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## Spiritual Frameworks in Pediatric Palliative Care: Understanding Parental Decision-making

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Spiritual Frameworks in Pediatric Palliative Care:  
Understanding Parental Decision-making

by

Lindy Grief Davidson

A dissertation submitted in partial fulfillment  
of the requirements for the degree of  
Doctor of Philosophy  
Department of Communication  
College of Arts and Sciences  
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## DEDICATION

I dedicate this work to my family. To Adam, my best friend, greatest champion and favorite chef; to Aaron and Levi, who remind me there is more to life than school; and to Will, who has inspired this degree from day one and remains the greatest teacher I know, I love you all dearly and am so grateful that you have joyfully and sacrificially supported me through this adventure. To my parents, Jim and Donna Grief, who set an example of lifelong learning for me through their constant academic pursuits, I am grateful for your love and encouragement. To my sister, Shannan Gabe, who has never been satisfied with less than her best, thank you for spurring me on to new and greater heights. I will only make you call me “doctor” when we are in public. I am blessed to have such a wonderful family. I love you all.

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## ABSTRACT

Parents of seriously ill children are charged with making complicated medical decisions, and many of those decisions are made during their children's hospitalizations. As medical staff seek to support parents, it is important for them to understand what resources parents are drawing upon for decision-making. This project explored parental decision-making by examining the following research questions: **RQ1**: What resources do parents draw upon to make medical decisions for their seriously ill children? **RQ2**: How do parents enact their spiritual or religious frameworks in clinical settings when faced with medical decisions for their seriously ill children? Methods of research included ethnographic observation of a pediatric palliative care team and semi-structured interviews with twenty parents and grandparents of seriously ill children. Analysis of the interview data brought out three main themes: the role of spirituality for parents of seriously ill children, the ways parents perceive spiritual conversations with hospital personnel, and the role of spirituality for parents making difficult decisions. A case study is presented as an exemplar of complex decision-making, and the author offers her personal narratives of parenting a seriously ill child. The author suggests new directions for practitioners based on a constitutive approach to communication in which practitioners and parents work together to build towards an understanding of the child's illness. The findings from this study contribute to the current understanding of families with seriously ill children and should shape medical education in a way that will benefit the next generation of professional care providers as they seek to meet the needs of children and their families.

CHAPTER ONE:  
PEDIATRIC PALLIATIVE CARE, SPIRITUALITY  
AND PARENTAL DECISION-MAKING

**Introduction**

In a small hospital room, a mother picks up her infant son from a crib. Managing a tangle of wires, IV lines and oxygen tubing, she sits on the vinyl couch where she sleeps at night. Her son is a patient receiving pediatric palliative care, and I have come to hear her story. She is anxious to tell it. Over the next hour or more, I am transported into the life of a family plagued by conflicts with institutions. She tells me of their trouble with schools, with doctors' missed diagnoses, and with law enforcement officials. These stories about her older children do not seem to be answers to the questions I am asking about the baby's illness, but I listen and I type. As the stories flow out of her, I realize why she is hesitant to accept the diagnosis doctors have given her child. Between the physical signs of the disease and the genetic tests confirming it, the doctors are baffled at her request to repeat the test. What is obvious and logical to them is neither obvious nor logical to her. She tells me she believes God has a special plan for her son. The way she makes sense of her world does not match theirs, but she and her son are in their world now. In a few weeks, she will storm out of the hospital, infuriated with one of the doctors; but on this day, she sits with me and opens a window into her world of decision-making.

Twelve years earlier, it was I who held a tiny baby tethered to his hospital bed with tubes and wires. As I attempted to feed my three-pound son milk from a tiny bottle, I looked up at the

video camera my father-in-law held and, full of hope, talked about how well he was eating. The next morning, on the way to the hospital I received a call on my new cell phone purchased so I could be contacted in an emergency. The doctor asked for verbal consent to take my son to his first surgery. There had been a cancellation and they wanted to bump him up on the schedule. I consented to the surgery, feeling as if I had little choice in the matter. It would be over a month before I would hold my son again due to his post-surgical dependence on a ventilator. He would suffer a brain hemorrhage, begin dialysis, and present innumerable medical conundrums before I would be able to feel the weight of his tiny head in the crook of my arm and pull him close to my chest again. I was helpless. Stripped of any inkling that I could solve this problem, I had only my faith. That was enough for me to survive our four and a half month Neonatal Intensive Care Unit (NICU) stay in 2002, so as I sat opposite the woman holding her baby, seemingly oblivious to what lay ahead, I wanted to know if and how faith would factor in for her.

Parents of seriously ill children are charged with making complicated medical decisions, and many of those decisions are made during their children's hospitalizations. As medical staff seek to support parents and their decisions, it is important for them to understand what resources parents are drawing upon as they consider their choices. To physicians and other practitioners, medical information may seem to be the most important factor in decision-making, but research demonstrates that parents rely upon many other resources including spirituality, emotions, and relationships (Carroll, Mollen, Aldridge, Hexem & Feudtner, 2012; Lyndes et al., 2012). For providers, the influence of spirituality may be particularly difficult to understand, especially when parents are hesitant to share their views (Browning, Myer, Brodsky & Truog, 2007; Robinson, Thiel, Backus & Meyer, 2006). Furthermore, when spirituality is expressed, physicians may have a difficult time accepting it as a valuable influence in decision-making

(Kurtz, 2012; Llewellyn et al., 2013). The significance of these findings to the present study will be explored in the next section. These differences in understanding the role as well as the value of spirituality in parental decision-making require further exploration into the complex world of parents of seriously ill children.

## **Literature Review**

Pediatric palliative care is an excellent location to study the decision-making of parents of seriously ill children and the ways they engage spirituality. Palliative care not only takes into consideration the patient's medical concerns but also the patient's comfort, family and spirituality. In order to understand more about parents, it is important to first consider the current landscape of research in pediatric palliative care, spirituality and parental decision-making.

### **Pediatric palliative care**

Palliative care is a philosophy of care applicable to both terminally and seriously ill patients. According to the World Health Organization (2015):

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative care emphasizes symptom management, holistic care and quality of life and encompasses hospice care, which is reserved for patients with a life expectancy of six months or less. For adults, palliative care is more frequently associated with end-of-life or hospice care, but

for children, palliative care may be an appropriate form of care spanning years of life for a child with a life-limiting illness. Himmelstein, Hilden, Boldt, and Weissman (2004) explain:

The aims of pediatric palliative care should best intersect with the aims of curing and healing, and this approach should be instituted when diagnosis, intervention, and treatment are not limited to a disease process, but rather become instrumental for improving the quality of life, maintaining the dignity, and ameliorating the suffering of seriously ill or dying children in ways that are appropriate to their upbringing, culture, and community (p. 1752).

The World Health Organization (2015) states, “Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.”

Over the past ten years, many children’s hospitals have developed pediatric palliative care teams to meet the needs of children suffering from life-limiting illness and their families (IOM, 2014). These interdisciplinary teams assist patients and their families with not only physical care but also social, emotional and spiritual care (Himmelstein et al., 2004). Teams may include a combination of physicians, nurses, social workers, chaplains, dietitians, child-life specialists, therapists and/or other healthcare providers. Hospitals may be certified for palliative care programs through the Joint Commission (IOM, 2014). The NICU is one frequent location of practice for pediatric palliative care teams in children’s hospitals. NICUs are specialized units of intensive care for pre-term newborns as well as full term newborns with serious medical problems. Research suggests that nearly seven percent of babies born in the US are admitted to NICUs with the highest admission rates attributed to black babies and babies born to women age forty and older (Osterman, Martin, Mathews & Hamilton, 2011). Babies admitted to the NICU



vary in length of stay from a few days to as long as five or six months, with long-term patients often requiring complex care making them appropriate candidates for palliative care services.

Kimman and Doumic (2014) provide an overview of palliative care provided for NICU patients. They describe decision-making as an on-going process for parents of NICU babies and warn practitioners not to “temper bad news, resulting in ‘partial’ truth that is sometimes, in the worst case scenarios, based on falsehoods and omissions” (pg. 147). Kimman and Doumic blame this inaccurate delivery of medical information for parents’ unrealistic expectations. Other published case studies focus specifically on NICU parents. Kurtz (2012), a NICU nurse, presents the case of a baby whose family insisted on continuing treatment when medical practitioners felt there was no hope for survival. When the grandmother insisted that God could still save the baby, Kurtz reflected that medical staff should have engaged the family in spiritual conversations. Janvier (2007), a neonatologist, presented the case of her own NICU child born at twenty-four weeks. Her experience as a parent helped shape her understanding of parents who make decisions that confound scientific logic. Stutts and Schloeman (2002) explore another case of a NICU baby with no chance of survival. The family maintained hope for a miracle while prolonging life-support, resulting in medical staff feeling that their actions were causing the baby to suffer. Stutts and Schloeman call for a “decision-making model that would allow for integration of medical knowledge and family spirituality...to foster open dialog and collaboration” (p. 27). From the literature, it is clear that NICUs are frequent locations of complex parental decision-making and practitioners who work with NICU babies and their parents need guidance in providing support.

Pediatricians who wish to specialize in hospice and palliative medicine (the specialty exists under one umbrella), may receive board certification through the American Board of

Medical Specialties, and between 2008 and 2012, over 200 pediatricians completed this certification. Additionally, training for other pediatric care providers has become available through groups such as the End of Life Nursing Education Consortium. This increase in training may not be enough to meet the current needs of patients, though, as estimates of complex chronic pediatric cases in the United States number approximately 500,000. Gaps in care could be addressed by the addition of formal pediatric palliative care training for residents (IOM, 2014).

### **Parental decision-making**

One of the main tasks of pediatric palliative care team members and NICU staff members is “to support problem solving and decision making for patients, their surrogate decision makers, and health care staff” (IOM, 2014, p. F-26). Although parents cannot control many aspects of their children’s care once they have consented to a hospitalization (e.g. treatment schedules, care providers, privacy), parents face innumerable decisions for their seriously ill children ranging from daily living choices regarding such things as nutrition or visitors to legal decisions that require signatures such as surgery or a decision to stop treatment. Additionally, these decisions must be made within the confines of an institution that values precision and creates a sense of urgency. In such a stressful environment, even small decisions may feel difficult. Life-or-death decisions, which many parents of palliative care patients face, may be incomprehensible.

Researchers have demonstrated a growing interest in parental decision-making. Stutts and Schloemann (2002) proposed a model of shared decision-making between parents and healthcare providers. This model emphasizes the delivery of medical information from healthcare providers to parents and encourages physicians to respectfully inform and influence parents’ decisions. Bingen, Kupst and Himmelstein (2011) developed a tool to measure parents’ self-efficacy when they face the serious concerns of having a child in palliative care. Parents who have higher self-

efficacy judge themselves more capable of caring for their seriously ill children and parents with lower self-efficacy doubt their capabilities for the same task. Of course, there are multiple areas of self-efficacy, and some parents may feel more confident about some types of care than others. For example, some parents may be confident in their ability to make medical decisions but unsure about caring for their child emotionally. Measuring parents' self-efficacy offers insight into support needs the palliative care team can then seek to meet. Kurtz (2012) calls for physicians' respect and influence over the decision-making process, saying that NICU physicians should engage parents in decision-making by recommending medical treatments limited to a specific timetable, allowing an opportunity to end futile care rather than continuing it indefinitely.

When chronically ill children get older, they may gain a role in the decision-making process. Bluebond-Langner, Belasco and Wander (2010) explored the ways in which children can be involved in their own healthcare decision-making, and Foster, Whitehead, Maybee and Cullens (2013) noted that newer studies among families with seriously ill children have begun to include the voices of children. "The inclusion of the child's voice has been a factor that has helped many parents make parental decisions" (p. 449). In other situations, the child's choice and the parent's choice may differ, bringing about conflict, particularly when the end-of-life is in view. Penner, Cantor and Siegel (2010) present the case study of Joseph, a terminally ill twenty-one year-old man who was at the end of his life due to Duchenne Muscular Dystrophy (DMD). Although his mother refused to engage in end-of-life discussions, Joseph understood his disease and accepted that he would die. In his final hospitalization, Joseph's mother was paralyzed by the decisions facing her, but as a competent adult, Joseph was able to both express his wishes and have them followed. Kaplinsky (2012) expresses concern over children who do not have

decision-making capacity, explaining that terminally ill children demonstrate an understanding and acceptance of death, yet parents may not. Since parents must own life-or-death decisions for their children and society questions whether or not a good parent would allow a child to die without pursuing every possible treatment, parents rarely entertain the child's contribution to decision-making if the child chooses death over treatment.

In addition to medical information and the child's input, published research shows countless other factors influence parental decision-making. Carroll and colleagues' (2012) qualitative study on decision-making revealed that "parents of children who were receiving pediatric palliative care...report grappling with several influences upon their decision-making processes that extend well beyond the standard discussions of medical information exchange and evaluation of risks and benefits" (p. 6). When asked about what they found important for decision-making, parents identified many factors including relationships, communication, and support; a spiritual orientation; and feelings and personal accountability. Parents considered decision-making an interactive process in which their relationships with medical staff were significant. Parents' talk of spirituality demonstrated the larger context in which decisions must be made, and their explanations of their feelings and personal accountability show the challenges they faced as they questioned their self-perception, role and responsibility to their children. Carroll and colleagues note that their findings do not include categories for medical information because "when mentioned at all by the parents, [they] almost always figured into their decision-making process as subsidiary to the broader themes" described in their findings (p. 6).

In light of these various influences, some authors view decision-making in terms of parents' sensemaking (Browning, Meyer, Brodsky, & Truog, 2007; Lyndes et al., 2012; Wiener, McConnell, Latella & Ludi, 2013). These studies look at a variety of factors influencing parents'

medical decisions, with findings that can be summed up by Browning et al.'s (2007) statement, "The process of getting to a decision seemed to have less to do with rational cognition and more to do with making sense, locating meaning, and situating themselves as parents in an uncertain moral universe" (p. 375). As implied by this statement, these authors find a direct tie between decision-making and spirituality. Stevenson, Achille and Lugasi's (2013) metasummary of pediatric palliative care patient and family needs reinforces this idea with their finding that spiritual needs and decision-making are two main concerns for parents.

### **Spirituality**

The International Workgroup of Dying, Death and Bereavement says spirituality is "concerned with the transcendental, inspirational and existential way to live one's life" (quoted in Kashtan, 2012, p. 192). Kashtan explains this broad definition of spirituality, which is deeply personal, differs from religion, which is a shared belief system that is communal in nature. Religion and spirituality are not the same, and it is possible to have one without the other. Board certified chaplains are the spiritual care specialists on pediatric palliative care teams (Lyndes et al., 2012). These chaplains are trained to help people from any and all forms of belief, as opposed to religious caregivers, who come from the perspective of specific systematic traditions (Kashtan, 2012). This is important in the diverse setting of the children's hospital, where parents want spiritual support consistent with their own beliefs, but a religious adviser from their faith community may not be available (Stevenson et al., 2013).

Hexem, Mollen, Carroll, Lanctot and Feudtner (2011) look specifically at the role of spirituality in coping with the difficulties of caring for seriously ill children. Noting the dearth of published literature on spirituality among this population, Hexem and colleagues conducted a qualitative study in which pediatric palliative care parents were asked if they have a spiritual

framework that helps them in difficult times. Findings suggested that parents' spiritual or philosophical frames were important tools for coping with their children's serious illnesses. Prayer and scripture reading reportedly influenced decision-making, but beyond the note that decisions were "less difficult when [parents] felt as if they knew or accepted God's will" (p. 42), these influences over decision-making were left unexplored. Similarly, many studies have viewed spirituality as a coping mechanism for parents navigating healthcare decisions for their children but not specifically explored it as an influence on decisions themselves (Meyer, Ritholz, Burns, & Truog, 2006; Penner et al., 2010; Stutts & Schloemann, 2002; Wang & Kearney, 2013). Lyndes and colleagues (2012) come closer to acknowledging spirituality's influence over the decision-making process by talking about spirituality as a sensemaking tool for parents, but the scope of their article is to describe the role of chaplains rather than spirituality's role in decision-making.

Ethicists also have shown particular interest in the spirituality of parents making decisions for their seriously ill children. Cowley (2003) and Miller (2003) both present cases in which parents were at odds with the opinions of medical professionals. Cowley (2003) argued the "limits of rationality in applied ethics" (p. 70), and examined a lawsuit that resulted in conjoined twins being forced to undergo a surgery that left one twin dead. In his critique of the judge he states, "[T]here is no *room* for God anymore... The only reference to spiritual concerns are as some sort of dubious placeholder to corroborate talk of rights, a placeholder that cannot please either the truly religious or the new high priests of secular philosophy" (p. 85). In Miller's (2003) case study, the parents' religious beliefs prolonged their son's life to the point that medical staff saw the boy as an example of the treatment doing more harm than the disease. While the mother in Miller's case pursued physicians to offer every possible treatment, the

treatments were prolonging his life without any hope of saving it. Roscoe and Tullis (2015) explored the communicative challenges when patients and families ask physicians to “do everything” for a dying person, such as the case Miller (2003) presents. Rather than a burdensome mandate for care, Roscoe and Tullis (2015) describe these events as opportunities to begin conversations about goals for patient care and the values families would like to uphold. In both Cowley’s (2003) and Miller’s (2003) cases, had physicians taken the time to engage with families about goals and values, outcomes may have been different for families.

In both cases, medical staff did not engage with the parents on spiritual terms, and in one, a life was ended before parents could accept it, while in the other a life was prolonged to the distress of professional caregivers and quite likely, the child. Browning and colleagues (2007) pointed out that, in spite of the comfort and guidance spirituality provides for parents, they are often hesitant to share this part of their lives with medical staff. Robinson and colleagues’ (2006) study with PICU parents also found that “parents were more willing to share their spiritual and religious perspectives with other parents, ...[but] they may be reluctant to share this perspective with health care providers” (p. e723). The spiritual gap between medical staff and parents may account for a significant amount of misunderstanding and distress for both groups.

Bateman and Clair (2015) undertook the project of examining the communication of pediatric palliative care physicians to see how their personal beliefs shaped their interactions with families. They found that many physicians felt their religion was significant in their end-of-life communication while others felt that discussing religion was inappropriate. Many physicians in the study indicated a need to maintain hope in families regardless of the prognosis. At the same time, they were concerned “that hope had to be balanced with realism and that providing accurate, timely information was critical even if the news was negative” (p. 260). These

physicians closely related hope and spirituality, with one participant describing hope as “sacred” (p. 260), however they considered accurate information the greatest tool they could give parents for the task of decision-making.

Several recent articles discuss parents’ hope for a miracle. Kurtz (2012) observes that the relationship between parents and medical staff often deteriorates when the parents appeal to a miracle. Llewellyn and colleagues (2013) explored the ways in which healthcare providers interacted with young patients and interpreted their families’ spiritual expressions. They found that while healthcare providers felt the need to be supportive of patient and family spirituality, they “found belief in miracles difficult to accept and especially problematic if they interfered with the decisions about care and treatment that [healthcare providers] felt were appropriate” (p. 6). It would be helpful for healthcare providers to accept talk of miracles if they could see that “parents’ hope for a miracle may provide stability and does not exclude their realistic acknowledgment of the potential or imminent end of their beloved child’s life. In this context, hope may be understood as part of a ‘healthy denial’” (Bergstraesser, 2013, p. 145). In his publication of the eulogy he gave at a young patient’s funeral, Himmelstein (2005) expanded the definition of “miracle” to include inspirational events beyond the concept of an inexplicable cure often associated with the term. Himmelstein’s use of the term “miracle” may help both physicians and parents reframe hope since research indicates neither group is willing to give up hope even when death is imminent.

Other discussions about spirituality and religion in medical contexts looked at the role of culture. Wiener and colleagues (2013) reviewed thirty-seven articles on culture and religion in pediatric palliative care and found that faith was central to parents of pediatric palliative care patients, but that ideas of faith varied widely depending on culture, religion, age, and gender. In



Stutts and Schloemann's (2002) case study of a NICU baby whose parents refused to cease treatment in spite of the child's irreversible decline, the variety of cultures represented by physicians, nurses, and the parents made it difficult for everyone to understand one another. When the multiple spiritual frameworks of professional healthcare providers and parents collide, "it is not surprising that problems arise when caregivers attempt to prescribe how the family should cope with the loss of a loved one" (p. 27). Recognizing the often-overlooked biomedical culture also present in the hospital, Stutts and Schloemann continued by saying, "[Problems] will also arise when the family attempts to push the health care team out of the decision-making process or does not base their decision-making process on the medical model" (p. 27).

### **Cases**

One case that illustrates the struggle between rational vs. spiritual decision-making is that of Janvier (2007), who offered her narrative of the birth of her daughter at 24 weeks gestation. Janvier's story serves as a rare example of what can happen when two neonatologists become NICU parents. In this poignant look at decision-making, Janvier told of an emotional decision she and her husband made to continue treatment for their daughter. The decision violated her rationality, but ultimately saved her daughter's life. She challenged the idea that parents need more information to combat the emotional and irrational decisions they make because she and her husband, both neonatologists, were arguably the most informed parents to ever give birth to a premature baby, yet they found rational decision-making outside the realm of possibility. "Even when one is maximally well informed, such decisions should not, in my mind, be approached only rationally—and cannot be" (p. 363).

Janvier's (2007) case perfectly illustrates the shift in understanding that is needed for many professional medical caregivers. Driven by the need to follow medical protocol and

manage incredibly challenging cases, doctors and nurses operate from the frame that parents need to understand the facts about their child's condition because when they understand those facts, parents will make rational decisions. Medical professionals believe the key is information. Weick (1995) explained that misunderstandings occur when people believe that an already overwhelmed person needs more information. Parents engage in a sensemaking process that requires them to manage information and events of significant importance, and adding more information to an already unmanageable load may result in slower, more difficult sensemaking and decision-making. Also, as the ethicists (Browning et al., 2007; Cowley, 2003; Miller, 2003) and Janvier (2007) point out, decision-making is not and should not be limited to scientific reasoning, an idea that has not yet taken hold among much of the medical science community.

Penner and colleagues' (2010) presentation of Joseph, the previously discussed DMD patient, demonstrates the overwhelming nature of the kinds of decisions parents face and how information may become impotent in helping parents deal with certain barriers to making decisions. With several possibilities for introducing or withdrawing treatments, Joseph's mother "was paralyzed by the enormity of the decisions and appeared content to maintain the status quo with Joseph intubated and on the ventilator" (p. 395). Although Joseph was able to make the decision in this case, his mother had to live with that decision afterwards. She was finally able to come to terms with Joseph's decision to end his care because in her view, it was "all left up to God" (p. 395). Information could do nothing for Joseph's mother, who was undoubtedly presented with many possible treatments, none of which would ultimately help her son. By viewing the outcome as God's responsibility, she was able to make sense of not simply the death of her son, but a decision that resulted in that death.

Kurtz (2012), a NICU nurse, presented a case in which parents insisted on continued aggressive care based on their spiritual beliefs but such treatment was against the recommendation of doctors. In evaluating her own mistakes with the case, she recommended medical staff explore “spiritual hooks” offered by parents, such as the mention of prayer or miracles. Additionally, Kurtz says that using a spirituality assessment could help staff see how spirituality will factor into decision-making, and she recommended that physicians guide decision-making with recommendations for treatment and time-limited trials.

While Kurtz (2012) ties spirituality to decision-making in pediatric palliative care, her perspective is one that is driven by the scientific frame of medicine. For example, after much discussion of a family’s spiritual stance in decision-making, she suggested physicians talk to families about medical treatments with time-limits. Kurtz made no recommendation that physicians communicate with families on the grounds of their spiritual frames. The persistence of the strictly scientific frame for the most elite medical staff (i.e. physicians) will continue to complicate communication between patients and physicians in moments of critical decision-making. On the other hand, Kurtz described how participation in the baby’s baptism lessened the moral distress of nurses who had been disturbed by the baby’s continued aggressive care. Kurtz recommended spiritual engagement for nurses but made no such recommendation for physicians, yet the most crucial decisions for a seriously ill child’s care typically involves communication between parents and physicians.

### **Research needs**

There is significant evidence that pediatric palliative care is an under-researched field. Orloff (2012) noted that research on pediatric hospice and palliative care is sparse, and the Institute of Medicine (2014) reports that research in the field of pediatric palliative care “may be

especially pressing” (p. 2-41), calling for more research focusing on several specific areas in pediatric palliative care, one being “approaches to decision support and communication” (p. B-20).

In a 2010 report of current trends, Kim, Park, Yoo and Shen mapped the 642 articles published over the previous twenty-two years in the journal, *Health Communication*. Their findings show a tendency to couple end-of-life with aging and geriatrics, which ignores the growing trend of pediatric end-of-life studies. Additionally, there is no mention of spirituality, religion or life philosophy in their report, and they note that there is an underrepresentation of research pertaining to children. They indicate a need for more interdisciplinary study and greater diversity. Since that report, Titus and de Souza (2011) published an article in the journal examining the narratives of chaos and quest in parents who have lost a child, but their article only begins to address the need for more research on pediatric hospice and palliative care from the perspective of health communication scholarship.

Outside the discipline of communication, Foster and colleagues (2013) published a metasynthesis of thirty articles focusing on family-centered care with seriously ill children. They found that among the many different explorations of facilities focusing on family-centered care, there was a link between patient, parent and employee satisfaction and the quality of communication, information, and relationships. Some of the emergent themes of these articles included religion and spirituality, parental decision-making and communication, but as with most of the articles published outside of the communication discipline, the concept of communication is presented as “the approaches used to deliver information to parents by health care providers” (p. 449), which does not account for the multiple factors impacting communication in the intense setting of a pediatric hospital nor the role of parents and children as participants in

communication.

When researchers use a model of communication that assumes messages are simply transmitted from one person to another, they ignore the complex nature of human interaction. Communication scholars understand that communication theory goes far beyond information delivery, and the transmission model is only one of many ways to describe the dynamic practice of communication (Craig, 1999). A more developed approach to communication, described by Craig as the constitutive model, sees communication as a “constitutive process that produces and reproduces shared meaning” (p. 125). While the transmission model elevates the importance of technical information, the constitutive model values each participant in the meaning-making process and promotes “freedom, toleration, and democracy” (p. 126). In short, communication should be viewed as a complex construction of meaning between participants rather than a simple transmission of information. For medical practitioners and the parents they seek to support in decision-making, a constitutive model more accurately describes their complicated interactions. Each participant in decision-making contributes to the construction project by which parents arrive at an understanding of their child’s illness and the best way to proceed with care. While medical practitioners contribute significant “building blocks” to the project, particularly concerning medical information, parents construct their understanding with many other blocks, including life circumstances, prior medical experiences, and spiritual understanding. As Foster and colleagues (2013) explained, parents’ satisfaction with their relationships with practitioners is as important as satisfaction with information and the way it is communicated.

Although there is some discussion in the literature about spirituality and palliative care, most of it centers around the comfort offered by spirituality, particularly at the very end of life or after a death (Kashtan, 2012; Meyer et al., 2006; Penner et al., 2010). Other research looks at

how spirituality operates as a coping mechanism (Hexem et al., 2011; Stutts & Schloemann, 2002; Wang & Kearney, 2013), but little research examines the function of spirituality in the intense moments of decision-making. Decision-making is often framed as a medical event and coping as a spiritual endeavor. Although spirituality recently has been identified as a factor in parental decision-making (Carroll et al., 2012), rarely is the question asked, “*How* does spirituality impact decision-making?” Recognizing this division, Carroll and colleagues called for future research to account for influences on medical decision-making outside of risk/benefit and information-seeking. Clearly, that would include research on the impact spirituality has on decision-making. Hexem and colleagues (2011) recommended further research on the role of religion, spirituality or life philosophy (spiritual frames) in parents’ decision-making, specifically how aphorisms function as a way to explain beliefs and make effective decisions in the moment.

The role of chaplains in decision-making is often overlooked as well. Lyndes and colleagues (2012) recommended future research that describes the “spiritual needs and resources of [pediatric palliative care] patients and families” as well as research that “examine[s] the contribution chaplains make to improved outcomes for families and children facing life-limiting illness” (p. 75).

## **Conclusion**

To date, most of the research on spirituality among parents of ill children has sought to describe different expressions of spirituality or examine spirituality’s role in offering comfort. In order to better understand the role of spirituality, though, it is important to ask how spirituality functions in parents’ actions, decisions and in their communication within the context of the hospital. While the scientifically driven hospital staff may use the language of biomedicine to

communicate with parents and with one another, parents' communication may have a spiritual quality that is overlooked, disregarded, or misunderstood. By examining the spiritual aspects of parents' communication, this project begins to address the often-noted communication gap between parents and physicians as they navigate the complexities of a seriously ill child.

CHAPTER TWO:  
NEGOTIATING PERSONAL REALITIES IN RESEARCH

Every time I walk into a children's hospital, I feel the pull towards my own past and my likely future. I enter this space as a scholar only because I also enter this space as the parent of a medically complex child. My own experiences of parenting and healthcare frame every conversation, whether with medical practitioners, chaplains, social workers, therapists, patients or parents. I can sense that the familiarity of such a place works to my advantage as a researcher because my participants (parents and grandparents of seriously ill children) trust me as an insider. "You understand," they often say. "You know what it's like." And I do. Or do I? I know what it was like for me, but why would I be here if I knew what it was like for everyone? What might these participants hold back under the assumption of me already understanding? Nevertheless, the familiarity allows us to talk about the difficulties of being in the hospital, of having a sick child, and of the world continuing on outside without the decency to stop and give us a chance to figure out what is going on.

I spoke at length with twenty participants who were either the parent or grandparent of a seriously ill child. As I listened, took notes, typed, and re-read each story, I experienced multiple points of connection to my own experiences. I physically felt the impact of some of my participants' struggles, as demonstrated through tears, rapid heart-rate and disorientation after reading through interviews and then "re-entering" my own world.



After several weeks of working through my interview data in which I read each interview carefully, I considered the lack of a designated place for parents in our children's hospital rooms. As I pondered this problem, a poem began to form in my mind. I put pen to paper and found myself able to express aspects of parenting I had never been able to convey through academic writing. As my creative juices continued to flow, within a few hours two more poems came to me, each expressing a different aspect of parenting a hospitalized child. The poems address issues I have personally experienced as a parent as well as observed as a researcher (Jenks, 2005). They are more than words on a page. They are performances meant to provoke thought, emotion and empathy, so I offer these poems as a window into the world of parenting a seriously ill, hospitalized child (Green, 2002).

### **Where Do I Belong?**

When my son was a patient in the Neonatal Intensive Care Unit (NICU), a four and a half month span of what my husband and I call "the lost year," a rolling office chair was my designated place to be with him. At that time, 2002, a standard NICU was designed as a ward with approximately a dozen patients in each brightly lit room. My son's NICU took the term "intensive care" to its full end. The intensity of that room was palpable, and our daily, vigilant, parental presence was the exception, not the rule. There were many reasons parents were unable to attend to their children. As the most advanced NICU in a 100-plus mile radius, some families lived over an hour from the hospital. Many did not have transportation or the luxury of time away from work. Some had other children to look after, and others were unable to face the reality of a premature, seriously ill baby. Thanks to support from our church, family, friends and employers, I was able to spend each day with my son, and my husband was able to join us each afternoon after work.

In the NICU, I observed life and death up close, constantly reminded that my own child's life was as contingent as the lives of the tiny patients surrounding him. The patients were the focus of care; parents were not. New NICUs, such as the one where I conducted my research, are now more private and have couches, roll-out beds and TVs. I could not stay all day and night with my son because there was no place to sleep. Additionally, I was not allowed to be present at my son's bedside at certain times because the doctors were doing rounds and openly discussing patients' medical conditions. The NICU is somewhat more accommodating to parents now, but a sense of being lost persists among parents in both the NICU and the children's hospital.

Like many long-term NICU babies, my son has been admitted to the hospital more times than I can count. Through his more than twenty surgeries and occasional seizures, infections and viruses, moving into a hospital room has become a routine process, though never a comfortable one. Let me show you what it is like.

When you walk into the hospital room, look in the back corner. There is usually a vinyl couch or chair that converts to a bed. As you move your child into the room, it will be the only available place to put your personal items, so as a parent, you assume it is "your spot." The pullout beds are never comfortable, and once you pull the bed out, you are forced to sit or lie down on it because it takes up every spare inch of the floor. In the unlikely event that you actually fall asleep on the uneven vinyl surface covered by a thin hospital sheet, a nurse will inevitably enter the room and wake you. At that point, even if you think you could return to sleep, you feel guilty because the nurse is caring for your child, and as a parent, that is your job. So you go over to the bedside where the nurse is performing some medical task that you, in your sleepy stupor, may or may not understand. You try to help the nurse and she says, "It's ok, you

can go back to sleep.” You aren’t needed. You want to sleep desperately, but what is the point of this torture if you have no job, no purpose?

You go back to the slippery sheet-covered vinyl bed and lie down with a crinkle and a thud. The fire in your belly rises up to your chest as you count the hours until the doctor might walk through the door. This time, you will not be caught dozing. This time, you will manage to form the words of the questions you want to ask. You hope.

You drift off again and awaken to the door opening and a sharply-dressed silhouette filling the door frame. As you sit up and grab your glasses, you are keenly aware of your bad breath and bedhead. You are at your worst. The sharply-dressed doctor enters the room and starts talking about lab results. “No need to get up,” the doctor says. Again, your efforts aren’t needed. You hoist yourself out of bed anyway, tripping over the corner of a chair to land at your child’s bedside. You remember, the pullout bed takes up all the floor space. The doctor has clearly been out for a run, had coffee and a healthy breakfast, read the day’s news and expertly treated several patients while you have been sliding around on a vinyl bed in the back corner of a hospital room, unable to contribute anything to the big, important, life-saving work of the hospital. While you were getting up, all of the new medical information about your child has been succinctly covered, and you missed it. “Do you have any questions?” the doctor asks. You have so many questions, but you hear yourself answer, “No.”

### ***The Other Side of the Bed***

*Doctor stands here, patient lies there, but where do I belong?*

*Answering questions about this and that, yes, no, wait, I can't remember.*

*Hot lava inside with nowhere to flow, I must keep calm and play mom.*

*What's going on? Is he going to die? How can you be so detached?*

*Can I touch him? Can I hold him? Where should I sleep?*

*Can I eat in his room? What if something happens while I'm gone?*

*How long will he be here? Will he ever come home?*

*"Do you have any questions?" ...No.*

*Left alone in a science lab with my son, I can't find a place for me.*

*Screens show all the data, pumps force in the cure, while I...*

*Sit. Stand. Adjust the pillows. Watch the slow drip, drip, drip of...*

*Hope? I hope. Life? Will he live? Where will my life be?*

*Drifting, snoozing, that 4am sleep, monochrome figures inhabit my dreams.*

*They attach wires and tubes to the one that I named. Is he mine or theirs?*

*"Everything is fine. You can go back to sleep." Should I? I'm nonessential.*

*Between sleep and guilt and defiance, I approach the bed, but where do I belong?*

I wrote “The Other Side of the Bed” with a sense of not belonging. This is beyond feeling lost, which is certainly a feeling I’ve also experienced in the hospital. Not belonging is more than that, because when you are lost, you have a sense that you are supposed to be somewhere and you cannot find it. When you feel as if you do not belong in a place, you desperately want to leave. When your child is hospitalized though, you have no option except to stay in a place where you feel your lack of fit. This is reinforced by the rapid fire questioning upon admission, the horrible furniture provided for “your comfort,” the constant interruptions that say, “What you’re doing is not as important as what I am doing,” and the requirement to be cogent while under this kind of duress. The people, the furniture, the system all seem to say, “You don’t belong here!,” but at the same time, they require you to stay.

## **Boredom**

One difficulty of hospital incarceration is how detached you are from the outside world. It seems impossible to participate in anything outside the walls of your child’s hospital room, although there is little to do in the room. You find yourself looking forward to any possible action, so you’re always waiting. Someone might say something like, “Radiology is coming to get him for an CT-scan,” leaving you with the impression that someone is currently walking up to get your child. You delay going to get lunch because you want to be there when the person arrives. After several hours, you ask the nurse when radiology is coming. “They haven’t come yet? I didn’t know, I was at lunch. They should be here soon. I’ll call and check.” You wait some more. Eventually, someone comes to take a chest x-ray and you say, “I thought he was going down to get a CT-scan.” The x-ray technician explains that he has an order for an x-ray and doesn’t know anything about a CT-scan. You don a lead apron for the x-ray. The tech asks you if

there is any chance you are pregnant. You awkwardly answer, “no.” Feeling the need to convince him, you say it again, with more confidence, “No. I couldn’t be pregnant.” The tech hurries out of the room, you imagine for fear of you elaborating on your recent reproductive activities. After the x-ray machine is rolled out of the room, you find the nurse and ask about the CT-scan. “Oh, the doctor changed the order.” You go to the cafeteria and find that they are cleaning up the line where the hot food was served for lunch. It’s 3:00. You get a granola bar.

Later that evening, some visitors come to see your son. “Hey, Buddy!” they say. “How’s the little guy doing?” You hear yourself relaying the information you’ve been told, but aren’t really certain what it all means. Your friends wear an expression of syrupy sadness on their faces. You are depressing them with this talk of illness. “What’s going on with you?” you say. Whatever they’ve done today, no matter how mundane, sounds immensely more exciting than your life. News of the outside world brings about feelings of both jealousy and incredulity. Your friends’ description of going to the grocery store sounds like a Roman holiday to you. How wonderfully freeing that must be. Then your jealousy turns to offense. How dare the world continue to spin without you?! Have they no respect for the crisis that is boring you to tears? You are less than your effervescent self and your friends only stay for twenty minutes. They’re going out to dinner at a cool restaurant because they made a trip into the city to come visit you. “Is there anything we can do?” they say. “Take me with you!” you want to plead, but instead you say, “No, I can’t think of anything.” You don’t even know what you can do to help, much less anyone else.

## ***Stark Raving Bored***

*So much going on and so little to do.*

*This vinyl chair may soon swallow me  
into its institutional mauve hide-a-bed belly.*

*I never realized a crisis could be so boring.*

*How many episodes of Law and Order are there?*

*What day is it? What month is it? Time stands still.*

*Only the menu changes, here comes the lunch tray!*

*Turkey Tuesday. No time to chat, trays to deliver.*

*Waiting for the doctor. Waiting for test results.*

*Waiting for the radiology tech to take him down.*

*Waiting for the surgeon's scheduler to call.*

*Waiting for ...something to change.*

*Friends drop by. Why is everyone calling him "Buddy"?*

*I hear myself repeating the story.*

*Is this really happening?*

*Can we talk about something else?*

*Is it sunny? Rainy? Cold? Hot?*

*Hard to tell from the double-paned, tinted windows.*

*What are you doing today while we are here?*

*I am list-less.*

Until you have been the family member of someone in the hospital, it is difficult to understand how boring it is to sit at a bedside day and night for an undetermined amount of time. People consider the medical crisis something intense, and we typically do not think boredom and intensity go together. Due to this, it feels wrong to complain that your child's medical crisis is boring you to death. I wrote "Stark Raving Bored" to illustrate this dichotomy. Without the ability to predict or plan for the next day or even hour, waiting is your only regular activity.

Although the doctors and nurses will say things like, "We're waiting for the labs to come back," they all seem to have plenty of other things to do. What they mean is, "You're waiting for the labs to come back, and when they do, you will wait for one of us to notice that the labs are back. After we notice the labs are back, you will be waiting for us to decide what to do as a result of the labs. Once we decide what to do based on the labs, you will wait for us to come in and tell you about the plan." In other words, you are always waiting and most of the time, you don't even know why or for what you are waiting. Waiting is constraining because you cannot go anywhere or do anything meaningful in anticipation of the wait's end. And as everyone knows, waiting is boring. Perhaps the hospital should consider renaming all the waiting rooms to "boring rooms" for the sake of truth in advertising.

### **It's Up to You**

In times of crisis, people often look to religion and spirituality. I happened to explore those things before crisis ever dared to raise its head in my life. At an early age, I was deeply interested in spiritual things. I went to church, but beyond religious practice, I felt a relational connection to my Maker. As I entered college, I became more and more interested in this



relational connection, and delved deeply into a Christian community that encouraged my growth and exploration of spiritual things.

I have always been an academic junkie. At age 41, I press on in my pursuit of higher education, but this is nothing new in my family. My mother or father or both were pursuing advanced degrees for most of my childhood. My sister has a master's degree. My husband has two bachelor's degrees, a teaching certificate, a master's certificate, and plans to pursue more graduate education in the next year. So, in my interest of Christian spirituality, it is understandable that I wanted to explore the subject by way of school. At age 23, I began a Master's of Divinity (M.Div.) I studied Greek, Hebrew, every book of the Bible, various forms of theology, practical aspects of Christianity, history, philosophy, counseling, exegesis and hermeneutics. I loved it.

As students, we had great conversations in and out of class, trying to determine how all of these ideas might work themselves out in our own lives of faith and in the world around us, but these conversations felt theoretical rather than applicable because I had never experienced anything near difficulty, pain, suffering, or hardship. One semester, a small group of us discussed II Corinthians in great detail. Paul and his audience knew about sacrifices and needs we had never considered as we lived our lives of relative affluence and freedom. Personally, I had never experienced the death of a family member, personal violence, neglect, discrimination or anything I would consider a real hardship. Application of the ideas of faith during trials did not come easy to me, and I resented the popular Christian women's culture that preferred story over theology. I knew my God was wonderful. He would carry me, I thought, through every difficulty I might encounter in the future, but it was all cerebral until suddenly, crisis came crashing down into my world.

One March day in 2002, less than a year after graduating from seminary, I received a phone call explaining that a recent sonogram of my four-month pregnancy indicated a problem. The following day, my husband and I found ourselves sitting across from a perinatal specialist who explained that our son's life was in grave danger. His urinary system was malfunctioning, his kidneys had been damaged, his lungs may not have developed. He would die in my womb unless we wanted to intervene by consenting to experimental measures.

At that moment the application of my theology became much more than an academic exercise. I felt as if someone had taken me by the scruff of the neck and shoved my face into all that I believed and said, "Really? Are you sure? This is what life is really like. Does your theology matter any more?" I was poised at the precipice of a cliff. Could I take a step?

We said yes to the experimental treatment and began a long, uncharted journey. I was never big on religious platitudes, but after being marked by crisis, I could not tolerate the thoughtless things people say when crisis strikes, platitudes full of vague philosophical concepts but with no foundation. This was particularly upsetting when Jesus got mixed up with such baseless sayings. The person who was born in obscurity, forced to flee as a baby, friend of the marginalized, homeless, brutally honest, powerful, self-sacrificing and eternal has no association with thoughtless platitudes.

In my conversations with parents of ill children, I heard this troublesome phrase over and over again, "I know God won't give me more than I can handle," or another version, "The Bible says God won't give me more than I can bear..." Parents repeat these sayings that have been offered up in the name of comfort and reassurance, but as they live out what feels like an unbearable existence, they begin to question their faith. I want to tell these parents, "No, the

Bible doesn't say God will not give you more than you can handle. God never says that. No one can "handle" a crisis, the Bible isn't charging believers to bear the impossible. This is not a test.

This is a disarmament. I thought I had a lot of tools in my personal arsenal. I thought I was pretty well set for the challenges of life, but I had nothing for this crisis when it came. This was way more than I could handle. The choices we faced were to do nothing and allow our child to die, abort, or subject me and our son to experimental science, which involved a twelve-inch needle and my uterus on seventeen different occasions. I sometimes hear medical personnel say to parents facing tough decisions, "There is no right choice." What that actually means is, "There is no good choice."

### ***The D Word***

*They've given me all the options.*

*Weighing it out. No, it is too heavy.*

*They say God won't give me more than I can bear.*

*I call bullshit.*

*I peek into door number one and I see darkness.*

*I peek into door number two and I see darkness*

*Is there a door number three? If there is, it's dark in there, too.*

*It IS more than I can bear. Paralysis.*

*I close my eyes and do nothing.*

*It is still dark. I'm afraid of the dark.*

*Where is the Light?*

*It is bearing all that I cannot.*

In “The D-Word,” I describe the options as paralyzing. The paralysis I experienced had to do with my ability to control and calculate. For some parents, the options are so untenable that they refuse to make a choice. How are you supposed to choose between death and suffering for your child? It IS unbearable. That platitude, God won’t give me more than I can bear, doesn’t make sense. Without relationship, without depth, without trust, all we have left is vague philosophy, but the God I know doesn’t place impossible choices in front of me and walk away. The God I know is present in the difficulty, sitting with me at the table of distraught parents who have been given impossible choices. The God I know is before me and behind me and all around me in the midst of whatever is going on. The God I know bears burdens rather than giving them to me to “handle.”

As my son has grown older, his health has stabilized. He is well most of the time, and we rarely spend more than a few hours a month with him in medical facilities. I enter and leave the hospital as a parent, but also as a researcher. In both cases, I am free to come and go, but it was not always this way. I was tethered to that institution as long as my son was a patient there, and there are only two ways to leave, discharge or death. Having sat in that place of not knowing which exit was in store, I willingly re-enter. I sit with parents who also do not know what the future holds. I walk alongside hospital staff who are caring for these young patients and their families. They all struggle with the uncertainty of these patients’ lives. These poems seem rather insignificant in the face of such struggles, but perhaps if you felt like the parent of a hospitalized child, without a clear place, bored and afraid, you might find comfort that someone else understands your struggle. And if you were working with patients and families in a hospital, you might gain some insight into the complex lives of parents you see everyday.

CHAPTER THREE:  
RESEARCH METHODS FOR THE PEDIATRIC PALLIATIVE CARE SETTING

**Introduction**

Researchers have issued a call for further study of spirituality and pediatric palliative care (Carroll, Mollen, Aldridge, Hexem & Feudtner, 2012; Hexem, Mollen, Carroll, Lanctot & Feudtner, 2011; IOM, 2014; Lyndes et al., 2012), and the most appropriate method for this kind of research, according to the Institute of Medicine (2014), is through close observation and conversations with people who are giving and receiving palliative care (p. F-2). This chapter includes the research questions that guided the project, theoretical frameworks that informed the project, and the methods employed to conduct research in a hospital with parents of seriously ill children. Qualitative research requires patience and perseverance due to the time-consuming data collection process and need for careful analysis. Additionally, this project required a significant amount of emotional energy because of the challenging topic and my personal history as the parent of a seriously ill child. The goal of the methods employed was to address the research questions while honoring the stories and the lives of the parents who participated and acknowledging my own experiences as well.

## **Research Questions**

In an effort to look more closely at spirituality and parental decision-making in pediatric palliative care from a communication perspective, it is helpful to interrogate parents' sensemaking processes. As parents encounter the crisis of caring for a seriously ill, hospitalized child, they must make sense of their situation in order to care for their child, make decisions for their child, and live with their decisions once the crisis is over. Sensemaking takes into account the many factors parents contend with, including life circumstances, previous medical experiences, and spiritual understandings, to name a few. In order to explore parents' sensemaking processes, I begin with the following research questions:

**RQ1:** What resources do parents draw upon to make medical decisions for their seriously ill children?

**RQ2:** How do parents enact their spiritual or religious frameworks in clinical settings when faced with medical decisions for their seriously ill children?

These questions guide the choices of research methods by focusing on parents' explanations of their decision-making processes and the ways in which spirituality impacts sensemaking.

## **Theoretical Framework**

### **Social construction**

Medical practitioners are taught to communicate with check-lists and multi-step models for conveying information (Roscoe & Tullis, 2015). For example, the SPIKES model (Baile et al., 2000) offers physicians a six-step model for delivering bad news to patients. The model, while acknowledging the importance of setting and emotion for patients and their families, is built around the delivery of information from the physician to the patient and family. The plan

for next steps, while viewed as collaborative, is assumed to be based on the medical information delivered by the physician.

The goal is to enable the clinician to fulfill the four most important objectives of the interview disclosing bad news: gathering information from the patient, transmitting the medical information, providing support to the patient, and eliciting the patient's collaboration in developing a strategy or treatment plan for the future (p. 302).

Such information-centric models are derived from the transmission model of communication, in which a sender delivers a message to a receiver through a channel (Craig, 1999). While this model is simple to understand, it is an insufficient description of complex meaning-making. Communication scholars offer a better framework for understanding the complexities of communication through the concept of social construction (Berger & Luckmann, 1967). Social construction is a theory that explains how humans collaborate to create meaning and understanding in their shared environments.

Bartesaghi and Cissna (2009) outline five propositions describing social construction in communication. First, social construction “questions the taken-for-granted” (p. 130). Simply put, asking questions is essential for good communication while making assumptions results in poor communication. Second, meaning exists “as a process of relationships” (p. 131). Meaning is shared between people and does not exist outside of relationships. Third, social construction considers the constitutive and consequential reality of communication, acknowledging that “each conversation is embedded within, will become a part of, will be influenced by, and will influence myriad other past and future conversations” (p. 131). Fourth, social construction “understands the world as very much real for those who live in it” (p. 132). Finally, social construction sees

power as material and embodied within relationships rather than an outside factor. Power is constituted through communication.

Looking at communication as a collaborative construction rather than a transaction offers an opportunity to consider factors beyond the transmission of information. A new model based on these concepts sees communication as a construction project in which each participant brings multiple “blocks” to the relationship. Such blocks not only include information, but also previous interactions, emotion, spirituality, life circumstances, other relationships, and many other possible contributions to the endeavor to make meaning of a situation. A theoretical model of communication that takes into account what information means to participants in an interaction is particularly appropriate for studying the communication and decision-making of parents of seriously ill children. Social construction sees communication as constitutive, in other words, communication is making and reinforcing the understandings and realities we hold to be true. As medical practitioners seek to communicate with patients and their families, they should see themselves as participants in a construction process that is both collaborative and on-going. Their role is not only to provide sufficient information, but also to develop relationships that take into account the parents’ unique position, values, beliefs, and preferences. Practitioners will contribute many blocks to the project, but they must also accept that patients and families will build towards an understanding of reality by bringing in their own valid contributions.

### **Principles of sensemaking**

As parents of seriously ill children endeavor to make decisions about medical care, their needs extend beyond accurate medical information. These parents experience a profound dislocation away from health and home into illness and institution, a move that requires them to make sense of their child’s medical condition and what it means for their lives and the lives of



their families. In his foundational work, *Sensemaking in Organizations* (1995), Karl Weick delineates seven properties of sensemaking. He describes sensemaking as a process that is:

1. Grounded in identity construction
2. Retrospective
3. Enactive of sensible environments
4. Social
5. Ongoing
6. Focused on and by extracted cues
7. Driven by plausibility rather than accuracy (p. 17).

In his examination of these seven principles, Weick explains the ways in which observers can see sensemaking processes in organizations, offering examples from military, leadership, management and production.

Certainly, healthcare organizations such as hospitals fit well within the scope of the organizations to which he applies his theory, and Weick's work has been used by others in describing sensemaking in health institutions (Apker, 2004; Ericson, 2001; Thurlow & Mills, 2009). Ericson (2001) found that "collective meaning is needed in order to accomplish radical organisational change" (p. 129), but in order for such change to begin, creative challenges must first be established against the taken-for-granted, a difficult task in healthcare settings. Thurlow and Mills (2009) demonstrated the discursive process of sensemaking during a regional health center's organizational merger, and Apker (2004) looked closely at nurses undergoing the shift to managed care. By applying sensemaking principles to nurses' interview transcripts, she noted the parallel between organizational change and professional identity, concluding that while collaboration seems to be positive on the surface, it actually "functions as a form of concertive

control” over nurses (p. 224). While the complexities and shifts in ever-growing healthcare institutional structures lend to innumerable opportunities to apply Weick’s (1995) sensemaking principles, his theory also can be applied to understanding families that exist within the confines of children’s hospitals, including neonatal intensive care units (NICU) and palliative care units.

Weick’s (1995) properties are particularly fitting for the smaller organizations that exist within the larger organization of the hospital, namely families. In fact, his properties so specifically describe the sensemaking I have observed in parents that in reading his work, his business examples served as periodic reminders that his original object of application was not, in fact, parents of children experiencing health crises but a different kind of system altogether. Perhaps the lesson here is that families, as a system, do not operate differently than larger organizations when it comes to sensemaking. As humans engaging with other humans in the context of life and society, it is understandable that our small organizations of family would behave much like larger organizations of human interaction. What is most interesting in this examination, though, is not simply finding that families engage in sensemaking in similar ways as large organizations, but in seeing what happens when the smaller organization of the family exists within the larger organization of the hospital. The intersection of these two systems and the ways they engage in sensemaking together expose some ruptures in communication, which can have serious implications for decision-making, patient outcomes and family function.

It is important to note the different settings in which patient care is discussed in the hospital. Pediatric palliative care team meetings occur backstage, or away from patient and parent attention. Goffman’s (1959) discussion of backstage vs. performance behavior examines the marked difference between actors’ interactions behind the curtain and in front of it. Ellingson (2003) applies Goffman’s theory to a medical clinic in her observations of informal

conversations between interdisciplinary team members outside of formal meetings finding that backstage teamwork had a significant impact on frontstage practitioner-patient communication. One problem Ellingson identified was that “[t]eam members strategize (often extensively) out of patients’ presence about how to persuade patients to adopt or discontinue specific behaviors” (p. 113). Such strategies increase the power practitioners have over patients, warranting further study on the relationship between backstage and frontstage conversations.

This project applies Ellingson’s (2003) theory of frontstage and backstage linkage (p. 111) by examining a meeting that exists on the continuum between out-front conversations of healthcare workers and patient families, and conversations of healthcare workers in settings removed from patient care. Team members perform their specific roles of doctor, nurse practitioner, social worker and chaplain for one another in the team meetings, but they do so away from the patients and families they are employed to serve. The way they speak of patients and families during the meeting is likely more direct and evaluative than it is in the frontstage setting, which is generally the patient’s room. Additionally, parents may engage in similar frontstage and backstage behavior as they speak with healthcare professionals in the frontstage of the patient room and with others in a backstage setting away from providers.

## **Methods**

After earning a B.A. in Communication Arts in 1996 and a Masters of Divinity in 2001, I began the most intense learning endeavor of my life. In the spring of 2002, halfway through my first pregnancy, my husband and I were told the devastating news that our tiny baby was in serious trouble and may not survive. After several medical interventions, my son was born at thirty-one weeks gestation with kidney failure. Four and a half months in the NICU, seven

surgeries later, and against the medical odds, we went home. While going home was a relief, it seemed as if the hospital followed us. The nursery included a dialysis machine, feeding pump and heart monitor. In addition to the intrusion of medical equipment in our small home, we had the feeling we were tethered to medical complexes due to multiple appointments with specialists every week.

In the spring of 2005, my son received a kidney transplant, relieving us of much of the medical intensity that had ruled our lives. Even so, in the years to come we spent many more nights at the hospital and logged plenty of hours in the Ronald McDonald House next door, now with two more sons. Since he was born in 2002, my oldest son has been to surgery over twenty times. Although he is now medically stable, he continues to see a number of specialists, takes seven different medications, and receives shipments of medical supplies monthly. All of this may seem like a burden, and it does require a significant amount of time, money and energy, but coupled with the delight of who my son is, we consider it part of the joy of caring for him.

My personal experience as a parent of a seriously ill child informs my research in every way. When I entered the hospital for research, I acted as an ethnographer, but I remained a parent as well. My personal experience allowed me to build rapport with other parents as well as understand the biomedical culture of the hospital better than others who, like me, are not formally trained in medicine. At the same time, my experience in seminary allowed me to build rapport with chaplains, who hold the same degree I do and use technical terms of theology and spirituality that are familiar to me. I also acknowledge that my background limited me to the unique purview of a scholar/parent/theologian. I was both uniquely fit for the task at hand and limited by my own perspective. With years of experience parenting a child who is in and out of the hospital, I easily relate to parents who are struggling with exhausting and unpredictable

schedules, contentious relationships with hospital staff, and the overwhelming uncertainty of what lies ahead, so I may tend to side with parents when they are at odds with practitioners. Additionally, my theological education grants a level of precision to my understanding of spirituality that does not exist within the general culture, so I resonate more deeply with some spiritual identities than others. Keeping in mind my own limitations, I entered the difficult research field of the children's hospital.

### **Procedures for gathering data**

The aims of this communication study focused on the crucial yet under-researched role of spirituality in pediatric palliative care in a hospital setting, with a particular focus on the role of parents' spirituality in decision-making for their seriously ill children. In an effort to begin to understand the complicated intersection of parent and child relationships with hospital staff, spiritual beliefs in a medical context, palliative care for seriously ill children, and decision-making, I engaged in the qualitative methods of ethnographic participant-observation and semi-structured interviewing.

### ***Ethnographic observation***

Ethnographic observations are well suited for studying the process of decision-making and information seeking in a healthcare setting (Ellingson, 2005). Conducting ethnographic research involves observing study participants, which allows researchers to witness the phenomenon they wish to investigate as it takes place in natural contexts, sometimes referred to as the field (VanMaanen, 1988). For this project, I studied how and if parents engaged their spiritual frames when talking with chaplains, physicians, social workers, and/or nurse practitioners, which varied from parent to parent as well as from provider to provider due to

differences in roles and beliefs (Stutts & Schloemann, 2002). Additionally, I looked at how parents used these spiritual frameworks to make decisions for their seriously ill children.

While I did not exclude participants based upon spiritual beliefs and parents within the study varied widely in their spiritual identifications, none of them completely rejected spirituality. This wide acceptance of spirituality could be due to a variety of factors. First, chaplains introduced me to most of the parents in the study, which may have impacted selection because these parents were already comfortable talking about spirituality with the chaplains. Also, participants may have held back their doubts about faith because of my association with the chaplains and their location in a Catholic hospital. Finally, all the parents I interviewed were in the midst of a medical crisis with their children, and crisis tends to bring about thoughts of spirituality. In other words, some of these participants may have been experiencing a kind of “fox-hole” religion.

Ethnographic methods have as their goal the description of members of a particular group of people or culture. Both the people and also the sights, sounds, smells, and other details of the environment are of importance and were recorded in notes. Ethnography is time-intensive and requires an inside view of “the life space of the cultural members” (Lindlof & Taylor, 2002, p. 17). This project was conducted between January and November of 2014 and consisted of twenty semi-structured interviews; observations of thirty weekly Pediatric Palliative Care Team meetings; shadowing of physicians, nurse practitioners, social workers and chaplains; and totaled approximately 150 hours of field work.

### *Setting*

This study took place in a large, Catholic, not-for-profit hospital in the Southeastern US. Institutional Review Board approval from both the University of South Florida and the medical

institution were obtained for the project. The institution operates a hospital for children, one for adults, and one for women on the same site. All of these units are part of a larger health system. The children's hospital has 202 beds including NICU, PICU, oncology, cardiac care, and standard care. The NICU is considered part of the children's hospital although it is located in the women's hospital. All rooms are private and parents are allowed to stay with their children in patient rooms if they choose and are able. With the exception of the PICU, patient rooms have private bathrooms with showers and sofas that fold out to make a bed for a parent. The PICU offers reclining chairs, but rooms are smaller and do not have space for fold out beds for parents or private bathrooms. The hospital offers daily mass as well as patient care by priests, nuns and Catholic volunteers, including Baptism, Holy Communion and Last Rights. The chaplaincy staff also includes members of other faith communities.

Two full-time chaplains, both Protestant women, work specifically with pediatric and neonatal patients and families. The chaplains seek to visit every patient at the children's and women's hospitals, but patients and families are not required to talk with them. Social workers are assigned to patient cases and oversee the psychosocial aspects of patient care and discharge and often work alongside chaplains in serving patient needs. In addition to standard medical care, psychosocial care and spiritual care, the hospital also offers child life specialty services and a physical therapy program called "healing touch." Child life specialists find out what interests the patients, bring them toys and games that will allow them to play, and seek to support parents and siblings in making a home-like environment for patients. Through healing touch, patients and parents can receive massages and training in relaxation techniques.

For parents with children receiving palliative care services, a hospital stay can last from a few days to a few months. Sometimes, children are in isolation and not allowed to leave their

rooms. Parents who choose to or are able to stay in the hospital with their children live in a confined space dominated by medical equipment and a 24-hour nursing schedule. Medical staff enter and leave patient rooms at all hours of the day and night, so privacy and sleep are constantly interrupted. Another basic necessity, food, may be a difficult negotiation for parents. There is no food preparation area in patient rooms, so parents must purchase food from the hospital cafeteria or leave the hospital to get food for themselves. Additionally, patients may be on a restricted diet or not allowed to eat, so parents may feel guilty about eating in front of their children.

While the hospital seeks to care for the whole family through programs such as spiritual care, healing touch and child life, parents are still considered visitors who must prove their identity before entering the protected space where their children are being treated. Each exit and permitted re-entrance reinforces the idea that parents are not at home and not in control, marking this as a site of particular interest for studying how parents enact their spirituality as they communicate about their children's care.

#### *Pediatric palliative care team meetings*

To gain entrance to the field, I attended weekly pediatric palliative care team meetings in which the pediatric palliative care physician, nurse practitioner, chaplains and social worker are joined by other hospital employees with an interest in palliative care patients. Attendees included child life specialists, social workers from oncology or the PICU, the healing touch coordinator, representatives from hospice agencies, and other students. In these meetings, team members discussed new patients admitted to palliative care, current palliative care patients, and each patient discharged since the previous meeting. (Discharge from palliative care may be due to discharge from the hospital, an end to palliative care treatment while a patient remains in the



hospital, patient transfer to another care facility, or patient death.) Team meetings provided an opportunity to learn more about palliative care, hear about the work team members do, and gain an understanding of what makes for a palliative care case. After attending a few weeks of team meetings and completing organizational training, I was given a badge and access to shadow team members. Team members were able to help me identify potential interview participants during the team meeting as well as during shadowing. Since rounds are conducted immediately after the meetings, I would often shadow one or more team members for several hours following the weekly meeting. On occasion, I would shadow a palliative care team member on an additional day of the week.

As pediatric palliative care team members spoke freely about their feelings regarding parents and the decisions they were making, I took notes in an effort to capture and identify ways team members constructed spirituality and decision-making away from the purview of parents and patients. I then compared my notes of team member conversations with field notes from patient/team member interactions and interview notes. Since interviews provided parents their own backstage space to speak freely away from the palliative care team, just as team meetings provided team members a space to speak freely away from parents, comparisons of notes revealed reasons for miscommunication and misunderstanding between team members and parents (Ellingson, 2003; 2005). These gaps in communication and understanding impacted both parents' reliance on team members for support as well as team members' understandings about how to best support parents in their decision-making.

#### *Shadowing team members*

This project took place in a challenging research environment. The families in this study faced life-threatening illnesses in their children. Some children in the study were gravely ill and a

few children died during the course of my eleven months of observation. Additionally, the medical intensity of the environment included the presence of medical equipment connected to or inserted into children, bodily fluids draining into tubes, and other difficult scenes that might be jarring to a researcher. My familiarity with the pediatric hospital intensive care setting due to my personal experience over the last thirteen years as the parent of a child with complex medical issues aided me in these encounters. I interviewed some parents while wearing a gown and latex gloves. I donned masks, “foamed in and out” by using the hand sanitizer on the walls each time I entered and exited a room, and excused myself from rounds when I had any suspicion I was sick in order to protect the vulnerable hospitalized patients. My understanding of the medical procedures and equipment being used as well as the situation of a parent with a hospitalized child aided me as I traversed this space.

I accompanied the chaplains, palliative care physician, nurse practitioner and social worker on rounds as they visited hospitalized pediatric palliative care patients and their parents or caregivers. I typically shadowed one or two team members, but occasionally I would enter a patient room with as many as three team members. Upon entrance, a palliative care team member introduced me as a doctoral student in health communication at the University of South Florida who was researching how parents and physicians interact and make decisions about their child’s care. The team member and I asked the parent(s) and child for their permission to observe their interactions. Based on the recommendation of palliative care team members, I asked some of these parents if they would be willing to participate in an interview, and if so, provided them with an informed consent document to read and sign prior to a scheduled interview. Parents who agreed to participate in an interview signed the consent document, which was approved by the USF Institutional Review Board and the hospital’s Institutional Review Board.

### *Field notes*

I took notes on a notepad during the weekly team meetings. Team members were aware of my presence and note taking, and only once during the eleven months of meetings did someone ask me not to write something down. I paid particular attention to the ways team members spoke about parents' decision-making, spirituality, and any difficulties they perceived in the cases. During shadowing, I typically carried my notepad but did not write notes until I ended my shadowing for the day. Occasionally I would write notes between interactions. I noted how team members approached parents about difficulties or decisions they were facing. I also noted how team members engaged parents spiritually. I typed my notes within a few days and saved them as electronic password protected documents.

In addition to my field notes, I occasionally journaled my own feelings, thoughts and responses to the events I observed. Such journaling allowed me to better understand my position as both a researcher and parent and to process the difficult situations I encountered in this complex field of research. Journaling also helped me think about the complicated job of palliative care team members and the communication challenges they face in the hospital.

### ***Semi-structured interviews with parents***

Interviews were conducted with twenty parents or grandparents of hospitalized children who were either receiving palliative care, had received palliative care in past admissions, or were good candidates to receive palliative care in the hospital if a referral were made. (Palliative care referrals must be made by the child's attending physician.) Participants included two fathers, three grandmothers, and fifteen mothers. For the sake of brevity, all participants are referred to as "parents" in discussions of the data. Participants included parents who represented the ethnic and racial diversity of the population served by this hospital. I interviewed nine White, seven Black,

two Hispanic and one Middle Eastern parents. Education levels of parents varied from two participants who were functionally illiterate to three who were pursuing advanced graduate degrees. Five parents were caring for babies in the NICU while the other fifteen had a child in another unit of the children's hospital, although of those fifteen, seven had previous experience caring for their child in a NICU. Two of the parents had a child enrolled in hospice. Nine parents related traumatic pregnancy and/or birth stories during their interviews with me. Some parents were employed full-time, but most of the interview participants either had flexible work schedules or were caring for their children full time in lieu of a paying job. Some explained their unemployment as a choice but others described it as a necessity due to the demands of their children.

The semi-structured interviews consisted of six questions (see Appendix A). In some cases, parents were so eager to tell me their stories they began talking before I could ask the first question about their child's condition. In some interviews, I asked parents what life was like in the hospital or what they might want to tell other parents of hospitalized children. These questions grew out of the data I collected in the initial interviews.

Since parents felt the need to stay close to their hospitalized children, all interviews took place in the hospital. Providing both convenience and privacy, important factors in the interview context (Lindlof & Taylor, 2002), was challenging. Flexibility was necessary in scheduling interviews since parents had little control over daily events in the hospital. When the child was very young or the parent felt as if the child was not cognitively alert to their conversations, interviews were conducted in the privacy of patient rooms. If the parent was uncomfortable talking about their child's health in the child's presence or if the child was able to follow the conversation, interviews were conducted in hospital locations such as conference rooms or other

unoccupied spaces that were available. When necessary, a hospital volunteer or chaplain sat with the child while I interviewed the parent(s).

By conducting interviews in the hospital, I was able to hear parents' thoughts as they lived out their spirituality and decision-making in real time. The Institute of Medicine (2014) points out that "[m]any of the most important aspects of pediatric [palliative] care can be understood only with what might be called the '3-foot view,' obtained by sitting with patients and parents and care providers and listening to and learning from their experiences" (p. F-2), so interviewing parents was essential to the project. I told parents to expect interviews to last approximately forty-five minutes to an hour, but many of them chose to continue talking much longer. With some parents who were eager for someone to hear and acknowledge their stories, interviews lasted as long as two hours.

Twenty parent interviews allowed me to witness a variety of approaches to parental decision-making, including some diversity in spiritual frameworks, orientations and belief systems. Parents and grandparents in the study came from a variety of spiritual backgrounds: Christian including mainline Protestant, charismatic, Catholic and Orthodox; Jewish; Buddhist, and spiritual but without a connection to a religious tradition. Even with a wide array of spiritual beliefs, I saw patterns and repetition in approaches to spirituality and decision-making. Each family has a unique story, so I also offer a case study that highlights some specific ways in which parents talked about spirituality and decision-making in this difficult context. The trends and patterns I observed among the twenty participants allowed me to generate themes that help address the research questions that guided this study.

### *Note taking during interviews*

During interviews with parents, I either wrote notes on a notepad or typed them on my laptop computer. Interviews were not audio-recorded and transcribed, though some direct quotes were attainable through note taking. The presence of a recording device in a children's hospital presents several barriers, both with the institution and with parents who are protective of their children's privacy, especially when talking about sensitive issues such as serious medical decisions and spirituality. A recording device has been shown to formalize the interview for participants, reducing their comfort level and willingness to be candid (Lindlof & Taylor, 2002). For this reason, I did not record interviews but took careful notes, paying particular attention to parents' mentions of spirituality, the decisions they made, and their use of religious or spiritual leaders, such as pastors or hospital chaplains, in dealing with their children's illnesses.

### *Identifying participants*

I identified potential interview participants through team meetings and shadowing. I built rapport with team members who acted as gatekeepers to parents and children (Lindlof & Taylor, 2002), and once I gained their trust, they identified parents and grandparents who might be willing to talk with me. I asked them specifically to think about parents who had made or were in the midst of making difficult decisions regarding their child's care. Team members took my project seriously and worked with me to find participants. At times, team members wanted to point me to parents who were "very spiritual," so I reminded them that I was looking for parents who had faced big decisions rather than parents who were spiritually interesting. Over time, the chaplains noted that parents seemed to benefit from talking to me, agreeing that it was beneficial for them to tell their stories to someone who was not a hospital employee and who had the time to sit and listen to them as long as they wanted to talk. Palliative care team members focus on

caring for the whole family, so as the gatekeepers, they maintained a concern for the participants' overall well-being.

By attending the meeting each week, I became familiar with patients who stayed in the hospital long term or frequently returned to the hospital for treatment. Palliative care patients often stay in the hospital for weeks at a time, so team members had more time to get to know patients and families and, as cases were discussed in team meetings, the team often determined that a particular parent would be a good candidate for my research project after several weeks in the hospital. On two occasions, a parent was identified as a good candidate and I followed up to find that they were not interested in participating. Several times, a parent would consent to interview and we would set a time, but when I returned the child had been discharged from the hospital. Other factors such as unforeseen medical procedures, a child's discomfort, or unexpected visitors caused some difficulty in securing interview times, but by shadowing the team weekly, I was able to interview twenty participants between March and November of 2014.

Some parents were identified as a result of shadowing rather than team meetings. As I met parents and children in their hospital rooms, team members sometimes determined that a parent was a good fit for my project and initiated a request for the parent to participate. Since chaplains visited both palliative care and non-palliative care patients, some interviews were conducted with parents of children the chaplains considered good candidates for palliative care, but were not being treated by palliative care at that time.

#### *Inviting parents to participate*

Once potential interview participants were identified, I introduced my project to them by explaining that I was interested in learning more about what different parents experience when their children are in the hospital. I said things such as, "I'm interested in hearing your story," or

“I would like to hear what it’s like from your perspective.” In my project introduction, I did not mention spirituality because one aspect of my research was discovering whether or not parents brought up religion or spirituality without being asked. I did, however, mention my own experience of parenting a hospitalized child unless the team member introducing me already had done so. In the NICU, I would tell parents my son had spent four and a half months in a NICU several years ago. For parents of chronically ill children in the pediatric hospital, I mentioned my son’s kidney transplant, seizure disorder or multiple surgeries. These introductions allowed parents to see me as an ally and someone who understood their situations. If parents indicated they were interested in participating in an interview, I briefly went over the consent form, left it with the parent to read, and determined a good time to return. When I returned for the interview, I asked if the parent had any questions and addressed any concerns before proceeding. In each case where two parents or caregivers of a child were available and willing to participate, I interviewed both at the same time. Although I gave them the option of being interviewed separately, they all preferred to speak with me together.

There were challenges to parent recruitment and participation. First, parents had to be present in order to participate. Since parents negotiate when they come to the hospital based on work and family responsibilities, some parents had more opportunity than others to be with their hospitalized children during the day, which is when I was shadowing team members and had the chance to meet them and be introduced. Second, parents do not dictate the schedule of their children’s care and were not able to predict a treatment or discharge. Sometimes, after scheduling a time for an interview, I returned to find that the patient had been discharged or taken for tests or surgery. Finally, caring for a seriously ill child is full of challenges, and some parents did not wish to share their stories with me due to their emotional state, a desire to



maintain privacy, or because they did not wish to leave their child's bedside. While most parents were quite willing to talk with me, a few did not want to talk about their child in a one-on-one interview. Even then, those parents assented to my presence in the room when palliative care team members were visiting.

Acknowledging these challenges, my personal experience as a parent of a chronically ill child allowed me to build rapport with parents who were present and willing to participate. My seminary training gave me particular insight into spiritual issues as well as skill in talking to people about difficult things. These unique aspects of my life allowed me insider-outsider status in the context of the interviews by simultaneously being a parent, a researcher and a trained spiritual leader (Dwyer & Buckle, 2009).

#### **Procedures for analyzing and interpreting data**

Data collection ended when saturation was signaled by repeated themes and experiences among participants. I spent approximately 150 hours in the field between observations and interviews. I had field notes from thirty weekly team meetings and subsequent shadowing opportunities. I also had interview notes from twenty parent interviews. In order to review the data, I employed thematic analysis to identify specific themes within the data. Thematic analysis allowed me to locate complex meanings within the data by "identifying and describing both implicit and explicit ideas" (Guest, MacQueen & Namey, 2012, p. 10). Since spirituality in pediatric palliative care is an under-researched field, and each family experiences spirituality differently, thematic analysis allowed me to view themes within the individual interviews while also exploring any relationships between the individuals' perspectives and to compare those themes with field note data. Thematic analysis worked well for my large data set because it offered flexibility in the expression of outcomes. The primary goal of analyzing themes from this

data set was to explore parents' decision-making processes and their use of spirituality in those processes.

Themes from the interview notes were developed into codes, which were recorded in a codebook. Raw data from the interview notes were linked to 103 axial codes. I then used the axial codes to create twenty-two open codes (see Appendix B) for analysis that explored individual perspectives as well as recurring themes across interviews and field notes. Thematic analysis is described by Guest and colleagues (2012) as a building process that creates “a rich summary description of the range and depth of the data, ...permit[ting] a systematic exploration of the relationships in the data as well as comparative analyses of those relationships” (p. 40).

For open coding, I used NVivo software for Mac, which allowed me to sort and compare data in several ways including matrix coding, word frequency, text search and word trees. By using the software, I was able to apply multiple codes to sections of interview text and then sort those texts based on their codes. For each of the twenty-two open codes, I created a single document containing all interview data to which I had applied that code. As themes were developed, I also used matrix coding to compare interview text coded in multiple categories. For example, I extracted interview texts that were coded with both “decisions” and “ideas of faith,” locating excerpts in which parents spoke about their faith and decision-making together. The matrix “medical staff” and “decisions” yielded locations where parents spoke about these two topics, and of course, these two example matrices yielded some redundancy. As combinations were explored, I created documents containing the texts for each matrix and used those documents to examine themes across the data. NVivo also allowed me to view a list of the one thousand most frequently used words within the interview data. I then used the text search feature to locate ways parents used certain frequently occurring words. The word tree function

displayed word search results so I could examine how a specific word was used in context across all the interviews. The analysis of the interview notes through these methods yielded large themes within the data that are described in the analysis chapter.

Parent interviews were coded and closely analyzed using NVivo software because the research questions guiding the project focus on parent perceptions. Field notes acted as supporting documents to represent the perspectives of the people and site not visible through the interview data (e.g. chaplain behaviors, physician explanations, etc.). Findings were validated through the presentation of preliminary findings to the chaplains who were present for the duration of the project and have many years of experience in the field. One of the chaplains reviewed the analysis in written form, offered feedback and corroborated findings. Findings were also presented to the Center for Hospice, Palliative Care and End-of-Life Studies at the University of South Florida, the administration of the hospital where the research was conducted, and a local hospice agency to verify that my initial findings were consistent with their experiences. Members of the dissertation committee reviewed the coding process and verified the coding scheme through a review of the data.

Considering that my personal experiences of parenting a seriously ill child deeply inform my research, my own experiences of spirituality and decision-making are applicable to this project. I use personal narrative to communicate my own stories of parenting a hospitalized child and as a point of comparison to other parent stories, a method employed in Jenks' (2005) research with parents of visually impaired children.

In *The Wounded Storyteller: Body, Illness and Ethics*, Arthur Frank (1995) explains the importance of narrative in the ill person's communication. Just as ill people need to tell their stories "in order to construct new maps and new perceptions of their relationships to the world"

(p. 3), parents need to do the same thing with their stories of parenting seriously ill children. In telling my own story of parenting a seriously ill child, I “recognize that more is involved in [my] experiences than the medical story can tell” (p. 6). As I explore my own experiences, I see examples of the narrative wreck Frank describes. “The illness story is wrecked because its present is not what the past was supposed to lead up to, and the future is scarcely thinkable” (p. 55). How much more so when considering an ill child? Frank categorizes illness stories as restitution narratives in which the desire is a return to health previously enjoyed, chaos narratives in which the emotional and physical disorientation of the crisis of illness is experienced through the story, and quest narratives in which the story-teller looks forward to personal, community or social change as a result of their illness experience. All three of these categories exist within my personal narratives as well as my interview participants’ narratives.

## **Conclusion**

This project examined parents of seriously ill children within the context of a children’s hospital through the use of interviews and observation. Additionally, observations of hospital staff interacting with families and discussing cases away from families informs the project significantly. While each pediatric hospital has unique characteristics, one commonality is that pediatric hospitals sit at the nexus of intense biomedical, systematic operations and families in crisis. Every family of a hospitalized child is managing a displacement from home, a change in routine, and a medical problem. Researching parental decision-making in such a tumultuous location brought about many challenges but also rich data that should guide future research and understandings of the role of spirituality for parents of seriously ill children.

## CHAPTER FOUR: THE ROLE OF SPIRITUALITY FOR PARENTS OF HOSPITALIZED CHILDREN

Parents who care for hospitalized children are an understudied population yet there is an immediate need for research among this group (IOM, 2104; Orloff, 2012) One parent described her experience in the hospital as a “secret life.” She was not talking about a desire to maintain privacy, rather she was indicating the lack of understanding she finds among friends and family. In order to gain a better understanding of the unseen lives of these parents, I spoke with them at the “3-foot view,” the up-close and personal conversations recommended by the Institute of Medicine (2014) for studying pediatric palliative care (p. F-2). From these one-on-one or one-on-two conversations, I was able to learn much more about parents’ understandings of their experiences, their sensemaking processes and the ways in which they talked about and lived out their spiritual understandings.

The analysis presented here is an interrogation of the interview data through the lens of communication theory. The principles of social construction and sensemaking open up a view of parental decision-making as an ongoing communicative experience rather than as isolated events. Healthcare literature often focuses on individual aspects of the patient or family experience (i.e. coping, decision-making, grief, behavior) and looks at communication as a transmission of information (Foster, Whitehead, Maybee, & Cullens, 2013), but when social construction is applied to health contexts, it pulls back the lens of examination to see how relationships,

circumstances and previous experiences relate to one another and to the ways people make sense of health crises. Spirituality, as a framework for understanding all of life, impacts relationships and decision-making in significant ways. Parents construct understandings of their children's illnesses using a variety of factors, one of which is spirituality. These constructions are not individual endeavors but are situated in relationships and experiences.

Another way of describing parental constructions of understanding is sensemaking. Weick's (1995) seven principles of sensemaking bring into view the importance of construction and relationship for sensemaking processes. Weick focuses on such things as the retrospective nature of sensemaking in which lived experiences (notice the past tense of "lived") are examined through extracted cues. Using Weick, we can see that decisions do not have results but rather "relatings" (p. 33), illustrating that people and their environments constantly influence one another just as people influence one another. The interviews in this study look at one moment in the ongoing sensemaking process of parents. Weick points out that the ever-changing situations of people in crisis means there can be no "stable representation of the situation" (p. 44). As Richard Pratt (2004) says, "When the deck of life is always shifting, balance can be nothing more than momentary synchronicity." For parents of seriously ill children, the boat is always rocking, and life balance may seem impossible. Finally, and potentially most important for this project, Weick (1995) stresses the importance of plausibility over accuracy. He explains that "accurate perceptions have the power to immobilize" (p. 60), so reasoning that is actionable takes priority over specific and accurate data.

Weick points out that significant misunderstandings result from already overwhelmed people being given more and more information in an effort to equip them for solving crises, so some information will be superseded by plausible explanations that lend themselves to action.

For example, a parent who has been given a life-altering diagnosis for a child may not be able to contend with the details of the choices they face. When detailed information about each choice is more than parents can take in, accuracy matters little and the most plausible choice is regarded as best. For example, one mother of a NICU infant was faced with the decision to send her very premature baby to surgery, where he was given a 1% chance of survival, or allow his bowel to continue to necrotize, which would eventually end his life. Although both options appeared they would result in the same outcome, the death of the child, the mother chose surgery because it was an action and the other option was to do nothing. Although the medical staff was concerned with the information of the case, which included a very poor prognosis for the child, the mother did not choose based on this information. In fact, the information became overwhelming and she began avoiding the doctors and their attempts to give her medical information.

By moving away from a transactional model of communication (Craig, 1999), which relies heavily on the transmission of information between a sender and receiver, towards a constructionist or constitutive approach, which values the relational and experiential aspects of participants, we find ourselves with a messier and more complex project; but should the process of analysis not reflect the subject at hand? What better way to delve into spirituality's role in parental decision-making for seriously ill children than to acknowledge the complexities of parents' lives with a view of communication that takes their lived experiences, spirituality, and relationships into account.

Keeping in mind these concepts of sensemaking and communication, I interviewed twenty parents and grandparents of seriously ill children ranging from newborn NICU babies to teenagers nearing adulthood in order to address the following research questions:

**RQ1:** What resources do parents draw upon to make medical decisions for their seriously ill children?

**RQ2:** How do parents enact their spiritual or religious frameworks in clinical settings when faced with medical decisions for their seriously ill children?

A thematic analysis of interview notes resulted in three major themes that will be explored in this chapter.

The following analysis will first explore spirituality's over-all impact on families' lived experiences in the hospital. Next is an examination of parents' reported engagement with hospital staff regarding spirituality. Finally, taking into consideration spirituality's place in families' experiences and interactions with hospital staff, is a look at parents' use of resources and decision-making for their seriously ill children.

### **Lived Experience and Spirituality of Parents**

Parents expressed their spirituality and its impact on their hospital experience in a variety of ways. As parents talked about their spiritual understandings and practices within the walls of the hospital, they explained that spirituality was helpful in their own lives as well as in the lives of their children. Many parents prayed both as a discipline and in times of crisis. They also recalled other stories of spiritual experiences or sought ways to use their own experience as a help to others. Many of the parents expressed that God was in control of their child's health or that their child's inner spirit was a particular strength. In some cases, spirituality was pitted against medicine with the view that spirituality was the stronger force. Finally, parents mentioned the role that chaplains played in their spiritual experiences within the hospital.



### **Faith helps parents**

Parents talked about the function of their spirituality in their own lived experiences within the hospital. Often, parents expressed that their faith kept them from falling apart emotionally. I asked one mother, “How does your faith factor in?” She responded, “It’s helping me stay strong. If I were doing this myself, like I told you, I’m scared of everything. It’s the greatest factor of the whole thing. If I didn’t have it, I would be lost. I wouldn’t be able to do it.” Another mother told me, “My relationship with God has kept me strong, so I could be here.” Two participants specifically stated that they were not struggling with depression and believed that God had helped them avoid it. Parents’ expressions of faith fell into two main categories, prayer/study and narrative connections.

### ***Prayer***

Parents talked about prayer in two ways, first as an exercise of spiritual discipline, and second as a desperate plea in times of crisis. Parents expressed the need for consistent spiritual connection. One mother took her daughter to the hospital chapel and herb garden for prayer and quiet meditation. Some practiced spiritual discipline daily. One parent said, “God gave me the strength every night because I would pray.” A grandmother told me prayer was a form of protection. “I always pray and ask the Lord to protect us and guide us. Satan is like a roaring lion ready to devour whoever he can. We have to stay prayed up and keep our hand in God’s hand.” Spiritual study was also important. One mother talked about her need to be more spiritually disciplined for the sake of her child. “I need to read his word. *Need* to. How can I teach [my son] if he doesn’t see me read it?”

Some parents had a specific prayer that was meaningful to them. One told me that a church leader had given her the serenity prayer, which she attributed to Mother Teresa but originates with Reinhold Niebuhr (1950). This prayer states:

God, give me grace to accept with serenity  
the things that cannot be changed,  
Courage to change the things  
which should be changed,  
and the Wisdom to distinguish  
the one from the other.

Living one day at a time,  
Enjoying one moment at a time,  
Accepting hardship as a pathway to peace,  
Taking, as Jesus did,  
This sinful world as it is,  
Not as I would have it,  
Trusting that You will make all things right,  
If I surrender to Your will,  
So that I may be reasonably happy in this life,  
And supremely happy with You forever in the next.  
Amen.

The mom saw this prayer as a reminder that “certain things are completely out of our control. If we learn not to borrow tomorrow’s problems, we can live a happier life.” Another participant

said the 23<sup>rd</sup> Psalm is “all that you need.” She explained that her grandmother prayed this familiar Psalm, which begins “The Lord is my Shepherd,” over her hospitalized child. She described her grandmother’s contentment after praying through the Psalm and said, “I need that.”

In addition to practicing daily prayer as a discipline, parents also prayed in times of crisis, sometimes resulting in their own spiritual change. Pre-term birth was one crisis that brought parents and grandparents to their knees. As one grandmother told me of her micropremie grandchild, “The very moment he was born, I fell on the floor. ‘Lord, I don’t know what to do. You do this.’” Another mother, fearful of her impending pre-term C-section said, “I was talking to myself, ‘Lord, please don’t let me have my baby early, and get cut too.’” Another mom spoke of the importance of a hospital staff person praying with her just before going in for her C-section. “I knew that my prayer was answered, otherwise I would have had a panic attack. I didn’t even have trouble breathing. I was getting nervous, [but] it went away.”

Crisis stretches beyond birth, though. Some parents in the study talked about the crisis of the hospital experience. One parent said the following about caring for a hospitalized child: “If you don’t have a relationship with God, you’ll get one. If you’re not a praying person, you will be by the time you leave. It was like my back was against the wall.” Illustrating the hospital as a location of crisis, one parent described life there as “pure stress.”

Prayer in times of crisis was often credited with spiritual and relational change for both parents and their extended families. In one mom’s case, a prayer in a time of crisis was credited with the restoration of hope. As she went into labor very early in an already troubled pregnancy, she said:

I was just praying, praying, praying, ‘Please God, please God! Just stop [the contractions].’ It was like divine intervention. Once that happened I started to have hope

that I could hold onto this baby long enough for her to live and be ok. So that was a pretty significant time for me.

Another mother described a tense conversation she had with God in which she said, “You took everything away from me.” Her lack of control over her son’s condition was palpable because even the arrangement of the blankets and toys in his room changed without her consent. Her expression of anger was coupled with a request to “keep my faith with [God] and my faith with my son.” After this long talk with God, others told her she looked much happier. “I think that was me getting over being mad. I wasn’t mad anymore. The choices and control being gone, so much frustration and anger built up, ...but after that I let the anger go. It was good. That’s what has helped me.”

One family, previously divided by family tensions, talked about how they spiritually came together through prayer after the crisis of a child’s serious illness. In the interview with these two family members, one said, “The Bible says, ‘A family that prays together stays together.’ We had to stay together for him.” When a crisis would come up, one of the interview participants would always encourage family members to pray. The other participant said this helped bring the family together. “There were times when I wanted to kill somebody,” she said, but the family prayers kept her from acting out in anger. Ultimately, this previously fractured family came together as a result of the crisis and their prayerful response.

Not everyone was quick to pray, though. One parent told me:

It feels weird for me to pray now because I’ve been through so much, is there really a God? Why did he do this to her? It’s not fair to him to pray and tell him, ‘Please do this for me,’ and when I’m not really being, ‘Thank you for everything you do for me.’ I blame him a lot for a lot of things that have happened in my life. I shouldn’t be praying

and asking for things when I'm not fixing my relationship with him. I really want to pray and tell him, 'Please, but I'm really sorry. I promise I'm going to be more faithful to you,' and then I don't.

For this mom who was wrestling with a spiritual crisis, prayer felt inappropriate because of her lack of faith.

### *Spiritual narratives*

Another way parents expressed their spirituality was through the telling of spiritual narratives. They told stories of other health crises from which they drew spiritual comfort. For example, one parent who is employed as a healthcare worker, told stories of patients' death or near-death experiences. One story involved a man who went into cardiac arrest but was revived. The man described his experience saying he ascended a marble staircase only to be sent back down by his deceased brother who told him, "You're not ready." This parent also told me of a nurse friend who witnessed a woman's spirit wave to her and walk out the door of a room where hospital staff were performing CPR. This parent, who was cynical about organized religion, gathered spiritual comfort from these stories evidencing the spiritual world.

A few parents told me about the deaths of their mothers, spiritually significant events they connected to their current hospital experiences. One single mother who decided to go ahead with a surgery that carried a high risk of fatality for her child confused hospital staff when she abruptly canceled the surgery after the date had been set. She later told me they had scheduled the surgery on the same date her mother had died a few years earlier after undergoing surgery. This participant drew a spiritual significance from dates, explaining that the numbers of her birthday and her son's birthday were the same but in reverse order. She said her son was

unplanned, so these numerical correlations caused her to feel more “sentimental” about him. Numerical correlations were interpreted as signs, both good and bad.

One participant, who was facing a dismal outlook for her child, told me of the death of her mother and grandmother while she was pregnant. The participant described it this way:

We said, ‘You’ve fought a good fight. If you need to go, you can go...’ And she says, ‘I found my cloud. I saw my cloud, that’s where I’m supposed to be.’ I told her, ‘The next time you see it, jump on your cloud.’ To this day, when we see clouds, we love it.

As an expression of this connection to her mother through clouds, her husband gave her a glider ride as a birthday gift so she could touch the clouds. She described talking to her relatives in heaven, asking that they would take care of the child she cared for in the confines of the hospital daily, away from the fresh air and clouds.

In addition to drawing comfort from the spiritual narratives of others, some parents looked forward to the ways their narratives could impact other parents in their same situation. One mother said she was “trying to find a reason for why all this happened to me.” In her quest (Frank, 1995), she said, “We don’t always know [God’s] plan, but there are great things that can come out of this.” She considered several options that would give purpose to her personal narrative, one being to write a book to encourage other parents going through similar circumstances.

Many parents told me their stories out of a hope that others would hear them, and they would have a positive impact both on other parents and on the medical community. In some of the later interviews, I asked participants what they would say to other parents of hospitalized children. One told me, “Get positive with other families and help them out to be positive and be honest and truthful.” This parent’s sense of connectedness was rooted in a faith in Jesus and a

hope for peace. “It’s all like teamwork, strangers, not strangers, with everybody to help one another out. Without that, you’d just be miserable and filled with anger and no one wants to be around you.” Thinking about the future was particularly difficult in this case because the child was “going to be with Jesus.” The family would have to live on after the child died, and one way they would move forward was by forming a narrative connection between the child’s life and the future.

### **Faith helps children**

In addition to finding personal help in their spirituality, parents also believed that spiritual realities were important for their children’s well-being. Of course, these two ideas are closely related. Parents’ crises stemmed from their children’s ill health, and much of their hope for the future was dependent upon their children improving. In other words, their deep need for spiritual connection was inextricably tied to their children. However, parents also talked specifically about how spirituality impacted their children.

Parents spoke about the importance of prayer and faith for their children’s improvement. Many parents saw prayer as an accompaniment to the medical care their children were receiving. When parents had little to no control over what was happening, a resonant feeling among many of the parents in my interview set, prayer was an important way they could participate in their children’s care. “For us, it’s hard because we have to watch him in pain, can’t do anything but hope the medicine can take care of it, and prayer,” explained one parent. Another parent talked about the connection between faith and medicine: “I believe God has a reason for each of us, the doctors and medicine. We are instruments of Him for His purpose....I pray [for my child] every night....and [for] her doctors.”

Other parents relied more heavily on spirituality than anything else for their child's well-being. One parent told me, "The faith and loving him is why he's thriving so much. ... When we come in he's totally more relaxed. He's more calm. ... It's amazing what love can do, if you care for anybody how they can come back quickly." In another description of spiritual care, I was told, "I used to just go make up songs and sing to her and she would be quiet. You see, this is all you have to do. Stay wired up with the Lord and pray." One mother said, "I really believe in positive thinking. I think good things happen when you think positively, put good thoughts out into the universe." Another parent described a desperate need for spiritual help when the medical treatments had failed: "He's on prayer chains throughout the world. ... [M]y mom's friend is putting oil on a cloth and praying for it. We're being sent the cloth. I will try anything at this point." Many parents expressed a belief that there was purpose in their child's illness, even if they did not understand it. "Everything happens for a reason," was a common phrase among parents. Many of these parents would also state their belief that God was in control of what was happening. "We keep it all in God's hands," said one.

Parents spoke about their own spirituality as important for their children's health, but also referenced their children's spirituality as important. One mom of an adolescent told about a time when her child was in the midst of a spiritual crisis. The chaplain came in and spent time praying with the child and improved her over-all well-being. Another father described his child's will as very strong. He referred to this as "inner drive" and "spunk" and equated it with the child's willingness to fight to live. While the father did not use the word "spirit" to describe this aspect of his son, he considered his son's spunk as more important than his medical diagnosis saying, "Lots of kids are as sick as he is, but if they don't have that inner drive, they just give up." One grandmother believed that the very young child for whom she was caring had personal



communication with God. As this baby was about to be discharged from a long hospitalization, the grandmother said, "...[H]e already knows. The Father already told him.... It's time to go home."

### **Spirituality vs. medicine**

As parents spoke about spirituality within the walls of a medical institution, they expressed a division between spirituality and medicine. For some, medical practitioners enforced this division, while other parents articulated their personal belief in the division between spirituality and medicine. One family became embroiled in a legal dispute due to their medical practitioner's challenge of their child's treatment with both natural and biomedical treatments. While this family was deeply committed to their faith in God and saw a connection between faith and medicine, the medical practitioner pursued legal action against them on the basis that they were doing "something spiritual." The parents had sought a combination of biomedical treatment and natural remedies outside the US and had been encouraged to return to the US for financial reasons. Upon returning, court proceedings forced them to seek treatment immediately, preventing them from going to their hospital of choice in another state. They did not return to their initial site of treatment but instead came to the hospital where I interviewed them. This parent told me, "We are spiritual, but that wasn't what we were doing. They think it's plants and remedies, but this has been used at the same time as traditional [biomedicine], but I believe you can use both in a good way." Due to their stressful dispute, this family found comfort with medical practitioners who valued spirituality in the new hospital.

Other parents pointed out a division between spirituality and medicine based on their own experiences and estimations. One participant told me, "You've got to really have faith. Doctors are practicing. They say they're *practicing* medicine, that's right, *practicing*! A lot of things they

said, [the baby] made them a liar.” Another reiterated that science and spirituality “don’t mix.” These participants reveled in the thought that fragile children would prove wrong the highly scientific predictions of medicine. For example, another parent told me, “I think [the baby]’s here to show everybody that the medical part’s not always correct.”

Some parents drew a distinction without the goal of proving science wrong. These parents, also practitioners of medicine, explained their complex thinking in this way: “We’ve done so many different things. I don’t know if it’s always a religious side to make the decision as it is our heart, and we are scientific and we have to make sense of it.”

Every participant was making sense of their child’s illness in some way. Their understanding of their child’s condition was coupled with their spiritual beliefs, lived experiences, and family situations. Each of these aspects served as building blocks for sense-making as they constructed a way of caring for their children daily. These constructions of meaning impacted their daily conversations with medical practitioners as well as their decision-making. Separating out each aspect allows a closer investigation of the ways parents construct meaning, but it is important that the larger picture is maintained in order to understand the behaviors and decisions that may seem irrational or erratic to medical professionals.

### **Parents’ Spiritual Engagement with Hospital Staff**

Considering that parents rely on both medical information and spirituality as important building blocks for decision-making, it is helpful to see how parents engage with medical staff spiritually. While medical practitioners receive a great deal of scientific training, it is rare to find a practitioner with training in matters of spirituality. Nevertheless, practitioners of pediatric palliative care contend with issues of spirituality on a daily basis. While the presence of a

chaplain on the interdisciplinary team is helpful, other hospital staff are frequently brought into spiritual conversations. Bateman and Clair (2015) examined pediatric end-of-life physicians' perspectives on religion/spirituality. Most of the participants in their qualitative study felt that religion/spirituality was important to patients and families regardless of the physician's personal beliefs, but the study indicated that even the physicians identified as "richly religious" believed that good decision-making was based on information rather than spirituality (p. 260).

Although the Bateman and Clair (2015) study indicated a welcoming view of spirituality by end-of-life physicians, seriously ill children are treated by a variety of medical staff including specialists, nurses, therapists, clinical techs, etc. Most of these practitioners also treat cases besides palliative care/end-of-life and may not have as much interaction with spiritual care professionals as palliative care providers do. With little to no training in spirituality, practitioners may shy away from spiritual conversations and focus on their expertise, medical science. While practitioners may consider their avoidance of spirituality as appropriate, it is important to know how parents view their spiritual encounters with hospital staff.

In my interviews, I heard several accounts of parents engaging with hospital personnel on a spiritual level. In some cases, these hospital personnel were chaplains, but in many others they were physicians, nurses, clinical assistants or non-medical support staff. Parents typically described their spiritual interactions with hospital personnel as either supportive and positive or frustrating and negative. There was a sense of surprise when parents had positive spiritual interactions, likely due to the previously discussed division between spirituality and medicine.

### **Negative interactions**

Parents described several negative interactions with hospital personnel, mainly physicians. In these interactions, some parents described their role in terms of messengers of

faith. One grandmother recounted a story from several years ago, just after her daughter died during childbirth. Now charged with caring for a seriously ill newborn infant, she was asked whether or not she wanted to release the child to the state or keep her. Although this was presented as a legal issue, she saw it from a spiritual perspective:

We had a big round table meeting and they said, ‘What do you want to do?’ I said, ‘I believe in God and God has the last say-so.’...At that meeting, I couldn’t think nothing but what God said in the book, that I have to depend on him and be his witness for those that don’t know him. And that’s what I did, I let them know I trust in God.

This grandmother was appalled at the suggestion that she would turn over her granddaughter to the state because she had become disabled at birth. The difference she perceived between her perspective and that of the people sitting at the table was a belief in God, and she saw herself as God’s messenger for the doctors who did not share her belief.

Frustrated with how blunt doctors can be, another grandmother talked about doctors telling her family, “Your baby is going to die,” and “Your baby is going to be blind.” Her response to such statements: “What do you mean? You’re not God!” In this case, bad news delivered without compassion was met with a contrary spiritual retort. Again, from the practitioner’s perspective, the goal was to deliver information, so the aggressive spiritual response places the practitioner and family at odds with one another.

As explored earlier, the division between spirituality and medicine exists in practitioners too. One parent reported a conversation she and her husband had with a physician regarding treatment options for their child diagnosed with cancer. “My husband, the first thing he asks is, ‘What can we do so she doesn’t have to go through this?’ The doctor says, ‘Miracles, and miracles don’t exist.’ That was our first experience with [an oncologist.]” This dismissal of

spiritual possibilities was poorly received by the parents and set the tone for a difficult relationship. Research indicates that medical practitioners avoid conversations with families who express the hope for a miracle (Kurtz, 2012; Rushton & Russell, 1996), but according to this parent, the doctor brought up the idea of miracles and then dismissed such occurrences as nonexistent. The mom told me, “We had a bad experience. Because we are Christians, we believe in God and miracles, but we’re realistic and we know he uses medicine as an instrument for healing.”

The understanding of medicine and God working in concert reflects a common understanding of spirituality and medicine among families. As noted by Rushton and Russell (1996), parents’ expressions of hope for a miracle should not be understood as unrealistic or irrational, rather these hopes are better understood in terms of immediate goals with the acknowledgement that what parents hope may not come to fruition. When practitioners interpret the use of spiritual language as a rejection of medical information, they are missing the opportunity to engage with families who see medicine and spirituality existing in concert rather than conflict. Unfortunately, practitioners of medicine may not understand the language of miracles in this way. In this family’s case, the relational animosity between the non-believing physician and the parents escalated over the coming months and resulted in their pursuit of a different doctor.

More common than overt disagreements over spirituality are the underlying feelings of parents that spirituality is not well accepted in the hospital. “At [a local hospital], people don’t talk much about God,” said one mom. Parents understand the physician’s role as that of a scientist who is required to give the data without any spiritual considerations. Discussing her conversation with another NICU mother, one participant told me, “I told her, the doctors have to

tell you about the outcome....You never know. God has the last say so, so when they tell you he might have a little retardation or he's not going to walk or talk, don't think of it like that. They have to tell you that.”

Offering spiritual platitudes was one other cause of frustration. A mother of multiple chronically ill children told me, “The saying that God doesn't give me more than I can handle, I laugh every time one of the nurses tells me that.” This common phrase, not found in any sacred text, exemplifies the emptiness of unthinking spiritual talk. Most of the parents I interviewed were in some sense overwhelmed. What they were dealing with felt like more than they could handle, (though a few parents stated their belief that God would not give them more than they could handle or bear). With this frustrated mom, I shared my own frustrations with this phrase and how I have frequently come to my wit's end caring for my own son in the hospital. I told her I was comforted by the thought that yes, God will allow me a life beyond what I can handle, but nothing that happens to me will ever be more than God can handle. She resonated with my reframed version of this familiar saying.

### **Positive spiritual encounters**

While some parents were frustrated by their conversations about spirituality with hospital personnel, most of the reported instances of hospital personnel talking with parents about spirituality were positive. When parents talked about spiritual conversations, they often mentioned hospital staff's participation in providing spiritual comfort in some form. Parents talked positively about medical staff's spiritual contributions in two ways: as spiritual representatives or messengers and as liaisons between the family and chaplains or clergy. Additionally, some parents mentioned significant spiritual support from non-medical hospital employees.

Parents drew comfort from medical staff who spoke overt messages of spiritual faith. For example, after dealing with what she perceived as some physicians' hostility towards faith, one parent recounted a conversation with a new doctor:

The first thing he said to us was, 'I heard you pray a lot.'

My husband said, 'Yes.'

[The doctor said] 'To Who?'

We say, 'God, the Lord.'

And he said, 'He made everything happen.'

It was a release.

While some parents may not draw comfort from such an overt message of God's omnipotence and sovereignty, these parents were relieved to find resonance between their faith and their child's physician. Based on this mother's account, it appears that the physician did a bit of spiritual probing before making any claims of his own. This strategy of listening for trigger words is described by some of the richly religious end-of-life physicians in Bateman and Clair's (2015) study. One fellow said, "...[I]f I get any clues from the family that they are Christian, I am not afraid to share scripture, talk about prayer..." (p. 259).

Context also seems to be important. The same physician who offered spiritual words of comfort to the parents described above refused to engage another family in a spiritual conversation after the chaplain told him, "These are praying people." With a chaplain and a researcher (me) in the room with him, this physician focused on describing the diagnosis and treatment plan for the patient. Upon leaving, the chaplain expressed frustration that this doctor, although he had a reputation for his spiritual commitment, never seemed to engage patients spiritually. Having heard multiple stories from families of this doctor's spiritual engagement

with them, it appears that he is unwilling to do so in front of other hospital staff, and perhaps particularly in front of the chaplain. The physicians in Bateman and Clair's (2015) richly religious group explained that they did not discuss their faith with their colleagues (p. 256). This physician exemplified this philosophy of caring, likely based on the expectation that physicians are committed to science and chaplains are committed to spiritual care. If a physician were to engage in spiritual care in front of a chaplain, there would be a collapse of roles (Weick, 1993).

Nurses, who in my observations were much more willing to talk about spiritual things, were also reported as sources of spiritual assurance. The mother of a hospice<sup>1</sup> patient nearing death talked about the nurse who told her, "We don't know when God is going to take him." The nurse's framing of the message reflected the mother's understanding of God's sovereignty over all of life. She responded to the information by posting an invitation on social media for friends and family to come and see her son before he died. Such an openness regarding death and God's role in it is likely more common among hospice patients' families than others who are still hoping for a cure, and once a child is enrolled in hospice, that may alter the way in which nurses and other medical practitioners engage with a hospitalized patient and family.

Medical practitioners may also be perceived as representatives of spirituality. "The doctors are awesome. Dr. Sanders<sup>2</sup> is like, he came in and he's like, \*exhale\*... He's just got this aura about him and that is wonderful," says one mother. Another describes an interaction with a clinical technician:

It was Sunday morning, and I was happy because I was able to get online and watch

Sunday service for my church, something to look forward to. I came back upstairs and

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<sup>1</sup> Hospice care is provided for terminally ill children within the final six months of life. Physicians hold a single certification for hospice and palliative care, so the palliative care specialist at the research site also treated hospice patients.

<sup>2</sup> All names have been changed to protect the privacy of participants.



couldn't get online and couldn't get onto the service. So Cindy, the aid, came in and I said, 'This is terrible, I can't get online,' and there was no coffee. Cindy said, 'I believe when God wants you to hear the word you are supposed to hear, the computer will come on.' Sure enough, and the message was very significant. 'Humble yourself to the Lord and He will lift you up' (James 4:10). Significant moment. From then on Cindy was very important to me. God had sent her to me, like an outside angel. She was always popping up when I needed her.

Another way hospital personnel functioned in the spiritual lives of parents was as liaisons between families and chaplains or clergy from their own tradition. One mother, frustrated by the medical practitioners who were constantly reminding her of her son's poor condition, was receptive to their offer of calling the chaplain. When the chaplain arrived, the mom felt free to pray, cry and show emotion she had been holding back with the medical staff. Another mom reported a time her teenaged daughter began questioning, "Why did God make me this way? Why can't I just be normal?" Her nurse called the chaplain, who met with the girl one-on-one and helped her by showing her a prayer and meeting her spiritual needs.

In addition to hospital chaplains, parents appreciated the relationship their own pastors or clergy-persons had with hospital personnel. When a family identified a particular church, synagogue or other local congregation, they appreciated the hospital (typically the chaplains) contacting their faith leaders and making them aware of the situation. When one family's pastor became a regular visitor, the mother was comforted by his relationship with the medical staff:

Once I introduced [my pastor] to the doctors, and he actually got to where he would come up here and when the doctors come in [he would talk to them], or he would request to

... speak with them... The pastor got involved, knows the doctor, feels comfortable talking to him.

This family was reassured by having a spiritual leader who could speak with physicians about their child's situation.

A few parents mentioned spiritual support that came from non-medical hospital staff members. A staff member delivering paperwork referred to by a participant only as "the lady" made a meaningful spiritual comment to one mother about to have a C-section. Without any prior conversations, she told the mother I interviewed, "Everybody in the operating room is a believer and God's taking care of you." The mom told me, "I was thinking I was in a fairytale because people don't talk like that, but I think God was talking through this lady because I'm so scared of surgery. So I knew that my prayer was answered." This hospital employee was most likely from the business office, an unexpected source of spiritual support.

A few parents told me about an environmental services worker who offered words of spiritual encouragement. One recounted this story:

Miss Janie, the janitor, she used to come in and talk to me. She said, 'You know, God has the last say-so. He is not your son; you're here to raise him. He's God's son. You're in his presence to raise him. He does not belong to you.... God is in control, and if he's not meant to be here, God will take him and if he is, he's meant to be here.'

This overt spiritual statement was received by the mother as a new frame through which she could see her role in her seriously ill son's life. In fact, the medical team had been working hard to get this mother to make a decision but had been confounded by her unwillingness to talk to them. After countless attempts to engage this mother by physicians, nurses and social workers, the janitor was the person to whom this mother was most willing to listen.

## **Parental Decision-making**

During semi-structured interviews with parents, I asked about some difficult decisions parents had faced. Many took this question to mean exclusively medical decisions, but some explored both medical and family decisions such as childcare, living situations and transportation, illustrating how parents see the larger implications of a hospitalization on all of life. I then asked what resources parents used in order to make the decisions they discussed in the previous question. Answers from parents fell into four different categories: online and academic sources; doctors and nurses; family, friends and self; and spiritual sources.

Parents named online sources such as Google, WebMD, hospital websites, Facebook support groups, and parent narratives on sites such as March of Dimes. Some parents with experience in academia spent time searching academic library holdings, either in person or online. One parent explained:

[I read] journals. When they were talking about medicines, I would just go online and search in the school library or Google scholar. I also read a few student papers of oncologists. They talked about the chemo medicines and what are their side effects, how do they work or interfere with other meds. I feel that's the best because they are really detailed.

Another resource named by parents included doctors and nurses. Parents not only considered medical information given by their child's current practitioners, but also searched for input from other medical experts in their personal networks, whether through friendships, family relationships, or prior treatment. A few parents sought advice from physicians in other states or,

in one case, in another country. Several parents had taken their children to other places for specialized treatments or clinical trials. One parent, after taking her daughter to participate in a year-long research project at a hospital in the northeast, flew to the west coast alone to continue researching her daughter's condition at another well-respected institution.

Many parents' pursuits of information were time consuming and resulted in physical and psychological distress as demonstrated by these parents' statements:

I was so exhausted... I was reading until two, four, five o'clock in the morning.

I Googled it, and that was the worst thing I've ever done.... There were things on there like children going into nursing homes.... It was just horrible.... Me and my husband were separated for a year and a half because of the diagnosis. He couldn't handle it.

You can do too much [internet research]. I wanted to know what the worst was. I looked up the worst of the worst. ...I cried the whole week leading up to come for the sonogram.

The other resources parents discussed were family, friends and self and spiritual sources. Participants explained the importance of family members being in agreement and considered the input of family members important, even when they were not legally responsible for the child or decision-making. Friends, especially if they had personal or professional medical experience, were also mentioned as resources. A few parents talked about themselves as resources for decision-making. Some parents indicated that they were guided by their feelings about the decision, while one parent said her personal experience with illness was a resource in making decisions for her child. "I went according to what I know for myself, and I put her in my shoes."

Among the spiritual sources, parents named “God” or “the Lord” as well as avenues to spiritually communicate with God. Some parents indicated that prayer was a resource for decision-making, saying, “I just called on the Lord,” or “[You] pray so you can make the right choice that God wants you to make.” One parent spoke about a family member’s vision from God as a resource for decision-making. “God says he’s gonna be ok,” said the trusted family member. This vision was particularly impactful because the recipient of the vision did not know the child was in need of surgery, but the message came just as the parent was making the decision to consent to the procedure, feeling full of dread that the baby would die.

When directly asked about resources for decision-making, parents spoke about accessing many kinds of sources, including both information sources (internet and medical practitioners) and emotional support sources (family, friends and self and spiritual sources), and most parents accessed more than one. While information is commonly seen as a tool for decision-making, sources of emotional support, particularly spiritual sources, are typically associated with coping (Hexem et al., 2011; Meyer, Ritholz, Burns, & Truog, 2006; Penner et al., 2010; Stutts & Schloemann, 2002; Wang & Kearney, 2013). It is important to ask how these particular resources are directly connected to decision-making, as indicated by parents’ answers.

Pediatric palliative care teams are tasked with supporting parents as they solve problems and make decisions for their seriously ill children (IOM, 2014, p.F-26). In my observation of palliative care providers, they often discussed parents who were facing big decisions. In fact, when a patient was in particularly poor condition, physicians delivered the bad news and then introduced the topic of decision-making. A line from my field notes taken in the weekly pediatric palliative care team meeting says, “[The patient is] declining. Neurologist said, ‘You will need to start making decisions.’” This sets up decision-making as a particularly weighty and grave task.

Although parents, doctors, nurses, and other practitioners make many decisions for child patients every day, only the very serious decisions are labeled “decisions,” and they become solely the parents’ responsibility.

Palliative care team members recognized the difficulty of the life-or-death decisions parents face. In my interactions with the team, I participated in discussions about the quandary of medical advances that can save the lives of some children but prolong the suffering of others. After a team conversation about a palliative care patient who fit this description, I wrote the following in my field notes:

The social workers talked about how parents are forced to make a decision they shouldn’t have to make because of the technology that keeps these babies alive who would have died naturally otherwise. ... Years ago, these kids would have died immediately and naturally. Now, some of them can be kept alive, but it only prolongs a life and then puts a difficult decision on parents because a child could be kept alive indefinitely using technology.

Due to the difficulty and ambiguity of the situations, when team members seek to support parents making life-or-death decisions, they are careful to say what I observed one team member tell parents of a declining NICU patient, “There is no right decision.” In saying this, palliative care team members hope to alleviate the guilt associated with choosing to do the wrong thing. In the backstage setting of rounds (Ellingson, 2003, 2005), however, the same team member said of these parents, “When they make a decision, it will be the right decision for them because of research and support.” This indicates that, while different parents may make different acceptable choices in similar circumstances, team members feel that good decisions are resourced by

research and support. Additionally, there is a sense that each situation has a “right” decision, even if parents are not told as much.

Practitioners view the driving force behind making the right decision as information much more than social support, though. When parents struggled to make a decision the team felt was the right decision for them, team members discussed ways to help parents understand the situation more than they sought non-information resources. After one NICU baby suffered a severe brain hemorrhage, the team spoke about communicating the severity of the injury to the baby’s mother. It was reported in the meeting that the neonatologist had shown the films of the baby’s brain to the mom, but she was not responding as if she understood the severity of the situation. In my field notes, I recorded the following advice from one of the team members: “Did they print the images? Printing it and leaving it at [the] bedside [will help mom] bring the questions up.” Team members frequently expressed concern over parents who were struggling to grasp their children’s medical prognoses. They collaborated on ways to help parents understand complicated medical information so that they would be equipped for decision-making, particularly life-or-death decision-making.

For parents, though, decisions are not always information driven. The same parent the social worker believed would make “the right decision ... because of research and support” told me, “I don’t want to connect the resources to [decision-making] because I couldn’t make any decision. [The NICU baby] made the decision about what we should do.” Parents perceived the decision-making burden as one that was able to be shared with others, in this case, a tiny baby, and in other cases, God. As stated earlier, one parent explained that prayer helped her “make the right choice that God wants...” For this parent, there is a definitive right choice, and she must pray so she knows what to do.

Highlighting the life-or-death decisions for parents heightens the burden they already feel. One parent perceived the conversations medical practitioners were having with her in this way, “They told me, ‘You have a choice to get rid of him. You can just end his care.’” After nearly a year of shadowing the palliative care team, I am confident none of them had spoken such harsh words to this parent; however, she had been subjected to many interactions in which palliative care team members had offered detailed medical information about the status and prognosis of her child, and her interpretation of these interactions demonstrates the disconnect between the medical providers and her. This mother began to avoid such interactions by staying away from the hospital during the day and coming to be with her child at night. Team members felt that she needed more information, but the constant reminders overwhelmed her.

Other parents looked at the implications for their whole family when facing the decision to stop treatment for their seriously ill child. The information about their child’s prognosis was not as compelling as the perception of their other child. “So what do you tell your thirteen year-old? ‘Oh, we’re giving up on your brother.’” Decision-making is not a linear process in which parents receive information and make sensible determinations based upon that information. Information is only one of many factors under consideration when parents are charged with decision-making. This is particularly difficult to see in parents who spend a significant amount of time researching their child’s illness and engaging medical staff in conversations about the details of their child’s medical information.

For example, the parent previously mentioned who said, “I couldn’t make any decision,” engaged in data mining through a variety of information sources. The palliative care team perceived that this parent was empowered for decision-making because of research. Research, however, did not satisfy the parent’s quest for knowledge, and a feeling of uncertainty persisted.



In an effort to understand more about the large volume of interview data collected, I conducted a word frequency search using NVivo for Mac software. Terms such as “decision,” “pray,” “god,” “want,” and “think” were used throughout the interviews, but the word “know” (including knows, knowing and knew) appeared 188 times, more than any other term except pronouns, conjunctions, articles, “like,” and “going.” I asked parents about their child’s condition, medical decisions, resources and spirituality, so I expected to see “decision” and “god” used frequently. When I saw “know” at the top of the search results list, I was curious. Just as “like” is often used apart from its definitions, I thought perhaps “know” appeared as a result of participants seeking affirmation by saying, “you know.” While this did occur a few times, “you know” comprised less than ten percent of total occurrences. A close look at parents’ usage of the word “know” revealed both statements of confidence and of uncertainty. Parents expressed confidence in their own medical knowledge:

“...we know that she needs a transplant...”

“I know this baby is coming...”

“After a week, I knew something was going on.”

“...I know [the surgery]’s going to benefit him...”

More often, though, they expressed confidence in their spiritual knowledge:

“I know that God has his hand on me...”

“I knew that my prayer was answered.”

“...we know [God] uses medicine as an instrument for healing.”

“...I know God has his hands on my son.”

“I know God won’t give me more than I can bear.”

“I know [God]’s there. He’s real.”

“I believe in heaven. I know my grandfather is there.”

Many uses of the word “know” dealt with uncertainty. For all parents’ data mining, a level of uncertainty remained. In one case, a mother and grandmother of a patient talked about the decision to send their child to surgery for a tracheotomy. The mother talked with a palliative care specialist as well as the child’s other physicians. Additionally, she called a physician who specializes in children with her child’s rare degenerative disorder in another state. After gathering all the data, they were left with a level of uncertainty that led to their decision to proceed with the surgery. The grandmother said, “But if we don’t try it, how will we know? We decided to trach her and it was the best decision we’ve ever made.... You don’t know if it’s not going to work. You do it to know if something’s going to work.”

Another NICU parent who had engaged in significant amounts of data mining said, “No one exactly knows what will happen until eighteen months or so when he starts to really use his hands and arms and legs and things like that. No one exactly knows.” Later, regarding the decision whether to continue or cease treatment, this parent concluded, “We didn’t know which direction to pick.”

When parents expressed uncertainty, it was often coupled with a sense of spirituality:

“You never know, God has the last say.”

“Lord, I don’t know what to do.”

“...we baptized him because we didn’t know if he was going to make it or not.”

“You don’t know how much time you have left, even without the cancer. You don’t know how long anybody has until God wants to take you home and you did the mission he had for you here on earth.”

“You don’t always know [God’s] plan.”

The sentiment of each of these statements is the same: I do not know what will happen, but God does. Many parents from a wide range of spiritual beliefs expressed faith in the omniscience of God. Erickson (1985) explains the theological concept of omniscience saying, “God...is aware of what is happening, has happened, and will happen at each point in time” (p. 275). Many parents, some after combing through volumes of data, arrived at the conclusion that they did not know what would happen nor did they know what to do, but they felt sure that God did know what would happen and God did know what to do. Now they had to determine what that was. In order to make such a determination, many parents relied on prayer or, in one case examined in another chapter, a coin toss.

## **Conclusion**

Parents explained how their spirituality impacted their lives in the hospital. The discipline of prayer and study as well as prayers offered during times of crisis were viewed as helpful for both parents and their children. Additionally, parents felt a great sense of meaning connected to narratives of spirituality, both from others and their own to carry forward. These spiritual expressions were somewhat hindered, though, as a result of the perceived and reinforced divide between spirituality and medicine, causing some parents to feel as if they needed to choose one over the other or fight for a spiritual purpose.

Parents reported having both positive and negative spiritual interactions with medical staff. Negative interactions included both overt and subtle rejections of spirituality by medical practitioners as well as one instance of an unwelcomed spiritual platitude. The division of spirituality and medicine seemed to prevail over some interactions between parents and

practitioners, but when hospital staff, both medical and non-medical, engaged in spiritual conversations, parents were typically appreciative.

An examination of parent interviews and observation field notes showed that parents and healthcare providers consider both information and emotional support as decision-making resources, but providers tend to rely heavily on clarifying medical information when parents face a big decision. Parents' intense data mining reinforces to providers that parents are basing decisions on medical information, but even the most active information-seekers' decisions may not reflect the logic of the data. While knowledge appears to be what parents want, ultimately it is their uncertainty in spite of the knowledge that leads them to look outside of themselves (and medical science) for spiritual guidance in decision-making. In retrospective conversations, parents may distance themselves from the act of decision-making by projecting responsibility onto others, including God and their child.

This project seeks to help pediatric palliative care providers in their efforts to support parents in decision-making. It is important to understand that decision-making is a constructive rather than linear process. Parents gather medical information as one of several building blocks they bring together in order to build up to a decision. In addition to information, parents consider their life circumstances, their uncertainty about medical projections and their spiritual beliefs; and many of these unseen building blocks may play a large role in reaching a decision.

## CHAPTER FIVE:

### FLIP A COIN:

#### A CASE STUDY IN LIFE AFTER LIFE-OR-DEATH DECISION-MAKING

The Institute of Medicine (IOM, 2014) states that parents of seriously ill children are best understood when their lives are investigated through close interactions. As a researcher engaging in such close interactions, I found each interview participant's story to be a window into the complexity of parenting a seriously ill child. I present this exemplary case to illustrate the complex ways in which these parents communicate and to explore better avenues of support.

I entered many hospital rooms while shadowing the palliative care team, but only once was I greeted by the patient. "Are you here to play with me?" asked an exuberant seven year-old girl. "Sure!" I said. "Ok, you be SpongeBob, I'll be Patrick," she said beaming with joy. The social worker and chaplain crossed the room to talk with the parents as I stayed by the bedside and played. Later, in a room across the hall, I interviewed both of her parents about their experiences in the hospital, their spirituality and the decisions they have made for their seriously ill, though remarkably happy and playful, little girl. As they spoke with me, it was clear that their daughter's exuberance was a family trait. Their stories were delivered with passion, and they often spoke over one another. This couple wanted to talk to me. They saw me as an avenue to communicate their story to the outside world, a goal that seemed impossible from their current

existence within the confines of the hospital. For well over an hour, I listened to them recount what I have summarized here.

### **Case Description**

Approximately half way through her third pregnancy, Emily received terrible news from her doctor. She had a healthy elementary-aged son from her first pregnancy and had miscarried in her second pregnancy. As she lay undressed on the exam table, the physician told her, “We think your daughter has a condition. What are your thoughts on termination?” Emily looked at Jerry, her husband. They were dumbfounded. After a second opinion that included more information about the potential diagnoses and some possible treatments, the outlook was still poor. The baby showed signs of multiple conditions impacting major organs necessary for survival. At twenty-one weeks of pregnancy, as they considered the decision to terminate or continue, Emily and Jerry were unsure. Both of them were medical practitioners, and they understood the complexities their unborn child would face. Jerry told me he knew they would be “in for pure hell.”

As Emily felt the baby kick within her womb, she and Jerry made lists of pros and cons. Emily would want to keep the baby and Jerry would want to terminate, then they both would change their minds. “We were never on the same page,” they told me. Finally, they said, “Let’s flip a coin. Heads we keep her, tails we terminate.” After the coin landed on heads three times in a row, Jerry said, “I just wish God would give me a sign.” Emily replied, “What more of a sign do you want?!”

Ella was born a few days before Emily’s scheduled C-section. Jerry described the birth as “a calamity of errors.” The C-section had been planned when a full staff of specialists would

attend to all of Ella's needs as well as the protocol for a research program in which Emily had enrolled. The surprise delivery a few days early was over a holiday weekend and resulted in chaos due to limited staffing and unfamiliarity with the protocol. Ella's surprise entrance was the first of many events in which she violated the expectations of both the medical staff and her parents. Her first year of life, Ella never went more than two weeks without being re-hospitalized, a common experience for families of babies with multiple and complex conditions. Besides treatments and surgeries, for Ella, there were no minor illnesses. A chest cold could tax her lungs, causing her heart to work too hard and placing her other vital organs in danger of oxygen deprivation. The hospital became their home. During this time, a neurologist called Emily into his office to discuss Ella's brain. "He throws the films up and says, 'See this? See this? She's losing grey matter.' I thought I had done something wrong," Emily told me. In the face of developmental devastation, she stimulated Ella as much as the baby could tolerate by reading to her in a dark room. Eventually, Ella began to respond and, to everyone's surprise, made great strides developmentally.

Emily and Jerry were pleased with Ella's progress, but her illness took its toll on them financially. With \$300,000 of debt and a pile of medical bills in spite of having health insurance, they cashed in Jerry's retirement. They tried to get help with their mortgage but were told that their credit was too good, so when all their other assets were exhausted, they filed for bankruptcy. They lost their house and car and thought they would be free and clear but encountered further financial trouble when they received a tax bill for withdrawing Jerry's retirement, a bill for court fees, and discovered that the bank was garnishing a huge portion of Jerry's wages for a disputed auto loan. They later recovered the garnished wages, but in the meantime, new medical bills and daily living expenses continued to pile up. Four years after this

financial devastation, they told me, “We still haven’t recovered. We’re not ever going to recover from it.”

In addition to fighting the financial system, Jerry and Emily felt that they were in a constant battle to get good treatment for their daughter. “We’re always having to fight,” they told me. “It’s sad what we have to do to get them to take care of her in a timely manner because it’s not always what they want to do.” The complexities of Ella’s medical diagnoses presented unusual challenges that frustrated doctors who may never have treated another case like hers. Typically, children with Ella’s diagnoses did not survive outside the womb, so although each medically fragile child is unique, her specific condition came with a significant learning curve for physicians. Her parents told me when the doctors would want to delay a treatment, she would force their hand by taking a sudden turn for the worse. “She pushes them to do stuff.”

Since the people most familiar with Ella’s condition were her parents, they found themselves constantly explaining the medical details of her case to practitioners. Emily and Jerry described a time when Ella stopped breathing at home and they used their medical training to revive her. When the paramedics arrived, Jerry gave specific instructions for care, some of which were disregarded. Ella nearly died in the hospital that night, Jerry and Emily believed, due to the paramedic’s negligence.

When I spoke with Emily and Jerry, they were in the midst of a long hospitalization for Ella. I asked them what life was like when Ella was in the hospital. Jerry replied, “Pure stress. Emotional turmoil.” While his wife spent all day and night at the hospital with Ella, he was worried about things at home. “I’m taking my son to school, to band, to school meetings, signing permission slips, grocery shopping, getting the mail, taking care of the cars, taking the garbage out, laundry, and then in my free time I go to work, and I work night shift.” On nights he was



working, Jerry would sleep from 9 a.m. to 2 p.m., but that was the most sleep possible because of the other responsibilities. He was taking antianxiety and anti-depression medications. He said he was “managing,” but if he did not take the medications, his anxiety level was “out of this world.”

Emily described her role of mothering her daughter in the hospital. “Life still goes on. I have to pay bills and order supplies, do laundry, eat, take a shower. I couldn’t go to the bathroom for three hours one day because she just needed something.” Her vigilance in the hospital was not simply to oversee every moment of her daughter’s care, it was also out of a hope that she would be able to talk to a doctor. “You leave and they show up and then you don’t get to talk to a doctor for days. . . . People who don’t live it don’t understand it. It’s rough.” When Ella was well and able to go home, Emily described the stress of life on the outside, “Is she well enough to be out of the hospital? Are we going back to the hospital today? Do I have clean clothes I can throw in a bag?”

Ella’s parents changed her specialists (e.g. gastroenterologist, cardiologist, pulmonologist, neurologist, etc.), which also meant changing hospitals, when they felt she was not receiving adequate treatment, but they were beginning to run out of places to go. They said that in one institution, the doctors “got tired of figuring it out, so they just sent us home. They’re done with her. It’s very sad.” Emily and Jerry were consistently proactive in Ella’s care. Jerry told a story about a man who prayed for help in a flood yet refused to go with the police officer, firefighter and helicopter that came to rescue him. When the man died and went to heaven, he asked God why he didn’t save him from the flood, and God replied that he sent the police, fire department and a helicopter. Jerry cited the moral of this story as reflective of his own reasoning for taking advantage of every medical treatment available for his daughter. He would not sit by and wait for God to heal her.

Emily and Jerry had different religious beliefs, though both had been through bad experiences with Christians. Emily told a story of briefly forsaking her Jewish upbringing to follow a boy she liked into a Christian church. When her family disowned her, her new Christian friends became uncomfortable with her questions and distanced themselves from her so she returned to Judaism. Emily felt a spiritual connection to her relatives who had died. She said she prayed and asked them to watch over her daughter. Sometimes the rabbi would come to the hospital and pray for Ella with them.

Jerry's jading experience with a Christian occurred when he was a rebellious teenager. At the encouragement of a neighbor, Jerry decided to become a Christian and soon after went to a small church gathering. His Led Zeppelin t-shirt drew a reprimand from one congregant and Jerry vowed never to return. He told me, "Organized religion is a bunch of bullshit." He is not a "die-hard atheist" like his parents, though. Jerry expressed a hope in something beyond this life, resonating with the book *Heaven is For Real* (Burpo, 2010) and telling stories of other spiritual encounters he believed to be significant.

Emily believed that their experiences with Ella were learning opportunities from God. "God's trying to teach us something, maybe not to be materialistic. I don't think it's a punishment but a teaching lesson. I think Ella has taught us so much, and we have to make different choices." When I asked how their spiritual beliefs factored into decision-making, Emily said, "I don't know if the decision-making has any spiritual side to it." She explained that she believes when Ella dies she will go to heaven, but that doesn't cause her to want to "let her go." "We are scientific and we have to make sense of it," they agreed. However, they also agreed that they followed their heart for decision-making. They ended the interview by describing Ella as

“spunky” and “a fighter.” They added, “Plus, we’re always fighting for her. We try not to let it get out of control.”

## **Discussion**

### **Lived experience and spirituality**

Emily and Jerry considered themselves first and foremost scientists and medical practitioners. They constantly researched their child’s medical condition and were well-versed on new surgeries and treatments they felt would help their child. When asked about spirituality, though, they both told impassioned stories of spiritual experiences. Their spiritual stories were all about death and near-death experiences, so they did not believe that spirituality had much place in their daily life. Emily mentioned that she prayed to her relatives who had died and asked them to help Ella, but she expressly stated that her hope in heaven did not cause her to think differently about Ella’s condition. Although Emily stated that she was Jewish, she did not mention any religious practices other than prayer when asked about her spirituality, and her view of heaven was not a part of Jewish teaching. She stated that her rabbi would come and pray for healing and peace for Ella. Jerry clearly stated that he had no use for religion. Although neither appeared to be following strict religious practices, both had a spiritual understanding of the world, particularly concerning life-or-death issues.

In addition to the crisis of having a seriously ill child, Ella and Jerry faced other challenges in life, many of which had been set in motion by Ella’s hospitalizations. They were financially bankrupt in spite of Jerry’s employment and the fact that Ella had health insurance through her father’s employer. The demands of parenting their older son and keeping up with work and household needs left this family with little emotional capital for further stress, yet they

were unsatisfied with Ella's care and constantly evaluated whether or not they wanted to change her treatments and/or her doctors. Based on their stories of reviving Ella at home and pushing doctors to keep treating her, Emily and Jerry believed their management of Ella's care was the difference between her life and her death. The responsibility of keeping Ella alive as well as keeping the rest of life in order stressed these parents to their limits.

### **Analysis of medical interactions**

Due to their life circumstances, medical training and experiences with Ella, Emily and Jerry approached medical interactions from a fighter stance. Since the time Ella's condition was diagnosed during Emily's pregnancy, they had had many contentious interactions with medical personnel. The doctors had asked Emily if she wanted to terminate while she was still lying on an exam table, told her matter-of-factly that Ella was losing grey matter in her brain, and sent Ella home from the hospital leaving Emily and Jerry with the feeling that they "were done" and did not want to treat her anymore. In their story of reviving Ella at home, Jerry talked about the ways they instructed the paramedic to do certain things. He disregarded them and they felt that Ella nearly died as a result. Based on experiences like these, Emily's vigilance in the hospital was, in part, to make sure no one made a mistake with Ella, but also to make sure she could talk to the doctors and ensure they were not giving up. In short, the complexities of Ella's medical diagnosis coupled with her parents' medical skill and prior interactions meant that Emily and Jerry did not see her doctors as experts on her specific situation, rather, Emily and Jerry saw themselves as the experts, but they needed the physicians and facility to access treatments.

### **Analysis of decision-making**

When I asked Emily and Jerry what decisions they had made, they talked about the daily decisions regarding Ella's treatment, such as giving or withholding certain medications, deciding

when to call a doctor and when to change doctors. They believed they approached these decisions scientifically without spiritual influences. Like many parents I interviewed, Emily and Jerry considered decision-making a daily task, not one reserved for larger questions of consent for treatment. Their medical decisions, financial decisions, even decisions about when to step out of their daughter's hospital room were important factors in their life they were trying to control.

Their first medical decision for Ella, however, occurred while Emily was pregnant. This was perhaps the biggest decision and served as a rudder steering their life ever since. They had decided to pursue treatment for their daughter's condition rather than terminating the pregnancy, and it was a decision from which they would not relent. They attempted to make this decision based on facts by gaining a second opinion, researching and making lists. In the end, though, these tools of information were not sufficient for them to feel confident in their decision. These committed, caring, skilled and informed parents flipped a coin in order to decide about life or death for Ella. Why? The weight of the decision, life or death, and its potential consequences, "in for pure hell," led them to look for divine counsel. The result of the coin toss, heads three times in a row, was considered a sign from God that Jerry and Emily should keep the baby. For this, the most important decision, their scientific reasoning would not suffice, and while they later stated that spirituality did not impact their decisions, their depiction of this decision-making process says otherwise. Even Emily's statement that they make decisions with their heart (as well as science) was a counter to the concept of spirituality factoring into decision-making. Their hearts were never on the same side of the decision until they left the decision to an outside force, both agreeing that it was God they were looking to.

## **Constructing Communication**

There are multiple models for understanding communication, but the model most prevalent in medical contexts is the transmission model (Craig, 1999). In the transmission model, communication is understood as the transmission of information from one person to another. Senders transmit messages to receivers. Problems in communication stem from interference in the transmission process. This model is woefully inadequate to understand the communication of parents such as Emily and Jerry, for whom information was one of many factors impacting their interactions with one another, the medical practitioners and me during the interview.

When medical practitioners identify a communication problem with parents, they often begin with information. They believe if they can transmit the right information to parents then parents will make rational decisions and behave in predictable ways. Parents reinforce this belief by seeking fervently for more and more information. Emily and Jerry were a clearinghouse of information on their daughter's condition, and many of the parents I interviewed spent extensive time researching their children's conditions, treatments, and alternatives. When it came to life-or-death decisions, though, parents drew upon other resources besides information. A transmission of information can only provide a limited amount of assurance when making life-or-death decisions.

Complex communication, in other words human communication, requires a more robust model. We find such a model in the constitutive approach to communication (Bartesaghi & Cissna, 2009; Craig, 1999). In this model, communication is a building exercise. The participants in the interaction construct meaning, and that construction is influenced not only by information but also by prior interactions and experiences, spirituality, and the larger lived experiences of

families. Each of these aspects contributes to communication and specifically to decision-making for parents of seriously ill children.

When practitioners see communication as a constructed meaning-making process rather than a transmission of information, they will be better situated to assist and support parents in decision-making. This approach to communication does not negate the importance of information, rather it sees information as one of many important factors in decision-making; therefore, medical practitioners should approach parents with an understanding of the multiple factors in play, acknowledging that parents will make decisions using more than what the medical practitioners are providing. Parents' use of a coin flip, for example, is not necessarily irrational but may be a sensible strategy when choosing between two bad options.

In the transmission model of communication, spirituality's role is limited to religious practices because information is all that lies within its purview. If a family holds to a tradition that refuses blood products, for example, that is a directive that can be calculated and understood. However, people influenced by spirituality, whether religious or not, may heavily rely on an unseen force for decision-making, like Emily's and Jerry's coin flip. Faith, as described in the New Testament, is "the assurance of things hoped for, the conviction of things not seen" (Hebrews 11:1 English Standard Version). Hope and the unseen are impossible to calculate and difficult to communicate, especially when the only understanding of communication is one of transmitting information.

When parents desire information, are given information, and then make a decision contrary to that information, medical practitioners may become confused, discouraged or put off by a seeming disregard of the data. A constitutive model of communication may help practitioners understand the way many factors come together (i.e. family situations, past

experiences, spirituality) as parents construct responses to difficult questions. Given the culture of medicine, where evidence-based practice is the goal, practitioners may struggle to step back from the data and consider these other factors. When the decision-making is in the practitioners' hands for their own children, though, they may be surprised to find that their decisions are not completely data-driven either. Rather, as Janvier (2007) illustrates, they may be more like Emily and Jerry.

## **Conclusion**

Emily and Jerry exemplify the concerns and behaviors of families I interviewed in the hospital. The crisis of having a sick child was one among a constellation of interrelated crises they were facing. Although their religious traditions did not specifically align with many of the other participants in the study, they considered God powerful, all-knowing, and good, and this basic concept of a divine being was reflected by most if not all participants. They also believed, or at least hoped, in the existence of heaven. When it comes to caring for their sick child, though, Emily and Jerry considered themselves scientific more than spiritual. They believed their thoughts and behaviors were based on research and rationality. They also struggled to engage with medical personnel and frequently criticized the people caring for Ella. Due to the many aspects of their lives that threatened their agency (i.e., schedules, finances, their daughter's illness), they constantly felt the need to fight for control. When it came to decision-making, although they described science as the driving force, their self-described behavior depicts spirituality as a deciding factor.

In order to better communicate with parents like Emily and Jerry, medical practitioners should acknowledge the many unseen influences such as life experiences, prior interactions and



spirituality that come to bear in the lives of parents with seriously ill children, but acknowledging this complexity is only a first step. Practitioners could greatly improve communication with parents by approaching interactions with curiosity and a malleable concept of what makes sense. Their questions should not simply gauge parents' understanding of medical information, but also how their child's condition is impacting their whole life. By leading with questions rather than information and solutions, practitioners can better understand parents' multiple influences over decision-making and participate in parental sensemaking as their allies. As they work with parents, practitioners may also alter their understandings of what makes sense in treating a seriously ill child and provide more appropriate and acceptable care resulting in less criticism and scrutiny from parents. When influences over parental decision-making are better understood, perhaps hospital personnel and parents can improve in their work together towards common goals of care for children.

CHAPTER SIX:  
WOULD YOU LIKE A MAP?  
EXPLORATIONS IN HOSPITAL CARTOGRAPHY<sup>3</sup>

**ACT 1: “Off the Map”**

*[A WOMAN enters a seating area arranged as a hospital lobby/waiting room. A red ribbon tied to a fixed object offstage unwinds from her shoulder bag as she weaves her way around the seats where some audience members sit.]*

WOMAN: I’ve got to get out of here. Where did I come in? Where was it? Was it over here? No. I can’t remember where I came in. I remember *how* I came in. It all started with a phone call. She said, “Your amniotic fluid is a little low, you need to see the doctor.” I saw the doctor the next day. He sent me here for tests, and now, I just can’t remember where I came in. If I could remember, maybe I could find my way out. *[After a few moments of searching her shoulder bag, the WOMAN finds a digital map of the hospital on her iPad.®]*

MAP: Welcome to MetroCare, how may I assist you?

WOMAN: Can you help me find the parking garage?

MAP: I’m sorry perky garbage is not in my database. Do you have another request?

WOMAN: *[Enunciating loudly.]* The parking garage!

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<sup>3</sup>Chapter Six first appeared in *Departures in Critical Qualitative Research*. Davidson, L. G. (2016). Would you like a map? Explorations in hospital cartography. *Departures in Critical Qualitative Research*, 5(1), 23–36. DOI: 10.1525/dcqr.2016.5.1.23

MAP: Parking garage: Go straight two hundred feet to the cafeteria. Today's cafeteria special is turkey tetrazzini. Turkey is a heart healthy choice. Here at MetroCare, we care about your health.

WOMAN: Wait, the cafeteria, oh yeah, that's where we told my mom what was going on. That was awful. We were all crying and blowing our noses on napkins. It was so public. I expected people to ask us what was wrong, but all the people in scrubs just ignored us. I guess they see people like us all the time. They were eating lunch and chatting with each other as if everything was right with the world. I didn't want anything to do with food or chatting. I wanted to yell at them, "How can you talk about *Saturday Night Live* at a time like this?!?" I didn't, but I wanted to. There was no energy for yelling that day.

MAP: Baby Boy. Thirty-one weeks gestation. 1565 grams. APGAR scores: 7 and 8. Gravida: 1. Hydronephrosis. End-stage renal disease. Prune belly syndrome. Referral to WIC, Medicaid and Early Steps. Breast milk? Yes. Turn right at the cafeteria and proceed 50 feet to the gift shop. On sale this week, mylar balloons, 2 for \$10.

WOMAN: The gift shop, I bet that's where my grandmother called to get me that flower arrangement. When they discharged me after I had the baby, I carried the arrangement in my lap in the wheelchair. Some man passed by me and said, "Where's the baby?" I guess he thought I was really leaving, and what mom could leave without her baby? I tried to leave, but it didn't work. As long as he's here, I'm here. Mommy and baby go together, right?

MAP: After the delivery of a baby, self care is very important. Be sure to drink plenty of fluids, rest, and seek help if you have disturbing thoughts. Social workers and chaplains are available by calling extension 4512. Here at MetroCare, we care about your health.

WOMAN: Radiology, oh yeah, the sonogram. That's the test I came in for. The tech didn't want to tell me anything, but her stoic face said it all. I felt so silly when I started crying, because she

hadn't said anything. I guess I just knew it was bad. I tried to tell myself she's just bad with people, but deep down I knew better. Her face said all I needed to know. The pictures and explanations and tissue box conversations afterwards only filled in the details. We were heading off the map, and no one could tell us what would happen next.

MAP: Due to the lack of amniotic fluid, your baby may have hypoplastic lungs. In this case, when the baby is born, he will take one breath, his lungs will explode, and he will die. He may be deformed. Your baby also has kidney damage. He may need dialysis and eventually a kidney transplant. In the United States, there are currently 101,133 patients awaiting a kidney transplant. Approximately 16 percent of these patients will receive a kidney this year (U.S. Department of Health and Human Services, 2015). Dialysis patients should eat a diet low in potassium, salt, and carbohydrates and monitor fluid intake. A healthy lifestyle can be attained with the correct diet and moderate exercise. Here at MetroCare, we care about your health. Please follow the hallway past radiology to the exit sign in order to reach your destination.

WOMAN: [*Stops suddenly at a sheet of plastic hanging from ceiling to floor, blocking the path she has been directed to take.*] What's this? Construction? No way! That's my way out! How can they block the way out? This map is useless!!! Paul Edwards (2006) says, "Maps construct, rather than reproduce the world" (p. 202). Well that's for sure. This map is a far cry from reproducing this world. What are they constructing, though? And who are "they"? "At MetroCare, we care about your health." Really? What health? Newsflash! Healthy people don't come to the hospital. I don't need you to care about health, I need you to care about illness. My baby's sick. Do you care about that? Do you care about him? What if he's never healthy? Are you just going to cast us aside?

Okay, calm down, what am I going to do? There's no way out. I have to stay here. "It takes time to accept these things." That's what they keep telling me. Time. Time? How much time have I been here? It feels like the world stopped spinning. What day is it? What month is it? Oh yeah, it's turkey tetrazzini day, organ transplant awareness month.

WOMAN: [*Speaking with a person off-stage.*] *Hola Floricela, cómo estás?*

...I didn't see you yesterday. Someone else came in to clean the room. Did you have the day off?

...Yes, the baby, he's not doing very well.

...No, I don't know what to do. They keep saying we need to make decisions. They say he might not have a very good future. How are we supposed to know what to do?

...What do you mean he's not my baby?

...Oh, right, I see.

...He's God's baby... I'm just his mama, here to take care of him. ...Hmm. I like that perspective.

...*De vera, Floricela, de vera. Muchas gracias.*

...*Sí, y tu también.*

[*The WOMAN turns away from the construction area and begins to walk in the opposite direction.*]

MAP: Warning: You are going in the wrong direction. Please turn around and proceed to the exit sign past radiology.

[*The WOMAN pauses and looks at the iPad®, then continues to walk away from the construction area.*]

MAP: Warning: You are going in the wrong direction. Please turn around and proceed to the exit sign past radiology.

[*The WOMAN places the iPad® on the floor and continues to walk away.*]

MAP: Warning: You are going in the wrong direction. Please turn around and proceed to the exit sign past radiology.

WOMAN: Deep breaths. [*Singing*] “Have I not commanded you, be strong and courageous, do not be frightened, do not be dismayed, for the Lord your God is with you, wherever you go, wherever you go” (Joshua 1:9, ESV). Look, I’m counting on you now. You know we’re off the map, here, right?

[*WOMAN exits stage.*]

## **ACT 2: Map Legend**

### **You are here**

In 2002, my life was forever altered when a doctor gave my husband and me a heart-breaking diagnosis for our unborn son. The complexity of his case was difficult to comprehend, but the gravity of having our crisply projected future family cast into darkness was palpable. That day, we returned home with tears flooding our eyes. I pounded my fist in defiance that my child would be taken from me. We prayed deep guttural prayers, the kind for which words cannot be formed but the spirit moans to the Creator. Stunned by the blow of our son’s peril, we proceeded with in-utero treatments resolutely, but aside from our initial response, without the outward displays of emotion one might expect. I put on my game face quickly in order to endure the unknown journey. Grieving that lost projected future family would be a slow process, and one I had little opportunity to explore in the early days. The confines of the institution were not hospitable to displays of intense emotion, and my pregnancy and the birth of my first son resulted in six months of hospitalization between the two of us. Logging many more hospital

hours than a medical resident would in a year, my husband and I were more than visitors. The hospital had become our home, and our experience there was not reproducible on a visitor map.

*[Operating room where a PATIENT is awake and being prepped for an amnio infusion. Her HUSBAND walks into the room and dons a sterile gown, hat and shoe covers without any direction from the NURSE. He approaches the operating table.]*

NURSE: I can never get this armrest on the operating table.

HUSBAND: Oh, I can do it. I figured it out last time we were in here. *[He attaches the arm rest to the table.]*

PATIENT: Could you strap me to the table? Sometimes he needs to tilt me and I feel better when I'm strapped down.

NURSE: *[Laughing.]* I'm not sure what to do when my patients are awake and order me around. *[Jokingly.]* Can we sedate this one?

*[PATIENT rises from bed, crosses stage, and sits in a chair next to a neonatal incubator, signifying that months have passed and she is now the MOM.]*

NURSE: Here, put on this mask and hat.

MOM: Why? What's going on?

NURSE: They need to do a surgery on the other side of the room and I don't want to make you leave again.

MOM: Thank you. You know last week when Baby V died? I had to stay out of the room almost all day. It was my birthday and I hardly got to see this little guy. *[Choking up.]* But sitting out in the waiting area watching that family lose their baby to kidney failure, well, that was a little too close to home. That could have been us. I'm just so grateful...

NURSE: [*Placing hand on MOM's shoulder.*] I know, I'm so sorry. This should be pretty quick, and you don't have to go anywhere. Just stay over here and keep the mask on, ok?

MOM: Okay. Oh yeah, I forgot to tell you. I restarted the pump after it alarmed. The medicine was occluding the feeding tube again.

NURSE: Ugh. Kayexalate. What a sticky mess! Thanks for letting me know.

After our lengthy stay, we were what Ronald Pelias and James VanOosting (1987) might call producers. We made ourselves at home by performing tasks generally assigned to hospital staff. While our production violated the scripts and responses prescribed by institutional utterances, we co-created our hospital performance with the nurses and doctors who work for the institution. Thus, although we performed resistance on a macro level, on a micro level we performed community.

### **You are where?**

*[The stage is split. On one side, a RESEARCHER stands in the busy corridor of a hospital checking her phone. On the other side, a FACULTY ADVISOR sits at her desk.]*

RESEARCHER: [*Holding the phone to her ear.*] Hi! How are you doing? Sorry I didn't pick up when you called. I'm at the hospital.

FACULTY ADVISOR: Oh no! Is everything okay? Is your son sick?

RESEARCHER: I'm working on my research project. Everything's fine.

FACULTY ADVISOR: Oh, right! (*Laughing.*) I should know your research is in the hospital! You had me worried.



RESEARCHER: I just completed my first parent interview! It went really well. I'm so excited this project is finally underway.

FACULTY ADVISOR: Way to go! Keep up the good work.

### **You are whom?**

I am the PATIENT. For seven weeks I was confined to the small space of a hospital room in an antipartum ward, a place I didn't know existed until I became incarcerated there. I am the MOM. Although my first baby didn't sleep under my roof until he was four and a half months old, I cared for him as best I could during his long stay in the neonatal intensive care unit (NICU). I am the RESEARCHER. Due to my personal experience, I chose to interview parents of seriously ill children for my dissertation research. These parents and I together make up the WOMAN in "Off the Map."

In the interviews I conducted, my own illness story served as a point of resonance for my participants. As parents of seriously ill children, we all need stories to make sense of the chaos that threatens to dominate our lives. As Arthur W. Frank (1995) says, "Stories have to *repair the* damage that illness has done to the ill person's sense of where she is in life, and where she may be going. Stories are a way of redrawing maps and finding new destinations" (p. 53). The same is true for parents of ill children, who face the disconcerting reality of their children's uncertain future. I found my interviews to be much more than data gathering sessions. My participants and I were sharing with one another these odd pieces of our lives that had altered our existences. Due to our mutual experiences of trauma, frustration and responsibility, we resonated with one another. We collaborated to construct alternative ways of navigating the rigid structures of

hospital life, of facing emotional pain and uncertainty, and of redoubling our efforts to parent our children in a place where our voices are often silenced.

### **ACT 3: Map Quest**

#### **Scene 1: Campus map**

[*STUDENTS applaud at the end of a classroom performance of Off the Map.*]

INSTRUCTOR: Thank you so much. (*To STUDENTS*) I asked you all to pay attention to the topics we've been discussing about health and family. What did you see and what questions do you have?

STUDENT 1: What was the red ribbon supposed to symbolize?

PERFORMER: What do you all think it symbolizes?

STUDENT 2: How much you walked around. How far you had to go?

STUDENT 3: You were walking in circles. It was hard to navigate the space you were in.

PERFORMER: Good. What else could it be?

STUDENT 1: The path you took to come to a decision?

PERFORMER: Uh, huh. What else?

STUDENT 4: Your frustration. You kept tripping on it. You were being pulled in the wrong direction.

STUDENT 1: Your path of memories? How you came to get some good advice?

PERFORMER: Sure. What else?

STUDENT 1: You're making your own map as you are going off the map.

PERFORMER: Why do you think parents or family members of someone who is ill might make their own maps?

STUDENT 5: They can't really follow the hospital's map. It just takes them to a dead end, like the hallway blocked by construction.

PERFORMER: What did you think about the construction?

STUDENT 6: There isn't always an easy way out.

STUDENT 7: No one can really help you do what you need to do. You end up going in circles.

STUDENT 8: But then she meets the janitor. What was that supposed to mean?

PERFORMER: What do you think it means?

STUDENT 1: You keep asking us, but you wrote the script. You lived this, and you did the research, right? What do you mean by it?

PERFORMER: What matters more? What the performer intends to convey or how the audience interprets it? I learn as much about what this performance "means" from you as you do from me or from one another. We are mapping out a meaning for this performance right now. How is that like what the woman is doing in the hospital?

## **Scene 2: Map inset of hospital information desk**

*[A RESEARCHER walks into a hospital lobby and approaches the reception desk.]*

RESEARCHER: Excuse me. Do you have a map of the hospital?

RECEPTIONIST: Sure, let me get one for you.

RESEARCHER: Great! Last week I got lost trying to find Building F. I followed the signs from the cafeteria, but they led me to a dead end where they were doing construction. I get so turned around in this place.

RECEPTIONIST: Oh yeah, it happens all the time. Even the hospital employees get lost. Here's the map. *[She tears off a map from a bound pad and takes out a highlighter and a red pen, crossing out some things and highlighting others as she speaks.]* The Emergency Room isn't

here anymore, now it's over there. The second floor of Building F used to be Gastro, but now it's over here. These paths are blocked right now due to construction, but if you go this way, you can get from here to the cafeteria.

RESEARCHER: Wow, that's a lot of changes.

RECEPTIONIST: It's tough to keep up with it all. Good luck!

RESEARCHER: [*Folds the map and places it in her binder.*] Thank you so much!

Paul Edwards (2006) writes about “map as discourse,” relying on Dennis Wood’s theory to explore performance and maps—describing them as utterances, mythical and dialogue-producing. He also draws attention to what is *not* on the map. Using his ideas, I look at the hospital map carefully. It appears authorless, as though it sprang forth from the info desk now highlighted. While its editor, the receptionist, made some changes, she could not have represented the territory as I experience it. Neither could she have represented the territory as my interview participants experience it.

The map’s key highlights what the institution considers important areas: Restrooms, Handicap parking, Elevator, Zones, Main Entrance, Temporary Route Around Construction Area (no longer accurate), and Level 1 Construction (also no longer accurate.) Printed on the map is a conglomeration of clay colored shapes designated by the letters A, B, C, D, E, F, and H. Only Visitor Parking and the Emergency Room (which is now in another location) are emphasized by bright colors. Areas of the buildings are labeled: Endoscopy, Outpatient Procedures, Children’s Day Hospital, Radiology, Medial Records, Cafeteria, Gift Shop, etc.

This flat description of a multi-level, multi-dimensional place does not indicate that people stay here for long periods of time, only that they visit. The map is silent about patient

rooms, areas of intensive care, the ubiquitous waiting areas and the unspeakable place in every hospital, the morgue. Its orderly, boxy representation of the space denies families' experiences of chaos, trauma, fear and loss. The map says the hospital is part of a "health system," but patients come to the hospital due to illness not health. The primacy of the word "health" in healthcare can be frustrating to patients and families struggling with chronic illness. Michael Bowman (2006) asks how tourists violate the maps given by tourist sites. In the same way, I want to know how patients and their families violate the map produced by the hospital. How does this map, and the institution that produced it, "stage-manage" the performances of families and govern their "performance choices" and expectations?

*[A RESEARCHER and a MOM sit in a NICU waiting area. The MOM is in the middle of telling her story about her son's four month-long hospital stay.]*

MOM: The doctors, they just kept coming in the room saying things like, "Your son's in a very bad condition, he will always be in a child state. He may not do this. He may not do that. You have a choice to get rid of him. You can just end his care."

RESEARCHER: How did you respond?

MOM: They did this several times a week...for like, a month! I started avoiding them. I would come at night and stay away during the day so I wouldn't have to hear them say the same thing over and over again. After awhile, they backed off. The janitor, she used to come in and talk to me. She said, "You know, God has the last say-so. He is not your son; you're here to raise him. He's God's son. You're in his presence to raise him. He does not belong to you." Then she said something like, "God is in control, and if he's not meant to be here, God will take him and if he

is, he's meant to be here." After all the crying, one Sunday morning, I woke up and said, "You know God, I'm ready, I'm content."

Parents' attempts to navigate the hospital system via alternate routes resonate with Michel de Certeau's (1984) concept of tactics and strategies. As parents encounter the hospital's designated strategies (i.e. protocol) for care, they develop their own tactics for survival in a foreign system. Describing how a North African might live in France, de Certeau says:

He... creates for himself a space in which he can find *ways of using* the constraining order of the place... Without leaving the place where he has no choice but to live and which lays down its law for him, he establishes within it a degree of *plurality* and creativity. By an art of being in between, he draws unexpected results from his situation (p. 30).

Without the ability to leave the institution and its strategic map, parents create new maps that work around and within the dominant system in order to exist within their location of family crisis and gain as much as possible from hospital resources.

Sonja Kuftinec (2006) describes her use of performance in Herzegovina, a location of crisis, where the labels applied to geography are contested and the reconstruction of a physical bridge masks the struggle embedded deeply in the relationships between the residents of the city of Mostar. Likewise, the map of the children's hospital, clearly labeled as a map for healthcare, cannot function as an appropriate simulacrum of the place itself as experienced by the seriously and chronically ill. Rather, it is the "projection of an opaque past and an uncertain future onto a surface that can be dealt with" de Certeau (1984, p. 93-4) describes.

Patients and families, like me and my husband, may move across Pelias and VanOosting's (1987) continuum of audience participation from the inactive "receiver" to the proactive "producer" (p. 226). While no one mistakes the hospital for a theatrical event, the map, like a playbill, expresses that "visitors" to the hospital have a specific role to play. As passive consumers in the "healthcare system," patients are constructed as recipients of care. When patients and families violate this expectation by questioning the system or by enacting a form of care that does not match what is prescribed, they move towards the role of producer. Families alter the script by becoming more than visitors. Children, especially premature babies, may stay in the hospital for months at a time. Families make the hospital their home during these long stays. Home is where families work out their identities, a private place to express emotions openly. When families relocate home to the hospital because of an ill child, privacy and emotion conflict with the structured machinations of the hospital, where expectations of order and control heighten frustrations of families in crisis by elevating protocol over emotion.

### **Scene 3: Creating a new map**

*[A RESEARCHER sits in a vacant waiting area of the children's hospital reading her notes.]*

RESEARCHER: What's it like when your child is in the hospital?

MOM 1: My son has been lying in a hospital bed for three weeks waiting on a test. It's terrible.

They need better beds for parents. My son and I have redesigned a hospital room with furniture because, well, what else are we going to do while we sit here and wait?

DAD: Pure stress, emotional turmoil, my wife's here 24-7. She's making decisions on his healthcare, coordinating, making sure the staff doesn't make a medical error. I'm working the night shift and taking care of our daughter.

MOM 2: Then I'm here, stuck in these four walls, trying to take care of him and entertain him. Who else will take care of my son? The staff isn't there. He wants interaction, but I can't always play with him.

MOM 3: Psychologically, it will really work on you. You have to have a wristband to get in to see *your* baby. You have to ask for the breast milk *you've* expressed to feed your child. If you don't have a relationship with God before you come in here, you'll get one. If you're not a praying person, you will be by the time you leave. It was like my back was against the wall.

MOM 4: Being in the hospital? What could I compare it to? I would say it's like having a secret life. You can go out and be around other people, but they don't know what you're going through.

RESEARCHER: So what could be better in this place?

MOM 4: The doctors need to talk. They may know what's going on at a high level with the child, but they need to bring it back into one setting and collaborate their efforts in one room, where they draw pictures, do visuals. Let's talk about this!

MOM 5: It's important to help someone else in the future who's going through something similar. My son is here for a little while to help us on our journey, but he's going to be out of pain soon... he'll be with Jesus. We need to be positive with other families and help them to be positive and honest and truthful.

PATIENT/MOM/RESEARCHER/PERFORMER/WOMAN: We need to construct our own map. The institutional map does not offer us a place to be, to parent, to participate in care. The institutional map does not acknowledge the vital role we play in guiding their patients, our children, on their own journeys through life. Their lives in the hospital are marked out by illness and treatment, but we help them contextualize these signposts on a greater journey. We, as parents, can create new maps, better maps, and we need to share these maps with one another,



because we all need help finding our way when the institutional map leads us on a path we cannot traverse.

### **EXIT: An Atlas**

Maps are useful tools, and they are ubiquitous. In the age of the Global Positioning System, we are prone to follow blindly a disembodied voice to a programmed destination. The more we do this, the less likely we are to look at a map, to study it, to question its construction and to make our own maps of the world as we experience it. The institutional map of a hospital is not to be tossed aside for an alternative, but it should not stand alone as the definitive representation of a dynamic place, a “stable location with unstable converging forces that cannot be delineated by...the perimeter of the map” (Solnit, 2010, p. vii).

The hospital, like every place, could be mapped from many perspectives. In addition to the hospital’s institutional map, other cartographers such as parents, children, physicians, nurses, maintenance workers, janitors, therapists, delivery drivers, researchers, etc. could express their experiences of the place. Additionally, the hospital could be mapped in terms of wait time, food consumption, monetary transactions, traffic flow, security calls, artistic performances, and the list goes on. Such a collection of perspectival maps would constitute an atlas. Rebecca Solnit (2010), in her atlas of San Francisco, argues that a place “exists in relation” (p. vii). In other words, if we who find ourselves wandering the halls of a hospital, whether by choice or by necessity, could see one another’s maps, perhaps we could better understand the interrelatedness of our lives. We could lay out our maps next to one another as a means of communal storytelling, not privileging the institutional representation, but placing it alongside many other expressions of the place, exposing our conflicts and commonalities in a location of crisis.

CHAPTER SEVEN:  
A CALL TO JOIN THE CONSTRUCTION PROJECT

**Introduction**

This project began long before I submitted a research proposal. The moment a perinatologist sat across from my husband and me and explained that something was wrong with our baby, I became concerned about parental decision-making. Through my personal experience and the experiences shared with me by other parents, I set out to explore the following research questions:

**RQ1:** What resources do parents draw upon to make medical decisions for their seriously ill children?

**RQ2:** How do parents enact their spiritual or religious frameworks in clinical settings when faced with medical decisions for their seriously ill children?

I employed the qualitative methods of observation and semi-structured interviews with parents to gather data, which I analyzed through coding and thematic analysis.

Analysis of the interview data brought out three main themes: the role of spirituality for parents of seriously ill children, the ways parents perceive spiritual conversations with hospital personnel, and the role of spirituality for parents making difficult decisions. These themes demonstrate that spirituality is an important resource for many parents caring for and making decisions for their seriously ill children.

Other factors such as circumstances and prior experiences also contribute complexity to the decision-making process for parents. For example, parents may encounter financial hardship as a result of their child's illness. Parents may have other children who need care at home. Additionally, parents may have experienced years of contentious interactions with medical professionals, and each of these factors may compound the chaos parents experience while facing the crisis of a hospitalized child. In fact, all three of these factors appropriately describe the lives of multiple parents I interviewed. Weick's (1995) explanation of sensemaking sheds light on the importance of constructing meaning through relationships. The recognized need of social support acknowledges the importance of family, friends, and community for patients and their parents, but the implications of Weick's principles stretch beyond the social support provided by close family and friends to include all relationships as potentially significant resources for sensemaking. As practitioners engage with parents of seriously ill children, they should consider the way in which they relate to parents and children as a critical aspect of support in decision-making, which itself is a process of construction, rather than a single event.

Additionally, Weick (1995) warns about difficulties that result when overwhelmed people encounter too much information. Medical staff need to recognize that parents will make choices based on plausibility rather than accuracy, even when parents seem to be interested in having as much information as possible. Plausibility allows action, while information alone may lead to greater uncertainty. One way parents may signal they are dealing with information overload is through avoidance. When medical staff continually presented one mom with information about her son's condition and talked about life-or-death decisions, she stopped coming to the hospital during the daytime so she could avoid these difficult encounters she characterized as conversations in which she was told, "You have a choice to get rid of him. You

can just end his care.” While the medical staff sought to give this mom as much accurate information as possible, she found a plausible understanding of events when an environmental services worker reframed her responsibilities by saying, “He is not your son; you’re here to raise him. He’s God’s son.”

As parents engage in sensemaking, they may contend with uncertainty about many things including their child’s illness, their personal circumstances, and their spiritual understandings, to name a few. A complete examination of the literature on uncertainty is beyond the scope of this work, which focused specifically on the influence of spirituality on decision making, but some of the ideas regarding uncertainty and the Theory of Problematic Integration (PI) explored by Babrow (2001) are applicable here. Two of the common misconceptions addressed by Babrow are: “that the main response to uncertainty is information seeking, and that the aim and significant outcome of any encounter with uncertainty are its reduction” (p. 562). Reflective of Weick’s (1995) depiction of overwhelmed people being given more information, Babrow (2001) goes on to say, “The PI analysis makes clear not only that uncertainty has a multiplicity of meanings and both positive and negative values. It also clarifies that many uncertainties cannot be resolved by more information” (p. 563).

One other clear connection between Problematic Integration (Babrow, 2001) and the findings of this study relate to epistemology. Parents indicated their uncertainty in terms of what they did and did not know. Parents said things such as, “No one exactly knows what will happen,” and “You don’t always know God’s plan,” indicating their uncertainty. Parents also expressed what they did know by saying, “I know God has his hands on my son” and “I know [the surgery]’s going to benefit him.” Babrow points out that “what it means to know—and hence, what it means to be uncertain—appear to vary substantially within and across individuals,

cultures, and historical contexts” (p. 559). Confidence and uncertainty may vary widely among parents facing similar circumstances due to many elements outside the view of practitioners within the hospitals where their seriously ill children are treated.

Beyond the interview data, my own personal narrative and performance piece illustrate the ways in which illness stories “construct new maps and new perceptions” (Frank, 1995, p. 3) as parents deal with the wrecked narrative of their child’s health and lack a clear plan for the future. Parents told many spiritual narratives to me during interviews, and narrative may be one way for hospital staff to connect with parents on a spiritual level. Frank points out that telling stories is a form of healing. Additionally, storytelling is a social way parents can engage in sensemaking. Parents have limited opportunities to work out their stories in the hospital, but they are eager to do so as exemplified by the twenty interview participants who spoke with me at length. Acknowledging the challenges of finding time and space for narrative in the rigid, maxed out hospital structure, parent stories merit attention from medical staff. Sitting with parents for an hour may be impractical, but medical professionals’ attempts at solving problems and delivering information to parents without their participation are equally impractical.

### **An Alternate Approach to Communication**

Carroll and colleagues (2012) issue a call for professionals treating and investigating families in pediatric palliative care as well as those researching this sensitive and important area to “deepen... their practice and conception of communicating with parents whose children are ill” (p. 7) because parents draw on many resources when making decisions for their seriously ill children. Since families must live on, together, after decisions are made, a constitutive approach to communication provides a better model than a simpler transmission or transactional model for

medical staff to conceptualize conversations with parents about decision-making and spirituality. A constitutive approach looks at communication as dynamic and complex rather than the typical sender-receiver model used in healthcare communication training. The constitutive approach to communication acknowledges that “each conversation is embedded within, will become a part of, will be influenced by, and will influence myriad other past and future conversations” (Bartesaghi & Cissna, 2009, p. 131).

Parental decision-making is a defining moment within the larger narrative of a family’s on-going life. Families have prior lived experiences that are unknown to medical staff, and they foresee a future that may be unexpressed, only one part of which will be lived within medical settings. As parents in this study considered past and future in their decision-making, they engaged with medical staff to participate in building a structure that made sense of their family medical crisis. In many cases, the medical staff was unaware of intervening contingencies in families’ lives coming to bear on their decision-making. These intervening contingencies included spiritual understandings, prior experiences of parenting their ill children in medical facilities, and life circumstances, demonstrating Browning and colleagues’ (2007) understanding that parents’ decision-making is about “making sense, locating meaning and situating themselves as parents in an uncertain moral universe” (p. 375). With this awareness of the complexities of parents’ lives and therefore decision-making, medical staff should reframe their understanding of support and recognize their role as participants in helping parents build towards decisions, acknowledging that some of the building blocks may remain unseen. Admittedly, this is a slower process than transmitting information to parents, and it may require patience as practitioners wait for parents to make what might appear to be an obvious decision, but by working with parents to construct an understanding of their children’s illnesses, medical practitioners may find that they

gain parents' trust and cooperation where they once experienced suspicion and resistance.

Considering that both practitioners and parents want the best possible outcome for each child, it makes sense that both would participate together in constructing an understanding and a plan for the child's care.

### **Direction for practitioners**

After eleven months of shadowing a pediatric palliative care team and interviewing parents of seriously ill children, my data contains many examples of miscommunication between medical providers and families. Their perceptions of the same conversation are sometimes remarkably different. Based on the data I collected from parents, I offer the following recommendations for medical practitioners seeking to communicate with parents of seriously ill children.

#### ***Ask questions before offering solutions***

When practitioners move away from the transmission model of communication and understand medical information as one of many factors in decision-making, they will need to adjust their approach to interacting with parents. First, practitioners should understand they enter conversations with parents holding an important aspect of parental sensemaking, the child's medical information, but in order to understand how best to communicate this information, they must move slowly. Many parents told stories of doctors giving them devastating information in an abrupt manner. For example, Emily and Jerry were asked about terminating a pregnancy while Emily was still lying on an exam table for the sonogram. Others reported doctors saying, "Your baby is blind," or "Your baby is going to die" in a very matter-of-fact, dispassionate manner.

While it is important to be honest and straightforward with parents, the abrupt delivery of difficult information does not benefit parents as they make sense of their child's illness. In order to make decisions, parents must build towards an understanding of what is going on with their child, and that construction can and should be supported by practitioners who enter conversations with parents interrogatively rather than declaratively. By asking questions not only about parents' understanding of their child's medical condition but also about their prior experiences in the hospital, the tensions they are facing in life outside the hospital, and what they consider important for themselves and their family, practitioners will be able to meet parents where they are and contribute to their ongoing structures of understanding.

If practitioners consider themselves co-constructors of the new realities parents are facing, they may find parents to be less adversarial with them and more willing to engage with the medical information when presented. Additionally, practitioners may reframe the medical information for parents based upon the ways parents talk about other influences in their lives. It is common practice for physicians to deliver information and then ask parents, "Do you have any questions?" When parents are paralyzed by information overload, they are incapable of engaging with doctors in meaningful and helpful ways. Additionally, this approach assumes that medical practitioners hold all of the answers and parents have nothing to add to the practitioners' understanding. A better approach would be for the medical practitioners to begin by asking questions so they can work with parents to care for seriously ill children in the best way possible.

***Engage with parents spiritually when appropriate***

In looking at the ways in which parents talk about their experiences with hospital staff and spirituality, we find both words of warning and direction. While parents perceive the distinction between medicine and spirituality in the hospital, the participants in my study



overwhelmingly appreciated it when hospital personnel merged the two. Only one time did a parent respond negatively to a spiritual statement that was meant to be supportive, and it was a cliché that disregarded her feelings of frustration and limitation. In every other instance in which hospital personnel offered words of spiritual support, parents responded favorably. When spirituality was discounted, however, parents felt distanced from practitioners and responded with mistrust and sometimes a need to refute the negative comments or perceived thoughts. While parents in this study were identified by chaplains and perhaps more inclined to value spirituality, the crisis of a child's illness may arouse a desire for spirituality in parents previously uninterested in exploring such things.

In some cases, parents felt a responsibility to exemplify their spirituality through their words and actions in opposition to the medical perspective. When a parent feels that the medical community does not respect his or her beliefs, they may perceive their child's health as a litmus test for which side is right. For example, the mother who said, "I think he's here to show everybody that the medical part's not always correct" eventually found herself at odds with the medical staff in the hospital. The physicians kept offering her scientific proof of her child's condition but did not engage her spiritually. The chaplain would come in and talk with her, but these visits were typically separate from the physicians' visits. The mother did not trust the physicians' assessments and insisted that her child was not as ill as the tests indicated because her worldview encompassed both scientific and spiritual realities, and she believed there was more to her son's situation than lab tests could show.

Practitioners should note that spirituality is a driving force for many families enduring crises, and for many families with a seriously ill child, this is the greatest crisis of their lives. Discounting spiritual ideas or factors, which doctors may feel ill equipped to discuss, does not

further their scientific treatments because it fosters mistrust between the physician and the patient's family. For example, the physician who told parents that "miracles don't exist" alienated them to the point of their exit from that doctor and medical facility. While medical practitioners may sense that parents' expectations are unrealistic when they talk about hoping for a miracle, it is important to remember "parents' hope for a miracle may provide stability and does not exclude their realistic acknowledgment of the potential or imminent end of their beloved child's life. In this context, hope may be understood as part of a 'healthy denial'" (Bergstraesser, 2013, p. 145). For example, the mother who was told "miracles don't exist," explained to me, "Because we are Christians, we believe in God and miracles, but we're realistic and we know he uses medicine as an instrument for healing." Rather than avoiding or shunning the subject of spirituality, spiritual wholeness should be considered part of the treatment plan, and chaplain interactions should be alongside physician interactions in order to support that science and spirituality are not at odds. Parents who invoke spiritual language and beliefs are not necessarily rejecting the medical realities their children face, but rather are seeking a way to make medical decisions that align with their spiritual beliefs and understandings about the world, their family life, and their individual roles.

Practitioners can also engage in spiritual probing (Bateman & Clair, 2015) when parents use language associated with religion or spirituality. By opening up interactions with questions, practitioners are more likely to encounter ideas of faith and discover how they impact parents' understandings of their children. Although spiritual conversations may be uncomfortable for some practitioners, they should rely on support from chaplains and also keep in mind that parents may also feel discomfort when they must discuss their children's difficult medical conditions.

***Remember that information is only one factor for parents***

While the “right decision” may seem clear to practitioners who focus specifically on medical information, parents will build towards decisions using a variety of factors. Although medical experience may grant practitioners valuable input that parents should consider, unless practitioners also value parents’ experiences, they will miss out on the opportunity to work with parents as allies in the meaning-making process. Additionally, practitioners should not see parents’ decisions as an evaluation of practitioners’ abilities to communicate medical information. Ultimately, parents must make decisions that make sense to them and they can live with after they leave the hospital. Since decisions made in the hospital may impact them for the rest of their lives, it makes sense that parents are influenced by the factors they consider most important, such as spirituality, life circumstances, and previous experiences with their seriously ill children. Even so, when parents ask for medical care practitioners deem harmful to a child, such requests should not be viewed as mandates but rather as opportunities to ask parents about their values, goals, hopes and spiritual understanding (Roscoe & Tullis, 2015). By asking questions and inviting dialogue, practitioners may find a way to meet parents’ needs for plausible solutions without violating their own ethical standards.

When parents face two bad choices, telling them, “there is no right choice,” or “you should choose what is right for you,” may not alleviate their anxiety. For example, parents who must choose between surgery with a minimal chance of survival or allowing a child to die slowly may already sense that neither choice is “right.” Parents may feel quite the opposite, that all the options are wrong, so the act of choosing seems impossible. In such cases, some parents may reassign responsibility for decision-making away from themselves to God or their child, such as the parent who said, “I couldn’t make any decision. [The NICU baby] made the decision about

what we should do.” While medical practitioners must talk to parents about their child’s medical information, they also must realize that this information alone cannot lead parents facing two bad choices to make a choice that feels right.

### **Direction for parents**

As the mother of a medically complex child, I have a significant amount of personal experience parenting and making decisions in the intense environment of a pediatric hospital. After shadowing the pediatric palliative care team, I had the opportunity to see the hospital through a different lens. Based on these experiences, I offer the following recommendations for parents of seriously ill hospitalized children.

#### ***Print out a medical history***

I keep a document on my computer with updated information about my son’s diagnoses, medications (including dose and schedule), list of specialists, surgical history, feeding schedule, shunt setting and other information they typically want when we go to the hospital. Before we leave home, I print the medical history and bring it with me. I also keep a copy in my purse or in my son’s backpack. This allows me to give the nurses and doctors the information they need quickly and accurately without relying on my memory. Many times, upon presenting this document, I have been asked if I could teach other parents to do the same thing.

When presenting hospital staff a printed medical history, parents improve their relationships with medical practitioners. First, the parents gain the appreciation of the medical staff. They work long hours and often struggle to get accurate information from weary and stressed out parents. They need this information in order to do their jobs, and their burden is eased a little when someone gives them what they need. Second, parents communicate a level of understanding and competence concerning their child’s medical condition and let the staff know,

“we speak science.” When parents bring their children into the hospital, they are entering a science culture and just like traveling to another place, the language and way of life are different. Understanding and accepting these differences allows parents to communicate in a way that is acceptable to the science culture while maintaining a different mother tongue. By presenting a printed medical history upon arrival, parents set up their relationship with medical staff as a collaborative effort.

### ***Tell your story***

Once the dust has settled from your initial check-in and arrival at the hospital, make an effort to let medical staff know what is going on beyond the list you printed. Browning (1992) explains there are two different types of communication found within organizations, lists and stories. While the hospital tends to communicate through lists, parents need to be able to tell their stories because the list is insufficient to explain what is going on in their child and family. Lists do not typically explain important issues such as financial concerns, family strife, sibling relationships, spiritual identity, or patient preferences. Parents need to recognize that these issues are significant and need to be brought up to the people treating their children in the hospital because they matter to the child’s and family’s well-being. While the doctors and nurses do not have the time to listen to a long story, in my experience, they are willing to listen, engage and consider the lived experience of families with seriously ill children. Additionally, by knowing about parent concerns, practitioners may be more patient and understanding of decisions and behaviors that otherwise might seem illogical or uncaring. For example, when one mother in my study disregarded lab results the medical practitioners considered conclusive, the doctors were dumbfounded. Had they known this mother had, on multiple occasions, received misdiagnoses for her older children, they might have been more understanding. The events that occur in the

hospital are only one part of the larger structure of a family's life, but unless parents allow medical practitioners to see that larger structure, they will not know how their work fits.

***Advocate for and protect your child***

When parents submit their children to the culture and rule of the hospital, they sign away many rights, making it difficult to locate their parental responsibilities. Doctors and nurses have told me on many occasions, "You are the expert on your child." Every seriously ill child is unique, and many of our children are alive as the result of unusual or creative measures and parental vigilance. The details of their winding journeys are difficult to ascertain from a medical chart, and as their parents, we can and should advocate for our children and protect them from anything we consider harmful. Parents have every right to say "no." However, we also must choose our battles wisely. I have, on many occasions, made myself a thorn in the side of someone assigned to treat my son. Each time I assert myself against someone, I wonder if I did the right thing. Before taking a stand, ask a few important questions:

Do I understand this action or procedure I am denying?

Will this action or procedure cause harm or is it simply not my preference?

Is there an alternative time or manner to accomplish the goals of this procedure?

By answering these questions, parents may find a more diplomatic way to engage with practitioners than simply refusing treatment. If the parent doesn't understand a procedure, they should simply say, "I don't understand why you need to do this." Such a statement will prompt an explanation and hopefully a conversation that will allow parents to feel more comfortable with the treatment and practitioners to understand parental concerns. In answering the second question, parents may discover their preferences are being violated constantly. This is the way of the hospital. It is another culture with another language, and advocating for parental preferences

may need to take a back seat to the work of treating the ill, and likely disgruntled, child. As parents, our best work with our kids may sometimes get the worst responses from them. The work of medical practitioners for them is no different. They will not like certain treatments they need, so their comfort and yours will be compromised on occasion. Advocate for their comfort as much as is reasonable, but unfortunately, some things hurt. Finally, there may be an alternative time or delivery of the treatment or procedure that is more suitable. For example, lab work at 4:00 in the morning may be delayed by a few hours, or a CT scan may be a suitable substitute for a more expensive and time-consuming MRI. Ask about alternatives that best satisfy your child's needs.

### ***Say "yes" to help***

The task of parenting a seriously ill child is exhausting, especially in a long hospitalization, so finding support is essential. Put aside pride and independence because your survival and happiness are at stake. Since my son was born, my family has been the recipient of many services that both humbled me and encouraged my heart. Friends, family, employers and churches have given us money, meals, house-cleaning, lawn service, babysitting, transportation, listening ears, home improvements, and so many other goods and services I have lost track. There were times when my family was receiving so many donations, I felt like we had become a non-profit organization. In receiving so much support, we are grateful, but we are not sheepish because when people offer to help us, they do so willingly. People have often told me that they enjoy helping us, and I believe them because when I have the opportunity to help someone else, I enjoy the work. When friends are hesitant to allow others to help them in times of need, I will ask, "Do you enjoy helping other people?" After they say that they do, I ask, "Why would you not allow someone else to enjoy helping you?"

It is important to acknowledge that people have a difficult time understanding what it is like to parent a seriously ill child unless they have experienced it personally. Medical professionals in pediatric hospitals have chosen a career in helping sick children and their families, so their general disposition towards children and families is positive. In order to help medical practitioners do their best work, parents can bring printed medical records, share their stories, advocate sensibly for their children, and invite others into their personal struggles for extra support. These recommendations are not meant to offer simple solutions to complex problems, rather I offer them in an effort to help parents manage the overwhelming task of caring for a seriously ill hospitalized child.

### **Chaplains at the intersection of spirituality and medicine**

I noticed parents' hesitation to access chaplains in the hospital. This is particularly noteworthy considering that I met most of these parents through the chaplains. A few parents felt that they did not need chaplain services because their own faith community leaders would come to the hospital to support them. "So many people want to come in and talk to you, it's overwhelming," explained one mom. But once parents met the chaplains and finally had conversations with them, they generally valued their presence and spiritual support. Another mom's hesitation to talk to the chaplain stemmed from her desire to hold in her emotions. "I'm trying to get everything out without crying, but when [the chaplain] came in, I couldn't hold it in no more." Although the mom had an emotional response she was trying to avoid, the presence of the chaplain offered her a safe person with whom she could express all that she had been avoiding. It was clear to me during the interview that the mom valued the chaplain, and the relationship I witnessed between them was one of trust and support.



The parents who participated in my study were overwhelmingly pleased with the chaplains once they were connected to them, although that often took some time due to the barriers previously mentioned. Even when parents had outside support from their faith communities, they found value and comfort in their interactions with the chaplains, partly because of their familiarity with the hospital and its procedures. “[The chaplain]’s been great, the palliative team has been great. I think if every hospital had a team like them, it would make things so much smoother and easier for everybody,” said one mom. Parents appreciated it when other hospital staff members would call for the chaplain in moments of crisis. One mom described how much she appreciated the chaplain’s quick response when the nurse called during a moment of spiritual crisis. “She dropped whatever she was doing and came,” said the mom appreciatively.

The availability and flexibility of the chaplains was a key feature I saw while shadowing them as well. One day, the chaplain for the children’s hospital brought a puppet with her while she rounded. Another day, she had an iPad application where the kids could make books about their feelings. She often asked about favorite books, hobbies, or scripture verses and then sought out ways to integrate these things into the child’s room. She would print the books the children made on her iPad and make posters of their favorite verses so they could hang them on their hospital room walls. The NICU chaplain also engaged with parents and their babies in creative ways. She collected items parents could use to make scrapbooks of their babies, some of whom would never come home from the hospital. She engaged with the babies, learning about them just as she did their parents. When a crisis arose, the chaplains were quick to respond both for families and hospital staff, who are not immune to the trauma of their workplace.

The chaplains sought to learn new ways to creatively engage with parents also. They participated in conferences and professional organizations to build their professional skills. When someone would talk about a creative way to engage a parent or child, they would ask questions and try to learn how to incorporate the activities into their interactions. For example, one of the chaplains was learning how to use the *Voicing My Choices* (Wiener et al., 2012) advance directive document with adolescent patients. This guide is designed for use with seriously ill children under age eighteen who are not legally responsible for their own medical decisions, but nevertheless desire agency in their care. The guide asks not only about medical preferences, but also about spiritual preferences, family, friends and legacy. The guide is intended to document a conversation in which adolescents express their preferences about how they wish to live life based on their unique identities. Hospital chaplains are well-suited for these kinds of discussions with adolescent patients because they focus on holistic care. Likewise, both chaplains were interested in the social worker's poetry project she had been using with patients and parents. Much like *Voicing My Choices*, the poetry project guided patients and parents through ideas of identity and helped them to access and express emotions, experiences and medical realities in a creative way.

I observed the chaplains as particularly skilled at helping patients and their families engage their spirituality in ways that were helpful for their daily existence in the hospital. One chaplain frequently explained to parents, "We care about you as a whole person." While parents' expectations for what chaplains do was minimal ("I can pray by myself," said one mom), once they met the chaplains and found out all they could and would do for them, they were pleased to have their support.

## **Weick's Principles of Sensemaking**

While Weick (1995) intended his principles of sensemaking for organizations, these principles are also applicable and useful in understanding how families enduring the crisis of a seriously ill, hospitalized child make sense of their situation. Although both parents and practitioners might make sense of crises using the same principles, it is necessary to note that every child's illness is not recognized as a crisis by medical practitioners but rather as an expected event. As Anatole Broyard (1990) wrote, "To most physicians, my illness is a routine incident in their rounds, while for me it's the crisis of my life. I would feel better if I had a doctor who, at least, perceived this incongruity." When one party considers an event a crisis and another does not, miscommunication is bound to occur. Practitioners must maintain some emotional distance from these crises in order to avoid caregiver fatigue, but it is important for them to acknowledge that for parents, their child's illness is a crisis and sensemaking must take place in order for the family to move forward. Just as practitioners would consider a threat of violence to their hospital a crisis and would need to engage in sensemaking to move forward, parents consider their child's illness a threat to their family and proceed with sensemaking in a similar manner. It is important to recognize that the same event is deemed a crisis by one group and an expected occurrence by another. As these two parties both seek to care for a child, they will not perceive the event in the same way, yet the child will be best served if they work in concert.

## **Strengths and Limitations**

Findings for this study should be understood in terms of its strengths and limitations. Since interviews were conducted during hospitalizations, findings are reflective of in-the-moment experiences of family crisis and decision-making. Since the researcher is both the parent

of a medically complex child and a health communication and spirituality scholar, this study offers a unique perspective from someone at the nexus of communication, spirituality and parental decision-making. While this is a strength, it also means these findings are limited to this unique perspective. The findings of this project are also limited by the small sample size of twenty participants. Additionally, the institution where interviews were conducted was a private, religious hospital, which may have impacted both the chaplains' influence over families' lives as well as the participant identification process. Finally, the researcher only interviewed parents who were accessible during the daytime, limiting participation to those who were able to be with their hospitalized children.

The semi-structured interview questions provided an opportunity for parents to tell their stories of parenting an ill child, and by placing the questions about spirituality later in the interviews, the topic arose naturally in many instances. I asked how spirituality factored into decision-making for parents, but I neglected to directly ask parents about their specific spiritual identities, which would have been helpful in determining parents' perceptions about spirituality as a whole. The use of software in the data analysis process allowed me to sort and manage a large volume of data, yielding three themes for exploration. Rich narrative data such as the interview notes from this project carries the potential for additional analysis guided by different research questions. Also, field notes from observing rounds and team meetings should be interrogated to gain a greater understanding of interdisciplinary teams, practitioners' understandings of parents, and the ways in which spirituality is manifested among hospital personnel.

Future research should further investigate spirituality's impact on decision-making among parents of seriously ill children in public, non-religious institutions. Since this project

specifically focused on parental decision-making and excluded children from participation, future studies should include children's voices and investigate the role of spirituality when parents include their seriously ill children in decision-making. The exclusion of minors from the study kept me from interviewing parents under the age of eighteen. Adolescent parents are not uncommon in the NICU, and their use of resources and spirituality may vary from their adult counterparts, so studies of young parents may provide helpful guidance for medical professionals seeking to support them in decision-making. Additionally, further studies should look at ways to change perceptions of chaplains' roles in pediatric hospitals in order to make better use of their skills. Moving forward, a closer look at uncertainty and Problematic Integration Theory (Babrow, 2001) may offer an alternate framework for studying parents of seriously ill children, particularly concerning their explanations of what they know and do not know. This theory may be particularly helpful when examining individual decisions.

## **Conclusion**

All over the United States, at this very moment, families are sitting at the bedsides of seriously ill children. In the midst of their medical crises, some are facing spiritual crises as well. All of them are making decisions that will impact their families for the rest of their lives. A call for further research to investigate the ways in which parents use their spiritual frames to make decisions for seriously ill children is significant beyond the opportunity to expand academic knowledge. Results of this research should be used to help bridge the communication gap between parents seeking spiritual answers and medical care providers offering scientific explanations. The findings from this study contribute to the current understanding of families with seriously ill children and should shape medical education in a way that will benefit the next

generation of professional care providers as they seek to meet the needs of children and their families.

Benefits of the project are not restricted to findings and future action, though. Even the act of conducting this research project assisted parents as they engaged in the sensemaking process of recounting their illness stories (Frank, 1995). On some occasions, palliative care team members commented about how participants seemed more at ease after talking with me. Since I have been one of those parents facing life-or-death decisions, wrestling with my faith in a good and powerful God, participants felt they were talking to someone who could understand their world. And before the project was over, I had the opportunity to experience life as the parent of a hospitalized child once again.

### **My Chaos Narrative**

**Thursday, January 21, 2016**

Tonight I'm staying in one of the most expensive rooms in a town known for high-dollar tourism. I might sleep a few hours, but people will awaken me with two quick knocks and then an entry into the room several times over the course of the night. There is no lock on the door. I had to make my own bed, which is hard as a rock, and for reasons I cannot explain, on wheels. I don't know how long I will be staying in this pricey room because information like that is given on a day-by-day basis, and the room rate is not listed on the door nor was it quoted to me upon check-in. I won't know exactly what this room costs for a few weeks. I'm not at a four-star hotel. No, that would be much cheaper. The place I am staying is so special, it actually has "special" in its name. My son and I are spending tonight in special care at a top tier children's hospital.

It was bound to happen. Four years into my Ph.D., I'm writing my dissertation and within view of the finish line. We have avoided my son, Will, being admitted to the hospital the entire time... until now. Late January of my final semester and I sit in the exact same space I used to visit two to three times a week with him when he was an infant and had to have his shunt tapped every few days. Back then, this space was called Urgent Care. Now it's the ED (Emergency Department). Not the ER like laypeople say. This is the ED. The place has expanded significantly over time. I've watched the changes come about, but many of the same people are here. I saw a nurse from the NICU when we were on our way in, but no one treating us now is familiar to me. The room we are in feels small, but the ED has come a long way since the ER days of curtains hanging between beds for patients. It's private and fairly quiet considering how bustling an ED typically is. There is a bed; a laundry hamper; a tray table; two chairs; cabinets full of supplies; a sink; the wall of medical plugs (the red ones stay connected even if the power goes out); all of the scopes; the monitor which registers his pulse, blood pressure, respirations, and oxygen saturations (the reason we were sure to be admitted when we got here); the oxygen connection; and a few other gauges, canisters, spiral cords and connections. It looks expensive. This trip will likely cost several thousand dollars, so, "Hello, deductible! Nice to meet you so early this year."

Will has pneumonia. So far he's been stuck with needles twice, once to get blood work, but when the IV didn't work, they had to try again. The second one was a success, thankfully. He's also had an oxygen mask placed on his face, an oximeter on his toe; he's had soft restraints we call "no no's" placed on his arms; he's been weighed; and he's been catheterized (by me.) We've watched several episodes of *Andy Griffith*, he's had an X-ray, and now he's getting an antibiotic. Here we will wait for someone to tell us it's time to go upstairs to a unit called

“special care.” It’s not intensive care, but it’s not “the floor” either. It’s somewhere in between. We’ve been here three and a half hours. It’s 7:00 pm, which means shift change, so I doubt anything will happen for at least thirty minutes, but it will probably be at least an hour. I would like to have dinner, but I don’t know when I will be able to order anything or go to the cafeteria. In anticipation of this, I heated up some spaghetti while I was packing up our stuff at home and I ate as much as I possibly could. That was at 1:30 this afternoon.

It’s now 8:00 and I’m still in the ED, so I’ll explain how I got here. Will started coughing last weekend. (Today is Thursday, I think.) He had a routine appointment with his nephrologist on Monday, and I canceled it because I didn’t want him to cough all over the other kids. Monday afternoon, I noticed him shiver, so I took his temperature and upon discovering a fever, I called the doctor. It was so late in the day, they couldn’t see him until morning. He seemed much better in the morning, so the appointment was canceled, but when he started with the fever again in the afternoon, I took him in to be seen. The doctor diagnosed him with mild pneumonia and gave him a prescription for amoxicillin.

While we were at the doctor, my husband Adam picked up the other boys from school and took them to the airport to fly to Texas for a funeral for his great aunt. This is not the first time Adam’s travel and/or a death in the family have correlated with a hospitalization. When it rains it pours. Anyhow, my friend was willing to pick up the prescription from the pharmacy so I didn’t have to get Will out of the car again. That was quite appreciated. That night, Will slept fine and so did I. Yesterday, he was still sick, and I knew by early in the day that he wouldn’t be able to go to school the next day so I canceled my classes for Thursday.

I put him to bed Thursday night, but when I went to check on him before I went to bed, I didn’t like the way he sounded. He was breathing hard and fast. When I put a stethoscope on his



chest to listen to him breathe, I noticed his heart was racing. I took his temperature and found a low-grade fever. I was worried, so I called the pediatrician on call and was told to give him Tylenol and to bring him to the hospital if he didn't improve in twenty to thirty minutes. He really didn't improve, but I remembered I had albuterol and a nebulizer, and at 1:00 am, rather than hauling him to the hospital, I decided to try to give him a breathing treatment. That was a rather unpopular idea. Will hates weed eaters, leaf blowers, hair clippers, and apparently, the motor to the nebulizer. He fought me hard, but with one foot in his bed and one on the floor, my left arm barring his hands from grabbing the nebulizer out of my right hand, I managed to get enough albuterol in him to slow his breathing a bit. I lay on the futon in his room counting respirations off and on until about 2:30 am. At that point, he was finally asleep and breathing well enough I could sleep in my bed a couple of hours.

This morning I got him up, but I thought he was still breathing really fast. By 10am I felt like we should return to the pediatrician, so I called and at 11:40 we went back. The doctor agreed that he was worse and that taking him to the large children's hospital one hour away made the most sense: first of all, because he was stable and not in need of medical transport, and also because no one in our local hospital can treat him due to his complex needs.

Will and I returned home and began our preparations to leave. All along I had been texting and talking with Adam in Texas. We had discussed who would be able to watch the dog. For the past two days, our Golden Retriever had become increasingly needy in the absence of my two younger sons. On Wednesday I walked her twice and played fetch three separate times with her in the back yard. This was not enough to keep her from insisting I pet her and play with her throughout the day and night. Those boys definitely have spoiled that dog. I decided I could call the kennel to see if they had space. At the moment the thought popped in my head, Adam texted

me to see about kenneling the dog. Great minds. So I loaded the car while stuffing my face with spaghetti. I brought clothes for Will and me, snacks, his feeding pump (but I forgot the cord), a bag of toys, Will's medicine for the next few days, an extra can of Pediasure, some food for Will and a spoon (why is it so hard to find a small spoon in a pediatric hospital?), a sweater for me, a jacket for Will, my purse, the dog's food, Will's backpack, and my backpack with my dissertation materials inside. After gathering all of these things, I put Will in the car, then the dog in the car, locked the door and drove away. And it's that simple!

It's 8:49 p.m. now, and I just saw the residents from special care. This is a good sign. We're heading up to the 2<sup>nd</sup> floor soon. The NICU was on the 2<sup>nd</sup> floor in 2002 when we spent four and a half months there. Everything has been moved since they built the new women's and babies' hospital across the street. I can't say what this familiarity brings about in me. There is some comfort to being in a place I know. My son has been treated well here over the past thirteen plus years. I am confident in these practitioners of medicine, but not completely so. I've had some tussles here. I've demanded specific treatments and specific people to perform those treatments. I'm certain I've been labeled a difficult mom at times, or worse. I've also spent many nights here. It is the most expensive accommodation one can find in a town full of hotels. Although there are over 100,000 hotel rooms here, the premium fold-out vinyl bed I will enjoy tonight will rate highest in price while lowest in comfort. I know this is coming, so I have my computer and I plan to work. I will write. I will write this.

At 11:30 tonight, Will finally was asleep and I was able to leave his room and go get my clothes out of the car. I just wanted my pj pants. I got them and came straight back up. As I walked the familiar halls, they were strangely empty. I typically move around this place during the day, so the still of the night brought an opportunity only an ethnographer would appreciate,

an empty hallway. It's hard to get an interior shot of a hospital because there are always people in the halls and taking pictures of people is a violation of privacy. But tonight, I was able to take a picture of a long empty hallway I have traveled hundreds of times. At the end, on the left side, there is a waiting room. I remember the first time we sat in that waiting room. It was before Will was born. Adam and I waited there to see a genetic counselor. As we sat in the room full of parents and children awaiting lab work and surgery and various treatments, we both had the feeling we were joining their club. Never has an intuition been more precise. At the time, we were full of dread. Who wants to sign up for a life that is signposted by hospitalizations and surgeries?

Now, though, nearly fourteen years later, that room is not a portal to despair, it's simply one of many familiar places I frequent. We go to that room every time Will needs lab work, which is every six weeks. Will is so accustomed to lab work, he hardly fusses about it any more. In fact, he would much rather have lab work drawn than a number of less invasive procedures including ultrasounds, x rays, ear exams and especially hair cuts. He once lay on an ultrasound table screaming, "I want lab work!" for twenty minutes. I know many adults who hate having their blood drawn. They will avoid it for weeks, perhaps years. I guess to them, Will's life might seem a bit problematic. That's the interesting thing about people looking at someone else's life from the outside and determining whether or not it is a good life, a quality life. They simply cannot know that.

### **Friday, January 22**

Thursday night was all that I expected and more. Every time I moved, the bed rolled a bit. The seam down the center of the "mattress" (and I use that term loosely) meant that I had to choose a half and stick with it. The room went from chilly to steamy at some point and I woke up

sweating. There were several instances of the nurse or others coming in. At one point, the nurse was trying to give him a bolus of water while his food was running. I was coherent enough to tell her that wasn't right. She had 3 p.m. and 3 a.m. mixed up. At 2:30 (a.m., that is), the respiratory therapist came in to do a therapy with him. I asked, "Will this wake him up?" She said, "Oh, yeah. Most definitely." I told her he had only been asleep since 11:30 and that it would be really great to let him rest. She did. My role on the bed-ish device felt like a position of defense. I would guard Will from unnecessary awakenings, but in doing so, I would sleep little.

Morning officially came when Will had labs drawn at 6:30. Then the resident walked in at 7:05. After he left, I staggered to the bathroom and the woman looking at me in the mirror was a pretty rough rendition of the self I like to project. There is a shower in the bathroom, and I began to think about how I could take advantage of it, but before I could consider a plan the nurse practitioner from neurology came in, then the nurse came back, then there was respiratory therapy, and the clinical tech who wanted to give him a bath, then his food arrived, and then nephrology showed up, and then all of neurology came back. I decided I would order breakfast since it was nearly 10:00. After ordering breakfast, I couldn't take a shower because I had to wait for someone to deliver the tray. After I ate breakfast, which was pretty darn good for four bucks I have to say, I started strategizing about the shower again. The nurse came in, then the respiratory therapist, then the tech, it was a never-ending cycle. Finally, I decided I would just go for it and told the nurse. She said she would keep a close eye on the monitors while I was away from the bedside. Then, just as I was about to walk in the bathroom, the woman from environmental services showed up to clean the bathroom I hadn't had time to use. She didn't speak English or Spanish, so I couldn't communicate very well with her. I asked her to come back later after I'd taken a shower, but when I got out of the shower and got dressed, I opened the door to find her

asking if it was ok for her to clean. I know at least two other people walked in and out during my five-minute shower, but I have no idea who.

While I was brushing my teeth, I thought there should be at least a designated thirty minutes to an hour of time every day when, unless called, no one enters the room. Will couldn't sleep. I couldn't shower. We were both frustrated and ready to scream. (In Will's case, he was screaming. I can't get away with that.) On the board next to the bed where it lists "today's plan," it says, "rest, breathe easy and get better." How is he supposed to rest with so many people coming in and out?

This isn't all terrible though. There are many thoughtful touches here. Child life offers movies and games for him. The specialist brought him some bubbles, which he loves. The music therapist came in and played his guitar while wearing latex gloves, a rather impressive feat! Because Will has RSV and it's highly contagious, everyone who enters has to wear gloves and a disposable gown. Well, everyone except me. I guess they assume I'm part of the quarantined more than part of the quarantining. The music therapist got Will to smile, and that's a pretty big deal right now. He let Will play on his iPad and play a little tambourine. It was such a great moment, I took a picture.

The treatment he is receiving is very advanced, so I can't take for granted this level of technology and care. This is all helping to save Will from what could have turned out to be a fatal illness for him. But gratitude and exhaustion are not mutually exclusive. This place and this process are exhausting. I have no control over who walks in the door and when. I am asked questions such as, "How does he feel about suctioning?" Is there a kid on the planet who is ok with someone sticking a twelve-inch rubber tube down his or her nose and having someone vacuum the snot out? I talk to a resident and then twenty minutes later have the same

conversation with the attending physician. And ultimately, isolation is isolating. My friends and family text me and want to help, but there is nothing anyone can do right now. I try to think of ways for them to help, but I don't even know what to do to help, so I say no and hope I don't sound ungrateful. My head is starting to pound. The air is so dry in here, the skin on my hands is cracking and my legs itch incessantly. These are the sacrifices we make for my son's return to health. They are small in comparison to his wellness, but they are sacrifices nonetheless. Perhaps there is a way to return him to health that would be less traumatic for both of us.

[Adam returned from Texas on Friday afternoon, dropped our other two children off with a friend and came straight to the hospital so he could stay with Will and I could spend the night at home in my own bed and spend a little time with my boys who had been in Texas for the past few days. It was a glorious night of sleep... for me. Adam's Friday night on the rolling vinyl bed was much like my Thursday night. On Saturday afternoon I drove back to the hospital and we traded places again. He had to work on Sunday morning, so he needed to sleep at home. We were making our life work as best we could, and other than helping us with our children for a few hours while we drove back and forth, there was little anyone else could do for us.]

### **Sunday, January 24**

Three nights of high tech, high interruption sleep and Will is being discharged. As he snores away in the bed, I'm grateful to get to take him home. The reality of it is, this is the kind of illness that will likely end his life some day. It could be many years, hopefully decades down the road, but kids like him fall victim to pneumonia and other respiratory diseases more frequently than others. Additionally, because his mobility is limited, he is less able to fight off illnesses others shake quickly. When his teacher found out he was hospitalized with pneumonia,

she was deeply concerned. I know she must have lost students to this disease, so it's particularly frightening for her. But this time, Will is better. He is snoring away in bed and will be quite happy to go home.

But the discharge process, oh the discharge process. It's 9:00 in the morning and I still haven't seen the nurse for today. That means he hasn't gotten any food or medicine, so we can't go home until the feeding pump is finished and it hasn't even started yet. Someone comes in to take his vitals (not the nurse) and I ask about breakfast. She comes back and says, "Oh yeah, you can feed him." I explain that I would feed him but I don't have the supplies. It's this, miscommunication, seeming neglect, the shift change gone wrong, that presents so much frustration. The nurse comes in apologetically. There is a sign on our door that asks that we not be disturbed. "See nurse," it says. That kept her away early this morning; then there was an emergency. That's how it is here. You do one thing to solve one problem (post a sign to keep people from coming in and out all night) and you create others (no breakfast in the morning.) Then the nurse wanted to give Will a medication that was discontinued yesterday. I said I was pretty sure there was an order to cancel it, so the nurse calls the resident (not the doctor who discontinued the drug.) She says, "You want me to give the last dose of antibiotic, right?" I tell her to ask if it was discontinued. "That wasn't discontinued, right?" Her phrasing is frustrating to me because it shows that she trusts the fact that the drug was in a drawer more than the information I am giving her and the inconsistencies she found in the computer. Never mind that I was given the pump bag to set up by myself this morning. Never mind that I was the one who catheterized him this morning, all by myself. Never mind that I am the one who replaced the oximeter about five times during the night. Never mind that I am the one administering the meds in his G-tube. I am doing work that should count me in as a colleague, not someone to be

doubted. But here, I always feel as if my trust must be earned, as if the fact that I've been parenting this child day and night for over thirteen years doesn't grant me any credibility. I will earn their trust, but then the shift will change again and I have to start all over. It's exhausting. This trip to the hospital keeps the subject of parents negotiating this strange place fresh in my mind. I am protector, defender, ambassador, displaced, uncertain, adamant, lonely, grateful, frustrated, ...and now, finally discharged from this place. Time to go home!



## REFERENCES

- Apker, J. (2004). Sensemaking of change in the managed care era: A case of hospital-based nurses. *Journal of Organizational Change Management*, 17(2), 211-227.
- Babrow, A. S. (2001). Uncertainty, value, communication, and problematic integration. *Journal of Communication*, 51(3), 553-573.
- Baile, W. F., Buckman, R., Lenzi, R., Glober, G., Beale, E. A., & Kudelka, A. P. (2000). SPIKES—A six-step protocol for delivering bad news: Application to the patient with cancer. *The Oncologist*, 5(4), 302-311.
- Bartesaghi, M. & Cissna, K. (2009). Social construction. *21st Century Communication: A Reference Handbook*. Sage Publications Inc.: London, 128-136.
- Bateman, L.B., & Clair, J.M. (2015). Physician religion and end-of-life pediatric care: A qualitative examination of physicians' perspectives. *Narrative Inquiry in Bioethics*, 5(3), 251-269.
- Berger, P. L. & Luckmann, T. (1967). *The social construction of reality: A treatise in the sociology of knowledge*. Anchor Books.
- Bergstraesser, E. (2013). Pediatric palliative care: When quality of life becomes the main focus of treatment. *European Journal of Pediatrics*, 172(2), 139-150.
- Bingen, K., Kupst, M. J., & Himmelstein, B. (2011). Development of the palliative care parental self-efficacy measure. *Journal of Palliative Medicine*, 14(9), 1009-1016.

- Bluebond-Langner, M., Belasco, J. B., & Wander, M. M. (2010). "I want to live, until I don't want to live anymore": Involving children with life-threatening and life-shortening illnesses in decision making about care and treatment. *Nursing Clinics of North America*, 45(3), 329-343.
- Bowman, M. S. (2006). Looking for Stonewall's arm: Tourist performance as research method. In J. Hamera (Ed.), *Opening Acts: Performance in/as communication and cultural studies* (102-133). Thousand Oaks, CA: SAGE Publications.
- Browning, D. M., Meyer, E. C., Brodsky, D., & Truog, R. D. (2007). Reflections on love, fear, and specializing in the impossible. *The Journal of Clinical Ethics*, 18(4), 373-376.
- Browing, L.D. (1992). Lists and stories as organizational communication. *Communication Theory*, 2(4), 281-302.
- Broyard, A. (1990, August 26). Doctor talk to me. *New York Times Magazine*.
- Burpo, T. (2010). *Heaven is for Real*. Nashville, TN: Thomas Nelson.
- Carroll, K. W., Mollen, C. J., Aldridge, S., Hexem, K. R., & Feudtner, C. (2012). Influences on decision making identified by parents of children receiving pediatric palliative care. *AJOB Primary Research*, 3(1), 1-7.
- Cowley, C. (2003). The conjoined twins and the limits of rationality in applied ethics. *Bioethics*, 17(1), 69-88.
- Craig, R.T. (1999). Communication theory as a field. *Communication Theory*, 9(2), 119-161.
- de Certeau, M. (1984). *The Practice of Everyday Life*. (S. Rendall, Trans.). Berkeley, CA: University of California Press. (Original work published in 1980).
- Dwyer, S.C. & Buckle, J.L. (2009). The space between: On being an insider-outsider in qualitative research. *International Journal of Qualitative Methods*, 8(1), 54-63.

- Edwards, P. (2006). The mechanical bride of Yonville-l'Abbaye (Batteries not included): Remapping the canonical landmark. In J. Hamera (Ed.), *Opening Acts: Performance in/as communication and cultural studies* (199-238). Thousand Oaks, CA: SAGE Publications.
- Ellingson, L.L. (2003). Interdisciplinary health care teamwork in the clinic backstage. *Journal of Applied Communication Research*, 31(2), 93-117.
- Ellingson, L. L. (2005). *Communicating in the clinic: Negotiating frontstage and backstage teamwork*. Cresskill, NJ: Hampton Press.
- Erickson, M.J. (1985). *Christian Theology*. Grand Rapids, MI: Baker Book House.
- Ericson, T. (2001). Sensemaking in organisations—Towards a conceptual framework for understanding strategic change. *Scandinavian Journal of Management*, 17(1), 109-131.
- Foster, M. J., Whitehead, L., Maybee, P., & Cullens, V. (2013). The parents', hospitalized child's, and health care providers' perceptions and experiences of family centered care within a pediatric critical care setting: A metasynthesis of qualitative research. *Journal of Family Nursing*, 19(4), 431-468.
- Frank, A. (1995). *The wounded storyteller: Body, illness and ethics*. Chicago: University of Chicago Press.
- Goffman, E. (1959). *The presentation of self in everyday life*. New York: Anchor Books.
- Green, Sara E. (2002). Mothering Amanda: Musings on the experience of raising a child with cerebral palsy. *Journal of Loss and Trauma*, 7, 21-34.
- Guest, G., MacQueen, K.M., and Namey, E. (2012). *Applied thematic analysis*. Los Angeles: Sage.

- Hexem, K. R., Mollen, C. J., Carroll, K., Lanctot, D. A., and Feudtner, C. (2011). How parents of children receiving pediatric palliative care use religion, spirituality, or life philosophy in tough times. *Journal of Palliative Medicine*, 14(1), 39-44.
- Himmelstein, B. P. (2005). Miracles. *Journal of Palliative Medicine*, 8(2), 451-452.
- Himmelstein, B. P., Hilden, J., Boldt, A. M., & Weissman, D. (2004). Medical progress: Pediatric palliative care. *The New England Journal of Medicine*, 350(17), 1752-1762.
- IOM (Institute of Medicine). (2014). *Dying in America: Improving quality and honoring individual preferences near the end of life*. Washington, DC: The National Academies Press.
- Janvier, A. (2007). How much emotion is enough? *Journal of Clinical Ethics*, 18(4), 362-365.
- Jenks, E.B. (2005). Explaining disability: Parents' stories of raising children with visual impairments in a sighted world. *Journal of Contemporary Ethnography*, 34(2), 143-169.
- Kaplinsky, C. (2012). Quality of death: The death of sick children. In S. Kreitler, & G. Fleck (Eds.), *Confronting Dying and Death* (229-234). Hauppauge, NY: Nova Science Publishers.
- Kashtan, B. (2012). The spiritual point of view: Spiritual care of the dying. In S. Kreitler, & G. Fleck (Eds.), *Confronting dying and death* (191-202). Hauppauge, NY: Nova Science Publishers.
- Kim, J., Park, S., Yoo, S., & Shen, H. (2010). Mapping health communication scholarship: Breadth, depth, and agenda of published research in health communication. *Health Communication*, 25(6-7), 487-503.
- Kiman, R., & Doumic, L. (2014). Perinatal palliative care: A developing specialty. *International Journal of Palliative Nursing*, 20(3), 143.

- Kuftinec, S. A. (2006). Bridging haunted places: Performance and the production of Mostar. In J. Hamera (Ed.), *Opening acts: Performance in/as communication and cultural studies* (81-101). Thousand Oaks, CA: SAGE Publications.
- Kurtz, M. J. (2012). God can still save my granddaughter: The role of spirituality in ethical decision-making for a critically ill neonate. *Progress in Palliative Care*, 20(2), 86-93.
- Lindlof, T. and Taylor, B. (2002). *Qualitative communication research methods*, 2<sup>nd</sup> ed. Thousand Oaks: Sage.
- Llewellyn, H., Jones, L., Kelly, P., Barnes, J., O'Gorman, B., Craig, F., et al. (2013). Experiences of healthcare professionals in the community dealing with the spiritual needs of children and young people with life-threatening and life-limiting conditions and their families: Report of a workshop. *BMJ Supportive & Palliative Care*, 1-7.
- Lyndes, K.A., Fitchett, G., Berlinger, N., Cadge, W., Misasi, J., & Flanagan, E. (2012). A survey of chaplains' roles in pediatric palliative care: Integral members of the team. *Journal of Health Care Chaplaincy*, 18, 74-93.
- Meyer, E. C., Ritholz, M. D., Burns, J. P., & Truog, R. D. (2006). Improving the quality of end-of-life care in the pediatric intensive care unit: Parents' priorities and recommendations. *Pediatrics*, 117(3), 649-657.
- Miller, R. B. (2003). *Children, ethics, and modern medicine*. Bloomington: Indiana University Press.
- Niebuhr, R. (1950). The serenity prayer. *The Alcoholics Anonymous Grapevine*.
- Orloff, S.F. (2012). Pediatric palliative care in the United States of America. In C. Knapp, V. Madden, & S. Fowler-Kerry (Eds.), *Pediatric palliative care: Global perspectives [electronic resource]*, (359-376). New York: Springer.

- Osterman, M.J.K., Martin, J.A., Mathews, T.J., & Hamilton, B.E. (2011). Expanded data from the new birth certificate, 2008. *National vital statistics reports*, 59(7). Hyattsville, MD: National Center for Health Statistics.
- Pelias, R. J., VanOosting, J. V. (1987). A paradigm for performance studies. *Quarterly Journal of Speech*, 73(2), 219-231.
- Penner, L., Cantor, R. M., & Siegel, L. (2010). Joseph's wishes: Ethical decision-making in duchenne muscular dystrophy. *Mount Sinai Journal of Medicine*, 77(4), 394-397.
- Pratt, R. (2004). What is theology? *Building Your Theology, Vol. 1*. Winter Springs, FL.  
<http://thirdmill.org/seminary/lesson.asp/vs/BYT/ln/1/df/>
- Robinson, M. R., Thiel, M. M., Backus, M. M., & Meyer, E. C. (2006). Matters of spirituality at the end of life in the pediatric intensive care unit. *Pediatrics*, 118(3), e719-29.
- Roscoe, L.A. & Tullis, J.A. (2015). The meaning of everything: Communication at the end of life. *Journal of Medicine and the Person*, 13(2), 75-81.
- Rushton, C. H., & Russell, K. (1996). The language of miracles: ethical challenges. *Pediatric Nursing*, 22(1), 64-67.
- Solnit, R. (2010). *Infinite city: A San Francisco atlas*. Berkeley: University of California Press.
- Stevenson, M., Achille, M., & Lugasi, T. (2013). Pediatric palliative care in canada and the united states: A qualitative metasummary of the needs of patients and families. *Journal of Palliative Medicine*, 16(5), 566-577.
- Stutts, A., & Schloemann, J. (2002). Life-sustaining support: Ethical, cultural, and spiritual conflicts part I: Family support--a neonatal case study. *Neonatal Network: NN*, 21(3), 23-29.

- Thurlow, A., & Mills, J. H. (2009). Change, talk and sensemaking. *Journal of Organizational Change Management*, 22(5), 459-479.
- Titus, B., & de Souza, R. (2011). Finding meaning in the loss of a child: Journeys of chaos and quest. *Health Communication*, 26, 450-460.
- U.S. Department of Health and Human Services. (2015). Organ procurement and transplantation network data. <http://optn.transplant.hrsa.gov/converge/data/default.asp>
- VanMaanen, J. (1988). *Tales of the field: On writing ethnography*. Chicago: University of Chicago Press.
- Wang, J., & Kearney, J. A. (2013). The experience of Chinese American parents of children with life-limiting illness: A comprehensive review. *International Journal of Palliative Nursing*, 19(7), 347.
- Weick, K. E. (1993). The collapse of sensemaking in organizations: The Mann Gulch disaster. *Administrative Science Quarterly*, 38, 628-652.
- Weick, K.E. (1995). *Sensemaking in organizations*. Thousand Oaks, CA: Sage Publications.
- Wiener, L., McConnell, D. G., LaTella, L., & Ludi, E. (2013). Cultural and religious considerations in pediatric palliative care. *Palliative and Supportive Care*, 11(1), 47-67.
- Wiener, L., Zadeh, S., Battles, H., Baird, K., Ballard, E., & Osherow, J. (2012). Allowing adolescents and young adults to plan their end-of-life care. *Pediatrics*, 130(5), 897-905.
- WHO (World Health Organization). (2015). WHO definition of palliative care. Geneva, Switzerland. <http://www.who.int/cancer/palliative/definition/en/>

APPENDIX A:  
INTERVIEW QUESTIONS

1. How would you describe your child's medical condition?
2. What are the most difficult decisions you have had to make?
3. What resources helped you make these decisions?
4. What role, if any, does religion or spirituality play in your life?
5. How have your religious and spiritual beliefs impacted your decision-making for your child?
6. Have you consulted with a chaplain or other religious leader during your child's illness? If so, what kind of information or guidance were you seeking from that person?



APPENDIX B:

AXIAL CODES

Church	Medical staff
Decisions	Mining for data
Diagnosis	Negative emotions
Difficulty with doctor or hospital	Other people
Divine person	Pain and suffering
What I don't know	Positive
Family	Questions
Hospital experience	Resources
How I cope and care	Spiritual change
Ideas of faith	Support
Logistics	Surgery or tests

APPENDIX C:  
IRB APPROVALS AND PUBLICATION AGREEMENT



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Institutional Review Boards, FWA No. 00001669  
12901 Bruce B. Downs Blvd., MDC035 • Tampa, FL 33612-4799  
(813) 974-5638 • FAX(813)974-7091

October 9, 2013

Lindy Davidson  
Communication  
Lakeland, FL 33815

**RE: Expedited Approval for Initial Review**

IRB#: Pro00014507

Title: Spiritual Frameworks in Pediatric Palliative Care: Understanding Parental Decision-making

**Study Approval Period: 10/8/2013 to 10/8/2014**

Dear Ms. Davidson:

On 10/8/2013, the Institutional Review Board (IRB) reviewed and **APPROVED** the above application and all documents outlined below.

**Approved Item(s):**

**Protocol Document(s):**

[Study Protocol.Spirituality.1.docx](#)

**Consent/Assent Document(s)\*:**

[adult informed consent.ver.1.spirituality.9-27-13.docx.pdf](#)

\*Please use only the official IRB stamped informed consent/assent document(s) found under the "Attachments" tab. Please note, these consent/assent document(s) are only valid during the approval period indicated at the top of the form(s).

It was the determination of the IRB that your study qualified for expedited review which includes activities that (1) present no more than minimal risk to human subjects, and (2) involve only procedures listed in one or more of the categories outlined below. The IRB may review research through the expedited review procedure authorized by 45CFR46.110 and 21 CFR 56.110. The research proposed in this study is categorized under the following expedited review category:

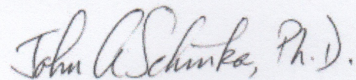


(7) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

As the principal investigator of this study, it is your responsibility to conduct this study in accordance with IRB policies and procedures and as approved by the IRB. Any changes to the approved research must be submitted to the IRB for review and approval by an amendment.

We appreciate your dedication to the ethical conduct of human subject research at the University of South Florida and your continued commitment to human research protections. If you have any questions regarding this matter, please call 813-974-5638.

Sincerely,

A handwritten signature in cursive script that reads "John A. Schinka, Ph.D.".

John Schinka, Ph.D., Chairperson  
USF Institutional Review Board





RESEARCH INTEGRITY AND COMPLIANCE  
Institutional Review Boards, FWA No. 00001669  
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10/7/2015

Lindy Davidson  
USF Department of Communication  
4202 E Fowler Ave, CIS 3057  
Tampa, FL 33620

**RE: Expedited Approval for Continuing Review**

IRB#: CR2\_Pro00014507

Title: Spiritual Frameworks in Pediatric Palliative Care: Understanding Parental Decision-making

**Study Approval Period: 10/8/2015 to 10/8/2016**

Dear Ms. Davidson:

On 10/4/2015, the Institutional Review Board (IRB) reviewed and **APPROVED** the above application and all documents contained within including those outlined below.

**Approved Item(s):**

**Protocol Document(s):**

[Study Protocol.Spirituality.1.docx](#)

The IRB determined that your study qualified for expedited review based on federal expedited category number(s):

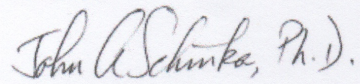
(7) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

As the principal investigator of this study, it is your responsibility to conduct this study in accordance with USF HRPP policies and procedures and as approved by the USF IRB. Any changes to the approved research must be submitted to the IRB for review and approval by an amendment. Additionally, all unanticipated problems must be reported to the USF IRB within five (5) calendar days.



We appreciate your dedication to the ethical conduct of human subject research at the University of South Florida and your continued commitment to human research protections. If you have any questions regarding this matter, please call 813-974-5638.

Sincerely,

A handwritten signature in black ink that reads "John A. Schinka, Ph.D." The signature is written in a cursive style with a large initial 'J' and 'S'.

John Schinka, Ph.D., Chairperson  
USF Institutional Review Board



[Redacted] Hospitals Institutional Review Board  
[Redacted] MD., Co-Chairperson  
[Redacted], MD., Co-Chairperson

**MEMORANDUM: EXPEDITED**

**TO:** Lindy Davidson  
**FROM:** [Redacted] IRB Coordinator  
**SUBJECT:** IRB File #3338

**PROTOCOL:** *"Spiritual Frameworks in Pediatric Palliative Care: Understanding Parental Decision-making" Category 5*

The Co-Chairperson of Institutional Review Board (IRB) has reviewed and approved the above protocol under Expedited Review. Dr. [Redacted] has determined that this project is exempt from Continuing IRB review (45 C.F.R 46.110 and 21 CAR 56.110.)

You need not resubmit the project for continuing IRB review. *A Final Report [IRB Progress Report] and or Journal article(s) should be submitted at the completion of the project.* This information will be maintained in the study folder.

This action will be reported at the **November 26, 2013** IRB Meeting.

[Redacted] MD.  
[Redacted] MD.  
Co-Chairperson

[Redacted] Institutional Review Board is governed by the regulations of the Food and Drug Administration as set forth in Title 21 of the Code of Federal Regulations Parts 50 and 56.





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Departures in Critical Qualitative Research

Editor: Stacy Holman Jones

Corresponding Author: Lindy Grief Davidson

Article Title: Would You Like a Map? Explorations in Hospital Cartography

Volume/Issue/Month/Year: Volume 5, Issue 1 Spring 2016

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