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Death of a Brother or Sister: Siblings' Perception of their Health, Treatments and the Associated Health Care Costs

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FLORIDA INTERNATIONAL UNIVERSITY

Miami, Florida

DEATH OF A BROTHER OR SISTER: SIBLINGS'
PERCEPTION OF THEIR HEALTH, TREATMENTS
AND THE ASSOCIATED HEALTH CARE COSTS

A dissertation submitted in partial fulfillment of

the requirements for the degree of

DOCTOR OF PHILOSOPHY

in

NURSING

by

Rosa M. Roche

2014

To: Dean Ora Lea Strickland
College of Nursing and Health Sciences

This dissertation, written by Rosa M. Roche, and entitled Death of a Brother or Sister: Siblings' Perception of their Health, Treatments and the Associated Health Care Costs, having been approved in respect to style and intellectual content, is referred to you for judgment.

We have read this dissertation and recommend that it be approved.

JoAnne Youngblut

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Date of Defense: June 17, 2014

The dissertation of Rosa M. Roche is approved.

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Florida International University, 2014

DEDICATION

I dedicate my dissertation work to my family and very close friends. A special feeling of gratitude to my loving mother for always being my support. To my father, who is in heaven, I would like to give a special thanks for having instilled in me since I was very young, to set high standards, set goals and persevere and to never give up reaching for my dreams, it is all possible. To my husband, thank you for being there when I needed you and for putting up with the sun lamp during those long nights during my course work. To my children and grand-daughter, thank you for providing meaning to my life during challenging times. To my friends, Ivette, Bela, Laura and Andy, thank you for being by my side throughout the entire doctoral program, always providing me with words of encouragement to continue on my journey.

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ABSTRACT OF THE DISSERTATION
DEATH OF A BROTHER OR SISTER: SIBLINGS
PERCEPTION OF THEIR HEALTH, TREATMENTS AND
ASSOCIATED HEALTH CARE COSTS

by

Rosa M. Roche

Florida International University, 2014

Miami, Florida

Professor Dorothy Brooten, Major Professor

Death of a child is a very painful experience for parents and remaining siblings who experience physiological and emotional symptoms as described by the parents. There are few reports from the remaining siblings on their physical and emotional health and even less data on their treatments and associated health care costs after sibling loss. The purpose of this study in children who have lost a sibling in the NICU/PICU, ER or those who have been sent home on technology dependent equipment to die, is to compare parents' and children's perceptions of the surviving sibling's health, identify factors related to these perceptions, and describe treatments for the sibling's physical and mental health at 2 and 4 months after a sibling's death. Sixty four surviving siblings and their parents reported on the siblings' mental and overall health. Available treatment charges (visits to the emergency room, physician office, hospitalization, and any health services (mental & physical) since the sibling death were collected from bills and insurance receipts. Cause of child death (acute or chronic) was collected from the deceased child's hospital record. The relationship between parent and sibling's perception of the

surviving sibling's health, and anxiety and depression at 2 and 4 months post the death were measured using the Children's Depression Inventory and the Spence Anxiety Scales. Data were analyzed using: T-Tests, ANOVA, Pearson correlations, frequencies and descriptive statistics. Findings indicated that at 2 and 4 months parent's perceived their surviving siblings' health to be better than the child perceived his/her health to be. At 4 months fathers rated the siblings' health compared to their peers lower than the siblings. Greater child anxiety was related to lower father's ratings of the child's health now and compared to peers. Treatments and charges increased from 2 months to 4 months with males having more treatments than females. The majority of the treatments consisted of routine physician visits, non-routine physician visits, emergency room/urgent care visits and counseling. Study findings can help guide healthcare providers and educators in identifying those children that are at high risk for negative health effects after the death of a sibling.

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CHAPTER I

INTRODUCTION

Significance

In the United States there are over 67,044 child deaths (over 1 year of age) and 26,531 infant deaths per year (The National Vital Statistics Report, 2011). Death of a child is a very painful experience for parents and siblings and has lasting effects on the family for years (Fletcher, Mailick, Song, & Wolfe, 2012). Approximately 2 million children experience the loss of a sibling each year leaving 25% of them in need of clinical intervention and more than 50% with significant behavioral problems (Charles, Charles, 2006; Packman, Horsley, Davies, & Kramer, 2006). Very few children receive any type of preventive or clinical intervention.

The surviving children experience a variety of emotions, ranging from anxiety and guilt to depression and suicide. Children respond to the death of a sibling with changed behaviors including acting out, aggression, withdrawal, lower school functioning and changed relationships with peers, parents and other siblings. Children also experience physiological symptoms that include allergies, asthma, stomach-aches, day wetting, and nausea and skin rashes (Birenbaum, 2000). These changes are dependent on the age and gender of the surviving sibling, the relationships with the deceased, the nature of the death and the child's support systems. Siblings lose not only their friend, mentor and life-companion but also the attention of their grief stricken parents who lack the energy to reach out to their surviving children.

Most physical and behavioral changes as well as morbidity and mortality occur within the first year following the death of the brother or sister but the effects on the surviving sibling may remain for decades. Children report experiencing changes in school work, activities/interest, personality, goals and life's perspectives during the first year after the death of their sibling (Foster, Gilmer, Vannatta, Barrera, et al., 2012). Bereaved adolescents show higher self-injury behaviors and higher rates of suicide during the first year following the death of a loved one than non-bereaved adolescents (Grenklo, Kreicbergs, Hauksdottir, Valdimarsdottir et al., 2013). However the effects of a brother or sisters death may be experienced during later years. Recent studies indicate that siblings' may experience increased myocardial infarctions up to 18 years later (Rostila, Saarela, & Kawachi, 2013). Other studies found consequential effects in adult years for those adults who had lost a brother or sister in early life (Fletcher et al., 2012). Girls and boys that had experienced the death of a sibling early in life (during the formative years) had higher school drop-out rates, less years of education, were less likely to attend college and girls had higher rates of teenage pregnancies and were more apt to be dependent on public assistance and food stamps (Fletcher et al., 2012).

The research on children responses to the death of a sibling is limited and what is available is from the parent's perspective. Research on children's responses to the death of their brother or sister from the child's own perspective is extremely limited. Studies have demonstrated that parent's and children's perceptions of the child's physical and mental health differ. These differences may be due to the parent's becoming overwhelmed by grief, overlooking the needs of their surviving child and not available to provide the support that the remaining children may require.

The lack of early identification of children “at risk” for physical and mental problems after losing a sibling leads to significant physical and mental problems in the later years and to rising healthcare costs (Glazebrook et al., 2002). Research has indicated that these surviving siblings are not being identified as being “at risk” from several perspectives. Parents are not identifying that their children are grieving and experiencing ill feelings because they are overwhelmed dealing with their own grief. Primary care providers are not assessing children’s emotional state during their routine visits and schools do not have trained personnel or programs in place that could lead to early identification of children “at risk”. As a result, the research on children’s physical and mental health for the first year and beyond following a sibling’s death is extremely limited.

There are both human and financial costs associated with the physical and mental health of children who lose a brother or sister. Human costs include changes in the physical and mental health of the surviving sibling, effects on the family and financial costs including costs for treatment of the surviving sibling. There is limited research reported on the financial treatment costs for sibling’s following the loss of a brother or sister including unscheduled physician visits, emergency room visits, hospitalizations and medications. The available literature consists of children’s experiences with support groups, summer camps, school intervention programs and having open communication with parents or others. All benefit children in a time of grief (Horsley and Patterson, 2006; Nolbris et al., 2010). Children have found that attending a support group helps them feel that they are not alone. Here they are able to share their thoughts and feelings without being judged.

There is a lack of child psychiatrists and mental health care services available for children. The few services that are available are not being used because children are not being identified and not being referred for care. In addition families have fear of their child being “labeled” as having emotional or behavioral problems. The lack of child psychiatrist is due to physicians not wanting to specialize in this field due to poor reimbursement rates and issues with medications for children with mental health issues. Many of the bereaved children are being seen for the first time in an emergency room when an acute situation arises. Research indicates that the most common mental health diagnoses in an emergency room for adolescents under the age of 19 are depression, anxiety, behavioral issues, suicide attempts and drug and alcohol use (Pittsenbarger, 2011). However it is not clear if these mental health issues were due to sibling bereavement. Data on the costs and use of health care services (mental health services, acute care, medications) for children after the death of a sibling are not reported. Research is needed to investigate the effects that losing a sibling has on resulting treatments and associated health care costs.

In summary, death of a child is a very painful experience for parents and siblings and approximately 2 million children experience the loss of a sibling each year. A quarter of them are in need of clinical intervention but very few receive these services. About half of these children experience behavioral and physical problems. There is ample literature from the parent’s perspective indicating that children experience both physical and emotional symptoms including acting out behaviors, self- injury behaviors, trouble focusing in school and even suicide. However there is very little literature from the child’s perspective about their physical and emotional health. In addition, there is very

little literature on treatments and associated health care costs for children who have lost a sibling. There is conflicting literature demonstrating when the effects on children occur, within the first few months, within the first years or over decades later (Leder, 1992; Lohan & Murphy, 2001; Qin & Mortensen, 2003; Rostila, Saarela, & Kawachi, 2013). Research is needed to address these knowledge gaps. Research is needed comparing the parent's and children's perceptions of the surviving sibling's physical and emotional health, treatment for health conditions and associated health care costs. Such data are needed to guide clinical care, healthcare policy decisions and direction for further research to promote the health and well-being of children who have lost a sibling and their families. Thus the purpose of this study is to begin to provide such data.

Study Purpose

The purpose of this study in children who have lost a sibling in the NICU/PICU, ER or those who have been sent home on technology dependent equipment to die peacefully, is to compare parents' and children's perception of the surviving sibling's health, identify factors related to these perceptions, and describe the treatments for the sibling's physical and mental health at 2 and 4 months after the death.

The study addresses the following research questions:

1. At 2 and 4 months post-death, are there differences between the parent's perception and the surviving child's perception of the child's own health:
 - a) now
 - b) now compared to before the death of their sibling, and
 - c) now compared to others their age?
2. Are there differences at 2 and 4 months post-death in the concordance

between parent and child perceptions on child's health by child age (6 to 10, 10 to 13, 13 to 18), race/ethnicity, gender and cause of the brother's or sister's death (acute vs. chronic illness)?

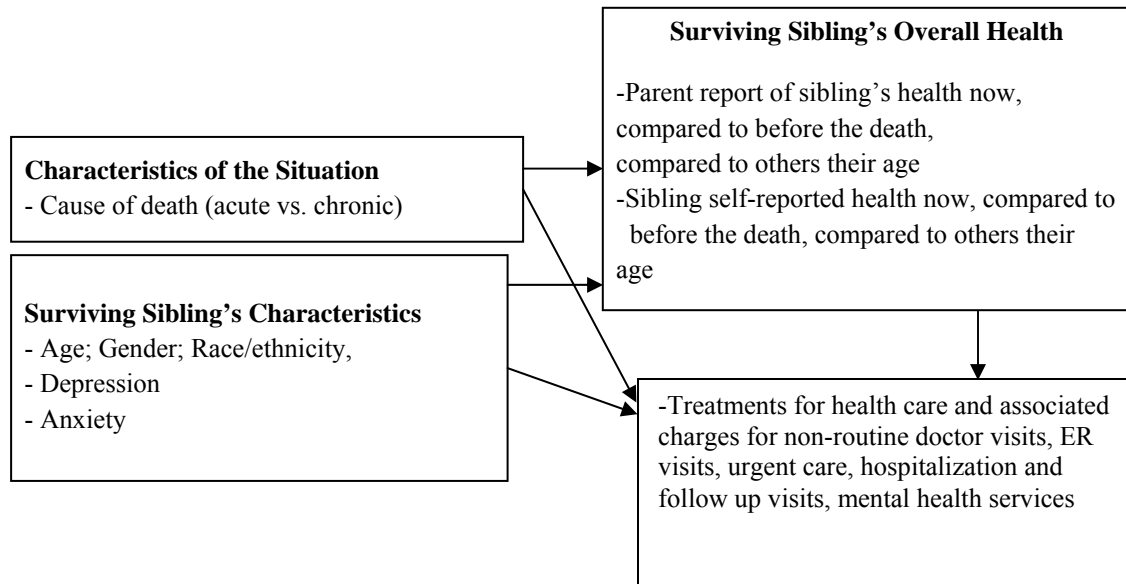
3. Are the parent's and the child's perception of the child's health related to the child's anxiety and depression at 2 and 4 months post death of a sibling?
4. What are the treatments and associated charges for the surviving child's physical and mental health (non-routine physician visits, urgent care, emergency care, hospitalizations, and mental health services) over the 4 months after the death of a sibling?

Data on the parent's and child's perception of the child's health including anxiety and depression were collected at 2 and 4 months after the death of the sibling. Copies of receipts and/or insurance claims of treatments (non-routine physician visits, urgent care, emergency care, hospitalizations, follow up visits for the former and mental health services) were collected over the first 4 months after the death of the sibling.

Conceptual/Theoretical Framework

The study's theoretical model is based on the Family Systems Theory. The characteristics of the situation include the nature of the child's death (acute vs. chronic). The surviving sibling's characteristics are (age, gender, race/ethnicity, depression and anxiety). Outcomes are parent report and siblings self-report of the sibling's health now, compared to before the death of the child, and compared to others the sibling's age as well as treatments for health care.

The treatments and associated charges for the surviving sibling's physical and mental health (non-routine physician visits, urgent care, emergency care, hospitalizations, follow-up visits for the former and mental health services) over the 4 months after the death of a child were collected.



The independent variables (cause of death, sibling's age, gender, race/ethnicity, depression and anxiety) are expected to have an effect on the health outcomes (parent report, sibling's self-report and treatment outcomes). Parent's report of sibling's health and sibling's self-report are expected to have a direct effect on treatment outcomes.

CHAPTER II

LITERATURE REVIEW

In the United States there are over 67,044 child deaths (more than 1 year) and 26,531 infant deaths per year (The National Vital Statistics Report, 2011). Causes of infant and child death vary from prematurity, congenital anomalies, respiratory diseases, neoplasms, and Sudden infant death syndrome (SIDS), to accidents, drowning, poisonings, fires, homicides, suicides and child abuse. No matter the cause, when a child dies it is a painful experience for the entire family, especially the siblings who lose not only their friend, mentor and life-companion but the attention of their grief stricken parents who often lack the energy to reach out to their surviving children. The impact of a sibling's death on surviving children can last a lifetime.

Approximately 2 million children experience losing a sibling each year leaving 25% of them in need of clinical intervention and more than 50% with significant behavioral problems (Charles & Charles, 2006; Packman, Horsley, Davies & Kramer, 2006). For young children, who have less developed coping skills and whose family members are their primary relationships, loss of a sibling may be especially devastating (Tonkins & Lambert, 1996). Factors that affect the surviving child's ability to cope with the death of a sibling include age of the surviving child, gender, closeness of the bond between the siblings, and whether the death was from an acute episode or a chronic illness. These factors leave surviving siblings vulnerable physically and mentally.

Age

A child's age and development affect their response to sibling death beginning with their understanding of death. Gibbons (1992) found children less than 3 years of

age, while capable of experiencing intense grief, do not know time and space, essential to the development of a concept of death. Children 3 to 7 years old while curious, literal and body oriented, have difficulty understanding what is lost in the process of dying. Their inability to express their feelings may appear being unconcerned about the death. Others may act out by destroying toys and other objects. Children under 9 years are limited in their ability to express themselves. They require more concrete information such as photographs and participation in rituals to cope. They gradually understand that death is irreversible and permanent.

In a classic qualitative study, Mening-Peterson and McCabe (1978) analyzed narratives about death from 96 children, ages 3 ½ to 9 ½ years old. Children who were close to 9 years of age were the only ones to talk about their affective reactions to death and emotional attachment to the deceased. In contrast, children under 5 years of age were reluctant to speak about death and those between 5 and 9 years spoke about death as if they were telling a television story plot. This is consistent with Piaget's developmental stage of concrete operations which typically occurs between the ages of 7 and 11 years, Edwards, L., Hopgood, J., Rosenberg, K., and Rush, K. (2000).

Children that have concrete operations understand the cause and effect relationship as well as how certain events can lead to death. They have a difficult time understanding and coping with death. With the exception of child who was almost 9 years old and had lost an immediate family member, almost all of the children between the ages of 3 ½ to 9 years showed absence of emotions as they spoke about death perhaps due to their lack of experience or their difficulty in emotionally coping with death. Mening-Peterson and McCabe concluded that a good way of getting a better

understanding on how death affects a child is using indirect conversation. Having a parent, who is the person who spends the most time with the child and perceives his actions and reactions to stressful situations, tell a similar story about death will most likely prompt the child to tell his own narrative of the event. Using open ended questions is the best approach to stimulating a conversation with a child (Mening-Peterson & McCabe, 1978).

Other researchers report that between 8 to 15 years of age children learn the meaning of mortality, however abstract concepts may still be difficult for them (Hindmarch, 1995). Adolescents' grief is profoundly personal and can be more intense, intermittent and overwhelming than grief adults' experience. Their bereavement reactions may include bravado, denial, anger and rage, shock, numbness, nightmares, loneliness, withdrawal, survivor guilt, substance abuse, great sadness and school problems. However, they may delay or repress their grieving to deny showing strong emotions (Malone, 2007). For some adolescents loss of a sibling may facilitate psychological growth with reported feelings of being "more mature" than most of their peers. This finding is consistent with that of Hogan and DeSantis (1996) who found that after adolescents experience a loss they not only experience negative effects and engage in high risk behaviors but some adolescents experience positive changes including being kind, having more compassion, being more tolerant and becoming more mature.

In related research, Christ (2000) used qualitative interviews to capture the grief responses of 157 children to the death of a parent from cancer. Children's ages ranged from 3 to 17 years, 80% were White, 7% were Hispanic, 7% were Black, 5% were Mixed and 1% was Asian. Children were recruited approximately 6 months before the death of

their parent. Interviews were performed at 3 Time points. Time 1 before the death of the parent, Time 2 at 8 months after the death and Time 3 was 14 months after the death of the parent. Each child responded to the death of a parent according to their developmental stage.

The 3 to 5 year olds could not understand that their parent's body would not return and function once again. Weeks after the death, they continued to ask where their parent was. Amanda a 4 year old became overly clinging and whining to her mother after her father's death. She had stomach-aches and when her mother took her to the doctor, she asked the doctor where her father was.

The 6 to 8 year olds understood that their parent had died. These children felt that the parent was watching them from heaven. They responded by being sad, angry, and fearful, had sleeping problems and had separation anxiety. These children displayed late pre-operational cognition. At times their magical thinking about the cause of the illness and death led them to self-blame and guilt. As one 7 year old stated, "I prayed that God would relieve my mother's pain the night before she died, I think I killed her" (Christ, 2000, p.76). She felt guilty because she thought God had taken her mother because she had asked him to.

Nine to 11 year olds wanted to get more details about the parent's illness and death. They were reluctant to show any emotion over the parent's death (Christ, 2000). Nine to eleven year olds responded by wanting to know facts about the illness and the death of the parent. They had aggressive behaviors, getting into fights with peers as well as poor school performance. They left letters and gifts in the parent's coffin.

Twelve to fourteen year olds showed no emotional expression with the exception of anger when learning about the parent's death. A twelve year old became upset at her mother for crying at her father's funeral. She felt that crying would not help nor bring her father back. A thirteen year old believed that her father was in heaven having fun.

Fifteen to seventeen year olds reacted like an adult. They felt helplessness, hopelessness, sadness and despair that interfered with their normal everyday activities. They engaged in externalizing behaviors such as drinking, having arguments with parents, bouts of anger and being defiant at home. Research studies on effects of losing a loved one help us understand that children as well as adults experience physical, emotional and behavioral responses according to their age and development after suffering the loss of a loved one.

It is important to assess a child's understanding of the concept of death and whether personal experiences have influenced how the child conceptualizes death. Bonoti, Leondari and Mastora (2013) studied 52 children (ages 7, 9 and 11 years) for their understanding of death through drawings. Twenty six children had personal experiences with death. Results indicated that children who had a personal death experience drew pictures related to the rituals surrounding death. They drew realistic scenes of the dead person, funerals and grave site. However children who had no experience with death drew violent scenes about death, perhaps reflecting what they see on television, in movies, and through video games.

Regardless of whether the child has had prior experience with death or not they will ask about the events surrounding the death of their sibling and often leave adults contemplating how to explain this to the young child. According to Weston (2009) adults

often avoid using the word “died” when informing children of the death of the loved one. Instead they choose to use the term “gone to sleep” or “gone away.” Because young children take things literally, this can lead to the child having difficulty falling asleep or feeling that the deceased has chosen to abandon them. Young children’s responses to a loss are exhibited by fear of the dark, fear of sirens, recurrent dreams, nightmares and night terrors, intense separation anxieties, excessive clinginess, a need to sleep with a sibling or parent, or overactive and aggressive behavior. Weston attributes this to the anxiety that a separation may provoke. In summary, research to date indicates that children respond to a sibling’s death according to their developmental age (Mening-Peterson & McCabe, 1978; Christ, 2000).

Gender

Several studies identified gender differences in children’s responses to the death of a sibling. In a study by McCown and Davies (1995) grief patterns were identified following the death of a sibling in a sample of 48 girls and 42 boys’ aged 4 to 16 years old. Their siblings had died 2 to 24 months earlier. Parents were asked to rate their child’s behavior with the Child Behavior Checklist (CBCL) from 0 to 2 with 0 = not true, 1 = somewhat or sometimes true and 2 = very true or often true. Girls were found to have more internalizing behaviors than boys. Boys had more externalizing behaviors. All boys 4 to 5 years old demanded a lot of attention whereas girls 4 to 5 years old were stubborn and irritable. The behavior of arguing a lot, being stubborn or irritable and self-conscious or easily embarrassed was found consistently more than 50% of the time across all age groups. Children’s somatic problems included eye problems (5.5%), stomachaches (20%), aches and pains (21%), headaches (21%), difficulty eating (28%)

and nightmares (30%). Nightmares were more common in children between 4 to 5 years of age. Girls were found to have more internalizing, depressed and withdrawn behaviors than boys while boys had acting out, attention seeking behaviors.

Paris et al. (2009) used child self-report to get a better understanding of the reaction of children to expected and unexpected sibling loss. Normal grief was defined as the expected process after the loss of a loved one, and as a situation where the death is anticipated. Traumatic Grief is defined as a situation where the loss of the loved one could lead to trauma of the individual resulting in post- traumatic stress disorder. Twenty six children ages 9 to 18 years old (from 22 families) who had lost a sibling participated in the study. All children were participants in a support group. Using Hogan's Inventory of Bereavement (HIB) child and adolescent forms, grief symptoms were assessed. The Impact of Events-8 (IES-8) was used to assess the child's trauma symptoms. Higher scores on both the HIB and IES-8 indicated more severe reactions. There were: 13 boys and 13 girls, racial breakdown was 17 Whites, 5 Hispanics, 3 Biracial and 1 African American. The lapse between the time of death and the start of the sibling orientation program was an average of 4.4 months. Demographics for the deceased siblings were: 17 boys and 5 girls, 17 deaths occurred suddenly (accidents, homicides, suicide and sudden illness), 5 deaths were anticipated (cancer, heart disease, chronic illness). Results indicated that grief and trauma scores were not significant, perhaps due to the small sample size or trauma and grief may overlap in responses to bereavement. Therefore the mean scores were presented instead. The results were as follows (females vs. males): anticipated death (M= 65.2 vs. 39.0), sudden death (M= 72.5 vs. 53.8) and overall grief scores (M= 69.9 vs. 52.6). In summary girls had higher

overall grief scores than boys; had a more severe reaction to sudden death than anticipated death; and reported greater grief scores and experienced more physical symptoms (withdrawn behavior) than boys after the loss of a sibling.

A study by Worden et al. (1999) compared children's responses to sibling and parental loss. The sample consisted of 125 parentally bereaved and 75 sibling bereaved school age children. Families were interviewed 4 months after the death, at the first year and at the second year anniversary of the death. The child's behavior was reported by parents using the Child Behavior Checklist (CBCL). Boys who lost a parent displayed more withdrawn behavior than boys who had lost a sibling. Pre-teen boys were even more withdrawn than teenage boys. Girls who had lost a sibling displayed more difficulty in solving problems, had higher levels of anxiety and depression than girls who had lost a parent. The investigators concluded that identifying children who are at risk for emotional and/or behavioral problems is possible. Regardless of gender, 24 % of children who had lost a parent and 25 % of children who had lost a sibling were at risk for emotional and/or behavioral issues.

In summary girls with a sibling loss exhibited higher anxiety, depression, withdrawn behavior and more attention and thought problems than boys and boys are at higher risk for emotional and behavioral problems after a parent's death. However teen girls who lost a parent or a sibling were found to be at higher risk for emotional and behavioral problems than teen boys.

Lehman et al. (1989) found that children regardless of gender were more negatively affected after suffering a sibling's death versus a parent death. These children suffered from depression, drug abuse and suicide. The timing of these symptoms was not

identified in the study. However, according to Worden et al. (1999) children were equally (25% for each) at risk for the first year after the death of either a sibling or a parent and three quarters of the children were doing well and did not need clinical intervention. Losing a sibling does not signify that a child has more emotional or behavioral issues than the child that loses a parent.

Gerhardt et al. (2011) compared bereaved children ($n = 105$) to non-bereaved classmates ($n = 311$) for social behavior, peer acceptance and friendship. Bereaved children were recruited from the cancer registry 3 to 12 months after their sibling's cancer death. Approximately 3 classmates were matched on gender, sex, age and race for every bereaved child. The existence of differences within gender, grade level and race were also addressed. The bereaved children were school age and adolescents (8 to 17 years old), 54% ($n = 57$) were females and the majority (81%, $n = 85$) were White. The deceased sibling's average age was 11.86 years and there was an average of 2.5 years from the time of diagnosis to death. Data were collected from 105 school teachers and 1,889 classmates. Teachers reported more pro-social behavior for the bereaved children than for their classmates. No differences were found in peer acceptance between bereaved children and their classmates. Peers perceived bereaved males as being more isolated and victimized than their classmates. These results contradict the findings of Worden et al. (1999) who reported that girls with a sibling loss show higher anxiety, depression, withdrawn behavior and more attention and thought problems than boys.

In the Gerhardt study differences in grade levels were also observed. Bereaved children in elementary school were perceived by their peers as less pro-social and as being more isolated than their classmates. Younger children may be less social and

become more isolated than the older bereaved children because bereaved young children are more dependent on parents. Parents may still be grieving and may not be able to help the young child cope and understand the death. Older bereaved child have a larger social network and depend on peers for support (Barrera et al. 2013). Overall this study demonstrated that bereaved male children in elementary school were more susceptible to social difficulties where as those in middle and high school presented with more leadership qualities and strengths. These leadership qualities and strengths that the older bereaved siblings display may be because of circumstances they endure after the loss of a sibling.

Rosner, Kruse and Hagl (2010) conducted 2 meta-analysis (1) controlled studies and (1) uncontrolled studies to evaluate existing treatments for bereavement and grief reactions in children and adolescents. Included in the meta-analysis were 27 treatment studies (15 studies with a controlled group design and 12 studies with an uncontrolled design) published before 2006. The results were based on the total number of children and adolescents $N = 1073$, with $n = 812$ from controlled studies and $n = 261$ from uncontrolled studies. Bereaved girls were found to be at higher risk for distressing symptoms and bereaved adolescent boys had more adjustment problems.

Overall findings indicated it was favorable to treat symptomatic bereaved children and adolescents with music therapy and school-based psycho-therapy that focused on trauma and grief. Girls benefited more from treatment than boys but as they got closer to adulthood, male adolescents benefited more from emotion- focused interventions and females from problem- focused treatment groups. These results favor the results of Little et al. (2009) study that states that girls tend to have more conflict behavior with

family members and peers due to them taking on parental tasks thus affecting their normal development. Since girls exhibit this type of behavior they benefit more from a problem-focused treatment groups where they are offered resolutions to problematic situations and ways of relieving stress.

In another study by Abdelnoor and Hollins (2004), the long term impact on school performance, level of anxiety and self- esteem were examined for children who had lost a parent ($n=73$) or sibling ($n=24$). A survey was conducted in schools across England from 1993 to 1995. Parents were asked for details of bereavements, associated circumstances, family history, school attendance and illness. Instruments included the “feelings” questionnaire which measures anxiety and self- esteem, the Spielberger State Trait Anxiety Scale for Children and the Coopersmith Self -Esteem Inventory. Participants were matched for school, age, gender, ethnicity and socio-economic status.

Results showed that parentally bereaved girls (especially after the loss of a mother) had higher anxiety scores than parentally bereaved boys. The items showing the most difference were “secret fears,” “worries” and “difficulty sleeping.” Parentally bereaved children scored lower on their examination than their controls. This was more significant for boys than girls. However, sibling bereaved girls scored lower on their examination than sibling bereaved boys and their controls. Parentally bereaved children had higher anxiety and lower examination results than sibling bereaved children. Examination scores were most affected by children who were bereaved before the age of 5 or at 12 years of age, compared to other age groups. No differences in self-esteem score, school absences or general health were found between participants and their controls.

In a related study, Little et al. (2009) examined parentally bereaved youths (N = 109) (ages 8 to 16, 52% boys) for gender differences in internalizing behavior problems. Parental death had occurred approximately 9 ½ months prior to Time 1. Ethnicity was as follows: 71% non-Hispanic Caucasian, 10% Hispanic, 7% African American, 7% Native American and 5% other. Parent's cause of death was as follows: 67% illness, 21% due to accident and 12% due to suicide or homicide. Little et al. looked closely at intrusive thoughts about grief, post death stressors, fear of abandonment and negative appraisals about interpersonal losses (separation from parents, loss of peer or adult support). Study results demonstrated that girls compared to boys showed more fear of abandonment in the first few months after the death of a parent and had higher anxiety and depression 14 months after the death. Girls initially were more stressed than boys due rising conflicts and difficulties in peer and family relationships within the first few months after the death of their parent. This resulted in higher levels of anxiety and depressive symptoms 14 months after the death of the parent. No gender differences were found relating to intrusive grief thoughts.

In summary, there are gender differences in children's reaction to both parental or sibling's death in social functioning, school performance and treatment outcomes. The evidence suggests that girls have more internalizing behaviors and boys exhibit more externalizing behaviors. Girls have more conflict behavior with family members and peers. This may be due to disruption in their normal development because they take on motherly tasks in bereaved families especially if it is the loss of a mother.

Relationship with sibling

The bond between siblings is unique and not easily understood (Tartakovsky, 2011). Siblings can be very close with one another, yet have a very complicated relationship. There can be a wide array of feelings towards one another. They can be very proud of one another and look up to each other or they can feel jealousy and rivalry. Due to the close bond that they hold, when a sibling dies, the impact on the surviving child can be immense (Packman, Horsley, Davies, & Kramer, 2006).

When a sibling dies the surviving children's self-concepts and identities are also affected, since surviving children have to redefine their personal identities as well as their role in the family (Kirwin & Hamrin, 2005). The continuing bonds that grieving siblings may have is most likely influenced by their former relationships. According to Devita-Raeburn (2004) siblings who have spent much time together have closely connected identities and are greatly affected by the death, and can feel that they are losing an integral part of the self.

Davies (1988) examined the pre-death relationship between siblings and how it relates to their grieving after the death of the sibling. The sample consisted of 55 children aged 6 to 16 years, 34 females and 21 males. There were 23 school aged children and 32 adolescents. The children were from 34 families. The demographics of the deceased siblings were as follows: 23 males and 32 females; 8 aged 1 to 5, 4 aged 6 to 8, 7 aged 9 to 11, 12 aged 12 to 14, and 3 aged 15 to 19; 16 died of leukemia and 18 had solid tumors. Ten children had been ill for less than 1 year, 11 had been ill for 1 to 2 years and 13 had been ill for more than 2 years. The Child Behavior Checklist (CBCL) was used to measure behavioral outcomes of the bereaved children. Results showed that

58.1 % of the children were rated as being very close to their siblings before the death. The children that scored the highest on the Internalizing Behavior scores (withdrawn, depressed behaviors) also scored the highest in the Closeness Index (siblings being very emotionally close). Siblings that had a close bond with their brother or sister prior to the death, were affected more and exhibited more internalizing behaviors than those siblings who did not have a close bond.

The bond between siblings' does not end at death. Studies have shown that children who have lost a sibling continue to have a relationship with the deceased sibling in some way. Batten and Oltjenbruns (1999) acknowledged that many siblings felt a presence of their deceased brother or sister and found it to be of comfort for them. The research of Forward and Garlie (2003) found spiritual beliefs to be comforting for siblings. They felt that their brother or sister was now watching over them and protecting them. They would wear their brother or sisters clothes to keep the memories alive and maintain some connection with the deceased.

Fanos, Little, and Edwards (2009) studied 14 White adults and adolescents years after the NICU death of a sibling. One participant reported that as a child he was confused seeing the infant sibling in the incubator. He thought the sibling would grow up and live in a bubble for the rest of his life. Another participant reportedly felt lucky but guilty that the infant died since her mother wanted only 2 children and had he not died she would not have been born. Others had repetitive nightmares of graveyards and zombies, and persistent anxiety. Observing fathers cry over sibling's death made children realize parents are not "all powerful or omnipotent" and affected their sense of safety and security (Fanos, et al., 2009).

Other research demonstrated that close sibling relationships, predisposes the bereaved sibling to complicated bereavement reactions including higher depression, anxiety and lower levels of mental health quality of life. However, no differences in reported physical health after controlling for age and gender effects were found (Mitchell, Sakraida, Kim, et al, 2009). This study of 60 White men and women, while including siblings did not report on sibling reactions separately.

In summary, research indicates that when a sibling dies, there is a void that cannot be filled. The child experiences an immediate sense of loss. The pre-death relationship between siblings has a relationship to the surviving sibling's reactions to the death of their brother or sister. Regardless of gender, if sibling's shared a close bond between each other, the surviving sibling exhibits withdrawn and depressed behaviors after the death of their brother or sister (Davies, 1988). Research also indicates that the bond between siblings last a lifetime and does not end at death. Many siblings keep their brother or sisters memory alive through spiritual means or family rituals such as lighting candles in memory of the deceased (Batten & Oltjenbruns, 1999; Fanos, Little, & Edwards, 2009).

Cause of Death

Studies demonstrate that surviving children are especially affected when the death of a sibling was a sudden death. In surviving siblings of children who committed suicide, feelings of guilt, shame and rejection were significantly greater than for accidental death survivors (Mitchell, 2009). In teen suicide studies, younger siblings receive little help to work through the crisis and have little parent support from their devastated parents (Dyregrov & Dyregrov, 2005). Research by Linqvist, Johansson, and Karisson (2008)

found that younger siblings received little help to work through the crisis. They were more likely to be burdened than older siblings and needed more time, persistence and uncompromising readiness by adults to deal with the most difficult questions. This problem is compounded by devastated parents with reduced capacity to care for the siblings.

Findings from Mandell, McAnulty and Carlson (1983) demonstrate that when a child loses a sibling to a sudden death such as Sudden Infant Death Syndrome (SIDS), changes in the relationship with the parents as well as in social interactions exist. Changes in sleep patterns and even having nightmares were found. Some children were more aggressive towards others (hitting other children) while others had withdrawn behavior. Approximately 1/3 of the children had changes in their eating patterns.

Lohan and Murphy (2001) report that surviving adolescents continue to have multiple grief reactions and behavioral changes up to 2 years after a sibling's sudden or violent death. In earlier research, Burns, House and Aukenbauer (1986) studied sibling grief in response to SIDS. Questionnaires that captured child grieving behaviors were distributed to families who had suffered the loss of a child due to SIDS and had a surviving child ages 2 to 16 years. Their findings in children older than 2 years of age indicated that 54% of the siblings grieved longer than 1 year, and that the length of sibling grieving was similar to that described for adults.

Koocher (1986) studying how families cope with a death from cancer stated that unlike a sudden death (where you have no preparation), death from a chronic disease such as cancer allows the family to prepare using interventions that assists the survivors

in coping with the loss. However, deaths due to chronic diseases can place great burdens on families due to the chronicity and a sense of emptiness once the child is gone.

Nolbris and Hellstrom (2005) explored the needs and reactions of children who had lost a sibling to cancer. Using a qualitative study, 10 children were recruited. Ages of participants ranged from 10 to 30 years old. The ages of the deceased siblings ranged from 7 to 20 years old. The results showed that the participants expressed feeling lonely, anxiety, anger and jealousy. When the deceased child was first diagnosed, the healthy child felt anxious about their sibling surviving. They also felt a bit of anger because the sick child was occupying so much time in their parent's life. One child expressed feeling jealous, "It felt like it was him all the time, there was no one else, just him" (Nolbris & Hellstrom, 2005, p. 230). Some even felt fear of getting cancer themselves.

The results of these studies show that regardless of the nature of the death (acute versus chronic) children do grieve and their physical and mental functioning become affected. Research has shown that providing open, honest communication and support has demonstrated to have a better outcome for the surviving child. Participating in sibling support groups appears to be helpful to the surviving siblings (Nolbris, Abrahamsson, Hellstrom et al, 2010).

Race/Ethnicity

Most studies examining effects of sibling death on surviving children include largely White samples with very limited research on the effects of race/ethnicity on the outcomes of surviving siblings. As McHale and team (2007) note, while demographic data document those families of minority youth include more siblings than European American families, most of what is known about siblings comes from research on

majority culture families. Reviews of studies on experiences and needs of parents with children in PICUs demonstrate the lack of inclusion of parents from different ethnic and cultural groups and lack of inclusion of siblings (Noyes, 1998). Shudy and team (2006) note, reports minimally investigate cultural diversity, effects on fathers versus mothers, siblings, and socioeconomic status. The studies are largely limited to those of English speaking families, White participants, and married mothers.

Nguyen and Scott (2013) examined the relationships between physical and academic self-concept, death of a family member and depression in children. The sample of children consisted of 58 boys and 60 girls and in the 5th grade. The majority were White (80.4%), Black (13%), Asian or Pacific Islander (1.6%), American Indian, Eskimo, Aleutian (0.3%) and other (4.7%). One quarter of the mothers had a Bachelor's degree or higher. Both the child and mother completed the forms used in this study. These forms were: the child's eating habits and body self- image survey (measures physical self-concept), the achievement motivation, efficacy, and educational aspirations survey (measures academic self-concept), life experience survey (mother's identified any deaths that had occurred in the family within the last year), and the Children behavior checklist (which measured depressive symptomology).

The results showed that children with lower physical self-concepts were rated by mothers' as having significantly more depressive symptoms after the loss of a family member. An unexpected finding that children with high math self-concept also had more depressive symptoms after suffering the loss of a family member. This is contrary to the study by Ward, Sylva, and Gresham, 2010 that found that children that had high academic self-concept had lower levels of depression. However one possible explanation

for this finding is that children who score high in math may tend to be high achievers and feel the pressure to succeed and when faced with an adverse event such as the death of a loved one, this may affect their achievement thus leading to feelings of depression. A limitation to this study is that the sample was predominantly White. A more diverse racial/ethnic group would give a more generalized result.

Lauri and Neimeyer (2008) studied 1,581 (940 Caucasians, 641 African Americans) bereaved college students' experiences with grief as it related to continuing bonds with the deceased, interpersonal dimensions of the loss and identity change. The Inventory of Complicated Grief-Revised, the Continuing Bonds Scale and questions related to circumstances surrounding the loss were answered by each participant. The results indicated that African Americans had more frequent bereavement due to homicide. They also maintained a stronger continued bond with the deceased, had more complicated grief symptoms, spent less time speaking to others or getting professional support than Caucasians.

Some of the limitations of these studies are that most of the population participating are Caucasians with only minor representation of other ethnic groups. Having a wider range and equal number of ethnicities in a study would give a better representation of grieving amongst children and adolescents. One example of differences in racial/ethnic groups is in the study of Lauri and Neimeyer (2008) that found that African Americans speak less to others about the deceased. This may be because African Americans rely on the support of family members, religion and their faith rather than seeking outside support.

Health

Physical Health

Grieving children may experience a variety of physical symptoms after the loss of a sibling including allergies, asthma, stomach-aches, day wetting, nausea and skin rashes (Birenbaum, 2000). In McCown and Davies (1995) research somatic problems that were observed in children who had lost a sibling were eye problems (5.5%), stomach-aches (29%), aches and pains (2%), headaches (21%), difficulty eating (28%) and nightmares (30%). Nightmares were more common in children between 4 to 5 years of age.

Zelter et al. (1996) looked at the health related finding of siblings of children with cancer. Siblings were found to be preoccupied with “catching” the sibling’s cancer. They had more concerns about their physical symptoms if the sibling’s death was related to a particular illness such as a brain tumor. They associated benign symptoms such as a headache with having a tumor and ultimately worried that death would occur. Children reported more somatic symptoms than their parents reported for them. Seventy two percent of the children reported problems with sleeping and 42% reported difficulty eating. Both physical symptoms and severity of the symptoms were under-reported by the parents. These parents were less likely to take the child to the doctor. This may be due to the parent feeling overwhelmed by their sick child’s disease or being grief stricken after their child’s death. This study supports the findings of other studies of siblings of chronically ill children and those that are bereaved from a sibling’s death which often times get overlooked by their parents (O’Haver et al. 2010; Guite et al. 2004).

Research has shown that there are associated risk of morbidity and mortality following the death of a loved one. There is a small amount of literature related to the

morbidity and mortality associated with sibling death. Most research is related to loss of a spouse, parent, or child and shows that risk of morbidity and mortality exists after suffering a loss. Grenklo et al. (2013) compared parentally bereaved young adolescents to their non-bereaved peers for self-injury behaviors including suicide after the death of a parent to cancer. One thousand two hundred seventy two (851 parentally bereaved, 421 non-bereaved) adolescents ages 13 to 16 participated in the study. The results indicated that 19% of the bereaved group versus 10% of the non-bereaved group exhibited self-injury behaviors. Of the 19% (94 participants) stated that self-injury behaviors occurred after bereavement and 24 participants stated that self-injury behaviors occurred before and after bereavement. Thirty six participants (30%) of the parentally bereaved group reported suicide attempts versus 13 participants (4%) of the non-bereaved group. This study demonstrates that self-injury behaviors and suicide risk are higher after losing a loved one. Although it is evident from this study that most self-injury behaviors occur after bereavement there is no indication of when this occurred after the death.

Some studies have demonstrated that most of the self-injury behaviors as well as suicide attempts occur within the first year after the loss. Qin and Mortensen (2003) conducted a longitudinal study over 17 years that compared bereaved parents (n = 18,611) ages 18 to 75 years to a control group (n = 372,220) for suicide risks. Bereaved parents were found to be at highest risk during the first few months after the loss of a young child. If the child had lost his life due to suicide, this increased the parents risk for suicide. In another study by Schaefer, Quesenberry and Wi (1995) 12,522 couples that were part of a prepaid health care plan in California were examined for mortality after suffering the loss of a spouse. There were a total of 1,453 bereaved men and 3,294

bereaved women. Study results indicated that the highest period for mortality occurred within 7 to 12 months after the death of a spouse.

In another study Rostila, Saarela and Kawachi, (2013) explored the association between losing a sibling as an adult and mortality due to a myocardial infarction. This study continued over 18 years after bereavement. Results indicated that both men and women had high mortality rates due to myocardial infarction after experiencing the death of an adult sibling. The timing of mortality for women was highest from 4 to 6 ½ years after the death of the sibling and for men it was during the 2nd to 6 ½ years after the death. Women had a higher mortality rate if their sibling died of an external cause (accidents or suicide) versus an internal cause. Bereaved siblings, both adults and children, suffer psycho-social stressors after the loss of a brother or sister. These psychosocial stressors can lead to morbidity and mortality years after suffering loss of a sibling (Milberg, Jakobsson, & Olsson, 2008).

In summary, although there is a dearth of literature related to morbidity and mortality after sibling death, there is ample literature that indicates that both children and adults experience physical and emotional symptoms after losing a loved one and that children have behavioral responses to the loss of a sibling according to their age and development (Grenklo et al. 2013; Qin and Mortensen 2003; Schaefer, Quesenberry and Wi 1995; Christ 2000). There is evidence in the literature that self-injury behaviors, physical and psychological symptoms do occur after losing a loved one including a sibling, however, the exact time frame of its occurrence needs further research.

Mental Health

Children who suffer the loss of a sibling exhibit a wide variety of physiologic and psychological reactions. Birenbaum (2000) found that preschool, school-age and adolescents experienced psychosocial symptoms including hyperactivity, trouble sleeping, impulsivity, nightmares, anxiety, guilt, social changes, depression, and even suicide. Adolescents were at higher risk of developing physiologic and psychosocial symptoms compared to the other age groups. The reason why adolescents exhibited more frequent bereavement behavior is not understood and needs further exploration. Some children may feel guilt that they caused the sibling's death and fear that someone else in the family will die (including themselves) and may experience sadness, anxiety, loss, distance from parents, and confusion.

In a classic study, Mandell et al. (1983) examined parents' report of the responses of 35 siblings to the death of their brother or sister due to SIDS. The surviving sibling's ages ranged from 16 months to 6 years of age at the time of the infant's death. There were 18 females and 17 males. The demographics of the deceased siblings were: ages ranged between 1 and 5 months except for an 18 month old, there 21 males and 5 females; there was one Oriental, 23 Whites and 2 Blacks. Parents participated in a 30 to 60 minute interview which took place 10 months after the loss. They shared their observations of the reactions of their child following the loss of the sibling.

Parents reported that 80% (28 siblings) had changes in the interaction between the parent and the child following the death. These changes were manifested as anxiety when separating from the parent. Such behaviors were manifested by temper tantrums. Other children manifested anger towards the mother, blaming her for the death of the

sibling. Although anger was exhibited, constant reassurance and closer physical contact from the parent was needed. A 3 ½ year old exhibited defiant behavior after the death of the sibling which the mother attributed to permissive behavior due to a traumatic event. The social interaction of thirty-seven percent (13 siblings) was affected. Playing and interacting with peers became troublesome with the 2 ½ to -6 year age group most affected. Symptoms ranged from withdrawn behavior to aggressiveness towards peers causing disturbance in day-care and school settings. Sixty-nine percent (24 siblings) suffered from changes in sleep patterns after the death of the sibling. Sleep disturbances (resistance in falling asleep) occurred as long as after 1 year following the death. Older children feared dying at night. Many of the children also experienced night mares, visualizing monsters in their sleep. There were a few instances where regression of toilet training occurred. Some parents reported that after the death of their infant they were consoled by their surviving child. A 3 ½ year old child asked the mother to stop crying and reminded the parent that they still had them. Another child reassured the parent that the child was in heaven with the angels.

In summary, children who lose a sibling suffer from several psychological and physiological changes. Some changes are noted in the child's sleep patterns, in the interactions of the child with the parent and in the child's social interactions. Children may exhibit behaviors of acting out, hyperactivity to depression and suicide. According to Goldman's (2004) research, if children do not resolve or explore their grief experienced during childhood years, it will affect them as adults and may be manifested by symptoms of extreme depression, panic disorders, anxiety, and suicidal thoughts.

Children may also be at increased risk for maladaptive behaviors resulting in rising physical health care and mental health care costs.

Perceptions of Children's Health

In the last decade pediatric clinicians, child psychologists and researchers have debated about children's self-report vs. parent report of the child's health. Several issues have strengthened the argument that child self-report should be used more than it has been. Literature on children's perception of their health after the death of a sibling is rather limited. The scarce literature available on the health of the surviving child is from the parent's perspective and much discordance exists between the perceptions of parents and children relating to the child's physical and mental health. Youngblade and Shenkman, (2003) reported that parents were four times more likely to report a mental health care need for their child than the child did, however, adolescents were more apt to report a mental health care need when the parent did not.

Patient-reported outcomes directly measure the patient's perceptions of the impact of disease and treatments and are the best way to evaluate how a patient is doing according to the Food and Drug Administration (2006). Some treatment effects are only known by the patient. Research on the child's self-report of his/her health after suffering a sibling's death is needed to get a better understanding of the child's own perception of their health after a sibling's death.

In related studies, Guite, Lobato, Kao and Plante (2004) compared parents' and children's reports on children's adjustment to living with a brother or sister who had a developmental disability or a chronic illness. Comparing parents' and children's reports, parents felt that the healthy child had a more difficult time adjusting to living with a

sibling with a disability compared to the children's reports. Johnston, Steele, Herrera and Phipps (2003) examined the consistency in child and parent reporting of child's negative life events (divorce, severe accidents or illnesses and problems with school). Children were either healthy, on active therapy for a chronic illness (Cystic Fibrosis, Diabetes Mellitus, Juvenile Rheumatoid Arthritis) or on active therapy for cancer. Results showed that children in the healthy group reported more negative life events than their parents reported about them. However, children with cancer and those with a chronic illness did not differ with their parents reports. This could be because of better communication between a child with an illness and the parent.

Sloper (2000) explored 94 sibling's reactions to the diagnosis of cancer of their brother or sister at 6 and 18 months after the diagnosis. Participating in the study were 46 males and 48 females, ages 8 to 16 years old and only 4% were from minority families. Of the 94 siblings', 47 were the eldest child in the family, 24 were the middle child and 23 were the youngest. Both qualitative and quantitative interviews were done with the siblings, 6 and 18 months after the diagnosis. Using semi-structured interviews, siblings were questioned regarding knowledge about their sibling's illness, how they felt when the sibling was diagnosed, how their family life has changed since the diagnosis, relationships with parents, friends and self, ways to cope and what they felt was helpful with coping.

Ninety-eight percent of the siblings reported at 6 months after the diagnosis (Time 1) feeling the "loss" since their sibling was diagnosed with cancer. Losses encompassed that of attention and family life, security and certainty as well as the companionship of the ill child. This loss was attributed to having the physical and emotional separation

from the parents due to the hospitalizations of the ill child. By 18 months after the diagnosis (Time 2), approximately 2/3 of the siblings reported negative parent-child interactions, most due to feeling secondary to the ill child. There was less feelings of loss. This was attributed to the ill child spending less time in the hospital and being able to participate in family activities. During this time period, some of siblings had worries about the possibility of their brother or sister having a relapse or perhaps even dying. They were not able and did not want to discuss these worries. A quote from one of the children's concern for their sibling's death, "because she might not, but there's just no saying. I've never liked to tell anyone because it sounds like no hope or anything but well really it could happen...I've never told anyone because I'm just scared that they might get upset or anything. Sometimes I don't want (to tell them) because I don't want to hear the answer even though I know it could be true but mostly I do because I want to share my feelings about what's happened" (Sloper, 2000, p.303). Resentment and anger was a common feeling at this stage. Siblings identified that having the ability to speak to somebody regarding the situation was very helpful.

The results of this study reinforce the need to obtain child self-reports so that providers can identify those children at risk and provide them with the necessary services. Many of these children see how their parents become physically and mentally exhausted after caring for a child that has a chronic disability, so they preferred not to discuss their own worries about the possibility of their sibling dying as to not stir up old worries with their parents. They also had concerns about their own health, feeling they were at increased risk for cancer. As one child stated, "I'm a bit on edge about whether cancer runs in the family. If I have children, if they're going to get it or I'm going to get it".

Siblings that reported having a positive support system (close relative, friend, teacher or professional) as they went through a difficult time in their life felt that this experience helped strengthen them and helped them deal with the situation on a positive level. They felt that their relationship with their family members strengthened due to having gone through this experience.

Children also respond to the death of parents and other family members in a similar way. Melhem et al. (2007) examined the effect that parental loss due to suicide, accident or natural death had on children and adolescents. One hundred and twenty nine children and adolescents, from 89 families participated in this 5 year study. The ages ranged from 7 to 18 years old with a mean age of 13.3 years. The demographics for this sample were as follows: 52.7% males, 47.3% females. Sixty percent had always lived with their deceased parent and 37.2% lived with them part-time and 2.3% never lived with the deceased parent. The assessments were performed one year after the death. They were given a modified version of the Inventory of Complicated Grief-Revised (ICGR) where higher scores indicate a higher level of functional impairment (depressive disorder, anxiety, post- traumatic stress disorder and suicidal ideation). The results showed that whether the death of the parent was due to suicide, accident or a natural death, there were no differences in the functioning of the child or the adolescents. The results of this study are in conflict with the results of other studies which demonstrate that bereavement by suicide has a strong correlation with psychopathology in children when compared to bereavement due to non-suicidal deaths (Cerel et al., 1999).

Losing a sibling has a long lasting effect on the child. This could affect the child's life either positively or negatively. For some children their physical and mental

health may be affected, however for others, they see this as an opportunity to experience growth and maturity. Having the child's self-report gives us an unbiased understanding of the child's feelings of his physical and mental health as well as any challenges or positive secondary concurrent changes that may occur in the child's life.

In order to obtain a complete understanding of how the surviving child responds to the death of a sibling it is best to get the child's self-report along with the parent's report and if possible a teacher's objective report (Zins, Bloodworth, Weissberg & Walberg, 2007). The parent's perception of their child's physical and emotional status is not always the same as the child's perception (Waters, Stewart-Brown & Fitzpatrick, 2003). After a child's passing, parent's may lack the energy or become preoccupied engulfed in their own grief. This leaves them little time to consider the surviving child's needs. Differences between child self-report and parent report do exist and could affect the adjustment to a potentially stressful situation.

Much research has been done to determine if children (who do not have a cognitive impairment or are not too young) are able to respond to developmentally age appropriate questionnaires. There have also been psychometric studies that show good reliability and validity of child self-report questionnaires that have determined that children have a good understanding of what is being asked as long as the instrument used is developmentally appropriate (Varni, Limbers, & Burwinkle, 2007). Instruments used for this purpose in children and adolescents should represent the lower age limit where children can give reliable and valid responses.

Eiser and Morse (2001) performed a meta-analysis of fourteen studies evaluating the agreement between child self-report and parent proxy-report on different measures of

the Health Related Quality of Life Questionnaire (HRQOL). There was good agreement ($r > .50$) between child self-report and parent proxy-report for domains reflecting physical activity, functioning, and some symptoms. However, child self-report and parent proxy-report had poor agreement ($r < .30$) for emotional and social Health Related Quality of Life (HRQOL) domains. According to Cremeens, Eiser, and Blades (2006), parent and child HRQOL instruments should measure the same constructs with parallel items to make comparisons between self and proxy report more meaningful.

A classic study by Craft and Craft (1989) compared parents and sibling's perception of the changes that endured during their brother or sister's hospitalization. When a child is hospitalized, parents' anxiety levels increase due to the uncertainty of the outcome of their hospitalized child as well as spending more time away from home, leaving the other sibling/s in the care of others. This leads to discordance between parent and sibling perception of the sibling's feelings and behavior. Craft used a 12-item Perceived Change Scale to examine parents and siblings questions related to feelings and behavior. The demographics were 123 sibling's ages 5 to 17 years and their parents. Seventy four siblings were teens, 64 were females and 59 were males. To be included in the study these siblings had to have a brother or sister hospitalized due to an acute, chronic or progressive illness. The length of hospital stay was between 2 to 42 days with a mean hospital stay of 6.5 days. The score on the Perceived Change Scale ranged from 0 to 12 asking both siblings and parent's questions about the healthy sibling's associated symptoms during their brother or sisters hospitalization. The following symptoms were assessed as greater, lesser or the same as before the hospitalization: trouble sleeping, food intake, getting mad, bed wetting, biting nails, feelings of health, and nightmares.

Siblings reported a much higher number of changes than did their parents. Sibling age had a big effect on parent-child agreement. The younger children had lower levels of agreement with their parents than did the older siblings. Parents and siblings mostly agreed on bedwetting, however, their main disagreement was them wanting to spend time with their parents, having difficulty concentrating on school and getting mad.

Foster et al. (2012) cross-sectional, qualitative study examined the parents' perception and the child's self-report of the changes that the surviving child endures after suffering the death of a sibling due to cancer. Foster also compared the parents' report to the child's self-report. The participants were from 41 families (N = 99) 36 mothers, 24 fathers and 39 siblings. More than $\frac{3}{4}$ of both the mothers' (78%) and fathers' (83%) were white, with an average age for mothers 40.5 and fathers 43.88. Siblings were females ($n = 25$) and males ($n = 13$). The average age was 12. Data was collected from 6 months to 19 months after the death of the sibling.

Children do experience personal changes as well as changes in relationships within the first year after the death of a sibling. Discrepancies did exist between children and the parents' perception. Children reported more positive changes which reflected adaptation to the environment and personal growth. Parents reported more negative changes that were attributed to sadness due to the death of the sibling. Changes in sibling relationships and more so peer relationships were reported more often by the child than by the parents.

Upton et al. (2008) and Eiser & Morse (2001) revealed that discrepancies exist between patient-reported outcomes given by children and those provided by proxy-respondents. Many parents are not able to find the balance between the needs of their

disabled child to the needs of the healthy sibling. When parents were interviewed, the majority felt that due to the lack of energy and preoccupation with the ill child, they were left with little time to consider the sibling's needs. Parents who are preoccupied living with a child that has a disability and then dealing with their death is an example of how the healthy child's real feelings can be overlooked or underestimated.

Guite, Lobato, Kao and Plante (2004) compared parent's and children's reports on children's adjustment living with a brother or sister who has a developmental disability or a chronic illness. The sample included 51 well siblings (24 boys, 27 girls) and 45% parents of which 98% were mothers. The well siblings age ranged from 8 to 13 years ($M = 9.88$). The child with the disability demographics were as follows: mean age 1 to 16 years ($M = 8.73$), 28 boys and 17 girls. The conditions were as follows: developmental disability (mental retardation) $n = 9$, physical disability (cerebral palsy) $n = 15$, chronic illness (cystic fibrosis and pervasive developmental disorder) $n = 12$. Seventy eight percent of the families included both parents. Both parents and siblings completed the Child Behavior Checklist, The Self-Perception Profile for Children, The Brief Symptom Inventory and the Impact on Family Scale. In comparing parent's and children's reports there were discrepancies. Parents reported the child having more negative adjustments to living with a sibling with a chronic illness than the child reported. When the child reported a greater negative adjustment to living with a sibling with a chronic illness, they were younger males. Parents were more concerned about how their children felt about living with a sibling that had a chronic illness than were the children themselves.

Sharpe and Rossiter (2002) performed a meta-analysis of published studies pertaining to the siblings of children with a chronic illness. An analysis of fifty-one

studies was performed examining effect size, the year of publication and method of data collection as well as categories of dependent measures such as differences by chronic illness, effects of gender, age of sibling and birth order. The results showed that parents' reported more negative psychological and social functioning behaviors for their well-child than did the child self-report.

Waters, Stewart-Brown and Fitzpatrick (2003) examined 2096 parent-adolescent dyads agreement on physical, mental, social and physical health. The adolescent's age ranged from 12 to 18 years old who lived in Victoria, Australia. Both parents and adolescents completed the Child Health Questionnaire which encompasses items such as physical functioning, social roles, emotional and mental health and well-being, general health, body pain, and family functioning. Adolescents reported their physical health and functioning higher than their parents reported for them, however it was not statistically significant. Adolescents who suffered from an illness reported significantly poorer general health, more frequent episodes of body pain and more symptoms of mental health affecting their family activities, than their parents on them.

A study by Sweeting and West (1998) surveyed 2586 children that were 11 years of age and their parents for concordance/disagreement between child self-report and parent report on the rating of child's health over the past 12 months including longstanding illnesses such as asthma, migraines, diabetes and skin problems. Parents were much more likely to describe their child's general health as "good" compared to the children's reports of themselves. Children also reported longstanding illness much more than parents did with the exception of diabetes.

Youngblade and Shenkman (2003) examined the congruency between parents' and adolescents report of the adolescent having a special health care need including mental health issues. The studies sample consisted of 522 matched parent/adolescents. Adolescent's ages ranged from 12 to 17 years old. There were 248 males and 274 female adolescents with 360 White, 162 Non-White, 116 Hispanics and 406 Non-Hispanics. Using the Children with Special Health Care Needs (CSHCN) screener, enrollees for the Florida Healthy Kids Program in 2000 to 2001 were surveyed. Parents were interviewed by phone asking them 5 questions related to their adolescents health using the CSHCN and then the adolescents were asked the same questions. The results showed that 17% of parents reported their child as having a chronic condition and 12.64% of the adolescents reported having a chronic condition. In all the health related areas that were examined, the biggest discrepancy came from parents reporting four times more mental health issues for their adolescents than the adolescent reported for themselves. This discrepancy raises much concern because it is unknown if the reason for the discrepancy in reporting is the parents perception of the adolescents behavior being interpreted as a dysfunction in mental health when it may be "normal" adolescent behavior, or is it that adolescents are reluctant to admit that they have an issue and are internalizing their behavior. This raises concern for understanding the need for support of the child/adolescent during difficult times such as death of a sibling.

Johnston, Steele, Herrera and Phipps (2003) examined the consistency in 516 parent -child dyads reporting the child's negative life events (divorce, severe accidents or illnesses and problems with school). Children were either healthy ($n = 287$), on active therapy for a chronic illness (Cystic Fibrosis, Diabetes Mellitus, Juvenile Rheumatoid

Arthritis) ($n=91$) or on active therapy for cancer ($n=116$). Total sample ages of the children ranged from 7 to 18 years old with a mean of 12.64 years; there were males = 206 (42%) and females = 288 (58%). There were 403 (81%) Whites, 72 (15%) African American and 17 (3%) were of other racial and ethnic background. Recruitment was as follows: chronically ill group were recruited from the specialty clinics at a local pediatric hospital, patients with cancer were recruited at a routine clinic visit in a large children's hospital during their active stage of therapy and the healthy group were recruited from 2 public and 2 private schools in the same metropolitan area as the other groups.

The study used a modified Coddington Life Events Questionnaire (CLEQ) to assess the experiences of the child's life events. The modified version focused on 22 items related to major negative life events. A "yes" or "no" response was required for each item. Two time points were examined, one being if the event had occurred at any point in the child's life and the other if the event had occurred within the past year. The CLEQ was administered to the healthy children during their regular school hours in a classroom setting. The research staff read the items aloud for the elementary school children. For the middle and high school children, the CLEQ was given and children completed it at their own pace during class time. Research assistants were available for questions. For children in the chronically ill group and those children with cancer, the CLEQ was individually given to participants to complete during their office or treatment visits. Parents for all groups were given the CLEQ and asked to return it via mail.

Results indicated that White children reported fewer negative life events than African American children. The same was true for the parents of the White children versus the parents of the African American children. Adolescents (13 to 18 years old)

reported more negative life events than 10 to 12 and 7 to 9 year olds. This may have been the result of them having had a longer life to experience these events. Likewise, the parents of adolescents reported more significantly negative life events than those parents of 7 to 9 and 10 to 12 year olds. There were no negative life events differences reported based on gender of children and parents. Children in the healthy group reported more negative life events than their parents reported for them. However, children and parents in the cancer and chronically ill group had no significant differences in reporting negative life events.

In summary, death of a child is a very painful experience for parents and siblings and has lasting effects on the surviving sibling for years. Surviving siblings experience a variety of health responses including physical and psychological symptoms ranging from stomach-aches and skin rashes to anxiety, guilt, depression and suicide. There are very few studies addressing the children's perception of their health prior to and after the death of a sibling and differences in these perceptions from the parent's and child view. Most studies that are available are from the parent's perspective. The literature has shown that both congruence and discordance exists between child self-report and parent-report. Parents' were more likely to under-report the physical and mental health of their surviving child after suffering the loss of a sibling (Waters, Stewart-Brown and Fitzpatrick, 2003). Although the parents' reports of a child's physical and mental health after the loss of a sibling are important, further research is needed on the child's self-report of his/her health.

Treatments and Treatment Costs for Children after Sibling Death

Financial Costs

There is a very little literature reported on financial treatment for children following the loss of a sibling including unscheduled physician visits, emergency room visits, hospitalizations and medications. The available literature consists of children's experiences with support groups, summer camps, school intervention programs, and having open communication with parents as part of prevention and treatment. Very few studies report the financial cost associated with these programs and treatments. However what is reported in studies is the need for the continued support and how it improves the outcome of the child's mental and physical health. According to MacPherson and Emeleus (2007) who identified the psychosocial needs of bereaved children most of the participants expressed a great need for continuity of support from before the death to several years after the death.

The cost for parents or children for bereavement support groups vary. Support groups can be found in various settings from churches (where there is usually no fee) to non-profit organizations such as the Children's Bereavement Center (<http://www.childbereavement.org>) that rely on tax deductible contributions of up to \$1200 per year in return for providing education, support and resources to the children. Hospice services also provide grief support for as low as thirty dollars a session.

While 25% of surviving siblings are in need of clinical intervention and more than 50% have significant behavioral problems, there is an absence of literature examining morbidity and the charges for treatment for these children after the death of a sibling (Charles & Charles, 2006; Packman et al., 2006).

Data on the costs and use of health care services (mental health services, acute care, medications) for children after the death of a sibling are not reported. It is estimated that the percentage of children and adolescents in need of mental health services in the U.S. is between 15 and 20 % (Bickman, 2002) with total costs for treating children's mental health (behavioral and emotional problems) at approximately \$11.75 billion (Ringel & Sturm, 2001). The overall economic costs for depression are estimated to be \$30 to \$44 billion dollars annually in the United States (Andrew, 2012). The costs for childhood depression alone have not been reported. Approximately $\frac{1}{4}$ of children who lose a sibling receive mental health services. This leaves more than half of the population of children who have experienced the loss of a loved one without any type of intervention which could lead to physiological and psychosocial manifestations. NIMH (2005) reports that only 1 out of 5 children diagnosed with a mental health problem receive mental health services. According to Van Cleve et al. (2013) children/adolescents in need of mental health services do not all receive these services either because of a shortage of child/adolescent psychiatrists and/or the stigma that is associated with being labeled with a mental disorder.

Since children attend preventive care visits to their primary care providers, it becomes the role of the primary care provider to diligently screen children and adolescents during every office visit for mental health related issues. In 2007, the number of annual of preventive care office visits for children under the age of 15 was 47,613. It decreased by half for adolescents between 15 to 24 years of age (22,225) National Health Statistics (2008). As children grow older, their visits to the primary healthcare provider are fewer.

Incorporating an appropriate age specific mental health assessment guide in every well visit is important in preventing future problems. However, once a screening is completed, referring to a mental health care provider and working with managed care services becomes the primary care provider's major hurdle. When children and adolescents go to their primary healthcare providers many do not discuss behavioral issues, social relationships or stressors that could affect physiological or mental health during routine visits (Britto et al. 1999).

Glazebrook et al. (2002) found that out of 307 children that attended an outpatient pediatric clinic, pediatricians identified 25% of the children with a psychiatric disorder and only 5% received help from a Child Mental Health Service. Improper mental health screenings, shortage of outpatient mental healthcare providers and not identifying children at risk in a timely manner leads to the unnecessary emergency room visits for mental health disorders.

In the United States in 2011 there were a total of 74,518 emergency room visits for children under 18 (CDC, 2011), specific data on the number of these visits for problems related to bereavement for loss of a sibling are not reported. Pittsenbarger (2011) reported that the most common psychiatric visits to the emergency room for adolescents under the age of 19 are for depression, anxiety, behavioral issues, suicide attempts, drug and alcohol use. He also found that the percentage of emergency room visits for uninsured or Medicaid patients rose from 46 % in 1999 to 54 % in 2007. Not being insured or having public health insurance (Medicaid) increases the use of emergency rooms for mental health related issues.

Due to low reimbursement rates on mental health issues, many providers choose not follow patients that have government assistance (Medicaid).

Hoffmann et al. (2012) explored outpatient health services given to adolescents with a diagnosis of depressive disorders. There were 140,563 adolescent's ages 12 to 18 years old diagnosed with a depressive disorder. There were 51.1% males and 48.9% females with a mean age of 15.1 years (SD = 2.0 years) for both males and females. More than 75% of females and 40% of males took anti-depressives. However more males (37%) than females (25%) visited a child/adolescent psychiatrist. Treatment for depression was higher for females 50.6% vs. males 38.7%. Approximately 69.2% of males and females received psychotherapy; however more girls received combination anti-depressive medications and psychotherapy. An annual prevalence of anti-depressive use of 5.84 per 1000 for 2009 was found in this study in Germany. However the use of anti-depressives in the United States largely exceeds this number (Zito et al. 2006).

Guevara et al. (2003) explored the differences in health care expenditures between children diagnosed with behavioral disorders (conduct disorder, ADHD, and oppositional defiant disorder), emotional disorders (anxiety, depression and affective psychosis) and those with physical health conditions (asthma, diabetes and epilepsy). The sample consisted of 3955 children ages 2 to 18 years old. The total expenditures for children with emotional disorders indicated that they had lower pharmacy expenses than children with disruptive disorders (\$154 vs. \$307). This may be due to the fact that children with depression or anxiety are not as readily diagnosed. For those children who were diagnosed with depression or anxiety and received prescription medications, their expenditures for pharmacy services were the same as those who had a behavioral disorder

(\$355 vs. \$359). Children with emotional disorders had greater hospital expenses than those with behavioral disorders (\$664 vs. \$43). Within the emotional disorder group, children with depression had total expenses of \$2555 whereas children with anxiety had expenses of \$1824. Those children that had the greatest total expenses were children with affective psychoses \$3237. The reason why children with affective psychoses had higher total expenditures was because of the increased number of office visits compared to the others. Children with depression had higher inpatient expenditures than those with anxiety or affective psychoses (\$815 vs. \$424, \$186, respectively). The findings of this study are consistent with Mandell et al. (2003) who also compared health care costs among several mental disorders. Their findings were similar to this study, where children with depression had higher expenses than those with a conduct disorder and those with Attention deficit hyperactivity disorder. This increase in costs is due to the high numbers of children hospitalized for anxiety and depression because of the lack of outpatient services (Guevara, 2003).

Treatment for depression in children and adolescents consists of psychotherapy (play therapy for children and individual therapy for adolescents) and various medications. According to Keamey and Silverman (1998) using combination pharmacological and psychosocial therapies have been beneficial in treating depression in children. However, Wethington et al. (2008) found that following a traumatic event, children who are displaying behavioral and psychological symptoms benefit most from individual and group cognitive-behavioral therapy. There is little research in the area of medications to treat depression in children. The research available has been with adults and extrapolated to children. According to Clein and Riddle (1996) most prescribed

medications given to children and adolescents lack short term or long term efficacy and safety as well as the pharmacokinetics of the drug due to lack of research with children.

This lack of research leads to the widespread use of “off-label” medication being prescribed by physicians to children and adolescents. This is consistent with Cohen, Berliner and Mannarino (2003) study showing that practitioners use medication to treat depression in children without having sufficient evidence to support the proper dosage and use in children. The Food and Drug Administration guidelines (2007) state that caution should be exercised when using antidepressants in the age group of 18 to 24 years old due to possible suicidal thoughts upon initiation of the treatment.

Human Costs

Addressing the psychological needs and identifying children and adolescents who are a risk for developing physical or mental disorders due to losing a sibling makes economic and health sense. Many children who lose a sibling and are suffering from physical or mental health issues are not diagnosed in a timely manner (Van Cleve et al. 2013). Parents do not recognize their child’s ill behavior until it is addressed by school personnel. It then becomes the responsibility of the primary care provider to identify those children at greater risk and refer them for appropriate treatment.

Presently there is a demand for mental health care services but due to the lack of reimbursement, services are not offered. Many patients are sent to the emergency rooms for care when an acute situation arises. The emergency room physicians take care of the acute situation and then have the patient follow up with their primary care provider. This leads to rising healthcare costs because of over- use of unnecessary services. The lack of proper screening by primary care providers for children at risk after losing a sibling as

well as the insufficient mental health services available to the public leads to the rising healthcare costs because of the over use of unnecessary or improper services (Britto, 1999). This presents a problem not only at the present moment for the child, but also for the future of the child who has suffered an adversity.

Cuijpers et al. (2011) examined the effects of childhood adversities on their mental and physical status as adults. One childhood adversity that was examined was suffering a major negative life event. The sample lived in the Netherlands and consisted of (N=7076). A Disability Weight (DW) was given to each participant. This DW is an indicator of the proportion of a healthy life year; when calculated represents the total number of life years lost due to a disability. The results indicated that childhood adversities have a strong impact on disease burden as adults.

The dearth of literature regarding the human costs associated with the physical and mental health and treatment for children that have lost a sibling is difficult to measure. Before calculating the human costs associated with a child losing a sibling, we need to evaluate the direct and the indirect costs associated with these. What is known is that children who lose a loved one are using emergency rooms for unexplained physical ailments and are being diagnosed with anxiety and depressive disorders and given anti-depressants without knowing the effectiveness and outcome.

The knowledge obtained from the current data available regarding the number of emergency room visits as well as amount of money spent on medications such as anti-depressive medications used in children that are diagnosed with anxiety and depression after losing a loved one, serves as a catalyst for further research. Such research should focus on appropriately identifying and developing age specific interventions for high risk

children. The continuing use of emergency room visits, the improper follow up treatments and lack of identifying children in a timely manner adds to rising health care costs. Public sector financing requires an increase in taxes or by other means that will ultimately affect society as a whole. Research needs to be directed at investigating how the allocation of indirect and direct costs relates to total health care costs for the bereaved child. This will reduce unnecessary human costs and decrease the burden on the economy of the United States. This can also prevent consequential negative outcomes during the transition into adulthood for the surviving child.

Related studies address parental and spousal bereavement and associated morbidity within a few months after the death. Olsen, Li, and Precht (2005) studied if losing a child put bereaved parents at increased risk of hospitalization. The premise was that stressful events such as bereavement due to the loss of a child or sibling can contribute to morbidity such as diabetes. Study results indicated that parental bereavement increased the risk of hospitalizations due to Type 2 diabetes, especially for mothers. Li, Precht, Mortensen, and Olsen (2003) also examined morbidity and mortality in bereaved parents. Fathers' greatest risk of morbidity and mortality was early after the child's death whereas mother's morbidity and mortality tended to be later, even as late as 18 years after the child's death. Murphy, Lohan, Braun, Johnson, Cain, Beaton, and Baugher (1999) compared the health of both parents after the violent death of their child. Mother's health deteriorated initially. Fourteen percent of fathers rated their health as poor 4 months after the death and it did not improve over time. McHorney and Mor (1988) studied caretakers of patient's diagnosed with cancer to examine the consequences of depression after the death and to see if there was an increase in health care use

associated with depression. Results indicated that depressed caretakers reported at least 3 physician visits in the first 4 months of the death; two-thirds (64%) of bereaved spouses visited a physician in the first year after the death; depressed spouses made 3.0 additional visits per year.

Stressful events in a child's life such as divorce, loss of a parent, grandparent or sibling can result in morbidity and associated health care costs. Bickman (2002) has identified that 15 to 20 percent of children and adolescents in the U.S. are in need of mental health services. The total costs for treating children's mental health (behavioral and emotional problems) approximates \$11.75 billion (Ringel & Sturm, 2001). Other studies demonstrate that health care providers frequently do not discuss behavioral issues, social relationships or stressors that could affect physiological or mental health during routine visits (Britto, et al, 1999). Not identifying children at risk and delaying treatment could lead to more severe and difficult illness to treat and possibly the development of co-occurring mental illnesses (National Institute of Mental Health, 2005).

In summary, the literature indicates that when a child loses a loved one there are human costs with his mental and physical status being affected. Since there is very little literature related to morbidity and mortality after sibling death as well as the health care costs that are associated with these, research is needed to determine the human and financial costs of a sibling's death on the surviving children, parents, insurers and society. There is ample literature that indicates that children experience both physical and emotional symptoms including acting out behaviors, self- injury behaviors, trouble focusing in school and even suicide. Much of the literature shows that children demonstrate symptoms within the first few months following the death of a sibling. Very

few studies are done longitudinally to measure the effects that losing a sibling has in later years. A study by Ford, Clark and Stansfeld (2011) looked at childhood adversities effect on anxiety disorders in adulthood. They found that having a smaller social network and poor relationship with close members of the immediate family was a strong predictor in developing affective disorders or anxiety as an adult. Some related study's findings indicate that symptoms begin within the first months after the death and others indicate that these behaviors affect adulthood behaviors.

Surviving siblings experience a variety of health responses including physical and psychological symptoms ranging from stomach-aches and skin rashes to anxiety, guilt, depression and suicide. Very few studies report the effects of age, gender, race/ethnicity on the surviving children's responses. There are also very few studies addressing the children's perception of their health prior to and after the death of a sibling. Most of the studies are from the parent's perspectives. There are a few studies that examine the child's self-report and the parent's report of the surviving child's physical and mental health after losing a loved one including a sibling. The studies that do exist demonstrate that there are differences between parent report and child report.

There is an absence of studies reporting treatments for morbidity and the associated charges for children after the death of a sibling despite reports indicating 25% of these children need clinical intervention. Poor reimbursements and lack of child psychiatrists and mental health services for children add to the existing problems of over use of inappropriate services such as emergency rooms. Bereaved children's physical and mental health is being treated in fragmented settings. As a result we can only estimate the health care costs for children who have lost a sibling.

This study is designed to help fill these knowledge gaps. Interviewing children at 2 and 4 months after the death of the sibling will capture surviving children's perception of how they view their health prior to and after the death of their sibling as well as how they compare their health to others their age. Capturing treatments for health care for surviving siblings will provide an indirect measure of children's health and a beginning examination of health care charges for this vulnerable group. Study findings will help to identify those children at risk so appropriate and effective interventions can be developed within the context of their developmental age, race/ethnicity and gender to prevent negative health outcomes.

This proposed study is innovative because there is little or no data on children's perception of their health following the death of their brother or sister. There is also an absence of data comparing the parent's and children's perceptions of the surviving child's health following the death of their brother or sister. This study included all children in the family that are willing to participate; most studies to date include one child in the family. It included sibling survivors from 3 racial/ethnic groups; studies to date have been conducted largely with White English speaking samples. The treatments and costs associated with the surviving children were examined for a period of 4 months post the death of the sibling. This helped provide an indirect measure of children's health and will begin to capture health care charges associated with children's health following sibling death.

CHAPTER III

DESIGN AND METHODS

Study Purpose

The purpose of this study in children who have lost a sibling in the NICU/PICU, ER or those who have been sent home on technology dependent equipment to die peacefully, is to compare parents' and sibling's perception of the surviving sibling's health, identify factors related to these perceptions, and describe the treatments and associated health care costs for the sibling's physical and mental health at 2 and 4 months after the death. The study addresses the following research questions:

1. At 2 and 4 months post-death, are there differences between the parent's perception and the surviving sibling's perception of the sibling's own health:
 - a) now; b) now compared to before the death of their brother or sister; and
 - c) now compared to others their age?
2. Are there differences in the concordance between parent and sibling's perceptions on sibling's health by child age (6 to 10, 10 to 13, 13 to 18), race/ethnicity, gender and cause of the brother's or sister's death (acute vs. chronic illness)?
3. Are the parent's and the sibling's perception of the sibling's health related to the sibling's anxiety and depression at 2 and 4 months post death of a brother or sister?

4. What are the treatments and associated charges for the surviving sibling's physical and mental health (non-routine physician visits, urgent care, emergency care, hospitalizations, follow-up visits for the former, and mental health services) over the 4 months after the death of a sibling?

This quantitative longitudinal study is embedded in part in the current R01 headed by PIs Brooten and Youngblut that focuses on sibling's responses to the death of a brother or sister in the NICU/PICU in 3 racial/ethnic groups. Surviving siblings reported on their own mental and overall health. Parents were asked if each surviving sibling has visited the emergency room or physician office, been admitted to the hospital, and needed health services (mental & physical) since the death of their brother or sister. Any available treatment charges were collected from the parents in the form of bills and insurance receipts. Data on cause of child death (acute or chronic) were collected from the deceased child's hospital record.

Settings

Surviving siblings and their parents were recruited from the NICUs, PICUs, Emergency Rooms and those who are discharged home on technology dependent equipment and die at home. The following hospitals participated in this study: Joe DiMaggio Children's Hospital, Jackson Memorial Hospital, Broward General Medical Center, and Miami Children's Hospital. The 4 hospitals have a total of 97 PICU beds and 172 level III NICU beds. Approximately 200 children die in these units annually. Racial/ethnic breakdown of the deceased children is approximately 40% Hispanic/Latino(a), 35% Black non-Hispanic, and 25% White non-Hispanic. Recruitment was also obtained from newspaper obituaries throughout Florida Counties.

Sample and sampling procedures

The sample size for the study included about equal numbers of Black non-Hispanic, White non-Hispanic, and Hispanic/Latino(a) children from 6 to 18 years old (N = 64) and their parents.

Inclusion Criteria

Inclusion criteria for the surviving sibling's include: 1) children ages 6 to 18 years old 2) lived with deceased sibling before PICU or ER admission, or with the mother of the deceased infant before NICU admission, 3) lives with the same parent(s) since the death, and 4) in their age-appropriate grade in school +/- 1 year. Both parent consent and child assent are necessary for the sibling to participate. Parent participants must be at least 18 years of age.

Exclusion Criteria

Exclusion criteria for the surviving sibling's include: 1) conditions that render a child unable to participate verbally – e.g., cerebral palsy, severe brain damage, severe autism – but the family's other children remain eligible, 2) living in foster care before or after the death, and 3) death of a parent or more than one child in the same event because the sibling will be dealing with the death of more than one nuclear family member at the same time. In single-parent families, non-custodial parents (mostly fathers) are invited to participate if the custodial parent provides his/her name and contact information.

Recruitment is based on nonprobability sampling; however, to minimize sampling bias, every possible effort will be made to approach all eligible families until the full sample is obtained. Since attrition is expected with longitudinal studies, despite using

techniques to minimize its occurrence over sampling by 12% will be done to allow for attrition from T1 to T2.

Power analysis

A sample size of 60 siblings from 6 to 18 years old and their parents is the minimum number necessary for a statistical power of 0.80, using a two-tailed alpha of 0.05 and a moderate effect size of 0.70 for a statistical analysis. To compensate for attrition, 68 siblings were projected to be recruited to account for an assumed 12 % attrition.

Procedure

The studies clinical consultants identify families of children (newborn to 18 years) who die at their hospital sites or have been sent home on technology dependent equipment to die at home and who have at least 1 surviving child between 6 and 18 years old. The project director (PD) contacts each clinical consultant every week to obtain names of eligible families. The following hospitals protocols for contacting families after the death of the child are as follows: Joe DiMaggio Children's Hospital the clinical consultant contacts the family 1 week after the death of the child in person or by phone to obtain a signed authorization for the RA from Florida International University (FIU) to contact the family. Once the authorization is obtained, the clinical consultant from Joe DiMaggio Children's Hospital sends a letter explaining the study to the family 6 weeks after the death of the child. At Jackson Memorial Hospital (JMH) the clinical consultant contacts the family 3 weeks after the death of the child and sends a letter explaining the study. This letter is on JMH letter head but in FIU's envelope. One week after the letter is sent the RA from FIU contacts the family to follow up on the letter. At Broward

General Medical Center the clinical consultant contacts the family 1 week after the death to obtain verbal authorization for RA from FIU to contact the family. The FIU RA sends a letter explaining the study 3 weeks after the death of the child and 1 week after the letter is sent. At Miami Children's Hospital (MCH) the clinical consultant contacts the family 3 weeks after the death of the child to obtain verbal authorization for FIU to contact the family. The clinical consultant sends the family a letter explaining the study 1 month after the death of the child.

All letters are sent either in (Spanish or English) explaining the study, identifying the RAs on the project, and providing the project office phone numbers and emails. About 1 week after the letter is sent an RA calls the family, screens for inclusion/exclusion criteria, and ascertains whether the family is willing to participate. The RA then sets an appointment to go to the family's home for the T1 data collection visit. At the home, the RA again explains the study to the parent(s), answers any questions and obtains their signed consent for their participation, and to talk with their eligible children about the study. The RA then explains the study to the eligible children, answers their questions, and obtains their signature on an assent form. Children are not asked to participate if the parent does not give consent for them. Only children who sign the assent form after their parent(s) give consent are interviewed. Two RAs make each visit so that the child(ren) and the parent(s) can be interviewed separately. Parents and children are told that: the children's data are private, parents will not have access to their child(ren)'s data, and the children do not have to talk to their parents about their study responses. If concerned for the child's welfare, the RAs talk with the parents (child mental &/or physical health issues) and/or the Florida Department of Children and

Families (child abuse/neglect issues). All families are given a booklet of resources for grieving children, parents and grandparents.

At least 1 of the 3 RAs is fluent in Spanish and English, and one RA is intimately involved with the Black and African American cultures in South Florida. RAs read the children's items to them to minimize the time for each child interview and the effect of the child's reading ability/level on their responses at each time point. Parent questionnaires are administered in the language chosen by the parent (either English or Spanish), including the family demographic form, and the questions regarding any medical treatment (physician office visits [non-routine], urgent care visits, emergency room visits, hospitalizations, mental health services) required by the surviving siblings since the death of the brother or sister. Charges for these health services were collected from parents via bills for the services or copies of bills sent to the parents from their insurance companies.

Attrition

Procedures to decrease attrition include: each parent receiving a \$25 store card and each child receiving a \$15 store card to a multi-purpose store for each interview completed. All data collection occurs in the family's home, unless they prefer different location, and at a time that is convenient for the family. If both parents are not available at the same time and or the family has more than one child in the study, the RAs return to the home several times over a week's period to complete data collection. Whenever possible, the same RAs conduct all of the data collection visits with a particular family. To facilitate retention, email addresses for each family member and the name, address, telephone number and email address of 2 close relatives who live elsewhere are obtained.

Measures

Demographics include surviving sibling's ages (date of birth from parent & child), parent and surviving sibling's gender, race/ethnicity –“White non-Hispanic,” “Black non-Hispanic,” or “Hispanic/ Latino(a)” based on self-identified Race (White, Black, Asian, Native American) and Ethnicity (Hispanic – yes/no). Parents age, marital status, income, education.

Instruments

Sibling's anxiety was measured using the Spence Children's Anxiety Scale – Child Report Version (SCAS) that has 45 items rated from 1 (never) to 4 (always). Spence reports coefficient alpha for the total scale of .93, and for the 6 subscales: separation anxiety (.74), social phobia (.74), obsessive compulsive (.76), panic (.82), generalized anxiety (.77), and physical injury fears (.60). The SCAS takes about 15 minutes to complete.

Sibling's depression was measured using The Child Depression Inventory (CDI) that has 27 items at a 1st grade reading level for children from 6 – 17 years old. Kovacs (2010), in a large ethnically diverse normative sample, reports internal consistencies of .71 to .89 and test-retest correlations of .74 to .83 after a 2-3 week interval. Validity is supported by a decrease in CDI scores from pretest to posttest in a pilot study of a group intervention for siblings of children with cancer (Grothe et al. 2005). Developed based on the Beck Depression Inventory (parent depression measure), the CDI takes 5-10 minutes to complete.

Parent's perception of surviving sibling's health – parents were asked to rate their child's health at 2 and 4 months post-death, now and in comparison to other children their

ages on a scale from 1 “poor” to 10 “excellent.” Parents were also be asked to rate their surviving child’s health now compared to before the death on a scale from 1 “much worse than before” to 10 “much better than before.”

The sibling’s perceptions of their own health were measured with the 3 single item indicators that the parent rates at both 2 and 4 months post-death. Siblings were asked to rate their health now and in comparison to other children their ages on a scale from 1 “poor” to 10 “excellent.” Siblings were also be asked to rate their health now compared to before the death on a scale from 1 “much worse than before” to 10 “much better than before.”

Treatments and Charges for health care for non-routine physician visits, emergency room visits, urgent care visits, hospitalizations, follow up visits for the former, and mental health services for each participating sibling were collected from parents at 2 and 4 months post death using bills for these services sent to them or copied to them from their insurance companies.

Data was collected on a standard sheet indicating the date and type of visit or hospitalization, reason for the visit or hospitalization and charges (bill) for the visit or hospitalization. Data on type and amount of medications, laboratory tests, examinations and counseling were also be examined. These data provided an indirect indication of the surviving siblings’ health and a beginning examination of the amount and type of treatments and charges for health care following the death of a brother or sister.

Data Management

Strategies were used to insure data integrity during its collection, coding, and entry in the study. Each family will be assigned a family ID number and each child, a unique child ID number. Data from the family data form and from both parents about themselves (with the family as the “case”) were entered into one file per time point tagged with the family ID. Data from the deceased sibling’s chart were entered into a separate SPSS file tagged with the family ID. Data about/from each child were entered in one file (per time point) with the child as the "case," tagged with their unique child ID and the family ID so files can be merged as needed for specific analyses.

RAs checked that the pre-assembled packet contains the appropriate forms before going to the family’s home and will review all forms for completeness before leaving the family's home. Completed quantitative forms get two levels of coding. In 1st level coding, the UGSA &/or RAs place missing codes where appropriate and assign numbers to open-ended or fill-in-the-blank items. Second level coding by the PD increases accuracy in decisions made by the 1st level coders. All coding decisions are recorded in the frequently updated codebook to ensure consistency in decision-making. Data entered into SPSS by two team members (RAs, UGSA, PD) separately are compared and discrepancies are resolved by referring to the raw data. Initial quantitative data analyses were exploratory. Descriptive statistics and distributions for each variable were inspected to clean the data and to look for skewed or grossly non-normal distributions. Having corrected errors in the data, other preliminary analyses were performed, namely investigating internal consistency reliability of the measures' scales and subscales with coefficient alpha.

Data Analysis

The following analyses were used to address each of the following research questions.

RQ#1

At 2 and 4 months post-death, are there differences between the parent's perception and the surviving sibling's perception of the surviving sibling's own health:

- a) now
- b) now compared to before the death of their brother or sister,
- c) and now compared to others their age?

Hypothesis 1

There will be differences between the parent's perception and the surviving sibling's perception of the surviving sibling's health now, now compared to before the death of their brother or sister and now compared to others their age.

The null hypothesis is that there will be no difference between parent's perception and the surviving sibling's perception of the surviving sibling's health now, now compared to before the death of their brother or sister and now compared to others their age.

Paired t-tests were used to compare the parent's ratings and the sibling's ratings of the surviving sibling's health at Time 1 and Time 2.

RQ#2

Are there differences in the concordance between parent and sibling's perceptions on sibling's health by sibling's age (6-10, 10-13, 13-18), race/ethnicity, gender and cause of the brother's or sister's death (acute vs. chronic illness)?

Hypothesis 2

The hypothesis is that differences in concordance exist between parent and sibling's perceptions of the sibling's health according to the surviving sibling's age, race/ethnicity, gender and cause of death (acute vs. chronic illness).

The null hypothesis is that there are no differences in concordance between parent and the sibling's perception of the surviving sibling's health according to the surviving sibling's age, race/ethnicity, gender and cause of death (acute vs. chronic illness).

The difference between the children's and parents' ([mother, father]) ratings of the child's health now, now compared to others and now compared to before the death of their sibling were calculated by creating scores subtracting the child's ratings from the mother's or father's rating. ANOVA was used to determine if the discrepancy in the child and parent's ratings of the child's health now, now compared to others the child's age and now compared to before the death of their sibling differed by age groups (6 to 9, 10 to 12 and 13 to 18) and race/ethnicity.

RQ#3

Are the parent's and the sibling's perception of the surviving sibling's health related to the surviving sibling's anxiety and depression at 2 and 4 months post death of a brother or sister?

Hypothesis 3

The hypothesis is that the parent's and the sibling's perception of the surviving sibling's health at 2 and 4 months post death of a brother or sister is related to the surviving sibling's anxiety and depression.

The null hypothesis is that the parent's and the sibling's perception of the surviving sibling's health at 2 and 4 months post death of a brother or sister is not related to the surviving sibling's anxiety and depression.

The relationship between the parent and the sibling's perception of the surviving sibling's health and the surviving sibling's anxiety and depression at 2 and 4 months post the death of a brother or sister were measured using Pearson's Correlation.

RQ#4

What are the treatments and associated charges for the surviving sibling's physical and mental health (non-routine physician visits, urgent care, emergency care, hospitalizations, and follow-up visits for the former, and mental health services) over the 4 months after the death of a brother or sister?

Hypothesis 4

The hypothesis is that there will be an increase in treatment and associated charges for the surviving sibling's physical and mental health (non-routine physician visits, urgent care, emergency care, hospitalizations, and follow-up visits for the former, and mental health services) over the 4 months after the death of a brother or sister.

The null hypothesis is that there will not be an increase in the treatment and associated charges for the surviving sibling's physical and mental health (non-routine physician visits, urgent care, emergency care, hospitalizations, and follow-up visits for the former, and mental health services) over the 4 months after the death of a brother or sister.

Treatments and associated charges for the surviving sibling's physical and mental health were described using frequencies and descriptive statistics.

CHAPTER IV

RESULTS

The purpose of this study in children who have lost a sibling in the NICU/PICU, ER or those who have been sent home on technology dependent equipment to die peacefully, was to compare parents' and children's perception of the surviving sibling's health, identify factors related to these perceptions, and describe the treatments for the sibling's physical and mental health at 2 and 4 months after the death of their brother or sister. The study was embedded in the current R01 headed by PIs Dr. Brooten and Youngblut that focuses on children's responses to a sibling's death in the NICU/PICU in 3 racial/ethnic groups. Surviving children reported on their own mental and overall health; parents reported on the same. Parents were asked if each surviving sibling had visited the emergency room or physician office, been admitted to the hospital, and needed health services (mental & physical) since the death of the sibling. Any available treatment charges were obtained from the parents in the form of bills and insurance receipts. Data on cause of child death (acute or chronic) were collected from the deceased child's hospital record.

Sample

A total sample of 48 parents (35 mothers, 13 fathers) and 64 siblings (25 males, 39 females) who lost a brother or sister were recruited from NICUs, PICUs, Emergency Rooms and those who were discharged home on technology dependent equipment to die at home. Recruitment sites consisted of Joe DiMaggio Children's Hospital, Jackson Memorial Hospital, Broward General Medical Center, Miami Children's Hospital and newspaper obituaries throughout Florida.

The surviving siblings ranged in age from 6 to 17 years with a mean of 10.5 years ($SD = 3.26$) see Table 1. Most were Black non-Hispanic $n = 32$ (50%), female $n = 39$ (60.9%) and between 6 to 9 years old $n=27$ (42.2%).

Mothers ranged in age from 24 to 52 with a mean age of 36.8 years ($SD = 7.33$) see Table 2. Most mothers spoke English and were Black non-Hispanic. Most mothers were college graduates. Equal numbers of mothers had a high school diploma or less or some college or a vocational degree. Fathers ranged in age from 29 to 50 with a mean age of 40.6 years ($SD = 6.32$). Most fathers' primary language was English and most were Black non-Hispanic. Thirty eight and half percent of the fathers had some college or a vocational degree.

Most parents were married or partnered in their current relationship for a mean of 13.0 years and a range of 3 to 27 years. Most families reported an annual family income of less than \$25,000; 2 families did not report these data. The majority of the families had public health insurance, mainly Medicaid coverage with far fewer having private insurance coverage; 9 did not report these data.

The deceased child's age ranged from birth to 18 years of age. Causes of death included prematurity complicated by a superimposed illness, congenital anomalies, respiratory diseases, neoplasms, motor vehicle accidents, head trauma and drowning. More than half of the deaths (56%) were related to a chronic illness.

Table 1*Sample Characteristic (Surviving Siblings)*

	<i>Total Sample</i> <i>N= 64</i>	<i>Male</i> <i>n= 25 (39%)</i>	<i>Female</i> <i>n= 39 (61%)</i>
Age categories			
6-9	27 (42.2)	11 (44)	16 (41)
10-12	18 (28.1)	6 (24)	12 (31)
13-18	19 (29.7)	8 (32)	11 (28)
Race			
White non-Hispanic	18 (28.1)	7 (28)	11 (28)
Black non-Hispanic	32 (50.0)	13(52)	19 (49)
Hispanic	14 (21.9)	5 (20)	9 (23)
Cause of Sibling death	<i>N = 36</i>		
acute	16 (44)		
chronic	20 (56)		

Table 2
Sample Characteristics (Parents)

	Total Sample (<i>N</i> =48)	Mothers (<i>n</i> = 35)	Fathers (<i>n</i> = 13)
Mean Age in Years		36.8 (<i>SD</i> =7.33)	40.62 (<i>SD</i> =6.31)
Relationship Status	<i>N</i> = 48	<i>n</i>=35	<i>n</i>=13
Married or partnered	42 (88)	30(85.7)	12(92.3)
Single or widowed	6 (13)	5(14.3)	1(7.7)
Mean Years in Current Relationship	<i>M</i> =13.0 years, <i>SD</i> = 5.81		
Primary Language		<i>n</i>=35 (%)	<i>n</i>=13 (%)
English	42 (88)	32 (91.4)	12 (92.3)
Spanish	4 (8)	3 (8.6)	1 (7.7)
Race/Ethnicity	<i>N</i>=48	<i>n</i>=35 (%)	<i>n</i>=13 (%)
Black non-Hispanic	21 (44)	15(42.9)	6(46.2)
White non-Hispanic	13 (27)	9(25.7)	4(33.3)
Hispanic	13 (27)	11(31.4)	2(15.4)

Other (Mestizo)	1 (2)	0	1(7.7)
Education	<i>N=48</i>	<i>n=35 (%)</i>	<i>n=13(%)</i>
High School or Less	15 (31)	11(31.4)	4(30.8)
Vocational or Some College	16 (33)	11(31.4)	5(38.5)
College (Associates, Bachelors, Masters or Doctoral Degree)	17 (35)	13(36.1)	4(30.8)
Yearly Household Income	<i>Families</i> <i>N = 34* (%)</i>		
Less than \$25,000	16(47.1)		
\$25,000 to \$59,999	11(32.4)		
\$60,000 to \$99,999	2(5.9)		
\$100,000 and above	5(14.7)		
Insurance Type	<i>Families</i> <i>N= 36 (%)</i>		
Public	18(50.0)		
Private	7(19.0)		
Self-Pay	2(6.0)		
No Answer	9 (25.0)		

*Not all families answered

Results

Research Question 1. At 2 and 4 months post-death, are there differences between the parent's perception and the surviving child's perception of the child's own health: a) now; b) now compared to before the death of their sibling; and c) now compared to others their age?

Parents were asked to rate their child's health at 2 and 4 months post-death, now and in comparison to other children their ages on a scale from 1 "poor" to 10 "excellent." Parents were also asked to rate their child's health now compared to before the death on a scale from 1 "much worse than before" to 10 "much better than before." Surviving children were also asked to rate their own health using the same measures.

Mothers vs Child perception of the Child's Health--Two Months and Four Months after Sibling's Death

As shown in Table 3, when children and mothers were interviewed two months after the sibling's death, the children's and mother's ratings of the child's current health differed significantly. The children's mean rating was significantly lower than the mothers' mean rating indicating that the mothers perceived their child to be in better health than the children's own perception of their health. However the children's and mothers ratings of the child's health compared to others their age did not differ significantly. Similarly the children's and mothers ratings of the child's health now compared to the child's health prior to the sibling's death also did not differ.

When the children and the mothers were interviewed four months after the sibling's death, the children's and mothers ratings on the children's health compared to other children the child's age differed significantly. The children's rated their health

lower than their mothers did. Mothers perceived their children's health compared to other children of the same age to be better than the perception of the child. However, the children's and mothers ratings of the children's current health and the child's rating of their health compared to before the sibling's death were not significant.

Table 3

Comparisons of Children's and Mothers' Ratings of Child Health at Two and Four Months

Variable	Child T1		Mother T1		<i>df</i>	<i>t</i>
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>		
Health now	7.89	2.10	8.54	1.86	55	-1.97*
Health compared to others	8.07	1.97	8.48	1.99	57	-1.28
Health prior to sibling's death	5.89	2.29	5.41	1.40	55	1.33
Variable	Child T2		Mother T2		<i>df</i>	<i>t</i>
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>		
Health now	8.31	1.85	8.56	1.86	51	-.84
Health compared to others	7.85	2.07	8.63	1.92	47	-1.98*
Health prior to sibling's death	6.02	2.08	5.45	1.75	50	1.43

* $p < .05$. ** $p < .01$. *** $p < .001$.

Fathers vs Child perception of the Child's Health--Two Months and Four Months after Sibling's Death

As shown in Table 4, when children and fathers were interviewed two months after the sibling's death, the children's and fathers ratings on the child's current health differed significantly. The children's mean rating of their health now was significantly lower than the fathers' mean rating indicating that the fathers perceived their child to be in better health than the children's own perception of their health. Similarly the children's and fathers ratings on the child's health compared to others their age also differed significantly. The children's mean rating of their health compared to others their age was significantly lower than the fathers' mean rating indicating that fathers perceived their children to be in better health compared to other children their age than the children perceived themselves to be. However, no significant differences were found on the child's health now compared to before the sibling's death.

When the children and the fathers were interviewed four months after the sibling's death, the children's and father's ratings on the children's current health, compared to others their age and before their sibling's death did not differ significantly.

Table 4

Comparisons of Children's and Father's Ratings of Child Health at Two and Four Months

Variable	Child T1		Father T1		<i>df</i>	<i>t</i>
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>		
Health now	7.36	1.97	8.77	1.57	21	-2.87*
Health compared to others	7.05	2.32	8.77	1.60	21	-3.47*
Health now vs. prior to sibling's death	5.35	1.53	5.25	0.97	19	.240
Variable	Child T2		Father T2		<i>df</i>	<i>t</i>
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>		
Health now	8.13	1.92	8.80	1.15	14	-1.44
Health compared to others	8.00	2.17	8.53	1.51	14	-1.29
Health now vs. prior to sibling's death	5.60	1.55	5.67	1.63	14	-0.13

* $p < .05$. ** $p < .01$. *** $p < .001$.

Research Question 2. Are there differences in the concordance between parent and child perceptions of the child's health by child age (6 to 9, 10 to 12, 13 to 18), race/ethnicity, gender and cause of the brother's or sister's death (acute vs. chronic illness)?

The difference between the children's and parents' ([mother, father]) ratings of the child's health now, now compared to others and now compared to before the death of their sibling were calculated by creating scores subtracting the child's ratings from the mother's or father's rating. ANOVA was used to determine if the discrepancy in the child and parent's ratings of the child's health now, now compared to others the child's

age and now compared to before the death of their sibling differed by age groups (6 to 9, 10 to 12 and 13 to 18) and race/ethnicity.

Children and Parents' Findings at Two and Four Months for Age Group

Findings at two months (T1) indicated that there were no significant differences in the discrepancies between children's and mothers' ratings and between children's and fathers' ratings of the child's health now, now compared to others the child's age and now compared to before the death of their sibling across age groups Table 5. However, at four months, the discrepancy between fathers and their children's ratings of the child's health now compared to others the same age across age group was significant $F(2,11) = 6.60, p = .01$. There were no significant differences in T1 concordance by age group. The only significant difference by age group at T2 was for father-child concordance. Post-hoc tests did not show which groups were significantly different. The biggest mean discrepancy was for the 10-12 age group. See Table 5. There were no significance differences between the child's and the mother's ratings.

Table 5

Concordance of Mothers' and Fathers' Ratings of their Child's Health with Children's Ratings at Two Months across Child Age Groups

Time 1 (2 months)	Mother-Child		Father-Child	
Age Group	<i>M (SD)</i>	<i>F (p)</i>	<i>M (SD)</i>	<i>F (p)</i>
Health now		1.93		.45
6 to 9 years old			2.20(2.59)	
10 to 12 years old			.75(2.22)	
13 to 18 years old			1.20(2.39)	
Health compared to others		1.34		.48
6 to 9 years old	.25(2.22)		3.0(2.45)	
10 to 12 years old	-1.0(2.32)		2.25(2.5)	
13 to 18 years old	.54(2.85)		1.70(2.41)	
Health prior to sibling's death		2.96		.52
6 to 9 years old	-1.83(3.65)		-.67(.58)	
10 to 12 years old	.45(1.75)		.75(1.50)	
13 to 18 years old	-.23(.93)		.40(2.17)	

* $p < .05$

Concordance of Mothers' and Fathers' Ratings of their Child's Health with Children's Ratings at Four Months across Child Age Groups

Time 2 (4 months)	Mother-Child		Father-Child		
	Age Group	M (SD)	F (p)	M (SD)	F (p)
Health now			1.67		3.17
6 to 9 years old		-.45(2.61)		-.60(.89)	
10 to 12 years old		.07(2.30)		.33(2.08)	
13 to 18 years old		.94(1.71)		1.83(1.84)	
Health compared to others			.67		6.60(.01)*
6 to 9 years old		.70(2.81)		.60(.89)	
10 to 12 years old		1.73(2.05)		-1.67(.58)	
13 to 18 years old		.67(2.69)		1.33(1.51)	
Health prior to sibling's death			2.48		2.02
6 to 9 years old		-1.48(2.50)		-1.20(2.39)	
10 to 12 years old		-.14(2.51)		.00(.00)	
13 to 18 years old		.06(1.73)		1.17(1.94)	

* $p < .05$

Children and Parents' Findings at Two and Four Months for Racial/Ethnic Groups

Findings at two months indicated that there were no differences in the discrepancies between mother-child and father-child ratings of the child's health now, now compared to others the child's age and now compared to before the death of the sibling across race. Findings at four months revealed that father-child concordance on the child's health compared to peers was significantly different by race, with the Black group having the biggest difference in the White group. Mother-child concordance at T2 on the child's health now compared to before the death was significantly difference by race with the Black group having a bigger discrepancy than the Hispanic group. See Table 6.

Table 6

Concordance of Mothers' and Fathers' Ratings of their Child's Health with Children's Ratings at Two Months across Child Race

Time 1 (2 months)	Mother-Child		Father-Child	
Child Race	<i>M (SD)</i>	<i>F (p)</i>	<i>M (SD)</i>	<i>F (p)</i>
Health now		.22 (.81)		1.42 (.27)
White non-Hispanic	1.0(1.67)		1.67(2.01)	
Black non-Hispanic	.26(2.90)		.180(1.81)	
Hispanic	.56(1.88)		-.67(4.04)	
Health now compared to others		.24 (.79)		1.56 (.24)
White non-Hispanic	.00 (1.41)		1.50(2.07)	
Black non-Hispanic	-.15(2.93)		3.00(1.83)	
Hispanic	.50(1.58)		.67(4.04)	
Health now prior to sibling's death		.78 (.47)		1.15 (.35)
White non-Hispanic	-.00(3.16)		1.0(1.41)	
Black non-Hispanic	-1.15(2.60)		.33(2.0)	
Hispanic	-.10(2.92)		-1.0(1.73)	

Concordance of Mothers' and Fathers' Ratings of their Child's Health with Children's ratings at Four Months across racial/ethnic Groups

Time 2 (4 months)	Mother-Child		Father-Child	
	<i>M (SD)</i>	<i>F (p)</i>	<i>M (SD)</i>	<i>F (p)</i>
Health now		.87(.42)		.70 (.52)
White non-Hispanic	.85(1.91)		.88(2.03)	
Black non-Hispanic	-.21(2.25)		-.25(1.50)	
Hispanic	.08(2.75)		1.50(2.12)	
Health now compared to others		.07 (.93)		4.51 (.04)*
White non-Hispanic	.79(2.01)		-.38(1.19)	
Black non-Hispanic	1.10(2.53)		2.0(1.63)	
Hispanic	.82(3.49)		.50(.71)	
Health now prior to sibling's death		3.58(.04)*		2.28(.15)
White non-Hispanic	-.57(1.95)		-.75(1.91)	
Black non-Hispanic	-1.38(2.39)		1.75(2.22)	
Hispanic	.69(2.25)		.00(.00)	

* $p < .05$

Children and Parents' Findings at Two and Four Months for Gender

An independent t-Test was used to test differences in the concordance between mother- child and father- child dyads across the child's gender. There were no significant differences in discrepancies between parent and child ratings of the child's health at two and four months by whether the child is male or female. See Table 7.

Concordance of Mothers' and Fathers' Ratings of their Child's Health with Children's ratings at Two Months by Child's gender

Table 7

Time 1 (2months)	Mother-Child				Father-Child			
Gender	<i>M</i>	<i>SD</i>	<i>df</i>	<i>t</i>	<i>M</i>	<i>SD</i>	<i>df</i>	<i>t</i>
Male								
Health now	.11	2.79	40	-.75	1.67	1.58	17	.52
Health compared to others	-.20	3.10	42	-.10	2.89	2.15	17	1.30
Health prior to death	-1.00	2.71	40	-.56	-.25	1.04	15	-1.17
Female								
Health now	.70	2.34	40	-.75	1.10	2.92	17	.52
Health compared to others	.21	1.84	42	-.54	1.50	2.46	17	1.30
Health prior to death	-.52	2.81	40	-.56	.78	2.28	15	-1.17
Time 2 (4months)								
Gender	<i>M</i>	<i>SD</i>	<i>df</i>	<i>t</i>	<i>M</i>	<i>SD</i>	<i>df</i>	<i>t</i>
Male								
Health now	.10	2.69	48	-.10	.33	1.75	12	-.52
Health compared to others	1.19	3.10	44	.61	1.00	.89	12	1.17
Health prior to death	-.81	2.72	49	-.46	.00	1.09	12	-.11
Female								
Health now	.17	2.05	48	-.10	.88	2.03	12	.52
Health compared to others	.72	2.64	44	.61	.00	1.93	12	1.17
Health prior to death	-.50	2.45	49	-.46	.13	2.70	12	-.11

Children and Parents' Findings at Two and Four Months for Deceased Siblings Acute vs. Chronic Illness

Independent t-Tests were used to determine differences in concordance between mother- child and father- child dyads across the cause of the sibling's death (acute vs chronic illness). Findings indicated that at two months there were no significant differences in the discrepancies of the ratings of the mother and child on the child's health now, now compared to other children the child's age and now compared to before the sibling's death whether the sibling's death was due to acute or chronic illness. At 2 months the father-child discrepancy could not be tested because there was only 1 father in the acute group.

There was no statistically significance difference found at four months between the mother-child concordance of the child's health now, now compared to other children their age and now compared to before the death of the sibling. Father-child concordance could not be tested because there was only 1 father in the acute group. See Table 8.

Concordance of Mothers' and Fathers' Ratings of their Child's Health with Children's ratings at Two Months by Deceased Siblings Acute vs Chronic Illness

Table 8

Time 1 (2months)	Mother-Child				Father-Child			
	<i>M</i>	<i>SD</i>	<i>df</i>	<i>t</i>	<i>M</i>	<i>SD</i>	<i>df</i>	<i>t</i>
Acute vs Chronic Illness								
Acute								
Health now	1.08	2.43	40	-1.11	2.50	2.43	17	-.71
Health compared to others	.77	2.12	42	-1.31	2.50	2.12	17	-.21
Health prior to death	-.67	3.00	40	-.11	5.00	--*	15	-3.43
Chronic								
Health now	.14	2.57	40	-1.11	1.24	2.39	17	-.71
Health compared to others	-.29	2.75	42	-1.31	2.12	2.45	17	-.21
Health prior to death	-.77	2.69	40	-.11	.00	1.41	15	-3.43

**Only 1 father in this group*

Time 2 (4months)	Mother-Child				Father-Child			
	<i>M</i>	<i>SD</i>	<i>df</i>	<i>t</i>	<i>M</i>	<i>SD</i>	<i>df</i>	<i>t</i>
Acute vs Chronic Illness								
Acute								
Health now	.59	2.30	48	-1.23	-.20	1.10	12	1.29
Health compared to others	1.55	2.52	44	-1.55	.60	2.19	12	-.29
Health prior to death	-.55	2.74	49	-.21	-.40	3.65	12	.61
Chronic								
Health now	-.21	2.28	48	-1.23	1.11	2.09	12	1.29
Health compared to others	.38	2.58	44	-1.55	.33	1.32	12	-.29
Health prior to death	-.69	2.07	49	-.21	.33	.50	12	.61

Research Question 3. Are the parent's and the child's perception of the child's health related to the child's anxiety and depression at 2 and 4 months post death of a sibling?

Parent and child measures of the child's health were examined using the child's rating of the children's anxiety (Spence Anxiety Scale for Children) and depression (Children's Depression Inventory). Both scales had high reliabilities. The Anxiety Scale for Children at T1 and T2 had Cronbach's $\alpha = 0.90$ and 0.91 respectively. The Child Depression Inventory at T1 and T2 had Cronbach's $\alpha = 0.72$ and 0.77 respectively. Pearson Correlations were used to analyze the 2-month (T1) and the 4-month (T2) time points separately.

Two months (T1) Ratings Correlations with T1 Depression and Anxiety

Greater child depression at T1 was significantly related to the child's lower ratings (at T1) of his/her health now, now vs compared to other children their age, and now vs before the death. See Table 9.

Greater child anxiety at T1 was significantly related to lower T1 ratings by fathers of the child's health now $r = -.63, p = .009$ and now compared to other children their age $r = -.50, p = .05$. This indicates that the higher the child's anxiety, the lower the father's rated their child's health right now and now compared to other children the child's age. Mother's ratings of the child's health were not related to the child's depression and anxiety.

Correlations of T1 depression and anxiety with T1 health ratings

Table 9

	T1child CDI total depression score	T1child anxiety total Spence
T1child health right now	$r = -.40$ $p = .009^*$	$r = -.071$ $p = .68$
T1child health now vs others their age	$r = -.336$ $p = .03^*$	$r = -.16$ $p = .33$
T1child health now vs before sib death	$r = -.346$ $p = .03^*$	$r = -.05$ $p = .79$
T1F child health now		$r = -.63$ $p = .009^*$
T1F child health now vs. others their age		$r = -.50$ $p = .05^*$

* $p < .05$

Four months (T2) Health Ratings Correlations with T1 Depression and Anxiety

Four month health ratings were not significantly related to four month (T2) scores on the children's depression and anxiety scales.

Research Question 4. What are the treatments and associated charges for the surviving child's physical and mental health (non-routine physician visits, urgent care, emergency care, hospitalizations, and mental health services) over the 4 months after the death of a sibling?

Treatments and charges for health care for non-routine physician visits, emergency room visits, urgent care visits, hospitalizations, and mental health services for each participating child were collected from parents at 2 and 4 months post death using bills for these services sent to them or copied to them from their insurance companies. Data on type and amount of medications, laboratory tests, examinations and counseling were also collected. See Table 10.

Table 10

Frequency of Children's Treatments from Sibling Death to 4 Months post the
Death

	T1 Treatments from the death-up to 2 months post death	T2 Treatments from 2 to 4 months post death	Total Treatments (N=94)	Treatment Males (n=25)	Treatment Females (n=39)
Routine physician visits	14	9	23	12	11
Non-routine physician visits	6	5	11	4	7
Specialists Office Visits	2	7	9	4	5
ER/Urgent Care Visits	3	6	9	4	5
Hospitalizatio ns	1	0	1	0	1
Medications	7	18	25	9	16
Laboratory tests	0	5	5	1	4
Counseling	4	7	11	8	3
TOTAL	37	57	94	42	52

There were a total of 94 treatments for the children from the death of the sibling to 4 months after the sibling's death. The numbers of treatments were greater at T2 (2 to 4 months) than T1 (death to 2 months). The numbers of total treatments for males were slightly less than for females. The majority of treatments were routine physician visits followed by equal numbers of visits for counseling and non-routine physician visits. More males received treatment for counseling than females. There was only one hospitalization at T1 for a female who was hospitalized with an exacerbation of her Cystic Fibrosis.

Reasons for routine physician visits included annual physical exams, flu shots, and immunizations. Non routine physician visits included visits for strep throat, stomach pains, gastritis, muscle pains, headaches, sleeping problems, skin rashes, asthma, and emotional distress with referrals to psychology for counseling. Counseling consisted of individual, group, art and school therapy as well as support groups. Reasons for emergency room and urgent care visits included depression, emotional issues, head injury, eye pain, stomach pain, sinusitis, exacerbation of asthma with shortness of breath and skin rashes. The use of medications also increased from Time 1 to Time 2 (7 vs 18). Medications that were prescribed were antibiotics oral and topical, pain relievers, bronchodilators and over the counter medications for physical ailments.

Most of the families had Medicaid insurance where there was either no cost or very little co-pay for the families. The total charges for treatment were \$1844.98. See Table 11. There were more charges at T2 than T1 and significantly more charges for males than for females (\$1314 vs \$530.98). The greatest total charges were for

counseling and therapy with males requiring more charges than females. The next greatest charges were in the category of emergency room and urgent care where the charges were equal across males and females. This was followed by charges for routine physician visits and specialist's visits. The latter had charges equally distributed among males and females; however, charges for males' routine physician visits were far greater than charges for females. There was an increase in the charges for medications for families that either paid a co-pay or paid out of pocket from T1 to T2 (\$5 vs \$289.98). The total charges for the medications were \$294.98. However, many children took medications that were covered by Medicaid or insurance. Females total charges for medications were slightly higher than for males (\$160.98 vs \$134.00).

Table 11

Total Out of Pocket Expenses for Children's Treatments from Sibling Death to
4 Months post Death

	Charges from the death-up to 2 months post death	Charges from 2 to 4 months post death	Total Out of Pocket Expenses (N=94)	Total Charges Males (n=25)	Total Charges Females (n=39)
Routine physician visits	14 visits 9 Medicaid 3 Insurance \$140 co-pay	9 visits 5 Medicaid 4 Insurance \$50 co-pay	\$190.00 co-pay	\$165.00	\$25
Non-routine physician visits	6 visits 5 Medicaid 1 Insurance	5 visits 4 Medicaid 1 Insurance \$30 co-pay	\$30.00 co-pay	\$30.00 co-pay	0
Specialists Office Visits	0	\$90 co-pay	\$90	\$45 co-pay	\$45 co-pay
ER/Urgent Care Visits	0	\$400 out of pocket	\$400 out of pocket	\$200	\$200
Hospitalizations	0	0	0	0	0
Medications	\$5 Co-pay	\$289.98	\$294.98	\$134.00	\$160.98
Laboratory tests	0	0	0	0	0
Counseling	\$420 out of pocket	\$420 out of pocket	\$840	\$740	\$100
TOTAL	\$565	\$1279.98	\$1844.98	\$1314	\$530.98

CHAPTER V

DISCUSSION

Death of a child is a very painful experience for parents and siblings and approximately 2 million children experience the loss of a sibling each year; 25% are in need of clinical intervention but very few receive these services; about 50% experience behavioral and physical problems (Charles & Charles, 2006; Packman, Horsley, Davies & Kramer, 2006). There is ample literature from the parent's perspective indicating that children experience both physical and emotional symptoms including acting out behaviors, withdrawal, changed relationships with peers, parents and other siblings, self-injury behaviors, trouble focusing in school and even suicide. Children also experience physiological symptoms that include allergies, asthma, stomach-aches, day wetting, and nausea and skin rashes (Birenbaum, 2000). However there is very little literature from the child's perspective about their physical and emotional health.

There are very few child self-reports after suffering a sibling's death and the few that exist have reported changes in school work, activities/interest, personality, goals and life's perspectives during the first year after the death of their sibling (Foster, Gilmer, Vannatta, Barrera, et al., 2012). Many times these children become the "forgotten mourners." Review of the literature points out that the surviving child's feelings are often overlooked and the child may mask the way he or she feels in an attempt not to cause more suffering to their parents (Sloper, 2000). Rolls and Payne (2007) explored the experiences of both children and parents attending a bereavement service in the United Kingdom. The findings indicated that children had a difficult time expressing and managing their feelings and sadness. They became pre-occupied and worried about the

health of their parent. Parents expressed their need to receive support and get advice from others on how to provide the appropriate care for their bereaved child.

In addition, there is very little literature on treatments and associated health care costs for children who have lost a sibling. Data comparing the parent's and children's perceptions of the surviving sibling's physical and emotional health, treatment for health conditions and associated health care costs are needed to guide clinical care, healthcare policy decisions and direction for further research to promote the health and well-being of children who have lost a sibling and their families. The purpose of this study was to begin to provide such data.

Discussion and Findings

In the present study when children and mothers were interviewed two months after their sibling's death, the children's and mothers' ratings on the child's current health differed significantly. Children rated their health lower than their mothers rated the children's health indicating that the mothers perceived their children to be in better health than the children's own perception of their health. However the children's and mothers' ratings on the child's health compared to others their age and compared to before their sibling's death did not differ significantly.

When the children and fathers were interviewed two months after the sibling's death the children's and fathers' ratings on the child's current health and on the children's health compared to other children their age differed significantly. Children perceived their current health as well as their health compared to others as poorer than their father's perceived their health. However, no significant differences were found on the child's health now compared to before the sibling's death.

At four months after the sibling's death, children and their parents were interviewed and the children and mother's ratings of the child's health compared to other children their age differed significantly. Children perceived their health to be lower than others their age unlike their mothers who rated them in better health than their peers. However, the children's and mothers' ratings of the children's current health and the children health compared to before the sibling's death were not significantly different. Likewise children's and fathers' ratings on the children's current health, compared to others their age and before their sibling's death did not differ significantly.

The findings from the present study cannot be compared to other studies because they are not available in the literature. However, it is evident from the present study that differences exist between parent and child perceptions of the child's health. The closest comparison that can be made from the existing literature are studies that have both parent and child self-report on the child's physical and emotional health but not necessarily after a sibling's death. A classic study by Craft and Craft (1989) compared the parents' and the children's perceptions of the changes that occur after a stressful event such as a sibling's hospitalization. The children's ages ranged between 5 to 17 years of age. Some symptoms that were assessed were changes in sleep patterns, appetite, temperament, bedwetting, nail biting, feelings of health and nightmares. The children reported a much higher number of changes than their parents did. The child's age had a big effect on parent-child agreement. The younger children had lower levels of agreement with their parents than did the older children. Parents and children mostly agreed on bedwetting,

however, their main disagreement was children wanting to spend time with their parents and having difficulty concentrating in school and getting angry.

In another study by Sweeting and West (1998), 2586 children that were 11 years of age were interviewed with their parents for concordance/disagreement between child self-report and parent report on the rating of the child's health over the past 12 months. Parents were much more likely to describe their child's general health as "good" compared to the children's reports of themselves.

Although the present study and the studies mentioned previously were not all examining concordance/disagreement between the children's and parent's ratings of the child's health after a sibling's death, findings are similar and the results indicate that children's and parents' ratings differ. These studies add to our knowledge in understanding that differences do exist in parent-child ratings. Obtaining the different perspectives from both parents and children provides their unique contribution for the best outcome of the family.

Differences by Age

In the present study parents and children were interviewed at 2 and 4 months after the death of the children's sibling. At 2 months there were no significant discrepancies between the parents' and the children's rating of their health across age groups, race/ethnicity, gender and the nature of sibling's death. However, at 4 months after the sibling's death, fathers rated their child's health compared to other children their age higher than the children rated themselves with the biggest discrepancy in the 10-12 age group. These findings differ from the Johnston et al. (2003) study that reported adolescents (13 to 18 years old) and their parents reported more negative life events than

10 to 12 and 7 to 9 year olds. Review of the literature indicates that adolescents (13 to 18 years old) have reported higher self-injury behaviors and higher rates of suicide during the first year following the death of a loved (Grenklo, Kreicbergs, Hauksdottir, Valdimarsdottir et al., 2013). Still another study by Hamden et al. (2012) compared the health risk behaviors of bereaved youth ages 7 to 25 years old within a three year period following their loss. Interviews were conducted at 9, 21 and 33 months after the death. Two main health risk behaviors identified and increased at each time point were in the adolescent group. The behaviors were not wearing a seat belt while driving in a car and engaging in physical fights especially in the adolescent period.

At 4 months there were no differences between mother-child health ratings across age groups and father-child health ratings of the child's current health and to their health before the sibling's death across age groups.

Differences by Race/Ethnicity

At 2 months after the sibling's death there were no significant differences between parent-child health ratings of the child's health now, compared to peers and compared to before the sibling's death by race/ethnicity. However at 4 months after the sibling's death differences between mother-child health ratings of the child's health compared to before the sibling's death differed across race. The Black group had a higher discrepancy than the Hispanic group. Likewise, findings at 4 months revealed that father-child concordance on the child's health compared to others their age differed, with the Black group having a bigger discrepancy than the White group. There were no significant differences between mother-child and father-child ratings of the child's health now, there were also no significant findings of the mother-child health ratings of the

child's health now compared to other children their age and the father-child health ratings of the child's health now compared to before the sibling's death.

The findings of the present study are unique. There are very few studies that explore the parent's and child's ratings of the child's health after a sibling's death across race. The studies that do exist include large samples of White parents and children. The findings from the present study are consistent with those of the Lauri and Neimeyer (2008) study that examined 1,581 (940 Caucasian, 641 Black African American) bereaved college students' grief as it related to continuing bonds with the deceased, interpersonal dimensions of the loss and identity change. The results of the Lauri and Neimeyer study indicated that the Black African American children suffered from complicated grief. They maintained a stronger continued bond with the deceased, had more complicated grief symptoms and spent less time speaking to others or getting professional support than Caucasians. In the present study the Black group had a bigger discrepancy than the White group in the father's ratings and in the mother's ratings and the Black group had a bigger discrepancy than the Hispanics. A possible reason for these results is that Blacks race rely more on their faith for support and speak less about the deceased with family and others. Children may be internalizing their feelings thus not verbalizing to their parents how they feel leaving parents unaware of the child's feelings.

In another study Nguyen and Scott (2013) examined the relationships between physical and academic self-concept, death of a family member and depression in children. The sample consisted of 80% Whites, 13% Blacks and 7% others. The results indicated that children with lower physical self-concepts were rated by their mothers as

having significantly more depressive symptoms after the loss of a family member. However, which racial group was responsible for these findings was not disclosed. Since the majority of the sample was White, it would be logical to conclude that they couldn't explore racial/ethnic differences. The dearth of literature in this area indicate a need for studies such as the present study that include a wider range and equal number of race/ethnicities to provide a better representation of grieving among children and adolescents.

Gender Differences

The findings from the present study show that when parents and children were interviewed at 2 and 4 months after their sibling's death, the parent-child health ratings of the child's health now, compared to peers and compared to before the sibling's death did not differ across gender of the surviving child. These findings differ from the existing literature that identifies gender differences in children's responses to the death of a sibling. Areas that are affected differently according to their gender are social functioning, school performance and treatment outcomes (Paris, Carter and Armsworth, 2009; Abdelnoor and Hollins, 2004). Rosner, Kruse and Hagl (2010) conducted 2 meta-analysis (1) controlled studies and (1) uncontrolled studies to evaluate existing treatments for bereavement and grief reactions in children and adolescents. Included in the meta-analysis were 27 treatment studies (15 studies were with a control group design and 12 studies were without a control group) that were published before 2006. The results were based on the total number of children and adolescents (N = 1073), with 812 from controlled studies and 261 from non-experimental studies. Bereaved girls were found to be at higher risk for distressing symptoms and bereaved adolescent boys had more

adjustment problems. In a related study, Little et al. (2009) examined bereaved youths (N = 109) (ages 8 to 16 years and 52% were boys) for gender differences in internalizing behavior problems. Ethnicity was as follows: 71% non-Hispanic Caucasian, 10% Hispanic, 7% African American, 7% Native American and 5% other. Girls were found to have more internalizing behaviors such as becoming withdrawn, depressed, poor academic performance and more conflicts with the family and boys have more externalizing behaviors such as acting out and engaging in physical fights.

The present study findings did not concur with previous study findings. This may be because of the racial/ethnic mix of the sample, the limited participation of fathers in the present study and the age groups of the respondents. In the present study there were more children responding in the 6 to 9 age group with more 6 year olds responding. Future research should incorporate equal number of males and females (the present study has 61% females), both parents, and a smaller variation in age group to give us a better understanding of the gender differences that may exist.

Differences by the Nature of the Death (Acute vs Chronic)

The findings from the present study show that at 2 and 4 months after a sibling's death, discrepancies in parent-child health ratings of the child's health now, compared to peers and compared to before the sibling's death did not differ when the sibling's death was acute or chronic. Existing literature indicates that when a child loses a sibling due to an acute or chronic illness, changes in their physical and emotional status are affected. The present study's findings differ from Foster et al's. (2012) cross-sectional, qualitative study that examined the parents' perception and the child's self-report of the changes that the surviving child endures after suffering the death of a sibling due to cancer.

Children reported more positive changes which reflected adaptation to the environment and personal growth. Parents reported more negative changes that were attributed to sadness due to the death of the sibling. Changes in sibling relationships and more so peer relationships were reported more often by the child than by the parents.

Nolbris and Hellstrom (2005) found that children who had lost a sibling to cancer were often affected by the thoughts of “catching their sibling’s cancer.” Burns, House and Ankenbauer (1986) found that after a child lost a sibling due to a sudden illness such as Sudden Infant Death Syndrome (SIDS) 54% of the children exhibited physical and emotional symptoms for more than a year.

Although the study by Lohan and Murphy (2001) was not based on parent-child health ratings, parents reported that surviving adolescents continued to have multiple grief reactions and behavioral changes up to 2 years after a sibling’s sudden or violent death. The present study’s findings are not consistent with previous studies but there is ample literature that indicates that regardless of the nature of the sibling’s death, the children’s physical and emotional health are affected. It is important to recognize that children suffer from physical and emotional symptoms especially after the death of a sibling regardless if the death of their brother or sister was acute or chronic. Limitations to the Lohan and Murphy study are that over half of the participants’ sibling’s death was due to a chronic disease. Future research should incorporate better representation in cause of death and better balancing within the acute and chronic illnesses.

At (T1) two months after the sibling’s death, T1 health ratings correlated with T1 child’s depression and anxiety indicating that the higher the child scored on the Child Depression Inventory (CDI) (indicating more depression) the lower he/she rated his/her

current health, health compared to peers and health compared to before the sibling's death at T1 (2 months).

The higher the child scored on the Spence Anxiety Scale (indicating more anxiety) at T1 (2months), the lower the fathers rated their child's current health and their health compared to others their age at T1. There were no significant differences between the mother and child's ratings and the child's anxiety and depression score at T1. Four month health ratings were not significantly related to four month (T2) scores on the children's depression and anxiety scales.

Findings from the present study indicate that children with depression rate their health lower. Findings also indicate that when the child had higher anxiety their fathers perceived their current health to be lower as well as lower than their peers.

There are very few studies available that assess the relationship between parent ratings of the child's health and children's rating of their anxiety and depression following the death of their sibling. However, there are a few studies that have addressed the child's emotional health, some after sibling loss or parent loss. The findings from the present study are consistent with those of Barrera, et al. (2013); Foster et al., (2012); and Birenbaum (2000) that indicate that bereavement has an association with mortality and morbidity especially within the first few months after suffering the loss of a loved one. The physical and emotional well-being may deteriorate due to feelings of loneliness, changes in eating habits and changes in the family structure. In Barrera's study parents reported that children less than 6 years of age expressed their sadness in missing their sibling by crying, anger and temper tantrums. Adolescents had a difficult time concentrating in schoolwork, avoided expressing their feelings to their parents and

engaged in high risk behaviors such as drinking, body piercing and tattooing. Birenbaum (2000) found that preschool, school-age and adolescents experienced psychosocial symptoms including hyperactivity, trouble sleeping, impulsivity, nightmares, anxiety, guilt, social changes, depression, and even suicide. Some children may even feel guilt that they caused the sibling's death and fear that someone else in the family will die (including them) and may experience sadness, anxiety, loss, distance from parents, and confusion.

Little et al. (2009) examined intrusive thoughts about grief, post death stressors, fear of abandonment and negative appraisals about interpersonal losses (separation from parents, loss of peer or adult support) and found that girls feared being abandoned in the first few months after suffering the loss of the loved one and had more anxiety and depression than boys within the first year following the loss. The present study findings show that children's depression and anxiety were significantly higher (indicating more depression and anxiety) within the first 2 months following the sibling's death.

There is a dearth of literature related to children's morbidity and mortality after sibling death. There is ample literature that indicates that both children and adults experience physical and emotional symptoms and children have behavioral responses according to their age and development (Grenklo et al. 2013; Qin and Mortensen 2003; Schaefer, Quesenberry and Wi 1995; Christ 2000). Findings from the present study indicate that there were more overall treatments at 4 months (T2) following the sibling's death than at 2 months (T1). There is evidence in the literature that self-injury behaviors, physical and psychological symptoms occur after losing a sibling especially during the first few months after the death (Barrera et al. 2013, Qin& Mortensen, 2003; Schaefer,

Quesenberry & Wi, 1995). However, the majority of treatments in the present study included routine physician visits for annual check-ups, flu vaccines and immunizations followed by non-routine physician visits and counseling. Males attended more counseling sessions than females. This finding is consistent with the Hoffman et al. (2012) study that explored outpatient health services provided to adolescents with a diagnosis of depressive disorders. More males (37%) than females (25%) visited child/adolescent psychiatrists. There was only one hospitalization in the 2 time points for the same child who had Cystic Fibrosis (CF). The use of medications increased from 2 months (T1) to 4 months (T2).

The total health care charges increased from T1 to T2. There were more charges for males than for females. The greatest amount of charges were for counseling followed by emergency room visits and urgent care visits then routine office visits and specialists visits. The findings from the present study are unique but correlate with the CDC's 2011 data of 74,518 emergency room visits in 1 year for children under 18 in the United States. Pittsenbarger (2011) reported that the most common psychiatric visits to the emergency room for adolescents under the age of 19 are for depression, anxiety, behavioral issues, suicide attempts, drug and alcohol use. It is uncertain if these emergency room visits are due to bereavement. Presently there is a demand for mental health care services but due to the lack of reimbursement, services are not offered. Many patients are sent to the emergency rooms for care when an acute situation arises. The emergency room physicians take care of the acute situation and then have the patient follow up with their primary care provider. This leads to rising healthcare costs because of over-use of unnecessary services. The lack of proper screening by primary care providers for

children at risk after losing a sibling as well as the insufficient mental health services available to the parents can lead to rising healthcare costs because of over use of unnecessary or improper services (Britto, 1999). This presents a problem not only at the present moment for the child, but also for the future of the child who has suffered an adversity.

There is very little literature reported on financial treatments for children following the loss of a sibling that include unscheduled physician visits, emergency room visits, hospitalizations and medications. The literature that is available is of children's experiences with support, treatment groups, summer camps, and school intervention programs however the total charges for these are not reported. The literature does express the need for the early identification and continued support that is associated with better outcomes for the child's physical and mental health (MacPherson & Emeleus, 2007). The present study findings add to our knowledge of the need for early identification and intervention to prevent prolonged undue human costs on the family and the child as well as increased financial costs to the family and society.

Study Limitations

This study has offered valuable information which has provided insight on how children feel after the death of a sibling. There are a few limitations with this study. First, although this study was conducted with 3 racial ethnic groups, Black non-Hispanic, White non-Hispanic and Hispanics 50% of the sample was Black non-Hispanic. For future research equal representation of racial/ethnic groups would help to get a culturally diverse aspect of the children's and parent's perceptions of the child's health following a sibling's death. Next, parents were not always able to provide receipts or insurance

billing; therefore we could only estimate the treatment charges associated with these. Future research could include a more detailed itemized treatment charges.

Implications of the Findings for Practice

The findings from this research can be beneficial for nursing practice, nursing educators, healthcare providers, and school personnel. The results from the study on children's perception of their health after the death of a sibling across three racial/ethnic groups provides health care providers and educators the clinical knowledge to help identify those children that are at risk for emotional and physical illness after suffering the loss of a sibling.

Additionally appropriate and effective interventions can be developed within the context of the child's developmental age, race/ethnicity and gender to prevent negative outcomes. Healthcare providers and personnel within the school system should be educated on the significant findings of this research study. They could be made aware that children's and parent's perceptions of the child's health after the death of a sibling do not always concur and that differences do exist.

Since educators spend many hours with the children while they are at school, it would be of great benefit for the teachers to be trained on the red flags that indicate that a child is not coping well with the loss of their sibling so that early intervention or referrals could be made. Healthcare providers can include an age-appropriate, culturally sensitive psychosocial plan of care to be able to capture the bereaved child's emotions.

The findings related to the treatments and treatment charges incurred by the child following the sibling's death can be used by healthcare providers and health care policy makers as a catalyst to prevent unnecessary human costs and decrease the burden on the

economy of the United States. This will prevent the consequential negative outcomes during the transition into adulthood for the surviving child.

Implications of the Findings for Policy

The present study has helped us understand that children's and parents' perceptions of the children's health after the death of a sibling differ. Parents' perceive their child's health to be better than the child's own perception. As evidenced by the present research children suffer from anxiety and depression within the first two months following the death of their sibling. Treatment and treatment charges increased from 2 months to 4 months after the sibling's death. An outstanding number of children went to the primary care providers, emergency rooms or urgent care centers within the first 4 months after the sibling's death. Many of the families had public sector Medicaid insurance.

The findings of this research should be used to guide healthcare policy makers in placing and training clinical personnel in schools to help identify children that are at risk. Hospitals should also be monetarily rewarded for having bereavement teams that can start interventions prior to the sibling's death and follow through 1 year after the death.

Policymakers should also help improve the reimbursement rates for child psychologists and psychiatrists so that more children may be seen and treated effectively. Insurance companies should mandate that healthcare providers include an age appropriate, culturally sensitive psychosocial assessment in their well-care visits to capture those children who are suffering from depression or anxiety as a result of the death of their sibling.

Implications of the Findings for Further Research

Findings from this research study have implications for future research. The responses obtained from the children and parents indicate that children do suffer from depression and anxiety within the first 2 months following a sibling's death. Further research is needed to capture the children and parents' perception of the child's health within the first year following the death of a sibling. Further research is also needed to capture the treatment and health care charges that occur longitudinally across the first year.

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PUBLICATIONS AND PRESENTATIONS

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Roche, R. (1997). Attacking asthma in Dade County Public Schools. *Preventive Medicine News*.

Roche, R. (February, 2014). *Sibling Health Parent report vs. Child self-report*. Poster presentation at the meeting of the Southern Nurses Research Society, San Antonio, Texas.

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