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Children at End-of-Life: How Families Manage Transitions

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Children at End-of-Life:
How Families Manage Transitions

by

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Abstract of Dissertation

Children at End-of-Life: How Families Manage Transitions

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This dissertation considers how families with a child with a life-limiting condition at end-of-life manage the transitions associated with the various locations of care: home, hospice, and hospital. Twenty-five participants were included in this grounded theory study: 9 mothers, 6 fathers, 4 grandmothers, 5 siblings, and one ill child. Families were recruited from either of two agencies: a pediatric hospice facility, or in-home hospice program.

Families had little to no support in transitions between locations of care; the transition process to the pediatric hospice facility was marked by a decision-making process that was dependent on the triad of messenger, delivery, and timing. Parents chose a hospice facility only if they had received accurate information from a trusted health care provider at a time when they were ready to consider such an option. The families' complex journey through end-of-life was inextricably tied to the care they received at each location of care.

The findings of the study underscore the importance of health care providers' role in parental decision-making, and provide insights into families' experiences from a family perspective. The findings indicate that families needed support in order to maintain family integrity and function; however, such support was rarely found, except through pediatric hospice. In-home hospice services were limited in the support during bereavement; however, the pediatric hospice facility continued to provide support as long as the family desired. The experience at the hospice facility was overwhelmingly positive.

The implications for practice include the need to provide guidance during the transitions between locations of care, including supporting families from diagnosis through bereavement, increasing access to information, and improving provider education in EOL care. The implications for research include the need to remove barriers that exclude families with children at EOL as there are few studies that include this population.

Dedication

This dissertation is dedicated to all the families with ill children who may or may not find themselves journeying the turbulent waters of end-of-life.

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CHAPTER ONE: INTRODUCTION

Children at End-of-Life: How Families Manage Transitions

In the United States, 55,000 children die each year and an additional one million are seriously ill with progressive medical conditions (American Academy of Pediatrics (AAP), 2000; Schmidt, 2003). Cancer is the leading cause of death from disease among children ages one through nineteen; the incidence of cancer is increasing annually (National Cancer Institute (NCI), 2003). Parents do not expect to outlive their children, and the loss of a child has profound effects on the entire family (Gowan, 2003). Children who die often suffer needlessly because of lack of palliative and hospice care (Schmidt; Stephenson, 2000). Thus, pediatric palliative care is vital in addressing end-of-life (EOL) needs for these children (AAP).

Background and Significance

Studies over the past decade have illuminated the suffering of children at EOL, as well as the lack of adequate services to support families (Gowan, 2003; Hynson, 2003; Schmidt, 2003; Stephenson, 2000; Wolfe et al., 2000; Woodgate, 1999). The emergence of the American Academy of Pediatrics (AAP) (2000) guidelines on pediatric palliative care has increased the focus on children at EOL, evident by the proliferation of recent research studies, and new pediatric palliative care programs across the nation. Despite this impetus to improve pediatric palliative care, there is a dearth of studies examining families' experiences during the child's EOL. Specifically, transitions in location of care for this population have not been studied. Transitions between locations of care can be extremely stressful for the individual who is dying and the caregivers; the experience can be filled with anxiety, and uncertainty (Burge, Lawson, Critchely, & Maxwell, 2005; Levine, 2002). Furthermore, the number of transitions to different locations of care increases as the patient's health deteriorates. At each new location, families may have to retell their stories, renegotiate the goals of care, and establish communication channels and bonds of trust with health professionals (Burge et al.). Transitions from one care setting to another can be problematic, particularly discharge from hospital to home or to another facility (Levine). Caregivers reported that the patient's hospitalization led them to confront the deterioration in the patient's condition and intensified their sadness and sense of loss (Levine). Patients with fewer transitions at end-of-life did better than those with greater transitions; multiple transitions were associated with discontinuity of care, financial stress, and psychological burden on the patient and caregivers (Burge et al.). Understanding transitions can reduce unnecessary changes, help to predict care needs, enhance quality of life for the patient and caregivers, and streamline the care received by improving communication between providers and family among the different settings (Burge et al.).

The few studies that have been done on transitions are mostly focused on the adult patient population transitioning from hospital to home, and have been hospital-based studies. At the inception of this study, no studies were found that focused on children with life-limiting conditions who have to transition not only from home to hospital, and vice versa, but also to hospice. There is now one recent Canadian study related to the transition to pediatric hospice (Steele et al., 2008a; Steele et al., 2008b), and there are to date no U.S. studies that have been published. In the US, pediatric hospice has only recently become available; only one free-standing pediatric hospice exists at this time:

George Mark Children's House (GMCH). Notably, this house cannot even be referred to as a hospice because according to the former program director at GMCH, it does not meet California's strict hospice eligibility criteria, which are adult-based (personal communication, C.Torkildson, March 30, 2008). GMCH is instead referred to as a children's house, respite house, or end-of-life facility. The services offered at GMCH mirror the services of most hospice programs, and are referred to as *end-of-life care*, a term that does not have strict regulations. Families in this study, however, did not make such distinctions, and repeatedly referred to GMCH as hospice. It is widely acknowledged that adult-based definitions of hospice and end-of-life are inadequate for pediatrics (AAP, 2000; Children's Project on Palliative/Hospice Services [CHIPPS], 2000; Feudtner et al., 2001; Gowan, 2003; Schmidt, 2003). The goal of this research is to increase our knowledge of pediatric end-of-life care, including hospice; therefore, throughout this dissertation references to hospice are inclusive of the services offered at GMCH, despite the use of the word being disallowed by the state of California. Furthermore, the term *hospice house* will be used instead of *children's house*, to differentiate between GMCH and the child's actual home.

With the addition of a hospice house to parents' options for EOL care in California, this is a crucial time to understand how families manage transitions in location of care, and the impact of having hospice services for families. One need only look to the United Kingdom to see that since the founding of the first hospice two decades ago, over 40 other hospices have been established (Association of Children's Hospices, n.d.). In Canada, with one-tenth of the US population, since the inception of Canuck Place in 1995, two other children's hospices have opened, and two others are under development (personal communication, Dr. B. Davies, August 6, 2008). Given the large population of the United States and the impetus to improve pediatric palliative care, it is anticipated that many more pediatric hospices will follow in the footsteps of GMCH. It is imperative that such future hospices be founded on evidence from what is learned at GMCH, so that children and their families can receive the care that they deserve.

The focus of this research is families with children at end-of-life and their experiences during this phase of illness as well as after the child's death. The purpose of the study is to understand how families with a child with a life-limiting condition at EOL manage the transitions associated with various locations of care: home, hospice, and hospital. The research questions addressed in this study were: How do families experience transition between locations of care? What processes are involved as families transition to a new location? How do families maintain integrity and function in different locations of care?

A qualitative approach was chosen, as this type of research is best suited for questions that are not quantifiable, phenomenon about which little is known, and laying the foundation for further studies (Koenig, 2003). It is often the most suitable design for exploratory research, especially in researching elements of quality of life (Waters, Maher, Salmon, Reddidough, & Boyd, 2005). Qualitative studies have greater flexibility in sample sizes, data collection methods, analysis, and reporting of findings. Grounded theory was the method chosen for the study design. Grounded theory is rooted in symbolic interactionism, thus suited for exploring patterns and processes, how people construct their realities, and create meanings in situations (Cutcliff, 2000; Speziale & Carpenter, 2003). Exploring how families manage transitions between locations of care involves examining processes, and how these develop and transform over time as the child’s health deteriorates and as locations are changed. Therefore, grounded theory was particularly well-suited for my specific research questions.

Researcher’s Background

In qualitative research, it is recognized that the researcher is the instrument and that no observation is void of bias or theory; all data are interpreted by the researcher and contextually situated (Denzin & Lincoln, 2005). My interest in pediatric EOL stems from my work as a pediatric hematology/oncology nurse both in the inpatient and outpatient setting. Caring for families and children with life-limiting conditions has made me aware of the many issues that they face and our short-comings as health care providers. Additionally, my background in psychology and linguistics previous to my nursing career has provided my foundation in child development. My master’s thesis and four years of doctoral study have contributed to the scholarly evolution of my interest in pediatric end-of-life care.

During my years of clinical practice, I observed a profound deficit in our ability to care for children at EOL. I noticed that our curative focus blinded us from providing the support and comfort measures that families so desperately needed. Unnecessary laboratory tests and procedures, radiographic imaging, inadequate pain control, coupled with a knowledge deficit on the part of health care providers regarding death contributed to inadequate care for the family. In my clinical experience, I observed that discussions about dying and preferred location for place of death were often initiated when options were exhausted, or after chest compressions and needless intubations. I had the experience of watching a child take his last breath, zipping up his lifeless body in a shroud, logging the body in the hospital morgue, sliding him onto the cold metal tray, and leaving the child who, with the click of the latch, was now sealed forever from the warmth of his parents' arms. Without the child's body in a bed, parents had no justifiable reason to stay, and were promptly discharged as I scurried to get the room ready for the next admission. I know that as a nurse, I felt as though I could barely muster a friendly smile for the next admit; I could not imagine how the family who had held the warm body of their child only a couple of hours prior could leave the hospital and go home without their child. I struggled with the concept of family-centered care, since there were seemingly few examples of where the family was actually at the center. In the child's dying hour, and the hours after death, the time of greatest need for the family, we, as nurses, were discharging them, bidding them farewell, and disappearing from their life that we had been occupying for 24 hours a day.

These repeated experiences made me ponder about how the families felt, and what could be done to improve the care for dying children. The lack of bereavement support in the hospital and fragmentation of care was striking to me. It seemed that grief support needed to begin with diagnosis. Therefore, I chose to do my Master's thesis on a family-centered case management model with bereavement support services that began at diagnosis. I sought to address the issue of fragmentation of care that I had observed in my practice. Not only was such fragmentation evident between units of the hospital; it was even greater between institutions. Complex discharges involving multiple agencies delivering durable medical equipment, supplies, and medications were stressful for both families and staff. Coordinating the care was often left to the parents to figure out. The American Academy of Pediatrics (AAP) (2000) published its recommendations the same year that I completed my thesis. The AAP recommends an integrated model of palliative care that begins at diagnosis and continues throughout the course of illness, regardless of the outcome.

In 2004, the first free-standing children's home in the U.S. opened in the San Francisco Bay Area. Although this paled in comparison to the over thirty pediatric hospice homes in the United Kingdom at the time, it was a step forward in meeting the unique needs of dying children. That same year I began my doctoral studies, and pondered how the addition of a children's home that offered end-of-life care would impact families. I began to formulate a study that would look at deaths in the different locations of care from which I could compare and contrast the different settings and impact on families.

My doctoral program provided a path through which I developed my emerging research ideas. As I reviewed the literature, I began to identify gaps in research and narrow my research questions. I was pleased with the proliferation of studies since the publication of the AAP guidelines in 2000. However, many gaps still remained and most importantly, studies from the perspective of the family were missing. In my quest to better understand family dynamics, I completed courses in family research, family theory, child development, and grief and loss. Thus my study is informed by several theoretical underpinnings: transition, child development, grief, family resiliency and symbolic interactionism.

This study fills a gap in knowledge about the transitions between locations from a family perspective, and illuminates the impact that a pediatric hospice house has on the family. All family members were included whenever possible; the perspectives of mothers, fathers, grandparents, siblings, and ill child have driven the findings and implications for care. Therefore, this study also brings a unique multi-faceted perspective to the growing body of research in pediatric end-of-life.

Dissertation overview

This dissertation is organized into five chapters. Chapter two provides the background and significance for the study and includes a review and discussion of the literature pertinent to the field of pediatric EOL as well as the theoretical underpinnings that informed the study.

Chapter Three discusses the research methodology, data collection and analysis, and includes description of the sample and settings. Chapters Four and Five present the findings. Chapter Four is entitled "Sailing the river waters" and describes the family's journey that begins with the child's diagnosis. Chapter Five, "Sailing the ocean waters", begins with the departure of the hospital setting and commencement of end-of-life care.

Chapter Six summarizes the findings, discusses the limitations of the study and offers implications for practice. It is my hope that the families' experiences will provide valuable insight to health care providers (HCP), and increase our understanding and ability to deliver optimal care to the families.

CHAPTER TWO: BACKGROUND AND SIGNIFICANCE

Children at End-of-Life: How Families Manage Transitions

This background chapter explains the rationale for the development of this study, and includes a review of the literature, and theoretical perspectives that informed the study. This chapter begins with a section on definitions of EOL/ palliative care, and life-limiting conditions.

Definitions

The terms palliative care and EOL appear to be used interchangeably throughout the literature, and the adult versus pediatric definitions muddle the terms even more. Given this ambiguity, it is necessary to begin by defining the terms.

Palliative Care

There are many different definitions of palliative care, although they include the basic premises of prevention of suffering and providing relief. The World Health Organization (WHO, 2008) defines palliative care as the following:

> 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. (¶ 1)

Furthermore, for pediatric palliative care, the WHO adds that:

> 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. It begins when illness is

> diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease. (¶2)

The AAP (2000) states that palliative care seeks to enhance quality of life in the face of an ultimately terminal condition; treatments focus on the relief of symptoms and conditions that cause distress and detract from the child's enjoyment of life. Palliative care must also ensure that bereaved families are able to remain functional and intact. However, the AAP recognizes the difficulty in determining which children may benefit from palliative care for several reasons. If palliative care were solely reserved for children who are dying or have a known terminal condition, then other patients, such as newly diagnosed cancer patients, who may benefit from these services, may not receive them. Furthermore, length of time to death is often difficult to predict. Thus, using nearness of death to determine whether children receive palliative care may exclude some dying children from receiving the benefits of individualized family-centered palliative care. Also, rigid distinctions between curative, life-prolonging, and palliative interventions may hinder the appropriate provision of palliative care to children living with a terminal condition. Physicians and family members may exhaust all curative options before they consider palliative care, which delays the timely introduction of palliative care or referral to palliative care specialists. Finally, it may be difficult to define individual therapies as either curative or palliative. Therefore, the AAP (2000) recommends a broader definition, proposing an integrated model of care in which palliative care is offered at diagnosis and continued throughout the course of illness, regardless of outcome. Instead of a cure *to* comfort approach, a cure *and* comfort approach occurring simultaneously is recommended. The current evolving practice embraces palliative care alongside curative treatment beginning at diagnosis (personal communication, Dr. S. Sehring, April 26, 2006).

Pediatric End-of-Life

Little consensus exists about what end-of-life (EOL) means. For adults, EOL is generally considered to refer to the last six months of life (Schmidt, 2003). However, since it is difficult to predict which children have six months left to live, this definition is inadequate for pediatrics (Children's Project on Palliative/Hospice Services (ChiPPS), 2000; Feudtner et al., 2001; Gowan, 2003; Schmidt, 2003). Generally, the terms palliative care and end-of-life care are used interchangeably. Indeed, palliative care is often not begun until a child is nearing the end of the child's life; however, the dying phase is difficult to discern. Much is written about recognizing symptoms of impending death, but there are no widely accepted definitions of end-of-life, and this ambiguity can impede delivery of care and communication between patients and providers (National Institutes of Health (NIH), 2004). Additionally, end-of-life seems to imply that curative treatments have been abandoned, yet many children are at EOL receiving aggressive treatment and no palliative care (Wolfe et al., 2000). Until we become better at predicting death, prognosticating the term end-of-life will remain fairly elusive. Currently, practitioners ideally view end-of-life as a time when a patient should receive hospice care, such that palliative care would begin at diagnosis, and encompass hospice care at EOL. However, in practice, few children are explicitly identified as being at EOL; therefore, referrals to hospice often occur in the last few days or hours before death (Hinds, Schum, Baker, & Wolfe, 2005), and only 1% of children with life-threatening illnesses receive hospice care before their death (Stephenson, 2000). Hence, the AAP

(2000) recommendation that palliative care accompany curative care makes the most sense in this population. This study did not exclude children receiving palliative care; parents made little distinction between palliative care and hospice care, and as such, the term *EOL care* includes both palliative care and hospice care for the purposes of this report.

Life-Limiting Conditions

The term, life-limiting conditions, is appearing more frequently in the literature, and is much broader than the term life-threatening illnesses (Donnelly, Huff, Lindsey, McMahon, & Schumacher, 2005; Hain, Miser, Devins, & Wallace, 2005; McCulloch and Collins, 2006). Some childhood conditions may not be immediately life-threatening but they can shorten life expectancy, such as sickle cell disease, resulting in an end-of-life phase, possibly before adult-hood, and many potentially close encounters with being near-death, based on an infection or other complication of the condition. Complex chronic conditions (CCC) is a term that is used to describe any medical condition that can be reasonably expected to last at least 12 months (unless death intervenes) and to involve either several different organ systems or one organ system severely enough to require specialty pediatric care and probably some period of hospitalization in a tertiary care center (Feudtner et al., 2001). CCCs include 9 major categories (cardiovascular, neuromuscular, malignancy, respiratory, renal, metabolic, gastrointestinal, hematologic/immunological, and other congenital/genetic) of illnesses. Sudden death is defined as death resulting from trauma for any child, or death of a previously healthy child (Serwint & Nellis, 2005). Many children who experience sudden death do not enter an end-of-life phase requiring palliative care. An unexpected death, in contrast to an anticipated death, is the death of a child with a chronic medical condition who was in a regular state of health and died unexpectedly (such as aspiration after a seizure episode) (Serwint & Nellis). For the purposes of this report, the term life-limiting-conditions includes life-threatening-conditions such as cancer and complex chronic illnesses, but excludes children who die from sudden death.

Background and Significance

Although research has shown the importance of pediatric palliative care, the majority of children who die, unfortunately, have not had the benefit of such services (AAP, 2000). The AAP recommends an integrated model of palliative care that begins at diagnosis and continues throughout the course of illness, regardless of the outcome. This is a departure from the notion that palliative care follows unsuccessful curative care. Palliative care seeks to enhance the quality of life in the face of a terminal condition, the goal being to "add life to the child's years, not simply years to the child's life" (AAP, p.353).

The needs for children are uniquely different from adults in many ways (ChIPPS, 2000). One important difference affecting EOL care is that in the adult population, physicians can predict time to death with *some* certainty, which is why the guideline of the six-month prognosis was developed for hospice eligibility (Schmidt, 2003), although this criterion is often problematic in adult populations. Pediatricians can rarely predict the length of time a child has to live; the time to death could be anywhere from a few days to several years. Many children do not meet the hospice eligibility criteria or are not referred to hospice (Schmidt); only 1% of children with life-limiting illnesses receive hospice care in the United States (Stephenson, 2000). Another important difference is that children are minors and often have little say in their treatment options, and their understanding of death and illness is influenced by their age, developmental level, culture and life experiences (American Association Colleges of Nurses (AACN) and City of Hope (COH), 2003). Unlike adults, the location of death for most children is in the hospital, usually in intensive care units while receiving aggressive treatments (Feudtner et al., 2001; Klopfenstein, Clark, Young, & Ruyman, 2001; Pritchard & Davies, 2002). Children suffer considerably at the end-of-life, as comfort measures are seldom prioritized over aggressive therapies (Wolfe, et al., 2000). Thus the multiple facets of pediatric end-of-life include: unpredictability of prognosis, developmental issues, minor status, and prioritization of aggressive treatments over comfort measures.

It is known that most families prefer that their child be cared for and die at home (Hynson et al., 2003). In classic studies in the field, families who cared for their dying children at home reported decreased feelings of helplessness, greater feelings of control, and better family communication than families whose child had died in the hospital (Mulhern, Lauer, & Hoffmann, 1983). Moreover, children who had participated in the home care of a dying sibling were better prepared for the death than those whose sibling died in the hospital. In the home setting, children had parental support and closer family relations after the child's death, whereas in the hospital care children felt isolated from the family and their dying sibling and reported deteriorated family relations following the death (Lauer, Mulhern, Bohne, & Camitta, 1985). In more recent studies, parents whose children died at home were more likely to report that their child had a calm and peaceful death than those whose children died in the hospital (Klopfenstein et al., 2001; Wolfe et al., 2000).

There are several reasons why children do not die at home despite the known benefits to the family and child, and family preferences. First, children are often readmitted to the hospital from home because of parents' uncertainty about how to manage unanticipated end-of-life symptoms (Davies, 1996). Second, children are more likely to die while still receiving anticancer therapy or aggressive supportive care such as mechanical ventilation (Wolfe et al., 2000). Third, many families find it psychologically and practically impossible to transition their child from curative care to comfort care (Levetown, 2000), an unfortunate result of not offering palliative care from diagnosis. Fourth, there are very few specialized hospice services for children; most are adult hospices that may have infrequent pediatric referrals and may lack connections to pediatric providers to assist them in providing proper care (Sumner, 2003). Fifth, the hospital may also provide a sense of security for the family since family members are already familiar with the team caring for their child (Davies), although as mentioned earlier, most children die in the pediatric intensive care unit, often amongst staff unfamiliar with the family. Lastly, a family's culture may influence whether a child may die at home, although there has been little published in this area as it pertains to pediatric palliative care. Thus, pediatric needs differ from those of adults because of the unpredictability of the disease trajectory, the developmental needs, the aggressive therapies chosen, and the dearth of specialized pediatric end-of-life care.

The AAP guidelines (2000) and the Institute of Medicine's (IOM) (2003) recognition of improving palliative care have provided an impetus to improving services for families, evident by the increasing number of pediatric palliative care programs across the nation. In fact, the first free-standing pediatric hospice in the US opened in 2004. All other existing pediatric hospice and palliative care programs are associated with hospitals or home care services. This new hospice and respite center, George Mark Children's House (GMCH), is in the Bay Area of Northern California, and is based on the Canadian and British hospice models, Canuck Place and Martin House respectively. GMCH offers families of children with life-limiting conditions respite care throughout the trajectory of the illness, transitional care, comprehensive end-of-life services, as well as a place for dying other than the home or hospital.

Since such care has only become available recently in the US, it is crucial to understand what the impact of having hospice services will be for the family. One need only look to the United Kingdom to see that since the founding of the first hospice two decades ago, over 40 pediatric hospices have been established (Association of Children's Services, n.d.). Given the large population of the United States and the impetus to improvement of pediatric palliative care, we can anticipate that many more pediatric hospices will follow in the footsteps of GMCH. It is vital to understand how families manage transitions among the locations of care, now inclusive of pediatric hospice, during their child's end-of-life. To date, no U.S. studies have been found examining the experiences of families with children with life-limiting conditions as they transition among locations of care. My study addresses this gap, and lays a foundation for future studies.

Literature Review

Although it is clear that location of care is important to families, and that transitions between locations can be very stressful for parents, no studies that examined the experiences of all members of families of children with life-limiting conditions at

EOL were found. Certainly, none were found from the perspective of the dying child, and none were found that explored transitions between locations of care for children at end-of-life. Therefore, peer-reviewed research articles covering four areas relevant to the phenomenon were chosen for the literature review: pediatric EOL, location of care, the family's experience at EOL, and transitions between locations of care. A detailed critical review was presented in the qualifying examination (Amidi-Nouri, 2007), therefore only a summary of the findings and limitations are included in this section.

General Pediatric End-of-Life Studies

The studies were selected for this section based on their broad purpose of gaining a better understanding of the field of pediatric end-of-life. The findings have affirmed the unique needs of dying children as described by earlier studies and revealed some of the shortcomings in how EOL care is provided. These studies provide directions for future research as well as recommendations for care of dying children. Location of death was found to be related to cause and diagnosis, and treatment, not simply family preference (Bradshaw, Hinds, Lensing, Gattuso, and Razzouk, 2005; Klopfenstein, et al., 2001; Wolfe, et al, 2000). The majority of children died in the hospital from treatment-related complications, and children were younger in age than those who died at home.

Additionally, providers and families had differing views on the child's symptoms, suffering, and support at end-of-life. Wolfe and colleagues (2000) found that parents reported that 89% of children experienced a lot or a great deal of suffering from at least one symptom, with 51% suffering from three or more symptoms, with fewer than 30% receiving successful treatment for pain ($p=0.04$). Parents were significantly more likely than physicians to report that their child had symptoms of fatigue, poor appetite, constipation (all $p<0.001$) and diarrhea ($p=0.04$), suggesting a considerable lack of awareness among physicians about the children's suffering. Additionally, parents' perception of their child having a peaceful and calm death was associated with early discussion of hospice care (Klopfenstein et al., 2001; Wolfe, et al.). Parents rated their child's care as being well managed despite their child's suffering (Andresen et al., 2004; Wolfe et al.). Factors associated with pain-related suffering included lack of active involvement by the oncologist, and perception of receiving conflicting information by providers (Wolfe et al.). The study results suggest that there may be a lack of awareness among physicians that suffering caused by certain symptoms may be helped by palliative care. There was an association between initiating early discussion of hospice care and parents' perception of their child having a peaceful and calm death. The location of death was related to whether the child died from progressive disease or treatment-related complications. Even in the hospital setting, deaths on the oncology ward or bone marrow transplant unit were disease related, whereas deaths in the PICU were treatment related ($p<0.001$).

Within providers, there were differences among nurses and physicians (Andresen et al., 2004; Contro, Larson, Scofield, Sourkes, & Cohen, 2004; Burns, Mitchell, Griffith, & Truog, 2001). Physicians were more likely than nurses to report that families were well-informed about the child's plan of care and relevant ethical issues, and nurses were more likely than physicians to advocate an addition or increase in narcotics as life support was withdrawn (Andresen et al.; Burns et al.). Nurses were also significantly less satisfied with the quality of communication on these issues than physicians.They were significantly more likely to report that nurses also initiated discussions on forgoing life-sustaining treatment (physicians were less likely to report nurses as having this role). Nurses were significantly less likely than physicians to report that a physician was actively involved in the actual process of caring for the dying patient at the bedside as life-sustaining treatment was withdrawn. The majority of physicians (92%) reported that ethical issues for the patient had been well-discussed with the care team; only 59% of the nurses shared this view (Burns et al.). Providers did not feel adequately trained in end-of-life issues, and had little support, which contributed to the families' negative experiences (Contro et al.). Staff described feeling inexperienced in communicating about end of life issues or managing dying patients' symptoms (especially pain), and expressed a lack of support, which resulted in emotional withdrawal and depression for staff, and for families it resulted in isolation and distress (Contro et al.).

These studies had several limitations. None of them used random selection; however, given the population, it may have been unrealistic to use such a method. One study claimed to use random selection, although it was evident that this was not actually the case (Burns et al., 2001). Three studies had rigorous analysis (Bradshaw et al., 2005; Klopfenstein et al., 2001; Wolfe et al., 2000); however, the other studies provided scant descriptions without statistically significant findings. These studies may not be generalizable to all children at end-of-life, because of being specific to a type of disease such as cancer, or type of setting such as the hospital, and including a mostly Caucasian sample. However, since they were purposefully broad, they do build upon each other, particularly in replicating findings, and confirmed what many needs' assessment articles have already described: children suffer at end-of-life and integrated palliative care is lacking.

Family Perspective Studies

Caring for the whole family is essential to quality care, especially for the child at EOL (Hudson, 2003; Whittam, 1993; Woodgate, 1999). The dying experience impacts all dimensions of life for the child and family, and is unique to each family (AACN & COH, 2003). Unfortunately, the importance of family-centered care in pediatrics has not been adequately reflected in research, such that few family studies have been conducted in the last decade for children at end-of-life. Most family studies used parental report, often from the mother, as the source for data, fewer included the father or sibling perspective. Studies that focus on siblings or fathers, are often not labeled *family* studies, rather they are labeled as *sibling* or *father* studies, whereas studies that include primarily mothers as the primary source are rarely labeled *mother* studies, unless there is a perinatal focus. Conjoint family perspective research studies in pediatric end-of-life were not found. Most of the literature on children at EOL focused on family bereavement programs and were descriptive in nature, without formal evaluation of the program. The peer-reviewed family research studies pertaining to children at EOL are summarized below.

Researchers found that the child's discomfort level during the end-of-life affected not only parental decision making, but also their bereavement and coping (Contro, Larson, Scofield, & Cohen, 2002; Meyer, Burns, Griffith, & Truog, 2002; Meyer, Ritholz, Burns, & Truog, 2006). Parental priorities were identified as follows: honest and complete information, ready access to staff, communication and care coordination, emotional expression and support by staff, preservation of the integrity of the parent-child relationship, and faith (Meyer, Burns et al.). Parents had to work very hard to obtain information, which added to the emotional and logistical burden of the already considerable stress shouldered by the parents (Contro et al., Meyer, Burns et al.). Another study examining parent's approaches to care found that parents did not shift to symptom-directed therapy only; they continued to seek curative measures along-side comfort directed measures (Bluebond-Langner, Belasco, Goldman, & Belasco, 2007). Parents went through exhaustive measures to seek information to cultivate available options for their ill child. Parents made suggestions for improved communication and access to information by seeking second opinions, maintaining family-staff journals, using email, and having bedside office hours (Bluebond-Langner et al.; Contro et al.; Meyer, Burns et al.). The PICU environment made parents feel displaced, vulnerable, and ashamed for not knowing how to help their child.

Another striking finding was that a single event could cause families profound and lasting emotional distress, such that this event haunted them and complicated their grief even years later after the child's death (Contro et al., 2002). None had ever filed a complaint because they were too overwhelmed or feared repercussions. Families stressed their need to have a familiar person deliver difficult news using straight-forward non-technical language. Families were grateful for continued contact with staff after the child's death, and felt dismissed and disappointed when they did not receive follow-up contact. Parents expressed wishing to have unhurried time to stay with the child's body (Meyer et al., 2006). Families received inconsistent bereavement follow-up, and expressed desiring continued contact with staff after the child's death (Contro et al., 2002). Parents felt they had the greatest control when the child was cared for at home (Vickers & Carlisle, 2000), and nursing home visits allowed fathers, in particular, to trust and count on nurses (Davies et al., 2004). Lack of expert pediatric palliative care programs were described by families in two studies as a reason for why their child remained at the hospital (Contro et al.; Meyer, Burns, et al.). As the child's condition worsened, the cumulative losses became intensive and exhaustive for parents, underscoring the importance of respite care for families (Gravelle, 1997).

Siblings were rarely included in studies. A recent study focusing on siblings found that the children felt excluded and ignored by staff, and lacked information pertaining to the ill child (Nolbris & Hellstrom, 2005). The siblings expressed a desire for support groups during the child's illness not only after death. Their mourning did not follow phases; the siblings weaved seemingly randomly in and out of their grief. Since the siblings' mourning did not mirror parental grief patterns, this often created tension and confusion within families. School was a place of refuge for them. The siblings continued to count the dead child as a member of the family.

These family studies underscore the importance of location of care for families, as well as how sorrow and grief are present during the child's illness, not just at death. Studies that have examined fathers' experiences highlight the importance of including multiple family members to gain a family perspective (Aho, Tarkka, Astedt-Kurki, & Kaunonen, 2006; Davies et al., 2004). Fathers' experiences differed from mothers' experiences, as they described their experience akin to a battle from which they incurred lifelong battle scars. Most of the family studies had small sample sizes, and the methodology was poorly described, except for the Gravelle (1997) and Davies et al. studies. The samples for the studies were primarily Caucasian, with the exception of Contro and colleagues' 2005 study where 25% of the sample was Latino/Asian/Other.

The studies were mostly limited to one setting. Siblings were only included in one *family* study (Contro et al.).

Large scale, rigorous studies that include dying children, their siblings, parents, and other relatives, as well different ethnicities and geographical locations are lacking, and certainly needed to broaden our knowledge base. Almost all the families are in the medical system during the child's end-of-life; therefore, being able to capture their experiences is a matter of networking among multiple sites, and establishing family research as a priority in delivering optimal family-centered care. The family studies included in this section emphasize the importance of health care providers, especially nurses, for families during the EOL phase. By conducting pediatric end-of-life studies that examine the entire family's experience in the different locations of care, insights would be gained in how to provide the best family-centered care.

Location of Care/Death Studies

Understanding the predictors of place of death is important to understanding the trajectory of illnesses, such as cancer (Bruera, Russell, Sweeney, Fisch, and Palmer, 2002). The place of death can be an indicator of where most of the end-of-life care was delivered based on length of stay at the location of death. Therefore, studies that focus on location are helpful in providing a broader picture of families' experiences during a child's EOL.

Feudtner and colleagues conducted three rigorous landmark studies identifying where children die. They found that 15,000 children die annually that could benefit from pediatric supportive services and that although most children still die in the hospital, home deaths have risen most significantly for older children, who are more likely to live in more affluent than poorer neighborhoods (Feudtner, Silveira, et al., 2002). In the same year, 2002, Feudtner, Christakis et al. conducted a national study identifying characteristics of children who died in the hospital. They found that 60% of hospital deaths were attributable to CCCs and children with these conditions experienced longer periods of mechanical ventilation and hospitalization before death than children without CCCs. Furthermore, a greater number of CCCs was related to less likelihood of rapid death. The authors hypothesized that this may have been related to uncertainty in predicting a child's death, thus prolonging courses of intensive therapy before withdrawal of support. These findings provide support for the need to design better palliative care programs that can serve the community and ensure that sufficient resources are available to care for children who die at home and in the hospital.

The findings underscore the importance of providing pediatric palliative care at initial diagnosis regardless of expected prognosis. On any given day there are 5,000 children with CCCs living within the last six months of their lives, yet it is not always possible to identify these 5,000 children (Feudtner et al., 2001). Uncertainty in predicting a child's death prolongs courses of intensive therapies (Feudtner, Christakis, et al., 2002). The AAP's (2000) position is that since children who will die cannot be identified with certainty, all children who have a life-limiting condition should be receiving integrated care that includes both curative and comfort measures. Our current system has the child shuffling between locations of care; instead of integration, there is fragmentation.

The studies on location of care focus mostly on location of death, which is not always an accurate reflection of where death occurred. One study found that information was rarely shared among institutions, and that parents often had to initiate notifying primary clinics of their child's death (Serwint & Nellis, 2005). Additionally, children who were transported to the hospital from home and died in an ambulance were considered to have died in the hospital. In a Brazilian study (Kurashima, Latorre, De Paiva Teixeira, & De Camarago, 2005), children were considered to have died at home, even if they died in the hospital, as long as it happened within 48 hours of admission. Feudtner and colleagues' studies which relied upon the reported location of death in the US, have been crucial in providing much needed national data. However, data from death certificates is not always an accurate reflection of a child's underlying diagnosis, and classification criteria change over time. The lack of consistent adequate documentation makes drawing conclusions regarding location of care and death difficult, and likely to be an underestimate of the actual percentages. There is a need for national, regional, and state studies, coordination and standardization of documentation to ensure accuracy in retrospective studies, and to improve how we track children's health status.

Transitions between Locations of Care Studies

The transitions between locations of care can be extremely stressful for the individual and the caregivers, and the experience can be full of anxiety, and uncertainty (Burge et al., 2005; Levine, 2002). Families move among the various locations of care according to the child's and family's needs, thus a responsive and flexible system is needed to ensure seamless transitions between these settings (Hynson et al., 2003). Changing location of care marks a turning point in the patient's condition and in the caregiver's responsibilities (Levine). Anticipatory preparation can facilitate the transition process, but not having knowledge of what to expect, or which strategies to use for managing transitions can greatly hinder the process (Meleis, 2000). Yet, little attention has been given to transitions between locations of care; few studies were found on transitions related to locations of care.

A recently published Canadian pilot study focused on the transition to pediatric hospice (Steele et al., 2008a; Steele et al., 2008b). The authors identified a gap in understanding how to best support families as they transition to hospice. They found that parents were likely to use hospice as a respite facility when the family needs had reached a critical level requiring additional services. The families' experiences at the hospice facility were unlike what they had expected; it was not the "death house" they had expected, instead the house was filled with life. The parents experienced changes in self-perception and their roles. This finding was similar to adult studies where caregivers' roles changed. Caregivers' process of understanding the patient's health status and terminality did not occur in successive stages, and decision making was influenced by information received from health care providers, the patient's fluctuating health during the end-of-life, the location of care, as well as family dynamics (Waldrop, Kramer, Skretny, Milch & Finn, 2005; Schulman-Green et al., 2004). Hospice admission hastened the family caregiver's comprehension of terminality (Schulman-Green et al.; Waldrop et al.).

Three key factors were identified in the process of comprehending terminality: information received (health care providers, friends, written sources), physical changes (weight loss, fatigue), and personality and role change (Waldrop et al., 2005). The decision to enroll in hospice did not simply reflect a deliberate plan based on objective assessment of the patient's disease progression, but rather a complex process of awareness, and understanding of the patient's needs as well as alternative choices. The findings revealed that patients who experienced multiple transitions between locations of care faced great challenges in coordinating their care and maintaining continuity of care, particularly in the areas of information transfer, and multiple discharge issues. Patients with multiple transitions were sicker, more likely to have cancer diagnosis, and less likely to die on the acute care ward of the hospital (Burge et al., 2005). Additionally, regulations to protect patient privacy, such as the Health Insurance Portability and Accountability Act (HIPAA) may have impeded families from gaining access to the information they needed to make decisions. The family dynamics shifted during this time as well, suggesting that the pressure of making a hospice decision may have been a stressful task for families. Families that did not have open communication before the terminal illness diagnosis had worsening family dynamics during this time (Schulman-Green et al.).

Clearly, transitions between locations of care are stressful and challenging for both the patient and caregivers, and the type of care provided in the locations is related to understanding the patient’s health and terminality. Waldrop and colleagues found transitions to be a complex process and suggested that the future research examine how families make meaning during EOL. Although the findings from these adult studies may not necessarily be generalizable to the pediatric population in the US, the importance of transitions is underscored. Future studies within the pediatric population are crucial in identifying issues unique to dying children and examining the complexities of transitions between locations for families.

Summary

Overall, the reviewed studies have focused mostly on white middle-class children; mothers were the primary research participants, and the diagnosis of cancer has received more attention than many other chronic illnesses affecting children. There is limited literature from a multicultural perspective. Study samples that have actually included subjects from a variety of ethnic backgrounds were so small that the data analysis did not reach significance when particular ethnicities were separated from the larger group. The lack of diversity in the samples does not provide adequate insight into the experience of families with dying children, thus research that focuses on the experiences of people from diverse cultures is needed.

The gaps in the current literature about dying children and their families raise research questions worthy of pursuit such as: What type of support best serves the needs of different families in different stages of the illness? How are families' grief and bereavement impacted by providers who cared for the child? Why are some families able to manage adversity whereas others are not? What are the barriers to providing optimal EOL care? How do families manage the transitions between the various locations? How does the availability of a free-standing hospice with palliative and respite services impact families' options of care? In my quest to answer such questions, I have chosen to begin with an explorative qualitative study that can serve as a foundation for future studies. The purpose of my dissertation study was to examine how families with children at EOL manage the transitions between locations of care, and I included parents (mothers and fathers), siblings, ill children, and other relatives whenever possible.

Theoretical Background

A single theory cannot explain the complexities involved in how families with children at EOL manage the transitions between locations of care. Although transition theory may seem like the logical fit, this proved not to be the case for this study. Interestingly, no studies on transitions in the review of the literature used transition theories. My dissertation study is informed by several pertinent theories: developmental theory, grief theory, family resiliency theory, and symbolic interactionism (SI). This section begins with a brief discussion of transition theory, followed by a more detailed description of the aforementioned four theories. A detailed description and analysis of each theory is included in the second chapter of my qualification examination papers (Amidi-Nouri, 2007).

Transition Theory

There has been little formal theory generated regarding transition; two authors' perspectives will be briefly discussed in this section. Bridges (2003) has written numerous books on managing transitions that have sold millions of copies, and has updated his book for managing transitions in the business world. He has not generated a formal theory; rather his perspective reflects his experience in working as an executive development consultant. He differentiates change from transition, referring to change as situational and transition as a three-phase psychological process as people internalize the new situation that the change brings about. Change implies a focus on outcome, whereas transition is the process letting go of an old situation. He asserts that transition begins with endings, after which there is a neutral zone, followed by a new beginning. Although he refers to them as phases he points out that they are not linear, but rather that all three must take place for a transition to be complete, and that at any given time one aspect of the transition will seem more dominant than the other two. The focus on the outcome of a change glosses over the losses and endings that are experienced. Bridges states that the neutral zone can be a time of feeling immobilized, where everything is in limbo, where there are no answers. He believes that how the neutral zone is managed is crucial as to whether people can move forward and embrace a new beginning, or whether they stay stuck in the ending. He argues that this is a time of re-patterning and ambivalence. Guidance and support during this time are essential in being able to launch a new beginning. A new beginning cannot be forced: it only occurs under the right timing, and will not happen if someone is still letting go of an ending or in the neutral zone; with support, new beginnings can be encouraged and reinforced. Each new beginning requires the four p's: purpose, picture, plan, and a part to play. His books are anecdotal and filled with recipes for success. Although he has clearly not articulated a formal theory, nor conducted formalized rigorous studies, his experiential writing seem to resonate well with society's perception of how they live through changes in their lives, as evidenced by the sales and multiple editions of his books.

Meleis' (2000) mid-range transition theory focuses on roles and unhealthy versus healthy transitions, with a focus on behaviors of caregivers. She asserts that anticipatory preparation can facilitate the transition process, but not having knowledge of what to expect, or which strategies to use for managing transitions can greatly hinder the process. She also acknowledges the importance of location to all transitions. Her approach to transition did not seem to capture the complexities involved in how families with dying children might manage transitions, and little has been published since 2000 pertaining to her emerging transition theory. In a study applying the transition theory, the transition model failed to adequately represent the interactive and dynamic nature of relationships between formal and informal caregivers in the nursing home context, and the author suggested that Meleis' theory might need further exploration and development (Davies, 2005). The theory has not been adequately tested or formalized, and although there are elements that are applicable to this study, irrefutably there are elements of all theories that could be applicable such as salutogenesis, pathogenesis, feminist, systems, and family life course development.

Developmental Theory

All members of the family are in continual states of development, and children’s concept of grief and death evolves as they mature, which adds a layer of complexity to any study that focuses on families with children at EOL. Two developmental theorists, Piaget (1950) and Erikson (1980), have greatly influenced our understanding of development in children and adults. Piaget outlined four stages through which cognition in children develops: sensorimotor, preoperational, concrete operational, and formal operational. Although the orderliness of the stages have now been disputed (Piattelli-Palmarini, 1994; Slaughter, 2005), it is clear that children have different cognitive abilities based on their maturation. Erikson focused on how children’s personalities develop by expanding Freud’s psychoanalytic framework. He identified eight stages of development from infancy through adulthood: trust vs. mistrust, autonomy vs. shame and doubt, initiative vs. guilt, industry vs. inferiority, identity vs. role confusion, intimacy vs. isolation, generativity vs. stagnation, and integrity vs. despair. Although these stages were also progressive in their order, Erikson, unlike Piaget and Freud, believed that unresolved issues were carried forward into the next stage, not that a person would be trapped in a particular phase.

Concept of Death

Much of what we know and presume about children's concept of death is based on Piagetian perspectives (Speece & Brent, 1984; Reilly, Hasazi, & Bond, 1983). The concept of death is based on understanding three components: irreversibility, non-functionality, and universality. Until a child can understand the irreversibility of death it has been assumed that children do not have an understanding of the concept of death. Based on Piaget's cognitive development stages, a concrete operational thinker (ages 7 and above) could understand such a concept. It is now known that understanding death is shaped by other concepts (such as *person, alive*, *sick*, *baby, growth, animal,* and *inanimate*), experience with death and illness, socio-cultural factors, as well as development of reasoning abilities (Reilly et al.; Slaughter; Speece & Brent). The media also has an influential role in cognitive development of very young children, those in the sensorimotor stage, through the portrayal of cartoon characters that only temporarily die (Norris-Shortle, Young, & Williams, 1993).

Death related experiences, especially those encountered before age six, can facilitate precocious understanding of death (Reilly et al., 1983). Young children with serious illnesses understand the notion of personal mortality (Blue-bond Langner, 1978; Reilly et al.; Wolfe, 2004). However, familial suppression, exclusion of children from funeral services, and euphemisms can greatly confuse children about the concept of death and forces them to create their own explanatory schemes of what was experienced

(Norris-Shortle et al., 1993; Reilly et al.). Throughout the literature, experts advise avoiding use of euphemisms for death, and to use a child's initiation of a conversation about death as a cue for talking about death (Kreicbergs, Valdimarsdottir, Onelov, Henter, & Steineck, 2004; Wolfe). Communication with children involves not only oral communication but also body language and symbolic methods, such as drawing pictures, playing with stuffed animals or dolls, and creating rituals (Himelstein, Hilden, Boldt, and Weissman, 2004). Communication should be developmentally appropriate and provide simple explanations situated in the context of sadness, with the understanding that questions and the concept of death evolve over time (Norris-Shortle et al.). Since children are at different levels of cognitive development and language acquisition, a child may question a parent many months after a death, and within a family the dying child's concept of death may differ from the siblings' concept.

Thus, understanding child development, and modifying the underlying assumptions of a child's understanding of death based on health status, culture, and experiential factors is crucial in guiding families and providers in communicating with children (Himelstein et al., 2004). By using developmental science as a basis of understanding, we can move away from prescriptive understanding of children and embrace a holistic view that guides practice and research. Thus, interview questions and analysis of data must be a reflection of the child's and adult's development. Gaining a theoretical awareness of how children understand the concept of death provided me with a foundation from which sensitive and developmentally appropriate questions were asked of participants. Through my clinical work, I have witnessed that children have much to say about their own illness when allowed to do so, and it is clear through research that they do share their views, which often differ greatly from their parents' perspectives (Bluebond-Langer, 1978; Houtzager, Grootenhuis, Caron, and Last, 2005). Therefore, I included children in my research whenever possible, and developed interview guides specifically for the sibling and ill child with language that was based on development and the child's understanding of illness and death as it unfolded during the interview.

Grief Theory

A child's end-of-life is an undeniably difficult and tragic time for the family (Gowan, 2003), and grief is the context in which families are situated. The loss of a child is unlike any other loss, it is out of the natural sequence of life; parents grieve the loss for the rest of their lives (Arnold & Gemma, 1994; IOM, 2003). Parental grief is not easily explained. Indeed, given the history of grief theory and the popularized subscription to stage theories, parental grief is easily categorized as pathological or unhealthy (Arnold & Gemma). The last two decades have marked a departure from stage theories, such as Kubler-Ross (1969), and psychoanalytic models that pathologize grief (Engel, 1961; Freud, 1957; Lindemann, 1944). Current approaches are task and process oriented emphasizing the individual nature and non-linear process of grief (Rando, 1986; Worden, 1982). The belief in an endpoint to grief with a replacement of the loss has been refuted, as has the orderliness of stage theories (Carter, 1989). Instead, grief is seen as a dynamic process that waxes and wanes, with sudden recurrences.

A current trend in grief theory is the focus on meaning-making. Thomas Attig (2001) defines the activity of *meaning making* in grieving as the bereaved being self-consciously active, taking deliberate initiative, and bringing new meanings into existence while grieving. Attig describes the substance of relearning the world inherent in grief as learning how to be and act in the physical absence of the loved one. Through the concept of narrative reconstruction the bereaved make meaning from what has been lost. Narrative construction is the evolving personal activity of story telling and story making with intention to make meaning and interpretation from what has been lost (Neimeyer, 2001). The construction of meaning is ever-evolving, and the narrative includes facts, perceptions and interpretations of the impact of the personal loss on one's identity, interpersonal functioning and opportunity existing within transitions and life sorrows (Neimeyer, Prigerson, and Davies, 2002). This approach provides room for ethnic and cultural perspectives, as well as understanding how meanings within the family between members might be created differently.

There is little known about how families construct meanings, although it is clear that there is a family narrative construction that occurs among the members that has shared meaning (Nadeau, 2001). For example, rituals, symbols, and a child's belongings are part of creating meaning, and hold special meaning for family members (Arnold & Gemma, 1994; Davies, 1988; Gudmundsdottir & Chesla, 2006; Norbris & Hellstrom, 2005). The meanings that these hold for the siblings may differ from those held by other family members (Davies, 1987). In creating meaning, parents often reach out to help others, and in giving back to others, their bond with the deceased child becomes part of their better selves (Klass, 2001). Despite this recent focus on meaning making, no specific research studies regarding meaning making for families were found, and no theories specifically incorporating a developmental perspective for meaning-making have been found. Family studies are still commonly limited in inclusion of fathers and children.

The theory of meaning-making sensitized me to data in the narratives both during analysis and data collection, where further probes were needed to better elucidate the meanings that families make. My interviews reflected my being aware that parents were at various points in their journey of grief, and that their willingness to participate in my study may have indicated their recognition of the interview as a forum where they could openly display their grief. The potential emotional nature of the interview heightened the need for protecting participants from undue distress, and providing referrals when necessary. Familiarity with parental bereavement theories allowed for anticipation of such distress, and development of protective measures in the study design that minimized risk to the participants.

Family Resiliency Theory

The death of a child, or the impending death of a child, can strain the stability of a family (Whittam, 1993). How a family searches for meaning and learns to live with the physical absence of the child can cause rifts or bonds between the members (Arnold & Gemma, 1994). Some parents may challenge their beliefs and values while others hold onto their beliefs as a stabilizing force. For some, survivorship connects them as they turn to each other for support and comfort, for others, it may lead to separation or divorce (Arnold & Gemma; Walsh,1996). Such differences in how families adapt to their situation reinforces the need for research about what leads to closeness or separation, and how families maintain and improve their functioning during a child's end-of-life and after his/her death.

Resiliency is a dynamic quality through which families focus on strengths and coping assets to address adversity (Hawley & Dehaan, 1996). It is also contextual, such that a family's capacity to be resilient depends on the fit between their strengths and resources, and the challenges and circumstances of a particular situation (McCubbin & McCubbin, 1993; Walsh, 1996). McCubbin and McCubbin's Resiliency Model has two phases: adjustment and adaptation. Adjustment is the first phase, and refers to how families adjust when faced with a stressor, such as an illness. The severity of the stressor, the family's vulnerability, the established pattern of functioning (typology), their capabilities and strengths (resistance resources), and appraisal of the stressor all interact to help solve the problem or cope with the situation. Often this involves minor adjustments such as changing routines and tasks. Families who are unable to adjust well (maladjustment) find themselves in a crisis situation, which places them in the adaptation phase (Appendix A). The adaptation phase requires new patterns, since minor adjustments are insufficient to bring balance to the family. The resulting outcome of adaptation is either bonadapation or maladaptation. However, the diagnosis of an illness, such as cancer, places the family into an immediate crisis situation, such that families do not have the opportunity to engage in the adjustment phase. The crisis necessitates that families move directly into the adaptation phase (McCubbin et al., 2002).

The adaptation phase includes appraisal, family support, and problem solving and coping. In McCubbin and McCubbin's model (1993), there are three levels of appraisal. The first level is appraisal of the family's strengths and capabilities. The family has to appraise what the family *has* (resources and strengths), and what the family *does* (coping behaviors and strategies). The second level is the situational appraisal that is formed from the perceived relationship between the family's resources and the demands of the situation. The family is constantly evaluating and interpreting their experience to break the problem situation into specific manageable tasks, and choosing strategies to help them cope with the situation.

The third level is the appraisal of family schema and meaning. The schema is the blueprint for functioning: the values, goals, priorities and rules. The family has to appraise its past and future to give meaning to the illness. McCubbin and McCubbin (1993) argue that this third level is of critical and central importance in changing family function to achieve the optimum fit between its resources and the challenges. This level of appraisal helps foster congruency between the changes in the family's schema and the family's patterns of functioning. If the family can find meaning in its grim circumstance, then they can push through the bereavement and foster a sense of cohesion in the family (Walsh, 1996). The family has to appraise its past and future to give meaning to the illness. Developing meaning is a demanding process that is only achieved through perseverance, patience, negotiation, understanding, and shared commitment to the family. This process can produce optimal problem solving for managing illness situations to facilitate family adaptation (McCubbin & McCubbin). Therefore, understanding how families make meaning of their situation, and the strengths and assets is crucial in examining how they are able to maintain bonds and function.

Symbolic Interactionism

Symbolic Interactionism (SI), a term coined by Herbert Blumer, draws from the writings of George Herbert Mead, John Dewey, William James, and others. It is founded on meaning, which is created in the process of interaction between people (Blumer, 1969). The human being is seen as an acting organism, one who is engaged in self-interaction and reflection. There are three premises upon which SI is based (Blumer).

First, human beings act toward objects based on the meaning they assign to the objects. Objects can include: physical objects, other people, the self, ideals, or situations. Second, the meaning of objects arises from social interaction with others. Third, meanings are handled and modified in an interpretive process by the person and the object. Objects are seen as social products that are formed and transformed through social interaction. Humans are situated in a world of meaningful objects, not merely an environment of stimuli. Understanding group life necessitates identifying its world of objects.

SI views meaning as a social product formed in and through activities of people as they interact. First, the actor indicates to himself the object that has meaning, thereby engaging in self-communication. Second, the actor selects, checks, transforms meanings based on the situation he or she is in. This is not an automatic reflex, but rather a formative process that can be used and revised. Social interaction forms human conduct (Blumer, 1969). Behavior is not merely a response to certain factors, but it actually arises out of interpretation with the self and others. Rather than being a responding organism, the human is an acting interpretive organism. Action may be initiated, halted, or abandoned based on such interpretations. Mead viewed action as constructed rather than merely evoked from the organism, and described society as a *process* of actions not merely a structure of relations. To understand joint action, he advised against breaking it into the individual acting lines, but rather to examine *how* those lines of action merge together. Joint action arises out of previous actions, such that there is a historical linkage between actions. The actors bring their world of objects, meanings and schemes of interpretations from previous actions. A simplistic focus on one action amputates it from the history that has generated the act.

From a research perspective, it is important to understand the world of an actor by examining the roles of the actor and seeing the world from his/her standpoint. For example, most researchers using methods based on SI rely heavily on data about the everyday lives of participants described in their own words (Charmaz, 2003). Blumer questioned the objective approach of research, stating that the observer cannot be detached and to remain that way may mean that the actor is described as the researcher sees him, from the researcher's world view. Indeed, the data are constructions; it is what the participants choose to tell us about the meanings of their worlds and how they act within them (Charmaz, 2000). The researcher must also consider the various contexts and how contextual elements shape action, thereby examining the *situation* in which joint action takes place (Clarke, 2005).

Symbolic interactionism is a perspective through which to view humans and examine their actions and the meanings that social and cultural situations have for them. Both grounded theory and sociologically-oriented ethnography are rooted in SI and employ immersion in the natural setting (field studies). Since symbolic interactionism, grief, and family resiliency are rooted in meaning-making, these frameworks laid a foundation for this dissertation research.

Summary

The theories discussed in this chapter have guided the multi-dimensional family-centered development of my research questions, as well as the methods for my study, including the analysis and discussion of the findings. A developmental lens captures the breadth of influences that shape the child and the family, and researchers should make concerted efforts to include the entire family and consider the contextual influences.

Moreover, future research on ill children must consider the cultural, ethnic, and socioeconomic factors that influence health and development through beliefs, values and health care access issues, as well as how these factors influence adaptation to acute and chronic illness (Miles & Holditch-Davis, 2003). Research through a salutogenic orientation allows for a focus on the innate abilities within each family, how families make meaning of their circumstances, and the strengths and assets that enable them to adapt, restore balance, and grow during this very difficult and challenging time. The narrow psychoanalytic lens has been widened to a developmental and contextual dispersive prism. Research must reflect such advances in theoretical understanding of phenomena, and shed new light upon our current health care practices and understanding of children at end-of-life, so that needless suffering of dying children and their families can be eliminated.

Purpose and Aims

The review of the literature revealed several gaps in the area of research pertaining to the area of pediatric end-of-life. The following research questions were generated based on the review of the literature and the theoretical perspectives: How do families experience transition between locations of care? What processes are involved as families transition to a new location? How do families maintain integrity and function while being split into different locations? The purpose of this dissertation study was to understand how families with a child with a life-limiting condition at EOL manage the transitions associated with various locations of care: home, hospice, and hospital. In preparation for this dissertation study, I conducted a small grounded theory pilot study with families whose children were receiving or had received care at a pediatric hospice.

The experiences gained from the pilot study served as a foundation for the direction of this dissertation study. I broadened the sample to include children receiving in-home hospice services, and I made a stronger effort to recruit children, which I had not been able to do in my pilot study. In my pilot I had a greater number of bereaved families; therefore in this study I made the effort to have a more balanced sample of bereaved families and families whose ill child was living at the time of the interview. I expanded my methods to more fully include situational analysis, and included poems, and drawings, and other visual data that families shared with me. The dissertation study methods are fully described in the chapter three.

CHAPTER THREE: METHODOLOGY

Research Design and Methods

Design

This prospective descriptive qualitative study used grounded theory methodology. Given the lack of existing research in this area, and the limited number of children using George Mark Children's House (GMCH) or Comfort for Kids (CFK, in-home hospice) services, it seemed most appropriate to conduct a study that could serve as a foundation for future research, be it qualitative or quantitative. A qualitative approach was deemed most appropriate for this study; the family's experience was explored through interviews and participant observation.

Grounded theory (GT) is rooted in symbolic interactionism, thus suited for exploring patterns and processes, how people construct their realities, and create meanings in situations (Cutcliff, 2000; Speziale & Carpenter, 2003). GT was developed by Glaser and Strauss (1967) who proposed that theory should be grounded in the data. They described systematic qualitative methods of constant comparative analysis and theoretical sampling for data collection and analysis which occur simultaneously in this approach. Analysis involves line by line, or even word by word coding, enabling the researcher to gain distance from one's own and the participant's taken for granted assumptions and meanings so that it can be seen in a new light (Charmaz, 2003). By distilling the data in this way, the need for further inquiry is illuminated early in the data collection process. Thus, interview questions may be modified, as well as further participants or additional interviews with same participants are sought (theoretical sampling) to provide a rich account of this new line of inquiry. Analysis includes conceptual development that can lead to theorizing or development of theory that is grounded in the data (Clarke, 2005; Glaser & Strauss)

Exploring how families manage transitions between locations of care involves examining processes, and how these develop and transform over time as the child's health deteriorates and as locations are changed. The detailed systematic methodology of GT analysis is appealing to a novice researcher such as I. Simultaneous data collection and analysis shape theoretical sampling, providing a directed approach to sampling which may be viewed as less intrusive to a hospice setting than gaining entrée for immersed observations common in ethnographic studies. This was clearly evident in my study where gaining entrée to families was tightly controlled. The design of my study, the decision making process for including more participants, as well as participant observations taking place only during interview times were key factors in recruiting families. My being as minimally intrusive as possible in the lives of families who were at the hospice was the expressed desire of the directors at GMCH. Thus, GT was not only suited for the purpose of my study, but also for the feasibility of conducting the study, providing me with a systematic method of analysis of the data to examine the processes associated with transitions between locations of care. Symbolic interactionism, in which GT is rooted, examines the meanings that joint interactions hold for the family members, and Clarke's (2005) situational analysis perspective is particularly fitting for families of children who are dying and the multiple negotiations that take place among the locations of care within the context of all the discourses surrounding end-of-life.

Research Questions

The following research questions were addressed in this study: How do families experience transition between locations of care? What processes are involved as the family transitions to a new location? How do families maintain integrity and function while being split into different locations?

Definition of Terms

Many of the terms used in this study can be interpreted in different ways; therefore, a clarification of commonly used terms used in this study is included in this section.

Palliative Care/Hospice Care

Palliative care and end-of-life care are generally terms used interchangeably. Hospice care has strict eligibility guidelines governed by state regulation and insurance policies, which are distinct from hospice philosophy. George Mark Children's House is technically not a hospice house, although the services offered mirror what other children's hospice homes in other countries offer. GMCH was modeled after Canuck Place, a children's hospice home in Canada, a country where the regulations surrounding hospice differ from the United States. Parents in this study did not make such distinctions, and often referred to GMCH as a hospice house. Similarly, Comfort for Kids is the pediatric division of a larger hospice organization, and offers both palliative care and hospice care. Again, parents saw little distinction between the types of care, except for what services were reimbursable through insurance. The findings reflect the parental perspectives, where the terms palliative, end-of-life, and hospice care are used interchangeably.

Family

The U.S. census bureau defines a family as, “A group of two people or more related by birth, marriage, or adoption and residing together” (U.S. Census Bureau, 2004, ¶ 10). Anyone residing in the household who is not related by the three previously mentioned categories is not considered part of the family. This narrow definition excludes a large number of families, such as unmarried co-habitating couples (including a majority of same-sex couples who do not have the right to marriage in most states). The AAP Family Task Force (2003) found that the concept of *family* was extremely complicated and strongly influenced by personal and social values, and thus purposefully chose not to define the concept of family. For the purposes of my research, a family includes persons living with and/or providing care for the ill/deceased child, exclusive of health care providers. At least one adult interviewed per family must have been the parent/guardian such that he/she could consent for the child’s treatment/research participation. All family members (ill child, siblings, parents, guardians, and other caregivers for the child such as grandparents, relatives and friends) were included whenever possible. In the case where grandparents were the actual primary caregivers, they were included under the term *parent* since they played a parental role in the child’s life, not simply extended family.

Settings

Setting was defined as any location where the child received care: home, hospital (and affiliated institutions such as clinics), and hospice.

Health Care Providers

Health Care Providers (HCP) were persons who provided care for the child as a scope of their practice and included (but not limited to): nurses, physicians, aides, respiratory therapists, occupational therapists, physical therapists, social workers, child life specialists, chaplains, and volunteers.

Population and Sample

Sample

Data collection began in January 2006 and continued through February 2008. Some families were interviewed while their child was alive since they experienced the death of their child during the study whereas others were interviewed subsequent to the child's death; in other families, children were still living at the completion of data collection. Given the unpredictability of the child's length of life, it was not possible to commit to including particular events (such as the child's death) as part of this study since it was not a longitudinal study. However, through theoretical sampling, the heterogeneity of the sample was assured despite the limited time frame. Thirteen families (8 Caucasian, 4 African-American, 1 Mexican-American,) participated in the study, for a total number of twenty-five participants: nine mothers (one pregnant at the time of interview), six fathers, and four grandmothers, five siblings, and one patient (Appendix B, Table 1). A total of twenty-two interviews was completed; five were conjoint, and seventeen were individual. In eight families, parents were married couples; five were single parent- or grandparent-headed households. Due to health circumstances or young age, only one ill child was interviewed for this study; ten children were included in participant observation. Although demographic data was collected for each participant, given the small sample size and selection of families by staff, this information is not included in this dissertation in order to protect the families' identities. The ethnic and gender demographics coupled with the other demographics would narrow the identifiers such that any staff would be able to identify exactly which families had chosen to participate. Moreover, given the small sample size, no conclusions could be drawn from age, education, income or religious background.

Inclusion/Exclusion Criteria. Any English-speaking family who had a child receiving care at GMCH was eligible to participate; non English-speaking families were excluded. Since any family at GMCH was eligible to participate, it was anticipated that in some families, the ill child was an infant, or the ill child may have had siblings that were infants or toddlers. Therefore, children 0-18 were included in the study; however, only children ages five and older were interviewed, children younger than five were included in participant observation. It was anticipated that the demographics of participating families would be reflective of the GMCH population, which had an approximate ethnic mix of 41% white, 20% Asian, 19% Latino, 15% African-American, with smaller percentages of American Indian, Native Hawaiian, or Other Pacific Islander. The demographics of this study reflected 62% Caucasian, 31% African-American, and only one Latino family (7%). Undoubtedly with a larger sample, these percentages would have shifted.

Study Settings

Participants were recruited from GMCH and CFK (Appendix C, Table 2); however, the interviews were arranged and located at the convenience of the participant (GMCH, home, hospital, or other preferred location), and information was gathered during the interview that related to other settings where the child had received care. Interviews took place in all three settings. In the home setting, some children received in-home support services through CFK , or home health agencies. The hospitals where children received care ranged from smaller community hospitals to large teaching hospitals. The location of families' homes ranged from low-income working class neighborhoods to more affluent suburban neighborhoods.

*Recruitment and Enrollment Procedure*s

Recruitment was achieved through staff referrals. Staff did not want flyers visibly posted for recruitment. The study was presented to staff at meetings; where staff members were asked to identify families that would be willing share their experiences, preferably choosing families with siblings. The staff was provided with written materials as to the nature of the study (Appendix D), the eligibility criteria, and the researchers' contact information. The meetings provided an opportunity for addressing concerns and discussion. Staff members used their judgment in assessing which families were appropriate for this study. Another information sheet written specifically for families was given to the staff to distribute to interested participants. The family information sheet (Appendix E) outlined a brief summary of the study, and had a perforated section that potential participants returned to staff. This perforated section provided three options that could be checked: N*ot interested* in the study, *Will contact the researcher*, or *the researcher can contact me*. Families who were not currently at GMCH were contacted by the directors who gave them a description of the study, and obtained telephone consent as to whether I could contact them.

During the initial phone conversation with parents who agreed to be contacted (or those that had initiated contact with the researcher), additional information was provided about the study, and if the family was interested, a convenient time was arranged for obtaining written consent (Appendix F). Once consents were obtained, participants were given the choice of being interviewed immediately, or postponing the interview up to two weeks. This was a requirement of CHR designed to allow the family time to reflect and raise any questions or concerns before the interview. Since this was a family study, it was desired that both parents (if and when possible) and child(ren) would participate. However, this was not always possible or desired by the family. Some families were single parent households with only one child, others had siblings that were too young or away at college, and some children were too ill to participate. Furthermore, some children were deceased. None of the parents whose children were able and willing to participate refused participation. Additionally, all parents who were contacted by phone agreed to participate, and no one chose to wait after informed consent was signed. No child was allowed to participate without the parent's consent. Parents were given the opportunity to ask questions regarding their concerns before agreeing to their child's participation. Furthermore, a parent could revoke the permission granted for interviewing the children at any time. Parents were interviewed before the interview with the child took place, except for conjoint interviews when parents and children were interviewed simultaneously (Appendix G, H, I). The minimum requirement for participation was the inclusion of one parental interview. No families were deemed ineligible for lack of desire of wanting their child(ren) to participate.

Since children were included as participants, their assent (Appendix J, K) was obtained. The National Commission for Protection of Human Subjects of Biomedical and Behavioral Research established age 7 as a reasonable minimum age for involving children in an assent process, since most children this age can understand information tailored for their knowledge and developmental level (National Cancer Institute, 2005). Children under age 7 were included with informal assent, and as developmentally appropriate, and extreme care was exercised in keeping interviews short and developmentally sensitive. Interviews with children took place after parents had been queried regarding what the child knew about the diagnosis. Questions pertaining to illness and end-of-life will were omitted or modified whenever appropriate. These questions were only asked after parental permission (Appendix L) had been obtained, and were documented on the parental query sheet (Appendix M) so that the interviewer could keep track of what information was appropriate or not. The child's interview guide was modified according to the parental query sheet prior to interviewing the child. The interview questionnaires had been developed with Dr. Susan Kools, expert in developmental science, and Dr. Betty Davies, expert in pediatric palliative care, to reflect sensitivity to the subject area and developmental appropriateness. All children in the study needed legal permission for participation from parent/guardian. All participants had the option of reading the consent/assent form or having the form read to them. The researcher was present to answer any questions that arose regarding the study. Participants could refuse to answer questions or terminate the interview at any time. Families were assured that declining to participate in the study or terminating an interview would not affect their care, and that there would be no further contact from the researcher. No participants terminated interviews. There were families with whom contact was never successful (due to disconnected phone numbers, or calls that were never answered); however, for the families with whom phone contact was successful, 100% chose to participate.

Each adult participant and each minor participant was given $10 in cash or a $10 retail store gift certificate respectively, for participation in each interview. The total amount that any one participant could potentially receive was $30 (either cash or gift certificate) if he/she were to participate in three interviews; no individual participant received more than $20 in this study.

Data Collection

In grounded theory, the sampling process is begun by interviewing significant individuals or choosing participants whose narratives will illuminate the phenomenon under study (Jensen, Bäck-Petterson, & Segesten, 2000), preferably starting with the most eloquent to obtain rich data (purposive sampling). Data generation includes interviews, but can also include documents, journals, and photos. Sample selection is theoretical, which is choosing participants based on emerging theory. This is a necessary process for grounded theory, since theory is developed as data is collected, and questions are modified based on previous data. Data collection continues until saturation is achieved, when no new information is presented and data becomes repetitive, or until themes are redundant and descriptions or theories are fully developed (Clarke, 2005; Speziale & Carpenter, 2003). Thus, theoretical sampling is based on accumulating enough data to meet achieve saturation as guided by the purpose of the study (Charmaz, 2005; Clarke, 2005).

Theoretical sampling guided the recruitment of participants and analysis of data in this study. Through the initial pilot study, it became evident that using GMCH services appeared to be a highly positive experience for families compared to the hospital experience; therefore, I expanded recruitment to include families that had used in-home hospice services. I wanted to be able to collect data in a different setting to see how the hospital experience was viewed by families who did not choose GMCH. Additionally, I interviewed families at the various locations of care: home, GMCH, hospital. I also included families at varying points along the trajectory of illness and bereavement: some who had just been admitted to GMCH for the first time, others who had been there for some time, or who had experienced multiple admissions, as well as families who had already experienced the death of their child, anywhere from a few months after death to over ten years.

The AAP (2003) guidelines recommend a focus on the entire family as well as the individual child during family crises and transitions, particularly in family research studies, thus underscoring the importance of inclusion of all family members in this study. Indeed, children are often overlooked as informants of their own functioning (Houtzager et al., 2005). Clarke (2005) suggests that theoretical sampling be explicitly directed toward seeking the broadest range of variation within the data, so that particular aspects of situatedness can be pursued. Therefore, in this study I sought heterogeneity by including all members of the family whenever possible, and by driving farther distances, up to 80 miles from GMCH, to interview families who lived far from urban centers. Clarke suggests being explicit about the inclusion of nonhuman objects, such as technologies, historical documents, visual representations, and discourses. I received photos, poems, drawings, and published newspaper articles from the families which I included, as part of my data and analysis.

Interviews

The family's world view cannot be derived individually, and is best assessed through conjoint family interviews (Hawley & Dehaan, 1996; Patterson & Garwick, 1994); thus, all members were interviewed together whenever possible. A multi-directed partiality interview is best suited for conjoint interviews. This approach requires that the interviewer be empathetic to all members, take sides with each of the individuals, and validate the struggles and injustices of each person as well as the couple (Benjamin & Benjamin, 1991; Moriarty, Cotroneo, DeFeudis, & Natale, 1995). I used this approach with the five conjoint family interviews, and found it to be very helpful in enabling family members to talk without one dominating the other, evidenced by balanced number of responses from each participant. Ideally, interviewing each family member individually first to gain insight into the experience of each member, and then conducting conjoint family interviews provides the broadest family perspective. However, this procedure was not feasible for reasons of participant availability, parent preferences, and participant burden. Some larger families would have required several visits in order to complete both individual and conjoint interviews. Conjoint interviews were conducted at the participants' request. Most interviews were individual interviews. All interviews with children took place in the presence of the parent, except for the one patient that was included, who was interviewed alone.

Prolonged engagement was achieved through lengthy interviews lasting 60-120 minutes, with shorter interviews (10-30 minutes) for children based on developmental age and health status. The interviews were conducted in person using an interview guide, which was digitally audio-taped, and extensive field notes were generated. The participants were interviewed a second and third time depending upon whether more in-depth information was needed after the initial interview. These subsequent interviews served as an extension to the first interview, the purpose being to follow-up on questions that served to clarify the participant's perspective which also allowed for more time with participants. Furthermore, it was often with the second interview that fathers or siblings would participate. Second interviews also allowed for observation in a different time or setting. One participant invited me to interview her on the day she was preparing to go to GMCH, and I was able to participate in helping her pack as she explained the elaborate routine she had developed in streamlining the transition to GMCH for her child's respite care. All participants had the choice to refuse subsequent interviews even if they had agreed to more interviews, or initiated them. Before commencing the semi-structured interview guide, efforts were made to establish rapport and trust with the family. Audio taping of the interview began only when the family (or individual member) was comfortable. I avoided asking too many questions initially and sought to not ask sensitive questions about feelings at the beginning of any interview. Interviews were designed to be conversational, semi-structured, and in-depth. My first interview questions began with asking the family member to share how the child was initially diagnosed and about the illness. However, typically upon my arrival to the interview, before I could even present the written consent, families had already pulled out albums and videotapes of their child, and wanted to walk me through their house to show me keepsakes, and I often found myself having to interrupt participants in order to obtain consent and begin audio-taping so that I would not miss any data. Many of the interviews actually began with looking through albums, and parents sharing the stories that each photo represented. Often, I would glance through my interview guide and find that they had already answered the majority of my questions without my having to even ask them. I had so carefully planned for the protection of families by avoiding sensitive questions at the beginning of interviews, but families eagerly shared their story with me from the moment I stepped through their door until I was standing in the doorway at the end of the interview.

The interview guide consisted of several questions, each with various probes to be used as needed. It was important to know whether this was a first or repeat admission, and whether the family was at GMCH for respite or end-of-life (although no families were excluded). Since families were recruited from GMCH and CFK, initial questions pertained to the transition to GMCH or CFK and what that was like. Further questions were about the experience at GMCH or home with CFK services, and they were also asked to remember previous transitions and what those were like. Of course, the interviews were not linear, and parents would begin chronologically, and then remember something else, skipping to a different experience, filling in gaps, and weaving their story together like a tapestry. I took notes during interviews so that I could clarify the experiences, and so that I could guide the interview back to the focus of the study. By allowing participants to speak freely, I often discovered data that I might have considered irrelevant or tangential often led to explaining their experience in a way that I would not have been able to elicit by simply following the interview guide verbatim. One participant was describing a pet, and I had thought that perhaps she was making polite conversation; however, as the conversation continued it was clear that she saw her pet as having saved her child's life on numerous occasions, and that realization enabled us to explore those experiences further.

The interviews for children differed from adult interviews. Short questions that built rapport were necessary at the beginning of the interview. Since I interviewed parents first, most of the children were eager to participate and have their say. Siblings younger than five would sometimes sit with their older sibling and interject from time to time. Children were given materials for creating drawings during the interview. Art is an expressive medium and can be a powerful tool for expression, especially if what the children are experiencing is too difficult for words, or that they developmentally lack the words to describe their experience (Rollins & Riccio, 2002). Children were given choices of paper, colors, and medium, as well as the choice not to participate. Such choices are considered crucial at a time when children are often making very few choices about their care (Rollins & Riccio). Children ages 7-12 were given the option to choose between the drawing activity or semi-structured interview, and those between the ages of 13-18 were interviewed using the interview guide. Some children were interested in making several drawings, others focused on one. Children had the option to keep their drawings, but some chose to give them to me instead (Appendix N). During assent I would ask the children if they wanted their parent present; they all did. The desire for parental presence stemmed from the child's need for comfort and security, not from the parent's need to hear the child's interview. This was explained to the parent during the permission process. During the interview, some parents simply remained in the room, others were in close proximity, sitting next to their child. All the parents were eager to hear their child's viewpoint, and rarely interjected during the interview.

Participant Observation

Participant observation is a key component of qualitative research methodology, since what people *do* is as important as what they *say* (Hammersly, 1990). Participant observation played an important role in the interviews, especially those with young children since their verbal abilities may be limited. Much was gained from observing interactions and watching children at play. Although, at times, the presence of children was a distraction from the interview, the distractions allowed me to observe the family dynamics and how families incorporated the children's needs into their tasks. This ranged anywhere from suctioning the ill child to nursing a baby sibling. For this study, the observations included anyone present during the interview (staff, siblings, and pets) as well as the environment where the interview took place. The observation took place during the interview process only; no other time was designated purely for observational purposes, which was a modification required by CHR for my pilot study. Given that much of communication is non-verbal, and since the participants were not being videotaped, participant observations were vital in obtaining rich data. The observations heightened my awareness of signs of emotional distress that presented during the interview, thereby determining the direction of next questions. Most parents cried during the interviews, and were comforted by periods of silence, hand holding, and being given tissue boxes and bottled water. Parents in conjoint interviews often comforted each other by placing a hand on the other's knee, giving a hug, and offering tissue. All parents wanted to continue the interview, and expressed gratitude for the opportunity to share their experience and emotionally express their sorrow.

Data Management

I used Atlas Ti software to organize and manage the data in my study. As my findings became more clearly defined, I also used word processing software to categorize sections of my findings.

Data Analysis

In grounded theory, data collection and analysis are simultaneous; there is a systematic manner in which data is analyzed beginning with coding that is then developed into theoretical concepts that provide the foundation for emerging theory (Strauss & Corbin, 1998). Interviews were audio taped, transcribed verbatim, and analyzed after each interview. I used constant comparative analysis through coding and memoing, in addition to situational analysis through use of mapping.

Using constant comparative analysis enables the researcher to compare segments of data to other data within and between interviews. The categories and concepts emerge from the researcher's *interactions* with the field and questions about the data; the researcher is composing the story, it is constructed (Charmaz, 2000). Grounded theory methodology proved to be quite useful since it includes line-by-line coding, and breaking the text into smaller sections for analysis. Transcripts ranged from 50-75 pages in length. Fragmenting the text in this manner enabled me to look at specific words that were used, pauses, which gave me much insight into how families led their lives during the child's end-of-life and after, as well as identifying areas where greater probing with questions was beneficial. Additionally, such analysis allowed me to distance myself from the very emotional data. I used open coding, axial coding, and selective coding to develop categories, along with their properties and dimensions in accordance with grounded theory methods, as well as situational maps as described by Clarke (2005) to examine the context in which the families are situated both on a macro and micro level.

Coding

Several levels of coding characterize grounded theory coding procedures: open coding, axial/focused coding, and selective coding. Strauss and Corbin (1998) define open coding as opening the text to expose thoughts and meanings contained in them so that concepts, their properties and dimensions can be identified. Charmaz (2003) recommends line by line coding with active codes that include gerunds, enabling the researcher to connote ongoing action at an abstract level. I began coding my data line by line using gerunds to reflect the action in the data, sometimes using *in vivo* codes using the participants' exact words. Initially, open coding did not seem like a difficult task. Indeed the data was so rich, it basically spoke to me. For example, Carol stated, "Let's just go check the place out. So I called." She was referring to visiting GMCH, so I coded it as *checking out GMCH*. However, analysis must involve delving into implicit meanings and conceptualizing them with abstract ideas and going beyond the reproduction of the participant's words (Charmaz). As I raised the level of analysis, I began to code using my own words. For instance, Earline described a situation where a surgeon was doing a procedure without local anesthesia on her child, and she quoted the surgeon's response to her which was, "Most of these children don't feel any pain." I coded this as *dehumanizing the child.* Connecting the codes, dimensionalizing them and identifying properties proved much more difficult. I felt as though everything I was uncovering was important. As I coded more sections of the transcripts, certain codes began to appear frequently such as: loss of function, loss of crying, loss of movement, loss of spontaneous breathing; hoping, keeping faith, believing, praying, doing everything. Categories emerged from the data that pertained to transitioning to pediatric hospice: declining health, running out of options, hoping, giving up, choosing George Mark. As I continued to contemplate these categories and write memos, I realized that families did not choose to go to GMCH if they were not ready. They had to be ready to receive information about GMCH in the first place, and also be ready to tour the facility. It was clear that the trajectory of transition was similar for the families. First, they would hear about it, react to it (positively or negatively), go on the tour, and then decide to try it out. So it seemed that some of the categories were really properties or dimensions of 'becoming ready.'

Strauss and Corbin (1998) explain that categories allow for reduction in number of concepts as well as increasing the analytic power since categories can explain and predict. For instance, one property of 'becoming ready' is the health status of the child. This property can be further dimensionalized into 'treatment response.' For children who did not respond to treatment, their health status declined, and their condition worsened. For example, parents described a particular treatment and talked about how their child did not respond, explaining how their child was motionless. Sandra described her daughter," She would just lay there as if you had a dead body." *Treatment response* occurred on a continuum with children who did better at one end, and those who did not at the other. Children at end-of-life generally do not respond to treatment. However, because some children had responded well in the past, parents believed the same response would continue to occur. Similarly *running out of options* was another dimension or property of treatment options, with having no options at one end of the continuum and cultivating options at the other.

Memo Writing

Analysis of the data requires memo writing, in which categories are explored in narrative form (Charmaz, 2003). Assumptions, ideas, raw data, comparisons, clarifications, and directions for further exploration are included in memos. Memos serve to define categories, properties and dimensions, and are an essential step in raising conceptual categories to theoretical categories. With my data I struggled to define what families were describing about their care at George Mark. The descriptions were remarkably similar both within and between families and vastly different from the way they described hospital care. Writing memos enabled me to explore these comparisons, and raise codes to a higher theoretical level. An excerpt from my memo on *partnered caring* follows:

> The nurses at GMCH are partners in caring, they do not just give it, they *offer* it respecting the family's wishes all the time. There is no hierarchy, or if there is one, it isn't mentioned in the interviews. Parents aren't being told what to do, they are equals, or as I said earlier at the helm. Is the term *partners* too equalizing then? Is it a president, vice-president relationship, such that in the absence of the president (parent) the vice-president can step in? The partner concept is appealing though, it seems to capture more than just the role.
>
> Definitions of partner (from Merriam-Webster, on-line): (a) One that is united or associated with another or others in an activity or a sphere of common interest, especially: a member of a business partnership; a spouse; a domestic partner;

> either of two persons dancing together; one of a pair or team in a sport or game, such as tennis or bridge. (b) Nautical: A wooden framework used to strengthen a ship's deck at the point where a mast or other structure passes through it. Often used in the plural. Synonyms: *partner, colleague, ally.* A *partner* participates in a relationship in which each member has equal status: *a partner in a law firm.* A *colleague* is an associate in an occupation or a profession: *a colleague and fellow professor.* An *ally* is one who associates with another, at least temporarily, in a common cause: *countries that were allies in World War II.*
>
> The nautical definition is an interesting one, does the nurse strengthen the family at this juncture where it seems they (or things) having been falling apart for them? The term ally is also interesting, in that both nurse and parents have a common cause, and it may indeed be temporary based on the length of time the child has left to live. Perhaps it is better as a verb since it implies action, something that develops, is negotiated: *partnered caring? Active partners in caring?*

Indeed, without theoretical memos theory cannot be generated (Glaser, 1978). Theoretical memos link the data to final analysis by conceptually raising the descriptive codes to a theoretical level and drawing out the analysis buried within descriptive information. The analyst has to relate the code and its relevance to the data. Memo writing allows for exploration and prevents the analyst from reaching conclusions prematurely (Glaser). Memos also allow the researcher to track ideas and develop theoretical categories, improving not only the writing of the final analysis, but also the rigor of the study.

Mapping

Clarke (2005) seeks to enrich traditional action-centered grounded theory analysis through situational analysis, which places the situation with all its complexities in the forefront. Mapping is a tool through which analysis of the situation is achieved. Clarke believes that this visual method breaks away from the mold of writing and the researcher gains a fresh perspective on the data. There are three cartographic approaches: situational maps, social worlds/arena maps, and positional maps. Situational maps articulate the elements (human and nonhuman) in the situation and examine the relation between them. She suggests starting with a messy map that can then be organized into an orderly situational map. Social worlds/arena maps are cartographies of collective commitments and sites of action, and capture the joint action described in SI. The map enables the researcher to see how the individuals act within the collective, and to visualize the relation among structures and agencies by laying out the segments of a world and drawing the boundaries. Positional maps plot positions that are articulated and not articulated in discourses. The researcher maps positions held within a discourse; the focus is removed from the individual or institution and is placed upon the discourses. Through use of mapping, the situation is placed in the foreground, forcing the researcher to examine data in new ways.

Situational mapping proved very useful in this analysis. The complexities of the families' experience had become muddled, and it was through visual mapping that the journey of the family became clearer as the discourses fell into place once the situation came into the foreground. I used what Clarke describes as an abstract situational map to include the human elements (family members, staff, institutions), non-human elements (treatment, location of care, location of death), and discursive constructions (technologic imperative, quality of life, uncertain prognosis). The initial messy/working version enabled me to list all the elements I thought comprised the situation of a child at end-of-life. I then further developed this messy map into an ordered map (Appendix O), listing the various elements under specific categories, which allowed me to see the interrelatedness of the discourses in a different manner. Through mapping I was able to distill the data in a different light than line-by-line coding. The situation and the discourses provided a greater context. I could see, for example the way in which the technologic imperative or uncertain prognosis was woven into the family's narrative. The transference of elements to a visual map, versus simply a list, enabled me to see the relations among the elements through the use of maps. I was able to visually see how different these relations were based on the location of care, particularly who was at the center of the relational analysis.

The use of mapping as part of study design, data collection, and data analysis, in addition to the coding of the text as described in more traditional grounded theory methods provided an approach to understanding the data that was contextually situated. Rather than focusing on a unidimensional basic social process as with traditional grounded theory, I was able to expand my findings to include multidimensional perspectives through use of mapping. Clarke (2005) states that the goal of GT need not be confined to generating theory; findings need to represent lived situations and varieties of positionalities that place variation in the foreground. Through mapping I was able to engage in the creative process of analyzing the data to construct the visual map of the family's complex journey. Situational analysis enabled me to break through the mold of the written word, and bring the situatedness of the family's experience to the foreground.

Rigor

Establishing rigor in qualitative research is very different from the standards of rigor in quantitative research that has been typically measured through reliability and validity. In qualitative research, the researcher is the instrument and studies are both subjective and creative. Criteria for rigor in qualitative inquiry must consider such characteristics. Whittemore, Chase & Mandle (2001) re-conceptualize criteria for rigor in qualitative research by establishing primary criteria and secondary criteria. Primary criteria include: credibility, authenticity, criticality, and integrity. These criteria are necessary for all qualitative studies. Reflexivity, open inquiry, critical analysis, a systematic research design, and recognition and exploration ambiguities are all part of primary criteria. The secondary criteria provide further indicators of rigor and are more flexible, certain criteria may pertain to a study, and others may not. Secondary criteria include: explicitness, vividness, creativity, thoroughness, congruence, and sensitivity. Whittemore et al. also describe techniques to improve rigor such as sampling decisions; data generation, such as prolonged engagement and verbatim transcription; analysis, such as member checking, memoing, reflexive journaling; and presentation, such as thick descriptions, and supportive evidence. The adherence to such criteria in qualitative research can greatly enhance the rigor of studies.

It was my goal to create a rigorous study that meets the criteria set forth by Whittemore and colleagues. I focused on using techniques to improve rigor, in particular: a systematic research design by using grounded theory methods, memoing, member checking, reflexivity, data generation, and presentation with thick descriptions and analysis reflecting creativity and sensitivity. In grounded theory, data collection and analysis occur simultaneously, not sequentially. Thus, although I engaged in reflexive journaling, I did not complete journaling and then begin with data generation. I journaled throughout the entire study whilst also generating data. This section will describe some of the techniques employed to increase rigor

Reflexivity

Reflexivity is an important aspect of rigorous qualitative research, and although it is often not described in the methodology sections of studies, the researcher cannot be an effective instrument without reflexivity. It refers to the process of reflecting critically on the self as both researcher and respondent, and recognizing that the research is situationally created (Guba & Lincoln, 2005). Without reflexivity, the researcher is taking a participant's story and retelling it from his or her own perspective, maintaining authority over the participant (Charmaz, 2005; Fine, 1994). Researchers should self-consciously work the hyphen between self and other to guard against speaking *of* and *for* the participant (Fine). Keeping a reflexive journal, memoing, writing extensive field notes, and working with a team is an important aspect of this. Grounded theory was particularly helpful to me in that the simultaneous data collection and analysis allowed for emerging concepts to be developed early in data collection and further interview questions were grounded in the analysis. I was also able to assess right away whether questions based on sensitizing concepts such as literature review and experiential knowledge, had any merit in the study. Being able to refine, re-define, and modify emerging theoretical concepts from analysis is the driving force of theoretical sampling

(Strauss & Corbin, 1998). Keeping a reflexive journal is one aspect of reflexivity. The writings in this journal should help the researcher examine his/her position in terms of class, gender, race and ethnicity, politics, location, power, motives and how those affect one's research. I wrote extensive field notes for each interview, as well as visits to GMCH and CFK. My journal writing presented a forum where I could express my own experiences as they related to the research both as a mother and a nurse. This enabled me to see my experiences and reactions to the data, so that I could have a better lens through which to judge my own biases. Two excerpts are included below, one as a single mother of a four-year old reacting to the data, and the other as an experienced pediatric oncology nurse:

> Excerpt 1: In interviewing families, I have to be aware of my own issues around parenting and loss and how the loss of my own family unit affects my understanding of what keeps families together through adversity, and the day to day grind of a chronically ill child (or children), or the tremendous grief around the dying child.
>
> In some respects, calorie counting since [my daughter]'s birth, has been an all consuming affair, I sometimes find that my moods are linked to her eating. If she eats a good breakfast, I'm usually in a good mood too. I have found what works, and this has helped in ensuring her caloric intake. I do worry that when someone else cares for her, she will not eat enough, not gain enough calories for the day. I think about the added stress this brings to my life, and think about the worry that parents have who give their kids thirty meds a day, or feeds, or suction hourly, and how difficult it is to leave their care to someone else.

Excerpt 2: As families describe their difficulty in being discharged, I think about how rushed the process is in the hospital - we're just trying to get them out the door, we've got another admission waiting, the supervisor is calling to see if the patient has been discharged yet. I always had anxiety discharging on a Friday, would the home supplies be there? How would we know? Parents wouldn't know until they got home, and what if they weren't there, sometimes we'd give them whatever stash of supplies was left in the room. I actually saw parents return to the hospital after a long drive home, because the medication was not delivered by home health, and the satellite pharmacy was closed on the weekends. Or parents who were kept in the hospital through the weekend when they could be discharged on Friday because there are not available services on the weekend. As I hear these same stories from families, I want to nod, saying, yes, I get it, and at the same time, I want to explain why we nurses in the hospital can't do more, how busy we are. And yet, as a researcher, I must explore their experience, I cannot assume that I know what they mean because it resonates with me, I need to have them explain more by what they mean when they say nurses are busy or rushed, or that they were unprepared to go home. This weekend issue seemed to come up for families who went home not for families who went to GM, since GM is actually a facility of care, it's not converting the home into a place where medical care is being delivered. I realize that these shortcomings are exactly why I wanted to do this research study, I have felt like we abandon families with children at end-of-life, so my disappointment in finding that the parents are

> indeed experiencing what I have observed as negative is an affirmation of why I wanted to explore their experiences further, and bring it to light in a study.

Memos should also be written in a reflexive manner. Glaser's (1978) writings show a positivistic bias in using language such as *discovering* concepts out of data, or finding it *buried* within, which places the researcher over the participant. All data is *constructed* through the interaction of researcher and participant (Charmaz, 2000; Clarke, 2005); therefore, concepts are not simply *uncovered* from the data. The data is not an objective account, it is mutually *created* and memo writing must include that perspective. To ignore the joint action and power positionality in the interview or participant observation is to shun the very premises upon which symbolic interactionism is founded. I found that reflexive journaling helped me greatly in my data collection and analysis of my pilot study, and I developed a grid (Appendix P) to summarize my awareness of how I was situated in my research, and my biases.

Member Checking

Another important aspect of improving the rigor of data analysis is through member checking (Whittemore et al., 2001). GT methods of simultaneous data collection and analysis enable the researcher to check with participants for both accuracy and understanding of data. The researcher's interpretation of the data can be checked during the interview, in subsequent interviews with other participants or the same participant. Through member checking the researcher develops an analysis that interprets the data in a manner that reflects the participants' experience (van Manen, 1990). In my study, member checking included not only the participants but also nurses who worked with children in a variety of settings. Member checking with participants was included during the interview process in reflecting back the data to clarify emerging concepts, as well in interviews with other participants. Group analysis was a regular part of this study, which included nurses with experience in end-of-life, oncology, and perinatal care, as well as professors with expertise in grounded theory methodology, family health, and end-of-life care. Upon completion of analysis, I conferred with both nurses in clinical practice and participants to determine whether the findings resonated with their experiences. I found that nurses were completing my thoughts on the findings before I could finish describing them, and that families seemed pleased that their metaphors and descriptions had been captured in a manner that reflected their experiences. During interviews, when I sought to clarify my understanding, I was generally met with enthusiastic agreement, followed by more in-depth explanations from the families. As such, my analysis remained grounded in the data.

Data Generation

Through reflexive journaling I realized that since data is constructed, I needed to be aware of how I was generating data. As a nurse, I am used to mothers being the caretakers of their children as well as usually the ones spending the most time in the hospital and communicating to staff. Being a mother myself, I had to make sure that as an interviewer I would draw out and listen to both parental perspectives, and not favor the mother. Therefore, I chose a "multi-directed partiality" interview approach for conjoint interviews in my pilot study, so that I would make a conscious effort to elicit the fathers' experiences as richly as possible.

Another issue that became important was my role as clinician and researcher. The families knew that I was nurse and had worked at Children's Hospital Oakland for many years. They were told this information before I was even given their contact information. This was helpful in establishing trust with the family, yet it also meant that they sometimes asked me clinical questions, wanting to know my opinions. Clinicians who are conducting research in their own clinical area can threaten the validity of data when clinician and researcher roles blend (Horowitz, Ladden, & Moriarty, 2002). Nurse researchers may struggle between their stance as researcher and wanting to intervene as a clinician in the face of difficulties. In order to prevent the participants' data from being affected, it is recommended that the clinical advice be given during debriefing after the interview has concluded (Horowitz et al.) Therefore, I suppressed instinctual answers to clinical questions until the conclusion of the interview, during the debriefing period. All participants were debriefed after the interview by beginning with a statement such as, "We've talked about a lot of difficult things today. How are you feeling right now?" I found the debriefing to be extremely important as it gave families a forum to relax and ask questions, many of which were clinically oriented. In fact, one parent who had a Hoyer lift for her child, had stated that no one was able to show her how to operate it, so I demonstrated how to use it. All parents were incredibly thankful that I had interviewed them, and several wanted transcripts of their interviews so that they could remember their thoughts.

Human Subjects

Risk and Benefits to Participants

Potential risks

Although this research did not involve any procedures that were hazardous, due to the sensitive nature of the topic, participants sometimes experienced emotional distress while recounting their experiences. The interview process brought up traumatic events for the family, such as remembering when the child was first diagnosed, or a difficult hospital admission, and for some, the child's death. For children, the risk of being exposed to the concept of death sooner than for typical children or than their parents wished for was a risk as well. There was also the risk of loss of privacy, although such loss was not expected to have any significant consequences; nonetheless, participants may not have wanted their views known by other family members or health care providers. In fact, the only concern parents had about being identified had to do with naming specific physicians, nurses and hospitals. Parents often needed multiple assurances during the interview that the names would be altered and that in no way would any staff be able to identify the participant. Although these families were no longer receiving services from the hospital, they were still worried about the possibility of linking hospital staff to negative experiences.

Protection Against Risks

Confidentiality/privacy. Any information obtained from the interviews was maintained as confidential and was not shared with any other family members; however, families by nature of consent were aware of which members had participated in the study. Extreme care was exercised when interviewing participants. Following appropriate interview guidelines was crucial in minimizing the risks and discomforts to participants. Participants were interviewed at their convenience. Trust and respect were developed with participants before beginning to audiotape. If any question made the participants uncomfortable, they need not answer, and they knew the interview would be discontinued if they wished. If a participant appeared distressed, or indicated that he/she was very distressed as a result of the interviewing process, support services referrals were offered. Interview questions for children were developmentally sensitive in order to minimize unnecessary exposure to concepts (such as death) that may be inappropriate. It was not anticipated that these questions would elicit any statements regarding abuse or neglect, as that was not the focus of this study; no such concerns arose from any participants. While complete confidentiality might not always be possible, great care was taken to protect the privacy of participants. All proper nouns and identifying words were changed to protect the privacy of participants. Additionally, any identifiers that would enable a staff member to recognize the family, such as the child's gender, age, diagnosis, were altered to protect the privacy of families; this was one of the many modifications that the CHR required for approval of my study. To date there has been no breach of confidentiality or privacy.

Data security. To minimize potential risk to confidentiality, information obtained from all participants was and is considered privileged communication of the highest order of confidentiality. Every effort has been made to ensure confidentiality of all sources of data. To assure confidentiality, no names or other identifying information have appeared on any data collection forms or interview transcripts. Instead, participant code numbers and pseudonyms were used throughout the project. All data has been and will continue to be kept in a locked filing cabinet. The master list of the participants' names and code numbers has been and will continue to be kept in a locked file separate from the actual data. Coded data, whether stored as computer records or hard copy (transcripts), has been and will continue to be protected against unauthorized observation through password protection or locked storage. Signed consent forms have been and will continue to be kept in locked storage. Since using rich quotes is part of qualitative research, great care was exercised in selecting quotes that highlight a theme rather than specific family circumstances that could possibly lead to recognition of participants. All tapes or computerized audio files will be destroyed upon completion of the dissertation.

Benefits

A potential direct benefit to the participants was the opportunity provided for them to tell their story. Expressing thoughts and feelings can often empower the family and validate their feelings (Gowan, 2003). Additionally, bereaved parents often want to give back something and participate in a meaningful way (Klass, 2001). Participants said that they wanted have their story heard and hoped that it would help another family. Families described the interview as “a gift” and “a privilege” and stated that although it was always emotional to talk about their child, it was very healing. One participant said that the time she allotted to the interview was her time to grieve and talk, and that she rarely had such opportunities in her life. All of them wanted to connect with other parents in the study, and hoped that their story would help another family and improve the care for future families. The benefit to society is that the knowledge gained from this study can improve the family-centered care we strive to provide dying children and their families, particularly as pediatric palliative and hospice care programs begin to proliferate in this country.

Conclusion

Although many approaches to qualitative inquiry could be used for studying children at EOL, grounded theory was the most appropriate match for the purpose of this study. The careful design of this rigorous study enabled me to gain access to what is considered to be a vulnerable population, thereby being able to elucidate the experiences of families that have often been excluded from research. The methods of data collection and analysis allowed for a heterogeneous sample; the findings provide valuable insight into the process of how families manage the transitions between locations of care. Ultimately, it is my hope that such knowledge will improve the care that we, as health care providers, deliver. The development of a substantive theory is beyond the scope of this dissertation research; however, through theorizing about families' process of transition, I intend to contribute to the ongoing generation of theory in future studies.

CHAPTER FOUR: FINDINGS

Sailing the River Waters

The findings are divided into two chapters that describe the family's journey. This first chapter describes the family's experience in the hospital setting from the moment of diagnosis; the second chapter follows the family's experience at other locations of care (home/hospice). Of the thirteen families in the study (Appendix B, Table 1), ten used George Mark Children's House (GMCH), and four used a pediatric in-home hospice service (which also provided palliative care). The locations of care varied for families depending on what services were needed and available (Appendix C, Table 2). Most families were discharged back to their home as the child's condition was deemed to be stable, such that continued hospitalization was not justifiable (n=11). Two families had the choice to remain in the hospital either to pursue aggressive treatments or palliative care, or to choose hospice services either at home or at GMCH; one family chose to go home, the other chose to go directly to GMCH. Of the twelve families that went home after discharge, three returned to the hospital because they were unable to manage being at home without support, at which point they chose GMCH. Four families chose to use in-home hospice services, and five chose to use GMCH for respite care. Three families were able to secure occasional additional home health nursing support.

Although the ill child in each of the 13 families in this study differed in age, diagnosis, and trajectory of illness (Appendix B, table 1), all families journeyed along a path that was remarkably similar, taking each family to various locations of care based on the child's health. With the exception of three families, who were diagnosed during pregnancy, all children were diagnosed in the hospital after numerous visits to their primary pediatrician. All thirteen families spent time in the hospital, and experienced either multiple hospitalizations or a prolonged initial hospitalization. Their hospital experiences shaped their understanding of health care, their child's condition and the subsequent choice to use hospice.

It became clear through data analysis that the families' experiences were shaped by each previous experience, such that understanding the chronology of events was crucial in understanding how families managed the transitions among locations of care. Families described many of their experiences metaphorically, using water analogies to explain how they had to "go against the stream" to meet their child's needs. Families shared similar journeys, which was marked by turning points. The journey that families took resembled that of a river that emptied into an ocean (Appendix Q). Before their children's diagnosis, the families were meandering along on the river of life, when a sudden subterranean volcanic eruption collapsed the solid rock shelf, resulting in a torrential waterfall that sent families plunging into the forceful whirlpool below, capsizing the boat and all the passengers.

As family members gasped for air, and struggled to keep their heads above water, they were assisted by other families and staff who provided them with buoyancy via lifesavers to stay afloat in the plunge pool. However, with prolonged immersion, the lifesavers began to deflate, and families realized that staff was unable to keep them afloat. Families themselves had to actively engage in swimming against the current that was drawing them back to the whirlpool. As they swam, they began to perfect their technique, each stroke taking them farther from the whirlpool toward the continued river course where they eventually reached shallower ground, and found that they could stand on their two feet and walk in the river. However, families had to carefully navigate the rocky turbulent terrain of rapids, placing each foot down cautiously as they walked.

Upon reaching the mouth of the river, families had to choose a vessel upon which to sail the ocean before them. They no longer had the option of returning to the prior river of life; their life had not only altered its *course* but the *shape*. Their life was forever changed and now they faced a vast ocean, upon which they would spend the rest of the child's remaining life and the family's lifelong journey of grief.

The findings in this chapter follow the families' journey on the river. In this first chapter, the dimensions of the journey are described as sailing along, plunging into the whirlpool, staying afloat, swimming against the current, walking the rapids, standing at the delta, and choosing a vessel. The word *family* includes all members of the family as well as the ill child; *parent* includes the ill child's caregivers and is inclusive of grandparents who were in a primary caregiving role. When differentiation of family members is needed, the terms 'sibling,' 'child,' or 'grandparent,' 'mother,' or 'father' are used.

Sailing Along

Before their child became ill, each family was sailing smoothly on the river of life and of parenting. Families were meandering along the river of life in their sailboats of varying sizes, managing the daily tasks of parenting and daily living, sailing and navigating the river, until the catastrophic change in course.

> Jonathon (father, Family 2): And so I was counting on my wife being home, my daughter being home, and my son being home. And myself. And uh, it seems like

> just when it started to get back to the normal living, something happened with my daughter.

Jonathon felt his family was complete, and he was looking forward to beginning this new part of their life journey happily joined with his wife and children in their sailboat after the birth of their daughter. The family was anticipating sailing on the slow-moving lazy loops of the river. Jonathon and his wife had little indication during the pregnancy that the smooth course was going to change. Similarly, other families had not had any warning:

> Trish (grandmother, Family 8): He had just gotten over an ear infection, which had been the first time that he had been sick since he'd been born…he was almost eight months old.
>
> Sabrina (mother, Family 13): Everyone gets to be so excited about pregnancy and everyone, "Oh my God! That's wonderful!"
>
> Carol (mother, Family 9): I had a normal healthy pregnancy and she was born um, you know, at like 40 weeks.
>
> Miriam (mother, Family 7): I was able to carry him to 34 weeks, and he was my healthiest… he did great.
>
> Mina (mother, Family 3): So *every* time up until- when they did the ultrasound they couldn't see anything, but up until like our last week *finally* they uh, managed to have a doctor come in and check. And he was just breech.

By every indication, the pregnancies and children were doing well until the day of diagnosis. The few symptoms that families noticed were discounted by medical professionals and ignored, such that when the diagnosis was eventually made, critical interventions were immediately necessary. The families perceived this as a sudden change; they had no indication that something life-threatening loomed ahead for their child. For the children who were not diagnosed at birth or in utero, things seemed to be sailing along smoothly. Parents observed few symptoms that could be distinguished from normal fussiness, or colic. Each time parents noted initial signs of something unusual, they were reassured that things were fine, and they continued to sail along the river, completely unaware of what lay ahead.

> Jim (father, Family 2): But the nurse practitioner was so adamant about [the pregnancy being normal]…You know? I mean, she had me convinced. I stopped going to the appointments and just telling Mina, "Now, everything's fine. You're crazy." [Giggles] I mean, 'cause- I mean, that's more or less what she was being told and it's like, "You know, you're just worrying too much."

> Carol (mother, Family 9): They couldn't find anything… we seemed to be in the doctor's like every other week or something. I don't know, it just seemed like, you know, either um- just different things were happening… Well, this doctor just did not do any blood tests, just kept passing us off… a doctor that wasn't doing anything for us. I mean, completely ignoring it, me….We were dealing with a pediatrician that was not doing one thing for us.

> Trish (grandmother, Family 8): They basically said he had some um, called it a …viral syndrome, whatever that is. They didn't wanna do a blood test because

> they thought it would do- just hurt him, it wouldn't do any good. So [we] took him home.
>
> Lisa (mother, Family 13): We started seeing little weird signs.

Each observation of something unusual represented an unfamiliar turn in the river's direction so parents checked their "compass" by taking their child to a health care provider who discounted the parents' concern and attributed the seemingly minor symptom to a normal occurrence for the child or to a virus for which only time and rest was prescribed. As a result, parents began to lose their sense of judgment, growing mistrustful of their senses and ability to sail the river waters. Each time they attempted to verify their sense of direction with the compass, the arrow pointed to a different direction. Their self-reliance eroded as they never considered the possibility of incorrect calibration of the compass. However, despite the failure of the compass and the erosion of the family's sense of self-reliance, the river's current ultimately determined the sailboat's course, pulling it along, until the signs of the life-threatening illness became impossible to ignore.

Plunging into the Whirlpool

The sudden urgency with which the child and family were thrust into the hospital setting resembled a subterranean volcanic eruption that severed the rock shelf upon which the river was meandering. The resulting torrential waterfall capsized the family's sail boat and hurled each family member into the depths of the whirlpool below. Families were 'drowning' at the time of their first entry into the hospital: they had no information, and sensed the urgency of the situation at how rapidly things were progressing. They were overwhelmed, anxious, and riddled with fear of the unknown:

> Lisa (mother, Family 13): And then she (the doctor) knew. I think she knew immediately and sent us for uh, the MRI. And we went and just kind of - our lives changed.
>
> Carol (mother, Family 9): They admitted her that same day. I mean, just so much was happening in one day to us. It was like crazy. It's like, you get the test results. Then you have the oncologist at [first hospital] saying, "No, I don't think this is it." Then you go over to [second hospital] and they're just like, "Oh my God! No, this is all…" So here it is like seven at night, we're not even in a room. We've been waiting all day for these doctors.
>
> Miriam (mother, Family 7): I was 19. I was completely terrified.- I didn't know what a preemie was. And I was scared and intimidated, and didn't know what was going on, and he had apnea, bradycardia, so every time he'd go to sleep, he'd stop breathing, and it was terrifying, so I probably was that emotional parent who didn't know what was going on.

After their sudden descent, families spiraled downward into the unanticipated forceful whirlpool below. Families plunged deeper into the whirlpool and struggled to rise to the top. Whenever they neared the surface, they were met with further waiting and not knowing, and found themselves submerged again.   Parents were panicked, bewildered, and feared for their child's life. They felt silenced by their lack of understanding and had little choice but to surrender to the medical experts and the lifesavers they threw out to them. To illustrate the chaotic entry into the hospital, a lengthy excerpt from Jonathon's experience follows:

Jonathon (father, Family 2): I mean, the room was so [packed]- I couldn’t really get within five feet of her, because the doctors were always doing something. And it was this one doctor that pulled me aside and told me - she said they were trying to find a room for Nicole as fast as they could, an isolated room. Because of the [virus] that she so-called had.

But about an hour after she told me that, she told me that they had no rooms available. So they were going to fly us over to [hospital 1] with a helicopter. And those plans got cancelled because of the rain. It was really raining really bad that day. And uh, they said that the flight probably wouldn’t be a good idea. That we were probably going to go in an ambulance. And then they called the ambulance about an hour after that…And uh, they actually said it was two reasons that they weren’t going to be able to fly us. One of the reasons was, of course, the weather. The other reason was if she was to fly in the helicopter, they would have to fly her to a certain point and then an ambulance would still have to come get her, and bring her to [hospital 2]… they don’t have a landing pad…. I mean, why would you want to fly my child to a whole other hospital if she just has a [virus]?

I mean - because most of the time, I think - I don't know about other people - but, when I hear someone flying someone somewhere because of a health issue, it’s most of the time pretty bad. It could be life-threatening. So being that they said we can go [by] ambulance, that kind of eased my pain.

And so the ambulance got there and uh, it was like another hour wait before we even got into the ambulance because they had to take her off of everything. Charge all of their things up. Hook her up to all of the ambulance's equipment. Which was probably not the best equipment, because when we were in the ambulance, the equipment they had started to have malfunctions and they couldn't get her saturation level to the point that they wanted it. To the point that they felt that it would be stable.

So uh, the ambulance ride was - that whole day was crazy. The ambulance ride was crazy. It was almost like a real scary - it was like one of the most scariest rides I've ever taken. I was sitting in the back of the ambulance beside the nurse. The two doctors were across from us, and I was sitting next to the nurse. And during our ambulance ride, we had uh, we got caught up in some traffic because [the bridge was closed]. And uh, while we were in this traffic, these doctors are inside having some problems with keeping my daughter's saturation levels at a stable - as stable as they could get it. Then, you know, finally someone on a motorcycle seen the ambulance's lights blinking, and uh, he came back and he weeded us through the traffic, and so we finally went on the bridge. And that day was so - I remember being frustrated for that reason- I have a child here that's fighting for her life.

And it seemed like it took forever to get the hospital. I mean, it - the ride was already stressful and long, and the doctors start to get stressed out. They're uh, speaking with some doctors at the hospital over like walkie-talkies or whatever.

And they're trying to stress the fact that they need to have everything ready for them to get there, because I mean, they're already having like a difficult time, and it was taking so long. And I think that it felt like it was taking a long time for them to get there, too. Because they’re having so many problems with stabilizing her. And when you see doctors panicking, you don’t know anything about medicine or medical, so you start to panic. Because you think these guys went to school forever, and if they’re breaking down, what - what am I going to do? You know, if they can’t do anything, I’m pretty hopeless.

I felt like this might - I actually felt like she wasn’t going to make it. I mean, I just stared at her little body sitting there so helpless, and I kept remembering the night before I was just feeding my daughter. You know, but reality struck and that didn’t matter anymore.

Because uh, she was fighting for - she and the doctors were fighting for her life. I mean, it was - and I didn’t say a word the whole time. I remember myself being in a daze after getting across the bridge. My palms were sweaty. And I was twiddling my thumbs. My breathing had all - started getting short, too. I started getting short of breath. I thought I was getting claustrophobic from being in this ambulance. It was like the box kind. And we finally got to [hospital 2], it felt like I had ran 20 miles. So they take her out - they leave me. They take her out on the stretcher. They start running towards the door, and I see like 4-5 doctors waiting on the - before we even turned into the parking area, the doctors were already at the door and they were pulling at the

> ambulance, and so *(sigh)* we finally got to the point where they wouldn't keep me in - and they told me that I couldn't go in the room with her. It'd be about an hour before I was able to see her.

The parents' control of their child's care and the situation was removed from them by providers. As result, parents were submerged in a whirlpool of uncertainty without any sense of direction. This set the tone for the hospitalization, with parents awaiting answers and directions from staff. Parents felt hopeless and abandoned, left to wait, with no support, in an unfamiliar environment, possibly many miles (and bridges) away from home. Cell phone reception was poor or lacking in the hospital and parents had difficulty getting in touch with family members. One mother, who was herself just recovering in the hospital from surgery left against medical advice when she learned from her husband about their daughter's hospitalization. Families were struck by a sense of panic and urgency; they interpreted the cascade of events that rapidly unfolded within the course of hours as an ominous sign. Although Jonathon had no medical knowledge, he understood that flying a child to another hospital was due to a greater medical threat than a virus, but he did not receive answers to his questions and the providers' actions made it clear that the situation was life-threatening.

Additionally, the physical symptoms such as shortness of breath, racing heart rate, sweaty palms, feeling dazed, and being unable to speak, were similar to symptoms of shock. Parents were drowning; whenever they attempted to take a gasp of air, they were met with a stronger downpour from the waterfall:

> Carol (mother, Family 9): It was just a series of just bad news upon bad news, upon bad news, and we never got any good news.

Instead of reassurance, parents were questioned about why the child's condition was not addressed sooner. The parents were already overwhelmed, and the flood of questions as to why their child had deteriorated to the point of admission only added to their anxiety and distrust of their previous providers. Parents had always believed the compass was reliable, and now they were being questioned as to why they relied upon their compass, and why they failed to notice the early rumblings of the subterranean volcanic eruption.

> Jim (father, Family 3): And a lot of the nurses…all of them…would ask, "Do you guys?" You know, they would ask, "You guys didn't know about this ahead of time?"
>
> Mina (mother, Family 3): And the EKG guy did a test and he's like looking at me going, "They sent you over here? Why aren't you in the hospital?"
>
> Charlie (father, Family 9): These doctors were like, "Um, who was your pediatrician?

The whirlpool continued to spiral them downward as families received mixed messages from providers at the hospital, each provider contradicting the other. Parents were left to sort through the conflicting information on their own.

> Carol (mother, Family 9): That blood test told everything. It was like, you know, she has had cancer. We did the ultrasound …It was like, "There's a tumor and it's huge and it's cancer. I'm getting you over to- in [city] to um…um, oncologist, um [name] and, you know, we're gonna do this." So we go there-… And he goes, "This is not cancer."… He's like, "I don't think this is cancer at all. I really don't. You know. Let me just take her blood pressure so I can like take some notes and

> then we'll get you over to [hospital]." He took her blood pressure and he's like, "This machine is broken." It was like two-hundred and something. He's like, "This is not right. There's something wrong. We'll do the other [arm]." And--she had the highest blood pressure.

Carol's child did have cancer, but it took visits to two hospitals and several physicians to confirm the diagnosis despite the initial blood test and ultrasound results. With each family, different teams of specialists gave differing opinions, leaving parents with essentially no answers and no direction. Their struggle to rise out of the whirlpool and keep their head above water was greatly hindered by the lack of support during the initial admission to the hospital and by the lack of guidance as to what families could expect.

Staying Afloat

Parents' plunge and subsequent immersion in the whirlpool was marked by extended periods of waiting for their child's test results of their child's illness. Ironically, during this time of drowning and feeling isolated in hospital waiting rooms and physically removed from their child, parents found themselves in a community of other parents also stricken with anxiety. Through their connections to one another, parents provided some buoyancy so that parents could determine the direction to go for air, rise above the abyss, finally lifting their heads above water.

> Jonathon (father, Family 2): I heard some sobbing, and I looked across the [waiting] room and it was this guy. He was crying…he told me that his daughter had been there for about uh, 28 days. And uh, he told me what was wrong with

> her, and what he had been going through… I had no one there and uh, I really needed someone there.

As they began to float, they said little, but were receptive to any help that came their way. They reacted to each new event as it unfolded, riding each rapid as it encroached upon them, unable to see far enough ahead to anticipate the course. In their quest to find answers, parents' lives were suspended as they waited in a floating limbo. Without answers to their questions, families in limbo could not begin to have expectations. They were shocked by their child's condition and the possible threat to their child's life. Technological interventions came to the foreground as parents were pushed into the background, such as when a child required surgery and parents were left in waiting rooms; the process of *medicalizing the child* began. Medicalizing the child changed the family structure: the child became a patient, parents became visitors and the child's fate was in the hands of the medical team. The family was *torn apart* physically because members were separated geographically, and when reunited, appearances had changed. The word *family* was no longer inclusive of the *child*, instead it became the patient *and* the family. The parents in Family 2 could barely recognize their child after her multiple procedures:

> Jonathon (father, Family 2): And it's like – it's this big bed and this little – little body with about a million tubes. I mean, it's like so many – it's so many tubes going to her body, it was almost like they were using her as a pin cushion... and I – I got kind of choked up and my breathing started getting short again.

> Sandra (mother, Family 2): …and I go in there, and I see my baby, and she's hooked up to all types of wires everywhere, big, oversized syringes at the end of her bed.

Families' expectations for their meandering river life were shattered, and they had no measure against which they could rebuild new expectations. Additionally, they had grown fearful of trusting another compass. Focusing on the child's immediate medical needs hindered their ability to anticipate their future course, even in the hospital. None of the families (except for the three families whose child was diagnosed in utero) expected their child to be admitted to the hospital until suddenly, it was evening and they realized they were there to stay.

Maintaining Buoyancy

As families floated, clutching onto their lifesaver, they caught their breath and finally got some answers from providers about their child's condition, and they began to trust the expert care provided to their child. This trust enabled them to maintain their buoyancy, as they stayed afloat in the plungepool:

> Carol (mother, Family 9): These really knowledgeable people that were like gonna give us some answers.

With their questions answered, families began to hope that their child's health would improve. They learned to question providers in order to build their hope. Sandra described how she fished for hope:

> Sandra (mother, Family 2): You're fishing for an optimistic response. "So is there any chance that – does she have any chance at all of recovering." You know? So

> at least they can say, "Well, everything is not definite." So we can still have that hope, and I found myself doing that to the doctors a lot.

With the first overnight stay, families realized the new uncertain situation called for change; they began to plan for which member would remain with the ill child and how life at home would be managed. In this study, mothers or grandmothers stayed with the ill child. The hospital admission was not about making a temporary adjustment for a few days, and then returning to a previous home life. This was a shift in the family structure, with hasty frantic initial makeshift planning that led eventually to deliberate organized planning that allowed families to simultaneously manage two residences. Each member needed to stay afloat: siblings who had been capsized from the boat needed to be accounted for and given lifesavers so that they could stay afloat too. Parents had to split up: one parent stayed with the ill child, the other stayed with the other children. No one could predict the course or when they would reunify as a family, so they all floated, awaiting direction from providers in the hospital.

Parents' focus broadened from the diagnosis itself to logistical issues; they learned there were policies, such as visitor policies, that governed whether they could remain with their child. Other logistical issues, such as dealing with work, arranging childcare for siblings, and parking, suddenly came to forefront as parents scrambled to adapt to staying in the hospital. Sadly, parents often found out retrospectively that they could have had more support initially from the hospital. A grandmother who had spent several months caring for her grandchild in the hospital while paying for daily parking, found out from another family that the hospital provided vouchers for parking. She had not been given this information by the social worker. Although she was able to use the vouchers for subsequent hospitalizations, she was frustrated they were not refunded the hundreds of dollars spent on parking. Another family with two siblings at home, and an ill child in a hospital located miles from their home could not even spend the first night with their ill child. Instead, they had to call a relative to stay with the child as they were completely unprepared for staying at the hospital:

> Carol (mother, Family 9): We're …like 30 [miles] or something from there, so we couldn't. … I think that first night - we did leave her there, because we didn't bring our stuff and ah, I felt horrible! That was the worst night.

Not knowing how long a child would remain in the hospital, made taking time off from work and planning for other children very challenging. The parents were not in control of decisions related to length of hospitalization; physicians made the determination. Parents were at the helm of managing their home life, and were therefore thrust into managing two worlds simultaneously, one in which they had little control, and the other in which they were relied upon to make all the decisions.

Initially, families were only familiar with the emergency room, surgical waiting areas, and the cafeteria. Parents quickly learned that they had to master the maze of corridors and elevators if they were going to navigate effectively during their prolonged stay. Parents needed to figure out overnight parking, sleeping arrangements, visiting hours; learn staff shift changes, names of staff caring for the child, the various roles that staff had; cell phone restrictions, how to dial from the rooms; patient rights; and how to inform other family members about their whereabouts. Through connecting with other families, parents were informally guided to navigate the unfamiliar river waters.

These families also provided emotional support to one another since such support was lacking from providers. Although all families received social worker services, such services were not initiated upon admission; thus, during the time of greatest uncertainty parents had to rely on themselves and other families.

Despite the great benefit provided by connecting with other families, opportunities for interaction were quite limited in the hospital, given the parents' desire to remain at the child's bedside, and the privacy policies that characterize hospitals. Parents met families mostly in the cafeteria, waiting rooms, bathrooms, and sometimes in their child's room if it was not a private room. Families also built relationships with the staff; however, these were most likely to occur on specialty units:

> Lisa (mother, Family 13): That connection you build, you know, with your nurses… - it's family. I mean, they became our family.
>
> Sabrina (mother, Family 12): All the NICU nurses…it was like a family to me. The NICU nurses helped us learn so much, you know.

Families stayed afloat buoyed primarily by other families and by some staff. However, as the child's condition deteriorated, the hospitalization lengthened and since the lifesavers sent out by the staff were only meant to support families for short periods of time, the lifesavers began to deflate.

Losing Buoyancy

With the deflation of the lifesavers, parents realized they needed to take a more active role by more fully participating in the care of their child. Slowly, they learned the direction of the shore, how the current was moving and they began to steer their own direction.

> Carol (mother, Family 9): We learned that at a hospital there's a learning curve there for people that haven't ever been in a hospital setting like us, that never really needed to realize what these teams of doctors do, which is great that there's specialists for everything. But there's no quarterback to- to like come and pull it all together and say-"Well, here's what this said."

Receiving fragmented information made parents realize they needed to learn medical jargon. They had to become more focused on the procedures, gain awareness of what the staff was doing to their child and understand the plan of care, so that they could coordinate the care.

> Miriam (mother, Family 7): It's amazing, you can feel so intimidated if you've got a bunch of people standing there going "da da da dada", and you're going, "What's that mean?"…You have no clue what's happening. No, if you learn the lingo, and you become, you know become an active part, they come in to do your rounds; I'm standing right there with them. I wanna hear. I wanna know. I wanna be informed.

As parents became more actively involved, they became even more observant and understood the skilled tasks and plan of care that were being provided to their child. Their prolonged hospitalization, and frequent subsequent hospitalizations, enabled them to develop expectations of care and a sense of mastery of meeting their child's needs. With this increased understanding and more astute observing, parents witnessed events that shook the foundation of trust they had begun to build. It was generally with the first breach of trust that the lifesaver deflated completely. The breaches of trust resulted in parents moving away from relying solely on providers' plan of care and instead, relying more on their own sense of intuition and knowledge:

> Earline (grandmother, Family 1): And um, I'll never forget these- that was the first time I seen how insensitive doctors can be. They work on these children so much, they just- they get numb. And they pulled out one of the drain tubes 'cause it wasn't draining or something like that. They felt that it was drained out, whatever. I'm standing right there in intensive care watching this little young jackass. And he told the nurse, "Give me the suture kit. I'm gonna pull this one out and close it up." 'Cause a hole about so big left in the skin (she makes a small circle with thumb and index finger). And uh, I'm standing there, I'm saying in my mind, "Okay, when is the needle gonna come for the numbing?" And I said, "Wait a minute. Wait a minute. Are you not gonna numb him? Are you not gonna put some jelly around that so he don't feel you sewing him up?" "Oh no, Grandma. No, Grandmother. Uh, most of these children they don't feel no way." And before I knew it, these words came out through my mouth, "You dumb son of a bitch! You, you better pack up right now and get the hell up out of here. And I wanna see your head boss supervisor." Because- then he said, "But wait a minute, wait a minute, wait a minute." Then he tried to explain, but during the process of explaining, he was sewing him up without anesthesia. And I stood right there and I just began to cry. And it's like, "Why?"

Although parents lost their trust through these encounters, they also realized they must ally themselves with staff in order to meet the medical needs of their child. Thus, parents learned to trust differentially; this was particularly evident in teaching hospitals where a hierarchical chain of command existed among physicians. In particular, residents were seen as unknowledgeable and curious about their child's situation. Charlie, father, Family 9, refers to residents as lunatics:

> And you know what? …come Friday at 5 o'clock till, Monday morning, you know, that was like the- the lunatics would run the asylum at that point [chuckles]. And you would have all these things of, you know- you know, you couldn't get anything done, you know, at that point. It was terrible.

Staff mistakes, misinformation, or withholding of information reinforced the parent's fears of leaving the child alone in the hospital:

> Trish (grandmother, Family 8): We found out they paid for meals. They paid for um, a bunch of other stuff that a lot of people hadn't even been told by the social workers at the hospital.

Mina could not rely on the staff to give her baby the correct breastmilk. Once eroded, trust was not regained; rather, families became more watchful and discerning, and fearful for their child's well being:

> Mina (mother, Family 3): They gave Toby some other woman's breast milk one time at the hospital and - it's not even like a sympathetic thing. It's like, "Well, this is what happened and we can give Toby a test, if you want to, for hepatitis." It was just kind of cold. Just kind of no emotion or feelings.

Sabrina was hospitalized during her pregnancy after her ultrasound, for continuous monitoring of her baby, and yet, the very reason for her admission was trivialized by one of the nurses:

> Sabrina (mother, Family 12): I also had a nurse one night who…came into my room. I buzzed her finally 'cause I couldn't find Jasmine's heart rate or heartbeat [on monitor]. And she came in and said, "Well, you know, everything's fine. I've been a nurse for 20 years and I've *never* had a baby die on my watch." And I was like, "Well, you know, 50 percent of these babies die and I want it on [monitor]- you know, the *whole* reason I'm here- I am only in here to watch these goddamn [monitors], so find [the heartbeat] for me." And she's like, "Have you taken your Ativan?" And I wasn't on regular anti-anxiety medication 'cause I was really trying to be present and just deal with what we'd been given. And- but I had a prescription for Ativan if I needed. Never taken it. "Have you taken your Ativan?" "No, I haven't taken it." "Well, you need to take your Ativan." I'm like, "I am only upset because I can't find her heart rate on the monitor." I'm like…you know. And her comment about, "You know, I've never lost a baby." Well, you know what? No time like the present, as far as I'm concerned, you know. What's to say it's not gonna happen now? So… - she *trivialized* the situation.

Prolonged hospital stays increased the likelihood that parents would observe errors. Only one breach of trust was needed to anchor parents at the child's bedside. Moreover, parents' deference to physicians declined as they gained confidence in determining what was in the best interest of the child.

> Charlie (father, Family 9): We-had also grown up in a time that, you know, the doctor's orders, you know. If the doctor says to do this, you just do it and that's

> what you do. And you know what? We've kind of come a way, we're now, you know, kind of beyond that.

Parents' trust in staff was intact for families in the Neonatal Intensive Care Unit (NICU). In fact, for children who had been in the critical care areas, parents did not necessarily spend the night at the hospital, choosing instead to spend long days at the bedside providing emotional comfort to the child, or nursing a baby. Once these children were moved to the wards, the parents' attitudes changed. The realization that nurses were assigned to more than one patient, or that they were not within earshot or eyesight of the child made parents anxious. For the children in this study who were either not developmentally able or whose health status made it impossible for them to use a call button for the nurse, this made families even more anxious. This anxiety and fear, coupled with the loss of buoyancy, moved families into action.

Swimming Against the Current

Without the lifesavers, families felt the current pulling them back to the whirlpool of uncertainty and lack of control. Parents perceived that health care providers had a particular agenda, whether it was aggressive curative measures, such as experimental chemotherapy, or a reluctance to perform futile surgery. Parents interpreted health care providers' goals as often incongruent with their own wishes:

> Lisa (mother, Family 13): Dr. Smith was there…to save his heartbeat …I wanted him to have a *life*.

> Darla (mother, Family 11): They were very negative about our [decision]…you know, I felt it a lot more than Dan did. But they were pretty negative: "You know,

> this baby has a lot of abnormalities, you know. It could be hard on your marriage. You know, it could.” [They said] all these kinds of things. Kind of…they never, well, for a while, they didn’t suggest an abortion, but, you know, you can kind of read between the lines and think…figure out [that] that’s what they were suggesting.

When Darla decided to continue with her pregnancy she was not given any encouragement by her health care providers, and, at each visit, she was told that she could still exercise her option to terminate.

Rather than relying on physicians’ opinions, all parents began to actively seek the opinions of others through checking Web sites or looking to their child for signs of the will to continue treatment. The parents began to place their *child* first, not the *diagnosis*, and, as they personalized their child in this way, their role as parents came into the foreground. Most parents pointed to some incident that brought them back to focusing on their child’s personality, whereby in the midst of all the tubes and wires, their child was at the center once more. Recognizing their child through the cloak of illness gave parents the strength to keep fighting their battle against the illness.

> Sandra (mother, Family 2): I remember her dad going to touch her hand, and she kind of moved her fingers while she was lying there. This is right after my husband and I was [*sic*] deciding maybe we should just let her go ‘cause she had suffered so much. And that’s when we just said no, we can’t, because she’s still moving. She’s still trying to wake up.
>
> Miriam (mother, family 7): We’ll fight as long as he wants to.

Families began to take control of the situation, shedding their passive role.

> Charlie (father, Family 9): You are the one that has to look out for what's best for your child. I mean, I like to think there's no…you know, the doctors all are in it for the greater good and to help people. But it's still up to the parents and far more heart than it is science, you know, [in the] medical profession, and you're dealing with people that are ill.

Families increased their swimming speed to fight against the current to reach waters where they could maintain greater control. They became skilled swimmers, perfecting their technique with each stroke, which took them farther from the whirlpool.

> Lisa (mother, Family 13): I felt like I took…Nursing 101 in about half an hour. You know? And it's amazing the things that you do and learn and…are able to do. Giving your child shots. I mean, who dreams they'd ever have to do that.

> Miriam (mother, Family 7): You've [got to] hold it together. [If] you need to cry, you go out to your car…you clean yourself up, and you get back inside, ready to take care of it. Take care of your business, talk to your doctors, become a firm…um, informed of what's happening, learn the lingo. Know what the tests are that they're doing and become an advocate for your child.
>
> Families also gained the confidence to speak up and tell staff what the plan of care was supposed to be.

> Mina (mother, Family 3): I'd have to stay [in his room] just to make sure that they were doing like their job. I'd have to constantly be on top: "No, you're not supposed to be doing that. You're supposed to be doing this." "Well, it says right

> here." I'd go, "Well, you need to go and check because this is what they just told me." Like constantly having to tell…I'd have to be there to constantly like, "Well, you can't give him that right now. We're not giving him that anymore."

Trust had to be earned by the health care providers, and as their trust grew, families began to develop favorite staff members, such as nurses and doctors. Hospital stays became about survival, with parents taking breaks only for bathroom visits and to purchase food.

> Earline (grandmother, Family 1): I go to the nurses' station, and I say, "I'm going down to get me some lunch. I want you"…I leave the door open. "I want you to know he's in there by himself." I'm down there scarfing [down] my food *(chuckles)* trying to hurry up and get back up to the room. You know, because I know how they are. It's not a caring situation there.

Parents remained at the bedside continuously for two reasons: fear that the child would die in their absence or that someone would harm their child. A very ill child could not use a call button or yell for help, and the parents knew this so they wanted to be constantly present with the child. This fear was absent among the parents whose children were in the NICU and ICU where parents felt that the expert nurses were constantly present, kept a watchful eye on their child, and were viewed as being experts in the medical care they provided.

> Dan (father, Family 11): A lot of the [NICU] nurses, nurses, they were exceptional. And they were angels…

> Miriam (mother, family 7): In ICU, I can very easily leave him, go sit in the cafeteria for a couple of hours, chat with friends or whatever, and then come back, so it just depends on where he's at.

Miriam described the consequences of not swimming against the current and getting drawn back into the whirlpool:

> Miriam (mother, Family 7): If you are a parent that wants to be oblivious to it, and, um, I don't wanna say irresponsible, but kind of, in denial [about] what you're doing and what your child's doing, then your child's not going to reach their full potential, and your family will probably not reach its full potential. Your marriage will probably fall apart because you…everybody is revolved around somebody else's decisions.

Parents saw active involvement as the key to maintaining the family and doing what was in the best interest of the child. Decisions about their child's welfare could not be left to the staff; otherwise, the result would be re-submersion in the whirlpool, from which there would be no return.

Walking the Rapids

As parents swam farther away from the whirlpool, they reached shallower waters, where they could now stand on their feet and walk along the river. However, the terrain remained rocky, and the flow of the shallow rapids was still turbulent, although manageable. Families had 'learned the lingo' and were making decisions. They were now part of the team.

> Miriam (mother, Family 7): You know, if they're considering changing a med, "Why? What [are] the pros and cons of changing this med? Discuss it with me"

> Because, ultimately, when I take him home, I'm on my own. You know, I've gotta be able to take care of him and do all the things that I think are right for him, and, you know, the doctors aren't. They aren't taking him home… You know, meds, same thing, you've gotta look at the pros and cons. "Well, what are the side effects with this one? Well, what's another med?" "Well, it's newer and it's more expensive." "Well, if it'll do the same thing and not have the same side effects, let's go with that one." But if *I* wasn't informed, *I* didn't research it, and I didn't look at it, I wouldn't have known, so you do have to become an active member of your medical team, and you do. You have to learn it.

Families also learned that alienating the staff would lead to alienation of the child and perhaps even less care. Therefore, they went to great lengths to be liked by staff and to be perceived as part of the team. Families had to learn how to get their needs met while at the same time respecting the hospital boundaries. They had to anticipate the flow of the water and the depths of the rapids and look for rocks and other obstacles as they deliberately waded through the rapids. They learned to recognize who could help them stand upright and lend a hand.

Families proudly described how well they knew the staff in the hospital and how this was the key to being able to get their needs met. They made no hierarchical distinction among staff; they knew the security guards, the housekeepers, the nurse managers, and the attendings by name. Having the floor mopped or being able to secure a private room was just as important as being able to engage with the physicians regarding the medical plan. Families were able to sustain residing in the hospital because of alliances with all staff members. Unlike staff members who were present only on varying shifts, families had to think about existing in the hospital because they, along with the patients, were the only full-time hospital residents.

> Fiona (grandmother, Family 4): Everybody at the hospital knows me as Grandma. From the security guards up, everybody knows me as Grandma. "Hey Grandma, Grandma, Grandma."

> Miriam (mother, Family 7): I know people in the cafeteria. I know the people that work security. I know the maintenance people. I know the housekeepers. I know most of the nurses. I know all of the charge nurses. I know the nursing coordinators on fourth and fifth floor. If I need something, I'll make sure it happens… you have to do it kindly, because– there's a fine line between being an advocate and being a bitch.

Yet the prognosis and progression of the child's illness remained uncertain, and families remained on guard, looking out for the next potential error. They could not get too complacent; otherwise, they would fall in the rocky terrain.

> Lisa (mother, Family 13): I had some struggles. I had to be his voice. I had to…you know, I got in[to] arguments with nurses who were trying to give him chemo agents that I knew he wasn't supposed to have anymore. [Chemo] stands out in my mind at the time where it was stopping at this point, and the nurse was giving it to him. She was gonna give it to him, and I fought her on it… I see Dr. Smith come around the corner, and I yelled down the hall, "Is he supposed to still get it?" She said, "Absolutely not," and I looked at the nurse, and said, "Thank you very much."

With every step forward into the unknown, parents became more skilled at assessing the river and determining the best path for their family. The water became more shallow and the ground less rocky, and the water flow slowed. Families developed a network of trusted health care providers among the staff and other families they met and learned they could lean on. They recognized where it was safe to place their foot for their next step and where they needed to hold a hand to get past a boulder. All families in this study successfully walked the rapids and reached the river delta.

Standing at the Delta

Families arrived at the delta after their child had endured many treatment procedures and interventions, after they families had struggled to stay afloat, after they had learned how to escape the whirlpool's strong current and eventually walk through the rapids. Now, at the river's end, they faced the next phase of their journey. Here, families stood on soft swampy soil and the river had slowed to a muddy crawl. This was a time for making decisions about moving forward or standing still, but the ground was soft, and parents were aware that their feet were beginning to sink in the soil. They had to move forward, along with the river that albeit slowly, continued to flow toward the ocean. However, families could not make the decision to move forward until they were ready. They knew little about the ocean waters, only what they saw with their own eyes and what they had been told about the ocean by other people on the river. They had to base their decision on their experience with the river and the information imparted to them, but they were ill prepared to decide. Although the journey in the river had been a struggle, the expansive ocean that awaited them aroused new fear. Some families were given the opportunity to stay at the river's mouth until they were ready to leave, while others were told they had to board their own sail boat which had also survived its journey down the river but which now lay on the shore mangled and neglected, in need of repair. These families were those whose child's medical condition had been stabilized or for whom no more services were offered in the hospital. Health care providers told them there was no medical justification for their continued hospital stay and they were pushed into their boat and directed to leave the river and enter the ocean waters in their recovered sail boat. All families who were sent home (n=12) felt inadequately prepared; they felt unprepared, abandoned, and forced to make uninformed decisions about how to sail the ocean waters.

Being Unprepared

The families felt completely unprepared to leave the river because they had been given minimal direction and guidance as to how to set sail on this new ocean of caring for a seriously ill child outside of the hospital. They were leaving an environment where all the necessary medical equipment and expertise were easily available and were going to an environment where there was little provision for the child's medical needs. Their 'crash course, Nursing 101', had served them well in the hospital setting in helping to care for their child and in gaining confidence in dealing with the staff. However, their hospital experience was not equivalent to the medical care they had received. The hospital discharge plan detailed medication administration, dressing changes, and the equipment needed for the next phase of their journey, but families were discharged home often without equipment and supplies and told to await instructions from home health care providers. Sally, mother, family 10, described what many other parents also echoed: They were told what they were supposed to do, but not necessarily how to do it. Sally was told to not to lift her daughter from under her shoulders, but was not shown how to move her correctly. In the hospital, her daughter was always moved with the assistance of two people, so Sally was at a loss as to how to do this on her own. Although parents felt unprepared to care for their child at home, the staff's underlying assumption was that the child was medically stable and therefore ready for discharge.

Furthermore, families had no sense of how long they would need to provide care for their child. They had been given inaccurate information about their child's length of life and were therefore unable to plan accordingly, each ill child lived longer than predicted, and some were still living at the time of interview. Families were told that death was not only inevitable but also imminent. Sabrina, mother, family 12, was told that her baby would die upon birth, possibly living a couple of hours afterward. Not only did her daughter live beyond a few hours, but she was discharged home:

> Sabrina (mother, Family 12): No one thought she would make it out of the hospital. Um, so we had no car seat. We had nothing because, um, we never dreamed we'd bring her home…So we didn't set up a nursery. We didn't have a changing table. We didn't have diapers. We didn't have a car seat. We didn't have anything for a baby…I didn't have any baby showers. I didn't have burp cloths. I didn't have bottles. I had absolutely nothing.

The family learned of the baby's discharge two days prior to the discharge date, thus giving them little time to prepare their home for the arrival of a baby, and they had not spent the pregnancy, as many couples might have, preparing the home. Not only were they bringing home their first baby, but also they were bringing their baby home to die. There was a lack of adequate time before discharge to establish the necessary support to maintain their life at sea, and they did not know for how long they needed to have provisions for their child. Sabrina's daughter lived over 50 days. Other families echoed a similar lack of preparedness. One family was discharged home and was told that the baby would probably not make it through the weekend, but the baby continued to live. The parents were faced with deciding if they could remain at home and manage the child's medical needs if she did not die as expected. :

> Carol (mother, Family 9): [The doctors were] like, "Honestly, we don't even know how long she will live. I mean, [the tumor is] around her windpipe and everything, and we don't know where…what stage she's at. We can't really tell you. It could be a, a, week. It could be tomorrow. We couldn't tell you when she's gonna die."
>
> Carol's baby lived 7 more weeks.

Being unprepared meant families did not feel ready to move forward; they were lacking the necessary provisions for sailing the ocean waters. Much like the waterfall that had earlier determined the sudden change in direction of their course along the river, the ocean now awaited them, whether or not they were ready. Families who had the option of pursuing either experimental treatment or palliative care in the hospital did have the option to stay in the river. These families had more time to get ready to leave the river. They had time to adjust to the vision of the ocean and carefully consider vessels other than their own sailboat upon which they would travel.

Abandoning Families

The failure to prepare families for the voyage on the ocean waters amounted to families feeling abandoned by the health care providers who had cared for their child. Not only were the families lacking the expert knowledge to medically manage their child, whose health condition was deteriorating day by day, but they also were exhausted from their grueling journey. Although they were empowered by their newfound voice and increased medical understanding, they could not board any vessel to navigate the ocean without some guidance. However, families did not receive such guidance. Instead, families were sent to board their sail boats with a firm nudge, a few ropes, and some suggestions as to which larger vessels might best help them at sea. These vessels included hospices, home health services, and follow-up clinic visits; the ropes they were given were in the form of referrals to these various agencies. However, families themselves were responsible for finding these other vessels to which they could connect their rope. Families described this sense of abandonment and the fear they felt in moving forward in their voyage:

> Lisa (mother, Family 12): I missed my family at that hospital…that connection you build, you know, with your nurses… it's family. I mean, they became our family. It was hard to let go of that family. Really hard. I still miss them.

> Darla (mother, Family 11): 'Cause we brought the baby home thinking one thing and everything was different, it was discombobulating…it felt like we had, kind of, um, fallen through the net, and, now, nobody was caring for us.

Families had spent much time in the river, had grown to know the staff, and had learned how to walk the rapids and how to survive in the river. They had learned which staff they could lean on and had built a community within the hospital to support them. However, they learned that these communities of support would remain on the river; they would not accompany them forward on their journey. The parents were alone. All the relationships they had built were suddenly severed, and their story would not be remembered as a success story. Even worse, few, if any, of the staff members attended funerals of the children who died:

> Lisa (mother, Family 13): Because none of our [staff] showed up, none of them…I was devastated that they weren't there. Not mad or upset with them. Sad that they…just sad that they weren't there. I think I just assumed they'd be there. For whatever reason, I had that in my head… that's a definitely, for me, a huge thing. And I was so sad, um, that none of them were there.

Families felt as though their connection to their hospital family had completely evaporated; their hospital family that had been there with them on the river was now absent from the voyage on the ocean waters. Families were set adrift having lost not only their hope for a cure for their child, but also having lost their hospital family. Every family described this sense of abandonment and was evident in feelings not of anger, but of great sadness and disappointment. Families did not expect their hospital family would accompany them on their ocean journey, but they all wished for some level of continuity with the hospital staff and with other families.

Choosing a Vessel

Often, families had no choice but to leave the delta, but they could choose whether they would board their own boat or another vessel, such as the ship (George Mark Children's House, GMCH), to sail the ocean waters. This was a choice predicated upon information given to them by their child's current health care providers or by other families. Families did not fully grasp the breadth or depth of the services offered, and they were not familiar with the concept of pediatric hospice prior to hospitalization. Thus, how the information was presented, what was presented, and by whom it was presented were paramount to the parents' decision-making process. Inaccurate, vague, or incorrect information prevented the families from making an informed choice. Since the length of the child's life could not be predicted, families could not anticipate the duration of the next phase of their journey on one of the vessels in the sea. Therefore, they could not judge what type of vessel would be most suitable for their journey. Furthermore, the mere sight of the ocean before them and the realization that their child was not going to achieve cure hindered the families from fully comprehending their choices and the best way to prepare for their continued journey. Feeling abandoned, families sought refuge in their own familiar sail boat, which was in need of repair, having suffered much damage during the harrowing river journey.

Families were not introduced to the concept of hospice until they had reached the delta, and knowledge about hospice was not available during the time they were struggling to stay afloat. Health care providers were the gatekeepers of pediatric hospice information.

> Sabrina (mother, Family 12): 'Cause I had no idea what hospice even was. You know, that it existed.

Parents were not told about the ocean until they were facing it. As the expansive ocean lay before them, they were expected to be able to not only enter it but to choose a vessel and sail away. Families bold enough to venture to the GMCH ship had an opportunity to take a tour before setting sail. Those who toured the ship stayed on board. Families decided to choose this based on three conditions: the person delivering the information (messenger), the manner and content of the information (delivery), and the timing of the delivery (timing) in relation to the severity of the child's illness and the families' readiness.

Messenger

None of the families had heard about pediatric hospice until they came to the hospital. Some of them did not find out about it until after discharge, from other families. Therefore, the relationship between the families and the person informing them about the available options was instrumental in the decision to choose a vessel. During the journey on the river, the families had learned whom they could trust and whom they could not. They had learned that they could not rely on a compass without checking its calibration and that they could not ignore their own instincts in favor of the compass arrow. Therefore, if the information came from a provider who was deemed to be unreliable, the options were discounted by the parents.

One family stated that it was the pediatrician who had missed the tell-tale signs of infection who told them about GMCH; the same one who had later told them they could not expect a miracle. In separate interviews, Sandra and Jonathon described their pediatrician:

> Sandra (mother, Family 2): It just felt like every time he'd come in our room, it was like another nick. You know? So by the time we had finished with him, I had a lot of paper cuts. But it just felt like I didn't want to…I didn't even want to deal with him because his aura was just so bad and negative. You know? It's like, that's fine if you don't believe in my daughter and you don't have any hope for her, but don't let me see that.

> Jonathon (father, Family 2): Actually, the one who told it to me was [the pediatrician]. And like I told you, I disagreed with everything that man had to say from that point on. You know, so he was the one who was telling us about [GMCH].

Jonathon and Sandra were angered by the pediatrician's suggestion that someone else might be more capable than they were of taking care of their daughter or that they might need help. They felt that his inaccurate judgment was to blame for their daughter's condition, so they did not trust him at all. Not only had he inaccurately diagnosed their child, but he had also robbed them of any hope of a miracle. In fact, his support of GMCH made them even more mistrustful of using the services.

In contrast, Jim and Mina were informed about GMCH by a trusted health care provider, a surgeon they trusted because she had agreed to perform surgery on their child against the opinions of other specialists who felt nothing could be done. This surgery prolonged their child's life although death was still inevitable. The surgeon tried every option to offer their child a cure, so they grew to trust her immensely. When she spoke to them of their options, they felt she had their child's best interest in mind.

Earline was mistrustful of everyone who took care of her grandson; she only trusted her county case manager who had made the extra effort to obtain special equipment for her grandson. Earline had grown very close to her case manager and trusted any suggestion from her. She believed that the case manager had her grandson's best interest in mind and would not suggest anything that would be to his detriment.

> Earline (grandmother, Family 1): She's my angel…she called me for George Mark's.

Some families learned about other services through other families who had either used or were planning to use the services. Families found comfort in suggestions from families in similar circumstances; their trust in such families was instantaneous. Families trusted information from other families more than information from health care providers. The desire to connect with other families in similar circumstances was evident in each interview.

Delivery

Not only was the person delivering the information crucial in the parents' decision-making process, but also the manner of its presentation and the description of the services provided were equally important. Toby's surgeon framed the options in a way that was palatable to his parents.

> Jim (father, Family 3): [She] said, you know, "Think of the things you can do *for* Toby or the things you're going to do *to* Toby."

Jim referred to this as the 'quality of life speech', where families were told their options, and urged to think about how they wanted to spend the rest of their remaining time with their child. This speech had to be delivered in a manner that reflected the difficult nature of the decision, one that placed the child above the disease and put the family at the helm of decision making.

Other families were given information in a way that resulted in their perceiving GMCH to be an option for parents who were unable to care for their own child at home:

> Jonathon (father, Family 2): And, uh, they said it (GMCH) was a nice place. And, uh, people would help us, you know, deal with Nicole. And our other option was [to] learn how to take care of Nicole and, uh, just step up to the plate.

Jonathon was offended by the implication that they would somehow be unable to learn how to care for their daughter and that they might need to put her in a pediatric hospice home. They chose not to go to GMCH, opting instead to learn how to take care of their daughter at home. They had already let other people care for their daughter, and, now, she was dying; they were going to learn what was necessary so that they could care for her at home themselves. They had grown mistrustful of the health care providers' ability to care for their daughter.

For other families, hospice was offered as a possibility, something to try out, knowing that they could still choose to go home or possibly return to the delta (the hospital). Earline describes how her case manager presented her with the first suggestion of GMCH:

> Earline (grandmother, Family 1): She said, "Earline,…I have something to share with you." And she said, "This place seems so awesome, and the first person I thought about was you and Spikey because I know that you would contact me and that you would be willing to try it out and then you would give me a good report or a bad report. You'd be honest with me about it. But I want you to go and check this out."

Earline was open to the possibility of *checking it out* and giving her opinion as to whether it was good. She did not see the decision as permanent, but felt in control of the decision. Jonathon was also receptive to GM when he saw it as an option, something he could try out, a place he could choose to leave. Jonathon described the caring manner in which a different health care provider presented the option of GMCH on a subsequent admission:

> Jonathon (father, Family 2): Dr. Johnson came in there, and he actually gave Nicole a kiss on the forehead. I was like, "Oh my gosh." This was just the…I mean, he's one of those neurologists that had traveled the world.

That a world-renowned neurologist would take the time to kiss their baby on the forehead, a gesture that put the child before the illness, one that humanized their child, made the parents receptive to the information he provided them.

> Mina (mother, Family 3): [Our surgeon] said, "The other thing is, is we have this wonderful place, and it's beautiful. and it's George Mark's." And I held Toby, and they took Jim over to the computer and showed him the pictures and everything. "And they have a room, if you guys wanna go there."

Many families received descriptions of GMCH as a beautiful home. Jim and Mina first went to the Web site, which had a picture of the home and the water fountain. This positive framing was enough for her husband, Jim, to feel compelled to take the tour that very same day. By pointing out the availability of a room, the surgeon enabled the parents to imagine themselves at GMCH right away instead of in their child's hospital room.

Other families had to base their decisions on conflicting or inadequate information about hospice. Therefore, they chose not to go to GMCH upon discharge and were hesitant about using home hospice services. Carol was told about GMCH, but was told it was in Union City, not San Leandro, and the oncologists were not even sure what they offered:

> Carol (mother, Family 9): They had to like tell us options, I think. And that, that, was the first time we had ever heard of the George Mark House. But I don't even

> know…they didn't even call it the George Mark House. They were like, "There's this house." And they didn't even say San Leandro. I don't even think they were sure. They're like, "In Union City." And I'm thinking, "Well, I don't even know Union City." I'm trying to picture a house in Union City, and I'm thinking, "I don't know. And I've never been through this." And we had never lost a parent yet. And we both didn't have grandparents that had to deal with hospice. So we had no clue like how hospice health…we were clueless on what hospice really did, right? So they were like, "Well, you can have her pass away…you know, she can go home, and Comfort for Kids will come and do all this stuff daily or every other day." You can have an end-of-life room [at the hospital], or there's this great place opening up. It's brand new, and it's just right."

Carol did not want someone coming to her house everyday and doing "stuff" to her child, she did not want to go to "some" house in Union City, and they did not like the end-of-life room at the hospital, so they chose to go home, thinking that perhaps their daughter might not even make it through the weekend. The information upon which they had to base their hasty decision was inaccurate, vague, and misleading.

Darla and Dan were similarly unclear as to what hospice services entailed and whether a do not resuscitate (DNR) had to be signed in order for them to receive services, whether it was revocable, and whether they had the right to access hospital services. Furthermore, distinctions between palliative care and hospice care were confusing, and they received contradictory information by various health care providers. This was clear in their expressed desire for something tangible:

> Darla (mother, Family 11): They should…I think maybe what would help them is to have a…like a checklist that hospice covers and that they…
>
> Dan (father, Family 11): Yeah, definitely. In writing so, you know, so the nurses, can't miscommunicate.
>
> Darla: …just like lay it out. Hospice covers [this], and, then, palliative care covers [this] and doesn't cover [this]. Like a checklist that people just say, "OK."
>
> Dan: Yeah, so that, you know, the nurse can hand you a copy and look over it with you. And even if she miscommunicates, what's written down is clearly communicated, you know.

Timing: Becoming Ready

Families could not choose a vessel unless they were ready to do so. If they were pushed to sail the ocean waters before being ready to make a decision, they chose to board their familiar, although damaged, home boat and cast lifelines to other vessels when it was possible to do so. The messenger could have been a trusted health care provider, and the manner in which their options were presented might have been optimal; however, if the family was not ready to move forward, they would not choose home hospice services (Comfort for Kids) or GMCH.

> Fiona (grandmother, Family 4): Everybody that we talked to just said how great and wonderful a place [GMCH] was and even though it's a place for dealing with death, it was so full of life. You know? Well, okay. I mean, we heard it. We heard what they said. We knew that this was a wonderful, great, fantastic place. But, you know, I just- I…I don't know how you would get that across to somebody.

> They offered it to us a bajillion times: “Well, why don’t you go there and take a look at the place. Go take a tour. Go over there and meet the people. Go take a look. Just go, go, go.” “Yeah, yeah. We’ll get around to it.” You know.

The families had to go through a process to become ready for such a decision, one where they moved from “not being ready’ to ‘being ready.”

Not being ready. Families described feeling not ready to give up the fight for their child’s cure and holding out for a miracle. They were *fishing for hope* by manipulatively questioning:

> Jonathon (father, Family 2): We’d ask questions like, “Okay, so you’re saying that there’s one in a million chance?” So there’s one in a million, so we want to drive off of that one. Forget about that million …that’s not going to happen. “So you’re telling me that there’s a chance.”

Families indicated that physicians were hesitant to tell them definitively that their child would die and reticent to predict when the child would die. Physicians who were blunt about the child’s death were met with indignation from families, who felt they were being robbed of hope or being told that their child had no chance of survival. This was particularly true for two families who were diagnosed in utero and given what they perceived as encouragement to terminate their pregnancies. Families turned to Web sites to search for information about children with a similar diagnosis who had survived, other families’ stories of survival, and alternative treatments in order to hold onto hope for their child’s survival:

> Darla (mother, Family 11): And you don't wanna ever give up hope until the very end. And even if, you know, the child's gonna die in a few days, you want everything to be done to give the child a chance.

Families wanted to exhaust all options. Their language reflected terms such as "fighting," "not giving up," and "trying everything." They had become their child's advocate and believed they must question health care providers and explore all avenues of treatment before they could feel that there was nothing more that could be done.

> Jim (father, Family 3): You know, and…and I don't know if I'd recommend jumping to George Mark's too early, um, and giving up. You know, 'cause there's a part of you that feels like you're giving up… Um *(pauses, eyes begin to tear up)*, you're accepting the fact that you're not going to do any more to fight. Um, and, in a lot of ways, that's giving up.

Parents had to feel that there was no more fight left, and their child's history of responding to treatment greatly affected their decision to continue with treatment.

Response history was often used as a benchmark for possible future or current response, and the trust in health care providers' opinions decreased as their predictions did not hold up. Mina stated that the first time her baby had been placed on a respirator, she had been told that he would not be able to be weaned and he would likely die. That did not prove true. The child lived a full month before he was again placed on a respirator. Health care providers once again told her that the baby would not successfully wean, but he did. He lived several more weeks. So the third time, when they offered the same prediction, the mother no longer believed anything they had to say. She had seen them be wrong over and over again and was convinced that they did not know her child was a fighter:

> Mina (mother, Family 3): He stopped by once to give us the the hard conversation. Telling us that he wasn't gonna get any better and he was gonna go. And I'm like, "You guys are nuts because you keep telling us he's not getting off the respirator and he is. So you're totally wrong. He's gonna get stronger and better." He'd gained weight. He looked good.

> Miriam (mother, Family 7): Mikey's had an end-of-life care plan for 6 years now, and we've been told countless times he's got 24 hours [to live].

For parents whose children had survived such predictions, physicians' opinions held little weight. Parents' faith in their child's survival was strengthened each time the child pulled through and contradicted these predictions. The consequences of an ill-timed suggestion for hospice were resistance, anger, or pressure to comply with the health care providers' expectations. Ultimately, only a parent could decide to "give up" and whether home health care or services like GMCH were going to be helpful.

> Carol (mother, Family 9): And I'm thinking, "Someone's gonna come to my house every day?" I just don't even…I couldn't even think of that. "We're going home, we're gonna come back and do this chemo, and we'll get through this, right?" That's…we were not like ready to say, "No, we're gonna go to this house (GM)." I mean, I was like, "Well…" It just wasn't…I don't know. We weren't…that wasn't an option to me. We were resolved not to…give up or something.

Parents were facing the ocean, looking at the vessels and wondering why they had to leave the river, why they could not remain on the delta. The river had ended too soon, and they believed that there must be more water, perhaps a tributary that would allow them more time to reach the ocean. They were not prepared for the ocean and not ready to leave the delta.

Being ready. As families began to recognize the futility of treatment, that is, their child's lack of response to continued treatment and observed their child's suffering, their perspective began to change. They realized that response history was precisely that: history. Their child was no longer able to respond to treatment.

> Charlie (father, Family 9): And then they come with this scan… this scan was horrible. Those pinhead dots had gone to over a hundred tumors the size of walnuts all the way up to her throat.

Families' goal then shifted from survival to comfort and easing their child's suffering. They no longer wanted to see their child being used as a pin cushion. The families were no longer fighting the battle, but moving forward to deciding how to live the rest of their days.

> Jim (father, Family 2): Once you get to the realization that you can fight this and fight this, and it's not gonna change the end…it's really just a decision, you know, are we gonna fight it in a world that you have little control? You don't get to enjoy a lot of time with your child. Your family is allowed in one at a time or two at a time, whatever. Do you fight it in that world, or do you move to a world where you can all enjoy the time you have left?"

The journey was no longer about giving up hope, but rather choosing to live. When parents were ready, they no longer felt the need to try everything. Parents stopped using words like “giving up” and began to use words like “living” and “enjoying.”

When the suggestion for services and various options coincided with parents’ being ready, they were receptive to hearing about their child’s grave condition and what options might be available to them:

> Carol (mother, Family 9): But this other oncologist, just…emotion came…he was just telling us how ill she was, and he pretty much laid out like, “Listen, you’re gonna have to make a choice. She’s not gonna make it. This is how it is.” And he just kind of told us how it was, and it was like we needed to hear that.

> Jonathon (father, Family 2): So, uh, I just…I was just willing to try…I mean, it goes to a point in time where all of the chances and luck [run] out, and it’s like you’re gonna have to try this. Either you can keep this foot on and let the gangrene eat up your whole leg, or we can just cut it off. Well, of course, I mean, we’re going to cut it off, so I was like okay, let’s just try it. You know what I mean? It’s worth a try.

The metaphor of the gangrenous foot was very telling. It represented an understanding of an all-consuming, relentless progression of the illness comparable to how gangrene in the foot could migrate upward and how an intervention, such as cutting off the foot, was necessary; otherwise, the whole leg would be lost. The intervention for Jonathon’s baby was to go to GMCH. He perceived that a continued stay at the hospital was an inevitable gangrenous death. He was willing to try GMCH, which was a very different reaction from his initial anger when he had indicated that he wanted to use a baseball bat on the pediatrician who had suggested GMCH. Thus, the timing of the decision was an essential element in the parents’ ability to make a choice that was in the best interest of the family.

Conclusion

Families thought that the river of life would continue indefinitely, perhaps with a few unexpected turns and a turbulent flow, but they expected to have oars and a reliable compass to support them on their journey. The unexpected diagnosis of a life-threatening condition sent the family plunging down a waterfall into a whirlpool of unfamiliar waters. They struggled to keep their head above the raging water as they tried to make sense of their child’s condition. Their boat had been capsized, and all family members were thrown into the water. Each family member struggled to stay afloat. Some were closer to the boat, perhaps able to cling on, while others were dependent on lifesavers thrown to them by supportive staff members and other families. As the child’s condition worsened and the families spent more time in the water, the lifesavers begin to deflate, for they were only designed to stay inflated for a short stay in the water. Families could no longer depend on the lifesavers and they learned that they needed to actively swim against the current to avoid being pulled back into the whirlpool. Parents learned that physicians were fallible and that, as parents, they had to seek information and trust their instincts to advocate for their child. They were no longer dependent on a compass and they walked along the edges of the now shallow river, expertly navigating the rapids. Having gained confidence in their ability to manage their child’s care in the hospital setting, families actively participated in their child’s care, Eventually, as families moved forward in their journey, they found themselves at the delta, the river’s mouth. An expansive ocean lay before them, and they had to choose a vessel upon which they would sail the ocean waters. The decision to choose a vessel was dependent on a triad of factors: the messenger, the delivery, and the timing. Even if families were ready to seek an option outside of the hospital, they needed accurate and comprehensive information about existing and available options, and, since health care providers were the gatekeepers, the parents were dependent upon them for information. Families who were ready and had not received any information searched for options on their own and found that they needed physician referrals in order to be enrolled for services. They were dependent on staff to exercise their options. Thus, without all three conditions being met, families would often make a decision that they later regretted. Families that initially refused GMCH, but then later chose to go to GMCH, wished that they had exercised that option much sooner. No parents wished that they could have continued the hospital stay. All were grateful to have made the decision for their child to die at home or at GMCH.

CHAPTER FIVE: FINDINGS

Sailing the Ocean Waters

The previous findings chapter traced the family's river journey to the delta, where they chose their vessel for the next segment of their journey. This chapter presents the family's journey on the ocean waters. The journey is shaped by the vessel they choose because the families' ability to sail the ocean waters depends on the help they receive. Families' experiences aboard the home boat differ from experiences on board the ship. Therefore, this chapter is divided into two main sections based on the parents' vessel choices: aboard the home boat and aboard the ship.

Aboard the Home Boat

Families who chose to sail on their home boat were faced with the task of remodeling the boat, managing the crew, and casting lifelines. The consequence of not successfully accomplishing these tasks is that families sailed alone, either being lost at sea or washing back to the delta shores.

Remodeling the Boat

Home boats suffered damage from the grueling river journey. Some boats acquired cracks in the wood, or holes in the sail, others were in need of complete overhaul requiring structural repairs in addition to cosmetic repairs. For some, the damage was irreparable, requiring the use of a completely different vessel: moving in with a relative who was able to accommodate the parent and child. This move occurred for single mothers who leaned on the child's grandmother for help; three grandmothers in the study had become the primary caretakers for the ill child.

Upon boarding the home boat, parents realized they had to not only repair the boat to stay afloat, but that the boat also needed to be remodeled for ease of access to the child and to accommodate the addition of medical equipment. They had to accomplish these renovations without having had any prior experience and without the necessary tools. Remodeling was necessitated by the need to see the child and to hear the child’s breathing or crying. Thus, parents generally chose a more central location, such as a living room, where the child was accessible to family members, or close to the front door to ensure proximity to transportation should the need for emergency care arise. Bathrooms were reconfigured for disabled children; Hoyer lifts, bath slings, wheelchairs, hospital beds, physical therapy equipment, and medical supplies had to be accommodated. One grandmother had an entire dresser dedicated simply to supplies and medications. In addition, parents made charts to keep track of medications and the child’s routine. In Family 6, the siblings’ rooms were reconfigured so that the ill child’s room was closest to the parents’ room, and during the day he stayed in the living room, on ‘his’ couch, where suction equipment and oxygen was nearby. Parents who had successfully remodeled their home or mastered their child’s elaborate routine of care made comments that reflected pride of ownership and proudly offered me a tour of their home’s set-up.

> Field notes, Family 10: At the end of the interview, the mom asked whether I wanted to see Savannah, and took me to see her room. She had a hospital bed, which had butterfly-themed sheets, her whole room was butterfly-themed, including her pajamas, her lamp, wallpaper, towels. Her room was very organized, with a suction machine nearby, oxygen set up, supplies neatly stacked

> on a dresser stand. Savannah looked very well cared for, smiling in response to our entry into her room… Again, as with other families, I was struck by the ‘pride of ownership’ in her care of her daughter and her home.

> Field notes, Family 1: I was shown the shelf of medications, and it was explained what they were for, and the morning routine that started with prayer and time in the wheelchair, followed by an elaborate bathing routine that included special soaps, and lotions and powders to keep the skin from breaking down. Earline wanted me to look at her grandson’s mouth as evidence of her exceptional care of him.

> Earline (grandmother, Family 1): And I watch his mouth, make sure his lips is [*sic*] not dry,… ‘cause I tell him every day that um, that’s why I brush his teeth every day…and the boy doesn’t have one cavity.

Through exhausting trial and error, families learned how to best adjust their environment and develop a routine to meet the child’s needs . Families were left alone to figure out and struggle with adjusting the home environment upon discharge from the hospital. Although the hospital discharge plan detailed medication administration and other aspects of care, parents found these instructions completely inadequate for the journey in the home vessel.

> Darla (mother, Family 11): It was really bad not to have everything really figured out before we left the hospital.

Parents set sail without the necessary equipment or supplies, and were told to await instructions from home health providers. No liaison bridged the transition between hospital and discharge. Families themselves had to call agencies, figure out the proper names for equipment, learn about additional parts needed for the equipment, reimbursement, and determine reimbursement regulations. Parents were not aware of their lack of preparedness for this next phase of the journey until they actually set sail, and discovered how ill-prepared they really were.

> Sandra (mother, Family 2): I mean, no sleep, mostly because, I mean, I had to take her - I mean she had a G-tube, so between hooking her up to feeds, taking her off, flushing her, and having to work. My husband had to work. I stayed home for a little bit, and just waking up every so often during the early morning hours was really hard. Giving her medications-it's like you have to switch your mind, like total 360.

When parents left the safety of the delta, they assumed they were prepared to handle the sail and that they would seamlessly connect with agencies. Families greatly underestimated the effort required to maintain the home boat.

Managing the Crew

In addition to remodeling and repairing the boat, parents needed to care for all the crew members on board, including the ill child who had medical needs with which they were inexperienced. The remodeling signaled to siblings and visitors the priority of accommodating to the child's needs, and each family member had to adjust to the newly altered environment. In Family 11, Daniella, a three-year old sibling, was rarely allowed into the front room, where all the medical equipment for Dottie, her dying sister, was located. Her parents said that she could be heard running through other rooms of the house with her grandparents, but she only came in to the front room for hugs and kisses, and for the most part she stayed out:

> Darla (mother, Family 11): Most of the time we kept her out because of all the medical supplies. She wanted to play with everything.

In Family 6, the two siblings learned that they could not touch their brother's equipment, and that the main couch in the living room was now designated only for their brother. In Family 7, the three brothers learned that the community space of the living room and dining room had to be vacated when the home nurse arrived. They had to learn new ways to play with their disabled brother who was restricted in the activities in which he could engage.

Not only were family members learning to adapt to being displaced from the familiar configuration of their boat, but they also had to learn how to connect with each other again. Family members had spent a great deal of time apart when they were on the river as they focused on just surviving. Much like the home boat, they too had suffered damage. The parent who spent the most time in the hospital had become distanced from the other family members. Each family member knew little of what was happening with one another. The prolonged separation in the hospital compromised parents' sense of family unity.

> Lisa (mother, Family 13): It took a really long time because I didn't know who I was anymore. I didn't know my kids anymore because I'd been away from them so much and I had so much of my focus on Bobby, that I lost track of my boys. And so I felt really guilty about that. Um, I was lost.

> Jonathon (father, Family 2): For two weeks straight we didn't see him (son, child's brother). We didn't talk to him. And that was terrible, man. That - that hurt me…I'd never been away from him that long. And it started to eat at me.*(sigh)*

Once families were reunited, they found they had to work as a crew in order to repair the damaged boat as they attempted to sail on unfamiliar ocean waters with no sense of direction. New routines and roles had to be established as the members began to learn how to live with each other again. Role differentiation was greater after the plunge than before, but families became more cohesive with each member having to help. Having been capsized once, families understood the risk they faced of being capsized again if they did not work together to sail the ocean waters. Siblings who may not have had previous responsibilities for navigation were now required to help as the parents tended to repairing the boat and meeting the ill child's needs:

> Mark (father, Family 7): The boys had to learn how to grow up, faster than normal kids.

> Matthew (sibling, Family 7, age 14): It taught us to be more self-reliant. We relied on mom and dad 95% of the time. After that we've been just self-reliant, looking out for each other and then taking care of business.

> Max (sibling, Family 7, age 9): I've learned how to cook.

> Joe (father, Family 6): Jenny’s smart. She understands what’s going on and has adapted herself… She’s six going on sixteen. She’s a big help to her mom.

Parents needed help with caring for the siblings as the care for their ill child often dominated their time. Dottie needed round the clock care at home; she was on continuous monitoring and literally needed to be watched all the time. Her parents took shifts watching her and resuscitating her, and therefore needed help with their other daughter, Daniella, as well as with managing the daily tasks of running a household. They had the help of both sets of grandparents. Dorothy, the maternal grandmother, took on the primary role of caring for the sibling:

> Dorothy (grandmother, Family 11): When Darla and Dan first came home, they were trying to decide whether to go to the little home (George Mark) or whatever or to stay with the baby there…. If they hadn’t had the help of the grandparents, they might have had to do something like that.

Carol and Charlie had two other children, were both working and needed additional help, thus enlisting the help of the child’s grandmother. This cramped their living quarters and led to role confusion with the grandmother taking over the role of home boat captain:

> Charlie (father, Family 9): But you know, also- I mean, I- I feel that, you know, that- almost like she hijacked our- our daughter. You know?

> Carol (mother, Family 9): She ended up acting like the mom. And I think the reason why she did that is because she felt like- she didn't- I mean, we had to be responsible parents to keep our finances going. Like to me, I didn’t wanna not have a house to live in after this whole ordeal. I mean, it’s the worst thing that’s

> ever happened to us. So I'm like, "Oh, I'm not gonna lose my house. We've gotta both work."

Carol and Charlie reluctantly let the grandmother take over the mother's role, since they both had to work and care for their ill child and their other healthy child. The grandmother had made it clear that she wanted her role to be caring for the baby, and being desperate for help, Carol and Charlie made that concession and put their other well child in daycare. Accepting help had a price in living space and family time, echoed in Charlie's comment about his mother-in-law staying with them during the child's end of life: "And you know, our house's small, we're just on top of each other. It was so uncomfortable for me." Moreover, family members who were caring for the well child and visitors were seen as intruding upon family time.

Grandparents were in the difficult position of wanting to be helpful and yet not intrude on the parent-child relationship. Dorothy, the grandmother in Family 11 describes this difficult balance:

> Do whatever you can in a supportive way, not in a hovering or a bossy way. Just be there for support when you are needed and love that baby and love the family as much as you can. Be there for them, but let them have their own say about things. It is their baby and their life and all. I guess just be a moral support and a physical support for them as well. I think if you give your opinion about something once then don't keep talking about it or harping on it or nagging. Also, if a person just knows that you're there to help and you tell them, "How can I best help you?" Instead of just getting in there and doing what you think - Do you know what I mean? Just kind of keeping yourself in the background but there.

However, in three families, the care of the ill child was eventually relinquished to the grandmother. Not all families had additional crew members. For one family, the grandmother who had been caring for the child passed away, and the mother had to stop working in order to care for her child herself. Even in families with helpful siblings and other relatives, their support was not sufficient to help families sail the ocean waters. Families also required help from services that could provide support for the child's medical needs as well as the family's emotional needs.

Casting Lifelines

Casting lifelines involved throwing lines to vessels that that were sources of services to families, enabling them to successfully navigate the ocean waters. Before leaving the delta, families were informed of services that could be helpful to them in their journey. They were given names and phone numbers of agencies, but it was the parents' responsibility to take the initiative and contact the agencies. Without such lifelines, they were alone at sea in their home boat. Parents realized how unprepared they were to sail the ocean waters and that they could not manage alone. They needed help and sought the services to which they had been referred. This was no simple task. Parents were not only responsible for finding the service vessels, but they also had to master how to cast the lines, again through trial and error. They had to assess the length of the lines, determine the appropriate force with which they must be thrown, the optimal distance to the vessel, and the right time to cast them. They were given no instructions on *how* to do this; some were provided with only information about the lines, and some parents were given no lines. Parents expressed their frustration with the fragmentation of care and lack of support to assist them in their ocean journey

> Sandra (mother, Family 2): It’s already hard enough taking care of a healthy baby when they’re that young, but then taking care of a baby that has all of these needs, and then all the programs that you have to go to, but nobody there to organize it. You have to organize it yourself, and… and it’s a lot of calling and waiting and…and a whole bunch of stressful other things that you shouldn’t have to go through when your child is already in so much trouble.

As families took on the task of finding service vessels, they found themselves caught in an endlessly tangled net of automated voicemail loops that made it difficult to find out what services were available, what was reimbursable, and who could help them. Furthermore, contacts had to be made during regular business hours. With so many factors required for successful casting, it is not surprising that parents were often unsuccessful in their attempts. Parents’ success in casting lines determined whether their family sailed alone or with support.

Successful casting. Obtaining help required practice and perseverance. All families who were told about Comfort for Kids (CFK), the in-home hospice program, called them within a few days of being home, generally on the Monday following the weekend, since that was a regular business day. Parents were very unclear as to what they could expect and what would be provided, and realized that, in the hospital, they had received very little information about the services. While at the hospital, parents had not met any staff members who represented the various services and therefore, had no clue as to how the services could be useful to them. Parents who were able to cast lifelines successfully described the relief they felt in knowing they were not alone and that there was someone who could assist them with their child’s needs. Having a life line to a larger vessel lessened the tension among crew members as they then had guidance on how to navigate the waters and how to best organize the child's care.

> Lisa (mother, Family 13): And I felt *saved* in a sense, you know. Somebody's finally gonna help me. And it's not that I didn't…think…I never felt like I didn't have help. But I think I took so much of it on myself, that I had in this situation somebody…I don't- I can't totally explain it except for that I felt some huge sense of relief with her [CFK nurse]. Um…she came in. You know, she hugged my aunt. She hugged everybody that was here that day.

> Sabrina (mother, Family 12): I mean, if it wasn't for Comfort for Kids we would've had no lifeline to- and that's what I said earlier, it's like that was our kind of lifeline to the medical community after being in [hospital] for eight weeks.

Families had varying experiences with the actual care from the nurses, ranging from being very pleased with the care to disappointment:

> Lisa (mother, Family 13): She never stepped on my toes. She never- she really paid attention to- I wanted- *I* wanted to care for my son. *I'm* not giving that up. She took- you know, she would *offer* things or, "If you can do this or that or you can…" you know…the- the areas where she saw that I needed the break, she was right in there. It's like I never really told her, "I don't want you to do this, but you can do that." She just really paid attention. And…she'd tell me how to do things that I didn't know. You know, or….she just really paid attention… she absolutely stood back, but stood forward depending on [what I needed].

Lisa wanted to be at the center of decision making, and yet she did not want to be alone in the process. She saw the nurse as a guide who could help her understand what the process of active dying would be like and who was there to help them through their most vulnerable moments. In contrast, Darla, whose baby had received expert clinical care in the NICU, was frustrated by the home nurse's lack of expertise:

> Darla (mother, Family 11): They didn't help out very much with the practical things. Like-Um…well, for instance, one of the nurses was here one day and I had been waiting till she got here because I needed to ask her to help me with Dottie's oral care…we needed help figuring out what to do to make her mouth more comfortable. And the nurse- she gave me a couple of suggestions and, you know, I was trying to get her to help me- you know, to look at the baby's mouth and to help me, you know, maybe moisten it with a little- I don't know. I was trying to get her to help me and she was basically sitting there indicating that I could take care of Dottie once she left. You know, "Here are a couple things you could try later." That type of thing. And so I just felt like, you know, I…I don't know. It felt like a big deal to me 'cause I felt- I was concerned that the baby was uncomfortable and I felt like I couldn't- I'd been trying to figure out. I'd e-mailed people and asked them for suggestions, what to do to help a baby with a [diagnosis] and dryness in her mouth and I was just having a really hard time finding information and, you know, the nurse didn't seem to be able to help either and didn't seem willing to help. That was the thing.

Although casting lifelines enabled families to stay connected to the medical world, parents did feel awkward at first and described the nurses as strangers, almost intruders into their homes. Some families were hesitant to trust them:

> Darla (mother, Family 11): The CFK nurses, were, you know, strangers for the most part. I wouldn't have let any stranger probably hold her.
>
> Sabrina (mother, Family 12): But when the CFK nurse came the first day, um, it was a little um- I will say it was a little clinical at- to start with 'cause she didn't know us, we didn't know her and um, it- it almost felt a little bit like an interrogation.
>
> Mark (father, Family 7): It was kinda odd. When the CFK nurses started coming over…bring their bags in, sit down, plus some equipment, checking him out. And it was kinda odd. And now we have someone else coming in, showing up and doing everything.
>
> Matthew (sibling, Family 7, age 14): Come home, "Hi", stranger in the house. "Hi." "Mom, who is that?" So we were just like completely confused, walk in and see some random person sitting on the couch playing with Mikey. You're like hmmm, "Where's mom?"

The more the family used the services and became familiar with the nurse, the more useful the visits became. Sabrina's initial skeptical impression of the visit evolved to perceiving the care as well rounded, providing both medical and emotional support.

> Sabrina (mother, Family 12): I think that um, you know, there's…a thread of sanity that Comfort for Kids brings parents during this time too. Um, and just, you know, the knowledge and-they provide both parts you know, "How much morphine do we give her?" Or, "When do we start the Ativan?" Or, you know, "What- you know, what's OK to do physically for her?"…They should be called Comfort for Families.

Miriam who used non-hospice home health nurses as well CFK nurses, was relieved with finding help after two exhausting years of casting lifelines: "Then we finally did find an agency that's willing to work with us, so we finally started getting nursing care, and that really started helping." Parents who had spent time casting lifelines eventually perfected their technique, such that they had an even greater grasp of the availability of services than the providers themselves. Parents were often the ones informing providers of what was actually available:

> Joe (father, Family 6): Jessica's pretty much got it figured out. She calls the advice nurse, she's basically telling her, like yesterday, we were trying to get an appointment for Jane, and she was telling him, "No, that's closed on Sundays," and [advice nurse] didn't even know.

Parents felt especially empowered to stay on their home boat when they had a lifeline successfully connected to a service vessel because they knew the nurses could evaluate and verify the child's death. Parents who had chosen to stay home did not want to return to the hospital upon the child's death or call the police. The presence of a familiar nurse was a great source of comfort. Parents were concerned for other families because they believed nurses were no longer going to be on-call 24 hours a day. They worried that a stranger might have to declare the child's death. This was a horrifying thought for all three families whose child had died at home during the middle of the night, not during regular business hours:

> Sabrina (mother, Family 12): And in fact, I've heard that there's- there's some issue- question as to whether or not the nurses will be available in the future after 5 o'clock. Like I've heard that they might just go to the 8 to 5 daytime nursing. But if your child dies like mine does- and like most kids seem to. Most people seem to die at 2 o'clock in the morning…they just- they don't die at 2 o'clock in the afternoon. And Steph died at four am and um, you know, the idea of not having Clarissa (CFK nurse) the night that Steph died, if- and I know that someone has to come and make sure that she's gone. If that had been a stranger, you know, I…that would've made the worst day of my life worse, you know, if possible [chuckles]. But that- you know, Clarissa- having her here and walk in the door and know us and know our family and um- she kind of held us all together that night. My parents were here and…I know she held us together. And I think also- and just recently I've gone back to ask her to refresh my memory about a certain thing that happened that night. 'Cause I didn't remember. And having that kind of witness is important 'cause you don't remember what's going on in the last moments with your child [crying]. At a very…a very vulnerable time for your family.

> Lisa (mother, Family 13): I called Sue- Uh, Bobby died in my arms in his room at two in the morning. And um, I sat with him for, you know, a few minutes and my

> husband wanted him. So he held him and I came out here and called Sue, and it was gonna take her probably half an hour to get here. And she got here- I mean, she must've been sleeping in her clothes. I mean, she literally was here- I can't believe how fast she got here. And um, and I think I called my sister and then she [Sue] took care of everybody else. And people started showing up and um…you know, she really- again, she took care of the people that were here. Our parents were here. You know, my sister and- and- just the family was here. Um…she'd come in and be with us and then do- you know, "Do you want this? Do you want me to do that?" Or we'd say to her, "Could you go tell whoever, whatever?" Um, you know, she suggested at the time that we cut his hair. His hair had grown back a lot. Um, "Why don't you think about cutting his- some hair to have." I would've never thought to do that.

Lisa went on to describe current budget cuts that were going to make it difficult to have nurses available during the night and weekends, and how the home care program was struggling to stay funded. She spoke of her concern for other families whose children also died at night, not during business hours. The fear of a lifeline being severed daily at 5 pm was echoed by all families who used CFK. Establishing a lifeline to the medical world through a service vessel was essential for families whose children were gravely ill. The lifeline facilitated a family's ability to sail the ocean waters on their home boat because they could safely and confidently provide for the child's medical needs at home, and have a nurse available on-call 24 hours a day.

Unsuccessful casting. Not all parents were able to successfully cast lifelines; some did not even have lines to throw and others experienced lengthy periods of unsuccessful casting. Parents navigated at length to locate vessels. After much hard work, and multiple direction changes, some families successfully located the target vessel. Yet, when they cast their lines, they found that no one aboard the vessel. The lack of available staff and expertise in pediatric care hindered parents' ability to sail the ocean waters and adequately care for their child:

> Miriam (mother, Family 7): But we couldn't find any services that could [care for Mikey] - they considered Mikey too high risk, and so a lot of the nursing agencies and everything else rejected us, plus there's not a lot of nursing agencies that will do kids, so yeah, we didn't have any help at all for the first two and a half years, so I did everything.
>
> Trish (grandmother, family 8): We're supposed to get 60 hours…a quarter through the Regional Center. The problem is, they don't have anybody who can come out here.

Often, the care families received was so inadequate that families preferred to not take advantage of the help available:

> Earline (grandmother, Family 1): When I try to trust people with him, it ends up they're not so kind. You know what I mean? ... Because it's like I'll- okay, perfect example: I uh- Regional Center sent me a nurse out here one time. And we had a meeting…And I left the woman in here with my grandson. Now, she's a nurse, a licensed nurse. I come back, Spikey's in here having a hard time breathing…And

> uh, the woman is- the nurse is sitting on the couch asleep. And I walked in and first thing I heard was him [makes choking noises] not being able to breathe. And I looked at her and I ran in Spikey's room and…And she was sitting there asleep. So after I got him clear, I walked over and I shook her. Now, I came in my house, she's still asleep. And I asked her, I said, "How in the hell did you get a job like this?" … And then I get crazy.
>
> Max (sibling, Family 7, age 9): There was one nurse [aide] that was here. She would just make Spanish rice and fall asleep on the couch.
>
> Trish (grandmother, Family 8): There's another [nurse] who makes [us] very uncomfortable and we use her if we absolutely have to, but she's- She'd rather spend time on her phone than- She let Tim [ill child] cry first, then….

Even for families who successfully cast lifelines, the connections were temporary, dependent on the child's needs and length of life. Some children were severed from all services if the child's health status improved, or upon the child's death. Once services were terminated, the lifelines were cast back. If the child lived longer than expected, then the family was no longer eligible for end-of-life services, such as hospice. One mother remarked how her child had had an end-of-life plan for five years, and had moved in and out of using CFK services multiple times:

> Miriam (mother, Family 7): Mikey's had an end of life care plan for five years now, and we've been told at least ten times he's got 24 hours…We started with CFK only for about a month or so, because Mikey had been placed on end-of-life care at that point. They're actually working with us again now. We'd graduated

> at one point and were off a bit. Now we're back on that list, because we'd had - Mikey was [in hospital] predominantly for about six months. We had a number of spells, so we started end of life care again a few months ago.

Some families found out quite accidentally about other services available to them, by connecting with other families or through watching a show on television. It was often in passing another child in a wheelchair, for example, that parents concluded that their children might share a common fate, and they cast a lifeline between the family boats. The connecting of lifelines facilitated families learning about services that could help them. Jessica's mother had seen a television show about a family who had received aid from a government program. In turn, Jessica informed another family whose child was wheelchair-bound about the services:

> Jessica (mother, Family 6): I was talking to her about that and because she's like, "Oh well I can't find a provider." And I said, "Well why aren't you his provider?" And she says, "They'll pay me?" And I said yes and she goes, "I didn't know that."

Having spent so much effort in trying to connect with other vessels, families were drained and felt alone, yet again; often, they decided their energy was best spent working on only their own boat and trying to manage their own situation. Inability to successfully cast lifelines left families alone and isolated. Although many families' small boats may have been connected to one large service vessel, little opportunity existed for families to cast lifelines to each other. Confidentiality policies and privacy acts that were intended to protect families, in fact isolated families form one another, and each endured its journey alone. Once a family's lifeline was removed they were again, alone. Some families maintained a continuing thread with the agency staff, through email lists and occasional phone calls, if the staff continued to work at the agency.

Sailing Alone

Families who were not able to cast lifelines successfully, whose lifelines were severed, or who were not provided lines to cast, sailed the ocean waters alone. Families that did not connect with others became lost at sea, hoping that someday they would intersect with another vessel as they traversed the unfamiliar ocean. Those who had support at home during their child's illness found that in bereavement, the support services were minimal and time limited. Lack of formal support groups left families unable to connect with each other. Thus in their grief, they received even less support than when their child was living. They had to recast their lifelines by themselves once again to a different vessel that might offer some support to grieving families; however, at this point in the journey, families were exhausted, grieving, and needing to continue to manage their boat. They were in need of support services that came to them, rather than services they had to seek out. A few parents maintained a thread of continuity through e-mail lists or on-line support groups; however, parents did not view such contacts as support.

As families became isolated in their care-giving, their burden increased. This was particularly true for families who had initiated end-of-life care, but whose child defied all expectations and survived. Such children were frequently one admission or one infection away from end-of-life, and the families had experienced the death and resuscitation of their child multiple times. The toll on these families was tremendous:

> Miriam (mother, Family 7): This is having a medically fragile, disabled child. Anything in that realm, it takes such a toll on a family. It's financial. It's emotional. It's physical. It affects everything that you have and not being able to escape that at all, it just eats away at you.

In their isolation, parents felt the care of their child was solely on their shoulders. Sally described a situation when she had her disabled teenage daughter on the floor to change her diaper:

> Sally (mother, Family 10): When I got ready to lift Savnannah back up, I couldn't get her up. I'm by myself and I'm like, "Oh no, what am I gonna do, Savannah?" And she's got this cast on and she got- and I'm like, "I can't lift you." And uh, she there down on the floor [sic]. So I'm looking and I'm thinking, "What am I gonna do? How am I gonna get this child up?" You know? So actually, I had to hurt her a little bit 'cause I know she was screaming a little bit. But I had no other choice to- and I rolled her to the sofa to get her up to the sofa. And they always told me I shouldn't pick her up under her arms, but I had to get her up. I had no other way I could get her up. And that would just scare the daylights out of me because I was really- we were on the floor for maybe 45 minutes. - I was wondering, "Who can I call to help me get her off the floor?" But I never put her back on the floor again.

Sally described what many parents pointed out -- that they were told what they were supposed to do, but not necessarily how to do it. There was no one Sally could call, she lived alone with her daughter, and she was on her own trying to figure out how to safely move her daughter to the sofa. Families struggled, some for years by themselves, trying to sail the ocean waters. The repeated futile attempts at casting lifelines necessitated families working harder to manage their crew and successfully sail the boat. The risk of not working together was capsizing and being separated from each other in an ocean where chances of rescue were minimal. The unsuccessful casting resulted in either sailing back to shore or being lost at sea.

Sailing ashore. Families who were sailing alone found it impossible to repair the boat, manage the crew, and cast lifelines; they were at great risk for capsizing. Some families simply could not stay afloat any longer; they dropped their oars, and let the waves carry them back to the river delta. These families were overwhelmed:

> Carol (mother, Family 9): Because you've got to have your sanity 'cause you wanna spend the quality time and, you know, you've gotta be in balance…. And I knew that it would strain our marriage even more because we would be at each other. We'd be tired from work, then it's like, "You do it, you do it. No, I'm not gonna- here she goes again!" … You- you'd go nuts. You would go nuts if you were the caregiver for the 24 hours/7 days [a week].

After their infant was discharged home with little preparation and no lifelines to other services, Carol and Charlie tried to manage their life for a full weekend and realized that they could not both go to work on Monday. They realized their child needed care 24 hours a day. The reality of their child dying on the boat and what that would mean to them and the sibling was clearer once they set sail on their boat. They realized that death at home was not an option they wanted to exercise.

> Charlie (father, Family 9): We did not want Carla to die in our house. I didn't want the image to be in Christopher's mind of, you know, carrying Carla out of

> our house in a, you know, on a gurney or something, you know, with a sheet over her. I didn't want that to be…his last images of Carla. And I'm like, "We can't- I wouldn't be able to live in this house thinking every day that this is where she passed away."

For other families, the rapid deterioration of the child's health brought them back to the river's delta:

> Fiona (grandmother, Family 4): We took him home, and six days later he hemorrhaged the first time…you know, we were so vulnerable at that…I mean, he'd actually hemorrhaged. They told us it was gonna happen, we knew it was gonna happen. We now know it's gonna happen. But it scared the shit out of us.

Although Fiona had been told that her child would probably die with the next hemorrhage, she did not think it would happen, and it was witnessing the event that made the family seek the familiar shores of the delta. They realized they could not care for their child at home.

Family 11 longed for the safety of the hospital, a place where medical supplies and interventions were abundant, a place that they had left for the unknown and they considered returning back to the hospital. Darla stated, "We considered taking the baby back to the hospital, you know."

Sandra and Jonathon returned to the hospital. Sandra found that after three weeks she was unable to manage her own medical needs and her child's along with those of the sibling. Her daughter's condition was worsening and Sandra felt the hospital was better equipped to manage her daughter's deteriorating health. These parents found the possibility of their daughter dying at home to be intolerable so they returned to the hospital. Jonathon feared that a death at home would mean calling the police and making a report, and having their daughter's body removed from them:

> Jonathon (father, Family 2): if she would have passed [at home], she probably would have had to go through an autopsy and they probably would have taken her from [our home].

Once back at the delta, these families reconsidered boarding the other vessel, the ship. All families who returned to the hospital after their initial stay at home subsequently chose to board the ship, George Mark Children's House. These families wished that they had chosen this option sooner, but they had not felt ready and also they did not understand what GMCH really offered.

> Jonathon (father, Family 2): I didn't like the fact that they wanted us to go to George Mark. Thinking back on it *now*, I probably would have took [sic] the option. I probably would have done that.

> Fiona (grandmother, Family 4): I mean, we were clueless. Had we have known, we would've been here a long time ago.

Having already tried to sail their home boat, parents were far more open to the possibility of boarding the ship. Although Fiona had been offered GMCH a "bajillion times", it was not until their return to the hospital after the hemorrhage that she was open to the possibility.

> Fiona (grandmother, Family 4): And we were really vulnerable and they just said, "Look, you need to go to George Mark. This is where you need to be." "Okay, fine. We'll go- we'll go check it out."

After her overwhelming weekend at home and returning to the hospital, Carol re-considered her options:

> Carol (mother, Family 9): And so I said, "Hey Charlie, I'm gonna-" my mom and Charlie were there and I go, "Listen you guys, these are our choices. I'm gonna call [staff at GMCH]. Let's just go check the place out." So I called her. I talked to her on the phone and she was like, "Just come. Bring her stuff, but you don't have to stay. Just come and check around and you can have dinner here and we'll talk and…"

When families decided to board the GMCH ship, they opened to the possibility of an experience vastly different from the overwhelming parts of their journeys on both the river and on their home boat.

Lost at sea. Families could not sail successfully without help. Those without lifelines or ability to sail back to the delta shore risked being lost at sea. Since all the families in this study were recruited from pediatric services such as hospice, all had successfully cast lifelines or returned to shore. However, in the struggle to cast these lines, even these families were lost at sea for periods of time.

> Sally (mother, Family 10): I didn't know where to turn. I was so, you know, I felt so alone at the time. So it was really, really hard and- and then trying to deal with her and I was really going into a deep depression… I just felt so- so lost and I

> didn't feel- I felt like I knew I was getting tired and burnt out… And- and overwhelmed.

> Miriam (mother, Family 7): I was completely drained…I'd been in and out of the hospital with Mikey…I just, you know, I'm trying to take care of my older kids and it was just like, I just couldn't keep up.

Many bereaved families were also lost at sea; family identity was compromised once lifelines to the service vessel were severed. Siblings did not know how to define themselves; parents counted their deceased child as part of the family, but there was no physical evidence of their child to the outside world. Parents tired of explaining that they really had three children, for instance, but that one was deceased. It was easier to simply nod when a passerby counted the number of living children, and so, the child's name was uttered less, and the memories became silenced to the outside world.

> Lisa (mother, family 13): People think you get over it. And I still- you know, I'll- it gets worse now. It's not worse, but it's kind of now to the point where you just stop talking about it to people. Even people you really were in tight with, you kind of don't talk so much about it because even I've noticed with my sister in the last year or two, she doesn't get it. And you kind of get to a point there's really almost nobody this far out that get it.

Families kept the memory of the child alive by displaying photos, keeping belongings, and talking among each other about the deceased child. However, this was a private family event taking place within the hulls of the boat. Parents described the consequences for being lost at sea as losing the family unit. They all senses that they could not maintain their boat afloat forever without help, and worried about the toll it was taking on each family member who was toiling to simply keep the boat afloat:

> Miriam (mother, Family 7): Too many people I think don't take the opportunity [of using available services], and marriages fail.

Miriam felt her marriage had nearly been lost during the two years she was doing everything by herself. Other families were concerned that without support they would not be able to maintain their ill child at home:

> Trish (grandmother, family 8): [Crying]. …if we were to put Tim in a facility, it would be in- it'd have to be in Sacramento or in San Jose. There's nothing around here. Um, he could go to um, a group home type environment, but then it would be foster care….Then we'd lose all control… But it's hard when, especially when, if you can't get anybody.

Providers sometimes encouraged parents to institutionalize their child as the condition deteriorated:

> Sally (mother, family 10): Some of the doctors had already kept mentioning I should put Savannah in a residential facility. So they said, "You know, it's gonna be too hard to handle her, so you should think about putting her in a residential facility."

Instead of providing guidance as to how to cast lifelines that could help families, providers offered options that would further jeopardize the family. Grandmothers, who had taken over the care of their grandchild, blamed lack of support as the reason for their daughters' inability to continue caring for their ill child. Earline describes how gravely ill children can become neglected by their parents:

> Earline (grandmother, Family 1): Maybe they're [ill children] being left in the room alone because the mother or the father is angry because this system treats them like shit. And see that's- and I think I can go back there because I watched my daughter mistreat my grandson due to the fact she didn't- she had too much pride. She didn't want mama to help. She was hurting on the inside because Spikey was this way. So she was mad at me and you know, but look how God worked it. Now I'm raising him.

Families could sail alone for some time, but if they were lost at sea, they could not remain an intact family unit. Being lost at sea meant the possibility of drowning. All parents believed that someone, either another family or a well-meaning provider, had rescued them from being lost at sea.

> Sally (mother, Family 10): You need to ask for someone to grab your hand because together you're stronger. But if you stand out there alone, you- you- you'll drown. You know, you'll go into a deeper depression…For a parent to feel like, "I can't deal with this child. This is my child, but I can't deal with her." They feel hopeless. They feel there is no hope- help out here. But that's where parents need to get together so, you know, you could tell each other things.

Parents asked me if I could share their information with other families so that they could connect with each other. They wished for a database through which they could search for families in similar circumstances and who resided nearby. Parents understood the confidentiality and privacy protections, but desired to waive those rights so that they could connect with each other. Families felt the support groups they had found were unhelpful or short-lived because participants had not had similar experiences:

> Sabrina (mother, Family12): If [support group] had been something affiliated with Comfort for Kids, I might've done it, especially because we would've shared that common thread of using the hospice. Yeah. Well -a child that you lose in a car accident, you know, is a lot different than the child that you are with them when they died. And no situation is of course easier or harder. They're just different. And I think that's what ties the Comfort for Kids families together and would've made a difference for us.

Some families found private counseling helped, but they still found that ultimately they were leaning on each other for support, unable to get their needs met outside their own boat:

> Lisa (mother, Family 13): We had counseling through Hospice and um, sometimes the gal would come here and uh - we had sibling bereavement um…that gal came- for the first six months after Bobby died, she came to the house every two weeks. And I loved her, they loved her. I cried when she wasn't coming anymore, you know.

The grief did not end for families after six months, and they felt the need for continued support although none was available. There was a need for a tangible connection with another family facing a similar plight in order to continue sailing:

> Sabrina (mother, Family 12): I think the biggest thing would be to connect the parents of Comfort for Kids with each other. And I'm trying to think, even through email, the phones calls…we didn't even answer our phone for like two months. It's too invasive… You wanna be able to do things when you're ready to, so like, an email from a buddy family, and I know, I would be willing to do that

> for someone else, and I imagine there's other people who'd want to do that for someone else too. But you know, to send an email and say, "Hey, I've been set up as your buddy family, this is my story, this is how, you know, I used Comfort for Kids, here's my number, and I'll email you back in a couple of days and see how you're doing,"

During the interviews, families volunteered their phone numbers, asking me if there was a way I could connect the families with each other after the study was completed. The need to connect with other families and maintain lifelines was essential to families' ability to stay afloat and sail the ocean waters.

Aboard the Ship

The experience for families who boarded the ship was markedly different from the experience of boarding the home boat. Families who were ready, and had received information from a trusted provider, or who had sailed ashore after attempting to sail the ocean on their own boat, were open to the possibility of boarding the ship. The majority of providers who were encouraging families to use GMCH had very little first hand experience with the services, and as such were not able to give detailed descriptions of the services offered.

Taking the Tour

Taking the tour was a non-committal way of families "checking out" what GMCH had to offer. Some parents went alone and reported back to the family, others decided to go with their child on their first visit. Some families were not able to take a tour due to distance; their first visit was the first admission. Knowing they could return to the hospital or home, or thinking of GMCH as a bridge between hospital and transfer to home was comforting and crucial to parents taking this first step.

The tour provided a stark contrast to the hospital setting, and families began to compare the GMCH and hospital environment. Until setting foot on the GMCH ship, families had no measure by which to judge the hospital setting. However, the tour gave them a glimpse of other possibilities. Of the ten families that used GMCH, eight took a tour before deciding to admit their child. The tour introduced them to a world beyond what they had imagined and solidified their decision to choose GMCH. Parents felt as though the hospital staff's descriptions inadequately captured the marvel of GMCH, which they perceived as a resort, a fantasy land, or a luxury ocean liner:

> Earline (grandmother, Family 1): At George Mark's the rooms are beautiful. It gives you "Oh wow!" It's like a fantasy land. It's like going- for a normal child to go to Great America…
>
> Mark (father, Family 7): It was just a whole different world… At George Mark it seems like it's always a celebration. It's almost like a child's-type Mardi Gras.
>
> Sally (mother, Family 10): They have these names on the rooms and they so adorable and I'm like, "Wow!" And I'm looking at these rooms and- and it was just- it's just like a fairyland in there… I'm telling my sisters and my family about this place. I said, "You gotta see this. It's like a fairy tale. It's like wonderland. It's like ah, yes!" And I was- it was just- you know, I think it was godsent….

And- and how bright the rooms is and how beautiful the scenery is. I- I just fell in love with it the moment I saw it.

Paul (teen patient, Family 5): And then they told me about that, how they have a pool table and some games, and I go, “Oooh, I’ll go there.”

Max (sibling, Family 7, age 9): It’s the best place in the world.

Jessica (mother, Family 6): Oh was nice! We didn’t want to go home. The kids didn’t want to leave. They were out playing on the playground so they thought it was great, they wanted to get in the spa so they didn’t want to go home. My mother-in-law loved it. All the rooms are great the way they’re painted. Nothing like the hospital where it’s sterile, where it’s white and there’s nothing to look at.

Sandra (mother, Family 2): And just the setting around George Marks with all the nature and birds, it just feels like you’re in some type of holy place or something.

Miriam (mother, Family 7): We call it his spa.

Trish (grandmother, Family 8): You pull up to the gate and you look at it and you think, “Oh my God! This is not anything like out there.” This is another world of its own… They even have the suction equipment behind pictures in the wall. And

> I thought, “Well, you know, what more can you do for a child than to keep that stuff hidden away from them-to- to keep them from being afraid.”

Parents were impressed with the environment, specifically the beauty of the home, the rooms, family apartments, and especially the grounds. To be able to take walks and to be in a peaceful tranquil place that Earline described as, “freedom from toxic places.” As well, during the tour parents met staff, volunteers, and other families. They felt a deep sense of community and of being understood from the beginning, and that help was finally available, and they were no longer alone:

> Jessica (mother, Family 6): Well when we were on the tour we actually talked to another family that was there, I think it was their first day… they said it was great. They said it was nice not being at their home because they weren’t worrying about doing their laundry and paying their bills, they said they were relaxing, playing in all the room, having a good time, playing outside and they said we wouldn’t have to worry about all the other world stuff, just worried about him.

Taking the tour, or visiting GMCH with the family, sealed the realization that this place was a different world from anything they had imagined. Here, they could focus on their child and the whole family instead of the illness and daily management of running a household.

Facing death. Parents equated GMCH with death, and there were reminders of death at GMCH. In particular, the tour included viewing the wake room, which some families referred to as the “cold room” or the “George Mark room”. Indeed the room is cold, cold enough to preserve the body for three days post mortem. The room looks just like a child’s bedroom. The deceased child can be placed in the bed, and he/she will appear as if sleeping, especially to siblings. Another large bed is in the room for the family to sleep in if they wish. The room is beautiful but the cool temperature is a reminder of its purpose:

> Earline (grandmother, Family 1): But not until George Mark's did I have to look death in the face. And to see this room, it was like- beautiful as it was, it was like - reality… It was the point of death. It was the point of death.

The tour of GMCH brought them face-to-face with the inevitability of their child's death. A wall of photos showed faces of children who had spent time at GMCH, many of whom had since died:

> Jonathon (father, Family 2): And when I walked in, it's like a wall - With all of the children and I think all the kids on that wall had passed… most of those kids had passed. And I'm like,"Oh, God." Is this - this like a place where - you know, elephants have a graveyard they go to before they die. I don't know if you know that. And I don't know how they know when they're going to die, but they go there and they spend however much longer it's going to be until they die there. They don't leave.

Although children could be at GMCH for respite, palliative care, or transitional care, it was clear that they all shared something in common: limited length of life.

> Miriam (mother, Family 7): And, you know, we all know. I mean, we - at George Mark, you know, there's the club of us. As parents, we'll be sitting there, you know, having dinner together or whatever. We talk about the fact that we're in a club. We're all dealing with different diseases, we're all dealing with different disabilities, we're all dealing - but we're all in a club. We all know at some point

> our kids are not gonna be with us any longer, whether that's another year, whether that's another couple of weeks, whether that's a few months, whether that's in 10 years. We are a different club of people, you know.

It was precisely this "club membership" that brought once isolated families together as a community. They had all faced the possibility of death and were now at a place where death actually occurred. Acknowledging that GMCH represented a place where children died was necessary for families to *be ready* before taking the tour. Knowing that other families they meet were going through something similar created a sense of belonging at GMCH.

> Sally (mother, Family 10): I felt like, "Wow, I'm not alone."
>
> Fiona (grandmother, Family 4): I'm not- I'm not alone.
>
> Sandra (mother, Family 2): And it was hard going to work because I would see pregnant women there, and women that had just had their babies, knowing that my daughter was in a situation that she was in, and - but it was really a nice feeling, being able to go to George Mark's and saying, "Help! Help!" Help is here. You know? These people are going to help us.
>
> Earline (grandmother, Family 1): They made me feel like, "God! I'm not in this battle alone."

Living on the Ship

Although families equated GMCH with death, and the tour provided reminders of that grim reality, what struck parents was the *life* that filled the home. This was a place where living occurred, where children could live until they died. The language of the interviews changed dramatically from a focus on describing the illness and details of the medical care, to descriptions of living: eating, sleeping, and playing. GMCH provided families with a place to be together, a place for spending quality time without the burden of home care and without the sense of isolation at the hospital. Ironically, GMCH was place for the children to die, but it was the place where the child and the family started to live again; it was a place of living until death.

After their hospital experience, families were cautious, their guard was up, they closely observed the staff interactions with their child; they ate alone in the child's room and the idea of eating together in a cafeteria or eating as a social event, a rusty memory:

> Charlie (father, Family 9): They encouraged us to eat at, you know, set times with everyone in the uh, you know, in the dining room. And we didn't do that at first, you know, because we were still kind of acting, "You know, hey, this is just a horrible, you know, kind of hideous thing that has happened to us and we're gonna deal with it on our own." But you know what? It- it took time to kind of come out of that shell and- and go and kind of, you know, sit with everybody and socialize and know that everybody- other people were dealing with the same thing. You know, it's every parent's nightmare. And so, you know, it took time to kind of break that shell open. But it broke, you know. It- we broke it open and um, it was because of the- of the staff and everybody.

Soon, families began to feel comfortable at GMCH, venturing away from the bedside, spending time with each other in the playroom, some returning to work, feeling peaceful and safe. Parents talked about 'living' at GMCH, and moved in with their whole family, even extended family. Eating, playing, and sleeping themes dominated the interviews:

> Carol (mother, Family 9): The last two weeks I think we didn't have [sibling] going to school. We just let him stay here with my mom and he played all day- because there were a lot of volunteers. That's what's awesome about this place. Um, people would do art with him. He could watch a movie or just all sorts of people around. Oh, it was so amazing! So amazing! They'd come play music. And so…I mean, it was just there was so much. And then of course it was just nice to have your meals. We could do our laundry here. I mean, it was like I- we weren't having to go home early. I mean, I would go home to get the bills- -and the mail and stuff, but that was it. We could entertain - for lack of a better word - meaning that, you know, if so many people- friends, family-They'd wanna come. So- And, you know- I mean, it just- you know, if it was at your house, I mean, it just couldn't happen. We would wanna straighten up and- You know, it couldn't have happened- And they would come here and you could- you could still carry on as a family. And not worry about like having them- stress out.

The pace slowed down, families had time to think, enjoy each other, and no longer lead split lives; they were living together as one united family at GMCH:

> Sandra (mother, Family 2): When my daughter got to George Marks, her brother was able to bond with her, because we were able to take her in our room, and just act like a normal family, even though we were in a different setting. He was able

> to hold her, kiss her, you know, He was able to, you know, - wherever she was, he could be. And that was really nice.

Parents began to take pictures, enjoy walks together; one family celebrated a first birthday party knowing their child would never reach the next birthday. During the interviews, families pulled out albums to show me photos taken at GM, and how a professional photographer had done family photo shoots capturing their life together. Families had very few photos had been taken at the hospital; most were taken at GMCH.

Jim shared that he had not even thought about using his camcorder until he got to GM; his one regret was that he wished he had captured the times at the hospital too, but he had just never thought about it:

> Mina (mother, Family 3): 'Cause you don't realize at the time, you know, you take some pictures and stuff and then took 'em mostly at George Marks. 'Cause I'm like, "No, we'll be fine. We'll have plenty of pictures." And then when we ended up there, I'm like, "We need pictures of him. We don't have that many pictures of him."

Sharing mealtimes and having meals provided was a central aspect of living at GMCH. All ten families that spent time at George Mark described the food in great detail.

> Jessica (mother, Family 6): And I gained 5 pounds in two days eating in the kitchen. Their cook is really good- really good and they always have cookies in the kitchen. You can go in any time and get cookies.

Paul, the one patient included in this study, who had been hospitalized many times, spent the majority of his interview focused on the food:

Paul: [George Mark] food is really fresh, it's not hospitalized food– it's fresh. I mean, last night I had steak for dinner, it was great. Hospital food it's – it's the same stuff every day, *every day*. I mean, you have a menu to go through, but after the second day you already know what's on that menu because they'd have like pancakes, hard boiled eggs, Joe's special eggs – that's really gross, oh, don't get it, yuk –I mean it – there's not much to choose from. It's the same stuff every day. You get real tired of it. But here, it's different. Like when I first got here my first meal was chicken. This is my second chicken, in a week since I've been here. And it was the first steak being here. I had lasagna here. I mean, it was – it's homemade. I mean, they buy it from the store, they bring it, and they cook it up and they serve it; it's home made. It's not frozen food. I mean, it's not like – it – hospital food tastes like somethin' that someone put in a blender, and grinded it up, and poured it out for you, and told you to drink it. It tastes like crap. I mean, I'm not gonna lie, I don't like the hospital food. But if the hospital food could have the food that they have here, I would have no problem with it. Plus they don't – they don't give you a very big plate. They don't – you have to ask for seconds, which is understandable, but you have to wait 20 minutes to get your second plate. So by the time it gets up there you're more hungry.

Jonathon (father, Family 2): And that cook - I forgot his name, but he cooked for all of our family. It was about - it was a lot of people. My mom, her mom. Her sisters. My brothers. My sister. My nephews. Uh, he cooked for everyone. He cooked for my whole family that day my daughter passed.

The provision of meals was missing from families' hospital experience. Only the patient received food, parents were left to fend on their own, which became expensive, and most of them ate hurriedly, rushing to get back to their child's room. At GMCH, not only were meals deliciously prepared, but also parents did not have to grocery shopping, cook, clean, or eat separately. Families ate together, and guests were always welcomed. Families' spontaneous focus on food during conversations in the interviews about GMCH indicated the level to which parents felt cared for, and why they likened the experience to that of a resort, hotel, or spa. The experience of living at George Mark was like sailing the ocean on an all-inclusive cruise package.

Additionally, there was constant entertainment in terms of play, art, music, which the children enjoyed immensely:

> Jessica (mother, Family 6): When Jerry was there they had a guy that came in and played guitar and they said, "Oh Jerry just loved him and his guitar," and then he took off with Jerry and they're somewhere, the guy took off and was just taking off with Jerry, playing with him, playing guitar, they were having a good time together.

> Sally (mother, Family 10): But these kids they have a life. They- they- they- they love music and- and soothing and touching and massages. Savannah loves the spa. She loves- I mean- she comes alive. And all she's, she's speaking through her motions, through her face, her facial expressions. And- and that's how she gets her joy. You know? She's living every moment just like you and I.

> Sandra (mother, Family 2): You know, and it's like they're actually able to be children and be ill at the same time. You do not get that in the hospital.

Families described about how they played together as a whole family:

> Fiona (grandmother, Family 4): For me and [my daughter] to be able to sit down and play with pencils together. You know? And this place helped that. It- it instigated, it provided the setting for that to happen. And whether it- you know, whether we knew how to play before or not, it still gave us the opportunity, you know, to grieve over [grandson] and to- to do it in- in a bunch of different ways.

Siblings felt particularly bonded with siblings of other sick children through play and sharing similar experiences. When asked about what he liked best about GMCH, Christopher, an eight year old sibling replied, "The playroom. They have a pool table, and - those things where you can be like red or blue and hit - smack the ball around. And ---uh ---they have a --- a play station, and yeah."

Other siblings had similar experiences:

> Jenny (sibling, Family 6, age six): We went there for Halloween, we got to see the - We got our face painting. We got to paint a pumpkin.
>
> Max (sibling, Family 7, age 9): Like I want to bring my friend out to George Mark to show him how - what it's like. 'Cause at [hospital] you can't like really like run around, be free - you can't be off a leash. But at George Mark you can be off a leash, you can go do what you want without like having somebody always holding you back. Like having - like putting your dog on a leash and tying it up to the pole. That's like having your dog not running around doing anything. But if you let your dog just like - when you go to the mall and you can't let your dog

> inside, you just take him off the leash, let him like run around and go do his own stuff.

> Matthew (sibling, Family 7, age 14): For me it's more like an arcade. You can do whatever you want pretty much. You can go to the jungle gym. You can mess around in the - with the pool room, mess around with computers, you can go outside, play basketball, nice little field.

At the hospital, siblings missed spending time with their ill brother or sister. At GMCH they enjoyed living together again with their whole family, and they drew comparisons to the hospital setting with its many rules and confined spaces. They received attention from staff and other families, and interacted with their ill sibling as they would at home. They met siblings who were experiencing similar circumstances and they formed friendships with other ill children and well siblings. When describing GMCH, siblings hardly spoke of illness; they focused on the fun they were having and they things they could *do*.

Parents too engaged in activities that helped them build relationships among one another. This bonding continued through bereavement, as families could continue to participate in activities and events, remaining connected:

> Sally (mother, Family 10): George Mark also have [activities] where they meet up. The parents get together for barbeques, for picnics and stuff like that, you know? So it's really, really, really the best thing that could've happened to me.

> Sandra (mother, family 2): And then you make friends with the other parents that are there.

> Mark (father, Family 7): And through that we have also met friends through George Mark.

Sailing Together

At GMCH, families no longer sailed alone; they sailed together as a community, where the families and staff were all like family:

> Max (sibling, family 7, age 9): When you're at George Mark, everyone is your family.

There was this sense of belonging and peace, and safety. Fiona, the grandmother in Family 4 stated," I feel safe here." Families felt that they were traveling this journey together; decisions would not be imposed upon them because the family was truly at the center of the care which was described as loving, heartfelt, and personal.

Here aboard the GMCH ship, not only were families together, sharing common experiences, but their homeboat was connected via a permanent lifeline, buoyantly floating alongside the mothership. Families received guidance on how to make repairs, how to care for siblings, how to navigate as a crew. The families could return home, knowing that they could re-board the ship whenever needed. In fact, families could even leave the child aboard, and stay on their home boat, taking a much needed break from the constant round-the-clock care that the child needed. George Mark offered counseling and support to everyone in the family, as well as remembrance days in which families participated during bereavement. The lifeline was permanent and provided families with a sense of security and companionship. Families received the message that George Mark would always be there for them:

> Fiona (grandmother, Family 4): [The director] said, “We’re here for you. We won’t let go of you. We’ll hold on to you as long as you let us.”

Partnered caring. At George Mark, parents felt that caring for a child is partnered where decision-making was a family-led shared process, and where nurses served to strengthen the family unit and support them through their journey. Families felt genuinely cared for, as though the staff cared for the child like he or she was their own. GMCH was like a family that wholeheartedly adopted other members, embracing the “forgotten ones,” and coating them with love. Parents felt that the staff members were extraordinary people who offered care different from care they received elsewhere:

> Earline (grandmother, Family 1): Everything at George Mark’s is heartfelt. Nothing is- or I haven’t yet run across an artificial person. They all- they volunteer because they love it. The nurses work there because they love it. And I know they- they go through things too. But it takes a very special person to walk into George, the doors of George Mark and put their problems behind to come in and take care of what the world don’t accept. And that’s what won me over.

An overarching theme of *being cared for* characterized family members’ responses. They felt the staff loved these children; they worked at GMCH because of their love, not a paycheck (contrasted with hospital staff by families), that staff could become emotionally involved and that was acceptable:

> Jessica (mother, Family 6): Well you know some of the nurses at the hospitals don’t like to listen to you. They’re just not friendly; they’re just there to do their

> job until they go home. Not at George Mark they're - they're mostly there not to care for the kids but to play with the kids you know so they keep 'em entertained and in between they slip in the care you know while they're not looking…At the hospital that's all they're there to do is give you meds, feed you and make sure your diaper's changed. They don't, you know, it's not based on any portion of fun. "We're here to make you well and send you home."

> Trish (grandmother, Family 8): It's like "we're here for him. We're here to take care of him. We're here to love him. We're here to play with him. We're here to do whatever he needs. It's not about us." We felt- it felt almost like- you know, at the hospital you know they care about the kids, you know. But they're busy and they're doing a job.

Nurses were partners in caring; they did not simply *give* care, they *offered* it while always respecting the families. There was no hierarchy. Parents consistently stated they were always asked by staff what they (staff) could do to help, rather than being told what needed to be done:

> Earline (grandmother, Family 1): They never just walk in your room without knocking first. You know what I mean? They never force things on you. They let you come to them, you know? They put the help- the offer out there and let you come and receive it.

> Mina (mother, Family 3): At George Marks you got nothing but, "Is there anything we can do for you?" And any explanation- you got that whole personal

> feeling…where they cared. Where the other ones you know they're just there doing their job and they really don't care that much at all. And uh, I think that's what's more special too about being at George Marks. Where the nurses at George Mark they cried with you. They hugged you. They- they- they helped so much.

> Trish (grandmother, Family 8): When he was there at the George Mark House, you feel like they're there because they wanna be there to help him, almost like even though they're getting paid, except for the volunteers, it's- it's like you're doing them a favor bringing your child there. The whole time, from the time you check in till you leave, you feel like they're- you're doing them the biggest favor by bringing your child there. And it really takes a load off to know that.

Families trusted the staff to care for their child in their absence, much the way a captain can rely on the first mate for managing a ship's voyage:

> Fiona (grandmother, Family 4): And…if- if [his death] would've happened while I was gone right now, I know that the people here would've loved him, really loved him. 'Cause I know… - I mean, you know, there are nurses at [the hospital] and I know most of them care, but it's- the nurse side of the scale is heavier than the love side. To me. It feels like these people *love* my grandson; they just *happen* to be nurses.

> Carol (mother, Family 9): You know, it's like you have someone there that wants to hold her so you can have a break. And it allowed Charlie and I to go- you

> know, Christopher was gonna be entering kindergarten that next year, so we had to go like meetings after work for that and get him registered and…we still were doing our regular scheduled [chuckles] stuff.

> Miriam (mother, Family 7): In the hospital, I'm not confident with nobody being [at the bedside]. At George Mark, I can leave and know that he's okay. That's the difference.

> Earline (grandmother, Family 1): I just had total peace. But like George Mark's I really can come home and go to sleep and rest all night. I totally trust this place with my grandson. And I know that if he's there, I don't have to worry about a thing.

Families felt they had found true peace, particularly noteworthy for these families who felt as though they had never had a break since the child's diagnosis. With the breaks and trust at GMCH, families felt as though they could once again focus on each other, strengthening their bonds:

> Miriam (mother, Family 7): And it's what's really helped us. It's saved my – you know, helped save my marriage and keep my marriage going strong. We've been married 15 years… So I really like that about George Mark 'cause it's – you don't feel as alone in the world of dealing with this kind of stuff.

The transition to GMCH marked the end of medicalizing the child and the beginning of humanizing the child and family. The impersonal care associated with the hospital was replaced with personal partnered care:

> Jonathon (father, Family 2): she's going to be uh, not only taken care of according to standards, but you know, on the other hand, you know, she's going to be loved. I mean, they pick her up. They kiss her. They hold her. They hug her. They do all of that. And she can *respond* to that.

> Mark (father, Family 7): Nobody treats him as he's a patient. They treat him more like family.

> Paul (teen patient, Family 5): They made me feel like I was at home, it was really nice. I mean, they asked – they wouldn't bother me at like 3:00 in the morning to put in an I.V. No, they let me get my sleep, which was great, I loved it… At hospitals I hardly get sleep. But here, George Mark, I've been sleepin'- no problem. And at the hospital – they get annoyed – the nurses there get – I'm gonna be honest with you, they get annoying, they get on my nerves. I mean sometimes I wish that there was a lock on the door so I couldn't let them in. At George Mark they'll do their best to make you feel like you're at home.

Families felt as though they were truly at the center of care and decision-making at GMCH. This was both liberating and burdensome for parents: liberating compared to previous experiences at the hospital or home, and burdensome because they felt the sense of responsibility in allowing or disallowing treatments. Sandra felt that it was great to hold one's baby in one's arms as the last breath is taken, but it was also hard to take that responsibility and let it happen without releasing an urge to scream for resuscitation. Jim could not imagine his son dying in the hospital; nor could he imagine him dying at home.

He asked me," What are you supposed to do when your child dies? What do you do when your child dies? Do you pick up the phone and call the police? The ambulance?" Jim did not have to consider those questions because when his child died, he had to focus only on his emotions because GMCH took care of everything else. They got to hold him for three days after the death in the "George Mark Room".

After an incredibly grueling journey on the river, and the stressful decision making process in leaving the river's delta to sail the ocean waters, families finally found a community where they belonged. Together, families shared the circumstances of facing a child's death. Although mostly invisible to society at large, families found themselves members of a community sailing together as an armada of families who comprise this 'different club', connected with lifelines not only to the mothership, but to each other. Through George Mark, families had a lifelong companion and community for their journey on the ocean waters.

Summary

The life of families in this study was markedly different from that of families without children at the end of life. Their journey led them to the ocean, an expanse of water far different from the river of life they had expected to sail. Although they were unprepared for this journey, families were able to cast lifelines and connect with support services. Those families that chose GMCH found a permanent lifeline, whereas families who chose homecare had temporary lifelines that did not support their boat on the ocean of ongoing care of a child at the end of life, nor during bereavement. Without a community to which families can belong, their sense of isolation increased. Families received the greatest support at GMCH where their daily needs and the medical management of their child was taken care of, and they were able to transition from simply *surviving* to *living*.

CHAPTER SIX: DISCUSSION

In this chapter, the findings, limitations of the study, and implications for practice are discussed. This chapter begins with a summary of the findings, followed by a discussion of their relation to the purpose and the research questions of this study that were presented in chapter one. Next, the findings are discussed for their relevance to the current knowledge base of pediatric end-of-life care and how these findings deepen the current understanding of the family's experience. This is followed by implications for practice and research and the limitations of the study. I conclude with directions for future research.

Summary of Findings

Although all families had children of different ages and with varying diagnoses, ranging from cancer to neuromuscular conditions, the families' journey through end-of-life was remarkably similar. Through the experience of prolonged or multiple hospitalizations, parents learned how to become advocates in their children's medical care in order to secure the attention that they believed was in their best interests. As they learned who they could count on for reliable information and support, the families developed a network of trusted healthcare providers (HCP). At the same time, parents resisted alienating staff members they did not trust, for they recognized that such alienation would present barriers to their children receiving optimal care. Even in interviews, parents were hesitant to name HCP and hospitals about whom they had complaints, despite repeated assurances of confidentiality; they did not want their names related to their negative experiences in the hospitals. Through active involvement in their children's care, parents effectively established a community within the hospital, eventually expertly helping to direct the plan of care.

However, with the deterioration of the health of their children, parents had to make difficult choices about where they wanted to continue their care. They received little to no guidance in reference to making these decisions and, upon discharge, they felt abandoned by the community that they had developed in the hospital. Location changes were more like rearrangements, the focus of which was the *destination*, not the process of *leaving* the current location and *moving* to a new one. Bridges (2003) asserts that change is not synonymous with transition, which begins with endings, followed by a neutral zone, and then a new beginning.

In this study, the families involved were each ending a hospital stay, leaving a curatively focused environment for one that would provide comfort and support. It was an ending of a segment in each of their journeys. However, few families had a chance to consider what they were leaving behind. The findings indicate no formalized or guided transition process for families; the only transition process evident was for families that chose to go to George Mark Children's House (GMCH) from the hospital. Families who chose in-home hospice services or who chose GMCH for respite did not experience the transition process that families who chose GMCH from the hospital setting did. Choosing GMCH involved a process of letting go, whereas going home was related to being discharged from the hospital, not necessarily making a choice for ongoing support of a different type of care than the hospital.

Transition to GMCH

The only parents who were able to engage in a transition process in the hospital were the families that chose GMCH from the hospital setting. These parents had gone through a process of letting go during the final periods of their children's hospitalizations, as described by Bridges (2003), and had become ready for a different type of care. An explanation for why GMCH was the only location where a transition was evident may rest in the fact that GMCH was a choice; parents could accept or reject it as a site of care. Families did not choose to have their children hospitalized; each hospitalization had been necessitated by a medical crisis. Similarly, most of the families were not offered a choice in terms of whether their children could remain in the hospital. Despite the child's deteriorating health, he or she was determined to be stable enough for discharge to the home or, in the case of two families, having the child institutionalized in a care facility was encouraged.

The decision to choose GMCH depended upon where families were in the transition process. Parents equated GMCH with death, even if they had been referred there for transitional care only, and many found it difficult to accept their children's limited life expectancies. The findings indicate that the transition process was dependent on a triad of conditions: messenger, delivery, and timing. A trusted provider needed to deliver accurate information at a time when the family was receptive to such options.

Messenger

Only trusted HCP were deemed by parents to be appropriate messengers; unfortunately, parents generally received information about EOL options from HCP whom they did not trust. Parents were able to clearly articulate what characterized trusted HCP. Although multiple factors were involved, such as being members of the same generation, using the same slang as parents, and having the same hair color as their children, there were two characteristics that all families described as important: perceiving an emotional connection and no breaches of trust. Parents placed great importance on emotional connections with the providers, which were displayed in their actions, words, humor, kindness, and facial expressions. Families placed trust in their providers on the basis of these emotional connections and human, personalized care. On rare occasions, this type of connection occurred in the hospital setting, such as when a physician was visibly emotional when sharing grim news with a family, when a nurse used humor, when HCP disregarded a two-person visitor policy and allowed siblings to visit, or when a nurse made popcorn for a family, although doing so was against the rules. Parents described feeling more trusting of HCP who shed tears with them or hugged them These findings are echoed in another study (Contro et al., 2002), in which families indicated that they preferred to have a familiar person deliver difficult news in a caring manner.

Breaches of trust were remembered well by families; and they did not have confidence in HCP who had broken their trust. There was no indication that HCP could earn this trust back from parents. Families discounted all information from non-trusted HCP, even if it was accurate or potentially helpful. Jonathon (father, Family 2) refused to consider the pediatrician’s suggestion of transferring their child to GMCH because the pediatrician had earlier misinterpreted the child’s initial symptoms.

Delivery

The manner in which options were presented and the information provided affected how families made their decisions. The HCP presenting GMCH as an option to families had not visited GMCH themselves; therefore, information was vague and inaccurate. HCP seemed unclear as to what GMCH truly provided and some did not even know where it was located. Families were skeptical of information that was vague, and were not willing to consider the possibility of allowing their children to die in an unfamiliar house. Only one family chose GMCH as soon as they were presented with the option because they had received an adequate amount of information about it from a trusted provider. Again, these findings are mirrored in other studies that have examined parental satisfaction. These studies found that family members were dissatisfied with receiving confusing and inadequate information and placed importance on straightforward information that they could understand (Contro et al., 2002; Nolbris & Hellstrom, 2005; Wolfe et al., 2000)

Timing

The parents' decision was based on where they were in the process of *becoming ready*. The process for some families took longer than for others; some had to go home and attempt to care for their own child before returning to the hospital and choosing GMCH. One family in the study, Family 3, chose GMCH directly from the hospital, based only on their viewing of the Web site and their surgeon's recommendation. This lack of readiness on the part of some families may, in part, be explained by their being immersed in an environment (hospital) where curative and comfort measures were separated. In a system where cure and comfort are not integrated, parents are forced to *abandon* curative measures before being able to think about quality of life care. The requirement means that parents have to wait until options are exhausted; they must wait until their *one in a million chance* has been eliminated.

Some children in the study suffered from very rare diseases; in some of these cases, the HCP involved had little to no experience with the illness. Some parents felt that their children had a one-in--million disease; how could they not ascribe to the belief in a one-in-a-million chance for a cure? Since this chance had never been dismissed by physicians, it was their children's suffering and lack of response to treatment that drove parents to abandon curative measures. Wolfe et al.'s study (2000), which examined the experiences of families with children who died, found that parents were more disturbed by their children's suffering than by any other aspect of the situation. Parents' recollections of their child's suffering and negative events haunted them during their periods of bereavement (Contro et al., 2002; Hinds, Schum, Baker, & Wolfe, 2005; Wolfe et al., 2000). In this study, parents initially perceived abandoning curative measures as 'giving up.' However, after witnessing the suffering of their children, they viewed abandonment as "choosing quality care," not giving up. Parents did not stop hoping for cures; instead, their focus shifted to easing their children's suffering and increasing the quality of their lives. The hope for cures and provision for their children's comfort co-existed, a finding echoed in recent studies (Bluebond-Langner, et al., 2007; Wolfe et al., 2008)

The expectation that families had to become ready was placed solely on the parents. Parents were not guided in this process, and their children were often discharged before they were ready, and made ill-informed choices that they later regretted. Three families who brought their children home, later returned to the hospital, and chose to go to GMCH; they regretted not having chosen GMCH sooner. Family 3, which went there directly, wished that they had gone sooner, as well, but admitted that they had not been ready to consider that option when it had first been offered. The families had to let go of their endings in order to consider the possibility of a new beginning. Only one family had been able to do this within the hospital setting; the other families had to return home and experience managing the children's care, only to return to the hospital in defeat, and then be ready to try something new. These three families did not receive in-home hospice care; therefore, they were unsupported at home.

It is surprising that when discharging a child, a frequent occurrence in a hospital, no formalized transition process existed. While it is true that HCP may be more familiar with death occurring in the hospital than with discharging patients for an impending death, the percentage of deaths that take place outside the hospital is increasing (Feudtner et al., 2001); therefore, HCP should be preparing families for the home experience. In fact, one might expect that in hospitals, where the majority of childhood deaths occur or are pronounced (Feudtner et al.), the staff would be able to guide families through such a difficult experience much in the way families are guided through birth by midwives. However, the findings of this study do not support this assumption; instead, providers are curatively focused, pushing the technological imperative,[2] prodded along by ever-hopeful parents who hold onto hope for a one-in-a-million cure. In this study, HCP in the hospital setting expected the parents to manage on their own, while the parents assumed that they would receive guidance from healthcare providers.

Maintaining Family Integrity and Function

The study sought to understand how families maintained their integrity and function. The findings indicate that families needed communities of support that included continued care from HCP and connections with other families in similar circumstances. The lack of support was attributed to the fact that the sick child could not remain at home and the risk of the family unit disintegrating through divorce or because of the institutionalizing of the ill child. Resiliency theory informs us that each family has strengths that can be tapped into (McCubbin & McCubbin, 1993; Patterson, 2002). However, in the face of persistent adversity, the families in this study depleted their strengths. The reliance on strong intra-familial bonds was insufficient in terms of maintaining family integrity. With the passing of time and deterioration of the child's health, the burden on the family increased, and, as each sibling got older, their needs changed and the family routine had to be continually adjusted. Parental exhaustion in relation to this increased burden was evident, echoing findings in other studies (Davies, 1996; Gravelle, 1997; Vickers & Carlisle, 2000) which examined home care of children with life-limiting conditions; no studies examining resiliency in the experience of families with children at end-of-life were found. The resiliency framework helps us to understand that, if families are not able to adapt, then they risk falling apart, known as maladaptation (McCubbin & McCubbin).

The families' ability to adapt was further complicated by the grief they felt while the child was alive as well as after the child's death. Grief theorists and researchers acknowledge that family members construct a narrative that has shared meanings, and all family members have their own grief process (Aho et al., 2006; Arnold & Gemma, 1994;

Davies et al., 2004; Nadeau, 2001). Furthermore, meaning-making is recognized as a crucial part of grieving, through which family members construct an ever-evolving narrative that is influenced through the connections with others in the family's community. The findings in this study extend this theory from a family perspective, whereby parents described the sense of loss they felt at the child's diagnosis and throughout the trajectory of illness. As they searched for meaning, parents relied upon staff and other families to seek answers to questions and constructed narratives through sharing their experience with others. Siblings became more involved as the child's health declined, and through the support of hospice staff, parents recognized that each sibling's grief experience was based on his or her developmental age and ever increasing understanding of the concept of death. Siblings often spoke of their deceased brother/sister in the present tense, an indication that the deceased child actively remained a family member, a concept echoed by Arnold and Gemma. Although family members were not asked specific questions about grief, grief was the context within which the interview took place, thus participants shared their sorrows as they narrated their experiences. These grief-stricken families who were facing the potential death of their child could not simply rely upon each other for support; it was only by virtue of communities of support that they were able to maintain their family integrity and function. The location of care during EOL, death, and bereavement determined the type of support available to families.

Support during EOL

Hospital. In the hospital setting, family members were physically separated from each other. This separation brought about role changes, with fathers or extended family members caring for siblings and daily management of the household, while the mother/grandmother stayed with the ill child in the hospital. Siblings had to bear greater responsibilities in terms of caring for themselves, as well as helping in relation to the home, such as cooking meals. Families were in survival mode, subsisting from day to day, without being able to anticipate what the following day would bring. The parents in the hospital were isolated from the outside world, often spending months with the ill child, confined in his or her hospital room. They built their communities of support within the hospital.

Nurses were central in these communities, as they, much like the parents, were present round-the-clock. Such availability of care was a source of comfort to families, although it varied, based on the location within the hospital. Parents perceived the greater availability of nurses in the critical care areas, where there were higher ratios of nurses to patients than in other units in the hospital. In the acute care wards, parents were more concerned about how busy nurses were than parents whose children were in other parts of the hospital, and hardly ever left their children's bedsides, except for bathroom and cafeteria breaks. Parents, whose children received care in specialty units, such as oncology or critical care, described the nurses as *being like family*, even though they were able to describe specific instances where breaches of trust occurred. The incongruence between the families' experiences and their reporting satisfaction with the care has been documented in other studies (Contro et al., 2002; Wolfe et al., 2000). An explanation that has been suggested is that families of dying children may perceive that there is little that HCP can do to ameliorate the situation. Parents in this study felt that errors were the consequence of the busy hospital environment; they did not file incident reports, instead they changed their behavior by remaining at the child's bedside and taking an active role in the plan of care.

Another important component of the community of support involved connections with other families. In the hospital, parents met other parents of ill children, although they were not necessarily confronting the same end-of-life issues that the families in this study faced. The hospital did not provide formalized ways for family members to connect with each other. Instead, parents, and sometimes siblings, met in waiting rooms, bathrooms, cafeterias, playrooms, or, sometimes, with their neighbors in a shared room. Strict privacy regulations often prevented parents from being able to find out whether a child had a similar diagnosis to another and, as the children in the study were gravely ill, many parents spent time alone in isolation rooms that prevented them from being able to connect with other families.

Home. At home, families were finally able to reunite under one roof; however, many of the homes had to be altered, both structurally and functionally. In many families, fathers and siblings had developed routines which had to be adapted to make room for the mothers and the ill children upon their return from the hospitalization. Furthermore, the environment in the homes had to be changed to accommodate equipment such as hospital beds, suction machines, and monitors, in addition to supplies and medications. Bedroom and living room configurations had to be altered to center around the medical needs of the ill children. Mothers had to learn to connect with the siblings from whom they had experienced prolonged separations. The daily management of household routines continued, with the added responsibility of caring for the ill children's complex medical needs.

Families remained in survival mode at home. Although families were, once again, living among neighbors, friends, and extended families, they were isolated from the round-the-clock medical care that had been available to them in the hospital. They had lost their medical community and the community of families of ill children. It was only through connections with services such as Comfort for Kids (CFK) that they were able to maintain lifelines to the medical community. Instead of their care being only a call light away, it was now a phone call away, with a longer wait time.

This connection to home hospice was crucial in allowing families to stay home. The hospice nurses visited the child as often or as little as the parents desired. This placed control fully in the hands of the parents, in contrast to the hospital setting, where families had to move against the current in order to maintain control. Although parents lamented the hospice nurses' lack of expertise as compared to that of hospital nurses, after continued visitations, they developed trust in their assessment skills and their ability to meet their children's needs. One family suggested that Comfort for Kids be renamed "Comfort for Families," as the care that they provided encompassed the entire family. Being at home enabled families to reunite since they were no longer isolated from each other; however, families were isolated from the support of a care community. The three families that were unable to build communities at home and had not established care through CFK, could not effectively care for their children, and they returned to the hospital, back to their familiar medical communities.

George Mark Children's House. At GMCH, families were reunited with each other also, much like in the home environment. A key difference from the home environment, however, was the round-the-clock availability of nurses, who were always physically present, and the connection with other families in similar circumstances who were also at GMCH. Rather than merely surviving, the families there were living. It was their previous experiences at the hospital and at home that led them to perceive GMCH as a resort, spa, or as heaven.

The interviews that were conducted moved from a focus on the illness to a focus on eating, sleeping, and playing. Families members who had spent time at home after being in the hospital, and then chose to go to GMCH, articulated that being at GMCH offered much more than allowing them to be physically together. Having already attempted to manage life at home, these families were grateful for the daily household tasks they no longer had to attend to. They said that, at home, they sometimes did not want visitors since it involved cleaning their houses, having to provide food, and readjusting the children's equipment to make space for guests. At GMCH, all meals were taken care of, the hospice house was always immaculately presentable, and there was food for all guests. Families were able to maintain ties with friends and relatives. The focus was on sharing memorable moments, often captured by photos and videos. GMCH provided the staff and support which helped families to rebuild their relationships and enjoy the time that remained with their children.

Although the families' raving reviews of GMCH seemed implausible, each family consistently had the same opinion of the care, and similar positive experiences have been found in international studies examining pediatric hospice care (Davies et al., 2007; Ferguson, 2001; Hudson, 2003; Steele et al., 2008b). The nurses at GMCH were described as loving and delivering heartfelt care; their "love side" was heavier than the "nurse side", and as special people who just happened to be nurses. Families emphasized the fact that the nurses were not there simply working at a job or collecting a paycheck; they indicated that, in contrast, hospital nurses treated their work as a job. Through the hospital experience, families shaped their understanding of the nursing role as being devoid of love and caring, equating the scope of nursing practice with the skilled tasks of helping children to become well and discharged and remaining professional by maintaining emotional distance. These hospital interactions laid the foundation through which subsequent interactions were judged. Parents found the nurses at GMCH differed sharply from the hospital nurses. Parents felt that the GMCH nurses cared wholeheartedly, lovingly. The nurses were described as placing their own issues aside and being ready for the families; they did not unnecessarily intrude nor did they keep a distance or provide impersonal care. In the nursing literature, these qualities have been encompassed by the concept of *presencing*, which is synonymous with being present, and implies that people are *presences* to each other rather than objects (Pettigrew, 1990; Rushton, 2005; Zerwekh, 1997). It is the willingness of the nurse to wholeheartedly enter the other person's suffering experience. It means being willing to sit in silence, not knowing the answers, not being able to fix or heal a situation. Presencing requires removing the façade of professionalism to be vulnerable with the patient; it is to be offered, never forced, and considered a privilege. In this study, the GMCH nurses who cared for the families, exemplified presencing.

Support during Death

None of the families in the study chose the hospital as the location for the death of their child; they each wanted to be together as a family in a home-like environment. Of the 13 families in this study, six had already experienced the death of their children at the time of the interview and one child died shortly after the interview. Of these seven children, three died at home and four died at GMCH. How families were supported during the deaths of their children greatly impacted their bereavement. It is known that families whose children died sometimes regret what they decided to do or they wish they could have done something differently, and this can intensify their grief (Contro et al, 2002; Hinds et al., 2005; Kreicbergs, et al., 2004; Wolfe et al., 2000). All families in this study felt that they had made the right decisions about their children's deaths.

Home. The only families that experienced a home death were the ones that had in-home hospice services through Comfort for Kids. Each of these families was empowered by virtue of their choice of a home death because a familiar nurse who could provide both medical and emotional support at the death of the child would be present. The nurse's ability to pronounce the death meant that they would not have to call the police or figure out what to do next; the experienced hospice nurse would be there to guide them. This comfort was assessed as immeasurably important. Parents stated that they would have not remained in their homes had they not had that support; the round-the-clock availability of on-call nurses was the reason they chose CFK.

Parents worried about budget cuts that were going to scale back the nurses' hours to regular business hours; and agonized about how families whose children died in the middle of the night would obtain support. They said that such cuts would force parents to call ambulances and request aggressive resuscitative measures, which they otherwise would not have considered. Parents described having the urge to scream for resuscitative measures as they watched their child struggle for the last breaths of life. The hospice nurses were able to offer such measures, and were willing to support families in any way possible. The knowledge that the nurses were capable of performing CPR enabled families to make choices about remaining in the home at the end. In reflecting back on the death, parents stated that they would not have wished for the deaths of their child to have occurred in any other way, adding quickly that, of course, they wished their child were still living. The hospice nurses were instrumental in helping them to preserve memories, with suggestions such as cutting a lock of hair or placing clothes in sealed plastic pouches to preserve their children's smell. Such symbols are a crucial part of meaning-making in the parents' grief process (Davies, 1987; Gudmundsdottir & Chesla, 2006), and through the nurses' guidance parents were assisted in cultivating symbols that would help them in bereavement. Preserving such memories preserved the parental role and the child's place within the family, and enabled the family to learn how to exist in the physical absence of the child. Parents described photos, video footage, and clothing as some of the only physical reminders of their child, and were thankful to be able to open sealed bags and inhale the scent of their child. Meaning-making grief theories illuminate such parental behavior. Parents sought to continue their ties to the child by deliberately creating and preserving memories, and the expert guidance of nurses who recognized this process fostered the family's ability to make meaning. Stage theories do little to further the understanding of parental grief. In fact, parents mockingly stated which stage of grief they were supposed to be in; none were familiar with meaning-making theories.

George Mark Children's House. Much like the parents who received in-home hospice services, families which utilized the services of George Mark Children's House felt greatly supported at the time of their children's deaths. Not only were nurses physically present round-the-clock, but they were able to guide parents through the physiology of death, enabling them to recognize the breathing associated with active dying. Nurses were available to offer resuscitative measures. After the death of a child, family members had the option to remain with the child in the wake room for up to three days. This was a great source of comfort, as it allowed the family to grieve in the presence of their child's physical body and to continue holding onto it. There was no sense of being rushed.

Families at GMCH were surrounded by other families in similar circumstances, and some had witnessed the death of other children during their stays at GMCH. One grandmother in Family 4 recalled the death of a child and the grief that the parents felt. She comforted them and let them hold her living child while they wept. Sharing in the grief allowed families to feel less isolated and it empowered them to believe that they had the strength to make it through their suffering. The grandmother in Family 4, Fiona stated, "So I know it's possible to get through this…because I saw them do it." Siblings and ill children befriended each other and shared in their mourning experiences. GMCH represented a "different kind of club," where all members could share in their similar experiences.

Studies have described how families are often angry and haunted by negative experiences surrounding their children's death or wishing that they had included all of the family members in the experience (Contro et al., 2002; Hinds et al., 2005; Wolfe et al, 2000). This was not evident in the findings of this study; the negative experiences were not described with anger or regret; instead, they were accompanied by sadness and disappointment. None of the parents wished to have changed their location of death of their children. The deaths were described as peaceful; the families took comfort in being surrounded by loved ones. The perception of the child's suffering affects families during bereavement; a good death, where the child is perceived as having suffered minimally, has been shown to lessen the risk of marital distress and siblings' abilities to make and maintain friendships (Hinds et al, 2005). Perhaps these *good deaths* softened the impact of the negative experiences. Resiliency studies have shown that subsequent positive experiences can be a protective factor for previous negative experiences (Coleman & Ganong, 2002; Walsh, 2003).

Support During Bereavement

Hospital. It is recognized that grief begins at diagnosis (AAP, 2000; IOM, 2003); however, there were no formalized supportive grief services in the hospital so families did not receive any support during bereavement. Although the parents of these children had built a community at the hospital, this did not continue outside of the hospital: associations with other families were not maintained and contact with staff did not continue. Family 13 expressed disappointment that no staff had attended their child's funeral. No families recalled receiving any cards or flowers from the hospital staff, although this has been documented as being a source of comfort to families whose children have died (Davies et al., 2007; Johnson, Rincon, Gober, & Rexin, 1993). Most families felt that, by not choosing a death in the hospital, staff had assumed that the family did not desire continued contact. This was contrary to the families' wishes; they wished for home visits from hospital nurses and for staff attendance at funerals, as well as cards or phone calls from them.

Home. Families felt very isolated at their home during bereavement. The hospice services from CFK were discontinued once the child had died, although, for one family, the siblings received grief therapy for a few months. Parents were not able to connect with other families who had used CFK services, and they described the loneliness of their grief and the lack of societal recognition of their place in the world of mostly non-bereaved parents, including most of their own relatives. The life-long nature of their grief was not served by the short-term services offered by hospice or grief support groups that included parents of children who had died suddenly. Many found, as time progressed, their grief remained as intense as during the first year and they lamented the increasing isolation that each year of bereavement brought to them. Rando's study (1983) found that parental grief worsened over time. The belief in an endpoint to grief has been refuted (Attig, 2001; Carter, 1989; Klass, 2001; Nadeau, 2001; Rando, 1986); however, there was an endpoint to services available to families if they chose a home death. Parents in this study had to seek private counseling, internet support sites, or local support groups that included bereaved parents of children who had experienced sudden death; none of these adequately met parents' needs. There were few options for siblings, even though child development theorists assert that the child's concept of death develops over time and that children continually rework their grief (Reilly et al., 1983; Speece & Brent, 1984; Slaughter, 2005). Grieving parents felt a responsibility in helping the grieving siblings, but often felt ill-equipped. The entire family was grieving and this made it challenging for family members to help one another in the process without support. One mother stated that she cried when the grief counselor from the hospice discontinued the sibling therapy a few months after the child's death. **P**arents felt isolated without continued connections to CFK, and strongly desired being connected with other CFK families.

George Mark Children's House. The lifelines cast at GMCH were permanent. Not only were families able to maintain contact with other families who had suffered similar losses, but they continued to receive services such as counseling (individual, family, sibling, group). Events such as picnics and remembrances kept families connected with each other, and the friendships that they made with each other continued. Neimeyer (2001) asserts that mourning is a social phenomenon, and that through narrative construction a future can be created with resilience. Families described how the continued connections with GMCH families and staff made them feel stronger, and less isolated. They were comforted by sharing in other families' grief. Family resiliency theory (Walsh, 1996) suggests that these meaningful relationships enable families to foster a sense of cohesion in the family, through which meaning and purpose can be created, promoting healing for the family. Through GMCH, parents had symbolic representations of their child that helped create meanings and preserve memories. Families often visited the house to remember their children much like visiting gravesites. At GMCH, however, the memories were tied to their times of living and enjoying and they reminisced about how they played with their children and about changes that had happened since their deaths.

Each family also had a special memory about the room their child had been in--as each room is differently-themed—and they often visited the room, if it was available. Preserving the child's memory through such experiences enabled parents to keep memories of their parenthood alive, which was an important aspect of meaning-making in their grief process (Arnold & Gemma, 1994). During their visits, they connected with new families; this maintained their ever-growing community. GMCH was a place beyond the virtual communities of the Internet, where they could connect with each other and find companionship during their journeys. The importance of these connections is echoed in the findings of a Canadian study where both bereaved parents and siblings described no longer feeling alone, and how participating in bereavement program at the hospice helped normalize their grief process (Davies et al., 2007)

Implications for Practice

Gaining an understanding of the families' journeys through the different locations of care enables health care providers to recognize the challenges that these families face. Interventions must be family-centered and based on what will be most helpful to families. For instance, questioning parents as to who their pediatrician was and why symptoms were not recognized sooner is not helpful to parents who have just plunged into the whirlpool of uncertainty that is part of this situation. At each segment of the journey, there are opportunities to deliver family-centered care and to reduce parental stress and exhaustion. Interventions must be situated within the context of where families are in the journey. Although the death of some children may be inevitable, the journey can be less arduous if parents are given the necessary support they need in order to be prepared. There are several aspects of care for families which can and should be improved.

Integrating Care

The findings of this study clearly indicate that the lack of an integrated model of care adversely affects families. The decision-making processes and access to information of the parents in this study were affected by an approach that segregated *phases* of cure and comfort. All parents feared for their child's life from the moment of admission to the hospital. They held onto the hope that their child would survive; being informed about choices would not have lessened this hope. Rather, they would have understood that some families use such EOL services as the need arises.

Although the AAP guidelines (2000) recommend an integrated model of palliative care that begins at diagnosis, *regardless* of outcome, the findings show that this is still not the experience of most families. Parents perceive their children as “pin cushions,” and it is when they have finally witnessed their children suffering or becoming unresponsive to treatment that they choose a different type of care, one that focuses on quality. The fact that parents mentioned receiving a “quality of life speech” when options were exhausted is an indication that there is little integration of a cure *and* comfort approach to care, as recommended by the AAP. It begs the question: Why is quality of life not acknowledged as important from the time of diagnosis? A discussion of quality and comfort, along with curative treatment options at diagnosis, would allow parents to consider the plan of care holistically. HCP would simultaneously be providing curative and comfort measures, and support services to all family members would be available from diagnosis. This implication of integrating care has been echoed in numerous studies (Bluebond-Langner et al., 2007; Davies et al., 2008; Gowan, 2003; Schmidt; 2003; Wolfe et al., 2008), yet it has still not been fully realized.

Guiding Transitions

Health care providers can prepare families for leaving the hospital and beginning the next segment by offering optimal support and guidance during the transition to another location of care. There are many examples of guided transitions in the field of early childhood and maternity. For instance, early childhood educators have recognized the struggle that children face in the transition from home to daycare, and have developed a formalized process to guide parents and children to enable the child to adapt more easily to the new environment (Read, Gardner, & Mahler, 1993).

The process begins with a parent-teacher meeting; the parent and child then visit the school, and, gradually, the duration of separation of the child from the parent is increased. Parents receive guidance on the best way to help their children and each child progresses at a pace that is most comfortable, with teachers and parents working together. Similarly, a pregnant mother might visit the hospital unit or birthing center, take birthing preparation classes, meet her doctor or midwife several times over the course of the pregnancy, take parenting classes, choose a pediatrician. This process is guided by HCP as well as society in the form of advice from other parents, books, magazines and television shows.

Ideally, in a seamless integrated health care system, each family would receive support and guidance on how set up the home to accommodate the child's needs, and staff would visit the home to assure that all supplies, medications, and equipment had arrived and were correctly set up. A follow-up visit with a home health nurse would be scheduled while the family is still in the hospital, and the visit would occur upon the family's arrival at home. They would meet staff from the home health agencies and GMCH at the hospital, and have the opportunity to ask questions and clarify concerns. The child would be seen as a child first, then as an individual suffering from a disease; care would include curative *and* comfort measures, eliminating the need to choose one over the other. The family would be at the center of decision making and care would be partnered. Such coordination rests in the realm of the advanced practice nurses, such as clinical nurse specialists and nurse case managers, who often coordinate complex care and provide expert guidance, coaching families through developmental, health, and illness transitions (Mahn & Zazworksky, 2000). However, in this study, no parents identified an advanced practice nurse as providing them with guidance; only one grandparent identified her county nurse case manager (a registered nurse, not advanced practice) as important in her decision-making process and ability to obtain the care she needed for her grandson. Parents perceived a lack of continuity in their child's care. The development of a more formalized transition process would serve the needs of families in this situation. Although no studies evaluating the effectiveness of guided transitions for this population were found, the implementation of such support should not be impeded. Wolfe et al. (2008) found that families would be more likely to choose a death outside of the intensive care unit when they were given choices for alternative settings, which was not only more satisfactory to parents, but also a greater cost savings to the hospital. The findings in this study indicate that parents wanted guidance from HCP; that this would have been helpful in preparing them for making decisions in choosing a different location of care.

Providing Access to Information

The ability of parents to make decisions related to their children's care rested on having accurate, comprehensive, and understandable information. However, much of the information given to parents who were the subjects of this study was inaccurate, vague, ill-timed, incorrect, or incomprehensible. Parents learned to ask questions repeatedly and they became information detectives, piecing the puzzle together in a manner that helped them to understand their situations. This confirms the findings from a recent study conducted in hospitals where parents learned how to seek and evaluate therapies available to their children, and to differentially question their providers to obtain information (Bluebond-Langner et al., 2007). Parents in that study felt that they had not been able to adequately obtain complete information that adequately met their needs from a single provider. Another study (Board & Ryan-Wenger, 2000) showed that parental stress and family functioning in the ICU was greatly affected by the need for information from health care professionals. A lack of information increased parental fears and anxiety, and their ability to make decisions (Kirchhoff et al., 2002). Similarly, in this study, parents felt that it was only through active involvement in the plan of care and the questioning of providers that they were able to glean the important information they would have otherwise not known. This behavior was reinforced by improvements in their children's plans of care, such as choosing medications with fewer side effects or eliminating unnecessary procedures, which enabled their children to sleep.

With lengthy admissions, parents learned that the curative approach often excluded comfort-directed measures, and that their decision making ability about curative interventions was limited by their lack of access to information. They quickly learned that providers were the gatekeepers of information. Parents regularly turned to the Internet and other sources and to the opinions of friends and other families in similar circumstances to gain information. Several parents wondered why they had not received brochures about hospice care at admission. They indicated they would have perceived them as informational only and that they would have assumed that they were handed out to everyone. HCP must learn to communicate openly with families and provide written materials whenever possible to decrease confusion, and can present information in the context of the continuum of care and the child's potential trajectory of illness. Parents of seriously ill children are often grieving, sleep-deprived, and filled with uncertainty; thus, they retain only some of the information provided to them. Furthermore, providers must not decide for families from what information they must be shielded. It is possible to discuss end-of-life issues without robbing parents of hopes for cures; services can still be offered and parents can still be helped to make informed choices.

Connecting with Other Families

Families expressed a great desire to connect with other families. The benefit of connections with other families in similar circumstances has been shown to decrease families' sense of isolation (Davies et al., 2007). Several parents in this study longed for a database through which they could search for families of children with similar diagnoses. Families who used GMCH described connections with other families as essential in terms of their feeling supported. However, at the hospital and at home, families felt isolated. One mother suggested a "buddy family" which would connect with a family at each location, providing much needed support. Given the privacy acts that protect information in these kinds of cases, families could indicate on a *discharge survey* whether they would wish to be open to mentoring another family in similar circumstances. Another mother suggested that there should be a support group that would meet on the same day of each month, such as the third Sunday; the group would meet, no matter how many or how few families were to attend. Her concern derived from her own experience of attempting to attend a group that upon her arrival had been cancelled due to a lack of response; as a grieving parent she had not confirmed her attendance and was disappointed in the cancellation. She did not make an attempt to attend any more groups. Her experience underscores the importance of having consistent group meetings regardless of attendance tallies. The maintaining of connections to other families determined whether families sailed alone or together during EOL and bereavement.

Increasing Staff Availability

The findings of this study indicate that the availability of nurses affected parents' comfort levels and trust in their providers. Although, in the hospital setting and at GMCH, nurses were physically present 24 hours a day, seven days a week, parents were more concerned with the actual availability of these health care providers for their children in times of need. In the intensive care units (ICU) areas such as NICU (neonatal) and PICU (pediatric), families felt that the nurses were always available and seemingly always at the bedside. They felt comfortable not only leaving their children, but in trusting the judgment and clinical expertise of staff members. In the acute care ward, parents described nurses as being busy and unavailable and they felt uncomfortable leaving their children alone. In Davies et al.'s study (2008), where the barriers to palliative care were examined, differences were found based on location within the hospital. Non-ICU staff reported more time constraints and staff shortages as compared to ICU staff. In this study, each family whose child had been in the NICU was extremely pleased with the level of care. They did not perceive the nurses as busy; they believed that the nurses were there just for their child. The staffing ratios in the NICU are often 1:1 for the sickest babies, and the babies in this study were gravely ill; therefore, they received very personalized care.

Thus, families which had received care in the critical care units found it difficult to transition to in-home hospice services, where the 24 hour availability of staff was by *phone*. Families wished for continuity at home, with home visitation from hospital nurses. They were comforted, however, by the availability of on-call staff, and said that they could not have remained at home otherwise. All parents mentioned their fear of the trend in which home care nurses would have to adhere to regular business hours, which would affect their availability. Families at GMCH were very much comforted by the round-the-clock nursing which afforded them peace of mind. It is vital that services for families in this situation be increased, not reduced. Families repeatedly mentioned budget cuts as the reason why nurses were not more available or why services were being eliminated or reduced. They felt that acute care wards needed more nurses so that they would be less busy, and that 24-hour availability for on-call hospice nurses should be continued. Families described the availability of care at GMCH as perfectly meeting their needs and they did not make any suggestions for changes. Although all programs face financial constraints, the availability of staff to families must be prioritized so that the needs of families can be met.

Continuing Contact with Staff

Parents felt abandoned at the end of their journeys at the hospital, and their desire for continued contact with staff was evident. This echoes the finding in the Contro et al. study (2002), in which families wished for continued contact with staff members after the death of their children. Parents in this study had built a community within the hospital; some even referred to their community of HCP as family, and were disappointed at the absence of hospital staff at the child's funeral. Families which used CFK services wanted a more formalized or organized opportunity for contact with staff and other families, such as a monthly support group. They felt that the continued connections with staff had helped them to maintain memories of their children's lives.

Connecting with the nurse who had witnessed the child's death was a way of helping families to process the experience. One mother revealed that even two years after her child's death, she still called the hospice nurse to ask about a detail about the day when her child died. Such connections were crucial in the families' grieving process and their ability to continue the bonds with the deceased child. Through these comforting interactions the narrative continued to evolve. Parents recalled specific instances of support from HCP that were meaningful and healing for them.

Attendance at funerals, cards acknowledging the child's birthday or death anniversary, phone calls, annual remembrances, and bereavement retreats are ways in which staff can remain connected to families (Johnson et al., 1993; Davies et al., 2007). Importantly, the contact needs to continue beyond the first year of bereavement. No families could recall such instances of connection with the hospital staff. Families do not experience an endpoint to their grief, and siblings rework their grief and understanding of death as they grow and develop (Nadeau, 2001). In this study, parents described their grief as intensifying over time, as their families became more isolated, and the deceased child was mentioned less frequently.

Health care providers need to gain a deeper understanding of the grief process and provide formalized support through which staff is able to continue to maintain connections with families. One way of facilitating this would be for each family to complete a *discharge survey* that would indicate the level of contact desired and with whom they want to remain in contact. Programs like Comfort for Kids could offer something similar, perhaps informing families if and when the nurse who had cared for their children had left the agency. Given that remaining in touch with the nurse was a way of CFK families remembering their children, it might be important for them to know that the nurse had relocated. GMCH provides lifelong contact to the family after the child's death, and parents perceived this continued support as extremely helpful in fostering the family's bonds. GMCH's example should be followed by health care providers in other settings; connections with each family should be maintained, as each location of care holds a unique experience for the family.

Implications for Research

Increasing Inclusions

Few families in the study had been involved in qualitative studies before their involvement in this study; their primary experience (if any) had involved completing questionnaires. Families wanted to talk about their experiences; they did not want to be silenced. They wanted their voices to be heard and they expressed gratitude for being allowed to participate in this study, saying that it was "a gift." The dearth of studies from a family perspective in the field of end-of-life is a clear indication that more family studies are needed. The priorities of parents differ from those of providers (Contro et al., 2002; Meyer et al., 2002); even among health care providers, there are different perspectives (Andresen et al., 2004; Burns et al., 2001). Family-centered care cannot be achieved if the research upon which care is based is not family-centered itself. Studies should be aimed at including the entire family whenever possible. The findings in this study indicate that, even with varying diagnoses, families whose children are facing death share remarkably similar journeys and face similar barriers to receiving the optimal level of care that they desire. By increasing the inclusion of families in research, the understanding of their experiences can be further expanded.

Reducing Barriers

Many protections are put in place in order to shield vulnerable populations from harmful research (Horowitz, et al., 2002). My contacting families with children at the end-of-life stage was described to me by the Committee on Human Research as a "double whammy," given that, not only was I researching the sensitive topic of EOL, but I was including *children* in my study, and actually *speaking* to families, instead of using a survey. There was much concern about the emotional distress that this research might cause families; consequently, my study received intense scrutiny. This is not unlike other studies in which researchers have had to overcome numerous obstacles in order to gain access to vulnerable populations (Casarett, Knebel, & Helmers, 2003; Horowitz). Such challenges make it simpler and more expeditious to interview health care providers and to use quantitative instruments.

The families in this study were eager to share their stories, hoping that their experiences would help other families and improve care. The interviews were very meaningful to them and, although they shed tears, they were grateful to have their experiences recognized as important enough to be included in a research study. They wanted recognition that their grief was not something they would get over; they wanted it understood that it would be with them always, like waves on the ocean, always present, with the distance between the waves varying over time, and that *being sad* did not mean that they did not want to participate in research. Although I provided all parents with a support services referral list at the end of the interview, none of the parents felt that they *needed* the referrals. The extent of emotional distress that had been anticipated, and for which protective measures had been implemented, was not evident in this study. In the quest to protect families, it is essential that their vulnerability not be used to exclude them from studies. Much like the approach in informing families about hospice care, families whose children are dying are often sheltered from participating in studies. This attitude must change; human protection committees are the gatekeepers for participation in research, and these gates must be opened to include family perspectives whenever possible. Furthermore, researchers must be educated to include families as research participants, rather than recoiling from the potential hurdles they must overcome in order to conduct such research.

Implications for Education

The findings of the study indicate that parents perceived heath care providers as lacking in information pertaining to end-of-life care. Parents' questions were often met with vague explanations, and no parents had a clear understanding of the differences between hospice care and palliative care or that a Do Not Resuscitate order was revocable at any time. HCP in the hospital had little personal experience with the services within the community such as CFK and GMCH. A study by Yates and Stetz (1999) found that parents perceived that healthcare professionals seemed uncomfortable with or even avoided dealing with the issue of dying. The lack of pediatric palliative care trained health care providers is well documented (Badger, 2005; Gowan, 2003; Wolfe, 2000). Very few dying children receive hospice care, which is probably a direct result of a deficiency in the educational system of physicians and other health professionals in the area of end-of-life care (Kane, Barber, Jordan, Tichenor, & Camp, 2000).

In this study, the consequence of such a lack of training was that families received little to no help in terms of obtaining adequate end-of-life services. Hospice providers have specialized EOL training, and parents noted how hospice providers were able to expertly guide them through the process of dying. Care during this phase of life is highly specialized and the children deserve the attention of expert professionals who are trained in this area (Sumner, 2003). Few curricula for medical and nursing providers pay attention to end-of-life care (Sumner). Many general pediatricians lack the confidence in facing EOL issues and in referring children to palliative care services (Sheetz & Bowman, 2008). The AAP (2000) recommends that all pediatric physicians have training in palliative care and that certifying examinations must include questions on palliative care. Clearly, EOL education programs exist to train hospice providers; these programs must be expanded so that all HCP can be trained in EOL issues. Without such education, the goal of an integrated model of care, as recommended by the AAP, will not be realized.

Limitations

Several limitations in this study must be addressed. First, the sample included only one patient, even though the goal had been to include several ill children. As such, the findings overwhelmingly represent parental and sibling perspectives, rather than the ill child's perspective. It was not possible to include more ill children from the 13 families because they were deceased, too ill, or too young (seven ill children were included in participant observation only). Also, there were more families from GMCH than CFK (ten compared to four); however, CFK serves a very small number of families, many of whom do not remain in contact with the organization, making it more challenging to recruit a greater number of families. Moreover, the total number of participants was 25, a sufficient sample size for a grounded theory study.

Second, there were only two agencies/facilities from which participants were chosen: CFK and GMCH. Families who never received pediatric end-of-life care services were not included. Therefore, the findings are representative of only a small, select group of parents who chose to use palliative/hospice/respite care. The experience of families who stayed in the hospital or who experienced the death of their children at home without hospice care might be vastly different from the families in this study. The hospice services were located in California, thus, the experience of families in other states across the country may differ.

Third, families were selected by staff, thereby potentially introducing a source of bias in favor of families who had the most positive experiences. However, families who used home services did not hesitate to point to shortcomings in their nurses, such as a lack of expert care on the part of some nurses; therefore, such bias may have been mitigated by families being given the opportunity to share their experiences and vent their frustrations. Families from GMCH described extraordinarily positive experiences related to their children's care; despite careful questioning, families could not suggest anything that they would have changed about their care at GMCH.

Fourth, the data was collected retrospective to the decision-making process of choosing services. Therefore, the findings may have been different had families been interviewed before leaving the hospital, and then afterwards. However, since it is impossible to predict which children and families are likely to need end-of-life care (Feudtner et al., 2001), it was not feasible to have interviewed every parent in the hospital, in anticipation of the fact that a select few would have continued on to hospice care.

Fifth, although data was collected over a period of two years, the families were not followed continuously during that entire time. Families were interviewed at various points along the trajectory of illness and bereavement, some during the end-of-life phase (n=7), others during bereavement (n=6). One child died after the interview; however, the parent was not available for a subsequent interview as she had become gravely ill. Interviewing the same families over the period of two years may have reflected different accounts of the same experience based on the length of time since the deaths of the children.

Directions for Future Research

Several possible directions are suggested for future research. The findings clearly point to shortcomings in the current level of care provided to families, particularly in how they are supported during their children's initial hospitalizations and with regard to changes in locations of care. Families described needing more guidance and support from both health care providers and other families in similar circumstances. Future studies should implement and evaluate guided transition programs and the development of mentorship among families. Furthermore, the families indicated that there was no continued contact with hospital staff. Serwint and Nellis (2005) have noted that tracking children who die in their communities is more difficult than those who die in hospitals. Whether or not continued support is based on location of death is a relatively unexplored area. Additionally, the inclusion of families who declined GMCH and chose to remain in the hospital for their children's deaths would broaden the understanding of the parental decision-making process during the children's dying process.

Examining comparative death experiences within the hospital on different units, such as ICU, acute care, and palliative care, would provide further insight into family decision making. Two families in the study chose not to use hospital palliative care services, as they did not want their children to remain in the hospital. As pediatric palliative care programs become increasingly more available within hospitals and show trends in terms of improvement of end-of-life care (Wolfe et al., 2008), it is important to understand why families would prefer to choose non-hospital based programs. Evaluation studies that include multiple family member perspectives are crucial in terms of being able to maximize resources to provide the care that best suits families' needs.

The transition process is ultimately best understood through longitudinal research designs that begin at diagnosis and follow families into bereavement. For instance, enrolling all children with a particular diagnosis that is known to have a statistically low cure rate upon entry into the hospital, and following each family through bereavement or cure would provide much greater insight into the family experiences. Multi-site national studies would illuminate the differences in terms of varying locations. Moreover, such large samples would ensure enrollment of families of different ethnicities and cultures. Creating research networks would provide greater access to families and it would generate research that could ultimately lead to improvements in the care provided to families.

Conclusion

Only in an integrated system in which curative and comfort measures co-exist can families of dying children receive the care that they deserve. In an integrated model of care, the process of transition will likely be very different from that described in this study, as parents will not feel the need to abandon curative measures in order to receive palliative care. This study illustrates the fact that the lack of a guided transition process hinders families from being able to make informed decisions in reference to choosing locations of care. The transition process to a new location of care should not begin with the discharge orders. Health care providers must anticipate the fact that families of children with life-limiting conditions face living on the ocean; the goal is not to simply prevent families from ever reaching the ocean. Inevitably, there will always be children whose lives are limited and who will die before their parents. Families must be guided and supported to reach new beginnings. As Charlie, the father in Family 9, stated, "There are so many procedures in place to bring a child into this world, but really nothing to help escort one out."

As pediatric palliative and hospice care programs begin to proliferate in the United States, family-centered care must be based on evidence from family perspective studies. This study has highlighted the importance of guided transitions and how families can best be supported during their journey though various locations of care. It is only through supporting families in their difficult journey, that family integrity and function can be maintained. The goal should not be disembarkment, but rather lifelong accompaniment, where permanent lifelines support the families. The recommendations of the AAP (2000) have yet to be realized; however, each study is a step forward in providing the evidence base for achieving the goal of integrated palliative care, where the "goal is to add *life* to the child's *years*, not simply *years* to the child's *life*" (p. 353).

FOOTNOTES

1. Quotations have been maintained verbatim reflecting the participant's use of slang and stylistic grammar. Identifiers have been changed to protect participants' privacy, and many pronouns have been replaced with nouns for clarity of understanding. The use of *[sic]* has been judicious, as this would have greatly impaired the ability to read the quotes.

2. Technological imperative refers to the concept that because a particular technology is available, then one ought to use it, such that once under way, this is unstoppable and progress is inevitable. It is the desire to use the most advanced technology currently available.

REFERENCES

Aho, A. L., Tarkka, M. T., Astedt-Kurki, P. & Kaunonen, M. (2006). Fathers' grief after the death of a child. *Issues in Mental Health Nursing, 27*(6), 647-663.

American Academy of Pediatrics (AAP). (2000). Pediatric palliative care. *Pediatrics, 106*(2), 351-357.

American Academy of Pediatrics (AAP). (2003). Family pediatrics: Report on the task force on the family. *Pediatrics, 111*, 1541-1571.

American Association Colleges of Nurses (AACN) & City Of Hope (COH). (2003). *End-of-life nursing consortium: Pediatric palliative care*. Los Angeles: Association of Pediatric Oncology Nurses.

Amidi-Nouri, A. (2007). Qualifying Examination Papers. Unpublished. University of California, San Francisco.

Andresen, E. M., Seecharan, G. A., & Toce, S. S. (2004). Provider perceptions of child deaths. *Archives of Pediatrics and Adolescent Medicine, 158*(5), 430-435.

Antonvosky, A. (1987). *Unraveling the mystery of health.* San Francisco: Jossey-Bass.

Arnold, J. A., & Gemma, P. B. (1994). *A child dies: A portrait of family grief* (2nd ed.). Philadelphia: The Charles Press Publishers.

Association of Children's Hospices (n.d). Retrieved April 26, 2007 from: http://www.childhospice.org.uk/sections/aboutus/index.html.

Attig, T. (2001). Relearning the world: Making and finding meanings. In Neimeyer, R. (Ed.), *Meaning reconstruction and the experience of loss* (pp.33-54). American Psychological Association: Washington, DC.

Badger, J. M. (2005). A descriptive study of coping strategies used by medical intensive care unit nurses during transitions from cure-to-comfort-oriented care. *Heart Lung, 34*(1), 63-68/

Benjamin, L., & Benjamin, R. (1994). Issues in the treatment of dissociative couples. *Dissociation, 8*(1)*, 229-238*

Bluebond-Langner, Myra. (1978). *The Private Worlds of Dying Children*. Princeton: Princeton University Press.

Bluebond-Langner, M., Belasco, J. B., Goldman, A., & Belasco, C. (2007). Understanding parents' approaches to care and treatment of children with cancer when standard therapy has failed. *Journal of Clinical Oncology, 25*(17), 2414-2419.

Blumer, H. (1969). *Symbolic Interactionism: Perspective and Method.* Englewood Cliffs: Prentice-Hall.

Bradshaw, G., Hinds, P. S., Lensing, S., Gattuso, J. S., & Razzouk, B. I. (2005). Cancer-related deaths in children and adolescents. *Journal of Palliative Medicine, 8*(1), 86-95.

Board, R., & Ryan-Wenger, N. (2000). State of the science on parental stress and family functioning in pediatric intensive care units. *American Journal of Critical Care*, *9*(2), 106-122

Bridges, W. (2003). *Managing Transitions.* Cambridge, MA: De Capo Press.

Bruera, E., Russell, N., Sweeney, C., Fisch, M., Palmer, J.L. (2002). Place of death and its predictors for local patients registered at a comprehensive cancer center. *Journal of Clinical Oncology*, *20* (8), 2127-2133.

Burge, F. I., Lawson, B., Critchley, P., & Maxwell, D. (2005). Transitions in care during end of life: Changes experienced following enrollment in a comprehensive palliative care program. *BioMed Central Palliative Care, 4*(3). Retrieved January 20, 2006 from http://www.biomedcentral.com/1472-684X/4/3.

Burns, J. P., Mitchell, C., Griffith, J. L., & Truog, R. D. (2001). End-of-life care in the pediatric intensive care unit: Attitudes and practices of pediatric critical care physicians and nurses. *Critical Care Medicine, 29*(3), 658-664.

Carter, S. L. (1989). Themes of Grief. *Nursing Research, 38*(6), 354-358.

Cassarett, D. J., Knebel, A., & Helmers, K. (2003). Ethical challenges of palliative care research. *Journal of Pain and Symptom Management, 25*(4), S3-5.

Charmaz, K. (2000). Grounded theory: Objectivist and constructivist methods. In N. K. Denzin, & Y. S. Lincoln (Eds.), *Handbook of Qualitative Research* (2nd ed., pp. 509-536). Thousand Oaks: Sage.

Charmaz, K. (2003). Grounded theory. In J. Smith (Ed.) *Qualitative Psychology* (pp. 81-110). London: Sage.

Charmaz, K. (2005). Grounded theory in the 21st century: Applications for advancing social justice studies. In N. K. Denzin, & Y. S. Lincoln (Eds.), *Handbook of Qualitative Research* (3rd ed., pp. 507-536). Thousand Oaks: Sage.

Children's Project on Palliative/Hospice Services (ChiPPS). (2000). *Compendium of pediatric palliative care* .Arlington: National Hopsice and Palliative Care Organization.

Clarke, A. (2005). *Situational analysis: Grounded theory after the postmodern turn.* Thousand Oaks, CA: Sage.

Coleman, M., & Ganong, L. (2002). Resilience and Families. *Family Relations, 51*(2), 101-102.

Contro, N., Larson, J., Scofield, S., Sourkes, B., & Cohen, H. (2002). Family perspectives on the quality of pediatric palliative care. *Archives of Pediatrics and Adolescent Medicine, 156*(1), 14-19.

Contro, N. A., Larson, J., Scofield, S., Sourkes, B., & Cohen, H. J. (2004). Hospital staff and family perspectives regarding quality of pediatric palliative care. *Pediatrics, 114*, 1248-1252.

Cutcliffe, J. R. (2000). Methodological issues in grounded theory. *Journal of Advanced Nursing, 41*(6), 1476-84.

Davies, B. (1996). Assessment of need for a children's hospice program. *Death Studies, 20*(3), 247-268.

Davies, B. (1987). Family responses to the death of a child: The meaning of memories. *Journal of Palliative Care, 3*(1), 9-15.

Davies, B. (1988). Shared life space and sibling bereavement responses. *Cancer Nursing 11*(6), 339-347.

Davies, B., Collins, J., Steele, R., Cook, K., Distler, V., & Brenner, A. (2007). Parents' and children's perspectives of a children's hospice bereavement program. *Journal of Palliative Care, 23*(1), 14-23.

Davies, B., Gudmundsdottir, M., Worden, B., Orloff, S., Sumner, L., & Brenner, P. (2004). "Living in the dragon's shadow" fathers' experiences of a child's life-limiting illness. *Death Studies, 28*(2), 111-135.

Davies, B., Sehring, S. A., Partridge, J. C., Cooper, B. A., Hughes, A., Philp, J. C., Amidi-Nouri, A., & Kramer, R. F. (2008). Barriers to palliative care for children: Perceptions of pediatric health care providers. *Pediatrics, 121*(2), 282-288.

Davies, S. (2005). Meleis's theory of nursing transitions and relatives' experiences of nursing home entry. *Journal of Advanced Nursing, 52*(6), 658-671.

Denzin, N. K.,, & Lincoln, Y. S. (2005). The discipline and practice of a qualitative research. In N. K. Denzin, & Y.S. Lincoln (Eds.), *Handbook of Qualitative Research* (3rd ed., pp. 1-32). Thousand Oaks: Sage.

Donnelly, J. P., Huff, S. M., Lindsey, M. L., McMahon, K. A., & Schumacher, J. D. (2005). The needs of children with life-limiting conditions: A healthcare-provider-based model. *American Journal of Hospice and Palliative Care, 22*(4), 259-267.

Engel, G. (1961). Is grief a disease? *Psychosomatic Medicine, 23*(1), 18-22.

Erikson, E. H. (1980). *Identity and the life cycle.* New York: W. W. Norton & Company

Ferguson, W. S. (2001). Exploring end-of-life care for children with cancer. *Journal of Pediatric Hematology and Oncology, 23*(8), 478-480.

Ferguson, W. S. (2001). Exploring end-of-life care for children with cancer. *Journal of Pediatric Hematology and Oncology, 23*(8), 478-480.

Feudtner, C., Christakis, D. A., Zimmerman, F. J., Muldoon, J. H., Neff, J. M., & Koepsell, T. D. (2002). Characteristics of deaths occurring in children's hospitals: Implications for support care services. *Pediatrics, 109*(5), 887-893.

Feudtner, C., Hays, R. M., Haynes, G., Geyer, J. R., Neff, J. M., & Koepsell, T. D. (2001). Deaths attributed to pediatric complex chronic conditions: National trends and implications for supportive care services. *Pediatrics, 107*(6), E99.

Feudtner, C., Silveira, M. J., & Christakis, D. A. (2002). Where do children with complex chronic conditions die? Patterns in Washington state, 1980-1998. *Pediatrics, 109*(4), 656-660.

Fine, M. (1994). Working the hyphens: Reinventing self and other in qualitative research. In N. K. Denzin, & Y. S. Lincoln (Eds.), *Handbook of Qualitative Research* (1st ed., pp. 70-82). Thousand Oaks: Sage.

Freud, S. (1957). Mourning and melancholia. In J. M. Strachey (Ed. & Trans.). *The complete psychological works of Sigmund Freud: Standard edition,* (Vol. 14, pp. 243–258). London: Hogarth Press. (Original work published 1917).

Glaser, B. (1978). Theoretical sensitivity: Advances in the methodology of grounded theory. Mill Valley: Sociology Press.

Glaser, B., & Strauss, A. (1967). *The discovery of grounded theory: Strategies for qualitative research.* Chicago: Aldine.

Gowan, D. (2003). End-of-life issues of children. *Pediatric Transplants, 7 Suppl 3*, 40-43.

Gravelle, A. M. (1997). Caring for a child with a progressive illness during the complex chronic phase: Parents' experience of facing adversity. *Journal of Advanced Nursing, 25*(4), 738-745.

Guba, E. G., & Lincoln, Y. S. (2005). Paradigmatic controversies, contradictions, and emerging confluences. In N. K. Denzin, & Y. S. Lincoln (Eds.), *Handbook of Qualitative Research* (3rd ed., pp. 191-216). Thousand Oaks: Sage.

Gudmundsdottir, M., & Chesla, C. (2006). Building a new world. *Journal of Family Nursing, 12*(2), 143-164.

Hain, R. D., Miser, A., Devins, M., & Wallace, W. H. (2005). Strong opioids in pediatric palliative medicine. *Paediatric Drugs, 7*(1), 1-9.

Hammersly, M. (1990). What's wrong with ethnography? The myth of theoretical description. *Sociology, 24,*597-615.

Hawley, D. R., & Dehaan, L. (1996). Toward a definition of family resilience: Integrating life-span and family perspectives. *Family Process, 35*, 283-298.

Himelstein, B. P., Hilden, J. M., Boldt, A. M., & Weissman, D. (2004). Pediatric palliative care. *New England Journal of Medicine, 350*, 1752-1762.

Hinds, P. S., Schum, L., Baker, J. N., & Wolfe, J. (2005). Key factors affecting dying children and their families. *Journal of Palliative Medicine, 8,* S-70-78.

Horowitz, J. A., Ladden, M. D., & Moriarty, H. J. (2002). Methodological challenges in research with vulnerable families. *Journal of Family Nursing, 8 (4),* 315-333.

Houtzager, B. A., Grootenhuis, M. A., Caron, H. N. & Last, B. F. (2005). Sibling self-report, parental proxies, and quality of life: the importance of multiple informants for siblings of a critically ill child. *Pediatric Hematology and Oncology, 22,* 25-40.

Hudson, P. (2003). Home-based support for palliative care families: Challenges and recommendations. *Medical Journal of Australia, 179*(6 Suppl), S35-37.

Hynson, J. L., Gillis, J., Collins, J. J., Irving, H., & Trethewie, S. J. (2003). The dying child: How is care different? *Medical Journal of Australia, 179*(6 Suppl), S20-22.

Institute of Medicine (IOM). (2003). *When children die: Improving palliative and end-of-life care for children and their families.* Washington, D.C.: The National Academies Press.

Jensen, K. P., Bäck-Petterson, S., & Segesten, K. (2000). The meaning of "not giving in." *Cancer Nursing*, *23*(1), 6-11.

Johnson, L. C., Rincon, B., Gober, C., & Rexin, D. The development of a comprehensive bereavement program to assist families experiencing pediatric loss. *Journal of Pediatric Nursing 8*, 385-391.

Kane,J., R, Barber, R. G, Jordan, M., Tichenor, K.T., & Camp, K. (2000). Supportive/palliative care of children suffering from life-threatening and terminal illness. *American Journal of Hospice and Palliative Care, 17*(13), 165-272.

Kirchhoff, K. T., Walker, L., Hutton, A., Spuhler, V., Cole, B. V., & Clemmer, T. The vortex: Families' experiences with death in the intensive care unit. *American Journal of Critical Care, 11*(3), 200-210.

Klass, D. (2001). The inner representation of the dead child in the psychic and social narratives of bereaved parents. In Neimeyer, R. (Ed.), *Meaning reconstruction and the experience of loss* (pp.77-94). Washington, D.C.: American Psychological Association

Klopfenstein, K. J., Hutchison, C., Clark, C., Young, D., & Ruymann, F. B. (2001). Variables influencing end-of-life care in children and adolescents with cancer. *Journal of Pediatric Hematology/Oncology, 23*(8), 481-486.

Koenig, B. (2003). Qualitative methods in end-of-life research recommendations to enhance the protection of human subjects. *Journal of Pain and Symptom Management, 25*(4), S43-52.

Kreicbergs, U., Valdimarsdottir, U., Onelov, E., Henter, J., & Steineck, G. (2004). Talking about death with children who have severe malignant disease. *New England Journal of Medicine, 351*(12), 1175-1253.

Kubler-Ross, E. (1969). *On death and dying*. New York: The MacMillan Company.

Kurashima, A. Y., Latorre, M. D. R. D., De Paiva Teixeira, S. A., & De Camargo, B. (2005). Factors associated with location of death of children with cancer in palliative care. *Palliative and Supportive Care, 3*, 115-119.

Lauer, M. E., Mulhern, R. K., Bohne, J. B., & Camitta, B. M. (1985). Children's perceptions of their sibling's death at home or hospital: The precursors of differential adjustment. *Cancer Nursing, 8*(1), 21-27.

Levetown, M. (2000). *Compendium of pediatric palliative care*.Alexandria: National Hospice and Palliative Care Organization.

Levine, C. (2002). Hospital based family caregiver programs: Building institutional resources and community ties. *Journal of Palliative Medicine, 5*(1), 175-179.

Lindemann, E. (1944). Symptomology and management of acute grief. *American Journal of Psychiatry*, 101, 141–148.

Mahn, V. A., & Zazworsky, D. (2000). The advanced practice nurse case manager. In A. B. Hamric, J. A. Spross, & C. M. Hanson (Eds.), *Advanced Nursing Practice* (pp.549-606). Philadelphia, PA: W. B. Saunders.

McCubbin, M. A., & McCubbin, H. I. (1993). Families coping with illness: the resiliency model of family stress, adjustment and adaptation. In C. B. Danielson, B. Hamel-Bissel, & P. Winstead-Fry (Eds.), *Families, health and illness: perspectives on coping and intervention* (pp. 21-63). St Louis: Mosby.

McCubbin, M., Balling, K., Possin, P., Frierdich, S., & Bryne, B. (2002). Family resiliency in childhood cancer. *Family Relations, 51*(2), 103-111.

McCubbin, M. (1988). Family stress, resources, and family types: chronic illness in children. *Family Relations, 37,* 203-210.

McCulloch, R., & Collins, J. J. (2006). Pain in children who have life-limiting conditions. *Child Adolescent Psychiatric Clinics of North America, 15*(3), 657-682.

Meleis, A. I. (2000). Experiencing transitions: An emerging middle-range theory. *Advances in Nursing Science, 23*(1), 12-28.

Meyer, E. C., Burns, J. P., Griffith, J. L., & Truog, R. D. (2002). Parental perspectives on end-of-life care in the pediatric intensive care unit. *Critical Care Medicine, 30,* 226-231.

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.

Miles, M. S., & Holditch-Davis, (2003). Enhancing nursing research with children and families using a developmental science perspective. *Annual Review of Nursing Research, 21,* 1-20.

Moriarty, H., Cotroneo, M., DeFeudis, R., & Natale, S. (1995). Key issues in cross-cultural family research. *Journal of Family Nursing, 1*(4), 359-381.

Mulhern, R. K., Lauer, M. E., & Hoffmann, R. G. (1983). Death of a child at home or in the hospital: Subsequent psychological adjustment of the family. *Pediatrics, 71*(5), 743-747.

Nadeau, J. W. (2001). Family construction of meaning. In Neimeyer, R. (Ed.), *Meaning reconstruction and the experience of loss* (pp.95-112). American Psychological Association: Washington, DC.

National Cancer Institute (NCI). (2003). Retrieved on April 29, 2007, from: www-seer.ims.nci.nih.gov/ Publications/PedMono.

National Cancer Institute. Consent guidelines (2005). Retrieved on April 21, 2005, from http://www.nci.nih.gov/clinicaltrials/understanding/childrensassent0101

National Institutes of Health (NIH) (2004). State-of-the-Science Conference Statement on improving end-of-life care**.** (conclusions section) Retrieved on March 29, 2007, from http://consensus.nih.gov/2004/2004EndOfLifeCareSOS024html.htm

Neimeyer, R., ed. (2001). *Meaning reconstruction and the experience of loss*. American Psychological Association: Washington, DC.

Neimeyer, R. A., Prigerson, H. G., Davies, B. (2002). Mourning and meaning. *American Behavioral Scientis, 46*, 235-251.

Nolbris, M., & Hellstrom, A. L. (2005). Siblings' need and issues when a brother or sister dies of cancer. *Journal of Pediatric Oncology Nursing, 22*(4), 227-233.

Norris-Shortle, C., Young, P. A., & Williams, M. (1993). Understanding death and grief for children three and younger. *Social Work 38*(6), 736-743.

Patterson, J. M. (2002). Understanding family resilience. *Journal of Clinical Psychology, 58*(3), 233-246.

Patterson, J. M., & Garwick, A. W. (1994). Theoretical linkages: Family meanings and sense of coherence. In H.I. McCubbin, E.A. Thompson, AI. Thompson, and J.E. Fromer (Eds.), *Sense of coherence and resiliency: stress, coping, and health* (pp. 71-89). Madison: University of Wisconsin Press.

Pettigrew, J. (1990). Intensive care nursing: The ministry of presence. *Critical Care Clinics of North America,2,* 503-508.

Piattelli-Palmarini, M. (1994). Ever since language and learning: Afterthoughts on Piaget-Chomsky debate. *Cognition, 50,* 315-346.

Piaget, J. (1950). *The psychology of intelligence.* New York: International Universities Press.

Pritchard, M., & Davies, B. (2002). End of life in pediatric oncology: How clinical practice leads to research. *Journal of Pediatric Oncology Nursing, 19*(6), 191-197.

Rando, T. A., (1986). A comprehensive analysis of anticipatory grief: perspectives, processes, promises, and problems. In T. A. Rando (Ed.), *Loss and Anticipatory Grief.* Lexington: Lexington Books.

Rando, T. A., (1983). An investigation of grief and adaptation in parents whose children have died from cancer. *Journal of Pediatric Psychology*, *8*, 3–20.

Read, K., Gardner, P., & Mahler, B. C. (1993). Helping children adjust to new experiences. In K. Read, P. Gardner, & B. C. Mahler (Eds). *Early Childhood Programs* (9th ed., pp. 138-159). Orlando: Harcourt Brace College.

Reilly, T. P., Hasazi, J. E., & Bond, L. A. (1993). Children's conceptions of death and personal mortality. *Journal of Pediatric Psychology, 8*(1), 21-31.

Rollins, J. A., & Riccio, L. L. (2002). ART is the heART: A palette of possibilities for hospice care. *Pediatric Nursing 28*(4), 255-362.

Rushton, C. H. (2005). A framework for integrated pediatric palliative care: being with dying. *Journal of Pediatric Nursing, 20*(5), 311-235.

Schmidt, L. M. (2003). Pediatric end-of-life care: Coming of age? *Caring, 22*(5), 20-22.

Schulman-Green, D., McCorkle, R., Curry, L., Cherlin, E., Johnson-Hurzeler, R., & Bradley, E. (2004). At the crossroads: Making the transition to hospice. *Palliative and Supportive Care, 2*, 351-360.

Serwint, J. R., & Nellis, M. E. (2005). Deaths of pediatric patients: Relevance to their medical home, and urban primarly care clinic. *Pediatrics, 115*(1), 57-63.

Sheetz, M. J., & Bowman, M. S. (2008). Pediatric palliative care: An assessment of physician's confidence in skills, desire for training, and willingness to refer for end-of-life care. *American Journal of Hospice & Palliative Medicine, 25*(2), 100-105.

Slaughter, V. (2003). Young children's understanding of death. *The Australian Psychological Society, 40*(3), 179-186.

Speece, M., & Brent, S. (1984). Children's understanding of death: A review of three components of a death concept. *Child Development, 55,* 1671-1686.

Speziale, H. J. & Carpenter, D. R. (2003). Phenomenology as method. *Qualitative research in nursing: Advancing the humanistic imperative* (3rd ed.). Philadelphia: Lippincott Williams & Wilkins.

Steele, R., Derman, S., Cadell, S., Davies, B., Siden, H., & Straatman, L. (2008). Families' transition to a Canadian paediatric hospice. Part one: planning a pilot study. *International Journal of Palliative Nursing, 14*(5), 248-256.

Steele, R., Derman, S., Cadell, S., Davies, B., Siden, H., & Straatman, L. (2008). Families' transition to a Canadian paediatric hospice. Part two: results of a pilot study. *International Journal of Palliative Nursing, 14*(6), 287-295.

Stephenson, J. (2000). Palliative and hospice care needed for children with life-threatening conditions. *JAMA, 284*(19), 2437-2438.

Strauss, A. (1987). Codes and Coding. In *Qualitative analysis for social scientists (pp.55-81).* Cambridge: Cambridge University Press.

Strauss, A., & Corbin, J. (1998). *Basics of qualitative research: Techniques and procedures for developing grounded theory.* Thousand Oaks: Sage

Sumner, L. H. (2003). Lighting the way: Improving the way children die in america. *Caring, 22*(5), 14-18.

U.S. Census Bureau (2004). Population Division, Fertility & Family Statistics Branch. Retrieved on June 29, 2007 from http://www.census.gov/population/www/cps/cpsdef.html.

Van Manen, M. (1990). *Researching lived experience: Human science for an action sensitive pedagogy.* Canada: Althouse Press/University of Western Ontario.

Vickers, J. L., & Carlisle, C. (2000). Choices and control: Parental experiences in pediatric terminal home care. *Journal of Pediatric Oncology Nursing, 17*(1), 12-21.

Waldrop, D. P., Kramer, B. J., Skretny, J. A., Milch, R. A., & Finn, W. (2005). Final transitions: Family caregiving at the end of life. *Journal of Palliative Medicine, 8*(3), 623-638.

Walsh, F. (2003). Family resilience: a framework for clinical practice. *Family Process, 42*(1), 1-18.

Walsh, F. (1996). The concept of family resilience: Crisis and challenge. *Family Process, 35*, 261-281.

Waters, E., Maher, E., Salmon, L., Reddihough, D., & Boyd, R., (2005). Development of a condition-specific measure of quality of life for children with cerebral palsy: empirical thematic data reported by parents and children. *Child: Care, Health and Development, 31*(2), 127-135.

Whittam, E. H. (1993). Terminal care of the dying child. Psychosocial implications of care. *Cancer, 71*(10 Suppl), 3450-3462.

Whittemore, R., Chase, S. K., & Mandle, C. L. (2001). Validity in qualitative research. *Qualitative Health Research, 11*(4), 522-537.

Wolfe, L. (2004). Should parents speak with a dying child about impending death? *New England Journal of Medicine, 351*(12), 1251-1253.

Wolfe, J., Hammel, J. F., Edwards, K. E., Duncan, J., Comeau, M., Breyer, J., Aldridge, S. A., Grier, H. E., Berde, C., Dussel, V., & Weeks, J. C. (2008). Easing of suffering in children with cancer at the end-of-life: Is care changing? *Journal of Clinical Oncology,28*(10), 1717-1723.

Wolfe, J., Grier, E. H., Klar, N., Levin, S. B., Ellenbogen, J. M., Salem-Schatz, S., et al. (2000). Symptoms and suffering at the end of life in children with cancer. *New England Journal of Medicine, 342*, 326-333.

Woodgate, R. L. (1999). Social support in children with cancer: A review of the literature. *J Pediatric Oncology Nursing, 16*(4), 201-213.

Worden, I. W. (1982). *Grief counseling and grief therapy: A handbook for the mental health practitioner.* New York: Springer.

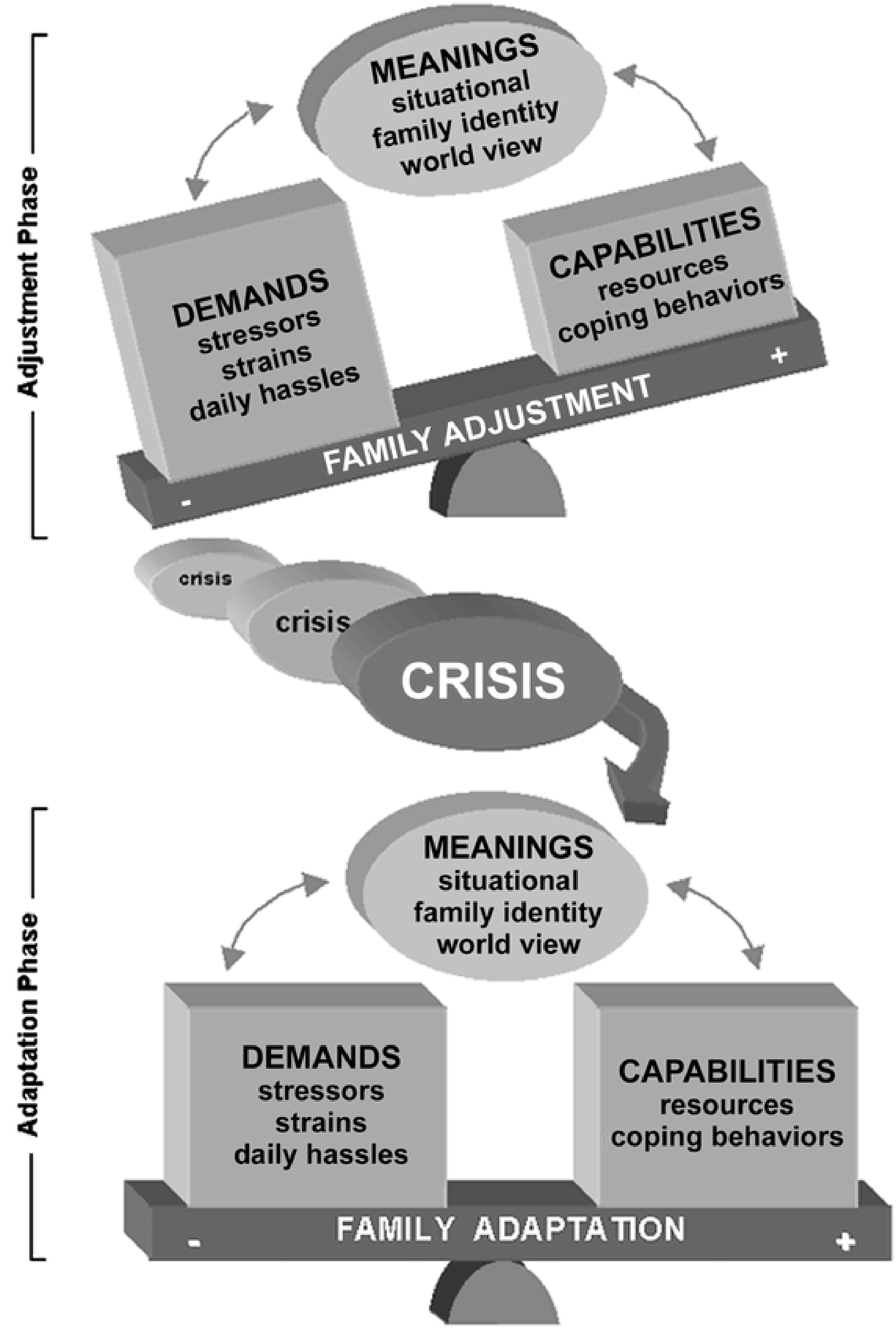
World Health Organization (WHO) (2008). Palliative care. Retrieved August 5, 2008, from: http://www.who.int/cancer/palliative/definition/en

Yates, P. & Stetz, K. M., (1999). Families awareness of and response to dying.*Oncology Nursing Forum, 26*(1), 113-120.

Zerwekh, J. V. (1997). The practice of presencing. *Seminars in Oncology Nursing, 13*(4), 260-262.

APPENDIX A

Family Adjustment and Adaptation Response Model. Copyright 1988 by Families, Systems & Health, Inc. Adapted with permission.



APPENDIX B

TABLE 1: Sample demographics

Family Member Role n=25 (age range)
Mothers – 9 (20-45) Fathers- 6 (20-45) Siblings- 5 (5-15) Grandmothers- 4 (55-70) Ill Child- 1 (adolescent)
Race/Ethnicity of Families n=13
Caucasian- 8 African-American- 4 Mexican-American- 1
Marital Status of Families n=13
Married- 8 Single parent/grandmother - 5
Bereaved Status of Families at time of interview n=13
Child living - 7 Child deceased - 6
Child’s life-limiting condition
Neuromuscular – 9 Malignancies – 2 Congenital - 2

APPENDIX C

TABLE 2: Settings

Location of Care n>13 due to overlap
Hospital - 13 GMCH - 10 Home w/ hospice-4
Location prior to admission to GMCH N=10
Hospital -5 Home -5
Initial reason for admission to GMCH n=10
Respite care -5 Transitional care -4 EOL care -1
Family admissions to GMCH *
One admission until child's death – 4 Multiple admissions (respite and transitional care) - 6

* Three families moved from transitional care to EOL care

APPENDIX D

Staff Information Sheet

Children at End-of-Life: How Families Manage Transitions

There are 55,000 children that die each year in the United States (US) and an additional one million are seriously ill with progressive medical conditions. Children who die often suffer needlessly because of lack of palliative and hospice care. Families with children at end-of-life often move between the various locations of care according to the child's and family's needs. To date, there have been no studies examining the experiences of families with children with life-limiting conditions as they transition among locations of care. Therefore the purpose of this study is to examine how families manage the transitions among the various locations of care.

This is a family study, inclusive of all members: child (if possible), parent (both if possible), and siblings (if any and possible). Each family member may be interviewed more than once if needed and reasonable, with interviews lasting anywhere from 60-90 minutes; the duration would be much shorter for children (20-30 minutes). I plan to rely on staff recommendations for choosing families that may want to participate in this pilot study. Ideally, these would be families who want to share their story and speak English. Although questions asked may at times invoke feelings of distress, the focus of the interview is ***not*** to bring out an emotional outpouring of sadness from the families. However, in anticipation of such a reaction, referrals to support services will be made.

As a pediatric hematology/oncology nurse who worked at Children's Hospital and Research Center Oakland, I have an understanding of the sensitive nature of this topic, and the delicate balance necessary between obtaining information and probing too far. My proposal has gone through rigorous review at UCSF's Committee on Human Research. Since I am including children as participants and due to the sensitive topic, I received a full review (18 committee members), rather than the usual expedited review (3 committee members) that most students receive. I share this information with you, so that you can rest assured that I have thoughtfully planned this study. My advisor, Dr. Betty Davies (primary investigator) and Dr. Susan Kools (child and adolescent specialist) will be guiding me throughout this study.

I also completed a pilot study last year with 3 families from GMCH. The experience was very positive and both mothers and fathers participated. They were eager to recommend other families for the study; however, referrals for my study come directly from staff. Therefore, I invite you to think about the families you care for, and suggest any families you think are appropriate for this study to the director of programs and services, Christy Torkildson, or the manager of psychosocial services, Marsha Blachman.

Of course, I welcome any input from staff, as your suggestions can only help strengthen this study.

Thank you for your time. Please feel free to contact me with any concerns.

Aara Amidi-Nouri, RN, MSN
Doctoral Student, Dept. Family Health Care Nursing
University of California, San Francisco
Aara.Amidi-Nouri@ucsf.edu

APPENDIX E

Family Flyer

Share your story...

Help others

We want to understand what it is like for you to be here at George Mark Children's House. Your experiences may hold the key to helping other families who are in similar circumstances. We would like to talk to you at a time and place that is convenient for you. Interviews will last about one hour, and you can choose to meet up to three times if you wish to give us more information. Please contact the researcher at the number below if you are interested in sharing your very important story with us.

Thank you.

Aara Amidi-Nouri, RN, MSN
University of California, San Francisco
Aara.Amidi-Nouri@ucsf.edu
(510) 507-2658

☐ Yes, I would like to share my story.
Please have the researcher contact me at: ___________________
Best times to reach me: __________________________________

☐ Yes, I would like to share my story. I will contact the researcher myself.

☐ No, I do not wish to participate at this time.

APPENDIX F

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO
CONSENT TO PARTICIPATE IN A RESEARCH STUDY

Study Title: Children at End-of-Life: How Families Manage Transitions

This is a research study about what it is like to be a family with a child at George Mark Children's House (GMCH). One of the study researchers, Betty Davies, PhD, RN, or Aara Amidi-Nouri, MSN, RN from the UCSF Department of Family Health Care Nursing will explain this study to you.

Research studies include only people who choose to take part. Please take your time to make your decision about participating. You may discuss your decision with your family and friends if you wish. If you have any questions, you may ask the researchers.

You are being asked to take part in this study because you have a child at GMCH.

Why is this study being done?

The purpose of this study is to understand what it is like for families to have a child at GMCH.

How many people will take part in this study?

About 15 people will take part in this study. About 6 parents, and nine children will be interviewed one, two, or three times. You may be interviewed more than once if there is more information the researcher would like to ask you, or if you would like to share something you did not have time to do in the first interview.

What will happen if I take part in this research study?

If you agree to be in the study, the following procedures will occur:

- You will be interviewed privately by the researcher at a place and time convenient for you. You will be asked questions about your child's illness, your decision to come to GMCH, and your experience at GMCH.
- The researcher will make a tape-recording of your conversation. After the interview, the recording will be typed into a computer, but all names will be removed. Then the tape- recording will be destroyed.

How long will I be in the study?

The researcher will interview you one time, but if you agree, she might also ask if she can talk with you again, but that's up to you. Each interview will take 60-90 minutes.

Can I stop being in the study?

Yes. You can decide to stop at any time. Tell the study researcher if you are thinking about stopping. Also, the study researcher may stop you from taking part in this study at any time if she believes it is in your best interest.

What side effects or risks can I expect from being in the study?

The interview is time consuming, but you can stop at any time. Some of the questions may make you uncomfortable or upset, but you can refuse to answer any questions you do not wish to answer, and you can stop the interview and the recording whenever you want. The researcher will offer you support services if you become upset or uncomfortable. You can also ask for support services if you feel they will help you.

Are there benefits to taking part in the study?

There will be no direct benefit to you from participating in this study. However, this study will help us learn more about families in your situation, and it is hoped that this information will help health professionals better understand how to provide care to families during this difficult time.

What other choices do I have if I do not take part in this study?

You are free to choose not to participate. There will be no penalty to you, and you will continue to get your care from GMCH the way you usually do.

Will my personal information be kept private?

We will do our best to make sure that the personal information that you share with us is kept confidential. However, we cannot guarantee total confidentiality. Your personal information may be given out if required by law. If information from this study is published or presented at scientific meetings, your name and other personal information will not be used. Also, certain information may be changed for publishing purposes so that no one can recognize who you are. Other family members will know that you are participating in this study, but the information you share during the interview will not be shared with other family members.

Organizations that may look at and/or copy your personal information for research, quality assurance, and data analysis include:

- UCSF’s Committee on Human Research: This committee is responsible for checking that this study is ethical and protects the participants. They may look at the information from this study to make sure that everything is being done correctly to protect you and others who participate.

What are the costs of taking part in this study?

There will be no costs to you as a result of taking part in this study.

Will I be paid for taking part in this study?

In return for your time and effort, you will be given $10 in cash for each interview in which you participate. You will receive this cash immediately after you participate in each interview.

What are my rights if I take part in this study?

Taking part in this study is your choice. You may choose either to take part or not to take part in the study. If you decide to take part in this study, you may leave the study at any time. No matter what decision you make, there will be no penalty to you and you will not lose any of your regular benefits, and will continue receiving your usual care from GMCH.

Who can answer my questions about the study?

You can talk to the researchers, Betty Davies, PhD, RN (415-476-4040) or Aara Amidi-Nouri, RN, MSN (510-507-2658) about any questions or concerns you have about this study.

For questions about your rights while taking part in this study, call the office of the **Committee on Human Research**, UCSF's Institutional Review Board (a group of people who review the research to protect your rights) at **415-476-1814**.

****

CONSENT

You have been given copies of this consent form to keep.

PARTICIPATION IN RESEARCH IS VOLUNTARY. You have the right to decline to participate or to withdraw at any point in this study without penalty or loss of benefits to which you are otherwise entitled.

If you wish to participate in this study, you should sign below.

____________	____
Date	Participant's Signature for Consent
____________	____
Date	Person Obtaining Consent

APPENDIX G

Interview Guide: Parents/guardians

Thank you for allowing me to talk with you. As I said on the consent I am interested in learning about your experiences in changing the location of your child's care to GMCH. I will ask some general questions about your child's illness, and more specific questions about your experience here at GMCH. The focus is on your experience, thoughts and feelings. I appreciate anything you want to share with me.

I will begin audiotaping the interview once you feel ready. There are no right or wrong answers, and you may refuse to answer any questions you wish, or end the interview whenever you want.

The illness.

1. I'd like you to think back to when your child first became ill. What was that like for you?

    - What did you notice?
    - When did you bring your child to be seen?
    - How was your child diagnosed?

2. When did you learn that your child would not recover?

    - What was that like?
    - Who helped you?
    - How did this affect your family?

Transition from home/hospital to GMCH.

3. How did you make the decision to come to GMCH?

    - Where were you? At home? Hospital?
    - How did you find out about it?
    - Whom did you talk with?
    - What factors did you consider?
    - What influenced you?
    - ***if not the first time then also***: How has it changed since the first time you came here?
    - What did you tell your children? How did your child/siblings react?

4. What preparations did you have to make?

    - How did you arrange for childcare (if applicable)?
    - How did you arrange for work?

- What equipment/medications had to be taken care of?
- How was it different from preparing to go to the hospital?
- How was it different from preparing to go home?

Current experience at GMCH.

5. What is it like for you to be here at GMCH?

    - What were your first impressions?
    - Is this what you expected?
    - How is it different from the last setting (home or hospital)?
    - What makes it easier for you?
    - What makes it more difficult?
    - Do you have a preference of where to be? (GMCH, home, hospital)
    - Do other family members have a preference of where to be?

6. How has being here at GMCH affected your family?

    - How are your relations with your spouse/children/siblings?
    - What do you do to get through this time?
    - What makes it better for you and your family?
    - What makes it worse?

<u>Closing</u>

7. What advice would you give to another family in your situation?

8. Is there anything else that you would like to tell me?
    - Is there anything you think I need to know?

9. How was this interview process for you?

10. I know we've discussed some difficult things. How are you feeling right now?

Thank you so much for sharing your experience with me. I have learned so much. Your story will help health care providers learn about what your experience is like. It is our hope that this knowledge will help doctors and nurses take better care of children and their families during this very difficult time. I truly appreciate the time you have given me today. Thank you.

APPENDIX H

Child's interview guide

The questions asked of the children will be based on information obtained from parents regarding what the children know about their illness and end-of-life status. No questions will be asked that bring up issues that the family has not discussed previously. A child may share information regarding their illness that may differ from what the parents perceive the child to know, however this will not be elicited via any questions, the child will have to volunteer such information of their own accord. The child may choose to have their parent present or not during the interview.

Thank you for letting me talk with you. I want to learn about you, what you think and what you feel. I will ask you some questions about you, your parents, and your brother/sister. Your mother/father/parents have already said it's okay to talk with you. But you don't have to talk with me if you don't want to. And you can also tell me if you want your mom/dad to be here with you. I'll start to record our talk when you are ready. Remember, there are no right or wrong answers, and you don't have to answer any questions you don't want to. And you can stop me whenever you want.

Introductory questions (designed to build trust and rapport).

How old are you? What grade are you in? Who lives with you? What is your favorite color? Do you like to draw? *(will offer drawing materials at this point for all children ages 5-7, as well children in the age group of 7-12 as appropriate). If there are stuffed animals, dolls, or other such props in the child room I will ask questions about that too, such as the name, etc. to build rapport and trust.*

The illness.

10. Now I'd like you to think back to when you first became ill. What was that like?

    - What did you notice?
    - How were you feeling?
    - What were you told? Who told you?
    - What helped you the most?
    - How did you tell your friends?

    The following questions (2 & 3) will be asked based on information gathered from parents previous to the child's interview. If inappropriate they will be omitted.

11. Do you think you will get better?
    - *(If yes)* what makes you think this?

12. *(If no)* When did you learn that you would not get better?

- What was that like?
- Who helped you?
- *How did this affect your family? (adolescent level question)*

Transition from home/hospital to GMCH.

13. Do you remember the first time you heard of GMCH?
    - What were you told?
    - What did you think about that?
    - Were you at home or in the hospital?

14. What did you have to do to get ready to come to GMCH?

- What did your mom/dad do?
- Who stays with you?
- Who stays with your brother/sister at home?
- What do you have to do when you get ready to go to the hospital?
- What do you have to do when you get ready to go back home?

Current experience at GMCH..

15. What is it like for you to be here at GMCH?

- What's different from when you are at home?
- What's the same?
- How is it different from when you are at the hospital?
- What's the same?
- What makes it easier for you?
- What makes it harder for you?
- Is there anyone that you talk to about your feelings?

16. Do you like being here?
    - Do you like the hospital better?
    - Do you like home better?
    - *Do you have a preference of where to be? (adolescent level question)*

17. Who visits you while you are at GMCH?

- What is that like for you?
- What do you like the best?
- What is the hardest part of visiting?
- How is it different from being at the hospital?

- How is it different from being at home?

Closing

18. What would you say to another kid who is coming here?
What advice would you give to another kid who is going to come to GMCH? (adolescent level)

19. How would you describe this place?(adolescent level question)

20. Is there anything else that you want like to tell me?
    - Is there anything you think I need to know?

Thank you so much for talking with me. I have learned so much. Your story will help us nurses and doctors understand what it is like for kids to be at GMCH. It was very nice of you to share your story with me. Thank you.

APPENDIX I

Sibling's interview guide

The questions asked of the children will be based on information obtained from parents regarding what the children know about their illness and end-of-life status. No questions will be asked that bring up issues that the family has not discussed previously. A child may share information regarding their illness that may differ from what the parents perceive the child to know, however this will not be elicited via any questions, the child will have to volunteer such information of their own accord. The child may choose to have their parent present or not during the interview.

Thank you for letting me talk with you. I want to learn about you, what you think and what you feel. I will ask you some questions about you, your parents, and your brother/sister. Your mother/father/parents have already said it's okay to talk with you. But you don't have to talk with me if you don't want to. And you can also tell me if you want your mom/dad to be here with you. I'll start to record our talk when you are ready. Remember, there are no right or wrong answers, and you don't have to answer any questions you don't want to. And you can stop me whenever you want.

Introductory questions (designed to build trust and rapport).

How old are you? What grade are you in? Who lives with you? What is your favorite color? Do you like to draw? *(will offer drawing materials at this point for all children ages 5-7, as well children in the age group of 7-12 as appropriate). If there are stuffed animals, dolls, or other such props in the child room I will ask questions about that too, such as the name, etc. to build rapport and trust.*

The illness.

21. I'd like you to think back to when your brother/sister first became ill. How did you find out about his/her illness? What was that like for you?

    - Who told you?
    - Who was with you?
    - What was the hardest part?
    - Who helped you?
    - What helped you the most?
    - What do you say to your friends? How do you explain it to your friends?

    The following questions (2 & 3) will be asked based on information gathered from parents previous to the child's interview. If inappropriate they will be omitted.

22. Do you think your brother/sister will get better?

- *(If yes)* what makes you think this?

23. *(If no)* When did you learn that your brother/sister would not get better?

    - What was that like?
    - Who helped you?
    - *How did this affect your family? (adolescent level question)*

Transition to from home/hospital to GMCH.

24. Do you remember the first time you heard of GMCH?
    - Who told you about it?
    - What were you told?
    - Who decided to come to GMCH?
    - What did you think about that?

25. What did all of you have to do to get ready for your brother/sister to come to GMCH?

    - Was your brother/sister at home or in the hospital?
    - What did you do? What did your mom/dad do?
    - Who stays with you?
    - Who stays with your brother/sister at GMCH?
    - What do you have to do when your brother/sister goes to the hospital?
    - What do you have to do when your brother/sister comes back home from the hospital?

Current experience at GMCH.

26. What is it like for you to be at home when your brother/sister is at GMCH?

    - What's different from when your brother/sister is at home?
    - What's the same?
    - How is it different from when your brother/sister is at the hospital?
    - What's the same?
    - What makes it easier for you?
    - What makes it harder for you?

27. What is school like for you?

    - Do things change at school when your brother/sister is at GMCH?
    - How?
    - Who helps you?

- Who takes you to school? Who picks you up?
- Is there anyone that you talk to about your feelings?
- What do you like best about school?
- What's the hardest part?

28. Do you visit your brother/sister at GMCH?

- What is that like for you?
- What do you like the best?
- What is the hardest part about visiting?

29. Have you visited your brother/sister at the hospital?

- What was that like for you?
- What was the best thing about visiting at the hospital?
- What was the hardest thing?

Closing

30. What advice would you give to another kid who is going to come to GMCH? (or what would you say to another kid who is coming here?)

31. Is there anything else that you want like to tell me?
    - Is there anything you think I need to know?

Thank you so much for talking with me. I have learned so much. Your story will help us nurses and doctors understand what it is like for kids who have a brother/sister at GMCH. It was very nice of you to share your story with me. Thank you.

APPENDIX J

Assent for 7-12 year olds

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO (UCSF)

ASSENT TO BE IN A RESEARCH STUDY ABOUT FAMILIES AT GMCH

For children 7-12 years old

Why are we meeting with you?

We want to tell you about something we are doing called a research study. A research study is when nurses get a lot of information to learn more about something. I am doing a study to learn more about families who are at George Mark Children's House (GMCH). After I tell you about it, I will ask if you'd like to be in this study or not.

Why are we doing this study?

We want to find out what it is like for you to be at GMCH or have a brother or sister at GMCH. So we are getting information from boys and girls like you.

In the whole study, there will be about 6 parents and 9 children who are either at GMCH or have a brother or sister at GMCH.

What will happen to you if you are in this study?

If you agree to be in this study I will ask you some questions about yourself, your parents, and your brother/sister. You can also make a drawing if you like and then tell me about your drawing. I will tape what you say so that I can remember it. If it's okay with you, I'd like to maybe talk to you again on another day about what you said or your drawing, but only if you want to. It's okay to only talk to me only one time. If you agree to be in this study, your family will know you agreed, but what I will not tell them what you say to me. If you want to, you can have your parent(s) with you while I ask you questions. It's up to you.

Will this study hurt?

This study will not hurt you, but sometimes a question I ask you might feel like it hurts. So you don't have to answer any question you don't want to. You can also stop this study at any time you want.

Will you get better if you are in this study?

No, this study won’t make you feel better or get well. But I might find out something that will help other children like you later.

Do you have any questions?

You can ask questions any time. You can ask now. You can ask later. You can talk to me or you can talk to someone else.

Do you have to be in this study?

No, you don’t. No one will be mad at you if you don’t want to do this. If you don’t want to be in this study, just tell us. Or if you do want to be in the study, tell us that. And, remember, you can say yes now and change your mind later. It’s up to you.

If you don’t want to be in this study, just tell us.

If you want to be in this study, just tell us.
The nurse will give you a copy of this form to keep.

****

SIGNATURE OF PERSON CONDUCTING ASSENT DISCUSSION
I have explained the study to ______________________(*print name of child here*) in language he/she can understand, and the child has agreed to be in the study.

___________________________________ ________________
Signature of Person Conducting Assent Discussion Date

____
Name of Person Conducting Assent Discussion (*print*)

APPENDIX K

Assents for 13-18 year olds

UNIVERSITY OF CALIFORNIA SAN FRANCISCO (UCSF)

ASSENT TO BE IN A RESEARCH STUDY ABOUT FAMILIES AT GMCH

For adolescents 13-18 years old

What is this study about?
Betty Davies, PhD, RN and Aara Amidi-Nouri, RN, MSN are doing a research study. This study will look at the experience of families at George Mark Children's House (GMCH).

We hope this study will help nurses and doctors learn what families need when they are in situations like yours.

Because you are at GMCH (or have a brother/sister at GMCH) you are being asked if you would like to be part of this study.

How many people will take part in this study?
About 6 parents and 9 children and adolescents (0-18 years old) will be in this study.

What will happen if you decide you might want to be in this research study?
Your parent(s) has(have) already agreed that it is okay for you to be in this study if you want to.

What happens during the study?
If you agree, I will ask you questions about yourself/ your parents/ and your brother/sister about what it is like to be at GMCH. If you agree, I will record the conversation, and I will also take notes so I can remember what you are saying. You don't have to answer any question you don't want to. There are no right or wrong answers. You can stop the interview anytime you want. If you agree to be in this study, your family will know, but I will not tell them anything that you say to me. They will only know that you agreed to be in the study. If you want to, you can have your parent(s) with you the whole time or part of the time I ask you questions.

Will any parts of this study hurt or have other risks?
This study will not hurt, but sometimes you might not want to answer a question because thinking about something might hurt. Sometimes people feel better after they talk about something, sometimes people feel worse after they talk about something. It's okay not to answer a question. You don't have to do anything you don't want to do. You can stop a question or the interview anytime you want to. If you want to, you can have your

parent(s) with you while I ask you questions, it's up to you. If you become upset, I will also let you know about who can help you, and we can stop the interview if you want.

Will you get better if you are in this study?
This study will not make you get better. But I might find out something that will help other children like you later.

What if you have questions?
You can ask me any questions you have. You can ask your questions now or later, any time you like. You can also ask your parents to ask questions for you.

What are your choices?
Your parent(s) has(have) agreed, so you can be in this study if you want to. But you don't have to be in it if you don't want to. Nobody will get mad at you if you don't want to do this.

If you decide to be in the study now and you change your mind later, that's okay, too. You just have to tell me, your parents, or the GMCH staff as soon as you change your mind, and you will be taken out of the study.

****

If you don't want to be in this study, just say so, and don't sign this form.

If you want to be in this study, please sign your name below.
If you sign here, it means you agree to participate in this study.
The nurse will give you a copy of this form to keep.

______________________________	____________	____
Adolescent's Signature	Date	Age

____
Adolescent's Name (*print*)

______________________________	____________
Signature of Person Conducting Assent Discussion	Date

____
Name of Person Conducting Assent Discussion (*print*)

APPENDIX L

Parental Permission Consent

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO CONSENT FOR YOUR CHILD TO PARTICIPATE IN A RESEARCH STUDY

Study Title: Children at End-of-Life: How Families Manage Transitions

This is a research study about what it is like to be a family with a child at George Mark Children's House (GMCH). One of the study researchers, Betty Davies, PhD, RN, or Aara Amidi-Nouri, MSN, RN from the UCSF Department of Family Health Care Nursing will explain this study to you.

Research studies include only people who choose to take part. Please take your time to make your decision about participating. You may discuss your decision with your family and friends if you wish. If you have any questions, you may ask the researchers.

You are being asked to take part in this study because you have a child at GMCH. Your child does not have to participate in order for you to participate. If you only want yourself to be interviewed we will not ask your child(ren) any questions; we will only interview you. If you agree to have your child(ren) interviewed, we will interview you and your child(ren). The opinions of children are very important and that is why we would like to talk to them, but it is your decision.

Why is this study being done?

The purpose of this study is to understand what it is like for families to have a child at GMCH.

How many people will take part in this study?

About 15 people will take part in this study. About 6 parents, and nine children will be interviewed one, two, or three times. All children who participate need to have parental permission first.

What will happen if my child takes part in this research study?

If you and your child agree for your child to be in the study, the following procedures will occur:

- Your child will be interviewed privately by the researcher at a place and time convenient for both you and your child. Your child will be asked questions about him/herself, others in the family, and the experience at GMCH. If your child is under age 7 he/she will be asked to make drawings and the interview questions will come from the pictures you're your child draws. If your child is between ages 7-12 he/she can choose between drawing and being interviewed. If your child is between the ages of 13-18 he/she will be interviewed using questions only. At the beginning of the child's interview your child will be asked if he/she would like to have you present at the interview. If so, I will ask you to join us, if not, I will continue with the interview privately.

- The researcher will make a tape-recording of the conversation. After the interview, the recording will be typed into a computer, but all names will be removed. Then the tape-recording will be destroyed.

How long will my child be in the study?

The researcher will interview your child one time, but if you and your child agree, she might also ask if she can talk with your child again, but that's up to you and your child. Your child will be interviewed more than once only if more information was needed, or if the child wanted to continue at a later time. Should there be a second interview it will take place at least one week and up to one month after the first interview depending on what is convenient for you and your child. If there is a need for a third interview, it will take place at least one week and up to one month after the second interview depending on what is convenient for you and your child. Each interview will take 20-60 minutes depending on the child's age and health.

Can my child stop being in the study?

Yes. You or your child can decide to stop at any time. Tell the study researcher if you or your child is thinking about stopping. Also, the study researcher may stop your child from taking part in this study at any time if she believes it is in your child's best interest.

What side effects or risks can I expect from my child being in the study?

The interview is time consuming, but your child can stop at any time. The focus of the interview is ***not*** to make your child feel uncomfortable or sad, it is to understand his/her experience. But if any questions make your child uncomfortable, your child can refuse to answer any questions he/she does not wish to answer, and your child can stop the interview whenever he/she wants. The researcher may also stop the interview at any time that she thinks your child appears upset. If your child wishes, you may also be present at the interview and you may stop questions, or end the interview whenever you want. The researcher will offer your child support services if your child becomes upset or uncomfortable. If your child has not requested your presence during their interview and he/she becomes upset, the researcher will again ask your child if he/she wants to have you present. You can also ask for support services if you feel they will help your child.

Are there benefits to taking part in the study?

There will be no direct benefit to your child from participating in this study. However, this study will help us learn more about families in your situation, and it is hoped that this information will help health professionals better understand how to provide care to families during this difficult time. Including the opinions of children as well as the parents is very important in making this a family study.

What other choices do I have if I do not want my child to take part in this study?

You are free to choose to participate in this study even if you do not want your child to participate. If you have more than one child, you can decide which child can participate, or choose all of them to participate. If you do not wish to have your child(ren) participate, there will be no penalty to your child, your child will continue to get care from GMCH the way your child usually does.

Will my personal information be kept private?

We will do our best to make sure that the personal information your child shares with us is kept confidential. Other family members will know about participation in the study, but the information from the interview will not be shared with other members. However, we cannot guarantee total confidentiality. Your child's personal information may be given out if required by law. If information from this study is published or presented at scientific meetings, your name and other personal information will not be used. Also, certain information may be changed for publishing purposes so that no one can recognize who your child is.

Organizations that may look at and/or copy your child's personal information for research, quality assurance, and data analysis include:

- UCSF's Committee on Human Research: This committee is responsible for checking that this study is ethical and protects the participants. They may look at the information from this study to make sure that everything is being done correctly to protect you and others who participate.

What are the costs of taking part in this study?

There will be no costs to you or your child as a result of taking part in this study.

Will my child be paid for taking part in this study?

In return for your child's time and effort, your child will be given a $10 bookstore gift certificate for each interview your child participates in. Your child will receive gift certificate immediately after he/she participates in each interview.

What are my rights if I take part in this study?

Taking part in this study is your choice. You may choose either to allow your child to take part or not to take part in the study. If you decide for your child to take part in this study, you can choose for your child to leave the study at any time. No matter what decision you make, there will be no penalty to your child and he/she will not lose any of his/her regular benefits, and will continue receiving the usual care from GMCH.

Who can answer my questions about the study?

You can talk to the researchers, Betty Davies, PhD, RN (415-476-4040) or Aara Amidi-Nouri, RN, MSN (510-507-2658) about any questions or concerns you have about this study.

For questions about your rights while taking part in this study, call the office of the Committee on Human Research, UCSF's Institutional Review Board (a group of people who review the research to protect your rights) at 415-476-1814.

****

CONSENT

You have been given copies of this consent form to keep.

PARTICIPATION IN RESEARCH IS VOLUNTARY. You have the right to decline to participate or to withdraw at any point in this study without penalty or loss of benefits to which you are otherwise entitled.

If you wish for your child to participate in this study, please write the name(s) of child(ren) and sign below.

____
Name(s) of child(ren) and age(s)

__________ ____
Date Participant's Signature for Consent

__________ ____
Date Person Obtaining Consent

APPENDIX M

Parental Query Guide

Who lives with you at home?

How many children do you have? What are their ages? Names?
(if more than one child , a query sheet for each child with the following questions will be filled out)

When was your child diagnosed?

How long has your child received treatment?

What does your child know about his/her diagnosis?

What do the siblings know?

What do they know about the current health status?

Do some of your children know more than the other children?

Do they know what GMCH is/means?

How much have you told them?

What information have you kept from them?

What are the words you use for the diagnosis/illness/recovery status/?

What words do you avoid using with your children?

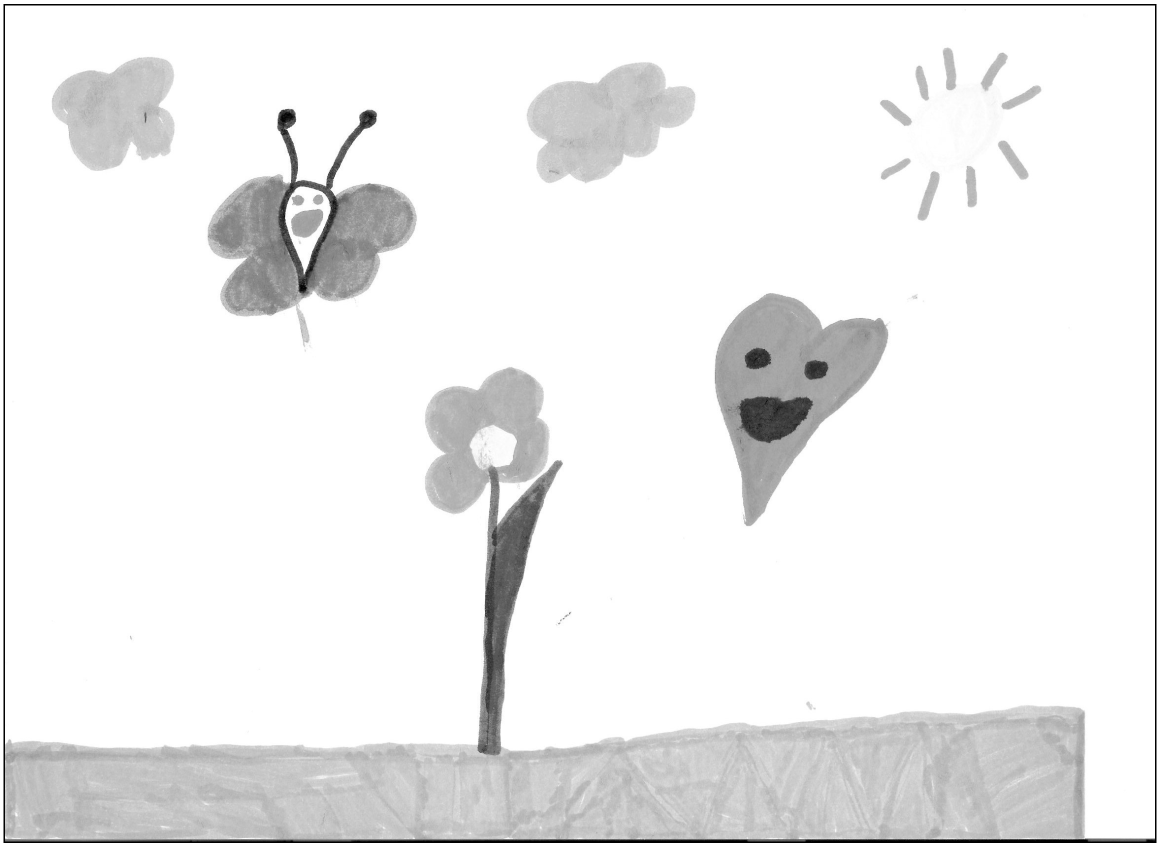
What do you tell non-family members (ie. Friends, teachers at school, coworkers, etc.)?

Is there anything else you would like to tell me that would be helpful in interviewing your child?

APPENDIX N

Jenny's (sibling, family 6) drawing in response to the question

"What is it like for you to be at GMCH?"



Picture drawn in color with markers: yellow sun with orange rays, green grass, red heart.

APPENDIX O

Ordered Situational Map: Pediatric end-of-life

Individual Human Elements/Actors
Child (ill child)
Sibling
Mother, Father
Grandparents
Other relatives
Colleagues
Friends
Teachers
Doctors (attendings, residents, family physician)
Nurses
Social workers
Chaplains (pastors, priests, etc.)

Collective Human Elements/Actors
Family
Interdisciplinary team
Health care professionals
Support groups
School
Hospital
Hospice
Home
Home health services
Insurers
CCS (California Children's Services)
Medical supply/DME companies
Community
Religious community
Professional organizations: AAP/IOM/WHO

Nonhuman Elements/Actants
Treatment
Location of care
Location of death
Internet

Implicated/Silent Actors/Actants
Ill child
Siblings
Adult palliative care models

AAP guidelines

Discursive Constructions of Individual/Collective Human Actors
Uncertain prognosis
Cure vs. comfort approach
Quality of life
Specialized Pedi EOL training
Attitudes towards dying children
Right to die/assisted suicide
Symptom management
Decision making
DNR status
Grief & loss

Discursive Constructions of Nonhuman Actants
Rising incidence of cancer (leading cause of death fr. disease)
Technologic imperative
Managed care

Political/Economic Elements
Hospice eligibility guidelines
Universal Health care
Health policies
Patients as minors, no voting power
Family's economic status
Family's legal status
Family's educational status
Employment

Sociolcultural/Symoblic Elements
Language barriers
Ethnicity/Race/Culture
Marital Status
Beliefs about disease and dying
Physical symbolisms of tx (alopecia, cushingoid appearance, pallor, emaciation)
Central line catheters
Markings on body for radiation

Spatial Elements
Fragmentation of care (specifically location)
Access and availability
Transportation

Temporal Elements
Trajectory of illness
Child's development

Sibling development
Family lifespan development
history of pediatric hospice options

Major Issues/Debates
Death in children
Underutilization of services
Integrated model inclusive of curative and palliative approaches

Related Discourses (Historical/Narrative/Visual)
Media
Other Western countries' hospice programs
Books
Movies

Other Key Elements
Inner family conflict
Spirituality
Hope

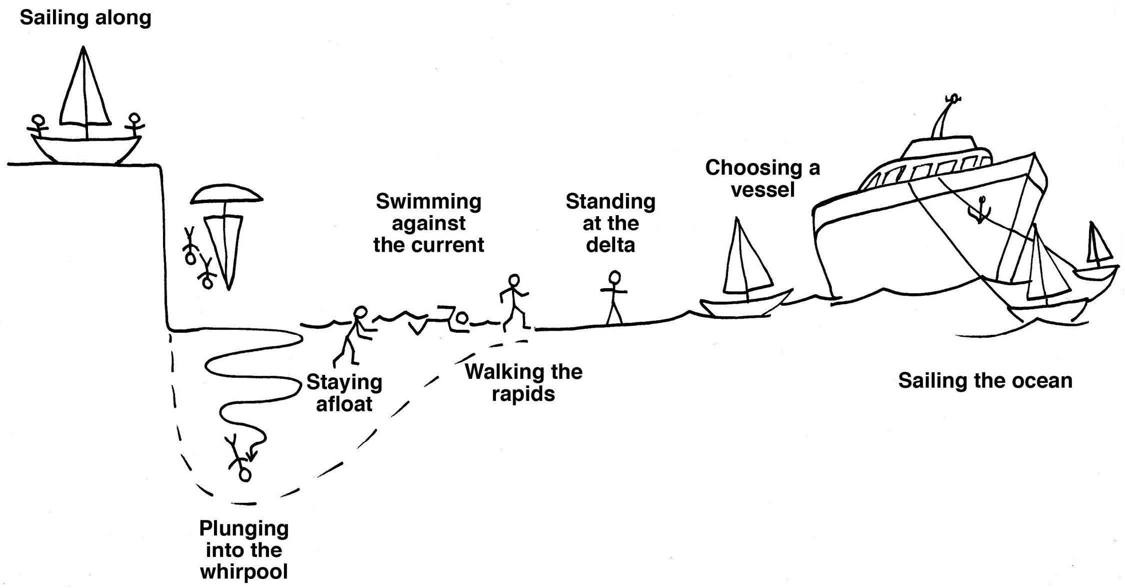
APPENDIX P

Awareness Grid

Influence of forestructure/ positionality	Forestructure description	OPENS	CLOSES
Lived world	Worked as nurse w/ families @ EOL, not a bereaved parent, have exp w/ loss	Understand sensitive nature of phenomenon and vulnerability of families	May be overly sensitized to what is considered appropriate care and grieving
Problem/ Disruption	Families' suffering, abandonment @ EOL/death	Awareness of difficulties family's face	Expectation of finding complaints, ways to improve care
Theory	Family resiliency, systems, SI	Sensitizes to looking at strengths, all members views, meanings	Might hinder being able to see pathology (salutogenesis lens), expectation that all members of system have influence, whereas some may be silenced/invisible , may falsely attach meaning to symbols
Relationship w/ families	Doctoral student	Do not hold power/access to provided services,	May receive answers based on what they think I should be told, be seen as not understanding their process.
Profession	Pedi RN	understand jargon/dx/illness	May be judged by family's prev. exp. w/ HCP, TFG meanings
Other	Mom w/ todd	Shared parenting	Might be difficult for families, esp. w/ loss of only child
Reflexivity	Have time for introspection	Sensitive to issues, interviewing format	Emotional stress from being 'with' the data, closing oneself to 'seeing' as a way of protection
Voice	Pedi RN, mom, student, researcher	Represent varied perspectives, use quotes/data, ground analysis/findings in data	May give more weight to mom's voice, issues surrounding nursing care, or areas that would be interest to the field/research/pub.

APPENDIX Q

Diagram of Family Journey



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Sara Amidi-Nouri

Author Signature