look like healthy children. “Knowing what I know about rehab, having a lot of developmental issues or neural issues, sometimes you’re better off dying than to be alive… There are some deaths that are more difficult than others” (III:9). In these situations physicians described feeling more pain from the interactions with parents than from the imminent or actual death of the child.

Specific emotions that participants mentioned as emerging in pediatric end-of-life care besides empathy and loss, include anger and burnout. Anger was a feeling that physicians felt towards parents who they believed had been incompetent or even abusive. A female PCC attending explained, “But I struggle with anger, I mean we had a patient this
week that I’m pretty sure was abused by the gentlemen that I sat down and talked to to get the story of what happened.” (II:2). They also dealt with anger when children die “because their parents are idiots” (II:7). “But getting upset or angry during the situation is not generally helpful when you’re taking care of somebody but when you think back on it, that was really dumb. It didn’t have to happen” (III:4). Anger also emerges when a dying child presents for care and it is apparent that health care providers have not addressed this fact with the parents. For example, one male PEM attending described his anger that emerged because, “…everyone knew this from the day the kid was born and no one talks to the parents about that” (I:7). A few mentioned the possibility of burnout from the emotional responses generated by the difficult work of caring for dying children because of the accumulation of the emotion felt over time, but burnout was not a major theme, indicating that these participants overall had developed strategies for dealing with emotional distress.

Dealing with Emotional Distress

In order to decrease physician burnout and personal emotional distress, appropriately addressing personal grief is crucial (Burns et al. 2001; Graham et al. 1996; Sahler et al. 2000). The Institute of Medicine (2003) suggests that strategies must be developed to support clinicians who deal with pediatric death in order for them to continue to provide quality care. In this study, besides relying solely on their faith and experience, physicians described other ways they dealt with the pain of EOL interactions. Personal strategies included working toward objectivity. One female PEM attending said she tried to cope by “putting armor on our hearts…so we can get up every day and go back” (III:8). Like-
wise, a female PCC fellow claimed, “If you take it personally every time, I mean you’d just be exhausted emotionally every day…you learn to close off certain portions of yourself when you do it and you just have to breathe through it” (III:19).

Another way of dealing with it is to use patient deaths as learning experiences and thus try to gain positive outcomes from tragedies. One male PEM attending stated that he used difficult deaths to help trainees learn about EOL communication with parents and to help them work through emotions. When deaths are due to obscure conditions, it helps them entertain that diagnosis in other cases (III:1). Others described using cases to try to help others. One female PCC fellow stated that in order to help her make meaning of her patients’ deaths, she shares stories with friends to warn them not to let that happen to their children (III:19). Another male PCC attending takes extra precautions with his own children, like making sure they are competent swimmers as early as possible and not keeping guns at his house (II:9). Participants also described leaning on the support of others. Several physicians mentioned the support they felt from their spouses. And, when spouses were unavailable or not understanding, they seemed to suffer. One attending who was not married stated that she found support among friends and her church. Colleagues are another source of support. Several participants mentioned the importance of community in helping physicians deal with their pain and moderating the level of pain that emerged from traumatic cases. “…we talk about it to each other, and we go, ‘I know that was hard,’ and we listen to each other when we talk about it” (II:8). Another PEM attending stated that working in a team helps with the pain. “Divided amongst the 20 attendings and 9 fellows, truly horrible stuff just doesn’t happen” (II:21). One female attending mentioned, however, that as she has advanced in medicine she felt she had fewer
people, at her same rank and level, to turn to for support. She felt uncomfortable relying on junior faculty because she felt that she really needed to be there for them and not vice versa.

Several suggested that there were institutional supports in place to help struggling physicians but that they were not well publicized. PEM attendings described “resuscitation debriefings” that were helpful, “…where the nurses and the doctors…and anybody involved in that child’s care could, at the end of the shift…could discuss it. So we could get some of it – we would discuss what went wrong, what went right, what supplies we didn’t have, what was frustrating about it, what our perceptions were of that.” Staff counselors could be useful, many agreed, but they did not seem to be utilized by physicians, even though available at the medical center. There also were opportunities for debriefings to get the whole staff together and this was not utilized well either (PICU). The consensus was that most physicians did not access services and instead tried to “tough it out” (III:20).

Perhaps the golden mean of balance is what is needed (III:21). Clearly physicians cannot be full time therapists for the family, but showing their humanity, by expressing empathy, care and concern is crucial for the family to establish trust in their physician. And, trust is essential for good physician-parent EOL communication. But in order for physicians to continue to do their work, they must find that balance, “Between empathy and not overwhelming your emotions,” (III:21) as one male PEM attending asserted. He continued, “…so if you’re giving so much that it’s taking so much out of you that you can’t continue to do this job then you’re showing probably too much empathy. So part...of being long term happy as a physician is finding that balance that provides empa-
thy…but also keeping your defenses up so it doesn’t hurt too much”. A female PEM attending explained her perception about the enduring pain of EOL interactions:

“I don’t know that it gets easier over time, but it becomes something that I give myself a chance to process, try not to rush, and try to give myself a break and understand it’s okay to feel sad, and it’s okay to feel bad and crappy about the outcome. It’s okay to mourn the death of another human, even though I didn’t know the child personally. So I’ve just kind of accepted that it’s going to be something that keeps me from sleeping, or when I wake up in the early morning hours and can’t go back to sleep because I’m thinking about it, or it might be something that kind of colors my day for a matter of days or weeks or a month or more sometimes” (II:8).

**Improving EOL Communication**

Learning to do EOL communication more appropriately, by building rapport, establishing a relationship, addressing emotions, and preparing parents could not only help families but also physicians in a myriad of ways. Many described specific cases in which they felt they could have communicated better that deeply affected them. Many believed that there should be more training in EOL communication for physicians. One female PEM attending stated, “Yeah. So I mean I think there probably is or are ways that we need to get better with it and I think we all probably need to be taught” (III:8). Another male PEM attending, agreed, “Anyway, so I just realized over time…that we need to start training physicians. We can provide more to those families by knowing how to talk about death…” (II:7). In order to improve training in EOL communication and better prepare physicians to interact with dying children and their families, several ideas emerged. First, timing of training is important; training should not be done too early in medical education. Because of the need to assimilate so much clinical information in the first two years of medical school, and the fact that students cannot fully understand the need to know how to communicate effectively until they are faced with interacting with patients in un-
comfortable situations, EOL communication training would ideally happen in the 3rd or 4th year of medical school as well as in residency and fellowship. One male PEM attending, explained that students need to understand how important EOL communication really will be to them in the future, “I think the point would be to really show the learner that this is a big deal that you’re probably vastly unprepared for by any kind of training you’ve ever received” (II:12).

Besides observing their mentors engaged in EOL communication and getting feedback from their mentors observing them, participants suggested that a structured rotation on pediatric EOL care, including communication, decision-making, and dealing with death would be quite helpful to trainees. Providing experiences for trainees to work with pediatric hospices or palliative care would enhance this experience. In addition to real life experiences, participants thought that case studies, role playing and simulation experiences could provide helpful insights to physicians as they learn to become better communicators. In particular several fellows mentioned how important simulation experiences in this medical center had been to them in getting practice and feedback from mentors to better prepare them for real life encounters.

Several participants said that hearing the perspectives of parents’ whose children have died on EOL conversations could have a significant impact on trainees. A male PEM attending summed up the feeling of his colleagues: “But, even better…is to talk to families who have gone through it and maybe collect several parents and say, “Hey, what would you have wanted to hear? How would you have wanted to hear from the ER doctor?” (II:1). Another male PEM attending described how he was asked to serve as an expert in a Sudden Infant Death Syndrome parent grief support group and he ended up
learning invaluable information from the parents on their perspective of their interactions with physicians. He stated, “And I found that I probably learned more from them then they learned from me” (II:7). This experience was foundational in his own growth as a physician. An experience such as this could provide preparation for the emotions that will ultimately emerge in pediatric EOL care as well as ideas for how to approach parents.

Regarding the use of role models and simulation experiences, one male PCC attending felt that kind of training was not genuine, “Yeah. I think all that kind of training that happens in medical school is in a way an exercise in acting. And that has some value. But I don't think it's what the families truly, deeply want. Do you know what I'm saying?” Further he claimed,

I think you can role play and yes you can desensitize yourself to the awkward conversations and you can learn to make a certain face and say certain words that work well but I'm not sure if that's what I would really want. Just to have a doctor who had practiced a lot of acting as much as to have the real thing (III:14).

This participant is highlighting the idea that no amount of training in strategies can preclude the preeminent theme of this section—that the key to effective physician-parent EOL communication is in the process. Through spending time to truly get to know the family by building rapport, establishing a relationship, addressing emotions and preparing parents for the EOL, the physician can “help a family begin their journey of grieving” (III:8).

“I fulfilled my mission”

Perhaps the best guard against personal emotional distress for physicians is feeling like they have done a good job. By becoming more effective communicators, many
participants pointed out that their grief decreased. A male PCC attending summed this idea up well:

I feel like it’s more painful when to me or more disappointing to me if I feel like the family was not prepared for it or had a bad experience, you know... When you feel like in the midst of a humongous loss and a lot of sadness you provided a spiritually appropriate, socially appropriate, or loving appropriate environment for them to grieve. In a weird way, you don’t know want to use positive words for death, but it’s like, you’re like, “I fulfilled my mission” (III:9).

If physicians can feel less emotional pain by feeling as if they “fulfilled” their mission, if they can learn how to interact with families appropriately and feel more comfortable doing it, then perhaps they will experience less burnout and less pain on the job and in their personal lives. Further, if their interactions with parents are better, than patient care will surely be improved as well.

In conclusion, the findings presented in this chapter suggest that individual physician characteristics emerging from their narratives, as well as biases they have developed through their practice, may influence physician-parent EOL interactions. As they struggle to find strategies to improve EOL interactions with families, they realize that their own emotional and moral distress, which is inherent in the work of taking care of dying children and communicating with their parents about EOL decisions, affects their approaches. Training and other supports can assist them in their work, but whether or not they feel satisfied with a job well done has much to do with how well they feel they communicated with the parents during the course of their child’s illness or injury. A conceptual model of physician-parent EOL communication based on the findings of this dissertation is presented in Figure 2. The model presented here is really one-sided and given from the physician’s perspective. And, this makes sense. After all it was physicians who were observed and interviewed, not parents. But, for communication to be effective it
must involve both parties. Physician-parent communication is influenced by physicians’ stories, as the research presented here suggests, but it also is equally influenced by parents’ stories, which include their relationship with the child, their religion and values, and their socioeconomic status, among a myriad of factors.

The concluding chapter will examine how physician narrative, physician-parent EOL communication, and ethical EOL decision making are integrated into a communicative ethic that seeks a transformed view of EOL interactions and takes into account both physicians’ and parents’ stories. It will be suggested that a communicative ethic could serve as a foundation for training pediatric physicians to be better communicators in order promote better care for dying children and more positive interactions with caregivers, as well as diminish their own emotional distress and moral distress that often results from caring for children at the EOL.
Figure 2. A Conceptual Model Effective Physician-Parent EOL Communication

Physician Narrative Influences
- Medical culture
- Specialty
- Seniority
- Gender
- Parental Status
- Religion
- Early experience w/ death
- Race/Ethnicity (not addressed in study)

Stages in Effective Communication
- Build Rapport
- Establish a Relationship
- Address Emotions
- Prepare Parents

EOL DECISION

Supportive Inputs
- Training
- Continuing Education
- Institutional Support
- Health care team
- Personal Relationships
- Professional Relationships

Aftermath
- Emotional Distress
- Moral Distress

Mission Fulfilled
CHAPTER 5

DISCUSSION

This dissertation emerged from a study that was initially entitled “Overtreatment in Pediatric Critical Care: A Simulation Study.” As the title suggests, it was believed by the research team that intubation of an EOL patient was “overtreatment”; the medical history clearly indicated the 8 year-old patient in respiratory distress was nearing the end of life. Would the physician rush in to intubate, taking care of physical problem at hand, but ignoring her EOL status? Or, would he or she have a conversation with the actor-mom about what she felt was in her child’s best interests? Also, would the communication from the physician invite the parent to share her own desires or would it be closed and coercive, in essence not giving her a choice? And, would the physician ultimately intubate?

As the simulations and post-simulation debriefing interviews progressed, we realized the issue was not primarily with overtreatment, but with EOL communication. The medically appropriate course of treatment for a patient in respiratory distress, as the patient in this study, is intubation. However, in this case, since the patient was at the EOL, a decision to use life-sustaining technology should have been made by the parent with the physician’s help. There was no DNR order mentioned in the case, so the physician had to address EOL issues with the actor-mom in order to understand the parent’s perspective: Has she ever talked about the progressive, degenerative nature of the syndrome with her child’s regular doctors? Has she thought about what her child would want if she should reach the terminal moment? Did she need to consult with family members? In the end,
only three participants decided not to intubate the patient (18 decided to intubate), and communication varied widely among the physicians. Most asked about EOL issues, but often the communication was awkward, ambiguous, and coercive.

A Communicative Ethic for Physician-Parent EOL Decision-Making

The inherent connection between communication and decision-making that emerged in this research led me to explore ways these crucial processes were connected in EOL care, to identify something deeper that would help explain the mechanisms that lead to good or poor communication. Watchwords for effective practices such as patient-centered communication and shared decision-making inform us, but the data generated in this study confirmed that communication goes beyond good practices; it is clearly ethical. How a physician communicates impacts the decisions made, which is critical, especially EOL decisions made on behalf of children.

The field of bioethics upholds that the most vulnerable populations are owed special protections, and children are included in this category of those deserving more safeguards (Beauchamp and Childress 2013). I contend that children who are dying are even more vulnerable and deserving of our attention and care. In a society that writes off the dying because they do not fit with our cultural narrative, we need to do all we can to protect the moral status of children at the EOL and afford them the best quality care, which may in fact be palliative care as opposed to life-sustaining measures. Improving physician-parent communication is an important place to begin.

Although models of communication did not seem comprehensive enough, neither did the predominant paradigm used in clinical ethics, principle-based ethics. One could
say that effective communication upholds the biomedical principles of autonomy and beneficence, but principle-baseethics is based on rational, objective decision-making. The data that emerged in this study suggest that decision-making, and thus communication that occurs in conjunction with it, is not wholly rational or objective.

Physicians’ narratives undoubtedly affect how they communicate with parents. Individual characteristics such as gender, religion, parental status, and personal experience with death as well as those that were related to their profession such as specialty and seniority influenced their perspectives on quality of life and futility. These characteristics also played a role in their comfort with EOL communication and the level of emotional and moral distress experienced. Because physicians typically control the communication process, their biases have a real potential to affect the tone and content of the information presented to parents. Although some physicians claimed that their biases did not affect their own communication with parents, many thought that their colleague’s biases did play a role in the EOL communication and medical decision-making. For example, a female PCC fellow explained how different colleagues used their language with parents of EOL patients:

Whereas the ones who want to limit care in some ways, are slightly more negative. They make sure that they [parents] always understand that things aren't getting better. And then there's the others that, 'we're going to keep going because nothing's better, but nothing's worse!’ I think that …the way they speak is different (III:19).

In medicine, it is generally suggested that the physician’s characteristics may have more influence on treatment decisions then the symptoms of the patients (Burns et al. 2001; McKinlay et al. 2002). The findings presented here also suggest that physicians vary in their approach to EOL communication and the decisions that arise out of that communication, based on their narratives.
My exploration ultimately led me to communicative ethics. Narrative ethics and virtue ethics also inform the findings in this study as both recognize the power of community and life experiences to shape the type of person one becomes. But, communicative ethics, while identifying these as well, elevates discourse as being primary in collaborative ethical decision-making, the ideal form of communication in physician-parent EOL care.

A communicative ethic is based on Jurgen Habermas’s theory of communicative action, which has been revised and expanded by feminist scholars, such as Benhabib (1992) and Smith (1996). The incorporation of communicative ethics into EOL care moves beyond striving for more effective physician-parent EOL communication strategies; it means embracing a “transformed view” of communication (Smith 1996:184). This view does not see communication as a disjointed three-step process where the interaction precedes decision-making, which in turn leads to an action. Instead, a communicative ethics approach posits that communication is in itself an action that is informed by the ethical values of the participants (Smith 1996). From a communicative ethics approach, communication, decision-making, and action are intertwined and take place simultaneously.

A communicative ethic brings together the themes that emerged most prominently in this study: the influence of physicians’ narrative characteristics on EOL physician-parent communication (called the lifeworld in Habermas’s theory of communicative action), the struggles physicians associate with these types of interactions, and finally, the ethical issues that inevitably arise from interactions with parents about their dying chil-
dren. As such, I propose that communicative ethics could serve as a foundation for the structured training of pediatric physicians in EOL care.

A communicative ethic is an ideal foundation for physician-parent EOL communication because of the following tenets: (1) it emphasizes the shared power of equal partners, the physician and parent, (2) it calls for participants to justify their appeals to universal norms, (3) it aims for a shared understanding of the situation, (4) its ultimate goal is for parties to reach a mutually agreed upon course of action, (5) it asks that all parties with a stake in the situation at hand be represented in the deliberation, and finally (6) if consensus on a course of action cannot be reached, coming to a shared understanding can be seen as a worthy outcome. Next, we will look at each of these tenets in more detail through examining the theory of communicative action.

The Theory of Communicative Action

Habermas lays out his theory in two volumes, The Theory of Communicative Action: Reason and the Rationalization of Society (1984) and Lifeworld and System: A Critique of Functionalist Reason (1987) and then later clarifies the consequences of his ideas for moral theory in Moral Consciousness and Communicative Action (1990). Habermas presents a two-level concept of society that on the micro level includes the lifeworld and the macro level, the system; it is through the dialectic relationship between these two entities that he believes human society is developed and shaped. The lifeworld, according to Habermas (1987, 1990) is the framework of assumptions, shared meanings, customs and norms (symbolic structures) that provides for the socialization of members of society and enables individuals to share an understanding of the social world. On the other hand,
the system consists of political and economic structures that control power relations and the production and distribution of resources. The lifeworld, which is structured commun- nicatively, is susceptible to negative influences from the system, such as what Habermas (1987) refers to as steering media (money and power).

Habermas claims that the classical sociologists Marx, Weber, and Parsons did not grasp the crucial importance of communication between individuals in shaping power relations in society. By relying heavily on Mead and the symbolic interactionists, he proposes his theory of communicative action to fill the gap. Habermas calls interactions communicative, “When the participants coordinate their plans of action consensually, with the agreement reached at any point being evaluated in terms of the intersubjective recognition of validity claims” (Habermas 1990:58). When parties come to a decision through their communication with one another, Habermas claims that they make three distinctly different claims to validity: claims to truth, claims to rightness, and claims to truthfulness. Claims to truth are those that refer to the objective world (facts), claims to rightness refer to something in the shared social world of the parties, and claims to truthfulness are those that come from one’s own subjective world that is unique to each individual. Understanding that discourse about facts is different from communication about norms is an important part of the communicative process. Normative claims to validity can be treated as claims to truth only if done through discourse (Habermas 1987;1990).

Much communication is based on actors who are primarily interested in convincing the other party that they are right. Therefore they do all they can to influence the other to buy into their positions. Habermas calls this strategic action and he distinguishes it from communicative action. According to Habermas, communicative action is when,
“actors are prepared to harmonize their plans of action through internal means, committing themselves to pursuing their goals only on the condition of an agreement—one that already exists or is negotiated—about definitions of the situation and prospective outcomes” (Habermas 1990:158). In strategic action, actors care most about their own success, whereas in a commutative action, an agreement is reached together. However, asking people to “harmonize their plans of action” may be ideal in theory, but in practice often is impractical. As discussed in Chapter 2, people have reasons for controlling their presentations of self strategically, especially in physician-parent EOL interactions where the stakes are high. Physicians’ biases that emerge from their narrative may lead them to steer parents, through impression management in a certain direction with regards to limiting or continuing life-sustaining measures (Goffman 1959). Studies confirm that physicians still report censoring information they share with patients (Fallowfield et al. 2002; Larochelle et al. 2009) and that EOL treatment intensity varies by physician (Larochelle et al. 2009). Parents also practice impression management in their efforts to be advocates for their child and have the best care available provided. They want to solicit truthful, comprehensive, understandable and timely communication about their child’s prognosis and treatment options (DeLemos et al. 2010; Meert et al. 2008; Meyer et al. 2002; Meyer et al. 2006; Meyer et al. 1998). Further, they often find it difficult to resolve that the time has come to limit life-sustaining measures (Baines 2008).

Habermas holds that consensus simply cannot be achieved by manipulation. The physician has traditionally held the power in physician-parent relationships, but some participants here shared real frustration over the fact that, because of patient autonomy and the best interests standard, they feel parents now have the power. If parents decide to
continue life-sustaining technology against the physician's recommendations, then the technology continues. Other power differentials, such as those related to gender, socio-economic status, race/ethnicity and seniority of each party also play a role in enhancing or diminishing egalitarian relationships between physicians and parents.

In the process of communicative action, actors, with their own unique lifeworlds, interact to reach a shared interpretation of the situation. But, how can two parties, physicians and parents, interact as equals in order to come to a mutual decision when they come from such very different lifeworlds, especially when so much is at stake as in EOL communication? Although not obtainable in all situations, as an ideal to strive for, a communicative ethic says that in order to reach a shared understanding about the situation, and eventually reach consensus as to the action that should be taken, the actors must communicate respectfully about their own positions. To do this they can present facts, they can present something from their unique lifeworld, or they can refer to something in the social world that they share with the hearer. According to Habermas (1990:136), “Thus, agreement in the communicative practice of everyday life rests simultaneously on intersubjectivity shared propositional knowledge, on normative accord, and on mutual trust.” Through the respectful sharing of facts, personal values, and shared understandings, actors can ideally reach consensus in a given situation. Consensus is reached if a hearer accepts the claims to validity made by the speaker. Habermas (1990:137) asserts, “When someone rejects what is offered in an intelligible speech act, he denies the validity of an utterance in at least one of three respects…” truth (something objective—the world of existing affairs), rightness (something normative—the world of legitimately ordered interpersonal relationships) or truthfulness (something subjective--each participants own
lived experience).” Therefore, in order for mutually agreed-upon decisions to be made, all parties must understand and accept the facts, or propositional statements, as well as the other party’s values, or normative statements.

A communicative ethic dovetails nicely with the ideas put forth by Stone, Patton and Heen (1999) of the Harvard Negotiation Project. The authors argue that in difficult conversations, such as EOL discussions between health care providers and parents, there are three conversations going at once, above and beyond the words that are spoken. These other conversations are mostly internal and involve the actors’ perceptions of the encounter and what it means to each. In the “What Happened” conversation actors go through their perceptions of the conversation—who said what, what did the other intend, who is right, and who is to blame. The problem is, individuals tend not to question their version of who is right and they fail to consider that difficult conversations are less about “getting the facts right” and more about what they mean. Difficult conversations are essentially conflicts of perceptions, interpretations, and values. However, if those involved can shift their conversational attitude from delivering a message to finding out how the other person may see things differently, immediately the conversation becomes less emotional. Instead of offering their interpretations of the situation as the truth, individuals can offer it as their perception.

The second conversation is focused on feelings--how we feel about what was said. Many strong feelings enter into an EOL conversation, but these often are not expressed. When two people are talking there is a parallel conversation going on in each of their minds concerning their feelings about the interaction. These kinds of conversations
centered on feelings. Therefore, addressing families’ emotions is important in effective EOL interactions, as many of the physicians in this study verified.

Finally, the third conversation, the “identity” conversation, centers on self-image or self-esteem. Not being able to cure a patient may be a blow to the physician’s perception of his or her role as a healer and this may affect EOL discussions. Similarly, for a parent, the idea of losing their child may alter their image of themselves as parents. By simply understanding that difficult conversations also are about self-image, those involved may be less likely to suddenly lose their balance on an emotional level.

Stone, Patton and Heen (1999) agree with Habermas that the goal of difficult conversations should not necessarily be mutual agreement, but shared understanding. And, they suggest that to do that each party must learn the other’s story that includes their perception of the situation. They, as Habermas, suggest that each must share his or her own story and perceptions. After each has been able to share his or her story and the other has genuinely listened, they can consider together how to go forward and work toward a mutually satisfying solution.

So how can all of this be applied to training in physician-parent EOL communication? Principally, physicians can be taught how to exercise communicative action in their interactions with parents. More details about components of training programs informed by communicative ethics will be discussed later. However, based on Habermas’s ideas, corroborated with Stone, Patton and Heen’s (1999), outlined above, a few areas stand out. First, before any communication about the EOL issue at hand ensues, physicians must get to know the patients and families they are treating. And, they need to be able to convince the parents, through their words and nonverbal behavior that they are equal partners in
decision-making. In the real world achieving this goal may not be possible due to differences in knowledge, power and potentially socioeconomic status between physicians and parents. But, letting parents know that an egalitarian relationship is genuinely desired could go a long way in opening the lines of communication. As presented in Chapter 4, this entails establishing rapport, building relationships, and addressing emotions, as information is shared to prepare parents about their child’s condition.

In the scheme of communicative action, physicians can be taught how to engage the family’s lifeworld and understand how their own lifeworld enters into the conversation. Physicians can learn to present information clearly, concisely and unambiguously. In order to do this, they need to have some understanding of the patient’s lifeworld, such as education level and religious values, and they can get a sense of this through establishing rapport and working to build a relationship. Further, physicians need to have the skills to both present and validate their own beliefs about this situation and the best course of action. Validating their beliefs for the family may take the form of sharing personal stories from their own lifeworld or even their own values in some cases where such disclosure may be appropriate. However, most importantly, in the process of validating their opinions, physicians can reflectively consider whether or not their own personal values, including their self-perceptions, are driving their ideas and whether or not this is appropriate in each particular situation.

As I mentioned earlier, though, communication is not just a good practice in medicine, it is ethical. Through interactions with parents, EOL decisions emerge. And, the content of these decisions has much to do with the communication surrounding them. From the theory of communicative action emerges communicative or discourse ethics.
Habermas (1987, 1990) argues for an ethics based on moral argumentation. While reminding us that modern society can no longer rely on sacred authority (i.e. the church) in making ethical decisions as in past epochs, Habermas states that problems cannot be solved by independent dispassionate knowers either, as ethics emerging from the Enlightenment presume. Instead, they can only be resolved within communicative dialogue.

Habermas (1987) claims that only an ethics based on communicatively derived norms is plausible. An illustration of Habermas’s assertion is apparent in his reformulation of Kant’s categorical imperative, from one that claims validity for any maxim that one can independently reason to be a universal law, to one that claims validity only for those maxims that are universally agreed upon through discourse (1987;1990). According to Habermas (1990: 68), morality is both universal and communal:

Discourse ethics, then, stands or falls with two assumptions: (a) that normative claims to validity have cognitive meaning and can be treated like claims to truth and (b) that the justifications of norms and commands requires that a real discourse be carried out and thus cannot occur in a strictly monological form, i.e. in the form of a hypothetical process of argumentation occurring in the individual mind.

Moral norms are derived from communally held beliefs and “the binding force of normative validity claims…can be redeemed only in discourse” (Habermas 1987:94-95). In this way, the theory of communicative action sheds light on universal ethical norms in the broader society as well as one-on-one interactions where ethical decisions are made in everyday life.

Habermas (1987) discusses that the elevation of mutual understanding above consensus is an important tenet of communicative ethics. There will be times, as in EOL situations discussed in this dissertation, when no amount of respectful deliberation can lead to a mutually agreed upon course of action. If a respectable goal is to reach a shared un-
understanding, actors are less tempted to use manipulation to get the other party to agree
with them on a course of action. Smith (1996:196) claims that, “The fundamental ethical
point lies in two subjects reaching reciprocal understanding while holding full respect for
each other’s reasoning process, feelings, and authentic non-coerced participation” (Smith
1996:196). Because of the assumed inherent egalitarian status of the parties, feminist eth-
icists point out that a communicative action model also can highlight power inequalities
in medicine, not only between physician and patient, but also inequities that arise from
gender, race/ethnicity and class (Smith 1996:185).

Communicative Ethics and Principlism

Although communicative ethics has not been addressed widely in bioethics,
Jonsen (1999) points out that bioethics at its most basic level has always been centered on
discourse. Since the beginning of medicine, in ancient Greece, physicians were told to
use their authority to direct conversations with patients, and until the mid-20th century,
paternalism prevailed in medicine. It was then that principles emerged as being the foun-
dation of bioethics. From the 1960s, principles widely considered as fundamental for bio-
ethics have included autonomy, nonmaleficence, beneficence, and justice (Beauchamp
and Childress 2013). The preeminence of principles may be primarily due to the plurality
of ethical systems, and since health care often is provided in large, impersonal institu-
tions, general principles are needed so that culturally diverse patients receive reliable care
by providers who also come from a variety of backgrounds (May 1994). Principles are
assumed to be rational and objective and thus can be used universally to reach ethical de-
cisions.
Among the established bioethical principles, autonomy emerged as primary due to cultural and societal factors of the 1960s and 1970s. By the mid-1970s, with the Karen Quinlan case, it became clear that autonomy had overtaken paternalism as the defining aspect of the physician-patient relationship (Veatch 1984). The establishment of autonomy pushed for equality in the physician-patient interaction. Although many would argue that autonomy continues to be the primary ethical principle in bioethics, some argue that, although crucial, autonomy cannot be assumed as the only value and does not necessarily trump other values, such as justice (Steinbock 1996). Central to this argument is the criticism that autonomy erodes a sense of community. Autonomy could be adversarial, creating undue tension and distrust in the physician-patient relationship. Although the autonomy of the patient is central, the autonomy of health care providers may be neglected by ignoring their professional judgment (Hamel 1995). Participants in this study expressed frustration and even moral distress when they felt parents were making decisions that were not in the best interests of their child patients, but felt they were powerless to act. Perhaps the pendulum has swung too far towards patient autonomy. No one would suggest moving backwards toward paternalism, but perhaps we have gotten off balance.

A communicative ethic could complement an ethic based solely on principles, because both parties, physician and patient/parent, are equally important and decisions are made communally. Through the premise of seeking mutual understanding and consensus, a communicative ethic has the potential to add a social ethical dimension to autonomy, something for which bioethicists have been calling (Callahan 1996). Because communicative ethics calls for the justification of claims to universal norms through egalitarian discourse, it has the potential to inform not only individual physician-patient (or phy-
sician-parent in our case) interactions, but to clarify and justify principles that have been universally accepted by the medical profession (Gatter 1998).

**Communicative Ethics and Best Interests**

As an example of how a communicative ethic might inform an objective principle-based ethic in EOL physician-parent communication, let us examine the best standard that is used in medical decision making for children. The best interests standard, which flows from the principle of autonomy, beckons a surrogate decision-maker to use an objective cost-benefit analysis to determine the best course of action for the patient who is unable to make decisions for him or herself, as in the case of a young child (Beauchamp and Childress 2013). In a rational assessment, the surrogate’s duty is to compare alternatives and choose the one that “locates the highest probable net benefit” (Beauchamp and Childress 2013:228).

There has been confusion over applying the best interests standard, especially to children at the EOL (de Vries et al. 2013), and this theme emerged in the findings. First, as we discussed in Chapter 2, asking parents to make rational judgments that could involve options that lead to hastening their child’s death seems naïve. Principles cannot explain the bond that parents feel toward their children and how that bond clouds rational decision-making ability (Moody 1996). According to Baines (2008:145), autonomy is not directly applicable to incompetent children, who are by definition, not autonomous, and the

…justification of a parent’s authority [inherent in the best interests standard] highlights the tension between the enormous commitment needed to be a good parent and the need to be impartial or disinterested to choose wisely based on an objective assessment of a child’s interests….When choosing in a child’s interests, a parent
must try to separate the love and commitment they have for their child (their interest in being a parent) from the interests of their child.

Separating these two commitments is extremely difficult for parents or for any surrogate making a decision for a loved one. For example, results of a review study examining the effect of making treatment decisions for others found that at least one third of surrogates experience a negative effect of decision making with effects lasting for extended periods of time (Wendler and Rid 2011).

Further, choosing the best alternative is a decision that, at its core, rests on quality-of-life determinations (Beauchamp and Childress 2013). Findings here highlight that on the whole physicians have different ideas about quality of life than the parents of their patients. Although most physicians felt comfortable allowing parents to make quality-of-life determinations as a basis for choosing treatment options, some experienced frustration when they felt that the child’s best interests were not being served.

The ambiguity they experience is not surprising given that ethicists cannot agree how to apply the best interests standard. For example, the President’s Commission for the Study of Ethical Problems in Medicine and Behavioral Research (1983) contends that the family’s well-being can be taken into account in making a best interests determination for a child. A male PCC attending in this study suggested that he agreed with this idea, “So, if that means…that you’re going to end up with a kid that’s only going to lay in bed and hurt …or not respond to you, and be non-interactive for the rest of his life, that’s fine with me if that’s what you want” (II:18). This physician felt that if the family felt it was best for them to keep their child alive at all costs, he felt no ambiguity in providing life-sustaining care. However, Beauchamp and Childress (2013) hold that the patient’s best interests must take precedence over the family’s, and others agree. A female PCC fellow
expressed her feelings: “You know that’s frustrating because you’re like, ‘What are you doing to this child. You’re keeping this child alive for yourselves’” (II:19). Similarly, a male PEM attending stated, “They want them intubated, put on a ventilator and sent home on a ventilator in the same vegetative existence. Is that in the child’s best interest? I don’t think it is, personally. But, boy suggest that. It’s certainly controversial.” These physicians expressed dissonance over their imperative to follow the parents’ wishes over what they thought was best for the child.

The American Academy of Pediatrics states that although parents have been given the legal responsibility to make decisions on their children’s behalf, “…health care providers have legal and ethical duties to their child patients to render competent medical care based on what the patient needs, not what someone else expresses…the pediatrician’s responsibilities to his or her patient exist independent of parental desires or proxy consent” (Committee on Bioethics 1995:315). In short, health care providers are legally obligated to parents, but are morally obligated to their child patient (Lantos 1997). When a physician feels that parents are making a decision not in the best interest of their child, this can be difficult, and a basis for moral distress.

Although some believe it should be re-evaluated (Baines 2008; de Vries et al. 2013), Kopelman (1997) argues that the best interests standard is useful standard because it can be applied consistently. She claims that ambiguities may ensue because the standard has three distinct, but related uses. First, it is a threshold for intervention in child abuse and neglect cases. Second, it is an ideal to promote the well-being of children through duties, policies or decisions. And, finally, it is a standard of reasonableness which “guides us to select what most informed, rational people of good will would regard
as maximizing net benefits and minimizing net harms for children, given the legitimate interests and rights of others and available options” (Kopelman 1997:287). As an ideal, the best interests standard may point us in a specific direction, but it is not a duty to provide the actual “best” choice in every instance, if outside circumstances make its fulfillment impossible or if it conflicts with the rights and claims to justice of others (Kopelman 2013).

Kopelman (2013:13) states that the best interests standard can be used as a guide in decision-making; however, in this way:

(1) decision makers should assess the child’s immediate and long-term interests and select an option based on maximizing good and minimizing harm (ideal). (2) if higher duties conflict with the decided upon goal, decision makers should make a choice that a reasonable, informed person would make to provide the particular person good care in their particular circumstance (threshold), (3) constraints exist such that decision makers should, at minimum, make choices compatible with the rights of or duties to the child.

The communicative action process could serve as a useful complement to the best interests standard in determining the course of action for of a child with a life-limiting condition. In order for someone else to decide what is another’s best interest, they must understand what is at stake—what good may be gained and what harm should be avoided (Kopelman 2013:11).

Facts are important, but EOL decisions very much are about values. Determining the best course of action requires each party to justify the values that lead to their beliefs about the course of action. Communicative ethics meshes will with the AAP Committee on Bioethics’ statement Informed Consent, Parental Permission and Assent in Pediatric Practice (1995:314):

“Decision-making power or authority is increasingly seen as something to be shared by equal partners in the physician-patient or physician-surrogate relationship. For
many patients and family members, personal values affect health care decisions, and physicians have a duty to respect the autonomy, rights and preferences of their patients and surrogates”.

With the emphasis on power that is “shared by equal partners”, and the emphasis on physicians’ respecting the “personal values” that arise out of the unique lifeworld of each family, the AAP’s statement upholds some of the most important tenets of a communicative ethic. In order to help family members determine the best interests of the child, the physician must understand nuances of their perspective, which emerges from their lifeworld.

In sum, a paradigm based strictly on principles may not be as useful in determining best interests as one complemented by communicative ethics. As ambiguities surrounding the best interests standard illustrate, applying principle-based ethics to children, especially young children who are incompetent to make their own decisions, is difficult. A principle-based ethic cannot adequately explain the bond that exists between parent and child or the moral obligation which emerges from one’s identity and history as a parent (Moody 1996). Participants in this study pointed out that parents of chronically ill, neurologically devastated children may insist on life-sustaining technologies at all costs, even to the detriment of their own families. Again, simply weighing the costs and benefits through the lens of principles to determine best interests does not adequately explain why families would make these decisions. However, understanding the parents’ narratives and the moral obligations that arise from those through the lens of communicative ethics may make understanding more possible.
Communicative Ethics and the Physician’s Narrative

In addition to failing to explain the lifeworlds of patients, principle-based ethics does not explain physicians’ own moral inclinations and duties that arise from their life stories. The AAP statement also leaves out the physician’s lifeworld. But in order to come to a consensus, in the view of communicative ethics, the physician brings his or her lifeworld to the table. Is it fair to expect patients and families to respect or even understand the physician’s perspective? Perhaps not. But physicians can understand how their own values and backgrounds may interact with the communication process, so that they can guard against their own unintentional manipulative practices. Physicians can work to separate their own values from objective information. And, when presenting values to parents, they should be able to justify them. In order to fairly justify their own positions to patients, it may take physicians explaining how they reached their opinion through their own personal experience, as well as from their professional expertise.

Throughout this study, we have been examining how physicians’ narratives influence their communication with parents of dying children. Narrative, although largely ignored in principle-based ethics, plays a key role in communicative ethics as it helps uncover one’s lifeworld. In fact, Habermas (1987:136) believes that narrative is a “methodologically promising way to clarify” the concept of the lifeworld.

In the grammar of narratives we can see how we identify and describe states and events that appear in a lifeworld; how we interlink and sequentially organize into complex unities members’ interactions in social spaces and historical times; how we explain the action of individuals and the events that befall them, the acts of collectivities and the fates they meet with, from the perspective of managing situations.

In this study, we have found that a physician’s narrative may affect his or her objectivity. For example, physicians may approach EOL communication, and thus decision-making,
differently based on their religious beliefs, whether or not they are a parent, and/or whether or not they experienced the death of a loved one early in their lives.

Burrell and Hauerwas (1977:111) suggest that when an individual’s moral reasoning is separated from the life narrative in which that reasoning occurs (the ideal in principle-based ethics), “a distorted account of moral experience” is created. In fact, all ethical approaches are, in some sense, narrative. The only difference between approaches is that some use narratives explicitly and some only implicitly (Brody 2003). Narrative elements may lie at the core of widely accepted principles. For example, the principle of autonomy most likely arose out of narrative in that at some point, people began to tell stories to illustrate how others thwarted their harmless actions. Listeners must have agreed and over the years the collection of these stories grew until eventually the term “autonomy” became a form of shorthand for this collection of narratives (Brody 2003).

Both narrative and principles are essential to ethical decision-making as they play mutually corrective roles. Principles move us to the general, whereas narrative moves us to the more particular. Childress (1997) argues that the difficult task for ethicists is not to determine which one is of greater importance, but to explore how they work together. While affirming that narrative is useful in ethical inquiry, although not a substitute for norms and principles, both narrators and listeners must test the sources of stories and maintain a healthy skepticism about answers (Hunter 2004). Not all stories are true, and furthermore, false implications and conclusions often are drawn from true stories. Thus, communicative action that compels actors to justify their claims to norms is crucial.

Although choice is crucial in ethical decision-making, one’s community and culture as well as an individual’s earlier acts have pre-conditioned options and predisposi-
tions (i.e. lifeworld). Narrative captures this complexity of human life in ways that principles cannot (Chambers and Hunter 2002). For example, a concept like hope or faith does not make sense from a principle-based perspective (Moody 1996). Hope in the most difficult of circumstances may not be rational, but when examining the narrative out of which hope emerges, the reasons for it may become clear. Communicative ethics encourages a structure for understanding inclinations like hope and faith, two important influences on EOL care for patients, families, and physicians.

Communicative ethics further upholds the importance of the parties communicating even though this discourse might lead to conflict. It is through a process, often over more than one conversation, that parties can gradually begin to understand one another’s perspective, and this can lead to eventual consensus (Moody 1996). But, sometimes consensus will not be reached. As one participant pointed out,

…and there are certainly situations when you just can’t communicate no matter how skillful you are. And, all you can do in those situations is to try to work on the confounders and wait until it gets to the point when you can effectively communicate. I mean I’ve seen situations when people are so anxious that they can’t concentrate and I’ve seen situations when people are crying and are so upset that they can’t communicate either, so you’ve got the situation that no matter how skillful you are you’re going to wait until things settle down a little bit (II:20).

If consensus cannot be reached, parents’ decisions will typically prevail unless these clearly violate the best interests standard of reasonableness. If so, there are options for physicians, such as ethics committee consults and court orders. Or, if the family is asking for a course of treatment that the physician in good conscious cannot support, he or she can refer the patient to another physician for a second opinion. But in most cases, shared understanding, even when a consensus is not possible, can decrease the moral and emo-
tional distress that physicians feel when parent make choices that physicians do not feel are best (Hamric and Blackhall 2007).

A model of physician-parent EOL communication based on communicative ethics is presented in Figure 3. Engaging in interactions, reaching a shared understanding, and formulating a mutual plan of action are three action-oriented processes that occur together in each particular EOL decision-making situation. In order to reach a shared understanding each party must present facts, but also justify the values that underlie their own preferred courses of action. Presenting facts and justifying values take place within the process of interactions.

The findings that emerged through this research suggest that interactions are processes as much as practices. Interactions must proceed in defined stages in order to be effective and where stages are missed, communication suffers. Through the process of building rapport, establishing relationships, addressing emotions, and preparing parents, reaching a shared understanding (sub-themes that emerged in the data) and ultimately a mutually agreed upon decision is achievable. The physician and the family exist as equals in the encounter and as such, both the physicians’ and the families’ lifeworlds inform the communicative process and are affected by it.
By engaging in the communicative process, even if a consensus on the course of action is not fulfilled, physicians will be more likely to feel satisfied with the ultimate decision.

*Communicative Ethics in Practice: In the PICU and PED*

Communicative ethics looks promising on paper, but how does in play out in practice? Charles, Gafni and Whelan (1999) set forth a framework to describe the way communication occurs in physician-patient interactions, and we will extrapolate to physician-parent conversations. Based on their work in medical-decision making in the con-
text of a patient being diagnosed with a life-threatening disease for which there are several options, they suggest that three physician-patient models of communication exist on a continuum. Within each of these models, there are three stages in coming to a treatment decision: information exchange, deliberation, and deciding on the course of treatment. The first model is paternalism, where the information flows in one direction from physician to patient, and the physician deliberates about the course of treatment and ultimately makes the decision. In the shared model, mirroring communicative action, information flows two ways: from physician to patient but also from patient to physician. Both the physician and the patient are involved in the deliberative process of deciding the best course of treatment, and together they make the decision as to the best course of treatment to pursue. Finally, in the informed model, information flows primarily one way, as in paternalism, from physician to patient. However, only the patient (and potential others, but not the physician) deliberates about the best course of action, and only the patient makes the final choice of treatment. Both the shared and informed models emerged as a reaction to paternalism, but in the shared model the physician and patient work together. In the informed model, the autonomous patient is largely left on his or her own to make the final decision. Charles et al. (1999) stress that these models operate on a continuum in reality. In some cases, the interaction may reflect a point somewhere in between shared and informed decision-making with the physician giving information and some limited input as to what he or she feels the best decision is.

The shared model presented by Charles et al. (1999) has much in common with communicative action. Through the information exchange process, both the physician and patient share their lifeworlds, including information (about the disease and treatment
options from the physician and about physical symptoms, values, and goals from the patient). Then, through deliberation, the physician and patient discuss treatment preferences and justifications for those preferences. The key to the deliberative process in the shared model is its interactional nature. In both paternalism and informed models, there is limited interaction between the physician and patient. In one (paternalism) the physician decides with little input from the patient and in the other (informed) the patient decides with little input from the physician. The informed model emphasizes patient autonomy in a consumerist mentality as the patient goes through the deliberative process on his or her own after hearing “the facts” from the physician. However, it largely ignores physicians’ clinical experience and expertise. According to Charles et al. (1999:658),

In a shared model, both physicians and patients are assumed to have an investment in the treatment decision. The physician can legitimately give a treatment recommendation to patients and try to persuade them to accept the recommendation. However, physicians would also have to concentrate on listening to and understanding why patients might favor a different treatment option. Perhaps the decision will be resolved through further clarification of values, preferences, and information, but perhaps not.

Some physicians in this study exemplified the informed model in their responses in that they explained how they simply presented all the facts and left it to the parents to make a decision. One male PCC attending explained:

They drive the train as far as I’m concerned in terms of where we go… I’m fine with either one of those extremes as long as they’re clear in their own mind where they want to go. The ones that are hard for us are the ones that sort of fall in the middle and can’t make a decision. Because if you can’t make a decision, basically what you’re doing is defaulting and saying that we’re going to do everything. Which is fine, but you have to also be willing to accept whatever the outcome of everything is on the other side (II:18).

However, the problem with an informed model is that it ignores emotions. Sometimes, parents, although they can have all the factual information about their child’s condition,
cannot emotionally make EOL decisions and may need more direction from the physi-
cian.

The Charles et al. (1999) framework highlights that in real practice there are mul-
tiple approaches to EOL decision-making and they lie on a continuum between paternal-
istic and informed models. Research has indicated that patients (and we extrapolate to
parents) vary in how much they want to be in involved in medical decision-making
(Benbassat, Pilpel and Tidhar 1998; Levinson et al. 2005). For example, a population-
based study found that although most (96%) of the respondents wanted to be offered
choices and asked about their opinions, more than half (52%) preferred to let their physi-
cian make the final decision (Levinson et al. 2005). Perhaps an important part of respect-
ing patient autonomy means allowing patients/parents to decide how much decision-
making they want to give to physicians. However, in order for a physician to know how
much decision-making capacity the parents want, he or she must ask them and genuinely
listen to the answer (inherent in a communicative ethic). And, their answer may change in
the course of their child’s illness and physicians should be in tune to shifts in their needs.

Let us look at the specialties examined in this study to see how a communicative
ethic may occur in real life settings. In the PICU, when patients and their families often
are present for an extended period of days, there may be time for a communicative ethic
(or shared model as in the Charles et al. (1999) framework) to be realized. For example,
a male PCC attending shared how he tries to understand the lifeworld of families he en-
counters,

It’s not the patient you have in front of you. So, a lot of times, getting to know
them, asking about the child, kind of prepares you, gives you empathy, makes you
closer to the family and then when the time comes [to discuss EOL issues], it’s a
two-way street. They know you, they know you care. You actually care, so your words come out easier (II:9).

Trying to understand the family’s unique context, in order to reach a shared understanding, takes time and effort on the part of the physician. But, this physician asserts that it is time well invested that will pay off in the deliberative process of coming to a consensus on a treatment course of action, which could save time over course of the child’s illness and help avoid unnecessary suffering for the child.

In some cases, as in the PED, acute crises simply do not permit time to understand the lifeworld of the family. In cases like these, when a comprehensive understanding is not possible, a communicative ethic can still inform communication and decision-making. The issue of resuscitation emerged in this research as being one of the most significant areas where physicians, especially those who practice in the PED, felt ethical ambiguity. Resuscitation decisions, like all EOL decisions, are value-laden from the perspectives of both the physician and the family, and because of this, identifying specific guidelines is difficult (Wilkinson and Savulescu 2012).

Sometimes good communication means that physician should be more directive, which may appear more paternalistic. Instead of asking parents whether they want CPR done on their child when it is not medically indicated, it may be best for physicians to simply tell them it is not the most appropriate course of action (Clark and Dudzinski 2013). CPR may not be indicated when the patient is close to death or when resuscitation would be futile. Further, it may actually violate an individual’s right to die with dignity (Paris, Angelos and Schreiber 2010). Because parents may never be able to be the one responsible for hastening their own child’s death, being directive about CPR may relieve parents of the burden of having to make the decision and allow their child to meet with a
peaceful, “good” death (Clark 2013). For example, a male PEM attending described a case where a young child accidentally hung himself. He was brought to the PED and during the resuscitation it became clear that he could not be brought back. His father, a physician himself, said, “‘I can't make that decision’… about whether to stop. And I said, ‘You aren't. I am. I'm making the decision’…And, that took a load off of him. I could see his child was still dying. He did not want to be the one to make the decision” (III:7).

On the other hand, in some cases parents may request CPR even when physicians believe it to be futile, as in accidents when the child was healthy one moment and near death the next. If physicians can understand the family’s perspective, the family’s “life-world”, perhaps their need to know that their child fought until the very end, then it may be the best ethical course of action, provided that the CPR would not cause the child undue suffering (Truog 2010). Troug asserts,

But actions surrounding the moment of death are highly symbolic and often of great significance to the surviving family. By sometimes agreeing to provide futile CPR, we send a message to our communities not that clinicians can be bullied into performing procedures that good medical judgment would oppose, but that our hospitals are invested in treating patients and families with respect and concern for their individual needs (Truog 2010:479)

A communicative ethic, where parties seek to understand the lifeworld of the other, could encourage the most compassionate EOL care for both the child and the family and allow physicians to feel that the best course of action was taken, perhaps ultimately protecting them from significant moral and emotional distress.

Although principles are upheld as primary in ethical deliberation during medical encounters, the face-to-face process of communication may trump abstract principles like autonomy. A communicative ethic that places the consensus that emerges through discourse above a rational determination of best interests may in fact be superior for all par-
ties involved. De Vries et al. (2013:8), in a study that examined the best interests of children in an oncology setting from the perspectives of health care providers, parents, and patients, concluded that the consultation process could be shaped by communicative ethics: “Our data suggest that the best interests standard is not defined only by abstract, philosophical, or legal terms. Eventually, the shared intention to act in the best interest of the child should be guided by a standard that understands best interests as a matter that comes about through consultations.”

**Limitations of Communicative Ethics**

A communicative ethic represents an ideal and as such has inherent limitations. First, a communication ethic calls for consensus but does not provide a way to address conflicts in cases where a consensus cannot be reached. Second, it is assumed that all actors will be respectful of others’ perspectives and not elevate self-interests over the goal of reaching a shared understanding, a naïve assumption given difficulty of separating facts from ingrained biases. Further, a communicative ethic calls for all parties that have a stake in the outcome to be represented in deliberations about an issue, but it is not possible to include all stakeholders in physician-parent decision making. For example, it would not be feasible to include all family, friends, health care providers, insurance companies and society as whole (Gatter 1998). It also is difficult to include the child-patient, the primary stakeholder, because of his or her young age.

Therefore, a communicative ethic cannot be the sole basis for bioethics in a pluralistic society, but it can inform our approach to ethical and effective EOL physician-
parent communication in significant ways. And, as such, it could serve as an effective way to structure the training and continuing education of physicians.

Implications for Training

Although most children who present for care eventually get better, in the U.S. 48,000 children die per year (Kochanek et al. 2012). As one participant pointed out, even when death is rare, “…I will guarantee you, that when you have to talk to families, you wish you had more training” (II:8). Participants in this study felt they received inadequate training in EOL communication as well as EOL ethics. Although accumulated experience provided them a measure of preparedness, some reported that even after decades of practice, they still felt uncomfortable with EOL interactions with parents. These finding are supported in the literature, indicating that a significant barrier to appropriate EOL care for children is the lack of prepared physicians (Basu 2013; Berlinger et al. 2013; Levetown 2008). For example, in one study examining physician’s self-reported confidence levels about delivering aspects of palliative care, the researchers found that only 19% of the respondents were “very confident” in their ability to deliver difficult news to children and 27% were very confident to deliver difficult news to children’s families (Sheetz and Bowman 2008). Even in hematology/oncology fellowship programs, a specialty where EOL issues frequently emerge, one study found that 92% did not require a rotation in palliative care and 37% did not offer any electives in palliative care (Roth et al. 2009). While the accreditation council on Graduate Medical Education now requires that pediatric training programs include formal instruction related to the ‘impact of chronic diseases, terminal conditions and death on patients and families (Rider and Keefer 2006) residents
and fellows still report none to moderate levels of training, experience, knowledge, competence and comfort in palliative care (Kolarik et al. 2006; McCabe, Hunt and Serwint 2008; Michelson et al. 2009; Wittenberg-Lyles et al. 2008)

An Institute of Medicine report (2004) Improving Medical Education: Enhancing the Behavioral and Social Science Content of Medical School Curricula, examined the extent to which the behavioral and social sciences were addressed in US medical schools and made recommendations for improvements. Because of the lack standardized course content, this task was difficult. However, the report identified six general domains of knowledge that were needed to enhance medical school curriculum, two of which were identified in this study: (1) physician role and behavior and (2) physician-patient interactions. Within each domain, high and medium priority content areas were identified. The six domains identified by the 2004 IOM report, including the two emphasized here, were integrated into a teaching and learning matrix published in a 2011 report from the Association of Medical Colleges (AAMC), Behavioral and Social Science Foundations for Future Physicians, indicating the sustained view of their importance.

All of these content areas within the two domains emerged and were integrated together in this study. Within the physician role behavior domain, high priority areas include “ethical guidelines for professional behavior” and “personal values, attitudes, and biases as they influence patient care and physician well-being.” This study suggests that physicians’ narratives may influence communication and care. Further, moral distress and emotional distress emerged as significant themes as well as ethical ambiguities that arise in EOL care, in particular those surrounding the best interests standard. In the domain of physician-patient interactions, high priority areas include basic communication
and complex communication skills. Medium priority topics include the “context of patient’s social and economic situation, capacity for self-care, and ability to participate in shared-decision making” as well as “the management of difficult or problematic physician-patient interactions” (Cuff and Vanselow 2004: 9). This study found a need for more training in EOL communication skills, especially with regard to challenging interactions. It also identified the importance of understanding the patients'/parents’ lifeworld and the need for physicians to address the moral and emotional distress they experience through self-care. In this study, all the concepts described in the IOM 2004 report, described above, were integrated together and linked to communication. A communicative ethics approach to training would address all areas, but in an integrated way.

The AAMC (2011) report identified several barriers to incorporating the recommendations into medical school training that were present in the 2004 IOM report such as the lack of faculty in behavioral and social science disciplines in medical schools, the lower status of these disciplines within medical education, the limited leadership, and inadequate financial resources. Training at all levels of practice has the potential to increase physicians’ comfort with EOL physician-parent communication and thus, improve outcomes from the perspective of all parties involved. And, utilizing the model of communicative action in training physicians could effectively get to each of these areas in an integrated and comprehensive manner. However, even if fellows are receiving more training in EOL communication than their attendings, as discussed in the findings here, they may lack effective role models and may be left to learn to communicate with patients through a process of trial and error (Levetown 2008). Therefore, any communication training pro-
grams should include both attendings and trainees as well as institutional changes to the structure in which medical education occurs.

The potential need to train the trainer is seen in the idea of the “hidden curriculum” in medical education that was discussed in Chapter 2. If it is true that most of what is learned in medical school does not come from formal courses and experiences, it is imperative that research examine how the hidden and informal curriculums affect training in EOL communication. Physicians in this study were in agreement that they learned by far the most about EOL communication from their mentors. If mentors are not equipped to model effective EOL communication, then skills learned in the classroom may not be effective.

_A Training Program Informed by a Communicative Ethic_

In Chapter 2 we discussed patient-centered communication (and extended the idea to parents), which is characterized by the physicians eliciting the patient’s perspective, seeking to understand the unique situation of the patient and reaching a shared understanding of the problem and treatment with the patient, while helping the patient share power (Epstein et al. 2005). Associated with quality health care, decreased health care expenditures (Bertakis et al. 2009) and higher rates of patient satisfaction (Bertakis et al. 2009; Christen et al. 2008), it was suggested that teaching physicians to engage in this kind of communication with parents could be beneficial in upholding parental autonomy as well as satisfaction with EOL decision-making.

Patient-centered communication naturally emerges from a communicative ethic, but to focus solely on patient-centered communication without taking into account the
other tenets of communicative ethics leaves the practice devoid of a foundation. It makes the process of communication vulnerable to what one participant described when he responded to a question about effective training practices, “I think all that kind of training that happens in medical school is in a way an exercise in acting. And that has some value. But I don't think it's not what the families truly, deeply want.” Further he claimed,

I think you can role-play and yes you can desensitize yourself to the awkward conversations and you can learn to make a certain face and say certain words that work well, but I'm not sure if that's what I would really want. Just to have a doctor who had practiced a lot of acting as much as to have the real thing (III:14).

Serious assent to a communicative ethic would prevent communication training from being focused on skills to enhance patient agreement to ends prescribed as desirable by the culture of medicine, or the physicians’ own values, without taking the patient’s perspective into account (Smith 1996). In order to be the “real thing” (referred to by the participant in the previous paragraph), communication must respect the lifeworlds of both parties while also realizing that sometimes consensual decisions are just not possible. But even in the absence of a consensus, mutual understanding can be reached. In short, communication training must go beyond strategies to encompass the lifeworlds of all parties involved and be integrated with training in ethics. Both the IOM (2004) and AAMC (2011) reports discussed above identify the importance of the lifeworlds of both physicians and patients (we extrapolate this to parents and families). For communication to be ethical, the physician must recognize how his or her own biases translate into communication and care decisions, and he or she also must genuinely seek to understand the lifeworld of the patient and family.

More closely linked to a communicative ethic than patient-centered communication is relationship-centered care (RCC). RCC is premised on the foundation that, “All
illness, care, and healing processes occur in relationship—relationships of an individual with self and with others” and “…can be defined as care in which all participants appreciate the importance of their relationships with one another” (Beach, Inui and Relationship-Centered Care Research 2006:S3). RCC emphasizes the importance of several aspects of the care process: the personhood of all those involved (patient, health care provider, and the community), the significance of emotions, the reciprocal nature of relationships, and the fact that working to form and maintain relationships holds moral significance. In the research presented here, the primacy of establishing relationships in the communication process in pediatric EOL care emerged as a prominent theme. Integrating the elements of RCC with components of a communicative ethic offers significant promise in the training and education of physicians in a communicative ethic.

EOL physician-parent communication training programs based on a communicative ethic would ideally include 3 distinct areas: (1) knowledge: understanding facts related to EOL care, (2) norms: recognizing how decisions are made and ethical judgments formed, and (3) communication: learning specific tenets of communicative action in the process of discourse. A list of competencies in each area is given below in Figure 4. This model is structured around a communicative ethic and the content is based on themes that emerged in this research and are substantiated by guidelines issued by professional medical organizations for both general communication training and training in EOL issues.

Figure 4: A Communicative Ethics Approach to EOL Physician-Parent Communication Training for Physicians
Area One: Clinical Knowledge
- Differentiate clinical facts from personal opinions and values
- Possess a comprehensive knowledge of palliative care, including when to refer
- Acquire an understanding of EOL ethics, particularly the best interests standard
Area Two: Physician Lifeworld and Normative Beliefs

- Reflect on the influence that one’s own lifeworld (narrative and personal characteristics and beliefs) has on physician-patient EOL communication and care, focusing on physician gender, religion, race/ethnicity (not covered in this dissertation due to lack of diversity in the participants), specialty, seniority, personal experience with death
- Consider how EOL interactions impact one’s lifeworld (including emotional well-being and personal relationships)
- Translate personal distress into more effective practice

Area Three: Communication

- Practice effective communication strategies:
  - Avoid ambiguous phrases such as “doing everything” and “taking care” in reference to life-sustaining technology.
  - Determine when to use appropriate acronyms with regard to EOL care, such as AND or DNAR as opposed to DNR and when to avoid them altogether.
  - Detect when one is using cautious optimism in communication
- Recognize that communication is a process that occurs simultaneously with decision making and reaching a shared understanding and includes the following components:
  - Build Rapport: create an egalitarian, non-coercive atmosphere for discourse; connect on points of shared understanding (i.e. religious concordance)
  - Establish a Relationship: build trust through shared understanding, listening, and spending time; solicit information related to crucial components of the family’s lifeworld (level of understanding of clinical aspects, religion, values, beliefs, where they are in the grief process); recognize situations that are appropriate for sharing pieces of one’s lifeworld (experiences, values, beliefs)
  - Address Emotions: empathize with parents; refer to other members of the healthcare team when appropriate (chaplains, social workers)
  - Prepare Parents: provide crystal-clear clinical information as well as ethical guidelines based on the best interests standard (area 1) and recommendations for treatment justified by facts and appeals to one’s own lifeworld (area 2).
- Appraise when the situation calls for more directive recommendations.
- Recognize that reaching a shared understanding of the situation at hand is the primary goal.
- Work to reach a mutually agreed upon course of action with the parents.
- Recognize when conflicting lifeworlds are making reaching consensus difficult or impossible.
- Resolve that parents sometimes need more time to make EOL decisions.
• Refer to outside sources such as the ethics committee or legal counsel in rare cases where patients’ best interests, based on a standard of reasonableness, are being violated.

• Model effective physician-parent EOL communication for colleagues and trainees

**Area One: Knowledge**

In order for dying children to have excellent care, effective communication is paramount. A communicative ethic says that communication is more than just information-giving. But, information is important. Understandable and honest information about the undisputable clinical facts related to their child’s condition is crucial in order for parents to make appropriate decisions. Physicians are well trained in their assessment of the clinical aspects of care. However, highlighted here are two potential knowledge gaps related to factual information: (a) palliative care and (b) ethics, particularly the best interests standard.

Physicians must not only understand the specifics of the patient’s condition, so they can explain them to the family, they also must have accurate knowledge about EOL care in general. Care for many seriously ill children should simultaneously include both curative and palliative aspects. Even amidst uncertainty in making EOL prognoses, physicians can ensure that pain and suffering can be ameliorated (Berlinger et al. 2013). Physicians treating children at the EOL also should be aware of health care policies, like the fact that under the Affordable Care Act, state Medicaid programs fund hospice care concurrently with curative care if needed (Berlinger et al. 2013; Lindley 2011). Physicians should be able to recognize their own knowledge gaps and when a referral to palliative care is appropriate. An interesting finding in this research was the fact that physicians, in relation to seeking assistance in EOL care and communication, rarely mentioned palliative care and hospice. In addition to clinical and policy knowledge, physicians need to be
able to comprehend and to explain the best interests standard to parents so they understand it as a standard of reasonableness, and that decisions must be based on the child’s interests, not their own (Berlinger et al. 2013). And, physicians should be able to anticipate when disputes over best interests will arise so they can work towards a shared understanding (Kopelman 2013).

Finally, physicians should be able to distinguish between clinical facts and their own opinions and represent information appropriately. Determining prognoses for children at the EOL can be ambiguous and it may help physicians to understand how to represent this appropriately to parents. Once facts are determined, the quality of information-giving becomes paramount and this is explicated more fully in Area 3 below.

**Area Two: Norms and Value Judgments**

In addition to information-giving, a communicative ethics approach calls for the justification of claims to universal norms. As mentioned above, physicians must be able to separate clinical facts about the case from their own personal opinions and values. Training would be an effective way to help physicians understand how their own narrative effects their interactions with families. As both the 2004 IOM and AAMC 2011 reports and this study confirm, physicians must reflect on aspects of their stories that have the potential to influence communication, such as their parental status, religious/spiritual beliefs, and crises in their lives such as their own experience with death.

For example, interviews in this study indicate that physicians’ personal religious narratives are integrated into their work. Whether intensely religious currently, culturally Catholic, or a professed atheist, religion affects many aspects of physicians’ practices in-
cluding communication, decision-making, and coping with the moral and emotional distress that results from dealing with patients who are at the EOL and their families. Physicians need to understand how their own values affect their interactions with families.

Further, helping physicians understand how their worldview may be shaped by the powerful culture of medicine could lead to critical self-reflection. Clark (2009) devised a Physician-Worldview Scale and found significant differences between allopathic physicians and naturopathic physicians in five dimensions: spirituality, deep ecology, nature of medicine, and critique of science and diagnosis and treatment. Sensitizing physicians as to how their training affects their worldview could lead to a more integrative approach to care (Clark, Clair and Culpepper 2014 under review).

Physicians in this study also recognized the significance of their own parental status in how they interacted with parents of their patients. Understanding the nuances of the effect of parental status is important in ensuring that communication is unbiased and appropriate. Personal emotional pain resulting from interactions with dying children and parents and grieving over patient deaths may influence EOL interactions. But, besides the potential for personal emotional pain to affect physicians’ practices negatively, if addressed properly, it also has the possibility to enrich physician-patient/parent relationship in positive ways. For example, one female PEM attending stated that, “If I don’t allow myself to grieve for my patients, then I’ve lost the humanity that made me want to go into medicine (II:8).

Communicative ethics tells us that both clinicians’ and patients’ stories are important in the therapeutic relationship. Physicians can be better caregivers by understanding their own backgrounds with illness and death including the deaths of their patients,
and how their religious/spiritual beliefs are integrated in to those. The concept of the wounded healer suggests that health care providers can perform their duties more authentically by recognizing their own suffering (Charon 1993; Kleinman 1988; Nouwen 1972). However, in order for personal grief to translate into more effective practice, the pain must be dealt with in constructive ways and this can be addressed in training. The Hastings Center’s guidelines for pediatric decision making also emphasize the importance of health care providers who treat dying children having opportunities to reflect on their own pain associated with interacting with families and dealing with their patients’ deaths (Berlinger et al. 2013).

**Area Three: Communication**

Finally, a structured program in EOL communication based on communicative ethics would include particular skills in effective communication, so that the physician can be sure that the parents understand factual information, as well as his or her normative perspective and corresponding justification. Training can help physicians and trainees recognize that EOL physician-parent communication is a process that occurs simultaneously with decision making and reaching a shared understanding and includes the components of building rapport, establishing a relationship, addressing emotions and preparing parents. It could be assumed that getting to know the parents’ stories (establishing rapport and building a relationship from Figure 3) is inherent in understanding their values and position. But it may not be. Understanding a family’s general ability to grasp clinical information, religious beliefs and “where they are in the process of letting their child go” as one participant put it, can help physicians communicate in ways that are ap-
appropriate for the situation. Understanding the child’s preferences also is important, even in very young children. And, child’s preferences should take precedence over the parents’ (Berlinger et al. 2013). The family is important, but the physician’s ethical responsibility is to the child (Lantos 1997; Truog 2010). This is an area that was not examined in this study, but should be in the future. An understanding of the best interests standard (area 1 above) can help physicians sort through the ethical ambiguities when parents’ objectives and decisions differ from their child’s.

Further, in establishing rapport and throughout the communication process, physicians need to understand the basics of egalitarian, non-manipulative/non-coercive and unambiguous communication. Simple strategies such as not interrupting when the patient/parent is talking and being cognizant of asking open ended questions can contribute to better, more egalitarian and non-manipulative communication. According to the Hastings Center guidelines and suggested in these findings, physicians should strive to avoid phrases like “withdrawing care” when talking about limiting life-sustaining measures and “doing everything” when talking about instigating them, so that that parents understand that their dying child will continue to be cared for in the best way possible (Beringer et al. 2013).

Physicians also can learn to avoid ambiguous acronyms such as DNR and use others such as DNAR or AND when appropriate or avoid them altogether. Training could help physicians understand how they may use cautious optimism (Clair 1990) in their interactions and unknowingly be building false hope in their parents and patients. This false hope has the potential to lead to substandard parental decisions about whether or not to cease life-sustaining technology and/or focus on palliative measures.
Establishing a relationship is key to building trust and this can be done through spending time with and listening to the family. Beach et al. (2006) offers concrete knowledge, attitudes, and behaviors that could be taught to work toward RCC outcomes. For example, physicians and trainees can be taught to solicit important information about the family’s lifeworld, such as their level of understanding of the child’s condition, religious beliefs, values and where they are in the grieving process. Basu (2013:734) outlines specific questions that can be asked of parents to help improve the “quality of pediatric death”. The questions include: “What is your understanding of your [child’s] prognosis? What fears do you have? What are your goals as time gets shorter? How do you want your child to live knowing that he/she is going to die? What are you willing to put your child through for the possible trade-off of more time?” Arming physicians and trainees with these questions such as these could provide them a basic framework for soliciting EOL feelings from parents.

Physicians need to know when sharing their own lifeworld is appropriate in order to reach a shared understanding of the situation at hand. This may include sharing his or her own struggles with losing a loved one or it may include sharing personal religious beliefs once religious concordance is established, as many physicians in this study described. On the other hand, physicians should also understand when personal sharing might not be appropriate. Several participants in the RRR group (the most religious) shared that they sometimes subtly imposed (or thought about imposing) their own religious beliefs on families with non-concordant beliefs.

Physicians also can be taught to address emotions in patients and parents as well as in themselves; however, currently there are no adequate models in medical education
that effectively address the emotions of trainees or their reactions to emotions in their patients (Shapiro 2011). We do know that precisely at the time in medical school when the curriculum shifts to patient care (the third year) there is a documented decline in empathy among medical students (Hojat et al. 2009). But, if “medicine ultimately is about human beings interacting with other human beings” (Shapiro 2011:330), then it is apparent that because interpersonal interactions always are centered around emotions (Stone et al. 1999) that developing skills in emotional dimensions of care is as important as other aspects of clinical care.

Hojat (2009) describes 10 approaches for retaining and enhancing empathy at all levels of medical education such as analyzing taped patient encounters, working with role models, and role-playing. Other suggestions include focusing on the medical humanities and integrating narrative medicine, mindfulness, and reflective writing to increase the emotional capacity of trainees (Shapiro 2011). At the very least, physicians could be sensitized to recognize situations when they cannot adequately address emotions in their patients and/or themselves, and learn when it is necessary to refer to chaplains, social workers, and therapists. Training also can help physicians use lay and unambiguous language in interactions with parents so that information about their child’s condition is presented clearly and effectively, including the physician’s recommendations for treatment. Phase I of this study found unclear and coercive language being used by well-intentioned physicians. Helping prepare parents also includes providing them with clear information about what the best interests standard means for their role in medical decision-making for their child (Kopelman 2013). Physicians need to understand the limits of patient/parent autonomy, and through training, physicians can learn how to be more directive in cases where
parents want them to make the decision about limiting life-sustaining technology (because their parental role conflict will not allow them to do it) or in cases involving discontinuing futile CPR (Clark and Dudzinski 2013; Truog 2010).

Finally, physicians can be taught the components of communicative ethics recognizing that reaching a shared understanding of the situation at hand is the primary goal. And even when they work to reach a mutually agreed upon course of action with the parents, they also will be able to better recognize when conflicting lifeworlds are making reaching consensus difficult or impossible. When a shared vision for the treatment decision cannot be made, physicians can learn that parents sometimes just need more time to make EOL decisions, a concept that emerged in this study. But, in rare cases when the physician feels the patient’s best interests are being violated, he or she needs to understand how to refer the case to outside sources such as another health care provider, the institutional ethics committee or legal counsel.

Pedagogies for EOL Training based on a Communicative Ethic

Physicians of all ranks in this study agreed that they were not trained adequately in EOL communication. The difficulty is finding time in curriculums that are already full and have many disciplines competing for time (Cuff and Vanselow 2004). Although more than 80% of medical school training in communication skills occurs in the first two years (Cuff and Vanselow 2004), participants here felt that training in EOL communication should come later, when students understood the importance of it based on their experiences with patient care. Most participants could not clearly remember the type of communication training they had, and many said they did not receive specific training in
EOL communication. Few mentioned any EOL communication training in residency. One male PCC fellow stated that EOL communication in residency was, “Trial by fire. You get good very good quickly at that, at giving bad news, but you botch it a lot more” (II:17).

The presence of the hidden curriculum in medical training makes thinking about training in communicative ethics more complex. However, since the most significant type of training that emerged in this study was that which they received from observing mentors, it is important that their attendings have adequate skills, so that poor EOL communication will not be what one male PEM attending called, “a self-fulfilling state” (I:20). Therefore, perhaps training in communicative ethics should start with attendings and medical school faculty (Paul et al. 2014). Offering continuing medical education (CME) for attending physicians in EOL physician-parent communication might be a way to achieve this goal.

Researchers have found that faculty development programs can teach medical school faculty to embody more humanistic characteristics (Branch et al. 2009) and even accomplish institutional change (Steinert et al. 2007). Many attending physicians in this study expressed discomfort with EOL interactions with families and for some of them the grief caused by these interactions lingered. Further, this research suggests that attending physicians might not fully understand how their biases, especially those related to religious beliefs, affect their EOL interactions with parents. Since so much training in communication happens through mentoring relationships, it is important that attending physicians model appropriate interactions for their trainees. Although no doubt many mentors are “masterful” at communication (II and III:20), both fellows and attendings reported
observing poor quality interactions between parents and attendings in their training, where attendings were pushy, abrupt, or using technical language that families may not understand. Some even felt that they had to go back, as residents, and try to do “damage control” with the family (II:2). Although asking attendings to change the way they practice communication may not be well received, providing continuing education in communicative ethics may be one way to stop the “self-fulfilling state” (I:20) of poor EOL communication among physicians.

For all levels of training, didactic approaches like lectures and case studies have value and serve to provide foundational information like evidence-based guidelines for palliative care and ethical guidance related to the best interests standard (Area 1 above). Didactic approaches also may work well for teaching basic effective communication strategies in egalitarian discourse with families in Area 3. In Area 2, reflective exercises like structured journal writing and small group discussions can help physicians understand how their own stories, including their biases about quality of life, influence their approach to EOL care and communication. In Area 3, observations provide physicians examples of good EOL interactions, and participants agreed that modeling is how they learned EOL communication most significantly. Practice, however, may be the most important pedagogy, and it should be implemented before physicians face real patients and families. Role playing and simulation, according to the participants here, are invaluable to this process as they provide opportunities for feedback and give learners a sense of the difficulties that will arise before they have the potential to hurt families and themselves through a poor EOL interaction. Further, in this study, the idea emerged of hearing from parents of children who have died as a way to help physicians understand the parents’
lifeworld. Parents could share their journeys related to having a dying child, particularly how their interactions with their health care providers affected them. If this is not possible, at the very least learners could read and discuss journal articles that give the parents’ perspectives on EOL communication. Training in EOL physician-parent communication, such as that based on communicative ethics, is important for medical students, residents and fellows, but it is also crucial for attending physicians.

Limitations

This study has several limitations. First, the use of high-fidelity simulation had limitations of its own; primarily, the extent to which the participant views the simulation as a real life setting will influence the validity of the results. If the participant sees the simulation as realistic, he or she will be more likely to engage the actor-mother as he or she would a real parent. However, if the participant does not view the simulation as realistic, there is a chance he or she will not put forth effort and the time to communicate effectively with the actor-mother, thus skewing the results. Fellows viewed the simulation as more realistic than attendings, most likely due to their experience in simulation in a variety of training capacities. Some attendings believed that their performance was compromised because the mannequin altered their ability to use their intuition and because they presented to the experience expecting to perform a procedural task. There also is the question of whether or not time of visit (a dependent variable) is a valid measurement of the quality of the communication. Although research points to the fact that time is a valid measure, there could be cases where longer sessions do not reflect better communication,
such as if the participant takes longer to diagnose the problem or if the simulation facilitator errors in manipulating the mannequin’s vital signs and symptoms.

Other limitations include sample size and selection. In Phase I of this study the small sample size limited the usefulness of the quantitative data, and I was merely able to use the quantitative findings to describe the participants as opposed to making any definitive claims of significance. Further, the participants came from only two specialties in one hospital setting; therefore, there is the possibility that clustering may occur and participants in the sample may be more similar to each other because they come from one setting. Finally, because this study utilizes a convenience sample of participants recruited through e-mail, there is the possibility of selection bias in that those who chose to participate may have different characteristics than those who did not choose to participate.

Future Research

This study raises questions that should be addressed in future research. More research is needed on the relationship between pediatric physicians’ gender, religious/spiritual beliefs, parental status and early experiences with death and their practice of medicine, particularly in relation to EOL physician-parent communication. Findings from more qualitative studies in different types of pediatric specialties would help ground large quantitative studies on narrative characteristics and practices (Curlin 2008). Further, large multi-site and multi-specialty high-fidelity simulation studies would verify the results that emerged here. Observational studies, notwithstanding their difficulties, to examine communication used by physicians in interactions with parents also would yield important information. Ultimately, the goal of these studies would be the development
of training interventions that help physicians better understand how their personal narratives influence their care of patients as well as interventions that help them communicate more appropriately with families of EOL pediatric patients. These types of training programs have the potential to lead to more appropriate care for children at the EOL, better interactions with families, and decreased moral and emotional distress of the physician.

In addition to training individual physicians, structural changes at the institutional level are necessary. Future research should explore ways that structural conditions influence pediatric EOL communication. For example, physicians in this study from both PCC and PEM felt the stress of not having enough time to spend with families. Exploring how medical financing influences the time available for doctors to build relationships with patients and parents is an important area of study.

Also, the quantitative data suggest that fear of malpractice may influence physicians' communication with parents, yet since the topic was not breached in the interviews, they may be unaware of its influence. Studies that examine how malpractice laws influence pediatric EOL physician-parent communication would make important contributions to the literature.

Further, examining how the hidden curriculum can be addressed to improve communication training is another important area of research. Research has indicated that both the hidden and informal curriculums are powerful forces in shaping physicians. Any training that is implemented could be neutralized if it does not comply with the powerful medical culture. But research has also indicated that the hidden curriculum can work in positive ways when it involves exceptional role models.
Studies indicate that the hospital environment, while feeling comfortable for health care providers, is unnatural and intimidating for patients and parents (Clair 1990; Meert et al. 2009). This could lead to impaired communication. Examining how the environment of the PED and the PICU could be altered to encourage better communication would be another area of research.

And finally, looking at how care can become more integrated, so that new providers can quickly understand more of the patient’s history and the parents’ perspectives related to EOL care is another significant topic for future research. For example, perhaps a flag in the electronic medical record could indicate whether or not a patient has a DNR status or if EOL discussions have occurred in patients with life-limiting conditions.

Conclusion

In conclusion, medicine is undergoing a fundamental shift and this is evidenced by the recent emphasis on including the social sciences in medical training (AAMC 2011). As medicine continues to change its focus from acute to chronic disease care, understanding the social contexts of patients and the social processes that occur during the medical encounter will become more important. Changes in the discipline of bioethics are paralleling this shift in medicine and the idea of moving beyond purely rational principles is being entertained (Wasserman and Stevenson 2013). But, much work is yet to be done in integrating social science theory into medicine. For example, observers have pointed out those two significant paradigms in modern medicine, evidence-based medicine and patient-centered medicine may not be compatible as they stand now. Evidence-based medicine comes from a positivistic, biomedical perspective, whereas patient-centeredness
(and RCC) is a humanistic, person-centered approach that lacks significant evidence (Bensing 2000). Bensing (2000) suggests that communication research could help bridge the gap between evidence-based medicine and patient-centered approaches. This research adds to the developing knowledge base of communication in medicine.

Although the quantitative results should be considered preliminary because of the small sample size (n=21) and limited statistical power, I am confident that the qualitative findings (n=17) are both replicable and generalizable to specialties beyond PCC and PEM and facilities beyond the one from which the participants came. The first round of interviews (post-simulation debriefing interviews) yielded 16 interviews (4 were lost due to technical error and one participant did not consent to have the interview taped) and phases II and III yielded 17 interviews each. Therefore 50 interviews were analyzed in this study, including 13 groups of 3 and 4 groups of 2 longitudinal interviews. Across the longitudinal interviews, by the third round the data became repetitive and saturated with themes and subthemes emerging as clearly dominant.

Although we expect physicians to be objective interpreters of clinical information, this research highlights the human side of physicians and suggests they cannot possibly be completely objective because of this humanity. They are people of faith as well as men and women, husbands and wives, parents, teachers, counselors and philosophers and all these roles affect their work as clinicians. That these physicians care immensely for the patients and families that they treat is a theme that came through often in these interviews. And, just as their unique narratives affect their professional practice, their interactions with patients and patient’s families affect their personal lives deeply.
The physicians studied here were overwhelmingly in agreement that their own background and experiences affected the way they cared for patients which ultimately affected their EOL communication with parents. They were aware that these effects were subtle, but present to varying degrees, and although they tried to be objective, personal emotions often were indicators of a compromised communicative action. However, that loss of objectivity was not always seen as negative as the physicians realized that their humanity played an important role in their care for patients and their families. Perhaps if physicians can be aware of their biases and how they shape their practice, they can connect with patients and their families on deeper level and provide far more quality care than as a dispassionate clinician.

Many participants discussed how their perceptions and beliefs related to EOL care had changed as they worked through the complexities inherent in their practices. Surely training could help them come to terms with these difficulties earlier in their careers. A communicative ethic could provide the structure for EOL physician-parent communication training that would encompass not only effective communication “strategies” but also help learners understand how to reach a shared understanding of the problem at hand and ultimately how to reach a consensus as to the most appropriate course of action. A communicative ethic is a person-centered, relationship-focused approach that contrasts to the rational objectivity inherent in principle-based ethics and the medical culture in general. There often is little effort put into how to teach a physician to work with the truly individual, subjective information in the medical encounter in a way that bolsters the care process. Rather, the goal is more to make the patient or parent feel good (to feel accom-
panied), which is not altogether a bad idea, but it sells short the process of integrating the humanistic content of the encounter in ways that truly benefit the care process.

The importance of viewing partners as equals and respecting the lifeworld of the other, while understanding how one’s own lifeworld affects communication, could be emphasized. Integrating clinical ethics into training, as a communicative ethic would do, could help learners understand the complexities involved in EOL decision-making. One attending recalled that simply watching a film with a case study on patient autonomy in EOL decisions helped him see gray areas emerge from what he previous regarded as his black and white view of always striving to save lives. Training in palliative care guidelines also could contribute to better EOL interactions with families, because physicians would be more comfortable with the most effective approaches to care.

Families and physicians each come to the table with their own set of life experiences, beliefs, and values and when those conflict there may be a discrepancy about the best course of action. The beauty of a communicative ethics approach is that communication is not seen as a failure if a consensus on a course of action cannot be reached. Simply reaching a shared understanding can be a worthy goal. And, then, even if the decision at hand is not one with which the physician completely agrees, he or she is less susceptible to moral and emotional distress because there is an understanding of the family’s position as well as the knowledge that his or her side was presented effectively. The outlines of a communicative ethic are most certainly practiced on a daily basis by many physicians. But, using communicative ethics as a foundation for training in physician-parent EOL care could provide a structured approach to increase the likelihood that physicians who treat children at the EOL will feel like they have fulfilled their mission.
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APPENDIX A

Simulation Medical History

Current Situation:
- 8 year old girl diagnosed with O’Neil-Needham disease, a progressive neuro-degenerative disorder with no cure.
- Brought to the ED for fast breathing which was noisy and bluish around lips. No fever, has not been around anyone who is sick. Started last night but much worse now.

Developmental History:
- A normal newborn and infant, your daughter has exhibited a steady and relentless decline in physical and cognitive ability.
- She stopped walking at 2 years, lost the ability to speak at 3 years, has been unable to use her hands since the age of 4, and for the past 3 years, has been essentially unresponsive.
- Her sole means of communication is an expression of discomfort when hungry or when she needs to be changed.
- She does not see, and no longer responds to sound.

Feeding History:
- Fed by a gastrostomy tube, placed at 4 years of age.

Doctors involved:
- Dr Davis, primary care doctor
- Dr. Mathisen, neurologist, sees her about once per year, or when she is in the hospital. She has seen multiple subspecialists in the past but none actively now

Recent Past History:
- She has been hospitalized 3 times in the past 4 months, each time for respiratory distress (trouble breathing).
- The last two times, she was intubated and placed on a ventilator – the first occasion for one week, the second for 4 weeks.

Family History (perspective of mother):
- You have no other children, and you provide the majority of care for your daughter.
- You prefer not to have your child in school or respite care.
• Your husband is supportive but is also the sole means of monetary support for your family. He is your daughter’s step father (her father passed away) and he says that he wants you to make the decisions about her care.
• There is no family history of a similar disorder.
APPENDIX B

SIMULATION SCRIPT FOR ACTOR-PARENT

**O’Neil Needham Dx**: A progressive neurodegenerative disease with no known cure. Leads to mental retardation, weakness and failure to eat. Can cause blindness but usually not deafness.

Doctor asks question like, “Is your child a DNR”,

**Mom answer**: “no”

Doctor “do you want your child intubated”

**Mom answer**, “I don’t know, what do you think I should do?”

Doctor replies, “whatever…”

**Mom answer**: “What do you mean?”

If doctor brings up BIPAP **mom says**, “She cannot tolerate that. The ICU team keeps trying but the mask never fits and she cannot coordinate with her breathing. Last month Dr Makris and the ICU team told me to not use again.”

If asked directly about DNR **mom can say** “Nobody has really talked to me about that before” or

**Mom**: “My husband and I have been talking about the fact that she keeps getting sick and we really don’t understand why”

Mom can emphasize that she wants her daughter to be comfortable.

**Mom**: “She looks like she’s in pain. What can you do?” or

If the doctor suggests that he doesn’t have to intubate: **Mom can say**. “If we’re not going to intubate, what can we do?”
APPENDIX C

Post-Simulation Questionnaire

1. What sex are you?
   1) Female
   2) Male

2. How old are you?
   _____ years

3. Are you of Hispanic or Latino origin?
   1) Yes
   2) No

4. Which one category best describes your racial background?
   1) White
   2) Black or African-American
   3) American Indian or Native American
   4) Asian or Pacific Islander
   5) Other

5. Where do you work?
   1) Emergency Department
   2) Pediatric Intensive Care Unit

6. What is your current job title?
   1) Resident
   2) Fellow
   3) Attending Physician

7. On a scale of 1 to 10, where 1=not tired at all and 10=worst tiredness you can imagine, what is your current level of fatigue?
   Not tired at all
   1 2 3 4 5 6 7 8 9 10
   Worst tiredness you can imagine

8. How many hours have you worked in the last 7 days? ________ hours

9. Are you a parent?
   1) Yes (go to Question 10)
   2) No (stop here)

10. If you answered yes to Question 9, please list the age(s) of your child(ren).
For Items 1-19, indicate your level of agreement on a scale of 1 to 7, where 1=strongly disagree and 7=strongly agree.

<p>| | | |</p>
<table>
<thead>
<tr>
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<tbody>
<tr>
<td>1</td>
<td>During this simulation I forgot I wasn’t dealing with a real child.</td>
<td>1</td>
</tr>
<tr>
<td>2</td>
<td>I am frequently worried about the legal consequences of an error in diagnosis or treatment.</td>
<td>1</td>
</tr>
<tr>
<td>3</td>
<td>A malpractice claim against a physician, whether justified or not, harms her or his reputation.</td>
<td>1</td>
</tr>
<tr>
<td>4</td>
<td>A malpractice claim against a physician, whether justified or not, harms her or his self-esteem.</td>
<td>1</td>
</tr>
<tr>
<td>5</td>
<td>An important component of the relationship with my patients is my understanding of the emotional status of the patients and their families.</td>
<td>1</td>
</tr>
<tr>
<td>6</td>
<td>I try to understand what is going on in my patients’ minds by paying attention to their nonverbal cues and body language.</td>
<td>1</td>
</tr>
<tr>
<td>7</td>
<td>I believe that empathy is an important therapeutic factor in medical treatment.</td>
<td>1</td>
</tr>
<tr>
<td>8</td>
<td>Empathy is a therapeutic skill without which my success as a physician would be limited.</td>
<td>1</td>
</tr>
<tr>
<td>9</td>
<td>My understanding of my patients’ feelings gives them a sense of validation that is therapeutic in its own right.</td>
<td>1</td>
</tr>
<tr>
<td>10</td>
<td>My patients feel better when I understand their feelings.</td>
<td>1</td>
</tr>
<tr>
<td>11</td>
<td>I consider understanding my patients’ body language as important as verbal communication in physician-patient relationships.</td>
<td>1</td>
</tr>
<tr>
<td>12</td>
<td>I try to imagine myself in my patients’ shoes when providing care to them.</td>
<td>1</td>
</tr>
<tr>
<td>13</td>
<td>I have a good sense of humor, which I think contributes to a better clinical outcome.</td>
<td>1</td>
</tr>
<tr>
<td>14</td>
<td>I try to think like my patients in order to render better care.</td>
<td>1</td>
</tr>
<tr>
<td>15</td>
<td>I feel confident in my ability to talk with patients or their surrogates about consent for medical procedures about which I am knowledgeable.</td>
<td>1</td>
</tr>
<tr>
<td>16</td>
<td>I feel confident in my ability to talk with patients or their surrogates about DNR orders.</td>
<td>1</td>
</tr>
<tr>
<td>17</td>
<td>I find talking to patients about DNR orders difficult.</td>
<td>1</td>
</tr>
<tr>
<td>18</td>
<td>When patients cannot speak for themselves, I find talking to patients’ surrogates about DNR orders difficult.</td>
<td>1</td>
</tr>
<tr>
<td>19</td>
<td>Have you ever been named in a malpractice suit?</td>
<td></td>
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</tbody>
</table>

Yes  No
APPENDIX D

Institutional Review Board for Human Use
UAB’s Institutional Review Boards for Human Use (IRBs) have an approved Federalwide Assurance with the Office for Human Research Protections (OHRP). The Assurance number is FWA00005960 and it expires on January 24, 2017. The UAB IRBs are also in compliance with 21 CFR Parts 50 and 56.

Principal Investigator: BATEMAN, LORI B
Co-Investigator(s):
Protocol Number: E120130002
Protocol Title: The Effect of Physician Characteristics, Experience, and Training on Pediatric End-of-Life Attitudes and Decision Making

The above project was reviewed on 2/8/12. The review was conducted in accordance with UAB’s Assurance of Compliance approved by the Department of Health and Human Services. This project qualifies as an exemption as defined in 45CF46.101, paragraph 2.

This project received EXEMPT review.
IRB Approval Date: 2-8-12
Date IRB Approval Issued: 2/8/12

Marilyn Doss, M.A.
Vice Chair of the Institutional Review Board for Human Use (IRB)

Investigators please note:

IRB approval is given for one year unless otherwise noted. For projects subject to annual review research activities may not continue past the one year anniversary of the IRB approval date.

Any modifications in the study methodology, protocol and/or consent form must be submitted for review and approval to the IRB prior to implementation.

Adverse Events and/or unanticipated risks to subjects or others at UAB or other participating institutions must be reported promptly to the IRB.