ANTICIPATORY MOURNING: INVESTIGATING CHILDREN AND YOUTH'S
SELF-REPORTED EXPERIENCES WITH LIFE-LIMITING ILLNESS

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ANTICIPATORY MOURNING: INVESTIGATING CHILDREN AND YOUTH’S SELF-REPORTED EXPERIENCES WITH LIFE-LIMITING ILLNESS

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ABSTRACT

Pediatric end-of-life care is an emerging area of research and specialization; however, the literature and empirical research are rather limited and focused primarily on medical aspects of care. The current study aimed to expand this area of research by moving beyond medical issues and by directly soliciting the perspectives of children and youth with life-limiting and/or life-threatening illnesses. Anticipatory Mourning as described by Rando (2000) was used as the theoretical guide for this study. The primary research questions for this study were: 1) In what ways do ill children and youth characterize their illness; 2) How do significant relationships change as a function of life-limiting/life-threatening illness in children and youth; and 3) How do ill children and youth characterize hope and their future in light of their illness? A total of 10 children and youth, aged 8 to 21 years, participated in this qualitative study. Grounded theory methods were used to analyze the interviews and a preliminary conceptual framework emerged with the core category of Living in Light of Life-Limiting Illness. Major categories included Aspects of Illness and Aspects of Living and the information obtained from the interviews addressed the three primary research questions. The participants described their illness through the ways that their diagnosis was obtained, the treatments they received, declines in physical functioning, treatment interventions, positive aspects of their experiences, as well as how they responded to their illness at
various points in time. The participants described significant relationships including the support of their immediate and extended families, the relationships with their pets, the roles of friends, and their interactions with individuals from the larger community. In regard to characterizing hope and their future, the participants described a tension between maintaining hope for health and survival, and their fear and recognition that death was a realistic possibility. Relatedly, the participants described short- and long–term hopes and goals for their futures. Most participants stated that they did not have specific ideas about planning for their end-of-life, but all did want the opportunities to say good-bye to significant others.
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CHAPTER I
STATEMENT OF THE PROBLEM

The number of children and youth who die in the United States has dropped considerably since 1980 (Institute of Medicine [IOM], 2003). Unfortunately, they still die in significant numbers: 53,501 children from birth to 19 years old died in 2005 from illnesses and injuries (Kung, Hoyert, Xu, & Murphy, 2008). Although the number of children and youth deaths in the U.S. is relatively small in comparison to adult deaths, the rarity of the event makes it particularly difficult to cope with (American Psychological Association [APA], 2005). Therefore, this is an area in which counseling psychologists could make a positive impact and facilitate improved coping in affected individuals. Furthermore, counseling psychologists have a unique perspective in understanding the relationships among the developmental aspects of children, family dynamics, and contextual factors such as culture, which puts them in a position to effectively work with youth, families, and systems involved with caring for children near the end-of-life.

There are a variety of factors that contribute to youth mortality. For example, infants, who account for about half of all childhood deaths, most often die as a result of prematurity and low birth weight (IOM, 2003). Younger children (ages 1 to 9 years) are much less likely to die than infants. The leading causes of death in this group are
unintentional injuries (e.g., motor vehicle accidents and drowning), congenital anomalies, cancer, and diseases of the heart (IOM). Older children (ages 10 to 12) and adolescents (ages 13 to 18) most often die from injuries that are unintentional, primarily motor vehicle accidents; or intentional, such as homicide and suicide (IOM). Within this larger group of older children and adolescents, there are significant disparities as to the causes of mortality in the subgroups. For example, rates of homicide and suicide increase dramatically for adolescents as compared to older children. Additionally, violent deaths are much more likely to occur among African American children than among White children (IOM). In addition to fatal injuries, mortality in this group is also often caused by cancer, congenital anomalies, and heart disease. Regardless of the cause of death, childhood mortality is generally perceived to be unexpected and particularly distressing, so affected individuals may benefit from psychological intervention (APA, 2005).

From the group of children and youth who die in the United States, this project focused on those individuals who are diagnosed with an illness and who are participating in a palliative care program. Because determining prognosis relative to which children will die is particularly difficult in the pediatric population; they are generally not classified as having a terminal illness, with the adult standard of having six months or less to live (IOM, 2003). Rather, children and youth are more often described as having life-threatening and/or life-limiting illnesses. A life-threatening condition, specifically in this group, is thought to have a substantial probability of death in childhood and is perceived as potentially being fatal (IOM); whereas life-limiting conditions refer to those illnesses that are not curable and cause premature death, especially in childhood (IOM).
The present research aimed to examine the end-of-life experiences of children and youth with life-threatening or life-limiting illnesses in order to contribute to the pediatric end-of-life literature as well as to suggest avenues for psychological intervention to better meet the needs of this population.

Palliative care programs provide an avenue to identify children with life-limiting or life-threatening illnesses. Palliative care is a model of caring for patients and their families that focuses on preventing, relieving, reducing, and/or soothing the negative symptoms related to illness and improving quality of life (IOM, 2003). Although it is not necessarily limited to end-of-life care, the discussion in this review focuses on the application of palliative care at the end-of-life. Palliative care is considered the “gold standard” of medical management for terminally ill patients, including children, youth, and adults, who face some of the same end-of-life and palliative care issues. For example, common concerns in palliative care patients of all ages include inadequate assessments and treatment of pain and psychosocial issues (APA, 2005; IOM, 2003). Additionally, most palliative care patients must make difficult treatment decisions. Advice in favor of a treatment option is often given to adult and child patients, without consideration and careful explanation of the potential adverse effects and minimal benefits (APA). Further, conflict may arise between a specialist’s desire to prolong life and patients’ sense of quality of life.

Children and youth, however, do present unique challenges in their end-of-life care. Specifically, developmental differences affect many aspects of diagnosis, prognosis, treatment, communication, and decision making as well as the understanding of their own
disease progression and terminal outcome (APA, 2005; Doka, 2009; Himelstein, Hilden, Mostad, Boldt, & Weissman, 2004). As a result of prognostic difficulties, palliative care is recommended as soon as children and youth are diagnosed with a life-threatening illness and throughout its course (Himelstein et al.; Hylton Rushton & Catlin, 2002). Additionally, children’s normal developmental needs require continued support despite their illness (Doka, 2009; Goldman, 1998; McCulloch, Comac, & Craig, 2008). Children also do not independently make their own medical decisions, with that responsibility generally left to their parents or guardians. Moreover, many terminally ill children are born with rare medical conditions that create a significant uncertainty in the medical management of the illness (IOM, 2003). Finally, youth also are more frequently impacted adversely by social and economic concerns such as limited access to health insurance (APA).

Because of the unique circumstances surrounding children and youth with terminal illnesses, adult standards of care are not sufficient in ensuring appropriate treatment (APA, 2005). End-of-life care for children and youth must, therefore, be studied independently in order to gain an understanding of the many special issues pertinent to this population. Literature and empirical research relating to end-of-life care for children and youth is limited and primarily focuses on the medical aspects of palliative care; however, there are indications that pediatric end-of-life is an emerging area of research and specialization beyond a consideration of the medical issues (APA; IOM, 2003; Hinds, 2004; Larkin, 2000; Liben, Papadatou, & Wolfe, 2008; Weisse, 2005).
Research focused at the end-of-life of children and youth has documented the challenges and importance of implementing strong pediatric palliative care programs within hospitals and oncology units (e.g., Baker et al., 2008; Golan et al., 2008; Liben et al., 2008). Some research has examined factors contributing to positive outcomes related to pediatric end-of-life care and experiences including location of death, provision of information, utilization of respite care, and facilitation of choice and control (e.g., Davies, Steele, Collins, & Cook, 2004; Dussel et al., 2009; Papadatou, Yfantopoulos, & Kosmidis, 1996; Price, 1989; Rini & Loriz, 2007). Other research has described institutional and personal difficulties around discussing sensitive end-of-life decision-making, particularly regarding withholding and withdrawing life sustaining medical treatment and issuing do-not-resuscitate orders. Additionally, theoretical literature has focused on describing ways children and youth can be appropriately involved in their own end-of-life decision making (e.g., Bluebond-Langner, DeCicco, & Belasco, 2005; Wier & Peters, 1997).

Another area that has received some attention is the impact of interacting with terminally ill children and youth on significant others. For example, some research has documented the effects of working in pediatric palliative care on physicians and nurses (Papadatou, Gellali, Papazoglou, & Petraki, 2002). Other studies have investigated the impact of interacting with a terminally ill child or youth on their parents and families (e.g., Davies et al., 2004; Freeman, O’Dell, & Meola, 2004; Papdatou, Yfantopoulos, & Kosmidis, 1996).
In summary, end-of-life research regarding children and youth is increasing. Much of the existing research is focused on pediatric palliative care, documenting the challenges of providing palliative care to a pediatric population, and improving care provided to patients and families at the end-of-life of a child. Some research also documented the needs and reactions of parents and families enduring the end-of-life of a terminally ill child. Additionally, the existing research has focused on improving the end-of-life experiences of patients, family members, and caregivers through improved medical management of the child’s/youth’s illness.

Essentially missing from the existing research is an understanding of the lived experiences of children with life-threatening illness. This broader perspective is the focus of this dissertation. The limited relevant research focused on children and youth’s self-reported experiences with life-threatening or life-limiting illnesses is described in greater detail in Chapter 2. The existing research has established that children’s cognitive understanding of death develops according to Piagetian stages of cognitive development. Additionally, the research has demonstrated that children and youth are aware of their terminal prognosis and that they gain increasing knowledge about their illnesses through experiences in medical settings regardless of whether there is open communication. This dissertation aimed to examine children and youth’s experiences with their own terminal illness from a phenomenological perspective. Of interest were children and youth’s experiences of living while dying from life-threatening/life-limiting illnesses. Specifically, descriptions of the thoughts, feelings, and actions stimulated by the losses derived from having an imminently life-threatening and/or life-limiting illness were
sought from the children and youth, themselves. Rando (2000) described Anticipatory Mourning as the experience of responding to the multiple losses encountered from the time of being diagnosed with a terminal illness until death. As such, the theoretical framework of Anticipatory Mourning served as the foundation for the present study.

Anticipatory Mourning

According to Rando (2000), individuals encountering a terminal illness face many intermediary losses to which they must adjust prior to dying and that impact their experience near the end-of-life. The approach to understanding and adjusting to the experience is described as anticipatory mourning. According to Rando’s theory, a person’s experience is shaped by a complex interaction of six major dimensions of anticipatory mourning. These six dimensions include perspective, time focus, and influencing factors, which are constants that frame the experience, as well as major sources of adaptational demands, contextual levels, and generic operations, which are experiential factors that constitute areas for intervention.

The theory suggests that terminal illness can be considered from several perspectives including that of the patient, intimate others, caregivers, and concerned others (Rando, 2000). The present study focused on the perspective of the patient with a terminal or life-limiting illness. A combination of social, psychological, and physiological influencing factors form a unique constellation that shape the patient’s particular anticipatory mourning experience. In addition, the time focus of the losses may include those that occurred in the past, losses presently occurring, or losses that have yet to come.
Throughout the anticipatory mourning process, patients are faced with adaptational demands, derived from trauma and loss, to which they must respond (Rando, 2000). Additionally, patients engage in seven generic operations that comprise activities characteristic of healthy anticipatory mourning and these generic operations occur on the intrapsychic, interpersonal, and systemic contextual levels.

Rando’s (2000) theory is a broad description of anticipatory mourning that encompasses multiple perspectives of individuals responding to an impending loss at the end-of-life. However, the theory is primarily focused on significant others rather than on the patient. Additionally, the underpinnings of the theory are taken predominantly from research and observations of adult mourners. Therefore, the theory of Anticipatory Mourning served as a guide for approaching this study, providing an initial framework; however, given the adult and caregiver foci when the theory was developed, examining the anticipatory mourning experience in terminally ill children and youth required an approach that allowed for the discovery of new important variables. Therefore, Grounded Theory was utilized in the design and analysis of this research (Strauss & Corbin, 1990).

This project aimed to expand the current pediatric end-of-life literature by examining the perspective of children and youth facing their own life-threatening or life-limiting illness and obtaining descriptions of their thoughts, feelings, and actions in response to the losses derived from their illness and its associated treatments. Thus, this dissertation sought to describe the experiences and adjustment of children and youth to their own life-threatening or life-limiting illnesses to better understand how they navigate the process of dying. In doing so, this research also aimed to identify avenues for
psychological intervention to assist these children and youth in managing these transitions and losses.
CHAPTER II
REVIEW OF THE LITERATURE

This section begins by describing the strategy employed in searching for relevant research. Anticipatory mourning is described as a theoretical heuristic with which to consider children and youth’s end-of-life experiences and the limited research examining anticipatory mourning is reviewed. Next, the broader perspective of the end-of-life literature as it pertains to children and youth is presented. An overview of pediatric end-of-life literature is presented. Developmental research is reviewed to illustrate the process by which children gain a more mature understanding of the concept of death. Additionally, research examining children and youth’s experiences with their own terminal illness is detailed to identify what is currently known in the area and to highlight the importance of the current research. Finally, the chapter concludes with a presentation of the research questions.

The pediatric end-of-life literature is expanding; however, research specifically focused on the phenomenological end-of-life experiences of children and youth with life-threatening or life-limiting illnesses is limited. In order to find as much of the published literature related to children and youth’s self-reported end-of-life experiences as possible, I performed searches of a number of research databases including PsycInfo 1967-,
Psychology and Behavioral Sciences Collection, Medline, Proquest Nursing and Allied Health Source, and Social Work Abstracts. I searched these databases using specific phrases such as (terminal* AND ill*) AND (child* OR adolescen* OR youth*), (end-of-life) AND (child* OR adolescen* OR youth*), (dying) AND (child* OR adolescent* OR youth*), (life limiting) AND (child* OR adolescen* OR youth), (life threatening) AND (child* OR adolescen* OR youth), (anticipatory AND mourning), and (anticipatory AND grief). I also used broader search strategies such as (end-of-life); (end-of-life) AND (coping); (dying) AND (coping); (terminal* AND ill*) AND (coping), (terminal* AND ill*), and (dying). Furthermore, reference lists of articles accessed and a reference list provided by an expert researcher in pediatric end-of-life were reviewed to find additional relevant literature.

From the broader end-of-life literature, research focusing on children and adolescents who are ill with a life-threatening illness or who have a life-limiting illness was selected, while studies describing individuals who recovered from life-threatening illness were generally excluded from review. Additionally, research was excluded if it was not written in the English language, focused primarily on medical interventions, focused on prenatal or infant illness, focused on non-human subjects, focused on adult mourners, described the experiences of orphans, or described children’s and adolescents’ attitudes toward death and dying based on hypothetical scenarios. Thus, studies focusing on the experiences of children and adolescents with life-threatening or life-limiting illness, from their own perspectives, were selected for a more detailed review in the subsequent sections. The limited amount of research I found is consistent with the results...
obtained by Hinds and colleagues (2007) who noted in a review of pediatric end-of-life research in oncology that a great majority of the research about the end-of-life experiences of children and adolescents relies on record review or observer reports, and does not include reports from the patients.

From the literature describing anticipatory mourning and/or anticipatory grief, abstracts of all articles were reviewed. Research investigating anticipatory mourning from the perspectives of the various mourners was reviewed. The studies describing the impact of anticipatory mourning from the patient’s perspective are described in subsequent sections.

Anticipatory Mourning: The Theory

Anticipatory mourning provides a framework for how an individual approaches an encounter with terminal illness (Rando, 2000). The experience of anticipatory mourning is framed by three constants: perspective, time focus, and influencing factors. In addition, the theory suggests that there are three experiential factors that constitute areas for intervention including major sources of adaptational demands, generic operations, and contextual levels. The interaction of these six dimensions: perspective, time focus, influencing factors, major sources of adaptational demands, generic operations, and contextual levels, comprise an individual’s experience of anticipatory mourning. (See Figure 1).

**Perspective**

The first dimension considers the perspective of the individual experiencing anticipatory mourning. The mourners as conceptualized within the theory of anticipatory
Figure 1: The six dimensions of anticipatory mourning

- **Perspective:** Patient, Caregiver, Intimate, Concerned Other
- **Influencing Factors:** Psychological, Social, Physiological
- **Time Focus:** Past, Present, Future
- **Major Sources of Adaptational Demands**
- **Contextual Levels:** Intrapsychic, Interpersonal, Systemic
- **Generic Operations:** Grief and Mourning, Coping, Interaction, Planning, Psychosocial Reorganization, Balancing Conflicting Demands, Facilitating Appropriate Death

Theoretically fluid factors amenable to intervention
mournings encounter terminal illness from four perspectives including the intimate, concerned other, caregiver, and patient (Rando, 2000).

*Intimates* are individuals within the close network of people who are in contact and have significant interaction with the dying individual. These relationships are characterized by strong reciprocal feelings and may include siblings, romantic partners, or close friends. According to Rando (2000), an intimate need not be a family member.

*A concerned other* is anyone who may know the patient from a distance and has feelings about the patient’s terminal illness. The relationship is not as close as an intimate. This category includes individuals who had limited contact with the patient such as students attending the same school as the patient or neighbors (Rando, 2000).

The *caregiver* is anyone who is playing a significant role in the care of the patient. This can include individuals such as physicians, nurses, parents, and siblings. This perspective can differ depending on the nature and meaning of the relationship between the caregiver and the patient (Rando, 2000). Individuals who are considered caregivers may also be an *intimate* or a *concerned other*; however, their role as a *caregiver* provides them a unique perspective beyond that of an intimate or concerned other.

The *patient* is the person with the life-threatening or terminal illness. This perspective reflects a transformation of an individual that occurs because of a life-threatening or terminal illness from a healthy individual to one who is ill or dying. This individual is simultaneously the dying individual of focus and an anticipatory mourner (Rando, 2000). Therefore the patient’s perspective within anticipatory mourning is unique and different from the experiences of other mourners. Although the theory
encompasses the perspectives of multiple mourners, the subsequent discussion focuses on the patient’s perspective, which in this study included children and youth diagnosed with terminal and/or life-limiting illness.

**Time Focus**

Time focus refers to the period of time during which a loss occurs. Rando (2000) explained, “after receipt of a life-threatening or fatal diagnosis, the experience of mourning is stimulated by losses that have occurred in the past, and those currently occurring, as well as by those to come” (p. 54). For example, as an illness progresses, a patient may become increasingly physically disabled. The individual may mourn the loss of function or of a role that has already occurred, such as a loss of the ability to play a favorite sport. The patient may also be mourning the continued physical deterioration and associated loss of functions as they are occurring (e.g., increased difficulty walking). Finally, a patient may be mourning future losses such as the inevitable loss of function or the loss of future opportunities such as being able to graduate from school or go to prom.

**Influencing Factors**

The experience of anticipatory mourning is determined by a combination of influencing factors, which include psychological, social, and physiological variables (Rando, 2000). These factors form unique constellations that make each individual’s anticipatory mourning process a distinctive experience.

Psychological factors include characteristics of the patient, the nature of the relationship between the patient and significant others, and factors characteristic to the particular illness and death process that is being endured (Rando, 2000). Psychological
characteristics of the patient include variables such as the individual’s cognitive level, maturity, past experiences, socio-cultural background, and co-occurring stressors. The nature of the relationship between the patient and significant others is defined by a number of variables including the quality and meaning of the relationships, the roles of the patient within the social/familial system, unfinished business, and the patient’s fulfillment in life. Finally, characteristics of the illness and death include factors such as the patient’s knowledge and fears about the illness and dying process, the patient’s experience and expectations regarding the illness and loss, the patient’s involvement with significant others, and the quality of life and functioning of the patient.

Social factors can encourage or discourage anticipatory mourning and shape the psychosocial context within which the anticipatory mourning process occurs. The first category of social factors includes characteristics of the patient’s knowledge of and response to the illness and ultimate death (Rando, 2000). This category includes the patient’s idiosyncratic reactions to the disease process and necessary treatments, comfort with communication, satisfaction with medical and social/emotional support, will to live, and acceptance of death (Rando).

Another category of social factors is the characteristics of the family system and its members’ responses to the illness and impending death (Rando, 2000). This category includes the entire network of the patient’s family and relatives. Important elements of this category include the make-up and characteristics of the familial system, quality of communication within the system, and the roles that the patient, as well as other mourners, play within this system. The patient must cope with the family members’
attitudes toward the illness and dying process that can consequently facilitate or impede the anticipatory mourning process.

A third category of social factors is the general socioeconomic and environmental factors (Rando, 2000). This category includes the patient’s economic resources, occupational status, and access to quality medical treatment. It also includes the religious and cultural backgrounds of the patient, the quality of the social support system, and familial traditions for coping with illness and loss.

Physiological factors include things that contribute to the overall physical health and well-being of the patient (Rando, 2000). Of particular importance are individual variables such as nutrition, ability to sleep, energy, and use of mood altering substances.

These first three dimensions (perspective, time focus, and influencing factors) are considered constants that frame the experience of anticipatory mourning; however, the following three dimensions (major sources of adaptational demands, contextual levels, and generic operations) are experiential factors and thus, are considered fluid. According to Rando (2000), these latter three dimensions constitute areas for intervention.

Major Sources of Adaptational Demands

Major sources of adaptational demands are conceptualized as significant stressors derived from experiences of trauma and loss that occur in response to the terminal illness that necessitate an adaptive response. Loss occurs throughout the dying process and is characterized by the physical and psychosocial losses experienced by the patient. Trauma is derived from loss and flows from the anxiety related to the understanding of the impending separation from loved ones, “…the characteristics of the anticipatory
mourners continuously respond to and cope with the occurrences of loss and trauma in anticipatory mourning.

**Contextual Levels**

Healthy anticipatory mourning occurs along three, interrelated contextual levels: the intrapsychic, interpersonal, and systemic levels (Rando, 2000). The intrapsychic level refers to the internal world of the patient. Anticipatory mourning on this level includes increasing awareness and recognition of the terminal diagnosis, the emotional reactions to the illness, and cognitive processes such as changes to one’s identity and assumptive world. The interpersonal level refers to the interaction between the patient and others who are also experiencing anticipatory mourning. Anticipatory mourning on this level can include interactions such as working to resolve conflicts between the ill person and significant others and loosening the connections between the patient and schoolmates. The systemic level refers to larger networks of individuals who are intimately and non-intimately involved with the dying individual and who are experiencing anticipatory mourning. These systems include familial networks, intimate acquaintances, groups of “concerned others,” institutional organizations, communities, and societal organizations. Anticipatory mourning on the systemic level includes activities related to reorganizing a system to accommodate for progressive debilitation and eventual loss of the dying person. For example, if an ill child previously played football, the child’s role and function on the team will change with increasing physical limitations and the team will have to adapt over time to the child’s loss of function and eventual death.
**Generic Operations**

The components of generic operations and contextual levels are closely intertwined. Rando (2000) suggested that there are seven generic operations that represent healthy anticipatory mourning and individuals may engage in any one or combination of these operations at any point in time during the anticipatory mourning experience. Additionally, these seven generic operations occur along the intrapsychic, interpersonal, and systemic contextual levels. The seven generic operations include grief and mourning, coping, interaction with the patient, psychosocial reorganization, planning, balancing conflicting demands, and facilitating an appropriate death.

**Grief and Mourning**

The concepts of *grief* and *mourning* are differentiated in that *grief* focuses on the experience of the reaction to loss whereas *mourning* focuses on the actions taken to accommodate the loss (Rando, 2000). Grief includes the mourner’s feelings about the loss and the desire for the loss to have not occurred. Losses include both physical and psychosocial losses. For example, a child may experience grief over increased debilitation and a loss of the ability to play soccer, as well as struggling with the desire for a restoration of function. In addition, both primary losses and secondary losses, losses that occur as a consequence to the primary loss, should be considered. In the previous example, the loss of physical function is considered the primary loss, which leads to the loss of social contact, a secondary loss. Rando suggested that mourning has three specific objectives including (1) undoing the psychosocial connections between the patient and significant others and developing new ties appropriate to the changed relationship, (2) the
patient adapting his or her assumptive world to the loss, and (3) continued living despite the experienced loss. Furthermore, Rando suggested that there are six processes of mourning that lead to healthy accommodation of loss: recognizing the loss, reacting to the separation, realistic recollection of the lost object, relinquishing old attachments, adapting to a world which incorporates the loss, and reinvesting oneself into the new world. In the case of the patient, he or she must accommodate to ongoing losses and reinvest in living during the end-of-life process, which is often unpredictable and may extend for a significant period of time.

Coping

Coping includes the internal and external actions undertaken to deal with stress (Rando, 2000). In particular, coping implies encountering a stressor with the intent to manage or overcome it in some way. It is differentiated from mourning in that coping occurs in response to the stressors that occur as part of the disease process and the stressors associated with ongoing living, and it is not exclusively focused on loss. Coping can be focused on altering problematic situations and factors or it can be focused on altering the perspective of the patient, thus changing the emotional response to the stressor.

Interaction with the Patient

Interaction with the patient includes some type of reciprocal contact between the patient and significant others. Rando suggested that interactions serve to maintain intimate relationships and connections between the individuals involved for as long as possible, while also facilitating a gradual withdrawal of the patient from social
relationships. These interactions include the attention, energy, and behavior directed toward the relationship between the patient and significant others and the resolution of the personal relationships between the life-threatened or dying person and significant others.

*Psychosocial Reorganization*

Psychosocial reorganization is a process that occurs on all contextual levels (intrapsychic, interpersonal, and systemic) related to the dying individual. It facilitates the establishment of an environment in which the dying person can live optimally when going through the end-of-life process surrounded by supportive intimates and caregivers. This reorganization is accomplished through four primary means: cognitive processing, adaptive readjustment, role redistribution and reassignment, and rehearsal and socialization.

Cognitive processing begins when a person is informed of his or her own terminal status and gradually, over time, comes to cognitively understand the full implications of that prognosis. This continues throughout the course of an illness as the patient learns more information about the disease process and assumptions are replaced with learned information.

Adaptive readjustment occurs in response to cognitive processing as the patient makes adjustments in response to his or her altered status. That is, the needs met by the patient for significant others will change over the course of the illness. The patient is therefore compelled to adjust to a change in roles and significant others must find alternative ways to meet their needs. Significant others may also potentially take on
changed roles and responsibilities within the relationship with the dying person, as well as within the larger social system in which they both exist.

Individuals fulfill certain roles and responsibilities within an intimate network. In the light of terminal illness and as a disease process progresses, role redistribution and reassignment occur. Rando (2000) suggested that in healthy role redistributions, decisions are made regarding changes in roles with consideration of the appropriateness of the role to the individual, the individual’s preparation for the responsibility of the role, and the congruence between the individual’s existing roles and new responsibilities. Rando also noted that during the course of a terminal illness, only a partial reassignment of roles may be necessary because the dying individual may lose the ability to perform certain functions but not others. Indeed, Rando emphasized, “One of the main agendas in healthy anticipatory mourning is to promote as much normalcy and appropriate interpersonal engagement among intimates as is possible” (p. 77).

Rehearsal is a cognitive and behavioral process of anticipating the bereaved role. In terms of the dying individual, rehearsal refers to anticipating becoming bereaved from a future loss such as imagining what it will be like to have reduced physical function or a change in physical appearance as the disease progresses. Socialization, however, refers to “the psychosocial education, indoctrination or acculturation processes through which an individual becomes a competent member of a group” (Rando, 2000. p. 77). Bluebond-Langner’s (1978) research provided a good example of this process in terminally ill children. She described how children with leukemia in one hospital learned the routines
and information regarding the course of their illness from other patients and consequently increasingly identified with each other and became more bonded to one another.

Planning

Rando (2000) suggested that planning occurs on intrapsychic, interpersonal, and systemic contextual levels as the patient prepares to respond to changes encountered over the course of a terminal illness. In addition, planning can focus on the immediate, more long-term, and post-death concerns encountered as the roles of the patient change and are eventually lost at death. Rando highlighted the importance of planning in anticipatory mourning and suggested that it can have both positive and negative impacts on the process. Planning allows for the opportunity to capitalize on the benefits of time to prepare for the loss of the relationship, something that is not possible when death is unexpected. However, as plans go awry, planning in anticipatory mourning may also be self-defeating. That is, when unanticipated events occur, and things do not unfold as planned, disappointments may arise, complicating the anticipatory mourning process for the patient. Rando stressed that “the efficacy and therapeutic value of planning depend on the amount, type, quality, accuracy, and timeliness of the information upon which the planning is based” (p. 83). She also suggested that in addition to planning on more abstract levels, planning for more basic, concrete, concerns is also an important focus throughout the anticipatory mourning process. Patients may engage in planning in a variety of ways such as expressing wishes regarding care as their disease process progresses and designating items that they wish to gift to significant others after their death.
Balancing Conflicting Demands

Conflicting demands occur along all three contextual levels and are a major source of stress and tension for the patient as he or she is pulled in different directions and is expected to prioritize the demands (Rando, 2000). Intrapsychically, conflict may exist with the way a patient and significant others believe that each should approach the other. Trying to arrive at a balanced perspective then shapes their behavior (e.g., trying to achieve balance between a realistic appraisal of illness versus maintaining a sense of hope). Interpersonally, conflict may arise between the needs of the patient and significant others, between the patient and the larger familial system, and between the patient and other members of the intimate network. Rando emphasized that a balance between caring for the patient and caring for the members of the intimate network must be achieved. Conflicts may arise between the many systems in which the patient is involved, such as conflicts between the familial/intimate network, caregivers, health care organizations, and so on. Conflicts at this level may be especially troubling for children and youth as they generally lack the ability to impact larger systems due to their age and role.

Facilitating an Appropriate Death

Although facilitating an “appropriate death” is ultimately the goal of the other generic operations, Rando (2000) suggested that it is also independently a fundamental component of anticipatory mourning. She indicated that an “appropriate death” is idiosyncratic to the dying individual. Furthermore, the goal is not to achieve an ideal death but to shape the dying process so that it is consistent with the perspective of the dying individual within his or her particular disease process. In order to achieve an
appropriate death several conditions are necessary: adequate care of the patient, maintaining appropriate control in decisions, emotional composure, effective communication, maintaining the continuity of the present experience within the context of the patient’s past, and closure of unfinished business (Rando). In addition, Rando emphasized that “a more appropriate death for the loved one promotes better post-death bereavement for survivors” (p. 90).

This dissertation used the six dimensions comprising anticipatory mourning including, perspective, time focus, influencing factors, major sources of adaptational demands, generic operations, and contextual levels; as a theoretical guide for the study. Specifically, the research focused on the theory as it applies to the perspective of a patient who is participating in a pediatric palliative care program. Research relating to theory is described in the subsequent section.

Anticipatory Mourning: The Research

Much of the existing research has used the terms *anticipatory grief* and *anticipatory mourning* interchangeably. In an attempt to minimize confusion and to facilitate standardization, Rando (2000) noted that *anticipatory grief* most precisely refers to the response to loss without consideration of the subsequent efforts to cope with and accommodate to that loss; whereas *anticipatory mourning* refers to the cumulative experience of reactions to loss and the ensuing processes undertaken to cope. The following discussion of the research utilizes the terms in this context regardless of term chosen by the researchers.
Lindemann (1944) was the first to describe grief reactions occurring prior to the death of a loved one. His observations are part of a larger study he performed with 101 patients who recently experienced a death of a loved one. He analyzed interviews for the symptoms reported and changes in mental status observed, to begin describing physical and psychological symptoms of grief. It is within this context that he observed what he termed to be “anticipatory grief” in patients who experienced separation from their loved ones who were going off to war. Lindemann detailed phases of the grief experienced by the patients including, “depression, heightened preoccupation with the departed, a review of all the forms of death which might befall him, and anticipation of the modes of readjustment which might be necessitated by it” (p. 148). Lindemann noted that anticipatory grief was helpful when it facilitated adjustment to the separation of loved ones; however, in some cases, it led to the premature termination of the relationship when the emotional bonds were severed and a reunification occurred. Lindemann’s early observations of anticipatory grief focused solely on the experiences of significant others, whereas this study focused on anticipatory mourning in patients. His study, however, suggested some of the adaptational benefits derived from progressing through the grief process.

Adaptational Benefits

Strang and Koop (2003) conducted a qualitative study examining coping in caregivers providing home-based care to family members dying from cancer. They interviewed 15 family caregivers after the death of their family member about how they coped while caring for the ill individual at home. The authors used three primary research
questions to guide their discussion including “How did you manage to cope with caregiving; What did you find helpful in caregiving; and What did you find unhelpful in this experience” (p. 108). Strang and Koop did not describe a standardized form for analyzing their data; however, they did describe searching for common, recurring themes and relationships within the data. Based on the interviews, the researchers described a simultaneous process of drawing closer and letting go of the relationship with the dying person. The caregivers increased contact and the amount of energy directed toward the dying individual and so the relationships became closer; however, the dying individuals withdrew from their daily roles and both the caregivers and the dying individuals prepared for the inevitable separation caused by death, thus letting go of the relationships. Although the authors did not specifically label their observations as “anticipatory mourning,” they clearly fit within the model. For example, the authors described the changing familial roles of the dying individual and the role adjustments made by the caregivers. They also observed that the acceptance of death by the dying individual helped the caregivers accept the impending death and facilitated coping. The authors noted that the values and beliefs of the dying individuals and caregivers were important in facilitating coping with the dying process.

Valdimarsdóttir, Helgason, Fürst, Adolfsson, and Steineck (2004) examined the effect of the length of time wives were aware of their husband’s impending death on their long-term anxiety subsequent to bereavement. The authors pointed out, Assessments of anticipatory grief have often been based on the assumption that a longer duration of illness is an indicator of anticipatory grief. Logically, one needs to understand intellectually that a relative will die before commencing anticipatory mourning and, consequently, anticipatory grief should be related to
awareness time rather than the duration of illness. It is reasonable to believe that the awareness time is a necessary, but not a sufficient condition, for such a process (p. 441).

They sent a questionnaire to 506 widows of men who had died of prostate or urinary cancers between 1995 and 1996 in Sweden. The authors assessed awareness time with the question, “When did you realize that your husband/partner would die of the disease” (p. 433). They included scaled questions assessing for anxiety, depression, wellbeing, physical health, quality of life, and sleep disturbance, as well as the State-Trait Anxiety Inventory and the Center for Epidemiological Studies measure of depression. The researchers received 379 responses, with an average of three years elapsing since the death of their husbands. According to their study, widows reporting awareness of their husbands’ impending death between three and six months prior to their death had the lowest reported long-term anxiety. However, widows reporting awareness times of 24 hours or less had the highest risk for long-term anxiety, followed by those reporting awareness times of 12 months or longer. The authors suggested that widows with awareness times of 12 months or greater are at a higher risk for long-term anxiety than those with awareness times between three and six months because they may experience exhaustion resulting from long-term care for their ailing spouse or they may acclimate to the ebb and flow of their husband’s illness and may be somewhat surprised once he actually died.

This study (Valdimarsdóttir et al., 2004) suggested that awareness of a loved one’s impending death facilitates preparations for bereavement and improves long-term coping. Additionally, the authors suggested that psychological interventions can mitigate
the effects of prolonged awareness and improve long-term coping for bereaved individuals. This study focused on the anticipatory mourning experiences of significant others; moreover it pointed to the adaptational benefits that may be derived from the mourning process, as well as demonstrated the impact of awareness time, which may generalize to patients.

The existing research suggests that engaging in anticipatory mourning has adaptational benefits for the mourner. In particular, the research highlights the function of anticipatory mourning in facilitating the transformation of the relational attachments between the dying individual and significant others. None of the research, however, has examined anticipatory mourning in children and youth.

_Anticipatory Mourning in the Dying Individual_

Rentz, Krikorian, and Keys (2005) presented a theoretical discussion and personal observation of the unique issues in the anticipatory mourning experienced by individuals diagnosed with Alzheimer’s disease or dementia. Because of the nature of the disease, the authors suggested that ongoing losses are of importance in this population. In particular, they emphasized that in cases when diagnosis is made early in the disease process, individuals have increased insight into their loss of function and its impact on those around them. Although these authors extended the understanding of anticipatory mourning to the ill patient, they presented only anecdotal observations of the process and did not systematically investigate the patients’ experiences.

A study performed by Mystakidou et al. (2006) is one of the few investigations examining anticipatory grief reactions in dying individuals and they attempted to include
grief reactions to losses that occurred in the past, losses presently occurring for the participants, as well as grief for losses that would occur in the future. These researchers assessed anticipatory grief in 200 advanced cancer patients, aged 31 to 87 years. The participants were patients in a palliative care program in Athens, Greece. The authors found that younger patients, women, and patients with a poorer response to treatment experienced higher levels of anticipatory grief. One limitation of the study is that the researchers used a scale they had developed and described in a previous study (Mystakidou et al., 2005). The researchers developed the items for the scale using their clinical experience and it is unclear the extent to which the items were based on a theoretical framework, thus it is unclear the extent to which the scale actually measures anticipatory grief. Additionally, the researchers limited their observations to negative emotions experienced as reactions to losses and thus their study was not sensitive to broader mourning processes.

Of direct relevance to the present study, Sourkes (1995) described anticipatory grief reactions of children diagnosed with life-threatening illness. The description is based on observations derived from her work providing therapy to this population. Sourkes suggested that anticipatory grief begins when a child is diagnosed with a life-threatening illness but that it is manifested differently throughout the trajectory of the illness depending on the saliency of sickness and impending death to the child. She conceptualized anticipatory grief as arising from a loss of control, loss of identity, and loss of relationships. Specifically, the author explained that loss of control derives not
only from the impending loss of life, but also from the frequent medical interventions that the child must endure.

In response to these losses, children frequently act out indirectly through expressions of anger, and the author asserted that behavior improves when children are given a measure of control over their environment. Loss of identity is derived from children’s recognition of being “different” from others, being different from their “former” selves, and/or being “abnormal” versus “normal.” Sourkes also wrote that loss of relationships is experienced as increased fear of separation, as well as through the child’s perception that he or she is separate and different from others. The author observed that this is frequently conveyed by children through omissions of themselves from their family drawings. Furthermore, Sourkes emphasized that the loss of relationships is particularly connected to anticipatory grief because it ultimately stems from a fear of not being here in the future. She suggested that children act out this fear by “testing” whether their absence will be noticed and if they will be missed. Additionally, Sourkes described how children experience concurrent grief when another ill child dies (e.g., another child with cancer being treated at the same clinic) and anticipatory grief because of their own fears of future losses and dying. She observed that at these times, children will seek to regain a measure of control through psychologically differentiating themselves from the deceased child.

Sourkes presented an insightful account of anticipatory grief reactions in children with a life-threatening illness based on observations obtained through providing psychotherapy to this population. Her account is particularly useful when considering the
indirect ways children may express their emotional reactions to loss. The present study extended the account presented by Sourkes by taking a systematic and direct approach in investigating children’s experiences with anticipatory mourning and by expanding beyond emotional grief responses to losses experienced in this population.

A case study presented by Horwitz, Duncan, and Wolfe (2004) presented medical management of an illness from the perspectives of a 13 year old youth with terminal cancer, his mother, and his physician. The authors provided direct quotations about anticipatory mourning and death from the child’s perspective. The child was described as being “afraid” of the dying process, concerned about changes in roles and treatment at home, and worried about his family’s coping after his death. The information presented regarding the perspectives of the child’s parent and physician were focused solely on the medical management of the child’s illness as well as the management of the child’s emotions and reactions to news of prognosis and treatment. For example, the authors included quotes from the child’s mother describing her consideration of three possible treatment options and her desire to try every possible intervention to cure her son. This study indicates that this child was actively engaged in anticipatory mourning and that he was able to clearly articulate aspects of the mourning process. The study is limited in that it focuses on caring for the terminally ill child and so only presented a cursory view of the mourning process of the child and significant others. Additionally, this study is limited to considering the child within the medical setting and the medical management of his illness, and it does not consider the child within a larger context.
A book chapter authored by Stevens, Dunsmore, Bennett, and Young (2009) presented theoretical descriptions of losses mourned by adolescents living with cancer. Although the authors do not label this as anticipatory mourning, they do describe specific losses that adolescents may endure when living with a life-threatening illness. In particular, the authors emphasize that adolescents mourn loss of the perception by others that they are healthy and independent individuals and, similarly, they mourn the loss of their previous healthy functioning. Additionally, adolescents mourn previous family functioning, increased dependence on their parents, changed relationships with their siblings, loss of relationships with friends, and loss of developmentally normal milestones, such as those associated with school, dating, and work (Stevens et al.). Finally, the authors also suggested that adolescents mourn changes to their body image, hope for a future, and hope for future happiness and joy. Although the chapter focused on the perspectives of adolescents, it is likely that children at earlier developmental stages also mourn similar losses.

Overview of Pediatric End-of-Life Research

Although pediatric end-of-life research is limited, the area has received increased attention (APA, 2005; Hinds, 2004; IOM, 2003; Liben, Papadatou, & Wolfe, 2008). Much of the existing literature has focused on improving the end-of-life experiences of children and youth through improved medical management of their illness. Additionally, a significant proportion of the research has focused on the experiences of others involved with caring for terminally ill children and youth such as parents, physicians, nurses, and palliative care staff, with less attention given to the ill children and youth. This section
presents a brief review of the broader pediatric end-of-life literature and then provides greater detail on the literature related to the lived experiences of terminally ill children and youth.

Pediatric Palliative Care Research

A number of articles have documented the benefits of implementing strong pediatric palliative care programs in hospitals and oncology units in order to facilitate the integration of curative treatment and effective palliative medical interventions throughout the course of a pediatric patient’s illness (e.g., Baker et al., 2008; Golan et al., 2008; Liben et al., 2008). One article also documented the challenges faced in providing palliative care to a pediatric population when expert resources are limited (O’Leary, MacCallion, Walsh, & McQuillan, 2006). In particular, these authors noted that members of an adult palliative care team experienced significant anxiety when pediatric patients were referred because no specialists in pediatric palliative care were available. Their anxiety was related to the novelty of the situation as well as their concerns regarding appropriate training. Other articles have described the ideal role and functioning of a pediatric palliative care program in facilitating decision making regarding “do not resuscitate/do not attempt resuscitation” orders, addressing symptoms of depression and anxiety in the patients and family members, providing palliative sedation, facilitating choices regarding place of death, and providing education to patients and family members about the terminal phases of illness (e.g., Dussel et al., 2009; Liben & Goldman, 1998; Masri, Farrell, & Lacroix, 2000; Postovsky & Weyl Ben Arush, 2004; Tadmor, 2004).
Some articles have examined factors contributing to relatively positive outcomes related to pediatric end-of-life, variously defined as satisfaction with care, feeling prepared for the death of a child, and achieving preferences for care and location of death. For example, a number of articles examined location of death as contributing to positive outcomes (e.g., Dussel et al., 2009; Papadatou, Yfantopoulos, & Kosmidis, 1996; Price, 1989; Rini & Loriz, 2007; Siden et al., 2008; Surkan, Dicman, Steineck, Onelov, & Kreicbergs, 2006; Vickers & Carlisle, 2000; Wolff & Wolff, 2008). The research indicates a clear preference for home as the location of death. Mitigating this preference are factors such as the child’s preferences and parents’ confidence in their ability to adequately meet their child’s needs at home (Papadatou, Yfantopoulos, & Kosmidis; Vickers & Carlisle). Additionally, the literature indicates that providing parents with information regarding treatment options for their child increases planning for location of death, which is associated with greater satisfaction with the end-of-life process, regardless of the location of death (Dussel et al.). The literature has established that the benefits of dying at home can include allowing dying children to maintain their position in their family, keeping children in familiar surroundings, increased privacy, and maintaining high quality medical care.

Similarly, communication and education regarding the child’s illness, prognosis, and end-of-life process provided by medical and mental health professionals have also been emphasized as contributing to positive outcomes (e.g., Hinds, 2007; Monterosso & Kristjanson, 2008; Monterosso, Kristjanson, Aoun, & Phillips, 2007; Tadmor, 2004). Indeed, the literature emphasizes that good communication increases parents’ feelings of
choice and control, which ultimately increases their satisfaction with their child’s care. A few articles also demonstrated positive outcomes related to utilization of respite care and specialized palliative programs by terminally ill children and youth and their families (e.g., Davies et al., 2005; Davies, Steele, Collins, & Cook, 2004; Horsburgh, Trenholme, & Huckle, 2002).

**Decision-Making in Pediatric End-of-Life Care**

Additionally, a number of articles have described important aspects of making difficult medical decisions such as withholding and withdrawing life-sustaining medical treatment and issuing do not resuscitate orders for terminally ill children and youth by parents and medical staff (e.g., Forbes, Goeman, Stark, Hynson, & Forrester, 2008; Kodadek & Feeg, 2002; Longden & Mayer, 2007; Lyon et al., 2008; Masri, Farrell, & Lacroix, 2000; Postovsky & Weyl Ben Arush, 2004; Stark, Hynson, & Forrester, 2008). The literature suggests that communicating sensitively about difficult medical decisions is an important component to providing quality palliative care to terminally ill children and their families (Longden & Mayer; Masri et al.; Postovsky & Weyl Ben Arush; Stark et al.). However, research indicates that new professionals are less comfortable discussing the withdrawal and withholding of life sustaining medical treatment than are more experienced professionals (Forbes et al.). Therefore, there was a consensus that additional education and training on communication in this area would be helpful (Forbes et al.; Lyon et al.; Stark et al.). The literature indicates that family members want to be involved in end-of-life decision making for a terminally ill child and that communication facilitates
this decision making and feelings of empowerment (Dussel et al., 2009; Logden & Meyer).

Other articles have focused on the interaction between parents and their terminally ill children in end-of-life decision-making (e.g., Bluebond-Langner, DeCicco, & Belasco, 2005; Dunsmore & Quine, 1995; Lyon, McCabe, Patel, & D’Angelo, 2004; Monterosso & Kristjanson, 2008; Vickers & Carlisle, 2000; Weir & Peters, 1997). The research has repeatedly demonstrated that the wishes of the dying child are of primary importance to parents when making decisions regarding their child’s end-of-life care. Additionally, adolescents, in particular, want to be heard in regard to decision-making. Indeed, authors (e.g., Bluebond-Langner et al.; Powell, 1984; Wier & Peters) have argued that adolescents are cognitively able to participate in even the most complex or difficult end-of-life decisions and they should be given an opportunity to do so, even if their parents ultimately choose something different.

Impact of Experiences with Pediatric End-of-Life on Significant Others

A number of articles have examined the impact of pediatric end-of-life experiences on individuals who have significant interactions with the ill child or youth. For example, Papdatou, Bellali, Papazoglou, and Petraki (2002) examined grief responses in nurses and physicians caring for children who were dying from cancer and found that the deaths of children were perceived as highly stressful and triggered grief responses. Nevertheless, nurses and physicians reported deriving personal meaning and satisfaction from caring for pediatric patients near the end-of-life. The authors also noted that physicians and nurses perceived differences in their roles in the end-of-life care for
terminally ill pediatric patients. Specifically, physicians focused on the physical care of their patients whereas the nurses viewed their roles as providing for the physical and psychosocial needs of the patients and their families.

A few studies have focused exclusively on fathers’ experiences with their child’s life-limiting illness (e.g., Davies et al., 2004; Ware & Raval, 2007), while others have focused specifically on mothers’ experiences with their child’s life-limiting illness (e.g., Papadatou, Yfantopoulos, & Kosmidis, 1996). The research suggests that mothers and fathers view themselves as having different perspectives and experiences from the other. Although mothers are frequently cited in research as being the primary caregivers, studies of fathers note that they also view themselves as providing important and meaningful care to their dying child. Fathers particularly struggled with demands consistent with their gender role of being providers and protectors of the family, and research indicated that this leads to feelings of helplessness as they saw their families being challenged. Research also emphasized that both mothers and fathers have a strong desire to maintain hope and do everything they can to save their dying child, which can impede their willingness to accept palliative treatment and to develop advanced directives for their child.

A larger number of articles have examined the needs of parents related to their child’s terminal illness (e.g., Freeman, O’Dell, & Meola, 2004; Monterosso & Kristjanson, 2008; Monterosso, Kristjanson, Aoun, & Phillips, 2007; Rini & Loriz, 2007; Steele, 2005a, 2005b; Surkan, Dickman, Steineck, Onelov, & Krecbergs, 2006; Tadmor, 2004; Vickers, & Carlisle, 2000). The research repeatedly demonstrated that parents want
to provide the best possible care for their child. Their confidence in the care increases with effective communication and interaction with medical professionals, perceptions of control and choice where possible, and when medical professionals are responsive to their concerns. Additionally, some articles documented experiences of posttraumatic growth and posttraumatic stress in parents of children who survived life-threatening illness (e.g., Alderfer, Cnaan, Annunziato, & Kazak, 2005; Barakat, Alderfer, & Kazak, 2006; Kazak et al., 2004).

Physical and Psychological Symptoms in Children and Youth at the End-of-Life

The extant research has primarily focused on the medical aspects of palliative care for children and youth. A number of articles have examined parents’ report of their children’s physical symptoms during the palliative phase of their illnesses (e.g., Hendricks-Ferguson, 2008; Pritchard et al., 2008; Theunisse et al, 2007; Wolfe et al., 2000). Parents most often reported that their children suffered from symptoms including pain, shortness of breath, fatigue, poor appetite, constipation, and diarrhea (Hendricks-Ferguson; Pritchard et al.; Theunisse et al.; Wolfe et al.).

Some research also described psychological symptoms experienced by children at the end-of-life (Theunisse et al., 2007). This study surveyed parents whose children had received palliative care prior to their death. The authors did not report the age range of children, but the mean age of the child at death was 10.9 years of age. Parents of thirty-two children responded to a checklist of 16 physical and 13 psychological symptoms. Regarding psychological symptoms specifically, parents most frequently reported sadness, difficulties in talking about their feelings, fear of being alone, and fear of dying.
and death. Additionally, the research suggested that providing medicine and strategies to improve physical comfort were seen as helpful to children at the end-of-life; however, this study also demonstrated that a large portion of parents reported that medical interventions were ineffective at alleviating the suffering of their children and that their children’s psychological needs were often unmet by medical professionals (Theunissen et al.).

Research also has examined important psychological symptoms in adolescents who are living with a life-threatening illness or who have survived a life-threatening illness. For example, Kazak and colleagues (2004) described posttraumatic stress symptoms in adolescent survivors of childhood cancers, and Bakarat, Alderfer, and Kazak (2006) described posttraumatic growth in this same population. Hinds and colleagues (1999) examined hopefulness in adolescents, aged 12 to 21 years, who were newly diagnosed with cancer. The researchers administered hopefulness and hopelessness scales developed in an earlier study at four points over the six months post-diagnosis. The authors found that hopefulness was generally high throughout the six months in this group of patients (Hinds et al.). Furthermore, they noted that hopefulness scores increased. Additionally, the study found that hopelessness was generally low in this sample and that average hopelessness scores decreased over time. Adolescents in this study hoped for health, normalcy, educational accomplishments, to minimize side-effects of treatment, social success, marriage, to have a family, survival, and return to normal appearance (Hinds et al.). The authors conclude that adolescents newly diagnosed with cancer begin treatment with high levels of hopefulness and they hypothesized that the
high level of hopefulness is adaptive to prevent negative psychological symptoms. This study presents an important examination of the psychological impact of confronting a life-threatening illness, although it differs from the sample of the present dissertation in that the adolescents were newly diagnosed with a life-threatening illness and had only begun medical treatment, whereas the individuals in this dissertation were confronting a more imminent and likely terminal condition.

Developmental Research

One area of research that is better developed is children’s understanding of death. Researchers generally describe a mature cognitive understanding of death as being marked by three subconcepts including: irreversibility – an understanding that once something dies, it physically cannot come back to life (separate from spiritual beliefs); finality or nonfunctionality – death is the cessation of life and/or bodily functions; and universality – all living beings will die someday (Lazar & Torney-Purta, 1991; Speece & Brent, 1984; Stillion & Papadatou, 2002). Some researchers also include a fourth subconcept, causality – death is caused by concrete, external factors and not by magic or wishful thinking, in their definition of a mature understanding of death (Lazar & Torney-Purta). The end-of-life experience of terminally ill youth will be affected by the extent to which they have acquired an understanding of death.

A mature understanding of death develops over time in parallel to the Piagetian theory of cognitive development (Himelstein et al., 2004; Speece & Brent, 1984; Stillion & Papadatou, 2002). Infants and toddlers (ages 1-2) in the sensorimotor stage generally learn about their world through their senses. It is accepted that although children of this
age may be able to distinguish the living from the dead, they essentially have no cognitive understanding of the concept of death (Stillion & Papadatou).

Children in the preoperational stage of development (ages 2 to 7) have an egocentric perspective of the world; they can only see the world from their own perspective and cannot take on the perspective of another. Furthermore, children at this stage have not mastered the cognitive skill of conservation, and logical thought is not yet developed. At this age, children see death as something that comes from the outside, that death is reversible, and that an ill person can be healed through wishing or magic (Stillion & Papadatou, 2002). Death is seen more like being asleep or going on a trip from which you can return (Speece & Brent, 1984).

In the concrete operational stage of development (ages 7 to 11), children begin to develop a more scientific understanding of the world as well as developing logical reasoning skills. It is at this point that children can acquire all the mature concepts of death (Stillion & Papadatou, 2002).

Speece and Bent (1984) reviewed studies in order to determine the age that children develop a comprehension of the three concepts (irreversibility, universality, and non-functionality) constituting a mature understanding of death. They concluded that the data in the reviewed studies suggested that children between the ages of five and seven years had developed some understanding of all three concepts. Additionally, a later study performed by Lazar and Torney-Purta (1991) confirmed that by the age of seven children had developed some understanding of each of the four subconcepts of death and they
observed that children must first understand universality and irreversibility before they can grasp nonfunctionality and causality.

During the formal operation stage (ages 11 and older) adolescents become capable of abstract thinking. At this age, the youth can consider questions related to spirituality and meaning in life and in death. Additionally, youth at this stage can better imagine their futures. In these ways, adolescents are similar to dying adults (Stillion & Papadatou, 2002). However, adolescents may also revert to a more egocentric view of death believing it can happen to others, but not to them (Stillion & Papadatou). This attitude can lead to difficulties in compliance with medical treatments.

Children and Youth’s Experiences with Their Terminal Illness

Research examining children and youth’s experiences with their own terminal illnesses is quite limited. However, one early study was performed by Bluebond-Langner (1978). She completed a naturalistic observation of children diagnosed with leukemia, as in-patients in a hospital and during their appointments at an oncology clinic. One of the most compelling observations made was that children gained progressively more information about their illness, ranging from an understanding that “it is serious” to viewing their illness as a series of remissions and relapses that may eventually end in death. She observed that children would increase their understanding even if adults (e.g., parents, physicians, nurses) never directly addressed their treatment or prognosis with them. Bluebond-Langner suggested that the children gained knowledge through their own experiences with treatment, through watching and talking to other ill children, and through observing the behavior of parents and staff who worked with them.
Bluebond-Langner (1978) also observed that as children gained more awareness of the terminal nature of their illness, they made statements disclosing increasing awareness of impending death. For example, she noted that these children made statements comparing themselves to someone who had died or who was in danger of dying. In particular, Bluebond-Langner noted that children who more recently gained an understanding of their terminal prognosis made statements that highlighted differences between themselves and the deceased individual, whereas children who were aware of their terminal prognosis for a longer period of time made statements that highlighted the similarities between themselves and the deceased. She also observed that children made statements indicating mourning for losses relating to different time-frames. Along these lines, Bluebond-Langner noted children making statements referring to present losses such as, “I’m not going to school anymore,” and future losses such as, “I won’t be here for your birthday” (pp. 189-190). In addition, she observed that as awareness of their terminal prognosis increased and death became more imminent, children spoke less about the future. She described a six year old boy who became distraught when reminded about “wanting to be a doctor when you grow up” and she wrote that he “screamed back, ‘I’m not going to be anything…[I’m going to be] a ghost’” (p. 194).

Additionally, Bluebond-Langner (1978) briefly referred to the anticipatory mourning experienced by the parents of the ill children and noted that their anxiety related to their physical separation from their children decreased as they moved through the process of anticipatory mourning. Bluebond-Langner’s research demonstrated that children do gain an understanding of their terminal prognosis and imminent death and
that they are able to verbalize losses which they are mourning. The research performed by Bluebond-Langner provided rich and insightful information, but it primarily focused on the children’s experiences in the medical setting and it did not directly examine their experiences of anticipatory mourning.

A study performed by Hedström, Skolin, and von Essen (2004) examined positive and negative experiences related to diagnosis of cancer, treatment for cancer, and admissions to the hospital as reported by 22 ill adolescents, aged 13 to 19 years. The researchers used a semi-structured interview with four questions including: “Has there been anything distressing/positive for you about being told the diagnosis;” “Has there been anything distressing/positive for you about receiving chemotherapy;” “Has there been anything distressing/positive for you about being admitted to the ward;” and “What caring aspects are important for you to feel cared for” (p. 8).

Participants’ responses were content analyzed and classified into categories. The authors concluded that when they were told of their diagnosis, most of the distress experienced by adolescents was related to fears of dying, missing activities, changing appearance, medical treatments, and fears related to previous experiences with cancer. However, when told of their diagnosis, adolescents also reported positive experiences such as relief with knowing their diagnosis, hope for recovery, and relief because the prognosis was less severe than anticipated. When questioned regarding distress related to chemotherapy, the participants expressed concerns over the physical effects of the treatment, such as the loss of hair, fatigue, nausea, mouth sores, and altered sense of taste. The major positive aspect of chemotherapy that was reported was the hope to get well. In
regard to being admitted to the hospital, the adolescents expressed distress regarding being confined, fear of treatments, and lack of privacy. Positive aspects of a hospital admission included being well cared for and pleasant interactions with staff.

This study demonstrated that adolescents can identify both positive and negative aspects to their illness (Hedström et al., 2004). Additionally, the research illustrated that adolescents focus on their experience with the medical management of their illness as well as being aware of the psychosocial losses that occur beyond the course of the illness. The current study aimed to expand on these results by performing a more systematic examination of children and youth’s experiences of living with terminal illness and considering the reactions to factors beyond the diagnosis and treatment.

Hinds and colleagues (2004) conducted a qualitative study investigating definitions of quality of life as conveyed by 23 pediatric patients, aged eight to 18 years, with cancer. Based on previous research, the authors concluded that existing measures of quality of life did not reflect reports of pediatric oncology patients. The authors asked participants four questions including: what makes a good day for you; what makes a bad day for you; are there some things you like to do that you cannot do now; and how has being sick been for you. Interviews were transcribed and entered in the qualitative software program, ETHNOGRAPH, and analyzed using a semantic content method. The authors found that pediatric patients reported quality of life as encompassing six domains including experiencing uncomfortable physical and mental symptoms of illness; being able to participate in usual activities; being able to interact with others and feel cared about; receiving positive treatment related news, being worried, angry, scared, or bored
or witnessing others being upset; and finding meaning in the illness experience. This study highlighted aspects of daily living important to pediatric patients as they are living with a life-threatening illness from their point of view. The authors also suggested that their results could be used in the development of new quality of life measures pertinent to children and adolescents. The present dissertation extended the literature by continuing the focus on the reports of ill children and youth and by gathering data regarding their lived anticipatory mourning experiences.

A study performed by Davies, Collins, Steele, Cook, Brenner, and Smith (2005) examined the perspectives of terminally ill children, aged six to 19 years, regarding a pediatric hospice program. The researchers initially developed a questionnaire by interviewing four ill children about their experiences with the hospice program. They entered the interviews into a qualitative program and content analyzed them. The data were used to develop a paper and pencil questionnaire that was mailed to families and children using this hospice program. The questions were formatted using Likert-style scales or checklists of possible responses. Responses were received from 26 ill children. Most of the children noted that they enjoyed the facilities of the program including the hot tub, play room, garden, outside play equipment, and having their own room. In addition, the children were particularly appreciative of the social aspects of the hospice program, because they were able to engage independently in “normal” social activities in an environment that was safe, given their terminal illness. In fact, researchers noted, “many commented that getting away was a rare luxury, given their chronic or terminal illness” (Davies et al., p. 256).
This study indicated that although terminally ill children enjoyed the facilities of the hospice program that would be attractive to all children, regardless of whether they were ill, the terminally ill children were aware of the changes and challenges to their social functioning that had occurred since they became ill and they were particularly appreciative of the opportunities to function “normally” in a safe environment. The study adds to literature that considers the perspectives of terminally ill children and youth. This dissertation aimed to extend that literature by investigating children’s and youth’s experiences beyond a palliative care program.

Research to this point has indicated that children and youth are aware of the seriousness of their illnesses regardless of the information that has been communicated to them. The research also suggests that terminally ill children and youth are aware of losses they are experiencing. However, the studies have focused primarily on terminally ill children and youth’s experience with the medical management of their illness and made only a cursory attempt to examine their experiences within a larger context. The theory of Anticipatory Mourning provides a framework for examining that larger context.

In summary, existing literature focused on children and youth’s perspectives of end-of-life and dying demonstrates that children develop their cognitive understanding of death with increasing complexity according to Piagetian stages of cognitive development. Furthermore, research demonstrates that children and youth’s understanding of death and dying is expedited when they are faced with their own life-limiting illness. Children and youth are also able to reflect on and describe their experiences living at the end-of-life. Much of the research to this point has focused on investigating children and youth’s
experiences within a medical setting and is focused on a medical perspective of illness management; however anticipatory mourning provides a broad, initial framework with which to approach investigating children and youth’s experiences at the end-of-life from a phenomenological perspective.

The Current Study

Research related to end-of-life care, dying, and death, and bereavement related to terminally ill children and their families is quite limited (APA, 2005; IOM, 2003). Consequently, there is little qualitative or quantitative evidence on which to base current practices (IOM). Therefore, a qualitative design is particularly appropriate given the limited base of existing research and the many challenges faced when attempting research in this area. For example, the Children and Adolescents Task Force of the Ad Hoc Committee on End-of-life Issues of the APA (2005) concluded that because this is a challenging area in which to conduct research, “flexibility in methodology and respect for autonomy of the children and families are essential” (p. 27). The Task Force also noted that because of the relative rarity of childhood death, acceptable levels of statistical power associated with quantitative studies may be difficult to achieve. A qualitative design can allow for sufficient interpersonal flexibility between the researcher and participants so they are more comfortable in cooperating with sharing their thoughts, feelings, and experiences. Additionally, a qualitative study can provide rich and useful information with fewer participants.

Another methodological concern when performing research in this area is related to defining the outcome. There exists no consensus as to what is considered “good” or
“healthy” outcome, or which measurable variables are most relevant to the end-of-life process in terminally ill children. This presents a serious challenge to performing quantitative research in this area (APA, 2005). Additionally, positive outcomes may vary across group variables. Consequently, the APA Taskforce concluded, “at this point in the development of science in this area, qualitative research strategies can be especially useful for gathering initial information about key variables” (p. 28).

Anticipatory mourning provides a guideline that enables the investigation of children and youth’s experiences near the end-of-life from a phenomenological perspective. The extant research supports that anticipatory mourning is an important process in individuals facing the end-of-life; however, there is little known regarding the anticipatory mourning processes from the patient’s perspectives. The primary research questions for this study were: 1) In what ways do ill children and youth characterize their illness; 2) How do significant relationships change as a function of life-limiting illness in children and youth; and 3) How do ill children and youth characterize hope and their future in light of their illness?
CHAPTER III
METHODOLOGY

Information describing children and youth’s experiences with their own terminal illness is limited in the existing research. The studies that have been performed have focused primarily on terminally ill children and youth in a medical setting and from a medical perspective. Anticipatory mourning presents a broad framework with which to approach investigating children and youth’s experiences near the end-of-life from a phenomenological perspective. This chapter provides the rationale for selecting a grounded theory research design. It describes the criteria for inclusion in the study and the sample. The development of the research forms and interview questions is described and the final versions are included as appendices. Finally, an account of the data analyses is presented.

Design

Grounded theory was chosen to guide the design of the present study because there was an assumption that data would yield new concepts pertaining to anticipatory mourning in children and youth that had not yet been identified (Corbin & Strauss, 2008; Strauss & Corbin, 1990). When working with vulnerable populations, extra steps are needed to protect participants and/or to respond to unexpected situations that arise in the
field. The flexibility in a grounded theory approach enables the researcher to be responsive to such situations, thus making it particularly suited to research with a vulnerable population (Fassinger, 2005). Additionally, grounded theory allowed for the experience gained in the field to contribute meaningfully and systematically to the ongoing collection of data. This is useful given the limited research and theory related to children and youth’s self-reported experiences with terminal and life-limiting illness. The flexibility in the data collection and analysis afforded by grounded theory facilitated the development of a new theory describing the lived experiences of children and youth by including data derived from the study of children and youth near the end-of-life. Indeed, Strauss and Corbin (1990) emphasized this as a major benefit of a grounded theory approach in that the analyses are designed to “provide the grounding, build the density, and develop the sensitivity and integration needed to generate a rich tightly woven, explanatory theory that closely approximates the reality it represents” (p. 57).

Participants

Participants were recruited from the Haslinger Family Pediatric Palliative Care Center (PPCC) at Children’s Hospital Medical Center of Akron (CHMCA). The PPCC was established in 2002 and it aims to maximize the quality of life and minimize the suffering of children and adolescents with life-limiting and terminal illnesses as well as provide services to their families and loved ones. Through my previous work at CHMCA, I established a relationship with the PPCC and they allowed me access to their patients and assisted me with recruitment for the study.
Potential participants were identified by staff from the PPCC. Frequently, the staff is involved with patients and their families on a long-term basis so they have an awareness of the course of the patients’ illnesses, as well as their level of cognitive and emotional functioning. They were able to identify individuals who were aware of their terminal prognosis, who were able to reflect on their understanding of their life-limiting and terminal illnesses, and who provided descriptive information about the impact of terminal illness on their life experiences and expectations for the future.

The participants ranged in age from 8 to 21 years. Eight years of age was chosen as the low cut-off point for age because developmental literature suggests that by this age most children will have gained a mature understanding of the concept of death (Speece & Brent, 1984). Additionally, descriptive literature suggests that in terminally ill children, the process of developing a mature understanding of death is accelerated; therefore, it is a reasonable assumption that children aged eight years and older would be able to reflect on their experiences with terminal/life-limiting illness. Twenty-one years of age was chosen as the upper limit for the study because this is the age limit for the PPCC at CHMCA. The PPCC only treats these individuals if they were diagnosed with their terminal/life-limiting illness prior to their 18th birthday. Therefore, the majority of the end-of-life experience of these individuals will have occurred during their youth and will better reflect that perspective rather than an adult perspective.

As is customary when performing qualitative research, the sample size was not fixed at the outset of the study (Strauss & Corbin, 1998). Instead, data collection continued until there was a saturation of themes. The extent to which the data reflected
saturation was monitored throughout the analyses as described in subsequent sections. The literature suggests that saturation of themes typically occurs within eight to 15 interviews (Charmaz, 2006; Morrow & Smith, 2000). Additionally, the purpose of the research, credibility, and available time and resources also impact the determination of the final sample size (Morrow & Smith). Given these considerations, in the present study it was estimated that eight to 15 interviews would be needed to allow for a sufficient investigation of the themes related to anticipatory mourning as experienced by terminally ill children and adolescents in the PPCC at CHMCA. A total of 10 interviews were completed at which point no additional significant themes were emerging from the interviews and saturation was achieved. The description of the sample is included with the results discussed in Chapter IV.

**Instruments**

*Demographic Information Form*

Demographic information regarding the participant and his or her family was obtained via a study questionnaire (see Appendix A). The questionnaire asked for information including participants’ education level, parents’ marital status, family’s income level, family’s religious affiliation, and psychosocial stressors experienced by the participants unrelated to their illness. This questionnaire was derived from a similar form used in other research studies at CHMCA. It was modified for the present study by excluding information that was extraneous to the purposes of this research. I also recorded the participants’ medical diagnoses on this form.
**Semi-structured Interview**

I developed initial interview questions with potential follow-up prompts, based on the dimensions of anticipatory mourning as described by Rando (2000). The questions were constructed with the intent to make the dimensions applicable to a pediatric population. The questions were then submitted to the director of the PPCC at CHMCA for review. The feedback was incorporated into the final version of the questionnaire (See Appendix B).

**Researcher as Instrument**

Intrinsic to qualitative research is the use of the researcher as a tool of the investigation (Fassinger, 2005; Morrow & Smith, 2000; Strauss & Corbin, 1998). The researcher interacts with the data during the collection process as well as during the analyses. For instance, the researcher influences participants during the interview and therefore impacts the information gathered. Additionally, the researcher’s perspective influences the interpretation of the data and the resulting conclusions (Corbin & Strauss, 2008). It would be counter-productive and unrealistic to attempt to eliminate the influence of the researcher from a qualitative study. Rather the impact of the researcher must be closely monitored so that it does not unduly bias the results and so that an accurate interpretation of the data is achieved. Therefore, the researcher must make efforts to identify implicit assumptions and biases, to increase self-awareness, and to convey these to others (Morrow, 2005). Specifically, Morrow suggested exploring the researcher’s emotional involvement with the area of study, the assumptions derived from
the literature and experience, and the ongoing impact resulting from interactions with the research participants.

Of potential relevance to the present study, I am a female in my early 30s, married, with no children. I have never experienced the death of a child with whom I was intimately involved. However, I have experienced the loss of a close family member. I was significantly engaged in her care and I experienced my own pre-death mourning process. I worked in a children’s hospital for over two years and so have developed a comfort with being around ill children; however, I am not currently employed in this setting. Additionally, I have provided mental health counseling to children who have experienced trauma and am therefore comfortable with speaking to children regarding topics that may be difficult for them to discuss.

The literature review and personal experience led me to believe that children do experience a mourning process when faced with their own terminal illness. Furthermore, I expected the participants in the study to be aware of losses that they are experiencing and to be able to discuss them. I also expected significant individual differences in the quantity and quality of participants’ verbal reports of their experiences, which could not be predicted solely based on their cognitive functioning or developmental level.

In addition, I significantly impacted the data collection process. During the course of the interview, I made a variety of judgments including assessing the comfort of the participants in responding to questions and making alterations in the ordering and wording of questions based on my perceptions of their comfort. I was also able to maintain my composure and tolerate asking questions that were potentially difficult for
the participants to discuss. I made judgments regarding areas to follow-up with additional questions and when to move on to the next topic area. Finally, I attempted to maintain an open and empathic attitude and to convey appropriate caring and concern for the patients as they were responding to my questions, without crossing boundaries into therapy. I believe that I was able to manage this appropriately.

I have always derived genuine enjoyment out of interacting with children and these children and youth were no exception. Through the experience of performing this research, I gained a tremendous respect for the strength, perseverance, and positive attitude of these patients as well as an appreciation for the challenges faced by their families. I also felt deep gratitude for the opportunity and privilege of being allowed to spend time with these individuals and their families, when their time may have been quite limited. In addition, I was grateful for the generosity of the patients in their willingness to take the time to participate in the interviews so that I could complete my dissertation.

Procedure

Potential participants were identified by pediatric palliative care staff members at CHMCA who were familiar with the goals and requirements for the study. They approached the parents of potential participants and assessed their willingness to receive more information regarding this study. If the parents were willing to consider having their child participate, the staff forwarded their contact information to me. I subsequently contacted the family and provided a more detailed description of the study and requirements for participation. In addition to obtaining the initial verbal permission from
the parent/guardian for their child’s participation in the study, I also assessed the child’s willingness to participate in the study.

After verbal consent was obtained, an appointment was scheduled for a place and time convenient for the child and the parent. At this appointment, consent forms were reviewed and signed by the parent and assent forms were reviewed and signed by the child. The parent also completed a demographic form. The child participated in a semi-structured interview that was audio-taped and subsequently transcribed for analysis.

Analyses

In grounded theory, analysis of the data begins with open coding, “the process of breaking down, examining, comparing, conceptualizing, and categorizing data” (Strauss & Corbin, 1990, p. 61). Open coding is performed by alternating between assigning conceptual labels and performing microanalysis of key words and phrases. Transcripts of the interviews were read and short phrases were assigned a conceptual label (approximately 1-3 words) that captured the meaning of the phrase and was closely tied to the original phrasing through using key words if possible. For example, one participant stated “And um, within that, I uh, lost hearing in my left ear” which was coded as loss of physical function. Another participant stated, “I’m going to school until college,” which was coded as future plans-education. Strauss and Corbin (1998) emphasized that the conceptual labels should relate closely to the context in which they occur, thus remaining closely tied to the data and most accurately reflecting the data. Once a paragraph or segment of the interview was analyzed for conceptual labels, key words and phrases in the section were reviewed and their conceptual labels compared to each other to consider
multiple possible interpretations and to search for patterns in the data across the labels. These considerations were recorded as memos and used to guide and refine analyses of subsequent interviews. I then returned to my original conceptual labels and determined if they accurately reflected the meaning of the participant, and refined them. This process continued until the entire transcript of the interview was analyzed.

Through the reciprocal processes of conceptual labeling and microanalysis, conceptual patterns began to emerge from the interviews. Conceptual labels that seemed to be related were grouped together, along with the text from the interviews, which led to the formation of sub-categories and major categories. Major categories and sub-categories represent increasingly abstract explanations of the phenomena being observed (Strauss & Corbin, 1998). Category labels were developed with efforts made to reflect the data that was grouped together. For example conceptual labels such as future plans-education, future plans-work, negative future expectation, and future/after-life were classified under the sub-category Plans/Hopes for the Future. Additionally, interview text assigned to the major categories and sub-categories was reviewed to discern the properties and dimensions that defined the categories, to ensure that each category and sub-category was unique and described an independent phenomenon, and to assess whether any proposed categories overlapped and should be combined. In this way, the patterns and variations within the major categories and subcategories were defined. Furthermore, when new major categories ceased to emerge, data saturation was achieved (Strauss & Corbin, 1998).
Data that were not assigned to a category or sub-category were reviewed within the context of the transcript to ensure understanding of the meaning being conveyed by the participant and to see if they “fit” in the category. After this additional step, most of the interview data were assigned to a sub-category unless they were unrelated to the interview (e.g., child asking for a drink or requesting a break to use the bathroom).

Once the concepts were organized with categories, axial coding was performed. Strauss and Corbin (1998) stated that “in axial coding, [major] categories are related to their subcategories to form more precise and complete explanations about phenomena” (p. 124). Additionally, the authors explained that major categories reflect phenomena and have explanatory power; whereas sub-categories describe aspects of the overall phenomenon (Strauss & Corbin, 1998). In axial coding, hypotheses were generated about the conditional and consequential relationships between major categories and sub-categories. These hypotheses were driven by data found in the interviews and they were examined and refined during the analysis of the interviews. Memos were maintained in order to document the ongoing process of axial coding throughout the research and analyses. In this way, assumptions regarding the relationships were documented and so they could be tested throughout the analyses. This contributes to the trustworthiness of the current study.

I worked closely with a licensed clinical psychologist who has significant experience in performing psychological research as well as clinical practice with a pediatric population. He served as an auditor through the open coding and axial coding process. The auditor reviewed demographic information, each transcript, and the research
memos. He compared the transcripts to the conceptual labels that were derived and provided notes and helpful feedback regarding the interpretations made. Subsequently, he was also helpful in considering the inclusiveness of the conceptual labels and sub-category labels. We discussed the phrasing chosen to describe the categories and worked together to refine them to be precise and inclusive of the data assigned to them. The primary goal in utilizing an auditor was as an additional check to minimize risk that the analyses were unduly impacted by my idiosyncratic perspective.

Selective coding is “the process of integrating and refining the theory” (Strauss & Corbin, 1998, p. 143). Once open coding and axial coding were completed, a central category was developed by examining the results of the axial coding and identifying an explanatory concept that encompassed the variability found in the interviews. The theory continued to be defined as the linkages between the central category and the major categories and sub-categories were developed. These linkages were then compared to the original interviews to ensure that they accurately reflected the experiences of the participants. The theory was then reviewed and refined. Strauss and Corbin (1998) described this final step as “reviewing the scheme for internal consistency and for gaps in logic, filling in poorly developed categories and trimming excess ones, and validating the scheme” (p.156). Any inconsistencies and gaps in logic were clarified by re-examining the interviews and refining identified relationships to better reflect the experience of the participants. The goal at this stage was to develop categories that encompassed sufficient variability to contribute meaningfully to the theory. Validating the theoretical scheme
was accomplished by returning to the interviews and considering whether the theory
reflected and accurately explained them.
CHAPTER IV

RESULTS

The purpose of Chapter IV is to present the findings from the data analyses and to show how the interview data correspond to the central research questions noted in Chapter II. The goal of the analyses was to provide a description of children’s and youth’s experiences with their terminal illness and to increase understanding of their perspectives of their own end-of-life process. Given that the primary goal of this research is to gain understanding of the experience of the participating children and youth, significant attention was paid to the content and form of the stories and responses derived from the interviews (Chase, 1995). I include my own interpretations of the data and themes in order to provide context and to suggest some ways of making meaning out of the data as well as to discuss how the various components relate to the existing theory and research (Riessman, 1993). Indeed, in her description of writing the results section of a grounded theory study, Charmaz (2006) suggested

go beyond an analysis of acts and facts. Think about what is relevant but lurks in the background of your analysis...See how rendering it explicitly in the text affects your writing and moves your analysis beyond reporting. In my studies, the gamut of emotions shades scenes and statements. Thus I evoke experiential feeling through rendering it in writing-as part of the analysis and evidence. This strategy includes taking the reader into a story and imparting its mood through linguistic style and narrative exposition (p172; emphasis original).
Josselson (1995) also emphasized that “People’s personal narratives are efforts to grapple with the confusion and complexity of the human condition. Our intellectual task as psychologists is to write a superordinate narrative that encompasses them” (p. 32). Thus, the presentation of both the data and interpretations in this chapter aims to provide a complete and meaningful description of the results of the research.

Additionally, the research aimed to compare themes from this sample to information found in the existing literature in order to systematically contribute to the current literature. I used Anticipatory Mourning an overarching framework designed to help make sense of the data and results. Therefore, examples of how I believe Anticipatory Mourning is manifested within the data and themes I identified are highlighted. Another goal of the analyses was to develop a conceptual framework that could be studied further, which I describe at the end of this chapter as “Living in Light of Life-Limiting Illness.”

This chapter begins by describing the participants and the interview process. Brief synopses of participant responses to the central questions are presented, followed by themes found across all interviews pertaining to the research questions. Finally, the initial conceptual framework derived from the interviews is introduced.

Participants

Ten children participated in the study. Their ages ranged from 8 to 21 years. Six of the participants were male, four were female, and all were Caucasian. All of the patients that were referred to the study by the palliative care staff ultimately chose to
participate in the study. Table 1 presents a more detailed description of the participants’ demographic and family information.

Table 1.
Participants’ Demographic/Family Information ($N = 10$)

<table>
<thead>
<tr>
<th>Category</th>
<th>Count or Range</th>
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</thead>
<tbody>
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<td>Gender</td>
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<tr>
<td></td>
<td>Female = 4</td>
</tr>
<tr>
<td>Race</td>
<td>Caucasian = 10</td>
</tr>
<tr>
<td>Parental Marital Status</td>
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<tr>
<td></td>
<td>Divorced = 3</td>
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<tr>
<td>Family Income</td>
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</tr>
<tr>
<td></td>
<td>$55,000 - $75,000 = 3</td>
</tr>
<tr>
<td></td>
<td>$75,000 - $125,000 = 2</td>
</tr>
<tr>
<td></td>
<td>Not Reported = 3</td>
</tr>
</tbody>
</table>

Interviewing the Participants

Seven interviews were conducted in a hospital setting and three were conducted in the participants’ homes, with the choice of location determined by the participants and their parents. Efforts were made to minimize the impact of the parents/guardians on the interview with the child by asking them to leave the room during the interview. The mothers of two hospitalized children (ages 12 and 8) wished to remain in the room and they were asked to refrain from interacting with the child, and to sit out of the child’s line of sight during the interview to the extent it was possible to do so. One of the mothers did prompt her child to provide more information when he seemed somewhat reticent to do so. Otherwise, neither mother seemed to have a significant impact on the interview process.
Length of the interviews ranged from 35 to 85 minutes, and depended primarily on the child’s level of talkativeness. Indeed, some of the children talked freely and extensively about their experiences, whereas others provided more brief responses and required follow-up questions to give additional details. All participants were able to complete the interview in one session. One child became somewhat emotional during the interview and required a short break to regain his composure. He was provided with the option to discontinue his participation; however, he declined to do so and he was able to complete the interview. At the conclusion of the interview, this child, and all of the other participants, verbalized that they enjoyed participating in the study and stated that it is important to them to contribute to the care of other children and youth who are in similar circumstances. They believed that participating in the study helped them to achieve this objective in some way. PPCC staff remained in contact with the children and families after their participation in the study to address any emotional concerns that arose as a consequence of the participation. No specific concerns or negative reactions were reported.

Researcher as Instrument

To help establish and enhance a relationship with the participants, I attempted to be open and genuine with each participant and his or her family members. Additionally, I spent some time prior to the interview getting to know the participants. For example, most of the individuals, who were interviewed bedside in the hospital, were engaged in an activity, such as watching a movie, playing video games, or drawing when I arrived
and so we spent time discussing the activity. This served to increase the participants’ comfort with me and to acclimate them to speaking with me.

Consistent with my training received as a counseling psychology doctoral student and with Fassinger’s (2005) position that flexibility is important in protecting vulnerable populations, I listened empathically to the responses to the semi-structured interview questions. Based on my perception of the participants’ comfort, as well as their individual responses, I adjusted the order of the questions and the follow-up questions as necessary.

When describing participant responses in the subsequent sections, the term “all” indicates 10 participants, the term “most” refers to 8 to 9 participants, the terms “many” and “several” refer to 5 to 8 participants, the term “few” refers to 2 to 4 participants.

Research Questions

The purpose of this research study was to obtain a description of children and youth’s experiences with their terminal illness, from their own perspectives.

The specific research questions addressed were:

1) In what ways do ill children and youth characterize their illness?

2) How do significant relationships change as a function of life-limiting illness in children and youth?

3) How do ill children and youth characterize hope and their future in light of their illness?

Each interview was individually analyzed to gain an understanding of how the participants addressed the three research questions. Rather than focusing on including every specific detail from each interview, this phase of the analyses concentrated on
discerning the overall message given by the participants. This was combined with information about the individuals’ presentations during the interview as well as background information to develop a synopsis that is descriptive of each participant in the present study. The case synopses, identified with pseudonyms for the participants, are presented first in order to provide the reader with a sense of the individual speakers that provided the data found throughout the study.

The interviews as a whole were also analyzed for themes occurring within the data that addressed the research questions. The thematic analysis is presented following the case synopses in order to provide a more complete, integrated review of how the data corresponded to the research questions.

Case Synopses

**Ella**

“...if I get good news, it does scare me that something bad’s gonna happen.”

Ella’s (age 20) interview took place in the living room of her home in the middle of the day, while her parents were at work. Her illness experience is characterized by initial “good” prognosis that unexpectedly goes “bad.” One way in which this pattern of good transforming into bad was manifested over the course of her illness was during the initial diagnosis. Ella had been experiencing frequent headaches and nausea. When her parents initially took her to a physician, she was diagnosed with and treated for migraine headaches. This was considered “good” as it is a more simple, straight-forward diagnosis with a prescribed treatment. Her symptoms did not remit as expected and instead intensified.
The continuation and intensification of her symptoms was considered “bad” because they did not respond to the treatment as was expected. She further recalled that she was sent home from camp because of her symptoms and that her mother took her to the emergency room, where she was finally diagnosed with a pituitary tumor. This pattern of good transforming into bad repeated again when she initially had emergency surgery to remove her tumor and was given a good prognosis. Soon thereafter, the remaining portion of her tumor hemorrhaged, she slipped into a coma, and almost died. These experiences seem to have left her feeling anxious, particularly when things seem to be going well, as she expects things to turn for the worse. Indeed, she stated, “But I got good news that time and then, all of a sudden, something bad happened. And it just seems like anymore, if I get good news, it does scare me that something bad’s gonna happen.” She tended to describe many aspects of her illness and her activities of living that were associated with the illness in this manner, initial positive expectations that are premature and transformed into a negative outcome.

Ella had been struggling with her illness for nine years at the time of the interview. The timing and the duration of her illness seemed to impact her relationships significantly and this was an area that she spent much time discussing. Specifically, while she was in school, she reported peers being very supportive; however, as she got older, her friends went off to college and were no longer available as they once were. Thus, instead of progressing and becoming more independent from her family of origin, as would be developmentally appropriate, Ella described being “left behind” and not attending college. She stated, “It’s very lonely during the day, sometimes when I’m here
pretty much by myself and I can’t go nowhere and I can’t get nobody to come and do anything. Can’t blame my parents because they have work.” Relatedly, she then described struggling to find activities, approximating “work” that would be fulfilling, yet accommodating of her physical and practical limitations (e.g., lack of college education). She was able to do this through volunteering with religious education activities (e.g., summer camps, Sunday school). Her volunteer work served to provide a sense of vocational fulfillment as well as a source of satisfying interpersonal interaction.

Ella’s discussion about the future was characterized by anxiety. Given the course of her illness and her near-death experience, she did not believe she could reliably predict her physical functioning and this prevented her from progressing as would be developmentally normal. For example, she described forgoing enrollment in college courses in case she became ill and required hospitalization. The fact that she experienced recent complications, which required a significant hospital stay, reinforced her decision to not to enroll in college. Finally, in regard to her thoughts on the end-of-life, Ella reported that she did not have specific plans, but was concerned about distributing her possessions. She stated that, “I don’t want them [her family] to get rid of them if I’m not around because they mean so much to me right now.”

Terry

“You’ve got to take the medications and keep going.”

Terry’s (age 21) interview was performed bedside during a hospitalization related to his illness. He was matter-of-fact regarding his leukemia. He described a series of relapses that increased in severity and have caused many serious and life-threatening
complications. Terry framed the illness within the broader picture of his life, which he described as being difficult given his “broken” family and necessary self-reliance. He described his coping with pain as “you’ve got to take the medications and keep going.” This style of encountering and persevering through pain also seems to exemplify an aspect of his personality that enables him to cope with difficult situations in his life beyond just his illness. Additionally, his pragmatic sensibility may also help to explain why his near-death experience resulted in decreased fear and anxiety surrounding death, rather than increased anxiety for the unknown.

In regard to relationships, there is a notable contrast between Terry’s experience and Ella’s. Whereas Ella felt increasing isolation from peers and increasing closeness and reliance on family members, Terry’s experience was the opposite. This is probably, due to familial dysfunction precipitated by his parents’ struggle with addiction, and consequently, his being the primary care-giver of his sisters. When he became ill, he described increased alienation from his family, with members blaming him for the stresses brought on to the family because of his illness. As a result of the relative lack of support from his family, Terry developed increased self-reliance and found support when needed from peers, neighbors, and a cousin. Unlike Ella, Terry described developing independence from his family of origin, although this likely occurred because of his familial circumstances.

Terry’s pragmatic tendency is evidenced in his discussion of the future. His hopes for his future are modest and short-term, and he seems to have an understanding of his prognosis, given the multiple relapses of his leukemia. Instead of discussing lofty career
goals, he expresses hope for improved physical health and strength, as well as being able to release music with his band. He is not fearful about the unknown and his end-of-life; however, he does maintain hope of survival. Nevertheless, he has thoughts about the end of his life, and described wanting to have certain music played, as well as his belief that the end-of-life is a transition into a new beginning.

*Brody*

“I don’t want to die too young.”

Brody’s (age 18) interview was performed bedside during a hospitalization. He was diagnosed with Cystic Fibrosis in infancy; however he began to experience debilitating symptoms two years prior to the interview. He reported a dramatic impact of his illness at that time because of increased difficulty breathing and hospitalizations occurring every few weeks. The trend of increasing physical debilitation and hospitalization continued over the two years, including the most recent hospital stay. At the time of the interview, he was considering the option of having a lung transplant because his condition was deteriorating. In addition to increasing debilitation, Brody, more than other participants, seemed to characterize his illness as a barrier. For example, he made statements such as “my lungs have got really bad and I can’t really do much anymore. It just takes too much out of me.” The idea of illness as a barrier was manifested in multiple ways in his living, such as his inability to maintain minimal privacy of even his room from his sisters, uncertainty about his prospects of attending college, and inability to move out of his parents’ home.
When discussing relationships, Brody described less disruption in peer relationships than many other participants. This may be a result of the chronic nature of his illness because he and his friends have accommodated his frequent absences within the structure of their friendship. The lack of disruption may also be attributed to his unique developmental period as he was approaching graduation from high school, but his friends had not yet left for college. His perception may have changed in the Fall when his friends left for school and he remained at home, as was the case with Ella. He did relate that his illness had caused him to become increasingly dependent on his family and siblings for assistance. This increased dependence was frustrating to him as he struggled with wanting to control his level of dependence and balance this with independence from his family. For example, he wanted to move out of his parents’ home, yet live close by in order to maintain support and his relationship with them. Brody also discussed developing friendships with others who are diagnosed with Cystic Fibrosis and that these friendships were particularly important to him because these individuals “know what I’m going through.”

In discussing his future, Brody expressed a fear of “dying too soon.” His fear is attributed to his decreased lung function and needing a lung transplant. His consideration of his future seems to be largely shaped by this concern. Nevertheless, he also expressed a desire to “think positive” and that he avoided thinking about his end-of-life. However his awareness of his terminal status was reflected in his vagueness when describing long-term plans and instead he chose to discuss more short-term goals. For example, he did not discuss career or relationship aspirations but instead focused on his desire to move out of
his parents’ home and considering ways to attend college that could also accommodate his illness. Brody’s interview was unique in the sense that he was the only one to explicitly state that he avoided thinking about the end-of-life due to a desire to “think positive.” He was also more resistant to discussing it than other participants. However, almost all others did state that they had not specifically thought about what they wanted their end-of-life to look like. It is unclear if they, like Brody, were trying to “think positive,” or if they were simply reluctant to discuss this sensitive topic with me, given that I was relatively unknown to them.

*Tim*

“Try to make the best out of my situation”

Tim’s (age 15) interview was performed in the kitchen of his home. His parents were present in the home but generally not within earshot of the kitchen. He described ignoring early symptoms at the onset of his Leukemia. He stated, “I was a tough kid and I wanted to stay with my friends, my team, and play soccer.” He described a dramatic and sudden impact of his illness in that he was quickly required to begin treatments that were physically debilitating. He described his illness, almost as an adversary that he was fighting by enduring difficult treatments and hoping for positive outcomes. He described his efforts to cope with his illness as, “I try to make the best out of my situation, no matter what it is.” He described ways that he did this through visiting his school, watching his team play in soccer games, and helping his younger brother develop soccer skills. For Tim, his identification as an athlete seemed to be important as he seemed to
parlay this into his approach to confronting his illness and used it as motivation to endure through challenging medical interventions.

Maintaining peer relationships was very important to Tim. He, in particular, spent much time discussing his efforts to remain involved with friends and teammates and struggling to find ways to accommodate his illness so that he would be able to continue participation in activities. For example, he described making efforts to visit his school or to attend games, even if he could not play. He also described the support that he felt from his coach and other players, particularly when he was hospitalized, through their visits and messages they sent to him. His situation seems to be somewhat similar to Ella’s because participation in community activities provided a sense of satisfaction and fulfillment. Additionally, like Ella and Jerry (discussed below), he also felt a strong sense of support from his community. Tim’s story provides an example of the importance of making accommodations for illness in an effort to maintain interpersonal connections, which seemed to be an important part of his Anticipatory Mourning process.

When discussing his future, Tim primarily focused on short-term goals. He was hopeful that his most recent round of treatment would result in some remission of his symptoms, enabling him to return to school. He also was hopeful of regaining his physical strength, a very important component to his identity. As expected, he also hoped that he would feel well enough to start driving and saw this as a way to increase his independence from his parents as well as to decrease his perceived burden on his family. He expressed some longer-term goals including “beating” cancer and being able to attend college.
Mindy

“I want to invent an oxygen tank that fits behind your ear.”

Mindy’s (age 14) interview was conducted in a conference room of the hospital during her visit for a routine appointment with her physician. Her illness, Pulmonary Fibrosis, is somewhat unique because it arose as a result of radiation given in the course of cancer treatment when she was a very young child, thus Mindy was battling her second life-threatening illness. She described recovering from her cancer and living without illness for a number of years before becoming ill with pneumonia and subsequently experiencing a significant and rapid decline in her lung functioning. Like Terry, Mindy was quite matter-of-fact when discussing her illness; however, she was somewhat less emotional than Terry and the other participants in describing her illness and its life-threatening aspects. The decreased level of emotional expression may be reflective of her personality or may be a result of her previous experience of confronting a life-threatening illness. Additionally, unlike Ella, she did not report increased anxiety related to overcoming one life-threatening situation only to be confronted with another.

Regarding her illness, she did express emotion about the necessity of having an oxygen tank with her at all times. She stated, “I hate this thing. Everyone stops and stares at me, and little kids ask me what it is.” She also said, “I want to invent an oxygen tank that’s small and can fit around your ear or something, so no one would notice it.” It was interesting to me that this was her primary concern at the time of the interview. Her oxygen tank may have been particularly salient to her because she was preparing to go on a trip and her mother was trying to arrange for a smaller, more portable tank that had
sufficient capacity for the trip. The tank may have also been perceived as cumbersome because it was certainly the most significant, outwardly, obvious symbol of her illness—one that was ever-present and would not change unless she was deemed an appropriate candidate for a lung transplant.

In terms of relationships, Mindy focused on her close-knit family, particularly her grandparents, whom she was preparing to visit. Again, the upcoming trip may have intensified the salience of this relationship for Mindy, nevertheless, it was clear that her family was a strong source of support. To illustrate her point, she stated, “my mom has always taken care of me and made sure that everything was ready before she lets me go anywhere.”

Similar to many of the other participants in the present study, when discussing the end-of-life, Mindy stated that she did not have specific plans, but that she did want to say good-bye to people who were important to her. In addition, it seemed very important to Mindy, in particular, to leave a legacy or to make a contribution. She primarily focused on this legacy when discussing the future. Specifically, she wanted to do something for other kids who were similar to her. Her most clearly articulated idea was to invent something that would make the oxygen tank less cumbersome and she developed the idea of small inconspicuous tank that would fit behind your ear. I imagine it would look like a Bluetooth headset. At this time, she also conveyed an understanding of the terminal nature of her illness by stating that “if I’m not around to do this, I hope that someone else will, to help out the rest of the kids.”
Jerry

“I said thank you a lot, that’s for sure.”

Jerry’s (age 12) interview took place bedside during a hospitalization. He described his illness as beginning with a rapid onset of unremitting symptoms that led to the eventual diagnosis of a brain tumor. His account of the illness varied from a factual retelling of its course and related treatments, to describing his responses to the illness and treatments on both physiological and emotional levels. For example, he recounted multiple home-remedy interventions, which “did not work” and caused him to continue experiencing severe nausea, including the following instance: “So my dad said, ok, bud, let’s try to get you better, it might just be a bug. I said, yeah, yeah. Even taking medicine, and he gave me grapefruit juice. That didn’t work, I just barfed that out.” He also described the initial fear and sadness that he felt in response to his diagnosis, which was intensified by sensing his parents’ apprehension, the presence of extended family members, and special interventions. He recalled understanding the seriousness of his situation when a nurse said “since your son has a tumor, this hospital doesn’t treat children, so we’re going to send you to Akron Children’s Hospital. I was like wow.” He described the scene of his father telling him about his tumor as follows:

He was just like, really sad. My mom was sitting beside him, my grandma, my grandpa, and probably my great-grandma...so they were all sitting beside me and he had something in his hand...And so he’s like, “Bud this is your brain, and this right here is a tumor.” A what? “A tumor. You have a brain tumor.” I’m like omigosh, and tears were just streaming down my face and everything. I tried to be more calm.

Additionally, he characterized his tumor as sickness or weakness in his body that could be addressed through natural, health-promoting interventions such as exercise and
healthy diet. However, he also acknowledged that this was the view espoused by his father who pressured him to work out and to maintain a strictly healthy diet, rather than his own idea. He elaborated further that one of the most frustrating things since he’s been sick is “trying to work out and stay on a diet...because my dad is a body builder and he wants me to work out like a lot. It’s kind of hard.” He also stated that his mom generally takes care of him, “because my dad doesn’t know what the heck to do, he just tells me to work out most of the time.”

Jerry spent a significant portion of the interview discussing relationships. He described his family as being extremely close-knit prior to his illness and that this continued after his diagnosis. He also highlighted the negative financial impact of his illness on his family and their efforts to raise money through selling familial possessions and through fund-raising efforts. These efforts brought him into greater contact with his community and he described a deep appreciation for the kindness of strangers who donated money and expressed sincere well wishes for his health. Jerry repeatedly expressed gratitude and appreciation for the generosity and support he felt from his family, his neighbors, and from strangers in his community. Truly, Jerry felt embraced and supported by those around him and he stated, “I mean, you have to have good friends and you know, and have to have friends that have good friends.”

Jerry spent very little time discussing his future. This may be because of his poor prognosis or because he had spent considerable time narrating other aspects and became tired by the time we were to discuss his future. He did express hope for survival and regaining his physical health and strength. He also stated that he had not specifically
considered end-of-life planning but that he wanted the opportunity to say goodbye to his family and other supportive individuals.

David

“Get the best IV stickers in the world...talking about the first shot.”

David’s (age 12) mother decided to remain present during the interview, which was performed bed-side in the hospital. David seemed to be comfortable with his mother present and she remained largely inconspicuous, except for prompting him to provide additional information about his illness. Indeed, he initially responded that he did not know much about his illness, Spinal Muscular Atrophy; however, with additional questioning, he was able to provide some of the characteristics that are salient to him. Specifically, he stated that he has had the illness since he was born and that he has had frequent hospitalizations because of respiratory problems and potential complications arising from colds and infections. Similar to a number of participants, David stated that the worst thing about his illness were the IVs. David’s account of IVs highlights how onerous the children and youth in the present study found this rather routine intervention and underscores the need to address this concern for patients in this population.

In regard to relationships, David primarily talked about his family and did not discuss his peers. This conspicuous absence of peer friendships may be because of the frequent hospitalizations that David has endured over the years, requiring him to be primarily home-schooled. His illness seems to have significantly interfered with his ability and/or opportunity to develop peer relationships. Instead, he discussed interactions
with his parents, brothers, and extended family members, including cousins. Specifically, he identified his mother and his aunt as people who are supportive when he is scared.

When discussing the end-of-life, David stated that he is “afraid I’ll die” when he is hospitalized, but that he does not think much about it when he is at home. He also stated that he would like to have the opportunity to say good-bye to “everyone” if he was at the end-of-life. Additionally, he stated that he was looking forward to getting a service dog in several months because he enjoyed the comfort and companionship of dogs. He also described an aspiration to be on American Idol.

*Eva*

“I like to watch movies and eat chocolate.”

Eva’s (age 10) interview took place in the living room of her family’s home with her parents remaining elsewhere in the house. She described her illness (Short Gut Syndrome/Esophageal Varices) as a series of difficult treatments that she had to endure. Her style of speaking and the content of her story were both dramatic; thus she also described in striking fashion her own and others’ reactions to her illness. She began her description of the illness by saying that she woke up and her father told her she had a surgery. She described the scene as follows:

And I got so scared, my dad started to cry, so I did. And my brothers, not Austin, Austin was crying a little...Now Aaron and Adam, they were just standing there and weren’t crying at all. Now, when they got home, they started crying like...

The reality of the details of her recollection was somewhat questionable, because she initially stated that a nephew was crying and then remembered that he had not been born yet. Rather, her recollection seems to indicate the drama associated with the experience
for her. Her flair for the dramatic continued in her description of the procedures associated with her illness including her “hate” of needles. She provided other vague details about surgeries and a few more details describing a vest that she has to wear; but, otherwise, she preferred to focus on aspects of daily living. This seems indicative of a way that she may cope with her illness, seeing it as something that interrupts her life and has to be endured before getting back to living.

In regard to relationships, Eva described her peer relationships as remaining largely the same before and after the onset of her illness. Conversely, her relationships with adults seemed to have changed after her illness and she described them largely acting as protective care-givers. She described deriving a good deal of comfort from interactions with various adults; however, she also noted that a nurse was over-protective in not allowing her to engage in certain activities despite the general consensus that they posed little risk to her. Nevertheless, Eva generally expressed very positive feelings about her relationships with others and frequent interpersonal contact was important to her. Additionally, Eva discussed her closeness to her dogs and believed that they were protective of her.

Related to the attachment that she had to others, Eva expressed that one of the most difficult ideas to cope with in regards to the future is “that I’ll be away from my family. Me going bye-bye, and then going up there...being without my parents, dogs, brother’s dogs, my sister’s two dogs...” She also stated that she wanted to have “tons” of people around at her end-of-life and her description was consistent with her generally theatrical presentation. For example, she imagined that during her last moments, she
would be surrounded by many others who cared for her and that they would be crying. She imagined herself being “brave” as she fell asleep and that she would be transported to heaven. She wondered if she will become an angel in heaven when she dies.

Eva’s dramatic presentation seems to be largely consistent with her personality, as the “drama” was present throughout all aspects of the interview, from her style of speech, to dramatic physical flourishes observed during the interview (e.g. throwing herself on the couch), to her future aspirations of being a veterinarian or a singer, performing in front of a live audience. She enjoys being the center of attention. It is possible that she may use this aspect of her personality in a protective and comforting way as well. For example, by casting herself as the lead in her own “story” surrounded by the “supporting cast” comprised of her family and friends, she reinforces her position of importance to these other people. This may be one way in which she is attempting to maintain a close connection to them and be assured that the connection will be maintained even when she has gone “up there.” Regardless of whether she is using her dramatic imagination as a source of comfort, I do strongly suspect that her flair for the dramatic was a firmly established part of her personality before her illness developed.

Maureen

“I like going fast in my wheel chair.”

Maureen’s (age 9) interview took place in a hospital conference room during her visit for a routine physician’s appointment. Her characterization of her illness and her discussion of her future are closely related and will therefore be discussed first. Maureen has Muscular Dystrophy which was diagnosed in infancy. Her characterization of her
illness can be seen in her statement that “I like going fast in my wheel chair;” this reflects her efforts to remain focused on her future despite experiencing progressive and significant decline in her physical functioning. She described an initial crisis point when she first experienced significant physical impairment. This occurred approximately two years prior to the interview, when she had considerable difficulty breathing and required the insertion of a tracheostomy tube. Additionally, she described other conditions related to her illness that impair her functioning including scoliosis in her spine, asthma, and lung disease. Despite the aggregate physical impairments, Maureen remained staunchly focused on her goals for the future, specifically, her career aspirations of becoming a veterinarian. Indeed, she spent very little time in the interview focusing on her impairments choosing to “zoom” through her illness to discuss her hopes for the future. The metaphor of “going fast in my wheel chair” reflects her determination to continue living life and pursuing her goals in spite of her illness and impairments. In addition to her long-term goals, Maureen also expressed short-term hopes including being able to swim again and going on rides at a fair.

With respect to relationships, similar to other participants, Maureen expressed a desire to maintain peer relationships. She has not been able to consistently attend school for the academic year and will likely be home-schooled next year. She is comfortable with this decision except for the loss of social contact and she explained, “home-schooling would mean I would miss out on the school I already went to, but I could still visit my friends.” When discussing her familial relationships, Maureen describes her relationships with her siblings as remaining consistent in ways such as ongoing sibling
disagreements and “fights,” as well as changing in that her siblings assisted in providing care for her. Additionally, she observed her mother devoting more time to caring for her and that, consequently, her older sister provided some care to their younger siblings.

*John*

“I’m a good kid.”

John’s (age 8) interview was conducted bed side during a hospitalization. His mother remained in the room for the beginning of the interview but did not interact with us and she eventually left during the course of the interview. John was diagnosed with brain cancer. He was the youngest and the most acutely ill of all the patients that I interviewed. The quality of his interview was different than the rest of the interviews because his answers were generally brief and he required more prompting to provide details. The characteristics of his participation may be reflective of his developmental stage, his level of health, the effects of the tumor on his cognitive level, or a combination of these factors. When he described his illness, he talked about it in terms of symptoms stating, “my head hurts a lot...I know something’s leaking in my head.” He also described treatments including having radiation, taking medicine, and having surgery, then stated “that’s all I remember.” In regard to relationships, John was concrete in describing his family by listing its members, including his parents, brothers, and dogs. Finally, when talking about his future, he described rather simple hopes including going back to school, where he said his teacher was “too nice” because she gave “too many warnings.” He explained that she gave warnings to the “bad kids” but that he was a “good kid.” He also
stated that he hoped to play football again, hoped to stand on his own, and just wanted to go home to see his dogs.

Thematic Analyses

*Question 1: How children and youth characterize their illness*

The semi-structured interview included specific questions regarding symptoms and effects of illness on the participants’ lives. Participants’ responses to these questions largely addressed this primary research question. One theme that emerged in the responses was that symptoms that initially appeared innocuous later led to the diagnosis of a serious, life-threatening illness. For example, several participants discussed initial symptoms such as nausea, vomiting, and headaches that, when they persisted, led to the diagnosis. A second related theme that emerged was that of a rapid progression from diagnosis to major intervention, specifically surgery. In response to this unexpected and rapid progression, the participants described emotional responses including shock, fear, and sadness experienced by themselves and their family. The participants generally described experiencing initial symptoms within the course of their daily living (e.g., attending camp, playing soccer, going to school) and when they did not remit, a chain reaction of sorts was initiated. Additional diagnostic tests led to a serious diagnosis and urgent intervention.

The participants barely had an opportunity to have their diagnosis sink in before their lives were severely disrupted. For example, Ella described being taken from 4-H camp, directly to the emergency room and within two days, she was having brain surgery. Jerry had a similar experience but was immediately taken into surgery. He described his
initial reaction to his illness and separation from friends as “And I was like, do I need to stay the night here...I’m like, but I want to see my class before I stay here. And so I had to stay there for three days.” These experiences were typical, particularly of those participants who were diagnosed with illness during the course of their childhood. They had very little time to initially grieve and adjust to the loss of their prior lives, their prior functioning, and their identity as healthy individuals. Instead, they were pulled into a whirlwind of medical intervention and living with a life-threatening diagnosis. The reality of their losses likely sank in over time, although how this process unfolded for this group is unclear from the present interviews.

Another theme that emerged was that of complications related to illness that required additional treatment, beyond interventions directly relating to their disease process. For example, several participants specifically discussed unexpected complications that led to imminently life-threatening situations including coma and resuscitation efforts. These individuals also spoke of residual feelings of uncertainty and feeling that there were no guarantees or that “things are random.” As a result of this experience, Ella expressed ongoing fear and anxiety about death, whereas Terry felt increased comfort and peace about facing death.

The discussion about complications underscores the ongoing challenges and losses being experienced by the participants in the present study. These losses pose adaptational demands that require continual responses from the patients. Additionally, the theme of complications continues the pattern of encountering the unexpected that began with diagnosis for some of these children and youth. The two examples suggest styles of
coping employed by individuals when encountering these unexpected events, specifically that of increased alertness leading to anxiety, always being on guard for the next unexpected event vs. an acceptance of events, and confidence in one’s ability to persevere or to come through them in some way. This process of encountering and responding to adaptational demands is an example of how the Anticipatory Mourning process is manifested within this group.

A fourth theme found in the interviews relating to the participants’ characterization of their illness was that of a progressive decline in physical functioning. Specifically, many described periods of health interspersed with increasing (in terms of duration and severity) levels of impairment. For example, those participants who were diagnosed with chronic illnesses that are terminal (i.e., Cystic Fibrosis or Muscular Dystrophy) described minimal symptoms early on, with increasing physical debilitation over time. Others (e.g., those diagnosed with cancers such as brain tumors or leukemia) described periods of illness, remission, and recurrence. The recurrence was often seen to be worse than the initial illness. Related to the progressive decline in physical functioning, all participants described prolonged absences from normal activities, such as school or vacation, as a result of physical weakness and mandatory utilization of cumbersome medical equipment (e.g., breathing machines). All participants also described partial or complete interference with previous physical activities (e.g., sports, dancing, 4-wheeling) and consequential development of other areas of interest including videogames, music, and art.
The pattern of decline in physical functioning and the resulting interference with activities are the major effects of illness described by these participants. These factors lead to many of the other effects in terms of emotional responses and impact on relationships experienced by participants in the present study. For example, Terry described missing three years of school and consequently being homeschooled because of his physical impairments. His physical functioning also led to increased dependence on others to care for him, inability to continue to play sports, and impaired ability to interact with his friends and generally participate in his community. He described a variety of emotional responses including disappointment at missing out on activities, frustration at being dependent on his family, and gratitude for the assistance of friends and neighbors. This general pattern was repeated for the other participants and is descriptive of the concrete impacts that the illnesses had on the lives of these patients.

In characterizing their illness, another theme that emerged from the interviews was that of the treatment interventions that were specific to their illness. Many noted having multiple surgeries as well as prolonged periods of follow-up treatment. All participants stated that shots and IV insertions were one of the worst aspects of their treatments. Additionally, although a few mentioned “getting used to being stuck,” there was universal consensus that the procedure “sucked” and was made worse by experiences during which they were “stuck” multiple times before a vein was found. Additionally, other interventions that were incorporated into their daily routines were also described as being onerous (e.g., using an oxygen tank or breathing vest).
Most of the interventions described by the participants were typical to their illness. However, rather than being concerned by the most drastic of procedures (e.g., surgeries), they consistently reported the most difficulty coping with routine interventions, with needles being the primary example. Secondarily, the participants also emphasized those interventions that were incorporated into their daily schedules, which suggest that children and youth require additional assistance to adapt to these more routine challenges. Additionally, considering the examples of Mindy’s concern about how noticeable her oxygen tank was and Brody’s complaint that his daily breathing treatments required too much time, it is also likely that these participants are struggling with mourning a variety of related losses. They could be mourning a loss of freedom from the daily restrictions imposed by their illness, the loss of an outwardly appearance of health, the loss of the relatively carefree living of childhood, and so forth. The data from the interviews provide only initial information about the meaning of these interventions to this sample so additional research is necessary to further explore this area.

Finally, a theme of positive aspects of illness also emerged. Some children and youth identified things such as enjoying having their own TV in the hospital and the “good lasagna” served in the hospital. Others noted valuing relationships formed as a result of their illness, such as connections with treatment providers and other individuals with the same or similar diagnoses. The presence of this theme suggests that the participants were able to derive some benefits from the anticipatory mourning process through finding ways to consider positive aspects of their lives with terminal illness.
However, the types of things described are generally simple and situational, which perhaps highlights the need for additional intervention to assist children and youth with deriving and recognizing benefits from their mourning process.

The characterization of illness described by the children and youth participating in this study provides an example of the frame within which Anticipatory Mourning occurs in this sample. They provided a description of their own perspectives regarding the demands and challenges posed by their illness, their attempts to cope with and respond to the challenges, as well as to make meaning from their experiences.

**Question 2: How significant relationships changed**

All participants noted the central importance of family during times of illness. For most of the participants, this was described by the increased care and closeness felt with parents and siblings. For example, Ella described the response of her family to her illness as

> I have two brothers, both older...they’ve all been very supportive and helped me through a lot of struggles and times. My parents have always been there for me. When I first went to the hospital for the tumor, I was very scared about it. My mom took off work the whole time and she stayed at the hospital with me through that first surgery and they’ve always stayed at the Ronald McDonald House after that.

Most described their parents, especially their mothers, taking on increased care-taking responsibilities. Several noted that this led to increased time away from the home for one or both parents. In these cases, extended family or older siblings stepped in to provide care for other family members such as younger siblings. On the other hand, Terry noted that his family was “broken” before his diagnosis as a result of parental chemical dependency and that he had taken on a care-taker role for his younger siblings. In his
situation, alienation from his parents reportedly increased, because they blamed him for the inconvenience of his illness, as well as from his siblings, who believed that he was getting “all the attention” and was no longer able to care for them. He noted the increased role of friends, neighbors, and the palliative care team, who met his emotional and physical care-taking needs throughout the course of his illness. His own role in the family also changed, as he focused more on caring for himself and less on care-taking for other family members. In Terry’s case, the role of family is also important, even though they were unable to fulfill the care-taking role that families took on for the other participants.

A notable observation is that when specifically asked, most of the participants did not explicitly report changes in their families that resulted from their illness. It is possible that they did not consciously recognize how their families were affected; however, descriptions of subtle changes in their familial roles were present throughout the interviews. Specifically, it is developmentally normal for children to be recipients of care provided by parents but in the cases of the participants in the present study, their needs were much greater than those of their siblings. Therefore, they often naturally required a greater proportion of care and attention from their parents. One common effect of this was that other family members had to take on increased care-giving roles for the other children. This subtle shift in roles generally occurred without significant difficulty for the participants. However, several (e.g., Jerry, Terry, Tim) expressed concerns about their increased reliance on their families and the time and energy their care required. They seemed to be acutely aware of the increased strain they placed on their family. For most of the younger participants (e.g., Eva, Mindy, John) the increase in dependence seemed to
be more acceptable. However, for Eva, in particular, this increased dependence also translated into a greater desire to be protected, and despite her obvious energy, she perceived herself as requiring the protective intervention of others, rather than being able to care for herself (e.g., in peer conflicts).

Most participants also identified the importance of extended family members. Specifically, several noted that aunts or grandparents took on increased care-taking roles for them and/or other younger family members. This was especially true when parents were busy either remaining at the hospital or if they had to return to work. Additionally, several participants stated that these individuals were sources of comfort for them and were available to talk when they felt “sad or scared.” One participant said that her aunt “answered all my questions and let me lay with her all night.” Several others also indicated that these individuals’ willingness to listen and to respond to questions was a source of significant comfort for them.

Additionally, most participants mentioned changes in their pets, specifically their dogs, after their illness. They developed special bonds with their dogs and missed them greatly when hospitalized. Jerry, who had difficulty with walking and coordination after surgery, said that two of his dogs would accompany him wherever he would walk and assist him with his balance. Several others stated that their dogs became more protective of them and were their constant companions when they were home. For many participants, their dogs were a source of great comfort. The role of pets is largely ignored in pediatric end-of-life literature, yet they were a significant source of comfort to many of the participants in this sample.
The role and salience of friends varied among the participants. In particular, interviewees who were more seriously physically debilitated by their illness, especially those who spent more time isolated (e.g., in the hospital), reported less information about friends. Conversely, those individuals whose diagnosis was more sudden and did not experience as much social isolation, reported more information about their friendships. For example, one individual who was diagnosed with a tumor and had spent many years battling this cancer, with prolonged absences from school, reported loneliness and struggling to develop relationships outside of her family. Instead, she reported increased closeness and reliance on family for socialization.

Many participants also described ways in which they attempted to maintain and/or develop new social relationships. For example, several reported reaching out to others diagnosed with the same illnesses (e.g., Cystic Fibrosis, Cancer, Muscular Dystrophy) through activities in the community and through online chats. Most also reported that they spent time visiting their schools even if they were unable to physically manage attendance for academic purposes. They did this in an attempt to maintain friendships as well as to maintain a sense of normalcy and routine. Indeed, it seemed important for many of the participants to develop a normal routine that was separate from their illness, and also could accommodate their illness. This accommodation was an important part of the Anticipatory Mourning process and illustrated one way that this sample adapted to ongoing, intermediary losses experienced during the course of their illness.

All participants discussed the differing roles of individuals within the larger community. Many expressed that the community was supportive of them and their
families during illness. For example, Jerry described monetary support received from the community when his family faced financial hardships as a result of his illness. Several participants identified teachers and students as being supportive through accommodation of their illnesses in various ways (e.g., extra time for assignments, assistance navigating the school building). Additionally, most participants described important care-giving activities performed by community members such as neighbors, religious leaders/clergy, and other professional care-givers (e.g., nurses, palliative care staff, physicians). The discussion of the larger community emphasizes the important and influential role community members have when they come into contact with this population. Additionally, in many cases, community members come into contact with these children during the course of their job/vocation, which suggests that it is important to consider interventions with ill children and youth from a variety of professional perspectives.

The description of the participants’ interpersonal interactions and changes endured in their relationships with various individuals provides an example of the activity of the interviewees on the interpersonal and systemic contextual levels as described by Anticipatory Mourning. The dynamics of these relationships and the interactions present a concrete articulation of the impact that interpersonal and systemic interactions have on the Anticipatory Mourning process of this group. Specifically, the participants emphasized the supportive roles that others played and their appreciation for their relationships with others.
Question 3: Hope and the future in light of terminal illness

When discussing the future, all participants expressed tension between being hopeful for survival and fear and/or recognition that death was a realistic possibility. Additionally, two participants acknowledged that thoughts of death were more salient when they felt physically ill and that they avoided thinking “negatively” when they were feeling better.

Most participants described fear and apprehension regarding aspects of their future. For example, some described worries about the implication of their treatments failing. Others (who are diagnosed with a definite life-limiting illness) described being afraid that they will die “too soon.” For example, Terry said

…but a lot of it is fearful stuff and what could happen. Me and my girlfriend, we have been together for four years now, and I would hate to just, after so long, you know, what could happen. Because it’s kind of a random thing, you know, anything could happen at any time. We just talk about stuff like that sometimes...

Several participants who experienced life-threatening complications described fear of similar episodes. Ella, in particular, expressed ongoing anxiety about her prognosis because of her previous experience of being given a good prognosis that was immediately followed by a life-threatening complication. Conversely, all participants also reported feeling hopeful about their future. Specifically, all participants described being hopeful that treatments would “work” in terms of being curative or significantly prolonging life.

All participants described short-term and long-term hopes/goals for their future. Short-term goals included improvements in physical functioning, decrease in negative symptoms and aversive treatments, and resumption of activities (e.g., sports, schooling). Additionally, two individuals expressed hopes regarding significant intervention that
could lead to prolonging life - they were hoping for lung transplants. Long-term goals included achieving developmentally appropriate independence, developing a career, achieving dreams (e.g., being on American Idol), travelling, and contributing to the community in meaningful ways. Several individuals also reported adjusting goals to realistically reflect changes in their physical functioning. For example, two individuals reported considering alternatives to college because of physical limitations, including fatigue and decreased physical stamina.

When asked specifically about end-of-life plans, most participants indicated that they did not have definite ideas about what they wanted their end-of-life to be like. However, all did report wanting to have opportunities to say good-bye to significant individuals. A few interviewees described additional desires including wanting to share themselves in some special way with others to leave a sort of legacy behind. For example, two participants indicated that wanting to give personal items as mementos of themselves to significant others. Another participant indicated that he wished to play a song that is meaningful to him for significant others.

Several participants also described thoughts and beliefs regarding after-life. For example, Eva described her family’s beliefs about after-life, including possibilities of “becoming an angel,” going to heaven, or being reborn. Terry stated that he viewed death “as a beginning rather than as an end.” He elaborated that he developed this belief after having a near-death experience with his illness and that he no longer feared dying.

Discussions about the future and end-of-life were characterized by a mix of emotions that demonstrate the complexity and the importance of the anticipatory
mourning process unfolding for the participants in the present study. Much of the process seems to be influenced by the seemingly contradictory motivations of establishing and/or maintaining connections with those who are important to the patients as well as reaching acceptance that these bonds will be severed in death. One way in which this paradox is manifested is in the importance of maintaining hope for more time (e.g., through prolonging life, being cured) that was expressed by all participants. On the flip side of this hope was anxiety about the possibility of treatments failing and time being too short. This hope and fear seemed to go hand in hand with one being more prominent at a particular point in time. For example, the anxiety was more prominent during hospitalizations.

Other authors (e.g., Davies, 2000; Rando, 2000) have described a paradox for mourners of struggling between “hanging on and letting go” of the dying person. Davies also described a contradiction in terms of patients struggling between wanting to fight and wanting to give up, both at the same time. These seem somewhat different than what was reported by the participants in this study. None had expressed a desire to “give up.” Rather, when discussing the end-of-life and the afterlife, the participants in the present study seemed to struggle with the desire to maintain connections with loved ones even in the face of the ultimate severing of connections, death. One way in which some participants seemed to cope with this conflict was in thinking about the afterlife. For the participants who did discuss their beliefs about the afterlife, this seemed to provide them with a vehicle with which they could imagine a transformation of their bonds with loved ones that enabled them to remain connected, even after their worldly death. Further
elaboration on this conflict is important to understanding one of the major challenges associated with the anticipatory mourning process in pediatric patients, and perhaps for individuals in the patient perspective in general.

Grounded Theory Analysis

There was a good deal of consistency across the various interviews in terms of the themes and concepts that emerged. Consistency was aided by the efforts made to recruit individuals who were more significantly ill, rather than recruiting individuals throughout the spectrum of life-threatening and/or life-limiting illness. Additionally, there was a good deal of consistency in themes that emerged from interviews with the younger and older participants. The resulting conceptual framework encompasses and reflects the information obtained through the interviews and is represented through Figures 2, 3 and 4. The figures are explained throughout this chapter as the components are discussed.

Major Categories and Subcategories

Two major categories emerged from the analysis: Aspects of Illness and Aspects of Living. These reflect phenomena that are important contributors to lived experiences of the participants in the present study. The sub-categories associated with each major category are also described below. Following the review of the categories and their respective sub-categories is the core category that emerged, which brings all the components together: Living in Light of Life-Limiting Illness.

Aspects of Illness

The sub-categories of Aspects of Illness include: determining the diagnosis and course of illness, symptoms, side-effects, treatments, and complications (See Figure 2).
Figure 2: Aspects of illness
The interaction of these sub-categories determines each individual’s illness experience. The illness experience in turn, is the lens through which the participants’ daily living experiences are filtered.

**Determining the diagnosis and course of illness.**

The first sub-category under aspects of illness describes how the diagnosis was determined and the overall course of the illness. The process of determining a diagnosis and the course of illness are characteristic of the specific illness and unique to the individual’s experience. Each participant was able to identify “the label” of his or her diagnosis (e.g., Cystic Fibrosis, Pituitary Tumor, Leukemia) and/or describe the primary area of the body that was affected (e.g., liver, lungs). Determining diagnosis generally occurred in one of two ways: (1) at birth or soon thereafter, as in the cases of illnesses such as Cystic Fibrosis or Spinal Muscular Atrophy, or (2) after assessment of initial symptoms and diagnostic tests, as in cases such as Leukemia or Pituitary Tumor. The individuals in this latter group provided the most descriptive accounts of symptoms and associated emotional responses experienced while going through the process of obtaining a diagnosis and initial treatments. This is probably because these events happened relatively recently, so the participants were older when they experienced the events, and the diagnosis was perceived to be relatively sudden. Additionally, the timing and the way that the diagnosis is made is important related to Anticipatory Mourning because Rando (2000) postulates that mourning begins with the awareness of the life-threatening condition. In regard to individuals diagnosed at birth, it is unclear how or when this awareness unfolds.
Additionally, some of the apprehension felt by the participants was related to the distress felt by their parents and observing reactions of other family members. This interaction is an example of the reciprocal connection between relationships and emotions depicted in Figure 3. For example, Jerry stated,

I think I had a CAT scan first that showed I had a tumor, but my mom didn’t want to tell me because she didn’t want to get me nervous or anything…my mom told my dad that she didn’t want to tell me but my dad told me. He tried to tell me really calmly and stuff…he said, ok, I got some really bad news bud. He was like really sad. My mom was sitting beside him, my grandma, my grandpa, and probably my great-grandma…and so, he’s like, Bud this is your brain, and this right here is a tumor…

In this way, this boy and others like him, gained understanding of the seriousness of their diagnoses from the reactions of their parents and other family members. This is in contrast to the participants who essentially carried a life-long diagnosis of illness. They did not have information regarding the time of diagnosis and when asked to tell me about their illness, generally replied, “I don’t know a lot about it.” Their initial response may be the result of a long-term assimilation of their diagnosis into their identity. They may be less primed to be aware of the risks and challenges associated with their illness because essentially, they have never known differently. When asked more specific questions, however, they were able to provide a good deal of information including describing a “crisis” event that was characterized by increased intervention and decreased physical functioning.

This event and the associated interventions and symptoms caused the illness and its life-threatening nature, to become more salient to this sub-set of the sample. It is unclear how this awareness emerges in children diagnosed with life-threatening illnesses.
at birth and how this factor specifically impacts their Anticipatory Mourning process. Nevertheless, all participants in the present study were aware of the life-threatening nature of their diagnosis as part of the criteria for enrollment. Their descriptions of mourning did not vary significantly from participants who were diagnosed later in life; rather, the children with life-long diagnoses described their illness becoming a more prominent feature in their life at some “crisis point.”

The overall course of illness was similar across all individuals within this sample and alternated between progressive decline in health and temporary improvement or stabilization of functioning. Decline in health included the illness affecting more areas of the body (e.g., tumor spreading to other parts of the body), experiencing increasingly severe symptoms (e.g., more difficulty breathing with more dramatic intervention required), or relapse of illness (e.g., recurrence of Leukemia). Temporary improvement or stabilization of functioning included things such as remission from cancer, improved digestion and weight gain, and recovery of function after surgery or significant treatments (e.g., radiation/chemotherapy). Additionally, all participants expressed anticipation of further progression of their illness, resulting in declines in physical functioning, as well as hope for regaining some physical function. In terms of Anticipatory Mourning, the course of illness is significant in providing the general context for the illness with which the patient must contend. The similarity in the overall course of illness among the participants also suggests potential similarities in the Anticipatory Mourning process across these individuals.
Symptoms.

Symptoms were described as the perceived physical effects of the disease process on the body. Some symptoms were described by individuals regardless of the diagnosis and were attributed to the effects of physically enduring a life-threatening condition. Table 2 presents specific symptoms reported by the participants. The interviewees spent a significant amount of time describing their symptoms and how they signaled the necessity for further intervention (e.g., diagnostic tests, hospitalization, medication). They did not describe personal attempts to cope with or respond to symptoms other than to seek assistance from others such as parents or physicians to determine their cause.

Table 2.
Physical symptoms reported by participants

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fatigue</td>
<td>10</td>
</tr>
<tr>
<td>Weakness</td>
<td>10</td>
</tr>
<tr>
<td>Pain</td>
<td>10</td>
</tr>
<tr>
<td>Nausea</td>
<td>7</td>
</tr>
<tr>
<td>Disturbed sleep</td>
<td>6</td>
</tr>
<tr>
<td>Difficulty breathing*</td>
<td>3</td>
</tr>
<tr>
<td>Headaches*</td>
<td>3</td>
</tr>
<tr>
<td>Impairments in vision*</td>
<td>2</td>
</tr>
<tr>
<td>Loss of balance and coordination*</td>
<td>2</td>
</tr>
<tr>
<td>Alteration in sense of taste*</td>
<td>2</td>
</tr>
</tbody>
</table>

*Symptom specific to diagnosis

Side-Effects.

Side-effects and symptoms are similar in that they relate to physical effects; however, side-effects result from various interventions related to the illness (e.g., chemotherapy, surgery, medications). Additionally, in contrast to their descriptions of symptoms, when the participants discussed side-effects, they described personal efforts to address and manage them and their consequences in some way. Table 3 presents the
specific side-effects reported by participants. When discussing efforts to manage side-effects, Ella recalled:

…after my first surgery, they shaved one part of my hair off and let the rest of it go and it was, I mean, past my shoulders. And I came home from the hospital at that time and told my mom to just shave it all off. I wasn’t going to go around with just half of my head with hair. That’s more embarrassing than going around with no hair.

A third participant, John described the difficulty of managing changes in appearance while maintaining peer contact through “just visits at least, like half a day. That’d be good, but it’s pretty hard on the steroids and gaining weight and everything.”

Table 3.
Side-effects reported by participants

<table>
<thead>
<tr>
<th>Side-Effects</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>10</td>
</tr>
<tr>
<td>Nausea</td>
<td>7</td>
</tr>
<tr>
<td>Changes in physical appearance</td>
<td>7</td>
</tr>
<tr>
<td>Fatigue</td>
<td>6</td>
</tr>
<tr>
<td>Disturbed sleep</td>
<td>5</td>
</tr>
<tr>
<td>Body temperature dysregulation</td>
<td>3</td>
</tr>
<tr>
<td>Dry mouth</td>
<td>2</td>
</tr>
<tr>
<td>Dizziness</td>
<td>2</td>
</tr>
</tbody>
</table>

Mindy described coping with fatigue by asking her teacher for extra time on an assignment,

I told her it was because I was going through…radiation at the time and I was very tired and things. It really wore me out and that I just didn’t have the time to get with the person that I was doing the report with.

These descriptions provide examples of how the participants in the present study engage in the generic operations of Anticipatory Mourning (Rando 2000). Specifically, they demonstrate how the participants engage in coping to minimize losses that occurred
because of their illness and how they attempt to maintain interactions with significant others.

* Treatments*

Treatments are interventions for illness-related conditions. This sub-category was defined somewhat broadly to include more general interventions (e.g., hospitalizations), specific interventions (e.g., surgery), and procedures used within interventions (e.g., IVs). All participants reported going through surgery at some point during the course of their illness. Although surgeries were viewed by participants as the most serious intervention received, they were not considered to be the most burdensome or endured with the most difficulty. Rather, the participants generally conveyed hopefulness that the surgeries would be curative or result in significant improvement in functioning. It was the more routine treatment interventions that were given on an ongoing or more frequent basis that were the most difficult to endure. Specifically, treatments involving needles (e.g., IVs, shots, spinal taps) were reported to be the most burdensome and disliked by all the participants. This sentiment was clearly articulated by Eva when she said, “whew, I don’t like shots. I am afraid of needles, AFRAID OF NEEDLES [emphasis original]. I hate it.” Another participant, Ella, stated, “…besides that [surgery] most of my pain would have to be being stuck by needles, I’ve always been terrified of them.” When asked what advice he would like to tell people that work with children like him, David said, “get the best IV stickers in the world…talking about getting it in the first shot.” This reaction increased in intensity for individuals who experienced many of these interventions and they continued to “hate” and/or fear needles.
Other routine treatments, including medication \((n=10)\) and mechanical intervention to aid in their physical functioning \((n=5)\) (e.g., c-pap machine, oxygen tanks, feeding tubes), were also described as being particularly onerous. Brody stated that the most frustrating thing about his illness is:

having to do all this stupid, taking all the pills, doing all the airway clearance, because it takes all together, two hours, unless I do it all at once, then it’s like an hour, but it’s still too long…It’d be fine if I didn’t have to do all that.

Finally, several participants also reported utilizing complementary or alternative therapies such as alterations of diet, exercise, and occupational therapy.

The descriptions of the participants’ reactions to treatments provide important information about the challenges faced by this sample when encountering their illnesses and associated treatments. They highlight the need to be sensitive to the experience of pediatric patients and challenge assumptions about what is perceived to be onerous in this population. They also suggest that additional intervention is necessary to decrease the burden associated with routine treatments.

Complications

Complications are disease processes arising from, but also separate from, the terminal illness and/or treatments. For example, one individual reported developing diabetes as a direct result of his illness. All participants also described a variety of disease-specific complications such as frequent kidney or lung infections, declines in vision and hearing, and pain. Four of the participants described unexpected life-threatening complications that they thought were particularly impactful in how they viewed their future. Ella described her life-threatening complication as follows:
right after I was done with chemo, I was feeling pretty good and they had done a PET scan and they said that the tumor was looking good. And then right after that, it hemorrhaged and I was in a coma…I’m just glad that I made it through that time…But I got good news that time and then, all of a sudden something bad happened. It just seems like anymore, if I get good news, it does scare me that something bad’s gonna happen.

All participants also reported a variety methods used to treat/manage complications including surgery, increased hospitalizations, alteration in behavior (e.g., avoidance of cold weather), and maintenance medications (e.g., insulin). The descriptions of complications provide further information about the illness context to which the participants are responding within the Anticipatory Mourning process. They also provide preliminary information about the cognitive processing that occurs in response to life-threatening complications.

Emerging Relationships Among the Sub-Categories.

Diagnosis/Course of Illness, Symptoms, Treatments, Side-Effects, and Complications are the sub-categories that fall under the major category of Aspects of Illness. These sub-categories are represented in all participants’ interviews. The relationships among the sub-categories are considered “emerging” because they are not as clearly articulated by the interviews; rather they were discerned by considering patterns reflected in the data across the interviews as well as being articulated by some individual interviews. These are offered as tentative observations of this sample, and additional research would be necessary to further generalize the results. Figure 2 illustrates the directional relationships among the sub-categories of Aspects of Illness observed in this sample.
In this study, the emergence of symptoms eventually led to the diagnosis of a life-limiting illness. This relationship between symptoms and diagnosis was most clearly elucidated by the individuals who were diagnosed with their illness during childhood. Participants who were diagnosed with their illness during infancy did not provide information in their interviews regarding the relationship between symptoms and determining a diagnosis. However, they did indicate that increased symptoms signaled a negative turn in the course of their illness. For example, Brody described increased fatigue and decreased stamina signaling that his lungs were failing. Thus, in the present sample, there appears to be a unidirectional relationship from symptoms to diagnosis/course of illness.

Another unidirectional relationship was observed from complications to diagnosis/course of illness. Participants in the current study described how complications altered the course of their illness. For example, participants \((n=3)\) described complications as causing poorer prognosis for long-term recovery from their illness or for significant improvement in their physical functioning. Complications were also described \((n=2)\) as leading to additional diagnoses (e.g., diabetes emerging as a result of complications from illness).

The relationships between symptoms and diagnosis/course of illness as well as complications and diagnosis/course of illness demonstrate that these participants have a well-developed understanding of their course of illness and reinforce their awareness of the terminal nature of their illness. They also suggest that the illness context is dynamic and changes, so it will impact the Anticipatory Mourning process differently over time.
Reciprocal relationships were observed among treatments and all other sub-categories. In regard to the relationship between treatments and symptoms, the symptoms being experienced led to the selection of particular treatments, whereas the efficacy of treatments changed the symptoms experienced. There was also a reciprocal relationship between treatments and side-effects, with treatments causing side-effects and side-effects requiring additional treatments. For example, steroids used as a treatment caused weight-gain as a side-effect. Conversely, pain as a side-effect of surgery triggered the use of prescription pain medication as a treatment. A similar reciprocal relationship was observed between complications and treatment, with treatments causing complications and complications requiring additional treatments. Finally, a reciprocal relationship between treatment and diagnosis/course of illness was observed. Specifically, the efficacy (or lack thereof) of treatment has the potential to dramatically alter the course of illness. Additionally, the diagnosis and course of illness determined which treatments were available to the patient.

The interactions among the sub-categories of Aspects of Illness determined the individual’s illness experience and provide information about how children and youth characterize their life-limiting illness. The individuals’ illness experiences significantly impact their daily living. Examination of the interactions between the illness and daily living provides us with a better understanding of the experiences and needs of children and youth diagnosed with life-limiting illness. For example, by paying attention to the pediatric patient’s perspective of which treatments and interventions are considered most burdensome, rather than assuming we know the answers, professionals who work with
this population will better know how to intervene appropriately to facilitate adjustment and to increase adherence to treatment in this group.

Aspects of Living

The sub-categories of Aspects of Living include Activities, Relationships, Emotions, and Plans and Hopes for the Future (See Figure 3). All of these sub-categories are inter-woven into the fabric of living.

Activities.

The first sub-category of aspects of living is Activities, which was broadly defined as things that the participants had done or continued to do prior to their diagnosis and since their diagnosis. Activities were elicited through specific questioning (e.g., about school) and through spontaneous report during interviews. Most participants generally described activities as falling into two groups: those enjoyed prior to illness and those enjoyed since their illness and in accommodation to the physical decline related to their illness. Activities enjoyed prior to illness included a variety of things, especially those requiring a significant amount of physical functioning (e.g. sports, 4-wheeling, dancing, attending school/church). For example, Jerry described his functioning prior to his illness as

I was able to ride on two wheels on my bike, pedaling and stuff. I used to be awesome climbing up the rope. I used to be really strong, until I was on these steroids. I mean, when I was two months old, I started doing pull-ups on the shower curtain bar. I was really strong. I was really healthy too. I used to be really skinny too and I was really awesome. And I just felt great when I was little.

This child’s description of his functioning prior to illness provides an example of ongoing mourning of past losses and functioning that had not been regained. Additionally, his
Figure 3: Aspects of living
discussion of his previous functioning also alludes to changes in his self-concept that occurred in response to his illness in that he describes how he was “really strong,” “really healthy,” “really skinny,” and “really awesome.” Using the past tense suggests that he no longer sees himself in these ways. Jerry also described working to regain function on the left side of his body through

Practicing with my left hand and stuff, it’s kind of hard to control it. So I’ve been swimming with it…punch on a punching bag….I open the fridge with my left hand, open the door with my left hand, get a cup…pour milk with my left hand…you know, small stuff.

Activities enjoyed after the onset of illness were generally less physically demanding such as playing video games, scrapbooking, drawing, playing musical instruments, and visiting with friends.

All participants also discussed accommodations made so that they could continue participation in activities including using tutors, decreasing time spent in school (without eliminating it), and continued attendance at functions with decreased participation. Ella stated,

My dad plays drums in a band and I would go with him a lot of times and listen to him. I still do that, but he plays ‘Wipe-out.’ That’s my favorite song that he played. I used to have a favorite dance to it and just lately…I can’t do it anymore because of my balance and things, which is really disappointing to me, because it is my favorite thing to do.

They also described many instances of how their illness and related treatments interfered with their activities. For example, several participants reported missing out on school functions and holiday gatherings as a result of hospitalizations. Some participants described activities in which they were able to participate because of their illness such as
attendance at a dance and a vacation granted through the Make-A-Wish program, although these were not always care-free events. For example, Brody described a vacation when “we went to Florida in October…to Disney for Make-A-Wish…I got sick the last like, three to four days there. We were only there a week, so half the time I was sick.”

The discussion of activities highlights the difficulties that the children and youth in this study had in maintaining optimal participation in activities that were important to them, while also accommodating the limitations imposed by their illness. It also alludes to the many small, daily changes encountered by these children and youth, which stimulate mourning. The discussion also provides examples of how Anticipatory Mourning is manifested on the interpersonal and intrapsychic contextual levels through the descriptions of changes in interpersonal interactions and through the expression of the individual’s reactions to the changes.

*Relationships.*

Three significant themes emerged under the sub-category of relationships including groups of people, reactions of others to their illness, and interactions with others. Participants generally discussed relationships with significant others who fell into one of several groups including parents, extended family, siblings, pets, professional caregivers, school peers and staff, friends, and the general community.

All participants spent time discussing the importance of their relationship with various family members and almost all described these individuals as reacting in
supportive and comforting ways to their illnesses. Most described receiving significant support and caring from their parents and selected other extended family members.

Sibling relationships were somewhat unique relative to all other relationships in that most of the participants described “typical” interactions with siblings, including arguments and rivalries generally found in these relationships. These relationships were different from interactions with others family members (e.g., parents, grandparents, aunts, and uncles), who were generally focused on providing care and support to the ill child. For example, Brody described being frustrated with his sisters taking his things while he was hospitalized, but also acknowledged the reciprocal care and support he felt for them. He summarized the relationship as “Well, they’re annoying. Uh, I like them, but at times they can be real annoying, because they just, I don’t know, I like them. I’m glad I have them.” Sibling relationships provide a good example of how certain aspects of living may be relatively unchanged by the illness experience.

Almost as significant as their relationships with family members was the participants’ relationships with their pets, specifically dogs. Most of the participants interviewed mentioned having dogs as pets and viewed them as part of their family. They believed that the animals were increasingly sensitive to them after diagnosis. They reported developing special bonds with their dogs and described ways in which the animals participated in care-giving and comfort for them. Jerry related how his dogs helped him walk to the bathroom. He stated, my dogs would try to help me, like Ollie, would come beside me and try to lift me up, he’d try his best…And Daisy tries to get like in front of me, in case I would fall down. But she has a big belly, pretty comfortable, better than the hard
floor…and so I mean like, they would help me out and stuff, I got some pretty good dogs.

Dogs in particular, were noted to provide a sense of caring and comfort to the participants. This is a unique observation from the present sample and has not been considered in the pediatric end-of-life literature. Further research is needed to better understand the impact of dogs and other pets on children and youth’s sense of well-being and feeling cared for.

In addition to comfort and support from family members, participants discussed various reactions of others in the community to them and their illness. Most described professional care-givers, especially nurses, as providing significant care and comfort to them. A few described parents and professional care-givers as being “over-protective” or “caring too much.” Jerry described being pressed to exercise and to eat only healthy and natural foods by his father. He stated, “my dad just pushes me too hard because he wants my tumor to die. He cares about me way too much.” Eva described her interactions with a nurse,

She thinks I’m not allowed, but she just tries to, she’s a little too protective. Like when I’m allowed to climb my tree, I was just swinging around on it and stuff, when I knew how to climb it. My parents let me, and she said, “No, I don’t want you climbing the tree.”

Some of the participants described peers and teachers as being unsupportive in various ways such as teasing them because of their impairments or not providing reasonable accommodations for their illness (e.g., extra time or assistance with assignments). However, each of these participants also described how they overcame these challenges and eventually received the needed support. Ella stated,
I had a little bit of trouble with a couple teachers. For some reason, they didn’t understand what I was going through; I guess…it wasn’t very easy getting some stuff. They thought they had given it to me and tried to fight the whole thing about that. But we got that all worked out and most teachers were very supportive most of the time.

Finally, all participants described changing interactions with significant others because of their illness. For example, all participants reported changes in their families as a result of their illness, including increased parental time and resources devoted to care-giving to the ill person. Consequently, siblings or other family members stepped-in to provide care-giving to younger siblings. David described these changes as:

I mean, sometimes my mom has been here [in the hospital] with me a lot, and I think that my little brothers are mad and also my sister. They don’t like to be with my dad too much because they have to clean a lot and carry in wood. I would have to do that if I was there, but they want to see my mom. It kind of sucks though, that’s really why I want to go home now, so we can all be together again.

Terry related coping to negative reactions to his illness in his family. He stated,

My dad kind of, kind of took it out on me. He lost his job and he said it was my fault. It just kind of backfired in a sense. My sister didn’t like it because I was getting all the attention but I never asked for it you know…I just dealt with it. I mean, there were some times when I got down in the hole and did some things that I probably shouldn’t of done. But me, for the most part, I got out, and just kind of managed to get a job and worked and everything.

His perspective was unique in the sample as he reported that his familial relationships were strained prior to his illness and became more so, after his diagnosis.

Another change described by many participants was their seeking comfort from specific family members and friends. Many times comfort was sought from parents, but in almost all cases, there were significant others who were perceived as providing a different quality of comfort, particularly in terms of allaying fears. For example, Brody
reported feeling comforted by speaking to a friend’s mother who was a nurse and who could answer questions about upcoming medical interventions. He stated,

…and she knows a lot about it because she works at a hospital…like soon, I may be getting evaluated to get a lung transplant, which I know nothing about yet and I can talk to her about it because she knows people who have had it done and everything. So I can talk to her about information and about them.

Maureen reported that when she is scared she talks to

my aunt, definitely my aunt. And my mom…my mom, not really, but my aunt all the time, my mom sometimes. When I got scared because I told my mom about my ear ache, when I was crying and scared because they wanted to have surgery on it. I was afraid of that, so then I went to my aunt Kim, because she said it was ok to go to her if I got scared. So I told her everything and she let me lay down inside of bed with her. It was really cool.

On the other hand, Ella did note that too much information communicated insensitively increased anxiety. She described her experience of

…and sitting in a room and they were sort of preparing some of the stuff they were going to do and that sort of really scared me. I didn’t want to have that done….It wasn’t like they were telling me straight, I sort of overheard some stuff.

Many participants also described other supportive interactions with friends and members from the larger community. For example, Jerry described efforts at fund-raising to assist with his medical expenses and how he was struck by the general outpouring of generosity and concern from individuals who were otherwise complete strangers. He related his experience as:

we tried to make some money selling pocket bikes, like raffling them off at the motor sports speed way. And people were so nice though. I mean the only thing we had there was a tent and a table and like the buckets and stuff. And people would just give us money and say, “I don’t want no ticket. I just want you to have this money.” …Like this one person had bought…$100 worth of raffle tickets, and so when I was having radiation, and he felt so bad because I had an old man’s tumor and he was an old man. He had the same tumor as me in the head. He just let me have the money. And I was like “thank you so much.” I mean, people were
just so nice to me. I mean, “you don’t have to do that, but thank you. We do need some money…thanks for helping my family and me.”

John described being involved in homecoming activities through a local high school and the general feelings of support and care he derived from being included in such a way. Ella highlighted positive interactions with individuals from her faith community as well as former teachers who were both supportive of her and allowed her to participate in activities as she was able. In this way, she felt both cared for by them as well as enabled to make meaningful contributions to her community.

Rando (2000) noted a dual function of Anticipatory Mourning as facilitating ongoing connection between the dying individual and significant others, as well as a loosening of these bonds. The preceding examples illustrate the importance of maintaining connections to these children and youth, be it with their families, with their friends, or with their peers in school. Additionally, the examples demonstrate the important role that others play in helping the participants to maintain these connections, to the extent possible, in light of the changes and limitations they experience in the course of their illness. Specifically, the examples of the participants being involved in their faith community and in the local homecoming celebration, show how the community and significant others can facilitate the development of new connections and the finding of new ways that these individuals can continue to contribute and interact significantly with others. Additionally, examples of “over-protection” and of others being unsupportive demonstrate the struggle that the participants in this study faced managing their own limitations and abilities in light of others’ expectations for them. The examples also
illustrate the difficulty of maintaining the balance between adjustment to and accommodation of ongoing losses and maintaining optimal functioning and relationships.

_Emotions._

This sub-category includes emotional responses to various aspects of the illness and living as felt and reported by the participants. Emotional responses are closely intertwined with the other sub-categories of Aspects of Living. Emotions were designated as an independent sub-category because they were frequently discussed throughout the interviews with this sample. However, in an effort to demonstrate the relationship between emotions and the other sub-categories, illustrative examples of emotional responses are included throughout the descriptions of the other sub-categories. Therefore, in order to minimize redundancy, this section includes a description of emotional responses in general, without the illustrative examples, because they are provided throughout this chapter.

A variety of positive and negative emotions were reported by all participants in response to various situations. Frequently reported positive emotions included joy (e.g., related to activities and interactions with significant others), relief (e.g., regarding diagnosis, positive treatment outcomes), comfort (e.g., related to interacting with significant others), gratitude (e.g., for the generosity and care-giving of others), and courage (e.g., with regard to the future). Respondents reported more negative emotions than positive ones, including sadness (e.g., about illness and separation from loved ones), disappointment (e.g., in reactions of others, own limitations), frustration (e.g., with treatments and physical limitations), loneliness, fear (e.g., of dying, of interventions),
regret (e.g., about lost opportunities), embarrassment (e.g., of physical changes), and uncertainty (e.g., about the future).

**Plans and Hopes for the Future.**

This sub-category is conceptualized as encompassing hopes and plans for the future as expressed by the participants. Most interviewees expressed a tension between fear that treatment interventions would not be effective and they would “die too soon,” and hopefulness for the future and living into adulthood. Maintaining hope was very important to this group of participants. They expressed short-term hopes including improved health, physical functioning, returning to school, and travelling. Short-term hopes were expressed by Terry as “Maybe getting better musically, well, physically first. Maybe getting an appetite back and gaining some weight. Staying healthy.” Similarly, Maureen stated, “I hope I will be able to swim again. And I hope that treatment won’t affect me and I hope it won’t affect me going on rides at the fair.”

All participants also reported long-term goals including hopes for adult careers, romantic relationships, accomplishments of dreams (e.g., to be on American Idol), and for increased independence from parents and caregivers. Maureen stated, “I want to be a vet, so I want to be really good in math and science…I do want to be able to run my own business as a vet, so I want to go to vet school and business school.” Brody cited “moving out of my parents’ house” as a significant long-term goal.

When asked about plans for their end-of-life, most participants indicated that they had not carefully thought about what they would like. Nevertheless, all participants indicated that they wanted an opportunity to say “good-bye” to significant others. Several
reported some specific ideas including sharing music or their possessions with loved ones as mementos. Terry expressed,

    I would like to, there’s a song that I bought actually today...that would be a good song to play. It’s pretty much about that, about going. I don’t know. I wouldn’t really want it to be a sad time. I don’t really think, it’s not the end, it’s just the beginning you know.

Additionally, many participants did not specify where they would like to spend their end-of-life and stated that it depended on how ill they felt. Several also expressed belief in the after-life and viewing death as a beginning of a transformation into the after-life. Eva stated:

    My dad thinks that I’ll probably be going to another mom’s stomach and stuff. And my mom thinks I’ll become an angel, and so do I. I think both...Now the Bible says that the only reason why that when you go up to heaven, that you sprout wings. But everyone does, people don’t know what you do in heaven. People don’t know what you are in heaven, right?

This quote exemplifies the struggle of these children and youth to make sense of their dying process, as well as suggesting the impact that familial beliefs and explanations have in shaping the child’s understanding. Additionally, the quote alludes to the child’s desire to maintain contact with her loved ones, which was more clearly articulated earlier in her interview.

Emerging Relationships Among the Sub-Categories.

Activities, relationships, emotions, and plans/hopes for the future are the sub-categories that comprise the major category of Aspects of Living. These sub-categories are represented in all participants’ interviews. The relationships among the sub-categories are considered “emerging” because they are not as clearly articulated by the interviews;
rather they were discerned by considering patterns reflected in the data across the interviews as well as being articulated by some individual interviews. These are offered as tentative observations of this sample, and additional research would be necessary to further generalize the results. Figure 3 illustrates the bi-directional relationships observed in this sample, among the sub-categories of Aspects of Living.

Aspects of Living were characterized by reciprocal relationships among all of the associated sub-categories. For example, the sub-category of Emotions was significantly connected to each of the other sub-categories (Relationships, Activities, Plans/Hopes for the Future). When participants discussed events or observations pertaining to other sub-categories, they generally included a description of their emotional responses. Additionally, their emotional responses shaped how they approached interactions associated with each sub-category. For example, Ella described regret (emotion) at not being able to say “good-bye” to her grandfather (relationship) prior to his death, because of her own illness. This regret (emotion) impacted her end-of-life plans (future) as she expressed that it was important to her to have the opportunity to have closure with people to whom she is close.

The Activities sub-category also had reciprocal relationships with the other sub-categories. For example, participants all described emotional responses to being able or unable to engage in favorite activities and this impacted their plans and hopes for the future. Terry described feeling disappointed (emotion) because he was unable to play basketball (activity) as part of his school team, which in turn also impacted his plan (future) to play basketball at the college level. Activities and Relationships were also
strongly connected as the participants described interacting with significant others and maintaining activities was important to maintaining relationships. For example, several of the younger children described wanting to maintain peer relationships (relationships) by continuing to attend school (activity), at least on a part-time basis.

Finally, there was also a reciprocal connection between Relationships and Plans and Hopes for the Future. Participants described supportive relationships as facilitating their hopes for the future. For example, Ella described a former teacher that allowed her to volunteer in her classroom, which in turn stimulated her interest in becoming an educator. This relationship exemplifies the impact that others can have on what these patients believe is possible for the future or the opportunities that they have. This particular relationship does not seem to be unique to Anticipatory Mourning because significant others often are thought to impact on a young person’s future aspirations (e.g. mentors, coaches, teachers).

*Living in Light of Life Limiting Illness*

The core category that emerged from the grounded theory analyses is Living in Light of Life Limiting Illness. This encompasses the major categories of Aspects of Living and Aspects of Illness. Figure 4 illustrates the directional, emerging relationship between the major categories. The relationship is considered emerging because it was not specifically articulated in interviews; rather it was discerned by considering the patterns reflected in the data across the interviews as well as being articulated by some individual interviews.
Figure 4: Living in light of life limiting illness
Aspects of Living are present before and after the illness. This demonstrates that the participants had “a life” prior to the inception of their illness and/or debilitating symptoms. Aspects of Illness become salient with the onset of significant symptoms. The illness acts as a lens that filters and impacts on daily living. For example, some participants in the present study described sibling relationships prior to the onset of illness, characterized by caring as well as typical arguments and shared activities. They also described activities they enjoyed such as playing sports, drawing, or driving. These factors did not simply disappear when the child/youth became ill, rather they may have become transformed in some way. Brody is a good example of this in that he described his sisters as intrusive prior to the onset of his symptoms and he perceived them as such after his illness; however, their relationship also changed as they became involved in providing care for him, when his parents were unavailable. Other participants who described enjoying sports such as basketball or football prior to illness, continued to enjoy these activities after their illness; however, they may not have been as able to engage in them because of increasing physical impairment. The relationship between Aspects of Living and Aspects of Illness demonstrates that although illness has a profound impact on the lives of these persons, it does not alter every aspect of their lives. Rather, their daily lives are filtered through their illness, necessitating accommodation and coping, which is part of the Anticipatory Mourning process.

Conclusion

Chapter IV presents an examination of the data in several ways. Individual interviews were considered to see how the participants addressed the central research
questions and brief synopses were developed for each participant to provide an introduction to their perspective and their contribution to the study. The interviews were then considered as a whole data set and thematic elements pertaining to the research questions were abstracted to provide a more global view of how the study data addressed the primary research questions. Finally, the results of the grounded theory analysis and the emerging conceptual framework were presented. Chapter V will continue the discussion of the conceptual framework and its relationship to Anticipatory Mourning as described by Rando (2000).
The conceptual framework derived from the grounded theory analyses in the present study includes the core category of Living in Light of Life Limiting Illness. The two major categories that elucidate the core category are Aspects of Illness and Aspects of Living. Subcategories of Aspects of Illness are: determining the diagnosis and course of illness, symptoms, side-effects, treatments, and complications. Subcategories of Aspects of Living are: activities, relationships, emotions, and plans and hopes for the future. The relationship between the conceptual framework derived from the present study and Anticipatory Mourning is described below. The results of the study, including information from the responses to the research questions and the grounded theory analyses, are then discussed within the context of the larger end-of-life literature. Finally, limitations of the present study, areas for further research, and implications for Counseling Psychologists, other professionals, and parents are described.

Relationship to Anticipatory Mourning

Anticipatory Mourning, as described by Rando (2000), was used as a theoretical guide for this study and the emergent theoretical structure reflects many aspects of Anticipatory Mourning. Figure 5 provides a representation of Anticipatory Mourning factors as they relate to the theoretical structure emerging from this study. Rando
Figure 5: Relationship between anticipatory mourning factors and the conceptual framework from the present study
explained that Anticipatory Mourning is comprised of three theoretical constants including Perspective, Influencing Factors, and Time Focus; and three theoretically fluid factors including Major Sources of Adaptational Demands, Contextual Levels, and Generic Operations (See Figure 1). Perspective, as described by Rando, includes the Patient, Caregiver, Intimate, and Concerned Other. The present study focused exclusively on the perspective of the patient and certainly all of the data obtained reflected this point of view.

The present study also provided information about how the participants came to identify with the patient perspective as their illness became more salient to them. Additionally, the results of the present study suggested a subtle difference in how children and youth with a life-long diagnosis discussed their illnesses versus those who were diagnosed during their childhood. Specifically, the participants with a life-long diagnosis initially provided little information about their illness and required additional, specific questioning in order to provide a detailed response. This was in contrast to children and youth who were more recently diagnosed with their illness. The initial response of the individuals with the life-ling diagnosis was likely reflective of the long-term assimilation of their diagnosis into their identity. They were less primed to be aware of the risks and challenges associated with their illness because essentially, they have never known differently.

Additionally, each of the participants also discussed the importance of individuals who comprise the other significant perspectives discussed in Anticipatory Mourning and highlighted the importance of these people in their lives. For example, all of the
participants talked about the importance of intimates such as their parents, other family members, and friends. They also described the significant roles of caregivers including their parents, siblings, nurses, and physicians.

Additionally, many participants discussed interactions with concerned others such as teachers, classmates, others with similar illnesses, and general community members. The results of the study demonstrate the impact that others have on the Anticipatory Mourning process of these children and youth. This impact was seen in the importance and appreciation given to significant caregivers, as well as to influence of community members on the participants’ hopes and dreams for the future.

Participants in the present study also emphasized the care and support received from extended family members and pets, which was somewhat unexpected because this is not a focus of the existing literature. Grandparents, aunts, and cousins were noted to provide support that was different from parents, especially in regard to providing comfort from fear and anxiety.

Rando (2000) described Time Focus as the focus on losses that occurred in the past, are happening in the present, and those that will occur in the future. Participants in the current study described losses that they have experienced across all these time dimensions. For example, many of them discussed how their illness interfered with specific activities (e.g., a music recital or school attendance), ongoing loss of function, as well as their fears about future losses (e.g., loss of future with their families).

Influencing Factors include psychological, social, and physiological variables pertinent to the individual going through the mourning process. In regard to
psychological variables, data obtained from the interviews reflected the personal characteristics of the participants, co-occurring stressors, and the participants’ socio-cultural backgrounds. Psychological variables were further considered when recruiting participants. For example, efforts were made to ensure a basic level of maturity and cognitive level among all participants. This increased the consistency across the interviews and ensured that all participants were physically, cognitively, and emotionally able to discuss their end-of-life experiences. In regard to social variables, the participants discussed many characteristics of their social interactions, ranging from interactions with their families and their families’ attitudes toward them and their illness, interactions with significant others, and contact with members from the community-at-large. They also described socio-economic factors that impacted them. In terms of physiological factors, all participants described how negative symptoms and side effects dramatically interfered with their sense of well-being and ability to function normally. Conversely, participants also described how alleviation of these symptoms and side effects restored their sense of well-being and functioning.

The overall conceptual framework that emerged from the present study provides illustrative examples of how the three theoretical constants (i.e., perspective, influencing factors, time focus) associated with Anticipatory Mourning are manifested in children and youth from the patient perspective. For example, Aspects of Illness and the associated sub-categories describe the physiological component of Rando’s Influencing Factors. They also illustrate losses that the patients are enduring related to their illness in
the past (e.g., loss of ability to walk), present (e.g., ongoing difficulty breathing), and potentially in the future (e.g., loss of life).

In regard to Aspects of Living and the associated sub-categories, these describe the psychological and social components of Rando’s Influencing Factors. Specifically, the sub-category of Emotions describes psychological reactions to circumstances arising from life-limiting illness in the patients as well as significant others. The sub-category of Relationships describes the impact of life-limiting illness on social relationships. Additionally, each of the sub-categories associated with Aspects of Living describes losses that occurred in the past, present, as well as expected future losses; as is predicted by Rando’s Time Focus factor.

Although Rando’s theoretical constants did not directly emerge as major categories in the conceptual framework derived from the current grounded theory analyses, they are reflected in the data. Similarly, the conceptual framework derived from the present study does not reflect every aspect of Rando’s theoretical constants; rather it offers an articulation of how the constants are manifested in children and youth in the patient perspective.

In addition to the three theoretical constants, Rando (2000) also articulated three experiential factors, considered to be theoretically fluid and amenable to intervention. The first of these factors is Major Sources of Adaptational Demands. This factor is described as the major stressors associated with trauma and loss that occur during the course of terminal illness. The conceptual framework emerging from the present study reflects this factor in a number of ways. For example, losses and traumatic experiences
are associated with a number of sub-categories falling under Aspects of Illness such as, Treatments, Complications, and Side-effects. Furthermore, secondary losses associated with these illness effects are reflected in the Activities sub-category of Aspects of Living. Certainly, all of the participants discussed the negative physical effects of the illness and the associated losses in terms of their roles and functions. However, the participants’ discussion of ways in which they regained function and/or resumed roles over time, as well as their hopes to continue acquiring developmentally appropriate functions (e.g., driver’s license) is notable. This may reflect the unique situation of life-limiting illness in this population. Indeed, although their lives are likely to be shortened, they continue to progressively develop as is typical for children and youth. This pattern of loss and regaining of function/gaining new functions may also be reflective of the course of illness in this population, which is frequently uncertain and difficult to predict.

The second and third fluid dimensions described by Rando (2000) are Contextual Levels and Generic Operations. These dimensions are closely intertwined, with Generic Operations representing much of the work and activity associated with Anticipatory Mourning. This work and activity occurs along three contextual levels: the intrapsychic, interpersonal, and systemic levels. The theoretical structure emerging from the present study reflects these two dimensions because they are inter-woven through many of the sub-categories. For example, the Relationships sub-category reflects the patient’s interactions with individuals representing the interpersonal as well as the systemic levels. The Activities sub-category represents things that the patient does in day-to-day living along all three contextual levels. The intrapsychic level is perhaps best reflected in the
Plans and Hopes for the Future sub-category. This sub-category reflects the participants’ own understanding and hopes regarding the course of their illness and its impact on their future. Within this category are the participants’ discussions of how their identity and assumptive worlds have changed in light of their illness. Additionally, the results of the study also highlight the paradox confronting the participants in the present study in their desire to maintain connection to loved ones, while recognizing that the ultimate severing occurs with death. One way in which the participants coped with this paradox is to explore ways that they could transform connections, such as in explanations about the afterlife.

The conceptual framework that emerged from the present study appears to encompass the six factors associated with Anticipatory Mourning. However, it seems to offer greater specificity as to the things that are most important and salient to children and youth from the patient perspective. It also appears to go beyond Rando’s (2000) definition of Anticipatory Mourning:

the phenomenon encompassing seven generic operations that within a context of adaptational demands caused by experiences of loss and trauma, is stimulated in response to the awareness of life-threatening or terminal illness in oneself or a significant other and the recognition of associated losses in the past, present and future (p. 51).

Specifically, I struggled with Rando’s definition of Anticipatory Mourning, which clearly focuses on the responses to loss and trauma associated with life-limiting illness, because the information shared by the participants in the present study seems to encompass a broader perspective. In particular, I was struck by the understanding that these children and youth had lives prior to their illness and that these did not simply disappear when the
illness struck. For example, a child may have enjoyed playing soccer or fought constantly with a sibling prior to the onset of symptoms. These aspects were not simply erased with the onset of the illness. Instead, the illness impacted on them in some minor or major ways, yet the basic characteristics endured.

This observation alludes to a limitation of Anticipatory Mourning as a theory, in that it is so broad, with its factors describing and being relevant to much more than Anticipatory Mourning. For example, Rando’s factors such as time focus, influencing factors, and contextual levels are important to consider when describing living and interactions in general, rather than being specific to Anticipatory Mourning. This feature made it both useful as a theoretical foundation when approaching this study, as well as limited in its practical utility in application with this population. In particular, it was useful in allowing me to consider a variety of factors that are important to understanding the lived experiences, in general, of children and youth diagnosed with life-limiting/life-threatening illnesses. However, the inclusiveness of Rando’s theory also makes it difficult to predict how it may apply to specific individuals or groups of individuals, which limits its practical utility.

Relationship to the End-of-Life Literature

The present study examined end-of-life experiences from the perspective of children and youth with life-limiting illness. In this way, it added to the limited research directly considering the perspectives of children and youth, rather than relying on record review or observer reports (e.g., Hinds et al., 2007). The present study fits within the broader end-of-life literature because it provides a rich description of the ongoing
challenges facing children and youth with life-limiting illness, particularly as they approach the end-of-life. For example, the current research described difficulties that participants encountered in terms of their own medical care including coping with needles and shots, multiple surgeries, and generally feeling ill. These are somewhat different than the foci of the pediatric palliative care research reviewed in Chapter II, which primarily emphasized location of death, communication with parents regarding the illness, and facilitating difficult decisions, as contributing to perceptions of positive outcomes of end-of-life care (e.g., Aoun & Phillips, 2007; Dussel, et al., 2009; Hinds, 2007; Papadatou, Yfantopolous, & Kosmidis, 1996; Vickers & Carlisle, 2000). However, the existing literature in this area relied on reports from parents and caregivers rather than the ill children and youth, which may explain the different areas of emphasis.

The participants in the present study also described difficulties in meeting their educational needs, adjusting to physical limitations and adjusting to changes in physical appearance resulting from their illness. These represent additional areas of importance to children and youth and therefore constitute potential opportunities for intervention by pediatric palliative care teams. For example, palliative care teams could provide cognitive-behavioral interventions geared toward helping children cope with difficult medical procedures. Further, they could provide direct information about medical procedures and options that may be available, as appropriate (e.g. discussing how much hair to shave/cut in preparation for surgery). Palliative care teams could also increase their role in acting as liaisons between children and families and various systems with
which they interact (e.g., treatment specialists, school systems), to facilitate greater understanding and appropriate accommodation of the ill children and youth’s needs.

Some focus in the pediatric palliative care research has been given to providing information and facilitating decision-making (e.g., Bluebond-Langner, DeCicco, & Belasco, 2004; Forbes, et al., 2008; Hinds, 2007; Monterosso & Kristjanson, 2008). Again, much of this research is focused on the perspectives of significant others. For example, the existing research has examined challenges of discussing difficult decisions from the perspective of professional care providers (e.g., Forbes, et al.) and how information increases parental satisfaction with their child’s care (e.g. Hinds, 2007; Monterosso & Kristjanson). Some of the existing literature also focused on the interaction between parents and their terminally ill children in regard to end-of-life decision making (e.g. Bluebond-Langner, DeCicco, & Belasco; Monterosso & Kristjanson; Weir & Peters, 1997).

Participants in the present study described deriving comfort from receiving information and being involved in decision-making. For example, many of the participants noted that individuals who provided the most comfort when they were scared were those individuals who were open to hearing about their fears and were able to provide information about upcoming interventions (e.g., surgeries) in a truthful, informative, and sensitive manner. However, one participant did note that too much information communicated insensitively increased anxiety. The results from the present study further emphasize the importance of information and decision-making at the end-
of-life and the contribution of sensitivity in these situations to the feeling of comfort and well-being in terminally ill children and youth.

Another broad area of end-of-life literature discussed in Chapter II described the physical and psychological symptoms in children and youth at the end-of-life (e.g., Hendricks-Ferguson, 2008, Pritchard et al., 2008; Wolfe et al., 2000). Most of the research in this area also relied on parental report and reviews of records rather than information provided by the ill children and youth. In the current study, the participants gave considerable attention to their symptoms and side effects. The differences in symptoms cited by parents in the existing literature and those reported by participants in this study are notable. In the existing literature, the most frequently mentioned symptoms experienced by children at the end-of-life (again, as reported by parents), included pain, shortness of breath, fatigue, poor appetite, constipation, and diarrhea (Hendricks-Ferguson; Pritchard et al.; Theunissen et al., 2007; Wolfe et al.). In contrast, the most common troubling symptoms described by the participants in the present study included headaches, nausea, pain, fatigue, weakness, and difficulty sleeping. Certainly there is some overlap in symptoms reported by the two groups (e.g., pain, fatigue); however, there were some variations as well. Some of the differences may be attributed to the time frame in question, because in most of the existing literature parents were questioned after the death of their child; whereas the participants in this study were reflecting on their overall experience of illness. Other differences may be the result of the participants’ insight into their own symptoms rather than their parents’ interpretations of the most troubling symptoms.
In terms of psychological symptoms, hope emerged as an important component to coping in the present study. This is consistent with a study performed by Hinds and colleagues (1999), which focused on adolescents newly diagnosed with cancer. Hopes expressed by participants in the present study included improved health, improved physical functioning, resumption of activities, living into adulthood, adult romantic relationships, and career achievements. The similarity between the hopes expressed by adolescents newly diagnosed with cancer and the hopes described by participants in the current study is notable, especially because the participants in the current study were more seriously ill and had been struggling with their respective illnesses for a prolonged period of time. This similarity suggests that maintaining hope is important regardless of the stage of illness and that the specific things hoped for may be similar throughout the course of an illness. One difference observed in this study is that the participants also expressed apprehension and fear that their treatment interventions would not be effective and they would die “too soon.” This anxiety probably resulted from the previous experiences of the participants, in terms of relapses, unexpected serious complications, and with treatments that were wholly or partially ineffective. In this way, the current study expands the understanding of the importance of maintaining hope with children and adolescents diagnosed with a life-limiting illness.

The present study also expanded on the limited existing literature studying children and youth’s experiences with their terminal illness. Studies performed by Bluebond-Langner (1978) and Hedström, Skolin, and von Essen (2004) specifically focused on children and adolescents diagnosed with cancer and their experiences in
medical settings. These authors provided descriptive accounts of children and adolescents’ understanding of their illness, ways they coped with the medical management of their illness, and the losses encountered in this population. The present study expanded on these accounts by focusing on children and youth who were generally more ill than those interviewed in the previous studies. Additionally, although a significant portion of the interview responses focused on the illnesses and their medical management, the present research explicitly investigated aspects of living beyond illness including interpersonal interactions and functioning in systems other than the medical setting (e.g., church, school, neighborhood).

One previous study that yielded results similar to those found in the present research was performed by Hinds and colleagues (2004). These researchers carried out a qualitative study with pediatric cancer patients to determine how this group defines quality of life. Six domains emerged from their data to describe quality of life in this population including: (1) experiencing uncomfortable physical and mental symptoms of illness, (2) being able to participate in usual activities, (3) being able to interact with others and feel cared about, (4) receiving positive treatment related news, (5) experiencing negative emotions or witnessing negative emotions in others, and (6) finding meaning in their illness experience (Hinds et al.). These domains are closely related to the subcategories that emerged in the present research including diagnosis and course of illness, symptoms, side effects, emotions, activities, and relationships. The similarities may have resulted from the fact that Hinds and colleagues used broad questions asking about “good” days and “bad” days in general and not questions that
were specifically tied to the illness. This allowed participants to respond more generally about how their illness impacts their daily living. Similarly, the participants in the present study described their experiences of living in light of their life-limiting illness, including positive and negative changes that have occurred resulting directly or indirectly from their illness.

Limitations and Areas for Further Research

There is a clear need for continued research on the experiences of children and youth with life-limiting illness from their own perspective. The present study contributed to the limited research considering the point of view of the ill child or youth; however, greater understanding of their experiences at various phases of their illness from diagnosis to the end-of-life is necessary. For example, additional research about the meaning of medical interventions to these patients, particularly those with obvious, outwardly signs, is necessary. Relatedly, a limitation of the present study is that the participants were interviewed at only one time point during their illness and their perspectives may be different at various times over the course of their illness. Specifically, it would be useful to explore how children and youth’s awareness and understanding of their terminal illness develops over time, how these factors impact on their identity and assumptive worlds, as well as their ideas for the future. These aspects were not fully explored in the present study and would be more amenable to a longitudinal design.

The potential benefits of a longitudinal study can be seen in a description of anticipatory grief reactions experienced by children and youth diagnosed with life-
threatening illness written by Sourkes (1995). The account presented by Sourkes, based on her work providing therapy to this population, described the dynamics of the manifestations of various losses, changes in identity, and children and youth’s attempts to manage and cope with losses over the course of their life-threatening illness. Longitudinal research would enable a greater understanding of how cognitive appraisals of illness and living change over time and over the course of the illness. For example, several participants in the current study acknowledged that the possibility of death was much more salient when they felt ill or were hospitalized and became less so when they felt well. However, it is difficult to believe that the shadow of their illness ever truly disappears. Longitudinal research would enable us to increase awareness of the needs of children and youth at various points over the course of their life-limiting illness. This increased understanding could translate into improved appropriate interventions along all points of their illness. Indeed, I suspect that ongoing intervention is warranted, given the accounts of participants who had a near-death experience and its lasting effects on their outlooks for the future, which varied from increased anxiety to increased comfort, regardless of their prognosis.

Another limitation of the present study is that the individuals interviewed in the present study were all Caucasian, generally came from middle class backgrounds, and were recruited from a respected pediatric palliative care program. Therefore, the extent to which these results may be similar to what would be found with individuals who have less access to medical care, those from other racial/ethnic backgrounds, and those from other socio-economic statuses, is unclear. Additional research is necessary to understand
needs of children and youth living with life-limiting illness from diverse backgrounds. It is likely that diversity factors such as racial/ethnic background and socio-economic status significantly impact the experiences and needs of these children and youth as well as those of their families. This is especially important for Counseling Psychologists as we strive to provide culturally competent care and scholarship. Recruiting from sources other than a palliative care program may facilitate obtaining greater diversity in terms of perspective as well as phase of illness. For example, potential participants could be recruited from illness-specific treatment clinics or community-based medical clinics. In these ways, future research could continue to develop a theoretical framework of the lived experiences of these individuals that would serve to convey greater understanding of their needs and the roles Counseling Psychologists and other professionals can play in providing intervention with this population.

Additionally, greater understanding of the impact of the illness on family dynamics is necessary. The participants in the present study described their perspective of the impact of their illness on their parents, siblings, and other family members; however, the present study is limited in that I did not interview any significant others to get their points of view and experiences. Furthermore, aside from the perspectives of parents, and specifically mothers, little information about the perspectives of these significant others can be found in the existing literature. Specifically, healthy siblings are especially underrepresented in the existing literature. The participants in the present study briefly mentioned that their illness impacted their siblings by disrupting the availability of one or both parents and in several cases; their siblings took on care-giving roles. Thus, it seems
that healthy siblings face unique challenges in their adjustments to their sibling’s illness. Therefore, it also seems reasonable to assume that siblings and families generally, represent another group in need of appropriate psychological intervention.

Interactions with pets, particularly dogs, emerged as important in the present study. Additional research exploring the benefits and potential drawbacks of interactions between pediatric end-of-life patients and their pets and/or other animals appears to be an important area for further investigation.

Consistent with existing literature (e.g., Hedström et al. 2004; Hinds et al., 1999; Stevens et al., 2009), hope emerged as an important concept in the results from the present study. Additional research is necessary to better understand the adaptive function of hopefulness, as well as to elucidate possible maladaptive effects of hope over the course of a life-limiting illness. For example, hope may play a protective role against depressive symptoms; however, it may also delay end-of-life planning, leaving important “business” unfinished. This increased understanding could lead to a more skillful utilization of hope in interventions with the ill children and youth, as well as with their families.

Implications for Psychological Practice

The results of this study may be particularly useful to Counseling Psychologists and other practitioners who provide therapeutic intervention to children and youth with life-threatening illnesses. Specifically, practitioners could benefit from recognizing the importance of maintaining hope throughout the course of the illness, while also being sensitive to opportunities to facilitate grieving and preparations for challenges faced as
children progress through stages of their illness. In addition to maintaining hope, the results of this study suggest that it is also important to be sensitive to the anxieties about the future that are experienced by this population. Assisting the individuals to manage these anxieties is important in facilitating taking risks toward achieving goals and continuing living life to the fullest in light of their life-threatening illness.

Additionally, the results of the study also challenge practitioners to be aware of their assumptions regarding what types of interventions are perceived as most burdensome by these children and youth. Specifically, the results suggest that these individuals may have more difficulty adjusting to the routine interventions that occur on a more regular basis rather than those that could be considered extraordinary measures (e.g., surgery).

Implications for Other Professionals

Terminally ill children and youth come into contact with a variety of professionals and individuals who are active in the community including educators, clergy, scout leaders, coaches, and so forth. The participants in the present study highlighted the significant roles that these individuals may play in facilitating their Anticipatory Mourning process through allowing for accommodations that enabled them to continue participation in activities that are important to them, as well as introducing them to new activities that keep them connected to other people. Maintaining these interpersonal connections and to participate in activities led to a sense of satisfaction and fulfillment for the participants.
The educational system is one specific system with which most of these children interact. The results of the study suggest that educators need to be aware of and sensitive to the particular needs of these children. For example, coordination between families and teachers to maximize a child’s ability to complete academic work is a practical intervention. Additionally, a flexible attitude and a deliberate consideration of how (rather than if) these children and youth can continue to be a part of their school and maintain peer relationships is important in facilitating the optimal functioning of this population. Maintaining flexibility and an open mind as to how to include these ill children and youth in various activities is also important for many other professionals (e.g., clergy, coaches) in order to facilitate maintenance of interpersonal connections.

Implications for Parents

The importance of the role of parents, particularly in terms of caregiving cannot be overstated. The participants in the present study were generally aware of and appreciative of the care and sacrifices provided by their parents. However, the results of the present study suggested that parents could care “too much.” This seemed to occur when parents were preoccupied with their own feelings about dealing with their child’s illness and because these emotions may then interfere with their ability to be open and sensitive to their child’s needs. Jerry’s story provides an example of this as I suspect his father likely felt helpless to “do” anything about Jerry’s cancer. He may have been trying to cope with this helpless feeling by “doing” the only thing he knew to promote health, which was to push Jerry to exercise and to monitor Jerry’s diet. In such cases, it may be helpful for parents to seek assistance from a helping professional to work out their own
feelings so that they may be more able to present for their ill child as well as for other family members.

Finally, some of the older children struggled with ongoing dependence on family members and trying to establish developmentally appropriate independence. Parents could also facilitate accommodations that enable their children to develop independence as appropriate, within the support of family. For example, Brody expressed frustration with his sisters’ entering his bedroom while he was hospitalized. Parents could reinforce appropriate boundaries that would give their child a sense of privacy that is necessary and appropriate given their ages.

Conclusion

In conclusion, the present study contributed to the limited pediatric end-of-life literature through providing an examination of children and youth’s perspectives on their own life-limiting/terminal illness using a qualitative methodology (i.e., Grounded Theory) and theoretical grounding in Anticipatory Mourning. The study contributed to developing an understanding of children and youth’s perspectives regarding their illnesses including the symptoms and treatments endured, their perceptions of interpersonal interactions, and their hopes and fears for their future. The results highlighted the perspectives of pediatric patients and illustrated important differences between their own perspectives versus the viewpoints of others (e.g., parents, physicians, nurses) most often considered in the existing literature. The results also suggested the need for much more research in this area, especially from the perspective of pediatric patients themselves, to better understand their perceptions over time, to gain knowledge
of the views of individuals from diverse backgrounds, as well as to develop understanding of the perspectives of significant others (e.g., siblings) who are also affected by the life-limiting illness of these children and youth.
REFERENCES


Horwitz, C. A., Duncan, J., & Wolfe, J. (2004). Caring for the child with cancer at the close of life: There are people who make it and I’m hoping I’m one of them. *JAMA, 292*, 2141-2149.


Appendix A

Anticipatory Mourning Study Questionnaire

A. Child Information

1. Child’s Name: ________________________________________________________

2. Age: _____

3. Sex (please check one)  (1) Male _____

          (2) Female _____

4. Race (please check one or more)

         (1) White _____

         (2) Black/African American _____

         (3) Spanish/Hispanic/Latino _____

         (4) Asian or Pacific Islander _____

         (5) American Indian _____

         (6) Other: ______________________

5. Grade in School: ________

B. Family Information

1. Parents/Caregivers are (please check one)

        (1) Married _____

        (2) Separated _____
(3) Divorced ____

If divorced, child lives mainly with:

Mother ____
Father ____
Grandparents ____
Other ____

(4) Re-married ____

(5) One parent deceased ____

(6) Other ________________________________

2. Relationship of child to parents/caregivers (please check one)

(1) Biological child ____
(2) Adopted ____
(3) Foster ____
(4) Other ________________________________

3. Approximate family income (please check one)

$0 - $15,000 ____
$15,001 - $35,000 ____
$35,001 - $55,000 ____
$55,001 - $75,000 ____
$75,001 - $125,000 ____
$125,001 and higher ____

4. Does your family have a particular religious affiliation? (1)Yes ____ (2) No ___
If so, what is your family’s affiliation? _______________________________

How often does your family attend religious services?

Never____ Daily ____ Weekly ____ Monthly ____ Holidays ____

5. Do you consider your family to be spiritual? (1) Yes ____ (2) No ____

C. Stressful Events

Children often have experiences that can be stressful for them. Please check any of the following that your child has experienced in the past year.

___ Death of a family member ___ Health problems in family
___ Parent’s separation or divorce ___ Removal from home
___ Remarriage of parent ___ Physical abuse
___ Sexual abuse ___ Neglect
___ Constant fighting with siblings ___ Birth of a sibling
___ Death or loss of a friend ___ School problems
___ Family money problems ___ Poor housing
___ Homelessness ___ Poor health care
___ Arrest ___ Incarceration/detention
___ Unsafe neighborhood ___ Victim of a crime

Other stressful events?

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

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Appendix B

Anticipatory Mourning Semi-Structured Interview

This questionnaire was meant as a guide for the interviewer. The exact format and ordering of the questions depended on the age of the child and the information that the child shared during the interview. For example, questions regarding enjoyed activities or school may have been asked first to help the child become comfortable with the interview. Also, the wording of the questions may have been altered so that they were understandable and age-appropriate for the individual participant. Possible areas for further follow-up are listed as examples of topics that may have been queried further if the child provided an overly brief response.

1. Tell me about your illness.

   Possible areas for further follow-up:
   - Time since diagnosis
   - Course of illness
   - Reactions to diagnosis, illness, and treatments
   - Treatments received
   - Physical symptoms related to illness and/or treatment

   The goal of this first question is to provide the background of the participants’ illness and their understanding of it from a medical perspective. According to Rando
(2000), anticipatory mourning occurs in response to an encounter with a life-threatening illness, thus this question establishes the circumstances that lead to the experience. The question also begins to address psychological and physiological characteristics related to the illness that are a part of the influencing factors impacting on the anticipatory mourning experience.

2. What has it been like for you since you were diagnosed?

Possible areas for further follow-up:
- Emotional responses to illness
- Behavioral changes and accommodations
- Cognitive responses
- Emotional, behavioral, cognitive responses over the course of the illness

The second question reflects the main research goal which is to describe the lived mourning experience of children and youth who have a life-limiting/terminal illness. This question was meant to be broad to allow the participants to respond freely. It also aimed to examine mourning occurring on the intrapsychic contextual level. The remaining questions assessed more specific aspects of their experience.

3. What kinds of things have you missed out on because you’ve been sick?

Possible areas for further follow-up:
- Coping with losses
- Past, present, and future losses

This third question aimed to identify losses in the past, present, and future that are salient to the participants and that they are mourning. It assesses for some generic
operations such as grief and mourning, coping, and psychosocial reorganization. This question also elicited responses that described major sources of adaptational demands, as well as losses that occurred on multiple contextual levels.

4. Who is important to you?

Possible areas for further follow-up:

- Ways they are important

5. Tell me about your family.

Possible areas for further follow-up:

- Composition of family
- Caregivers within family
- Child’s role within family
- Changes and adjustments in the family since child has been ill

6. Is your family religious? Is your family spiritual? (If no, skip to the next question)

Possible areas for follow-up:

- Involvement of child within church community
- Importance of faith to child

7. Who have you been able to talk to about your feelings since you have been sick (or been diagnosed)?

Possible areas for follow-up:

- Thoughts/events that prompted feelings
- Effectiveness of coping
Questions four, five, six, and seven aimed to assess interpersonal relationships that are important to the participants. These relationships contribute to the participants’ psychological and social influencing factors. The questions elicited descriptions of the participants’ functioning along interpersonal and systemic contextual levels. They also elicited information about generic operations such as coping, interactions, and psychosocial reorganization.

8. What kinds of activities do you enjoy (e.g., sports, reading, school clubs, etc.)

   Possible areas for additional follow-up:
   - Interference of illness with participation in activities
   - Changes in which activities are chosen and enjoyed since diagnosis

9. Have you been attending school, regularly?

   If yes: How has that been going?

   Possible areas for additional follow-up:
   - Changes in school
   - Goals related to school

   If no: How long have you been out of school?

   Possible areas for additional follow-up:
   - Things missed related to school
   - Hopes related to school/education

10. Are you involved in any other groups in the community (besides family and religion)? (e.g., boy scouts/girl scouts, sports teams, clubs)

    Possible areas for additional follow-up:
- Any groups that child was previously involved in but is no longer involved with.
- Any organizations (e.g., Livestrong, Make a Wish) providing services to child

Questions eight, nine, and ten address additional areas of losses related to children’s involvement in school and the community that participants may be mourning. These questions elicited responses regarding participants’ functioning on the interpersonal and systemic contextual levels and they elicited information regarding sources of adaptational demands.

11. What is most frustrating to you (or makes you sad) about having your illness? Or what bothers you the most?

12. What has been good about having your illness? (e.g., I know that it may be kind of weird to think about, but some kids think that they get to have some good things/experiences that they wouldn’t have had if they didn’t have their illness.)

13. What are you hoping for in your future?

Possible areas for additional follow-up:

- Accomplishments
- Events

14. Is there anything that you think you might miss out on (if you’re not around)?

15. If the time comes and you have to say good-bye, have you thought about what you want that to be like?

Possible areas for additional follow-up:

- Location
- Individuals present
- Physical condition

- Emotional condition

- Unfinished business

Questions 11, 12, 13, and 14 specifically focused on generic operations including grief and mourning, coping, planning, and facilitating an appropriate death. Additionally, they assessed mourning that is occurring on the various contextual levels and losses that are occurring in the past, present, and future.

16. What else do you think I should know/any questions that I didn’t ask about what it’s been like for you since you’ve been sick?
Table 4.
Summary of Research Related to Anticipatory Mourning (AM) Reviewed in Chapter II

<table>
<thead>
<tr>
<th>Study</th>
<th>Sample</th>
<th>Method</th>
<th>Variables</th>
<th>Outcomes</th>
<th>Relation to AM</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Lindemann (1944)</strong></td>
<td>101 psychiatric outpatient females who recently experienced the death of a loved one.</td>
<td>Qualitative analysis</td>
<td>Symptoms reported and changes in mental status</td>
<td>Description of physical and psychological symptoms of grief</td>
<td>First person to define and coin phrase “Anticipatory Grief” in describing grief responses occurring prior to the death of a loved one.</td>
</tr>
<tr>
<td><strong>Strang and Koop (2003)</strong></td>
<td>15 caregivers provided home-based care to family members dying from cancer.</td>
<td>Interview and analysis for themes</td>
<td>How did you manage to cope with care-giving? How did you find helpful in care-giving? What did you find unhelpful in this experience?</td>
<td>Described simultaneous process of drawing closer and letting go of relationships with dying person. Described changing daily living roles for the care-giver and patient.</td>
<td>Did not label observations as AM, but did describe perspective of care-givers and patients (secondarily). Described Generic Operations including processes of grief and mourning occurring within the relationship, interactions with the patient, and balancing conflicting demands.</td>
</tr>
<tr>
<td><strong>Valdimarsdóttir, Helgason, Fürst, Adolfsson, and Steineck (2004)</strong></td>
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<tr>
<td><strong>Sample:</strong></td>
<td>379 widows of men who had died of prostate or urinary cancers in Sweden between 1995 and 1996.</td>
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<tr>
<td><strong>Method:</strong></td>
<td>Self-report questionnaires and statistical analysis.</td>
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<tr>
<td><strong>Variables:</strong></td>
<td>Awareness time of husband’s impending death, anxiety, depression, well-being, physical health, quality of life, and sleep disturbance.</td>
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<tr>
<td><strong>Outcomes:</strong></td>
<td>Widows reporting awareness times of 3-6 months prior to the death of their husbands had the lowest level of anxiety. Widows reporting awareness times of 24 hours or less had the highest levels of anxiety, followed by those reporting awareness times of 12 months or longer.</td>
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<tr>
<td><strong>Relation to AM:</strong></td>
<td>There was no direct measure of AM, but was assumed to have occurred after onset of awareness of impending death. Suggests potential benefits and drawbacks to AM process on long-term post-death functioning.</td>
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<tr>
<th><strong>Mystakidou, et al. (2006)</strong></th>
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</thead>
<tbody>
<tr>
<td><strong>Sample:</strong></td>
<td>200 advanced cancer patients ages 31-87 years</td>
</tr>
<tr>
<td><strong>Method:</strong></td>
<td>Used scale developed for earlier study, with unclear reliability and validity, to measure levels of anticipatory grief.</td>
</tr>
<tr>
<td><strong>Variables:</strong></td>
<td>Negative emotions in responses to losses experienced, defined as anticipatory grief.</td>
</tr>
<tr>
<td><strong>Outcomes:</strong></td>
<td>Younger patients, women, and patients with poorer treatment responses reported higher levels of anticipatory grief.</td>
</tr>
<tr>
<td><strong>Relation to AM:</strong></td>
<td>Attempt to measure and quantify anticipatory grief in a sample; however focused on only negative emotional responses which limited exploration of broader grief and mourning process.</td>
</tr>
</tbody>
</table>

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<tr>
<th><strong>Horowitz, Duncan, and Wolfe (2004)</strong></th>
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<tbody>
<tr>
<td><strong>Sample:</strong></td>
<td>13 year old youth diagnosed with terminal cancer, his mother, and his physician.</td>
</tr>
<tr>
<td><strong>Method:</strong></td>
<td>Case study.</td>
</tr>
<tr>
<td><strong>Variables:</strong></td>
<td>Perspectives of medical management of illness.</td>
</tr>
<tr>
<td><strong>Outcomes:</strong></td>
<td>Youth was described as being “afraid of dying,” worried about changes in roles in family, about his treatment, and about his family’s coping after his death. Perspective of his mother and his physician focused on medical management and medical decision-making.</td>
</tr>
<tr>
<td><strong>Relation to AM:</strong></td>
<td>Described aspects of AM from a child-patient perspective, especially in regards to his focus on future losses.</td>
</tr>
</tbody>
</table>
APPENDIX D

IRB APPROVAL LETTER AND INFORMED CONSENT

This appendix includes the IRB approval letter from Children’s Hospital Medical Center of Akron (CHMCA). IRB approval was sought from this institution because participants for the study were recruited through the hospital. Additionally, CHMCA and The University of Akron have an authorization agreement and thus separate approval from The University of Akron IRB was not necessary. The Informed Consent form, bearing the stamp of approval from the CHMCA IRB, is also included.
May 26, 2009

Sarah Friebert, M.D.
Palliative Care
Akron Children’s Hospital
One Perkins Square
Akron, Oh. 44308

Re: Children’s Experiences with Life-Limited Illness: Anticipatory Mourning and End of Life Therapeutic Videography
IRB No: 060807

Dear Dr. Friebert:

The IRB received the following materials in support of renewal of the above-named studies due for review on June 23, 2009:
- A report indicating current status and activity, adverse reactions or unexpected events and approved change to protocol or risks since the last review.
- A current copy of the informed consent and assent.
- An interim report of the study including any findings or any new literature which has relevance for the study.

Upon review of these materials:

Expedited review was deemed appropriate because:
- The study is minimal risk and no new risks have been identified.

Approval was granted as of May 26, 2009.

The original stipulations remain in full effect as if restated here. This renewal is time-limited and extends from May 26, 2009 to May 25, 2010 at which time it expires if not submitted for review and renewal.

Sincerely,

Robert Navarino, M.D.
Chairman, Institutional Review Board

RWN/hs
Consent Form

If you are a parent, as you read the information in this Consent Form, you should put yourself in your child’s place to decide whether or not to allow your child to take part. Therefore, for the rest of the form, the word “you” refers to your child. If you are a child, adolescent, or adult who is reading the form, the word “you” refers to you.

Title of Protocol:
Children’s Experiences with Life-Limiting Illness:
Anticipatory Mourning and End of Life Therapeutic Videography

Who is conducting this study?
Principal Investigator: Sarah Frieberg, M.D.
Co-Investigators: Cassandra D. Hirs, D.O.
Andrea Loucaides, M.A.
Ryan Seitz, M.S., M.A.

Sponsor: Children’s Hospital Medical Center of Akron
University of Arkansas for Medical Sciences

Why have I been asked to take part in this research study?

You are being asked to participate in a clinical research study at Akron Children’s Hospital. In order to decide whether or not you wish to participate in this research study, it is important to understand its benefits and risks so that you will be able to make an informed decision about participating in the study. The principal investigator or sub-investigator of the study will answer any questions you might have about the form or the study. The nature of this study, the risks, inconveniences, discomforts, and other important information about this study are discussed below. You are urged to discuss any questions you have about this study with the staff member(s) who explain it to you.

Your child has been diagnosed with a life-threatening illness. This has likely impacted you in numerous ways including physically, emotionally, and socially. The purpose of this study is to see what kinds of things about your life have changed since the diagnosis, such as interactions with friends and family and changes in routines. We would like to know the good and bad things you have encountered and you have been dealing with them. We are also interested in finding out what hopes they have for their future.

The purpose of this study is to make the quality of your remaining life better. It involves making a videotape for family to help you create a lasting memorial or prepare to say goodbye.

Participation in this study will not affect your treatment in a negative manner.

CHMCA IRB
MAY 26 2009

CHMCA IRB
JUL 24 2007
IRB stamp
Why is this study being conducted?

Demographic questionnaires and a semi-structured interview will be used to assess which aspects of anticipatory mourning are most relevant to this group of individuals. The intent of this study is to increase our understanding of the complex experience of children over the course of their terminal illness. This understanding could facilitate a more holistic approach to the care of children at the end of life. A secondary goal for this study is to allow for a forum during which children can reflect on their experiences with life-limiting illness.

This study is different from standard care because it allows you to videotape what you may wish to say to family, friends or community, helping you to leave something of yourself behind for them. This study will examine if therapeutic videography can ease the distress of dying. Therapeutic videography is the act of making a tape as mentioned above that may have a therapeutic effect on the patient (i.e. improve the patient’s quality of life). This research is being done because there is evidence that finishing unfinished business in this manner has positive effects on quality of life. Piloted versions of this intervention and the literature associated with it have shown encouraging results.

How many people will participate in this study?

About 35 persons (eight years old and up) will take part in the study. Ten will be from Children’s Hospital Medical Center of Akron.

What is involved in this study?

Participation in this study involves answering a questionnaire regarding some background information on your family as well as your history. You will then be interviewed about your experience since knowing of your diagnosis. The interview will be tape-recorded. It is estimated that the interview will last between one and two hours, but the length will depend on your answers. If you should become fatigued during the interview, we may choose to take a break or to schedule another time to continue, whichever is more convenient.

The investigator or staff will talk with you prior to the video taping session to prepare you for what could be a very emotional event. You will be given a list of possible topics you may want to discuss when making your video. Your video-taping will be done with a common video-camera and copied to a regular videotape that you can either keep or give to anyone you wish. Immediately prior to making the video, both you and your parent will complete a pre-video questionnaire. You will be given instructions on how to make the video. You will be informed that you can say or do anything you wish on the video, and that present during the videography session will only be an investigator who tapes the session. You will be informed that there is no time limit on the video. Approximately two to five days after the video is made, as determined by your and the investigator’s availability, you will complete a post-video questionnaire and you will be debriefed.
through a structured exit interview that will be audiotaped for analysis. You will be given a copy of the video which can be shared with friends/family immediately, or they can choose to have it viewed after death. If you wish, a copy of your tape can be kept in the office in case your copy gets damaged so that another can be requested. If you would like to, you can also sign a line at the bottom of this form to give a copy of your tape to the principal investigator for educational purposes or further study so your tape can help others.

The investigator will keep a copy of the video as well. Approximately three months after death, if it occurs, the parent/guardian will be asked to fill out a post-videoography questionnaire.

If you decide that you want to drop out of the study, or if you have any questions now or at a later date, you can page the principal investigator at (330) 543-3343 at any time. Your participation is voluntary and if you choose not to be in the study you will not lose any of the care you already receive. If at any point during or after the study you desire or need further help or would like to speak to someone about the experience, contact the principal investigator at the number above and arrangements will be made.

How long will I be in the study?

You will be in the study for a brief period of time, long enough to complete the interview and videography. You will be involved in the study for the time it takes to complete the three surveys, less than one hour of audiotaping, one hour of videotaping, and 1 1/4 hour of exit interview. The interview and videography may be performed at Akron Children’s Hospital or another location that is convenient for you (e.g. at your home). This may be completed during up to three or four sessions.

What are the risks involved in this study?

The potential risks and discomforts associated with this project include the possibility of emotional distress for you (the patient doing the taping) and family (upon review of the tape) and potential discovery of intent to harm self, abuse of minors, elders or other vulnerable persons. The researcher and staff are legally and ethically obligated to report all disclosure of abuse or neglect to appropriate authorities.

There are not additional physical or social risks involved. However, there is a small chance that you may become emotionally upset or uncomfortable during the interview. Every effort will be made to minimize any discomfort during the interview, but if you continue to be distressed, you may certainly contact the Palliative Care Team for additional emotional support and intervention. While every effort was made to predict the risks to your participation in this study, it is possible but unlikely that there may be other risks that may arise in the future that we did not foresee.

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What are the benefits to taking part in the study?

The possible benefits of taking part in the study include a possible reduction or relief of spiritual distress and pain and an improvement in your quality of remaining life. You may derive the benefits associated with talking about stressful experiences but will not be receiving psychotherapy. If therapeutic videography is demonstrated as a positive intervention, your participation in the study may also help others benefit from such an intervention in the future. In addition, the information gathered about your experience may be used by your doctors and the Palliative Care Team to improve the way your child's needs are addressed.

What other treatment options are there?

Whether or not you choose to participate, you may access appropriate services through the Palliative Care Team.

Compensation for Injury or Adverse Reactions

The study methods used in this study are not experimental or unsafe. In the event any complication, injury, or illness requiring emergency medical treatment results from your participation in this study, appropriate acute medical care will be provided at no cost to you. However, the principal investigator and these institutions have made no provision to reimburse you for the cost of medical care beyond emergency medical treatment or to pay for any lost wages, pain and suffering, hospitalization, or other expenses you may incur as the result of any such complication, injury, or illness. If you develop medical or psychological problems related to the study or have any questions concerning the study, please contact (330) 543-3343 (the principal investigator).

How will information be kept private?

No identifiers will be used to connect the quantitative measures to the subject who completes the project other than a random numerical identifier that will connect the pre and post questionnaires of each participant and participant's parent/guardian. All recordings and paperwork will be coded with identification numbers in order to minimize access to identifiable information. Audiotapes of the exit interview will have the patient's same and assigned number. Any identifying information that is connected with these assigned numbers will be destroyed following completion of the study. All HIPAA regulations will be followed in the recruitment of subjects and disclosure of information. Given that personal information will be revealed and recorded, all reasonable means of protecting privacy and confidentiality will be invoked. All records and recordings will be kept in a locked file cabinet in a locked office.

Individuals within the Department of Psychology at The University of Akron and individuals within the Community Health Sciences Department of Northeastern Ohio Universities College of Medicine will be involved in the compilation of this data and will...
adhere strictly to HIPAA regulations. As the portion of the study involving therapeutic videography is serving as a pilot study for a study being conducted by the University of Arkansas for Medical Sciences and Hospice Home Care/Kaleidoscope Kids, the analyzed data for that portion of the study will be shared with researchers at the aforementioned institutions.

What are the costs?

There is no cost to you for participating in this study. You will not be paid for your participation.

What are my rights as a research participant?

Your decision to take part in this study is voluntary — you do not have to take part. Your decision to stay or not stay in the study will not affect your regular medical treatment, care or the relationship you currently enjoy in any way. You are free to withdraw from this study at any time.

In addition to choosing not to be in or to withdraw from the study, the principal investigator can withdraw you if she feels it is best for you. If you end the study early for any reason, you may be asked to complete the final assessments that would occur at the end of the study.

You have not waived any legal right to which you are legally entitled by signing this form.

Who can I call if I have questions or problems?

You can ask any questions that you have about the study to the doctors participating in the study or the research staff. The doctor in charge of the study is Sarah Friebert. She works with a team of people at Akron Children’s Hospital for this study. If you have a question later that you didn’t think of now, you can call her team members at 330-543-3343 or ask them next time. Signing your name at the bottom of this page means that you agree to be in this study. Your doctors will continue to treat you whether or not you participate in this study. You will be given a copy of this form.

For questions concerning this research project and/or research subjects’ rights, you should call Dr. Sarah Friebert at 330-543-3343 or the Institutional Review Board Office at 330-543-8735.

Financial Disclosure

The study sponsor is reimbursing the participating site for costs associated with data collection. None of the investigators is receiving payment from the study sponsor for participation in this protocol.

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New Information

Any new findings developed during the course of this study, which may relate to your willingness to participate in this study will be provided to you.

Consent

I have read this form or this form has been read to me. Upon consideration of the possible benefits and risks of the study outlined, I authorize you to use and disclose the health information about my child in this study, as you have explained in this document.

I understand that appropriate medical care is my child's doctor's main concern and that he/she may stop my child's participation in the study and change the treatment plan according to his/her best judgment. My questions regarding participation in this study have been answered and I understand the explanation. I have been given a copy of this consent form. By signing this consent form, I have not waived any of the legal rights, which I otherwise would have as a participant in a research study.

I hereby consent (to have my child/ward consent) to participate.

Person Obtaining Consent

Signature of Person Obtaining Consent ___________________________ Date ___________________________

Subject's Name

Signature of Subject (If participant is 18 years old or older) ___________________________ Date ___________________________
Or Signature of Legally Authorized Representative ___________________________

Parent/Guardian's Name if Participant

Is a Minor or Legally Authorized Representative

Signature ___________________________ Date ___________________________

A witness is someone who has no connection with the clinical trial. A witness is only required in cases where the subject cannot read or is not able to understand the consent document. By signing the consent form, the witness attests that the information in the consent form and any other written information was accurately explained and apparently understood by the subject or the subjects legally acceptable representative and that the

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Informed consent was freely given by the subject of the subjects acceptable representative. In cases where this does not apply N/A should be placed in the witness.

Witness (Someone not connected to this research project) ___________________________ Date: ___________________________

Witness Identification: (nurse, friend, receptionist, etc.) ___________________________