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Family Experiences of Ambiguous Loss in Response to Serious Childhood Illness: Parental Perspectives

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Family Experiences of Ambiguous Loss in Response to Serious Childhood Illness:
Parental Perspectives

Submitted by Erin Hillegas
May 2012

MSW Clinical Research Paper

The Clinical Research Project is a graduation requirement for MSW students at St. Catherine University/University of St. Thomas School of Social Work in St. Paul, Minnesota and is conducted within a nine-month time frame to demonstrate facility with basic social research methods. Students must independently conceptualize a research problem, formulate a research design that is approved by a research committee and the university Institutional Review Board, implement the project, and publicly present their findings. This project is neither a Master's thesis nor a dissertation.

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Abstract

The diagnosis and treatment of a serious childhood illness impacts the entire family system and causes a wide range of changes and losses. This research explored the experience of eight families faced with the extended hospitalization of a child and investigated how their experiences could be understood from an ambiguous loss framework. Qualitative interviews were conducted with eight mothers to explore their perception of the changes within the family unit during extended hospitalization. Results indicated families do experience ambiguous loss during extended hospitalization, particularly family boundary ambiguity and the loss of a normative family experience. Participants indicated these losses were related to the ambiguous absence of the patient and caregiver. Social workers should be aware of these unrecognized or uncertain losses and how they impact the entire family system when working with children with a serious medical illness.

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The diagnosis of a child's serious illness and the subsequent treatment and hospitalizations change the dynamics of the family system and greatly affects the child's loved ones. Medical crises bring sudden changes and stressors to the family and even when the child survives the illness, the stress and adjustments that accompany the disease process leave lasting imprints on the family. Due to the interconnectedness of the family system, the family experiences changes in roles, boundaries, and communication during treatment for a serious illness.

Children can experience a variety of serious illnesses. Any illness that requires a lengthy hospitalization interferes with the normal functioning of a family. Using the Family and Medical Leave Act (FMLA) definition, a *serious health condition* is any "illness, injury, impairment or any physical or mental condition that requires inpatient medical care or continuing treatment by a health care provider" (United States Department of Labor, 2010). The most common serious illness facing children is cancer, specifically leukemia and brain and central nervous system cancers. In children under age 15, approximately 8,600 new cases of cancer are diagnosed each year in the United States (Pizzo, 2001). However, childhood serious illnesses are not limited to cancer. In Minnesota alone, 4,764 babies were born prematurely in 2009 (The Annie E. Casey Foundation, 2009). In 2004, there were 2,300 children awaiting organ transplants in the United States (United Network for Organ Sharing, 2004). Advances in medical technology and increased parental awareness have resulted in better outcomes for children with serious illness, however the fact remains that treatment for serious illness is often lengthy and disruptive for the family system.

Traditional grief theories, typically used with bereaved individuals, offer some relevant information for families faced with a heartbreaking diagnosis. The diagnosis of a serious or terminal illness of a family member can result in grief reactions similar to those surrounding death. Individuals may experience feelings such as shock, denial, disbelief, anger, guilt, sadness, and depression (Schoeneck, 2003). While loss and grief are triggered not only by death, when a child survives their serious illness traditional grief theories fail to accurately describe the family's losses.

During the course of a serious pediatric illness, the losses experienced by the family are unclear and often unnamed; they are ambiguous. Ambiguous loss framework is "based on the premise that a lack of information or chronic uncertainty is traumatic for most people" (Boss, 2006, p. 9). Treatment for serious illness produces a variety of uncertainties. The family is faced with the uncertainty of the illness, the nature of the course of treatment, and the final outcome.

The struggles faced by families during a child's serious illness encompass not only the stress of the illness and subsequent hospitalization but the stress of role changes, absent members, and the loss of a normative family experience. Treatment of a serious illness requires shifts in family organization and functioning. At times families are required to travel great distances to seek appropriate medical care for their child. The parent must spend an increased amount of time focusing on the patient and medical treatment. Stress levels are high during a medical crisis and priorities shift. In this way, the family experiences a variety of losses during the treatment process even when the child does not die.

Families experiencing the serious illness of a child can provide valuable information to social workers regarding the changes within the family system and the losses experienced during treatment. Social workers are most likely to encounter such families in a hospital or clinic setting. While the medical model of health care focuses primarily on the care of the patient with limited attention given to the child's primary caregivers, social work values point to the necessity of not only addressing the patient's emotional struggles with serious illness but the entire family's adjustment. Furthermore, the ambiguous loss framework understands such losses to be externally caused relational disorders rather than an individual pathology (Boss, 2006). While each member of the family has an important story to tell, this study will consider the parent as the spokesperson for the family unit. The primary goal of this study is to explore the parent's perspective of the changes within the family structure during a child's serious medical illness and hospitalization and how these changes can be understood from an ambiguous loss framework.

Literature Review

There is limited research investigating the impact of a pediatric medical crisis on the entire family system, especially from the lens of ambiguous loss. Research in the area of grief and loss, family systems, and pediatric illness will help inform the current research. To understand the applicability of ambiguous loss theory to pediatric serious illness, the literature review will first explore the history of grief and loss theories as well as the history of pediatric medical care. Since the current research is interested in understanding the impact of a pediatric hospitalization on the family unit as a whole, the literature review will also explore the interconnectedness of the family unit and the impact of change. At this point, the literature review will investigate how ambiguous loss theory has been applied to other loss situations and how it may apply to medical crisis and hospitalization. The blending of these research areas, as well as a lack of research conducted on this topic from a social work perspective, will present the need for the current research to explore ambiguous loss and changes within the family system during treatment for serious pediatric illness.

As mentioned, the current research will use the Family Medical Leave Act definition of a serious health condition: “illness, injury, impairment or any physical or mental condition that requires inpatient medical care or continuing treatment by a health care provider” (United States Department of Labor, 2010). Furthermore, the research will consider a lengthy hospitalization to be any inpatient hospitalization lasting two weeks or longer. The research will also take into consideration outpatient treatments that require the patient and caregiver to be present at an outpatient clinic on a daily basis. The research will presuppose that the outcome of the medical treatment is

uncertain. In other words, during the course of the treatment or hospitalization, the family is unsure of the length of time in which the crisis will interrupt the typical family functioning.

The Applicability of Traditional Grief Work Models

Grief work has its origins in Sigmund Freud's *Mourning and Melancholia* (1917). Freud argues mourning is the "normal" response to death while melancholia is the "pathological" response to an unconscious loss. Freud explains "in grief the world becomes poor and empty; in melancholia it is the ego itself" (Freud, 1917, p. 164). Under Freud's grief model, a normal response of mourning entails working through the grief while in a pathological response, one becomes trapped in the grief. Working through grief involves a process of detachment. Mourning begins with the bereaved creating an imaginary presence of the lost object in the psyche. When the mourner comes to an objective determination that the lost object no longer exists, by comparing the imaginary presence to reality, detachment can occur. Grief work is complete when the mourner can detach from the lost object and reattach to a new object. In this way, Freud views mourning to be a selfish process aimed at restoring the narcissist self rather than grieving the loss of a loved one.

John Bowlby further contributed to the field of grief work through his work with attachment theory. Bowlby's *Processes of Mourning* (1961) explains grief to be a biological response to separation and loss. Bowlby explored the response of children separated from their mothers. He concluded that children experience three stages following the separation: bewilderment and anger, despair and disorganization, and finally an acceptance and reorganization directed towards a new object. Bowlby and

Parkes went on to develop a stage-based theory of mourning (Corr, Nabe, & Corr, 2006). The stages include shock and numbness, yearning and searching, disorganization and despair, and reorganization. These stages are part of the “overall process of *realization*-making real in one’s inner, psychic world what is already real in the outer, objective world” (Corr et al., 2006, p. 213).

Possibly the most well known and most often referred to model of grief is Elisabeth Kubler-Ross’ five stages of grief (1969). Kubler-Ross’ model, based on her interviews with more than 500 dying patients, describes how people cope with grief and tragedy. The five stages of grief are denial, anger, bargaining, depression, and acceptance. While Bowlby described a linear model for grief, Kubler-Ross’ model acknowledges that grief is an experience unique to each individual. Kubler-Ross acknowledges that individuals may not experience every stage, may experience them in a different order, or may experience a stage more than once. However, as seen in earlier grief work theories, closure is to be obtained at some point if the grief work is to be considered successful.

Extended hospitalizations pose a challenge to traditional grief theories. While the patient’s life may be in danger, there is also the strong possibility that the child will survive their illness and return to family life. Even so, the family experiences a variety of losses even without being faced with death. When death does not occur, the losses must still be addressed and traditional “bereavement terminologies and models do not adequately describe how individuals experience this kind of loss” (Collings, 2007, p. 1502). There can be no final stage of grief, such as acceptance or reorganization, because to resolve the grief would be to deny the loved one continues to live. The minimization

of the loss, lack of permission to mourn, lack of acknowledgement from support systems, and an absence of rituals leaves the family frozen in their grief (Collings, 2007). The family is unable to find a socially accepted method of grief and oftentimes cannot even find a name for the unusual feelings of loss experienced.

The History of Pediatric Hospitalizations

In the early 1940s, the potentially negative effects of inpatient hospitalizations on children began to be studied (Van der Horst & Van der Veer, 2008). Prior to this time, children admitted to the hospital were separated from their parents, with little or no visitation allowed, and resided in sterile and isolated environments. The term *hospitalism* was used to describe the condition in which hospitalized children, separated from their loved ones and human connection, wasted away (Spitz, 1983). Van der Horst & Van der Veer (2008) explain that despite good medical care, the isolative environment and lack of motherly attention was damaging for children and lead to mortality in many cases.

James Robertson conducted two experiments on the subject of hospitalized children. The 1952 film *A Two-Year-Old Goes to the Hospital* (Robertson, 1952) offered a visual account of a child hospitalized without her mother. Separated from her mother while undergoing scary and painful medical procedures, the child's trust in her mother is shaken. With frequent changes in nursing staff, the child does not have anyone familiar to cling to. In 1958, the film *Going to the Hospital with Mother* (Robertson, 1958) demonstrated that with presence of the child's mother, the child did not show signs of anxiety, depression, or withdrawal as seen in the first film. In this way, Robertson's

work contributed to changes in the policy of hospitals and enlightened professionals as to the negative effects hospitalization can have on children.

Fortunately, vast improvements have been made in the treatment of hospitalized children. Pediatric hospitals cater to the special needs of children, child life staff provide age appropriate information, and parents are encouraged, if not required, to stay with their child. While the hospital experience has improved, the uncertainty surrounding a medical crisis still has an impact on the child, the parents, and the entire family system.

Family Systems Theory and Hospitalizations

The hospitalization of a child has lasting effects on the entire family system in addition to the impact on the patient. For the purposes of this research, *family* is defined as “that intimate group of people whom we can count on over time for comfort, nurturance, support, sustenance, and emotional closeness” (Boss, 1999, p. 4). This research will also assume the interconnectedness of the family unit as described in family systems theory, “the functioning of one person... could not be adequately understood out of the context of the functioning of the people closely involved with him” (Kerr & Bowen, 1988, p. 7).

Family systems theory, developed by Murray Bowen in the 1950s, conceptualizes the family as an emotional unit (Kerr & Bowen, 1988). Family systems theory acknowledges that “the family as a whole is more than the sum of its parts, families try to balance change and stability, [and] a change in one family member affects all of the family members” (Collins, Jordan, & Coleman, 2007, p. 44). The concept of family systems theory is that the system does not simply account for what is occurring; rather it drives what is occurring within the family. Therefore, the *family system* is a dynamic

force in and of itself. Interactions between family members should be evaluated both by their *content*, the information shared among members, as well as by their *process*, the way in which the information is communicated (Kerr & Bowen, 1988).

Roles are an important aspect of family systems theory. Each family member fulfills both explicit and implied roles. The *role* of each family member stems from the expectations of other family members and impacts the individual's attitudes, feelings, and behavior (Kerr & Bowen, 1988). Roles act in reciprocal relationship to one another, therefore when a family member is missing, the dynamic of the system is changed due to the lack of role fulfillment. Similarly, family systems have boundaries. *Boundaries* determine who is considered to be in, and who is considered to be out of, the family. Healthy families have clear and flexible boundaries (Collins et al., 2007).

Each family's encounter with serious pediatric illness and hospitalization will be unique. Not only will individual members of the family respond in a distinctive fashion, but the response of the family unit as a whole will vary. Responses to the illness may vary depending upon the cohesiveness of the family prior to the diagnosis, the family's support network, and the extent to which the treatment process interrupts every day life for the family. Nonetheless, the treatment of a serious illness impacts the communication patterns between family members, the roles each member fulfills, and the boundaries of the family.

Parental Response to Extended Hospitalizations

The serious illness of a child has substantial emotional implications for parents. The unique dynamics of the parent-child relationship cause grief reactions that are stronger than those associated with other losses (Rando, 1985). In the past a diagnosis

such as leukemia would trigger the process of anticipatory mourning in parents as the likelihood of survival was rare. Therefore, much of the early literature, which was conceptual in nature, focuses on anticipatory mourning or bereavement (Knapp & Hanson, 1975; Rando, 1985). Knapp and Hanson (1975) examined the discussions of support groups for parents with children diagnosed with leukemia. In this early literature, it was found that the parents displayed anticipatory grief which mirrored Kubler-Ross' mourning process. Parents moved through feelings of denial, anger, bargaining, depression, and acceptance. With advances in medical technology and improved treatment outcomes, the diagnosis of a serious illness no longer implies the child will die. However, parents must face the possibility of death while clinging to the hope of survival.

Parents face uncertainty when confronted with the illness of a child. The delicate balance of preparing for the worst outcome while hoping for the best places the parent in a state of uncertainty. The parent's goal of restoring *homeostasis*, or balance, to the family is arrested due to the ambiguity of how long the crisis will last and what the final outcome will be. The parent cannot problem solve or plan for the future of the family as they do not know whether the loss of the child within the family system will be temporary or final (Cox, 2006).

In the absence of research conducted in this specific field, literature regarding the chronic mental illness of a child can be considered applicable especially when the pediatric illness has poor prognosis of complete recovery. Eakes (1995) used the Burke/Nursing Consortium for Research on Chronic Sorrow (NCRCS) Questionnaire to investigate the incidence of chronic sorrow in ten parents of children diagnosed with

severe and persistent mental illness. Parents reported feelings of anger, frustration, and confusion at the time of diagnosis as well as when the grief was retriggered. Grief was most often retriggered by the unending caregiving responsibilities. MacGregor (1994) also found grief reactions similar to those of bereavement in parents with a child diagnosed with mental illness.

Parents are often faced with a lack of support during their child's hospitalization. At times the parent and child have traveled away from their home and community to seek specialized treatment. While family and friends may attempt to support the family, the distance and lack of understanding cause barriers. The family's current situation also represents every parent's worst nightmare and may cause others anxiety and fear (Rando, 1985). Furthermore, the individual one typically turns to during times of great sadness, one's spouse, is struggling with their own grief and may be emotionally unavailable (Patrick-Ott & Ladd, 2010; Rando, 1985).

Research has revealed negative effects on the mental health of parents during the hospitalization of a child or when confronted with a child's serious illness (Mu, Ma, Ku, Shu, Hwang, & Kuo, 2001; Mu, 2005). Mu et al. (2001) surveyed 100 mothers to explore the impact of pediatric cancer treatment on the mother's mental health. The occurrence of childhood cancer, and particularly a relapse of the cancer, negatively affected the mother's sense of mastery. A diminished sense of mastery led to increased anxiety (Mu et al., 2001). Similarly, studies conducted on both the paternal and maternal reaction to a child's epilepsy revealed the strong association between the uncertainty of disease's outcomes and depression (Mu, 2005; Mu, Kuo, & Chang, 2005). In the case of chronic physical illness, Boss and Couden (2002) reveal that the helplessness caused by

an uncertain future leads to depression, anxiety, and relationship conflicts. A sense of participation in the child's care as well as receiving information from the medical team regarding the disease and possible outcomes has proved helpful in minimizing feelings of depression and anxiety in parents (Heims, Huckabay, Mu, & Tomlinson, 1997).

While a child is hospitalized, the role of the parent changes dramatically. A primary aspect of parental identity centers around providing for one's children and keeping them safe (Rando, 1985). In the midst of treatment for a serious illness, the child is often extremely physically sick, emotionally drained, and psychologically transformed. These changes can leave the parent feeling helpless and inadequate. Also contributing to feelings of helplessness is the fact that many caregiving duties are assumed by health care professionals while the child is hospitalized (Heims et al., 1997). Additionally, while the parent is surrendering the caregiving role to health care professionals, they often must also surrender such roles for their healthy children. The hospitalization of a child takes the parent away from the home and the daily functions of parenting the other children. Many parents rely on extended family members to fill the caregiving role for siblings. The transfer of such duties can be useful in limiting disruptions for the siblings (Heims et al., 1997), however the losses associated with the disruption cannot be overlooked.

Sibling Response to Extended Hospitalizations

Children respond to life stressors with both internalized and externalized reactions. Hamama, Ronen, and Feigin (2000) point to feelings of anxiety and loneliness as the primary internal reactions during a sibling's serious illness. These internalized reactions to the perceived threat of serious illness can have a lasting effect on the sibling's ability to cope with future life stressors. An effective coping skill is the

development of self control, such as self-instruction or positive thinking (Hamama et al., 2000). Higher levels of self control have been linked to lessened role overload, lower levels of anxiety, and fewer behavioral symptoms (Hamana, Ronen, Rahav, 2008).

Hamana et al. (2008) administered self report questionnaires to 100 children with a sibling diagnosed with cancer. Findings reveal that additional expectations and responsibilities are placed on a healthy sibling as the family dynamics change under the stress of an illness. Hamana et al. (2008) call this *role overload* and it is a relatively new concept being studied in families coping with serious pediatric illness. As parents are less available to the healthy siblings, due to the need to focus on medical treatment, older siblings often take on the parental role for younger siblings (Madan-Swain, Sexson, Brown, & Ragab, 1993). This shift in family dynamics may lead to the blurring of boundaries and feelings of loneliness and separation for the healthy siblings. Furthermore, a strengthened relationship between the patient and parent may lead to further feelings of alienation and parental unavailability for the healthy sibling.

The lack of availability and the shifting relationship between the parent and the healthy siblings can lead the healthy sibling to attempt to place fewer burdens on the family system. Madan-Swain et al. (1993) used self report questionnaires with 32 siblings of patients with leukemia and found that older siblings experienced increased responsibility and decreased participation in family activities resulting in less positive feelings regarding the family and the treatment experience. To maintain order in the family, the healthy sibling may shy away from bringing feelings of fear or sadness to their parents' attention or may take on additional roles to ease the parent's burden (McGrath, 2001). Children have questions regarding whether they caused the illness,

whether the illness will happen to them, and who will take care of them (Schoeneck, 2003), these questions should be addressed by the parent but often go unanswered in the chaos of treatment. The loss of the pre-illness family as well as the loss of routine rituals and events that used to occur within the family can feed the feelings of loneliness and anxiety felt by many siblings (McGrath, 2001).

Ambiguous Loss

Pauline Boss began exploring the concept of ambiguous loss in the early 1970s when interviewing wives of pilots missing in action in Vietnam and South Asia (Boss, 2006). *Ambiguous loss* refers to “a loss situation that remains incomplete, confusing, or uncertain for family members” (Dupuis, 2002, p. 94). Such losses are experienced on a spectrum throughout one’s life. Divorce, an emotionally unavailable parent or spouse, a friend that moves away, and a child leaving home are ambiguous losses that are common occurrences in today’s society. More traumatic losses include deployment, brain injuries, missing children, and foster care placement. No matter the situation, an ambiguous loss is one that is unclear, traumatic, externally caused, confusing, and incomprehensible (Boss, 2010). An ambiguous loss is not an individual pathology, it is a relational disorder.

Boss (1999) describes two types of ambiguous loss. In the first, *ambiguous presence*, the loved one is physically present but psychologically absent. This occurs in instances of dementia, traumatic brain injury, addiction, or when one is simply distracted by work or other matters. In the second case, *ambiguous absence*, the loved one is physically absent but is perceived as psychologically present. This is the case with missing children, soldiers in active duty service, adoption, or divorce. The wide variety

of current research involving ambiguous loss reveals both the frequency of ambiguous losses in every day life as well the negative implications if such losses remain unaddressed.

The ambiguous losses experienced during a child's extended inpatient hospitalization are two-fold. On one hand, the child is physically removed from the family unit while hospitalized. Furthermore, one or both parents are also physically removed from the family while assuming increased caregiving duties for the sick child. On the other hand, the effects of invasive medical treatment take the child psychologically away from the family. While the child is physically present in the hospital, interactions with other family members are greatly altered.

Ambiguous presence: Psychologically absent family members. In the case of psychologically absent family members, research reveals grief reactions stem from the loss of the family member as they had been, the loss of the essence of the person (Dupuis, 2002; Collings, 2008; Kean, 2010). While the family member is still physically present, their ability to participate and engage in the family unit is drastically changed. The psychologically absent family member is unable to fill their usual role in the family. Dupuis (2002) explored ambiguous loss in the context of dementia care by interviewing 61 adult children. As the parent's dementia continued to decline, many of the adult children eventually recognized that their parent, as they had always known them, no longer existed. Similarly, Kean (2010) interviewed nine families of brain injured intensive care unit patients and found family members recognized that the essence of their family member was gone due to the brain injury. In fact, one of the families interviewed began talking about the brain injury victim in the past tense as the loss of

who the person had been was so profound (Kean, 2010). In this way, the psychological loss of the family member was viewed as a true loss, with reactions similar to those surrounding death, even though the individual had not died.

Those with psychologically absent family members struggle greatly with uncertainty regarding the future. Uncertainty centers around the course of the disease, the patient's current capabilities, and future caregiving roles and responsibilities for other family members (Dupuis, 2002; O'Brien, 2007; Blieszner, Roberto, Wilcox, Barham, & Winston, 2007; Kean, 2010). Blieszner et al. (2007) interviewed 67 couples in which one partner had a diagnosis of mild cognitive impairment. This study is of particular interest because the individual whom the ambiguity is regarding was able to participate in the interviews. Couples reported that fluctuations in the daily functioning of the partner with mild cognitive impairment as well as uncertainty regarding the course of the illness contributed to the ambiguity of the situation. Likewise, in O'Brien's (2007) study of ambiguous loss in families of children with autism, interviews with 63 mothers revealed that varying skills in different areas of functioning left the mothers uncertain of what to expect from their child.

Families alternate between hope and hopeless when the future of the patient is uncertain (O'Brien, 2007; Blieszner et al., 2007). Without knowing what to expect from the patient or the disease process, the family's grief is frozen. Dupuis (2002) and Collings (2008) both found that when family members were able to accept and reframe the situation, rather than use avoidance as a coping mechanism, the family as a whole fared better.

Ambiguous absence: Physically absent family members. Research regarding physically absent family members also found high levels of uncertainty. In the case of physical absence, uncertainty arises from whether the loved one will return to the family. When a member of the family leaves, the family unit must reorganize in order to maintain optimal functioning. However, when it is uncertain whether the missing member will return, the family is wary to reorganize and becomes immobilized (Boss & Couden, 2002).

For children experiencing the physical loss of a loved one, sharing age appropriate information with the child has proved to be very important for coping (Lee & Whiting, 2007; Bocknek, Sanderson, & Britner, 2009). Adults often attempt to shield a child from the loss or are themselves suffering with the loss and feel ill-equipped to discuss the situation with a child. However, Lee and Whiting (2007) found in their interviews with foster care children that without proper information, children use fantasy to explain the absence of their loved one. The use of fantasy can compound feelings of helplessness or hopelessness.

In the absence of research conducted on ambiguous loss in a medical setting, military deployments offer applicable information. Similar to extended hospitalizations, the deployed member's life is in danger while away but the chances of returning to the family unit are relatively high. Therefore, family members are hesitant to fill the role of the deployed person as the hope is he or she will be returning to the family. Huebner, Mancini, Wilcox, Grass, and Grass (2007) conducted a focus group with 107 children, between the ages of 12 and 18, of deployed service members. Findings reveal boundary ambiguity surrounding the redistribution of roles and responsibilities. In order to

effectively cope with the deployment, the family must reorganize. Faber, Willerton, Clymer, MacDermid, and Weiss (2008) also found the restructuring of the family system during deployment to be necessary but a cause for uncertainty. Furthermore, reorganization can complicate the reentry of the deployed member into family life (Huebner et al., 2007; Faber et al., 2008). As with deployment, families experiencing extended hospitalizations must learn to reorganize and restructure in order to cope all the while anticipating the reentry of their loved one.

Family Boundary Ambiguity

Family boundary ambiguity occurs when family members are uncertain of their personal views of who is in the family versus who is outside of the family and what roles or tasks are being performed by each family member (Boss & Greenberg, 1984). When a child is receiving treatment for a serious illness, the normal functioning of the family is turned upside-down. The child is absent from the home while hospitalized and unable to fill their role within the family system. Likewise, one or both parents may be physically absent from the home and, when present, psychologically preoccupied. Extended family and friends may be increasingly involved and siblings may feel obligated to fill roles left empty by the hospitalized child or caregiving parent.

During the hospitalization, the family boundaries must expand to ensure all members are properly cared for. Limited research is available on the topic of family boundaries during hospitalization. Heims et al. (1997) found that by expanding the family boundary to include extended family as well as health care professionals, the family was able to attain equilibrium. As mentioned earlier, a parent experiences increased distress when a child's hospitalization takes them away from caring for healthy

siblings. By including extended family and friends in the day to day operations of the family, parents hope the siblings experience a lessened disruption. Along these same lines, parents appeared to be comforted when the health care professionals caring for the patient were viewed within the family system rather than as outsiders (Heims et al., 1997). Unfortunately, the study did not speak to the importance of health care workers maintaining proper professional boundaries in such instances. This would be an important aspect to explore as professional boundaries protect both the vulnerable family members as well as the health care workers.

For family members remaining in the home, attempting to maintain a sense of normalcy can be difficult. Others may step in to provide practical assistance, such as preparing meals, driving children to school, or helping with homework. However, families function on more than just a practical level. The ways in which the family interacts, the unspoken rules and roles, and communication are altered.

Depending on the patient's prognosis, the family may be unsure of whether to plan for the child's presence in the future family unit. If the child does return to a healthy status, questions regarding how to return to the pre-illness family abound. As seen in the research conducted with military families, the reintegration of the missing member into the family alters the family boundaries and roles (Huebner et al., 2007; Faber et al., 2008). When faced with a health crisis, each family member responds in a unique fashion. The greater the differences in individual responses, the greater the conflict among members (Sobel & Cowan, 2003). Thus, the loss does not resolve when the child's illness is cured. Individuals will continue to mourn the loss of the pre-illness

family and a normative family experience and need to once again work on restructuring the family system.

Therapeutic Work with Ambiguous Loss

As seen in the current literature on ambiguous loss, uncertainty regarding a loss has detrimental effects on family functioning. The family is immobilized as a result of the ambiguity. Due to a lack of social acceptance and support surrounding ambiguous loss, feelings are often internalized. Individuals may feel depression or anxiety because they are unable to “get over” the loss, have mixed feelings towards the psychologically or physically absent member, or are simply confused by how to respond. Individuals are unaware that their feelings of ambiguity are a natural response to such a loss. Families need support and guidance to normalize their feelings and learn that the culprit is the ambiguity itself and is not an individual flaw or pathology (Boss, 2006).

The very nature of an ambiguous loss is often confusing. Without a socially recognized loss, such as death, the family’s loss lacks validation. Families often respond by refusing to discuss the loss which further adds to each member’s uncertainty of the situation, “a person’s story of loss is not real, and thus not resolvable, until someone is willing to hear it” (Boss, 2004, p. 557). Families may also be tempted to cancel traditions due to the absence of a family member. However, maintaining rituals, albeit revised rituals, is important in helping the family find a new normal (Boss, 1999).

As mentioned, traditional grief work aims for a sense of closure and professionals often gauge their success on helping individuals achieve closure. Closure is rarely possible in the case of ambiguous loss (Boss, 2004). Rather, the ambiguous loss approach “is not focused on finding a solution, but rather is based on regaining resiliency

despite the unresolved loss” (Boss, 2006, p. 9). In a culture intolerant of ambiguity, the professional must help family members tolerate uncertainty.

Conclusion

While ambiguous losses have occurred throughout history, it is only in the past forty years that such losses have received clinical attention. While the research conducted in this field is varied, it is also quite limited. Likewise, the literature concerning the experience of the entire family system during an extended hospitalization is limited. While Heims et al. (1997) provide some preliminary research on the parental experience during a pediatric health crisis; the study is conducted from a nursing perspective and does not consider the effect of a health crisis from the family systems approach. Hanama et al. (2000) and Hanama et al. (2008) provide groundwork for considering the impact of hospitalization on families through their research regarding the response of siblings to childhood cancer. Perhaps the most closely linked to the current research, McGrath (2001) explores the impact of the initial cancer treatment on family relationships. The current research is arguably not extensive enough to provide an adequate amount of information for social workers in this field. Therefore, the primary goal of this study is to explore the parent’s perspective of the changes within the family structure during a child’s serious medical illness and hospitalization and how these changes can be understood from an ambiguous loss framework.

Conceptual Framework

The current study is informed by previous research and accepted social work theories as well as the researcher's personal and professional bias. In an attempt to fully disclose any bias or assumptions, the framework from which this research was developed will be discussed along with the researcher's professional and personal lens.

Systems Theory

As mentioned previously, systems theory was developed by psychiatrist Murray Bowen in the 1950s. Systems theory understands the family to be a group of interconnected and interrelated individuals (Sheafor & Horejsi, 2006). Systems theory recognizes that a change with one member of the family affects all other family members. Furthermore, when change is experienced the family will attempt to maintain stability through adjustments in other members or interactions (Collins et al., 2007). The family system is comprised of subsystems, such as the sibling subsystem or the spouse subsystem, as well as a suprasystem, the family's place in the larger community (Sheafor & Horejsi, 2006).

Systems theory assumes a symbolic relationship exists among the individuals and subsystems through mutually understood rules. Rules and roles, while often unspoken, maintain the homeostasis of the family (Collins et al., 2007). *Homeostasis* is the balance that maintains the family's customary organization and functioning over time. When a member of the system is physically or psychologically absent, the symbolic role the member filled is left empty thus affecting the balance of the system and altering the entire family functioning.

Systems theory also assumes that all systems have boundaries. Boundaries determine who is in the system and who is outside of the system (Sheafor & Horejsi, 2006). Healthy families have clear and flexible boundaries (Collins et al., 2007). When boundaries are too closed, open, rigid, or diffuse the family will likely struggle during times of crisis.

The current research, as informed by Boss' theory of ambiguous loss, assumes the feelings associated with an ambiguous loss are not a personal pathology or weakness (Boss, 1999). Rather, an ambiguous loss is an externally caused stressor that alters the family system. Even healthy and resilient families will be impacted by the stress and challenges of serious pediatric illness. In any family, the symbolic relationship of the family members and the boundaries within the system are altered when a member is psychologically or physically missing from the system.

Professional and Personal Lens

The current study stemmed from the researcher's perception that a medical crisis affects not only the individual, but the entire family system. This perception began when the researcher had the opportunity to witness the long term affects of a pediatric medical crisis within the researcher's own extended family. From these observations, the researcher became curious about the experiences of other families.

Three years prior to beginning this study, the researcher worked for a non-profit agency that provides housing to families traveling great distances to seek pediatric medical care at area hospitals. During this time, the researcher became increasingly interested in the effect of serious pediatric illness on siblings. This interest grew into an interest in the experience of the family unit as a whole. The researcher is currently

completing a clinical social work internship at a children's hospital working with families of children experiencing a serious pediatric illness.

It is through these personal and professional experiences that the current research grew. The goal of the current study is to explore the ambiguous losses experienced by the family during an extended hospitalization. Through this exploration, the researcher hopes to add to the current knowledge base of both ambiguous loss and family systems during hospitalizations.

Methodology

This research study seeks to explore the parent's perspective of the changes within the family structure during a child's serious medical illness and hospitalization and how these changes can be understood from an ambiguous loss framework. To give voice to the family's experience, qualitative research methods were used. Due to the lack of research conducted in this specific field, this research was exploratory in nature.

Exploratory research is conducted with the goal of determining why or how something occurs (Monette, Sullivan, & DeJong, 2008). It is less structured and utilizes open-ended methods of data collection. Furthermore, this research drew from *grounded theory*, an inductive approach that allows for a continual interplay between data collection, data analysis, and theory development (Monette et al., 2008).

Sample

The researcher recruited and interviewed eight parents in the midst of seeking medical treatment for their child's serious illness. As mentioned, while each member of the family has an important story to tell, this study considered the parent as the spokesperson for the family unit. Participants were recruited through an agency that provides housing to families seeking medical treatment at area hospitals. The agency serves families in which the patient is 19 years of age or younger and lives at least 60 miles away from the hospital. The participants in this study had a child that was hospitalized at the time of the interview or had experienced an extended hospitalization in the 30 days prior to the interview. An extended hospitalization is considered to be at least two weeks.

While the research study was open to families of any structure, the current sample included only mothers (n=8, 100%). All of the participants were Caucasian women of low to moderate socio-economic status. The patients ranged in age from two months to 14 years old. Diagnoses of the patients were varied, and included leukemia, pancreatitis, premature birth with subsequent complications, and esophageal atresia.

Four of the participants were interviewed during their family's first experience with extended hospitalization. The other four families had experienced multiple extended hospitalizations and health concerns. For six of the families, the initial extended hospitalization coincided with the birth of the patient. The other two patients were diagnosed with a serious illness later in childhood.

Family systems ranged from four to five members. All of the participants had multiple children. Five of the participants had two other children while the other three participants had one additional child. Six of the participants were married to the father of the patient, one lived with the father as a couple, and one was divorced with no involvement from the father of the patient. Three of the families were from states other than Minnesota while the other five were from rural communities in Minnesota. Table 4.1 offers additional information regarding the family systems of the participants as well as a picture of their experience with extended hospitalization.

Table 4.1
Demographics of Participants' Families & Hospital Experience

Family	Family size	Age of patient (years)	Length of current hospitalization (weeks)	Years since initial hospitalization
A	5	1.5	3	1
B	5	14	2	13
C	4	0.66	24	0
D	4	0.2	8	0
E	4	8	28	0
F	4	12	4	0
G	5	3	4	2
H	5	4	12	3

The structure and constellation of the participant's families were diverse. *Structure* is the relationship of the members within the family. As mentioned, seven of the participants were in a relationship with the father of the patient while the remaining participant was single. All of the participants had multiple children. *Constellation* refers to how the family was configured during the hospitalization. Please refer to Table 4.2 for information on the structure and constellation of the families.

Table 4.2
Family Structure and Constellation

Descriptor	n (%)
Structure	
Married/partnered	7 (88%)
No partner	1 (12%)
One other child (besides patient)	3 (38%)
Two other children (besides patient)	5 (62%)
Constellation	
Family separated during hospitalization	5 (62%)
Family relocated together during hospitalization	3 (38%)
Patient currently inpatient	3 (38%)
Patient currently outpatient	5 (62%)

Recruitment

The researcher used availability sampling to find participants for this study. *Availability sampling* is used when it would be difficult to develop a sampling frame. Availability samples are comprised of individuals readily available or convenient to the researcher (Monette et al., 2008). A recruitment flyer was posted on the bulletin board in an agency that provides housing for families seeking medical treatment at area hospitals. Please refer to Appendix A for a copy of the recruitment flyer. Interested individuals were asked to contact the researcher via telephone or email. Eight participants were recruited using these methods.

Recruitment proved to be somewhat difficult. This was likely related to the demanding schedules of parents with hospitalized children, the caregivers' reluctance to leave the patient unattended, and the unpredictability of a seriously ill child's condition. Therefore, when contacted for an interview, the researcher made arrangements to conduct the interview on the same day given the changeability of the caregivers' schedule.

Protection of Participants

Prior to any contact with participants or data collection, the research proposal was reviewed by a number of individuals to ensure protection of the participants. The proposal was reviewed by the researcher's peers and committee members. The committee reviewed and approved the goals, design, and methodology of the research. The committee members have extensive experience working with the families of seriously ill children, thus they have a heightened awareness of potentially harmful methods. The research was also approved by the agency from which the participants were recruited. Please refer to Appendix B for the agency consent letter. Furthermore,

the research underwent an expedited board review and was approved by the University of St. Thomas institutional review board prior to contacting participants and beginning data collection.

The researcher took care to minimize the risks of the study. The decision to consider the parent as the spokesperson of the family unit, rather than seeking to interview the entire family, was made so the vulnerable population of children would not be included in the interviews. Furthermore, risks were reduced by recruiting families that were in a supportive environment; families seeking treatment for a childhood illness are in the supportive care of the hospital in which they have access to social workers and other mental health professionals. The parents recruited for this study were also residing in a supportive environment, surrounded by professionals familiar with the challenges of pediatric hospitalization as well as other families undergoing a similar experience. In addition, the participants were provided with a resource list in the event that the interview roused feelings that necessitated follow up emotional care outside of the supportive services already available to the parent. The resource list can be found in Appendix C.

The researcher provided the participants with an *informed consent* prior to beginning the interview. The researcher reviewed the content of the informed consent with each participant to ensure understanding. A copy of the consent form can be found in Appendix D. The researcher reminded participants of the voluntary nature of the study and explained the methods used to guarantee confidentiality.

The participants were compensated with a \$10.00 Target gift card for participation in the research study. Participants were reminded that even if they chose to terminate the interview, they would still be provided with the gift card. None of the

participants chose to terminate the interview. The participants were given the opportunity to share their family's personal experience with serious childhood illness; this opportunity may have provided some personal benefit to the participants as well.

Data Collection

Interviews were conducted in a private setting determined by the researcher and the participant. All of the interviews were held in a private meeting room within the agency from which participants were recruited. The researcher reviewed the content of the informed consent with the participants on the telephone prior to scheduling the interview and again before beginning the interview. The participants were asked four questions to ensure their understanding of the purpose of the research as well as their rights as participants. Participants were also encouraged to ask the researcher questions before signing the consent form. Once the consent form was signed, the interview began.

The interviews were *semi-structured*, meaning the researcher asked predetermined questions but also allowed for new questions to be brought up depending on the participant's responses. The interviews began with demographic questions to obtain information regarding the structure of the family and the functioning of the members prior to the medical crisis. From there, each participant was asked six open-ended questions about their family structure prior to hospitalization, the current family structure, and their anticipation of the family structure following the hospitalization. As mentioned, the semi-structured nature of the interview allowed for the flexibility in which the researcher asked clarifying questions to elicit more information as needed. The researcher also omitted questions if the answer had been addressed through another question or the question was deemed unnecessary. Please refer to Appendix E for a full

list of interview questions. The interviews ranged from 20 to 70 minutes in length and were digitally recorded. The researcher used field notes to record nonverbal communication and mannerisms.

Following the interviews, the researcher transcribed each interview. The researcher transcribed the interviews, rather than using a transcriber, to maintain the highest level of confidentiality. The transcriptions were stored on a password protected computer to which only this researcher has access. Names and identifying information were removed from the transcriptions. Rather, the family system was assigned a letter to represent the family (such as *family A*, *family B*, and so forth). Subsequent descriptions referred to the individual by their role within the family and the family's assigned letter (for example *mother A*, *child B*, or *brother C*).

Data Analysis

The researcher used a grounded approach to data analysis. In grounded theory the data is analyzed without a preexisting coding scheme. This allows the data to drive the study rather than previous themes (Monette et al., 2008). This inductive approach began by examining the specifics of the data and then moved towards the more general themes. The data was first reviewed for similarities. Once the similarities were coded and potential themes identified, differences were also considered. It was important to code for both similarities and differences in the data to determine any common elements amongst families. The themes were then compared and contrasted with the current available literature.

Findings

Each participant was asked to answer questions about their family's experience with extended hospitalization. The eight mothers who agreed to be interviewed were asked to describe their family life prior to the diagnosis and hospitalization of the patient, their experience with extended hospitalization, and how the women anticipated the hospitalization impacting their family in the future. All eight participants acknowledged a substantial impact of extended hospitalization on their family structure and functioning.

The themes that surfaced during the interviews align with the course of illness. The family experience can be separated into three stages: pre-illness, illness (this is the stage in which the interviews occurred), and anticipation of post-illness. Participants described their families as "normal" prior to the illness, acknowledged the family was "different" or "changed" at the time of the interview, and anticipated the family being "stronger" after the illness. Subthemes developed within each of these themes. The subthemes offer a look at the impact of extended hospitalization on the family unit. Table 5.1 illustrates the stage of the illness along with the corresponding themes and subthemes.

Table 5.1
Participants' Perceptions of Family throughout the Illness

Stage	Theme	Subthemes
Pre-illness	View family as “normal”	
During illness	View family as “changed”	<ul style="list-style-type: none"> ·Sharing caregiving responsibilities. ·Need for intentional communication within marriage. ·Negative impact on siblings. ·Patient is “missing out” on life. ·Caregiver guilt. ·Feeling as though family and friends do not understand the experience.
Post-illness	View the family as “stronger” than before	<ul style="list-style-type: none"> ·Loss of a normative family experience. ·Coping with uncertainty by taking things “day by day” and use of faith ·Simplified hopes for the future.

The current research aimed to gain an understanding of the changes within the family system during serious childhood illness and extended hospitalization as well as how these changes can be understood from an ambiguous loss framework. A thorough examination of the subthemes makes clear the participants experienced ambiguous losses during the extended hospitalization. These losses stemmed from the concept of ambiguous absence. The *ambiguous absence*, separation for an unknown amount of time, of the participant and patient from the family system required the family to restructure. Participants also described strong elements of family boundary ambiguity

due to the extended hospitalization. Table 5.2 displays the relevant themes and subthemes along with their link to ambiguous loss.

Table 5.2
Elements of Ambiguous Loss

Theme	Subtheme	Elements of ambiguous loss
Family is “changed”	Sharing caregiving responsibilities	Mothers’ need to surrender caregiving roles to other family members or medical staff; family boundary ambiguity.
	Negative impact on siblings	Impact of ambiguous absence (physical separation during hospitalization); loss of a normative family experience due to primary focus on the patient.
	Patient is “missing out” on life	Loss of normative experience for the patient; ambiguous absence.
	Caregiver guilt	Feeling as though they are not “doing enough” as the mom.
Family is “stronger”	Feeling as though friends do not understand the experience	Losses and changes are unrecognized and invalidated
	Loss of a normative family experience.	Loss of a normative family experience.
	Simplified hopes for the future	Loss of expectations and hopes for the patient.

Perceptions of Family Life Prior to the Hospitalization

Participants were asked to describe family life prior to the diagnosis and hospitalization of the child. The mothers described typical family activities and many described their days as “busy” and “normal.” Mother E explains her family was “just going through life, just crazy busy.” Another mother described typical family life before

the hospitalization, “we always did a lot of walks and took the kids sledding, to movies and probably got together more with our friends that have kids similar ages and a lot of that kind of stuff. We were always kind of on the go.” Mother C described her family as “just the average, young unmarried family.”

It is important to note that for six of the families the diagnosis and extended hospitalization coincided with the birth of the child. Not only were the mothers adjusting to the birth of a baby, they were adjusting to life in the hospital. Mother G noted,

We have my step-daughter every other week so we kind of had a week off every other week with no kids so it was just my husband and I. And then we had Patient G and first of all we had a full time child and then second of all we had a full time child that was living in an ICU.

Six of the parents described life stressors that were occurring at the time of diagnosis that further complicated the family’s coping. Mother B acknowledged her son was conceived unexpectedly and born at a time when her marriage was on rocky ground. Mother E also described a marriage that was less than ideal prior to the hospitalization, “we would fight more.” Mother A stated her family was adjusting to having two children when she found out she was pregnant with the patient, “we had just had my other son, so we were adjusting to having two kids.” Families F and H were in the process of moving when they received the patient’s diagnosis. Mother C described financial strains prior to the birth and diagnosis of her daughter that continued to impact their family, “we always struggle because his family always wants money from him... and his parents always want money from us and so we’ve always had that issue. And the issue remains.” In spite of these additional life stressors, the participants felt their families were coping adequately and were stable prior to the hospitalization.

In summary, the participants portrayed their families as typical prior to the life-changing event of serious childhood illness and extended hospitalization. Although some of the participants were faced with additional life stressors, they did not feel as though their families were different from other families. It is important to note the participants described their families as “normal” because it indicates the feelings of abnormality or confusion associated with the experience of extended hospitalization.

The Impact of the Hospitalization

All of the participants agreed the extended hospitalization had an impact on the structure of their family. The participants also agreed the hospitalization impacted each member of the family in unique ways. The participants cited the separation of the patient and caregiver from the rest of the family while hospitalized as the primary reason for the changes within the family. Additional factors included increased attention given to the patient, the caregiver’s inability to work, and the need to depend on extended family and friends.

Impact on family structure. All of the mothers interviewed described themselves as the primary caregivers for all of their children prior to the diagnosis of the patient, “[I] did all the grocery shopping, took the kids to all their appointments, you know, everything. I took the kids with me everywhere and did everything with them.” The mothers reported they remained the primary caregiver for the patient during the hospitalization but found they needed to surrender the caregiving responsibilities for siblings. Due to increased needs of the patient and the physical separation as a result of the hospitalization, the participants were not able to continue caregiving for both the patient and the siblings.

Caregiving responsibilities were most often shared with the participant's partner. Participants shared it was necessary to learn to rely on their partner to ensure the needs of their other children were met. The majority of the participants felt their partner displayed competence in managing the additional parenting responsibilities although it was difficult to surrender those roles. When Mother E relocated for her daughter's medical care, her husband stayed at home to care for their son. She explained she needed to,

...focus on what's really important here and help Patient E get through it. And that's something I have to tell myself everyday. To focus on the goal here and trusting that my husband can do it and he's capable of doing it. There for a while I thought only I can do that, he can't do that, I'm the mom. And so I had to let that go too. Like, okay, I need to get over this, he is an adult, he is capable of taking care of that stuff. And he did.

The participants described varying levels of support from those outside of their immediate family. Support came primarily from the patient's grandparents but also from friends and faith communities. Five of the mothers stated they were able to count on grandparents for emotional and practical support. Two of the participants shared they relied on the patient's grandparents, rather than a partner, to assist in caring for siblings. Mother A stated "we basically just lived at my in-laws because I never knew when I would have to leave again" during a time when her son was receiving outpatient care. Another mother reported her parents helped with finances while another counted on her own mother to help with cleaning and organizing the house prior to the patient being discharged from the hospital. A fourth shared her father came to the hospital to sit with her as she received some particularly difficult news. As one mother stated, "there were a few family members that helped us out that I didn't expect to... I have a few more people that I know I can call on if I need help."

The participants stated the experience of an extended hospitalization expanded

their views of family. Five of the participants explained they had a “hospital family” comprised of other patients and families undergoing treatment for serious childhood illness. As Mother G described,

What’s interesting is we refer to our family and then we refer to our hospital family. So, I think that when you look at family dynamics it’s also important to realize that there’s so much more to our family since we’ve gone through this.

Participants explained the importance of connecting with other families, who understood the stressors of extended hospitalization, for support.

Impact on marriage. Of the seven participants who were in a relationship, six shared they felt the hospitalization had a substantial impact on the relationship with their partner. Four of the participants stated they paid special attention to the state of their relationship because they were told specifically by hospital staff that a child’s serious illness can be detrimental to a marriage. “Luckily, we were told this. And I believe that knowing is half the battle” reported Mother B. The mothers acknowledged the hospitalization of their child had been very difficult and had the potential to end their marriage,

We would probably be divorced if it wasn’t for our faith and for the love that the Lord shows us as a couple, because I will say that it has not been a pretty ride... when you have a kid with chronic illness, who my life is him, and you add other children into the mix and you... try and balance all three of them. And I also have a husband and he has absolutely gotten kicked to the curb. Absolutely.

Similarly, Mother H stated “it’s a lot of stress on a relationship. I can really see how some couples don’t make it cause there are times like oh my gosh are we going to do this?”

The participants felt intentional communication was essential in maintaining their relationship during the hospitalization. Mother E shared “[Husband E]’s been at home

and he has my son and so it's kind of like we're spilt right in half. And so, we kind of depend on that talking and communicating." Mother H acknowledged the need to be intentional in communication,

That has been very hard to really try and stay together and on the same page and it ends up being so much repetition and Patient H's always sick, always has something going on that I would like to just kind of stop telling him things even though he wants to know... it really makes you have to stop and think like, what do I need to do to do my part?

Two of the mothers believed communication with their partner had improved as a result of being separated, "and honestly, it's brought us closer together and I just hope that it keeps on." On the other hand, Mother D felt the hospitalization was having a negative impact on her marriage due to decreased communication, "we don't spend as much time together since we're in different places... We don't really talk. But we probably should."

Impact on siblings. All of the participants had multiple children. However, one mother's other children were grown and living outside of the home and another's other child was under a year old. Therefore, these two mothers did not feel the hospitalization had an impact on the patient's siblings. The remaining six mothers talked in depth about the impact of the patient's hospitalization and medical needs on the other children in the family. Three of the mothers felt the impact of the hospitalization was so significant they had sought therapy for the patient's siblings.

Three of the participants felt the additional attention the patient received led to siblings desiring medical attention of their own. They shared siblings' responses to their own physical ailments and requests for medical care. Mother G explained,

Recently [step-sister G] fell and had to get a couple of stitches on her foot and she broke two toes and it became such a huge dramatic event... So we had to kind of

baby her and let her broken toes be a major catastrophe and take care of her too. And she liked using some of Patient G's medical supplies to wrap her foot.

Along the same lines, Mother B shared, "there were many times when [Sister B] would say she wanted a G-tube, she wanted to have braces, she even still to this day will wrap up her arm and act like it's broken or want to use crutches."

Three of the participants talked about the impact of being separated from their other children while caring for the patient. The mothers felt this separation had a negative impact on their other children. They noted surrendering their role as a caregiver was particularly difficult and confusing for the children. Mother A shared,

I would lay down next to [Brother A] and he would cry because he wanted his grandma. She basically had become his mom... He would see his grandma before and mom was gone. You know, I don't listen to mom because grandma's here and that's who I listen to.

Mother C explained how her relationship with her two year old daughter changed since the patient's hospitalization,

She doesn't care if I say no, she screams at the top of her lungs. She doesn't care if I pull her away from something she shouldn't be doing, she'll scream and kick and throw a fit and it's just, you know it's hard... I go home for a couple of days to spend time with them but then I spend half the time getting mad at her because she's just screaming and doing what she wants to do and you know it just gets frustrating.

Impact on the patient. Five of the participants talked about the impact of the hospitalization on the patient. Three brought up the physical and mental strain of treatment on the patient's body. Mother B explained,

I remember being just so tired with therapy, so tired. And of course then I had to say, you're tired what about him? You're just dragging him there. That's all you have to do, you just have to make sure he gets there. He had to put in the physical work and the mental work.

Another mother described the emotional impact of the long hospitalization on her daughter, “she had a tough time with it and would cry, which is normal. To be away from home and being in the hospital for that long but she’s really strong, really strong spirit.”

The participants also talked about their perception that the patient had missed out on life due to the hospitalization. “I mean she has spent so much of her life in the hospital or away from home... she’s just missed out on so much” explained Mother H. Participants worried the patient would have a difficult time fitting in once they returned home. Mother E shared,

Sometimes I worry that she will have a hard time fitting back in because she’s grown so much. I think she’s matured more than she should have had to, like a little eight year old girl shouldn’t have to go through as much as she did and she had to grow up fast. And sometimes I think that she’s, maturity wise, up on a higher level and sometimes I worry that she’ll have a hard time being able to fit in with her age group again.

Similarly, Mother F shared her son’s concerns that his classmates would make fun of him once he returned to school due to persistent physical challenges. Mother G talked about how she became protective of her son due to his physical differences and described her hopes for his future, “I just want him to go to school, go outside and play and not to have one of us there with a suction machine. So, a little bit more normal.”

Impact on caregiver. As mentioned, all of the participants described themselves as the primary caregivers for the patient both before and during the hospitalization. Two of the participants were homemakers prior to the diagnosis and hospitalization. Three reported they were no longer able to work outside the home once the patient was hospitalized due to increased caregiving responsibilities and did not plan to seek employment in the near future. Two mothers were not working at the time of the

interview but planned to pursue employment once the patient was out of the hospital. One mother was still employed and utilizing Family Medical Leave Act (FMLA) benefits. Five of the participants shared they were worried about their ability to find a job, earn money, or simply fill their time after spending an extended amount of time focused on the care of the patient. When thinking about the future, Mother E reflected on going home and stated, “sometimes I wonder where that will leave me.”

The caregivers reported an increase in personal responsibility due to their child’s illness. Furthermore, the participants did not feel they had a choice in whether to accept the increased responsibility. Perceived increases in responsibility stemmed from increased caregiving responsibilities, the need to make difficult decisions about the child’s medical care, and the need to make sacrifices to ensure the patient’s needs were met. Mother F, the single mom, acknowledged seeking treatment for her son’s illness had been difficult but she felt “no one else is going to do that for him right now.” Similarly, Mother D acknowledged how difficult it was to relocate for her daughter’s medical care, “but, I guess we had to... We’d do anything for her.” Mother E, when discussing the decision to begin a risky treatment for her daughter, stated “you look at your other options and there is no other option. Either you try or not. You know, you just give it every shot you possibly can.”

The participants experienced not only an increase in personal responsibility but also experienced feelings of guilt, as though they were not doing enough for their family. Feelings of guilt stemmed from the need to surrender caregiving responsibilities. Participants shared they felt guilty when relying on family members to care for siblings and for relying on medical professionals to care for the patient. Mother E described an

instance in which her young son broke his leg and she was unable to care for him due to the hospitalization of her daughter,

It's like, that's my job! And I feel like I'm not doing my job 100%... It was really hard for me as the mom to sit back and not do anything. You know, you're so many miles away, it feels so helpless.

Mother H, who has 20 hours of nursing care a day when her daughter is not hospitalized, describes the impact of having medical professionals in her home to care for her daughter,

And just as a mom, there's a lot of guilt that I still feel. Like, I'm the mom I should be doing all this. But then I have to sit back and be like, okay most 4 year olds can walk, can talk, can go to the bathroom on the toilet, you know, and aren't connected to a ventilator.

While some of the participants were able to accept the need to rely on others, two mothers continued to struggle with sharing the caregiving responsibilities. As one mother shared, "I don't want someone else to take care of him. I don't, nobody else would take care of him like I would."

The understanding of extended family and friends. Participants were asked to share whether they felt their extended family and friends understood what the experience of serious childhood illness and extended hospitalization has been like for the family. All but one participant stated they did not believe others understood the experience. Four of the participants felt as though, unless someone has personally experienced the serious illness of a child, they cannot understand the situation. Mother A reflects, "the extended family, they want to hear about everything but as far as, you know [understanding], and even my husband doesn't completely understand everything, he wasn't here the whole time." Mother G echoes that sentiment, "I think they try. And I think they have a basic

understanding. But, no, I don't think, I don't think until you've lived in an ICU, you can really understand what it's like."

Four participants felt that since their friends and extended family did not understand the situation, they lost connection with them. Mother A explained,

My very close friends, I don't have any anymore. It got really hard because some of them had babies at the same time and they are walking now, and talking, and playing with toys the appropriate way. And they look at Patient A and they're just like 'oh I don't know how you do it' and I really don't like that... We don't connect. We are not on the same level anymore.

Another participant stated,

Our lives still stay the same, we're constantly going through this and Patient H constantly struggles everyday. I mean, that never changes and everybody else's lives go on. Like, I almost relate [it] to when somebody dies, you know, everybody wants to be there to help and then it's like, they go on with their lives and kind of forget, and the person that lost somebody is still struggling with that. And it's kind of the same thing. You know, we still go through this all the time but everybody else kind of goes on with their life.

Along these same lines, two participants felt as though the support of friends and family dwindled the longer the patient needed medical care, "once Patient B turned one and people were like, okay he's not going to die, they were like, once in a while, oh hey, how you doing, do you need anything?" Another mother described her family as supportive and involved when the patient was "on her death bed" but once she was stable the support faded away.

In summary, the experience of serious childhood illness and extended hospitalization impacted several facets of the family structure and functioning. While the participants had described their families as "normal" prior to the hospitalization, they acknowledged their family had now "changed". Transformations in the family were reflected in relationships among the family members, perceptions of oneself within the

family unit, and the family's relationship to those outside of the family unit. It is these changes that generate ambiguous loss. The loss of the family as it had been, along with the lack of understanding and validation from those outside of the family, resulted in the uncertain or vague loss that is ambiguous loss.

Coping and Hopes for the Future

Losses. The participants were asked what they missed about life prior to the diagnosis and hospitalization of their child. While the answers varied somewhat depending on unique features of each family, the common theme was that mothers missed the normative family experience. Mother A stated, "I miss being able to play. That's it. There's so much time in the hospitals." Mother C shared that she misses the routine of everyday life at home. Mother F misses "just being at home with your own stuff."

Two of the mothers whose children experienced extended hospitalization immediately after birth shared that they missed normal interactions with their baby. They compared interactions with the patient to their experience with their other children. "With Brother D [I was] at home a lot. And holding him whenever. And feeding him. And... (Pause) Patient D, we can hold, but... It's not the same. I don't know. And she's on a feeding tube" explained Mother D. Mother B shared a similar experience,

The thing with Patient B was that because he was tube fed and because he was small, we had to set our alarm and wake up every two hours to feed him, even though he never woke up. So it's a totally different dynamic... I will never forget when the doctor said you can stop giving the 4 o'clock feeding. And he was two and half [years old].

Coping with uncertainty. When asked how they cope with the uncertainty of their child's diagnosis, treatment, and future, all but one of the participants stated they

take things day by day. “Just kind of go a day at a time. There’s not much more that we can do than that” explained Mother A. Participants noted this can be difficult,

I just take it day by day... I’m one who I want to know, I’m like okay, so in a year it’s going to be all good then? I mean, I want to know. But, I’ve learned to be a little bit more, you know, a little bit more flexible with the fact that we don’t know.

Mother B stated “to worry about the future is silly because no matter what I do it’s not going to necessarily match up with what [God] is going to do.” Mother H stated “we don’t always try to plan the future because with her we’ve found that we just can’t. Take it day by day.”

Five of the participants also stated they relied on their faith to help them cope with uncertainty. Mother A stated,

I had grasped in my mind several times that he may die. He may die and we might have to go home empty-handed after being here for months. And, I lost two children through miscarriages, so my faith is very secure where my children are going... I was at peace through very difficult times and I don’t know what’s coming.

Mother C also put her trust in God, “keep the faith alive and just trust in Him, which is the hardest thing. It’s like here’s my baby God, do what you got to do.” Similarly,

Mother E shared,

I just put a lot of trust in God, like you know what to do. And I’m not going to worry about it anymore because it is what it is, if it’s her time, then it would be her time and if not, then she would be here to wake up the next morning. And she has woken up every morning ever since then.

Two of the mothers noted they tried to stop worrying about the patient because there is uncertainty in many areas of life. Mother H stated, “I was always so concerned about something bad happening to Patient H. But its like I don't know, the other kids could get hit by a car, you just never know.” Mother B shared a similar attitude,

Even when you think you have a full term healthy baby, doesn't mean that there's not going to be something wrong down the road. Whether it is a physical, mental or, I mean it could be a car accident and you lose them mentally forever.

Hopes for the future. The participants were asked to describe their hopes for the future. Again, these responses were varied but the common thread was that mothers hoped their children grew up to be strong and lead a normal life. While the mothers described their hopes as “grand” or “big”, the hopes are actually quite simple. Mom A stated,

I have grand hopes. I don't know how many of them are going to be fulfilled... I want him to walk, I want him to be able to play, I want him to talk, communicate, and I guess I just I want him to be done with surgeries for a while.

Mom B also stated she had big hopes for her children, “I always have big dreams and big hopes for all of my children... I think the biggest thing you can hope for is just happiness, I want them to do what makes them happy”. Mother E talked about her daughter's future,

I think that she will grow up and be a very strong person. I think she'll continue to touch people. And she'll be able to use her story to help other people with problems that they might face, knowing that you don't give up, never give up cause there's always a hope no matter how small that window is. There's still always a glimpse. And, I think she'll do great things. I really do.

Lessons learned. Participants were asked to share what they have learned throughout the experience of serious childhood illness. Five of the mothers reflected that they learned their family is stronger than they initially thought. Mother G reflected,

I think it's made us realize that we're a lot tougher than we thought we were. That we can handle a lot more and that we don't necessarily need as much from our families as we thought we did... since we've had Patient G, it's just been up to us, and so we've realized that, you know, we can make these decisions. We can take care of him and take care of our other children and still be a family at the same time.

Mother C shared a similar sentiment,

And the experience is amazing. I mean, I would never hope that this would happen to me or anybody, but for it to happen to you, you grow strong and you see your own strengths. I never knew I was this strong.

The participants accepted the experience of serious childhood illness as part of their family's story. There was mention of the positive effects on the family in the midst of a difficult time. "I think she's definitely made our family stronger. And I mean every person in your family has their part, but she's taught a lot of people a lot of things" shared Mother H. The participants acknowledged the experience would continue to impact their family. As one participant shared, the experience would be a "forever changing thing."

In summary, the participants acknowledged losses as a result of the extended hospitalization, most notably the loss of a normative family experience. The participants did not believe their family would return to its pre-illness state, however trusted the experience would leave a positive impact on the family. While the participants described the losses, uncertainty, and changes as difficult, they felt their families were already stronger as a result of the experience with extended hospitalization and believed they would continue to grow stronger.

Discussion

The findings from this study begin to shed light on the family's experience of ambiguous loss during extended hospitalization. For the purposes of this discussion, the ambiguous loss framework developed by Pauline Boss (1999) will be used to explore the impact of extended hospitalization on the family system. The findings reveal the participants experienced elements of ambiguous loss, particularly ambiguous absence and family boundary ambiguity, during serious childhood illness and extended hospitalization. However, the results did not support the experience of ambiguous presence as previously anticipated. Furthermore, the impact of ambiguity on the participant's coping and hopes for the future will be discussed.

Results

Each family had a distinctive experience with serious childhood illness. When examining the results, it is important to remember each family's experiences had been impacted by features unique to their family. Factors impacting the experience included the family's structure and constellation, the age at which the patient was diagnosed, the number of hospitalizations the patient had experienced, and the prognosis of the illness.

For half of the families, the patient had experienced multiple hospitalizations and their health concerns had become chronic rather than acute. Although the prognosis of the patient continued to be uncertain, these families had additional time to adjust to the ambiguity. For six of the families the initial hospitalization coincided with the birth of the patient. This type of experience with extended hospitalization is quite different from the instance in which a child, who has an established role in the family, is hospitalized. Although the specifics of the participant's stories varied based on these factors,

similarities in their experience with ambiguous absence, family boundary ambiguity, and coping resounded.

Perceptions of family life prior to the hospitalization. It is essential to have a clear understanding of how the participants viewed their family prior to the extended hospitalization. An understanding of the family prior to the hospitalization sheds light onto the impact of the changes and the experience of loss. Previous research does little to explore how one's perception of life prior to an event that triggers loss impacts the development of ambiguous loss.

Participants in this research were somewhat perplexed by how to describe their family prior to the hospitalization. Participants described their family and routines simply, believing their families to be "just average" with nothing out of the ordinary. Although the responses did not provide in-depth details of family life, they painted a picture of normalcy. The participants went on to describe the serious illness and hospitalization as an occurrence that changed their family and resulted in a family experience that was outside of the norm.

The impact of the hospitalization. The participants were physically removed from their home and family for the course of the patient's medical treatment. In all of the cases, the length of treatment was uncertain, thus resulting in the patient and caregiver's ambiguous absence from the family system. Past research suggests high levels of uncertainty for the family members at home when a loved one is absent for an unknown length of time as the absent member is still perceived as psychologically present (Huebner et al., 2007; Lee & Whiting, 2007; Faber et al., 2008; Bocknek, et al., 2009).

Ambiguous absence was particularly difficult for the patient's siblings. The participants described themselves as the primary caregivers for their children prior to the hospitalization. During the hospitalization, caregiving responsibilities for the siblings were shifted to the other parent or grandparents. This change in the primary caregiver was described as confusing for the siblings. Previous research points to the importance of sharing age appropriate information with children to help them cope with uncertainty (Lee & Whiting, 2007; Bocknek et al., 2009). While participants in this research acknowledged the negative impact of uncertainty on the siblings they did not address how much information was shared with the children. More than one participant stated they were hopeful their children would simply be too young to remember the experience with extended hospitalization leading the researcher to believe the hospitalization was not being discussed with the siblings. The change in the primary caregiver, coupled with a lack of information, made the situation difficult for the siblings to comprehend.

The participants with young children shared painful descriptions of the short visits they had with their other children while the patient was hospitalized. The young siblings lacked the ability to tolerate their mother's presence for only short amounts of time and were often distressed by the presence, then absence, of the mother. Participants also shared behavioral responses of siblings, such as acting out, desiring medical attention, becoming clingy, or rejecting the caregiver. However, the participants did not make mention of the internal experience of the siblings. Previous research has revealed increased feelings of loneliness and anxiety for healthy siblings during treatment for serious childhood illness (Hamama et al., 2000; McGrath, 2001; Hamama et al., 2008). The participants in this research did not make mention of such feelings in the siblings.

Some participants made statements such as “he’s a big boy, he’s tough” and “it’s just the way it’s got to be” when discussing the impact of the hospitalization on the siblings. It is important to note the participants also shared personal feelings of guilt regarding their absence from the siblings’ life; perhaps discounting the full impact on healthy siblings was self protective in nature. In this way, the interconnectedness of the family’s coping is further revealed; each family member’s understanding of the situation and ability to cope with the changes was impacted by others within the family unit.

The findings also reveal an impact of ambiguous absence on the marriage relationship. While only one participant revealed she felt her marriage was suffering as a result of the extended hospitalization, several participants agreed the extended illness had a strong potential to end their relationship. Drawing upon previous research conducted on military deployments, the findings of this study concur with previous results indicating that a lack of information, or communication, is stress provoking for partners at home (Faber et al., 2008). Increased attention to communication was the primary method described to maintain the marriage relationship.

A predominant theme throughout the interviews involved the changes within the family structure as a result of the extended hospitalization. Participants described changes in roles, family boundaries, and the definition of family. Similar to studies exploring the impact of military deployments on the family structure, the participants reported the need to restructure and redistribute roles to maintain homeostasis (Huebner et al., 2007; Faber et al., 2008). In this study, restructuring led to expanding the family boundaries to include extended family, friends, and medical staff. It also resulted in the caregiver surrendering caregiving responsibilities for the healthy siblings. Families

found it was essential to restructure to ensure the needs of all the family members were met.

The participants shared mixed feelings regarding the expansion of family boundaries. While many were eager to include families they met during the hospitalization into their “hospital family”, they also found it difficult, albeit necessary, to share caregiving responsibilities with extended family or medical staff. While the participants were thankful for the medical care received, none felt as though members of the medical team were part of their “hospital family.” The results of this study run counter to previous research conducted by Heims et al. (1997) in which parents were comforted when the health care professionals caring for the patient were viewed within the family system rather than as outsiders. Rather, the participants of this study welcomed expanding the family boundaries to increase emotional support but hesitated when it came to accepting practical assistance.

As a result of the family’s restructuring, the time spent undergoing medical treatment, and the lasting implications of a child with a serious medical illness, the findings reveal participants felt as though their family was missing out on a normative family experience. This loss of a normative family experience agrees with previous research on the topic of acquired brain injury and autism (O’Brien, 2007; Collings, 2008; Kean, 2010). While the participants continued to have hopes and dreams for their children, these hopes became simplified. The participants in this study shared hopes that the child would be able to fit in with peers in the future, experience a normal developmental trajectory, be free of medical intervention in the future, and the hope that their child would simply survive. These findings indicate participants were faced with

continued uncertainty about the patient's future along with the loss of a normative family experience.

Impact of ambiguity on coping. Ambiguity impacts one's ability to cope. Due to the uncertainty of the situation, individuals are often immobilized or frozen in their grief. A lack of social acceptance or understanding further complicates coping (Boss, 2006). The primary method of coping with uncertainty, for this research's participants, was to take life "one day at a time." Many of the participants shared there was no other option than to take things day by day due to the unknowns of the future. Previous research conducted on coping with uncertainty provides mixed results. Research by Eakes (1995) concurs with the current findings of taking each day as it comes. Conversely, other research points to the benefit of receiving constant information regarding the patient's care (Heims et al., 1997) or promoting the parent's sense of mastery over the situation (Mu et al., 2001) to defuse uncertainty.

Participants in this research also reported relying on their faith to help them cope with ambiguity. Previous research has not explored the benefit of faith when faced with ambiguous loss. Participants in this research found it easier to handle the unknown if they believed God was in control of the situation and aware of the outcomes. Participants shared how their faith also helped them cope with the potentially negative outcomes, such as death. By placing their faith in another entity, God, the participants were able to focus on the present rather than worry about the future.

The participants described how they did not feel others understood their experience of serious childhood illness and hospitalization. Participants also explained support faded away the longer the child required medical care. This lack of

understanding and involvement impacted the participants' perceived level of support. Participants described minimal emotional support from friends and family due to a disconnect and lack of understanding. A common response was that unless someone has experienced the serious illness and hospitalization of a child, they cannot begin to understand the situation. Participants' ability to cope increased when they made connections with other parents experiencing extended hospitalization. This further supports findings by Patrick-Ott and Ladd (2010) regarding the benefits of support groups. The understanding of others is particularly important when one is faced with ambiguous loss. It is the lack of recognition that makes ambiguous loss particularly difficult to cope with.

Limitations

The primary limitation of this study was the small sample size, and for this reason, the generalizability of the findings is limited. Additional research is needed to obtain substantial results. Furthermore, the sample consisted of eight Caucasian women of low to moderate socioeconomic status and thus cannot be generalized to the greater population.

Another limitation of the current study was the use of availability sampling. Since participation in the research was voluntary, one can deduce the participants were at a point in their personal experience in which they felt comfortable sharing their story. As mentioned, half of the participants had experienced multiple extended hospitalizations and the illness of the patient had become chronic, rather than acute, in nature. The ambiguity of a situation is likely to change over time as the family adjusts to a new definition of normal.

The study set out to explore the parents' perspective of the changes within the family structure during a child's serious medical illness and hospitalization and how these changes can be understood from an ambiguous loss framework. While the perspective of the caregiving parent is valuable, it is an interpretation of responses rather than first hand accounts of the patient, siblings, and partner. Important elements and reactions of other family members may have been overlooked in this study due to the interpretation of the participant.

Directions for Future Research

Given that the current amount of available research on serious childhood illness and ambiguous loss is fairly limited, additional studies are needed to draw conclusions on how serious childhood illness impacts the family system and interventions that can be utilized to assist families in coping. Future researchers would be wise to interview the patient, siblings, and the other parent, both during the treatment process as well as in years following. Longitudinal research would shed light onto the lasting effects serious illness has on a family system.

There may also be benefit in researching the experience of ambiguous loss within each illness group. Future researchers may also consider the amount of time lapsed since the initial diagnosis. As seen in this research study, a family facing the premature birth of a baby encounters a different set of challenges and adjustments than a family faced with the cancer diagnosis of their school aged child. Furthermore, long term implications and outcomes of serious childhood illness vary depending upon diagnosis and this also impacts feelings of ambiguous loss.

The researcher had anticipated finding elements of ambiguous presence in the interviews. Previous research on psychologically absent family member reveals grief reactions stem from the loss of the family member as they had once been (Dupuis, 2002; Collings, 2008; Kean, 2010). Six of the participants experienced an extended hospitalization that coincided with the birth of the patient. Therefore, the child did not have an opportunity to enter into family life or develop an identity within the family outside of being the patient. Additional research focusing on the new diagnosis of older children would likely shed additional light onto this area of ambiguous loss.

Implications for Social Work Practice

Serious illness and the impact it has on the family system is of utmost importance for social workers. Family systems theory highlights the interrelatedness of family members and the importance of considering the family as a whole rather than the members in isolation (Kerr & Bowen, 1988). Therefore, knowledge of how an illness impacts each member of the family, and the family as a whole, is crucial for professionals no matter the age of the patient.

Ambiguous loss and uncertainty are prevalent in many areas of life, not only in the context of serious childhood illness and extended hospitalization as seen in the current research. Ambiguous losses continue to be under recognized and receive little clinical attention. However, as Boss (1999) and Worden (2009) point out, the solution is not to focus on training additional grief specialists. Rather, clinicians in every area of practice should be aware of and address the grief that is embedded in the daily life of clients. An acknowledgement of the presence and impact of ambiguous loss is necessary if social workers are to help clients through these difficult and confusing losses.

Furthermore, social workers have the responsibility of providing education for clients. As many of the participants in this research study noted, they benefited from being told that serious childhood illness can have a detrimental impact on the marriage relationship. Offering such education to clients regarding the potential for ambiguous loss and changes within the family system during extended hospitalization can assist with coping. Likewise, social workers can provide education to foster mindfulness of the struggles each family member may be facing and the impact of these struggles on the functioning of the family unit.

When working with families faced with an ambiguous loss, it is essential to be aware of factors that impact the experience and expression of loss. Although grief is a universal experience, no two people grieve in the same manner (Schoeneck, 2003). As seen in this research study, although the participants were a relatively homogenous group, each mother experienced ambiguous loss in a unique way. Social workers should be aware of factors impacting grief such as gender, culture, spirituality, and cognitive ability as well as one's personal history pertaining to loss (Corr et al., 2006).

This research study provided valuable information on the topic of serious childhood illness. However, there is much work to be done in this area to adequately assist families in coping with serious childhood illness and extended hospitalization. Too often the needs of family members fade into the background during the treatment process, leaving each to cope with feelings on their own. It is important for professionals to "listen, validate feelings, show on-going concern, offer realistic hope, listen again" (Schoeneck, 2003, p. 142).

Social workers are obligated to provide comprehensive care to individuals and families as well as advocate for care on a larger, systemic level. Since social workers are aware of the impact of serious childhood illness on the entire family, they are ethically required to advocate for programs and policies that support the family system. Taking into consideration the losses that are experienced during treatment for serious illness, larger systems would be wise to provide increased supportive care to families as they cope with the changes brought about by a heartbreaking diagnosis, the restructuring of the family unit throughout treatment, and alterations in the family following treatment for serious childhood illness.

Conclusion

This research study explored the important topic of ambiguous loss within the family system during serious childhood illness. It established the family does experience ambiguous loss during extended hospitalization. The eight women interviewed for this study shared their experience with ambiguous absence, family boundary ambiguity, and the loss of a normative family experience. Ambiguous losses continue to be under recognized despite their impact on the family's coping and functioning. Clinical awareness and treatment of ambiguous losses are necessary to provide the highest level of holistic care to families faced with the serious illness of a child.

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Research Opportunity

Please consider sharing your family's story of childhood illness and hospitalization.

This research is being conducted through the University of St. Thomas graduate social work program.

The purpose of this study is to explore how your family has changed, and how your family is managing during your child's serious illness and hospitalization.

The only thing you will be asked to do is participate in one interview, approximately an hour long.

**If interested, please
contact the researcher:
Erin Hillegas**

*Unfortunately, Blood & Marrow Transplant (BMT) families cannot be considered for this particular research study.

Appendix B: Agency Approval

November 28, 2011

Dr. Eleni Roulis, Chair
Institutional Review Board
2115 Summit Avenue
Mail AQU 319
St. Paul, MN 55105

Dear Erin,

Thank you for contacting this agency to discuss the proposed research you embarking on as a graduate student at the University of St. Thomas/St. Catherine University School of Social Work. I am pleased to confirm that you have the support of this agency in recruiting our families as part of your research project: Family Experiences of Ambiguous Loss in Response to Serious Childhood Illness: Parental Perspectives.

I understand that your study is qualitative research project that will invite families staying at this agency to participate in interviews. This agency will display a recruitment flyer on our bulletin board and interested families will be asked to contact you directly. I appreciate the care you will take to implement the appropriate measures to protect the confidentiality of the research participants as well as the organization.

I understand that you will not proceed with your research until you have received the approval of your research committee and the Institutional Review Board at the University of St. Thomas. I also understand your research project is a part of your graduate work and will be published and presented in a public forum.

I do not anticipate any direct benefit or risk to our organization. However, I certainly believe there will be an indirect benefit from your research, in that you will be adding to the knowledge base in the field of social work in an important area of study that has received little attention.

Appendix C: Resource List

Crisis Connection

Offers 24-hour crisis counseling by telephone at 612-379-6363

Parent to Parent Support

Offered through Children's Hospital. Call 612-813-6059

National Children's Cancer Society

Offers emotional support at www.thenccs.org or 1-800-532-6459

Neighborhood Involvement Program

Offers sliding scale counseling services. Call 612-374-4601

Appendix D: Consent Form

Consent Form
University of St. Thomas

Family Experiences of Ambiguous Loss in Response to Serious Childhood Illness:
Parental Perspectives
[288840-1]

I am conducting a study about the changes within the family system during a child's medical illness and hospitalization. I am interested to know how these changes can be understood from an ambiguous loss framework. Ambiguous loss refers to a situation that remains incomplete, confusing, or uncertain for family members. I invite you to participate in this research. You were selected as a possible participant because you are the parent of a child experiencing a lengthy hospitalization or medical treatment. Please read this form and ask any questions you may have before agreeing to be in the study.

This study is being conducted by Erin Hillegas, a graduate student in social work, and supervised by Kari Fletcher, social work professor and research advisor, from the St. Catherine University/University of St. Thomas School of Social Work.

Background Information:

The purpose of this study is to explore the parent's perspective of the changes within the family structure during a child's serious medical illness and hospitalization and how these changes can be understood from an ambiguous loss framework.

Procedures:

If you agree to be in this study, I will ask you to participate in a one hour in-person digitally recorded interview about your experience with extended hospitalization. Interviews will take place in a private location determined with the researcher and interviewee.

Risks and Benefits of Being in the Study:

The study has some risk. You will be asked to share information about your family that is personal and may be potentially difficult to discuss. I will provide you with a list of counseling and support resources for parents experiencing the serious illness of a child. Please note that you (or a third party payer) will be responsible for the cost of any subsequent treatment.

There are some benefits for your participation. Sharing your story will add needed information to the field of serious childhood illness and potentially help families in a similar situation in the future. Furthermore, you will receive a \$10.00 Target gift card for your participation in this study.

Confidentiality:

The records of this study will be kept confidential. In any report published, I will not include information that will make it possible to identify you in any way. The types of records I will create include digital recordings, handwritten notes, and typed transcriptions of the interview. The handwritten notes and any printed transcriptions will be kept in my home in a locked file cabinet that only I will have access to and will be shredded by June 1, 2012. The digital recordings and typed transcriptions will be stored on my personal, password protected computer that only I have access to. These will also be destroyed by June 1, 2012. All identifying information will be removed from the data.

Voluntary Nature of the Study:

Your participation in this study is entirely voluntary. Your decision whether or not to participate will not affect your current or future relationship with St. Catherine University, the University of St. Thomas, or the agency from which you were recruited. If you decide to participate, you are free to withdraw at any time during the interview or up to one week following the interview without consequence. Should you decide to withdraw in that time frame, data collected from you will not be used and you will still be provided with the \$10.00 Target gift card. You are also free to skip any questions I may ask.

Contacts and Questions

My name is Erin Hillegas. You may ask any questions you have now. If you have questions later, you may contact me. You may also contact Kari Fletcher, research advisor. You may also contact the University of St. Thomas Institutional Review Board with any questions or concerns.

You will be given a copy of this form to keep for your records.

Statement of Consent:

I have read the above information. My questions have been answered to my satisfaction. I consent to participate in the study. I am at least 18 years of age.

Signature of Study Participant

Date

Print Name of Study Participant

Signature of Researcher

Date

Appendix E: Interview Questions

Demographic information

Participant and relationship to child:

Who are the important members of your family?

Roles, ages:

Child's diagnosis:

Date of first diagnosis:

Length of hospitalization:

Length of treatment:

Family structure prior to hospitalization

Tell me about your family prior to this medical crisis.

Who was considered to be "in" the family?

How did you communicate with one another?

What roles did each member fulfill?

What activities did your family enjoy doing together?

Current family structure

How has your family changed since diagnosis/hospitalization?

Who is "family" for you now? Has it changed? Who's in, who's out?

How do you see (the child's) place in your family now?

Who is caring for your other children during this time?

Have some of the professional team become "like family" to you now?

Have family rules and roles changed?

Who does what? (meals, housekeeping, finances, caregiving, decision making)

What family role/tasks have you lost? What family role/tasks have you gained?

How do you manage these changes?

What sorts of activities does your family enjoy doing together now?

Ambiguous loss

What do you miss about the way things were prior to hospitalization?

Do your friends and extended family understand what this experience has been like for your family?

How do you think your family will look when this hospitalization/treatment is over?

Do you hope to return to your "pre-illness" family structure? How will you accomplish this?

Is there anything else you would like to share with me?