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2020

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## The relation between parental relationship adjustment and sibling emotional adjustment in pediatric cancer

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## The relation between parental relationship adjustment and sibling emotional adjustment in pediatric cancer

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#### Dissertation

Presented to the Faculty of the Graduate School of

The University of Texas at Austin

in Partial Fulfillment

of the Requirements

for the Degree of

## **Doctor of Philosophy**

The University of Texas at Austin August 2020

#### Acknowledgements

First and foremost, I would like to thank my advisor and academic, Dr. Erin Rodriguez, for her support and guidance throughout my graduate career. I am grateful for the many research opportunities you have given me, and for contributing and supporting my interest pediatric psychology.

I would also like to extend my gratitude to my cohort mates. Thank you for listening to me when times were tough. We've been through many stressful moments, and these five years would not have been the same without you.

To my friends and family, thank you for the love and support over the last five years. This journey would have been much more difficult without your constant encouragement. A special thank you to my aunt and uncle who have been my Austin "parents" and given me more support throughout my academic career than I could have asked for.

Finally, to my parents, who moved to this country in search of better opportunities for their children, thank you. This would not have been possible without your many sacrifices and constant encouragement. Thank you for always being interested in my research and clinical work, and for supporting all of my decisions no matter what.

# The relation between parental relationship adjustment and sibling emotional adjustment in pediatric cancer

Juliana Alba-Suarez, Ph.D. The University of Texas at Austin, 2020

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In 2016, approximately 10,000 children were diagnosed with cancer (American Cancer Society, 2016). A diagnosis of cancer can have a negative psychological impact on parents, the marital relationship, and the family unit (McGrath et al. 2005; Yeh 2002). For most siblings, psychological distress is highest close to time of diagnosis but distress may return to average levels after 6 months (Alderfer, 2010). Research shows that factors such as age and gender are related to sibling emotional distress (Alderfer & Kazak., 2006; Hamama, Ronen, & Feigin, 2000; Houtzager, Grootenhuis, Hoekstra-Weebers, Caron, & Last., 2003; Sloper & While, 1996).

Parents of newly diagnosed cancer patients report higher levels of marital dissatisfaction, than parents of children in other treatment phases, and mothers report higher levels of marital dissatisfaction when the child is off treatment or in remission (Yeh, 2002). However, research has yet to explore whether parents' relationship adjustment impacts siblings' emotional adjustment in families of pediatric cancer patients. The current study examined the relationship between mothers' report of relationship adjustment and siblings' emotional adjustment in families of pediatric cancer patients, controlling for time since diagnosis, and whether sibling age and gender moderated the relationship between relationship adjustment and sibling emotional adjustment. The study also used a sequential mixed methods approach to incorporate qualitative data on father perspectives. Results showed that a large proportion of siblings met or exceeded the clinical cutoff score for emotional problems, and sibling age was significantly related to sibling emotional adjustment. Parent relationship adjustment was not related to sibling emotional adjustment, and age and gender did not moderate the relationship between relationship adjustment and sibling emotional adjustment. Qualitative results showed that partner communication and communication challenges were important aspects of overall relationship adjustment. Further, couples identified parent emotional adjustment, cancer stressors, and roles as important factors affected by a cancer diagnosis. Overall, siblings continue to be at risk for emotional adjustment problems and age may be a risk factor for poor emotional adjustment. However, relationship adjustment does not appear to be a factor involved in sibling emotional adjustment to cancer.

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#### **INTEGRATIVE ANALYSIS**

Approximately 14,000 children in the United States are diagnosed with pediatric cancer each year (Ries et al., 2008). In order to meet the medical needs of the child with cancer, families alter roles, responsibilities, and day to day routines (Long & Marsland, 2011). While much research has been done examining the emotional impact of pediatric cancer on parents, less is known about the effect pediatric cancer has on well siblings. Existing studies suggest that pediatric cancer is related to elevated levels of depression, anxiety, and posttraumatic stress symptoms for siblings. Family aspects, such as role modification and cohesion, may moderate the effect of pediatric cancer on these symptoms (Alderfer, 2010; Gerhardt et al., 2012; Van Schoors et al. 2015). Factors such as age and gender have been shown to significantly impact sibling emotional distress in the face of cancer, but findings are inconsistent about whether girls rather than boys and older children rather than younger children face more distress (Alderfer & Kazak, 2006; Hamama, Ronen, & Feigin, 2000).

In the general population, parental marital adjustment has been linked to child emotional adjustment. For parents of pediatric cancer patients, cancer may place a significant strain on the partner relationship (Lavee & Mey-Dan, 2003; Yeh, 2002). Though research has shown that a subset of siblings are at risk for depression, anxiety, and posttraumatic stress symptoms (Alderfer, 2010), little is known about the factors that put this subset of siblings at risk. In particular, studies have not looked at whether partner relationship adjustment is associated with the emotional adjustment of siblings of cancer patients. The current study proposes a model in which poorer relationship adjustment leads to poorer sibling adjustment. Significant results would indicate which siblings may be at risk for emotional adjustment problems. Thus, it is

important to explore the impact of relationship adjustment on sibling emotional adjustment in order to understand the factors that place these siblings at risk for emotional problems.

The current study is based on an adapted version of Conger's Family Stress Model. The Family Stress Model provides an understanding of the pathway between hardship conditions (such as a child's cancer diagnosis), pressures of everyday living, partner relationship functioning, and child emotional adjustment (see figure 1a) (Conger et al., 1992). The model accounts for inter-caregiver interactions that may influence child emotional adjustment and has been found to be valid among families of varying cultural backgrounds (Aytac & Rankin, 2009; Conger et al., 2002; Kwon, Rueter, Lee, Koh, & Ok, 2003; Parke et al., 2004; Solantaus, Leinonen, & Punamaki, 2004). As a result, the proposed study will examine one component of the adapted version of The Family Stress Model: the relation between parents' relationship adjustment and sibling emotional adjustment following a child's cancer diagnosis (see Figure 1b).

The original Family Stress model suggests that the factors such as caregiver mental health, parental relationship conflict, and parenting practices mediate the relationship between economic hardship and child maladjustment (Conger et al., 2000). A cancer diagnosis creates a similar strain on the family as that of economic hardship, and at times, cancer pressures may even include economic stress, with many parents reporting changes in income or employment status as stressful consequences of accommodating the treatment needs to the ill child (McGrath et al. 2005; Neil-Urban & Jones 2002). The current study used an adapted version of the Family Stress Model (see Figure 1b). The adapted model posits that a cancer diagnosis leads to cancer

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related stress, which increases the risk for child emotional adjustment problems via disruptions in marital functioning (Conger et al., 1990).

The current study is also informed by Kazak's Model of Pediatric Medical Traumatic Stress (Kazak et al., 2005). Kazak's model focuses on family members' subjective experience of the potentially traumatic event of a cancer diagnosis, the experiences during treatment phases, and the long-term responses to these experiences (Kazak et al., 2005). The model identifies three phases involved in the treatment of a potentially traumatic event: peritrauma, early/ongoing/evolving responses, and longer term pediatric medical traumatic stress. According to Kazak's model, a family member's subjective experience of the potentially traumatic event and emotional response may differ depending on which phase of treatment the patient is in (Kazak et al., 2005). As such, the goals of intervention vary across the course of the pediatric illness. While the goal of intervention in the peritrauma phase may be to change the subjective experience of the potentially traumatic event, the goal of the early, ongoing, and evolving response phase may be to prevent the development of posttraumatic stress symptoms. Kazak's model, along with empirical studies with siblings of cancer patients, posits the importance of accounting for differences in time since diagnosis when examining emotional adjustment in response to a cancer diagnosis (Alderfer, 2010; Alderfer, 2013; Houtzager et al., 2003; Kazak et al., 2005). As a result, the current study controlled for time since diagnosis when examining the relationship between relationship adjustment and sibling emotional adjustment.

#### **Emotional Adjustment**

Emotional adjustment to illness is described as the absence of psychological disorders or significant negative mood (Stanton, Collins, & Sworowski, 2001). Emotional adjustment

includes psychological constructs such as depression, anxiety, distress, and posttraumatic stress (Aldrige & Roesch, 2007). Models of emotional adjustment suggest that positive emotional adjustment results from protective factors that minimize the psychological impact of stressors (Sorgen & Manne, 2002), such as an individual's coping skills (Houtzager et al., 2003) and supportive family factors like family cohesion and communication (Alderfer & Kazak, 2006).

When a child is diagnosed with cancer, siblings find themselves facing significant role changes within the family, including increased responsibility around the house and taking on a caregiver role to help care for the sick child (Neville et al., 2016). These roles changes can have a significant impact on the emotional well-being of the sibling. Close to diagnosis, siblings of pediatric cancer patients report high levels of internalizing problems when compared to a group of children with healthy siblings (Houtzager et al., 2003), but levels of internalizing problems ultimately decrease to normal levels by six months post-diagnosis (Alderfer, 2010). Further, studies have found that sibling conflict and emotional distress is higher closer to the time of diagnosis (within 2-6 months) and again at 11 months within the first year of treatment (Katz et al., 2018; Alderfer, 2010). Higher levels of cancer-related stress, life stress, and financial stress were found to be associated with higher sibling conflict at end of the first year of treatment (Fladeboe et al. 2018a). This suggests that, as a whole, sibling emotional adjustment is related to time since diagnosis. However, a significant subset of siblings experience long term posttraumatic stress symptoms, negative emotional outcomes, and poorer emotional, family and social quality of life (Alderfer, 2010). Qualitative studies with siblings have highlighted the importance for siblings to feel reassured of the relationship with their parents, to improve the family relationship as a whole, and to have a support group with other siblings to cope with the

illness more effectively (Barrera et al., 2018). A review of literature on sibling of cancer patients performed by Gerhardt, Lehmann, Long, & Alderfer (2015) further highlight that siblings experience unique stressors accompanied by a cancer diagnosis, are impacted psychologically, have unique communication needs, and may require supportive care by parents and mental health professionals. Gerhardt et al. (2015) emphasized two important standards of care for siblings of cancer patients. The first is that siblings of cancer patients are at psychological risk and should be provided with appropriate support services; the second, that parents and professionals should be informed of ways to anticipate and meet sibling needs, particularly when the sibling is unable to make regular hospital visits. The review further highlighted barriers in meeting these psychosocial standards of care for siblings including: availability of trained psychosocial staff and community resources, lack of staff knowledge of sibling stressors, lack of access to standardized screening tools to assess sibling distress, limited healthcare provider access to and communication with siblings, and limited research on evidence-based interventions for sibling (Gerhardt et al., 2015). In order to understand why some siblings are at risk for long term emotional problems, it is imperative to identify the factors that contribute to poor emotional adjustment for siblings. Specific findings about different aspects of emotional distress are discussed below.

#### ASPECTS OF EMOTIONAL ADJUSTMENT

#### Anxiety symptoms.

Studies have found that siblings of pediatric cancer patients show maladaptive levels of anxiety (Sahler & Carpenter, 1989; Walker, 1990). Parents of cancer patients report that siblings endorse continuous anxiety as a result of the unpredictability of the disease (Sidhu, Passmore, &

Baker, 2006). In the same study, parents also reported that sibling were constantly worried, especially during a time of crisis. Hamama, Ronen, & Feigin (2000) found that siblings of cancer patients report fears of getting ill themselves. In a qualitative study conducted by Prchal & Landolt (2009), siblings reported feeling worried about the efficacy of treatment, fears of the ill child getting additional diagnoses, and fears of the ill child dying. Houtzager et al. (2003) found that greater family cohesion and adaptability predicted higher levels of anxiety specifically. While more unified families may provide a greater support system, it is possible that this close support system involves more in-depth communication about the ill child's condition with each other which could increase anxiety in siblings. Siblings also felt increasingly worried when the ill child was sick, unhappy, or they did not spend as much time as they used to with the ill child and the sick child will feel left out (Neville et al., 2016; Shapiro & Brack, 1994). Siblings reported feeling less anxious if the ill child spent more days in the hospital six months after diagnosis (Houtzager et al. 2003). Those siblings who relied on optimism, rather than seeking medical expertise, reported less symptoms of anxiety (Hamama et al., 2000). As time since diagnosis increases, it appears that siblings' feelings of anxiety decrease, perhaps due to habituation to the situation (Alderfer, 2010). Across studies, findings suggest that siblings may experience maladaptive worries and fears about the illness that are related to the cancer's unpredictable nature.

#### Depressive symptoms.

Symptoms of depression include feelings of sadness, hopelessness, guilt, worthlessness, fatigue, irritability, and loss of interest in activities (American Psychiatric Association, 2013), as well as accompanying feelings of loneliness (Radloff, 1977). Siblings of children with cancer

may experience feelings of loneliness and guilt (Hamama et al., 2000). Specifically, siblings feel guilty that they have escaped the disease, especially when their ill sibling cannot engage in certain activities like sports (Hamama et al., 2000; Neville et al., 2016; Sourkes, 1987; Shapiro & Brack, 1994). Siblings also feel sorrow and helplessness in response to witnessing the ill child suffering and change in appearance (Prchal & Landolt, 2009), and those siblings that tried to understand the illness reported fewer positive emotions (Houtzager et al., 2005). Siblings reported feelings of guilt related to feeling like a burden and not wanting to trouble family members with personal struggles, as well as feelings of sadness related to spending less time with the sick child, feeling overlooked and ignored by family members, and feeling less involved and loved (Neville et al., 2016). When siblings relied on optimism they had lower levels of loneliness than those siblings who sought out medical knowledge as a way of coping (Hamama et al., 2000). Siblings also found that becoming actively involved, either in the ill child's treatment or in the home, helped reduce feelings of helplessness (Prchal & Landolt, 2011). While the literature on sibling depressive symptoms in relation to pediatric cancer is relatively sparse, the findings suggest that these symptoms may be common in siblings over the course of treatment. However, some siblings may experience more depressive symptoms than others depending on the way they cope with the illness.

#### Posttraumatic stress symptoms (PTSS).

Cancer is a life-threatening event that can have a lasting psychological impact and lead to uncertainty about the future. For siblings, cancer means witnessing the physical and emotional pain of the ill child and parental distress (Alderfer, Labay, & Kazak, 2003). Moreover, a diagnosis of cancer brings changes in the structure of everyday life which may mean sudden and extended separations from the ill child and parents (Shannon, Barbarin, McManus, & Freeman, 1994). Criteria for posttraumatic stress disorder include exposure to actual or threatened death, presence of one or more symptoms of intrusion (e.g. recurrent, involuntary, and intrusive distressing memories of the event), persistent avoidance of stimuli associated with the traumatic event, negative changes in thoughts and mood, and changes in arousal and reactivity associated with the traumatic event (American Psychiatric Association, 2013). Few studies have looked at posttraumatic stress symptoms (PTSS) in siblings, but results suggest that siblings may experience moderate to severe symptoms of posttraumatic stress (Alderfer, 2010). Kaplan, Kaal, Bradley, & Alderfer (2013) found that symptoms of posttraumatic stress could be seen as early as four months since diagnosis through two years since diagnosis. Alderfer, Labay, & Kazak (2003) conducted a study examining posttraumatic stress symptoms (PTSS) in siblings of childhood cancer survivors 1-10 years post treatment. Nearly half of the siblings measured had mild posttraumatic stress reactions, a third had moderate to severe reactions, and 16% of siblings believed the cancer survivor could still die from cancer. Siblings reported more PTSS compared to the reference group of non-affected teens. Additionally, Alderfer, Labay, & Kazak found that siblings reported more symptoms of post-traumatic stress than the childhood cancer survivors themselves. Overall, levels of PTSS for siblings of cancer survivors were found to be elevated. Another study found that more than 60% of the sibling sample experienced moderate to severe PTSS and 22% fulfilled full criteria for posttraumatic stress disorder (Kaplan, Kaal, Bradley, & Alderfer, 2003). While most siblings may not meet criteria for PTSD, symptoms of posttraumatic stress may still be evident for a significant portion of the population. These findings

suggest that a diagnosis of cancer may have lasting psychological consequences for siblings, regardless of positive medical outcomes for the ill child.

#### **Relationship Adjustment and Sibling Emotional Adjustment**

Relationship adjustment is defined as perceived satisfaction based on several separate, yet related subsystems, and includes factors such as satisfaction, consensus, cohesion, and affection in the marital relationship (Spanier, 1976). While family functioning refers to all of the members in the immediate family, relationship adjustment refers to the partner/partner dyad. The majority of studies on parental relationship adjustment and child emotional adjustment have focused on married couples specifically. However, studies have shown that married and unmarried partner relationships function similarly in terms of relationship roles and are comparable when examining overall relationship adjustment (Kurdek, 2006). Further, rates of cohabitation in the United States have increased since the 1995, with 24% of adults ages 25-34 cohabitating and nearly half of women ages 15 to 44 reporting cohabitation with a partner prior to marriage (Copen, Daniels, & Mosher, 2013). Finally, some studies use the term "marital" in reference to all partnered couples, regardless of marital status, in their sample (Katz et al., 2018; Lavi et al., 2018). Therefore, in the context of the current study we conceptualize unmarried partner relationships as similar to married relationships; the implications of married vs. unmarried status are considered further in the Discussion section.

Marital adjustment has been linked to child emotional adjustment in the general population (Camisasca, Miragoli, & Blasio, 2016). In families of pediatric cancer patients, cancer places a significant strain on the partner relationship (Lavee & Mey-Dan, 2003; Yeh,

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2002). Thus, it is important to understand the ways in which relationship adjustment impacts child emotional adjustment, and how cancer impacts relationship adjustment.

#### Relationship adjustment and emotional adjustment in community youth.

Relationship adjustment can impact child emotional adjustment in community samples (Camisasca, Miragoli, & Blasio, 2016; Low & Stocker, 2005; Oh, Lee, & Park, 2011). Children have been found to perceive their parents' marital conflict at a similar rate as their parents (Ablow, Measelle, Cowan, & Cowan, 2009). Additionally, teacher reports of child internalizing and externalizing problems are related to child perceptions of parental marital conflict (Ablow et al., 2009). Low & Stocker (2005) found that mother and father marital hostility were linked to parent-child hostility, which in turn was associated with internalizing problems for children. Research has shown that marital conflict is related to child adjustment directly and indirectly through parent-child relationships (Osborne & Fincham, 1996). Stroud, Meyers, Wilson, & Durbin (2015) found that marital functioning was related to child internalizing problems by way of reductions in co-parenting warmth. Similarly, Coln, Jordan, & Mercer (2013) found that there is a direct pathway between destructive marital conflict (i.e. verbal or physical aggression, withdrawal, nonverbal disputes, and conflicts regarding child-related issues), negative parenting practices and child internalizing problems. A study by Fishman & Meyers (2000) found that parental levels of marital satisfaction were directly associated with levels of child psychological distress.

In a community sample, cross-sectional studies have found that marital conflict characterized by anger and hostility is associated with greater self-blame and fear that the conflict will escalate and involve the child (Oh, Lee, & Park, 2011). Camisasca, Miragoli, & Blasio (2016) found that inter-parental conflict is negatively associated with children's overall emotional adjustment. In addition to cross-sectional research, a longitudinal study found that children who vent their emotions in response to marital conflict have increased levels of psychological distress up to 1 year later (Shelton & Harold, 2007). These children were also found to have higher levels of anxiety and depression compared to children of inter-parental conflict who don't vent their emotions. Ablow et al. (2009) conducted a mediational study that found child self-blame mediates the relationship between marital conflict and child internalizing problems (Ablow et al., 2009). These findings from community samples suggest that parents' relationship adjustment may be important for the emotional adjustment of siblings of children with cancer.

#### The family stress model.

The family stress model provides a guide for understanding the pathway between hardship conditions (such as a child's cancer diagnosis), pressures of everyday living, partner relationship functioning, and child emotional adjustment (Conger et al., 1992). Originally, the family stress model was applied to families undergoing economic hardship; i.e., economic stress affects relationship processes that lead to child maladjustment. The original model hypothesizes that the relationship between economic hardship and child maladjustment is mediated by factors such as caregiver mental health, caregiver conflict, and parenting practices (Conger et al., 2000). Early studies of the model with European American families have shown that economic hardships are related to economic distress which is related to caregiver emotional distress. Further, caregiver distress is related to inter-caregiver conflict which in turn is associated with poorer parenting practices and predicts higher child internalizing and externalizing problems (Conger et al., 1992; Conger et al., 1993). A later study by Conger et al. (2002) replicated these findings with African American families. A 2004 study by Parke et al. further replicated Conger's findings with Mexican American families. However, in the Parke et al. study, they found that relationship problems and child adjustment were directly related without the mediation of parenting. This was found to be especially true for Mexican American families in particular. Additionally, studies have shown that the family stress model is not only applicable to American families, but also Finnish, Korean, and Turkish families (Aytac & Rankin, 2009; Kwon, Rueter, Lee, Koh, & Ok, 2003; Solantaus, Leinonen, & Punamaki, 2004). For Korean and Turkish populations in particular, emotional distress only mediated the relationship between economic strain and marital problems for women and not men. This finding was different from previous findings of the model with American families. The family stress model has shown to be a model for explaining the relationship between financial hardship and child adjustment by way of parental distress, marital conflict, and parenting. Overall, the model has been shown to be valid among families of varying cultural backgrounds with few variations in the way the model is applied between cultures.

A cancer diagnosis creates a similar strain on the family as that of economic hardship, and at times, cancer pressures may even include economic stress. Parents of pediatric cancer patients face a variety of stressors related to the cancer diagnosis. Cancer creates a disruption to a family's daily routines (Bjork et al., 2005) and warrants the need to integrate intensive treatment and hospitalizations into daily routines (Mercer & Ritchie, 1997). Parents find it difficult to balance the needs of the ill child with those of other members of the family or employment (McGrath et al. 2005; Mercer & Ritchie, 1997). However, not all stressors are seen as equally stressful to parents. Rodriguez et al. (2012) found that stressors related to caregiving responsibilities were more frequently endorsed at high levels compared to role functioning and communication stressors for mothers and fathers. Additionally, research shows that changes in income or employment status are stressful consequences of accommodating the treatment needs of the ill child (McGrath et al. 2005; Neil-Urban & Jones 2002). James et al. (2002) found that 46% of parents resigned or switched to part time employment to meet the caregiving needs of the ill child. In addition to the decreased income, the costs associated with cancer treatment can place a financial strain on parents (McGrath et al. 2005; Mercer & Ritchie, 1997).

In an adapted version of The Family Stress Model (see Figure 1b), a cancer diagnosis leads to high cancer related stress, which increases the risk for relationship distress which can lead to child emotional adjustment problems (Conger et al., 1990). The current study examined one component of this model: the relation between relationship adjustment and sibling emotional adjustment following a child's cancer diagnosis.

## Relationship adjustment in families of children with cancer: Experiences of mothers and fathers.

Studies of marital adjustment in parents of children with cancer report mixed findings for mean levels of marital satisfaction and associations with time since diagnosis (Long & Marsland, 2011). A longitudinal study by Hoekstra-Weebers, Jaspers, & Kamps (1998) found that mean levels of marital satisfaction decreased six months following diagnosis. Overall, they found that partners fell into one of three groups: decreased marital satisfaction (43% mothers, 43% fathers), no change (43% mothers, 29% fathers), and increased marital satisfaction (14% mothers, 26% fathers). A more recent study found that 25-30% of couples were in the distressed range of functioning at at least one time-point during the first year of treatment, but that couple distress

generally occurred in the earlier months of treatment, specifically around month 3 (Katz et al., 2018). Similarly, Dahlquist et al. (1996) found that 19% of mothers and 24% of fathers reported clinically elevated levels of marital distress at 20 months post diagnosis. Compared to parents in off treatment, remission, and relapse groups, parents of newly diagnosed children report higher levels of marital dissatisfaction (Yeh, 2002). Mothers report the highest levels of dissatisfaction when the child is off treatment or in remission. In contrast, fathers do not report differences in marital dissatisfaction across illness stages (Yeh, 2002). A longitudinal study by Lavee & Mey-Dan (2003) found that marital quality declines in the first-year post-diagnosis, improved over the next two years, and then remained unchanged four years post-diagnosis. They also found that when treatment lasted five or more years, marital quality decreased considerably. In addition, couples report better marital quality in strenuous times relating to treatment when compared to less strenuous times (Enskar et al. 1997).

A cancer diagnosis often means daily routines are disrupted and parents report that the need to integrate intensive treatment and hospitalizations into daily routines is a challenge (Mercer & Ritchie 1997). Parents find it hard to balance the needs of the ill child with those of other members of the family and their employment needs (McGrath, Paton, & Huff, 2005; Mercer & Ritchie 1997). Parents indicated that changes in income or employment status are stressful consequences of accommodating the treatment needs to the ill child (McGrath et al. 2005; Neil-Urban & Jones 2002). In one study, higher economic stress was related to poorer marital adjustment over time, and higher average frequency of treatment-related events and negative life events were related to decreasing adjustment over time and lower adjustment at the

end of 1<sup>st</sup> year of treatment (Lavi et al., 2018). The same study found that higher cumulative stress was associated with consistently poorer martial adjustment across time (Lavi et al., 2018).

In addition to economic and employment shifts, parents report reorganization of roles and responsibilities among family members. Parents indicate that the ill child's needs are prioritized over those of other members of the family (James et al. 2002; Mercer & Ritchie 1997). In many cases, reorganization involves one parent at the hospital and the other parents managing household, work, and sibling care. Mothers generally assume primary responsibility for the ill child during treatment and indicate the need to be with the child at all times. Mothers also report difficulty giving responsibility of care for the ill child to fathers (Kars et al. 2008; McGrath 2005; Mercer & Ritchie 1997). During active treatment, fathers report their primary concern is to address day-to-day need of the family with primary focus on the siblings (Nicholas, Gearing, McNeil, Fung, Lucchetta, & Selkirk, 2009). The prioritization of the ill child's needs can often compromise relationships between spouses. Parents report that when the child is on active treatment, reorganization of the family reduces spousal interaction and shared decision making, communication, and emotional closeness with the spouse (Bjork et al. 2005; McGrath 2001a; Mercer & Ritchie 1997). Fathers report withholding their emotions to demonstrate strength or protect their wives and thus grieving alone (Jones & Neil-Urban 2003; Nicholas et al. 2009). On the other hand, mothers report their partners as uncaring, isolating themselves, or denying the seriousness of the situation (Reay, Bignold, Ball, & Cribb, 1998). This mismatch and the decreased time spent together can strain the relationship between spouses. Another source of strain is conflict over parenting the ill child (Norberg & Steneby 2009). Though there are reports of marital strain, mothers and fathers view their spouses as a big source of practical support

(McGrath 2001a, b). However, mothers report that their husbands do not give sufficient emotional support so instead they prefer support from other mothers (Reay et al. 1998).

Previous research has primarily focused on the experiences of mothers of cancer patients or the family as a whole, many times due to the difficulty enrolling fathers as a result of the reorganization of household roles (Kazak et al., 2004; Phares, Lopez, Fields, Kamboukos, & Duhig, 2005). However, fathers of cancer patients have unique experiences that are important to account for. Jones, Pelletier, Decker, Barczyk, & Dungan (2010) conducted a systematic review to highlight the experiences of fathers. The review highlighted five categories of stress fathers, specifically, experience in response to their child's cancer diagnosis: informational, practical, emotional, interpersonal or social, and existential or spiritual stress (Jones et al. 2010). It is important to consider gender-related differences in research and in clinical work, in order to better serve all members of the family. Given the difficulty enrolling fathers due to cancerrelated household roles, the current study only collected quantitative data from mothers, and used a case-narrative approach to further expand on the unique experiences of fathers.

## MODERATORS OF THE RELATION BETWEEN RELATIONSHIP ADJUSTMENT AND SIBLING EMOTIONAL ADJUSTMENT

To better identify which siblings may be at risk for emotional adjustment problems and design interventions for those at risk, it is also important to identify factors that could buffer, or moderate, the impact of marital adjustment on siblings' emotional adjustment. A moderator is a variable that affects the strength of the relationship between two other variables (Rose, Holmbeck, Coakley, & Franks, 2004). Sibling age and gender have been shown to be associated with sibling adjustment to pediatric cancer, and those factors may moderate the effect of marital

adjustment on sibling emotional adjustment (Alderfer et al., 2006; Long, Alderfer, Ewing, & Marsland, 2013). Each of these potential moderators is discussed below.

#### Age.

Sibling age has been examined in relation to adjustment. Studies have shown mixed results on whether the age of the sibling plays a role in adjustment. One study by Cordaro et al. (2012) found that older siblings were more likely to experience higher levels of emotional distress. Some studies found that preschool age siblings do not seem to be affected much by the illness, but school age siblings do experience adjustment problems (Bendor, 1990; Horwitz & Kazak, 1990). On the other hand, Schuler et al. (1985) conducted a longitudinal study and found that younger siblings experienced more emotional adjustment problems than older siblings. This difference may be due to the difference in methodologies between the two studies. Schuler et al.'s longitudinal study may be more helpful at capturing long-term emotional adjustment outcomes that may not have been apparent in cross sectional and short term studies such as Bendor (1990) and Horwitz & Kazak (1990). Another study by Long, Alderfer, Ewing, & Marsland (2013) found that siblings who are younger than the ill child experience more overall distress than siblings who are older than the ill child. On the other hand, Spinetta (1981) found that siblings between ages 4 and 6 had lower levels of self-esteem and negative self-image, while siblings between the ages of 7 and 12 showed higher levels of anxiety and depression. Siblings ages 13 to 18 perceived their families as conflict ridden and having low cohesion. This difference between age groups may be due to developmental differences in perceiving family changes following a cancer diagnosis. Younger siblings may perceive spending less time with parents as a consequence of their behavior, while older children may be trying to establish an identity

outside of cancer. Hamama et al. (2000) found that older siblings felt less anxious than younger siblings, loneliness also decreases as the sibling gets older, and siblings that are higher up in the birth order experience lower levels of loneliness. On the other hand, Houtzager et al. (2003) found that older siblings felt more anxious about the cancer diagnosis. However, this may be due to the difference in time since diagnosis that siblings were studied. Hamama, Ronen, & Rahav, (2008) found that siblings who indicated greater role overload within the family had higher levels of anxiety. Siblings older than 12, that had greater self-control exhibited lower levels of anxiety (Hamama, Ronen, & Rahav, 2008). This may be due to older children's ability to better manage their time and communicate their needs. A study by Lahteenmaki et al. (2004) found that presenting concerns also differ by age. Siblings between the ages of 3 and 7 exhibited more psychosocial problems in play routines compared to the control group (siblings of healthy children) and were more confrontational with parents. Siblings in this age group also showed signs of impulsivity and hyperactivity. Like previous studies, Lahteenmaki et al. found that older siblings (age 7 and older) experienced symptoms of anxiety, and lower-self-esteem compared to the control group. Overall, studies have shown mixed findings about the relation between age and sibling adjustment. In general, younger siblings struggle more with feelings of loneliness while older siblings feel more anxious. These differences may be due to differences in developmental stages. For example, younger children may rely more heavily on adults to meet their daily needs, thus feeling lonely when parents need to readjust schedules to meet the needs of the ill child, while older siblings may better understand the medical implications of cancer which may create more feelings of anxiety.

Studies have also shown that marital adjustment has differing effects on child adjustment based on the child's age. Mahoney, Jouriles, & Scavone (1997) found that younger children showed higher rates internalizing and externalizing when fathers reported poorer marital adjustment. Similarly, Ulu & Fisiloglu (2002) found that teachers noted more internalizing and externalizing problems for younger children compared to older children when children reported perceived marital conflict. It is possible that younger children are more affected by poor marital adjustment because they rely more heavily on their parents to meet their needs.

#### Gender.

Though the role of gender on well siblings' emotional adjustment has been studied to a lesser extent, studies find that girls are at risk for poorer levels of adjustment (Alderfer & Kazak, 2006). Additionally, female siblings have higher levels of anxiety in response to the diagnosis than male siblings (Houtzager et al., 2003). Barrera, Fleming, & Khan (2004) found that adolescent girl siblings had higher rates of depressive symptoms compared to adolescent boy siblings. Girls that were siblings of cancer patients also exhibited higher rates of anxiety than girls with healthy siblings, while no differences were found between boys with ill siblings and boys with healthy siblings (Barrera et al., 2004). Another study found that a sibling group intervention showed reduction in symptoms of anxiety for female siblings compared to siblings as a whole and males (Barrera et al., 2018). Findings suggest that girls are at higher risk for developing emotional adjustment problems when they have a sibling with pediatric cancer compared to boys, which may be because girls perceive the cancer to be more disruptive to the family (Alderfer & Kazak, 2006).

Similar to age, relationship adjustment has been found to be related child adjustment differently by gender in community samples. O'Leary & Vadair found that when mothers reported poorer marital adjustment, boys had higher rates of externalizing problems and girls had higher rates of internalizing problems. Ulu & Fisiloglu (2002) found that teachers reported higher rates of internalizing problems for girls compared to boy in families of parents with poor relationship adjustment. A study by Cummings, Davies, & Simpson found that girls had higher rates of self-blame whereas boys reported higher rates of perceived threat and attunement to marital conflict. Marital conflict has also been found to be negatively associated with poor mother-son relationships compared to same-gender dyads or father-daughter relationships (Osborne & Fincham, 1996). Children's responses to poor relationship adjustment also influence emotional adjustment differently based on gender. When girls engage in problem solving and social support seeking behaviors they are less likely to exhibit depressive symptoms and selfesteem problems (Nicolotti, El-Sheikh, & Whitson, 2003). For boys, engaging in avoidant behaviors in response to poor marital adjustment increased the likelihood of externalizing and internalizing problems (Nicolotti et al., 2003).

#### SUMMARY OF THE LITERATURE

Many siblings of pediatric cancer patients exhibit clinically significant emotional problems, with the highest levels of problems in the 6 months following diagnosis. Though most siblings return to normal levels of emotional adjustment, a significant subset of siblings experience maladaptive levels of anxiety, loneliness, guilt, and fear that lasts longer than 6 months post diagnosis. Findings are mixed across age and gender. Girls typically experiencing more emotional symptoms than boys. Findings on age vary by type of emotional symptom, with younger siblings experiencing more loneliness and overall distress than older siblings, who may have other protective factors.

Additionally, partner roles are often put on hold to deal with the needs of the ill child, and some parents exhibit significant challenges to relationship adjustment. Research with community youth suggests that relationship distress negatively impacts child emotional adjustment. Though studies have not looked at the effects of relationship adjustment on sibling emotional adjustment in pediatric cancer, existing literature with community samples points to a possible connection between relationship adjustment and sibling emotional adjustment. Younger sibling age and female gender may increase the negative effects of relationship adjustment on sibling emotional adjustment.

#### THE CURRENT STUDY

The current study used a quantitative approach with the inclusion of two qualitative case studies to examine the association between parents' relationship adjustment and sibling emotional adjustment in families of pediatric cancer patients at Dell Children's Medical Center of Texas. My quantitative research questions were as follows: 1) What is the relationship between mothers' reports of parental relationship adjustment and sibling emotional adjustment when controlling for time since diagnosis? 2) Does gender moderate the relationship between parental relationship adjustment? 3) Does age moderate the relationship between parental relationship adjustment and sibling emotional adjustment? The case studies were designed to expand upon these research questions by incorporating the perspectives of fathers and exploring possible processes that connected relationship adjustment and sibling emotional adjustment.

Figure 2 represents the statistical model used to guide hypotheses and analyses. The quantitative phase of the study collected questionnaire data from mothers about their own relationship satisfaction. Mothers also reported on the emotional functioning of the patient's sibling in order to examine the relationship between relationship adjustment and sibling emotional adjustment in pediatric cancer. In the qualitative phase of the study, four mother-father couples also participated in an observation task in which they discussed their experiences with the child's cancer (e.g., family disruptions, relationship, etc.) and we coded the content of their conversations using thematic analysis.

We hypothesized that (1) poorer relationship adjustment, measured as lower rates of relationship satisfaction, would be related to poorer emotional adjustment for siblings, controlling for time since diagnosis. We predicted this based on previous research findings suggesting that parental relationship conflict is related to poorer emotional adjustment in children from community samples (e.g., Camisasca, Miragoli, & Blasio, 2016). We also hypothesized that (2) gender would moderate the relationship between marital adjustment and sibling emotional adjustment problems, such that marital adjustment will be related to poorer emotional functioning for female siblings compared to male siblings. We predicted this based on previous findings that show girls have higher rates of internalizing problems when relationship satisfaction is low (Hess & Camara, 1979), and in siblings of cancer patients, female siblings have higher levels of emotional distress than male siblings (Alderfer et al., 2006). Finally, we hypothesized that (3) age would moderate the relationship between marital adjustment and sibling emotional adjustment problems. We predicted that younger siblings will have poorer emotional adjustment problems. We predicted that younger siblings will have poorer emotional adjustment problems. We predicted that younger siblings will have poorer emotional adjustment when parents have lower relationship adjustment, based on previous

research that suggests that younger children compared to older children in the general population experience more internalizing and externalizing behaviors in response to poorer relationship adjustment (Mahoney, Jouriles, & Scavone, 1997). Additionally, in pediatric cancer populations, some studies indicate that younger siblings experience more overall distress, indicating older age may be a buffer for the impact of relationship adjustment and disruptions due to the stress of cancer (Long, Alderfer, Ewing, & Marsland, 2013). Following analysis of quantitative data, qualitative findings were used to expand upon quantitative findings by incorporating the perspectives of fathers, who were underrepresented in the quantitative part of the study.

#### **METHODS**

#### **QUANTITATIVE PHASE**

#### Participants.

Participants were 40 parents/caregivers of children diagnosed with cancer who reported on a total of 49 siblings (see Figure 3). Eligibility for participation included having a child diagnosed with cancer within the last 12 months (to allow for information from families at various stages of active treatment), being 18 years old or older, fluent in English and/or Spanish, being married or partnered, and having one or more well children between the ages of 4 and 17. Siblings (i.e., the well child or children) had to be between ages 4 and 17 because the measure used to collect data about emotional functioning has been validated for children between these ages.

Ninety percent of parents who participated in the quantitative phase were mothers; 33% of participants were non-Hispanic White and 61% of participants were Hispanic. Due to the higher percentage of mothers participating in the quantitative phase of the study compared to fathers, only mothers' data was used in the quantitative analyses (N = 36 mothers reporting on 49 siblings). There were not enough fathers enrolled to compare differences between mothers and fathers in the analysis or have sufficient statistical power to analyze fathers' quantitative data. In addition, fathers were less likely to attend the appointment, so data collection time for fathers lagged. Our experience is consistent with previous studies, which have shown that mothers tend to be more involved in the medical care of the ill child (Kars et al. 2008; McGrath 2005; Mercer & Ritchie 1997). The mean age for mothers participating was 39 years (range: 26 to 58), and they completed an average of 14 years of school (range: 10 to 20 years). 30% of mothers earned

below \$30,000 per year, 29% earned between \$30,001 and \$70,000 per year, and 41% earned above \$70,000 per year. 70% of mothers were married and 88% of mothers chose to complete the forms in English, with the remainder completing forms in Spanish. On average, mothers completed the questionnaires nine months post-diagnosis (range: 5 to 19months). In terms of diagnoses, 37% of patients had a type of leukemia (e.g., acute myeloid leukemia or acute lymphoblastic leukemia), 14% had a type of lymphoma (e.g., Hodgkin lymphoma or Non-Hodgkin lymphoma), 29% had a brain tumor (e.g., ependymoma or neuroblastoma), and 20% had any other solid tumor (e.g., Wilms' tumor or osteosarcoma) (see Table 1). The average number of children living in the home was 2 and the average number of well siblings per family was 1. Data was collected for 49 siblings; 48% of siblings were male, and siblings had a mean age of 10 years (range: 4 to 17 years).

#### **Procedure.**

The study was conducted in person at the outpatient clinic at the Children's Blood and Cancer Center (CBCC) of Dell Children's Medical Center, or, if more convenient for the participant, by phone or online. CBCC staff forwarded the names of newly diagnosed/relapsed patients to the research team. The research team began recruiting parents 8-weeks post diagnosis in order to allow families time to adjust to the immediate stress of diagnosis. Prior to approaching families at outpatient appointments or calling families by phone, research staff screened for initial eligibility based on diagnosis type and date of diagnosis using the child's medical records. Research staff approached families in person in the outpatient clinic of the Children's Blood and Cancer Center or contacted families by phone. All eligible participants, as identified through the child's medical records, were recruited.
In the questionnaire of the study, participants completed questionnaires about the parent and sibling's demographic information, the sibling's emotional adjustment, and relationship satisfaction. Participants had the option to complete questionnaires in English or Spanish. All of the measures used were translated and validated in Spanish. Research personnel approached potential participants at the child's outpatient appointment to describe the study, use a screening form to confirm that they met all eligibility criteria, and consent participants. Participants had the option of completing the forms during the appointment, either on paper or electronically on a tablet, or giving researchers their email and completing the questionnaires online at a later time. Families that did not have upcoming appointments were contacted by phone. Interested participants had the option to fill out the consent form at their next appointment or sign and return a scanned copy through email. Participants had the option to complete the questionnaires over the phone with a research assistant, online through a Qualtrics survey sent to them via email, or in person at a location convenient to the participant.

# **QUALITATIVE PHASE**

## Participants.

Participants were 8 parents/caregivers, 4 couples, of children diagnosed with cancer who. Eligibility for participation included having participated in the questionnaire phase of the study, being 18 years old or older, fluent in English and/or Spanish, and being married or partnered. Both partners in the dyad had to agree to participate in the qualitative phase in order for a couple to be eligible to participate in the interview. All of the couples who participated were married and in heterosexual relationships. All of the couples chose to complete the qualitative interview in English.

# **Procedure.**

All participants who participated in the questionnaire phase were eligible to participate in the qualitative observation task with their partner. Participants who had completed the questionnaires within the past 12 months were contacted by phone and recruited for participation in the observation phase. Couples were eligible to participate in the observation task if at least one partner completed the questionnaires within the last 12 months. Of the 10 couples recruited, 4 couples agreed to participate in the observation task. Participants had the option to complete the observation at home or at The University of Texas at Austin. Couples participated in a video recorded conversation about several aspects of their child's cancer and how cancer affected various domains (e.g., relationship, family, and well siblings).

## MEASURES

The measures described below were used directly in the analyses of the current study.

## Quantitative.

# Sibling emotional adjustment.

The Strengths and Difficulties Questionnaire (SDQ) is a brief parent-report behavioral questionnaire for children ages 4-17. The SDQ yields scores for five subscales. The current study used the emotional symptoms to measure sibling emotional adjustment. Questions were answered on a scale of 1 (not true) to 3 (certainly true). Sample questions include: often unhappy, depressed or tearful, and often loses temper. The SDQ has adequate internal consistency for the emotional symptoms subscale scores (0.67) (Goodman, 2001, Kersten et al., 2016). The test-retest reliability for the SDQ is adequate to good. The SDQ is correlated with DSM diagnoses indicating content validity and is correlated as expected with Rutter scales and

the Achenbach System of Empirically Based Assessment (ASEBA) indicating concurrent validity (Goodman, 2001). The five-factor structure is supported indicating construct validity (Goodman, 2001). The Spanish version of the Strengths and Difficulties Questionnaire has adequate internal consistency (0.71) for the emotional symptoms subscale scores (Ortuño-Sierra, Fonseca-Pedrero, Paino, Sastre i Riba, & Muñiz, 2015). Additionally, the Spanish version supports the five-factor structure just as the English version does (Ortuño-Sierra et al., 2015). Although the reliability of the SDQ is not as high as other broadband measures available, it has been found to be more acceptable than the ASEBA forms in pediatric settings. Goodman & Scott (1999) found that mothers recruited in pediatric settings were twice as likely to prefer the SDQ over the Child Behavior Checklist, which is part of the ASEBA measures. In order to make participation more feasible, the SDQ was chosen over a longer more reliable measure. The internal consistency for the SDQ Total Emotional Problems scale for the current study was 0.77.

# Relationship adjustment.

The Dyadic Adjustment Scale (DAS-7) is a 7 item self-report measure of relationship adjustment. Participants were asked to rate how much partners agree in different domains (e.g. philosophy of life or amount of time spend together), how often they engage in different activities together (e.g. calmly discuss something together or work together on a project), and the degree of happiness with their relationship. The DAS-7 has been found to have good internal consistency (0.80). The reliability of the DAS ranges from 0.75 to 0.80 (Hunsley, Best, Lefebvre, & Vito, 2001). Hunsley et al. also found that the DAS-7 also has the ability to discriminate between distressed and adjusted relationships, indicating adequate criterion validity. Hunsley et al. (2001) found that the concurrent validity for the DAS-7 was adequate, ranging from a 0.67 to 0.73 correlation with the KMSS and a 0.41 to 0.50 correlation with the ESDS. The current study used degree of happiness with the relationship as a measure of relationship adjustment. Participants scored their level of happiness with the relationship on a scale of 1 to 7 (1 being completely unhappy and 7 being completely happy). This subscale represents the degree of relationship satisfaction. Cano-Prous et al. (2014) validated the Spanish version of the Dyadic Adjustment Scale. They found good internal consistency (0.88) and a sensitivity of 0.75 and specificity of .82. Additionally, the Spanish version has adequate convergent validity (Cano-Prous et al., 2014). The internal consistency for the DAS scale for the current study was 0.76.

# Sibling age and gender.

The demographic questionnaire reported parent and child age, sex, race/ethnicity. The questionnaire also gathered information about parental relationship status, education, socioeconomic status, occupation, languages spoken, and number of individuals living in the home. The demographic questionnaire was used to measure child age and gender, as well as describe the demographics of the sample.

# Time since diagnosis.

The demographic questionnaire also gathered information about the ill child's date of diagnosis. Researchers confirmed date of diagnosis through the patient's medical records. Time since diagnosis was calculated as the number of days between the date of diagnosis and the date the research team received the participant's completed questionnaires.

# Qualitative.

## **Cancer Conversation Questions.**

The questions for the conversation task were developed to examine the experiences of couples surrounding pediatric cancer in families, including emotions about the diagnosis, the effect of cancer on the couples' lives, the effect of cancer on the family, and the effect of cancer on the couple relationship. Couples were provided a list of suggested questions on a card to facilitate the interaction, but were told they could discuss any topic related to the child's cancer. Questions on the card included *"How has our child's cancer impacted our relationship? How has it impacted us as a family?; How do we each try to deal with these feelings, emotions, and experiences?; What is it about cancer that has most affected our lives? What has been the biggest challenge?"*.

# **STATISTICAL ANALYSIS**

# Power analysis.

A power analysis was conducted using G\*Power software to determine the number of participants needed to find significance for each hypothesis.

#### Hypothesis 1.

A power analysis for finding a significant r requires 46 participants to obtain a moderate effect size (0.30) at an 0.80 level of power and an alpha of 0.05. The effect size was estimated based on similar effect sizes from previous studies (Barrera et al., 2017).

# Hypothesis 2.

A power analysis for finding a significant  $R^2$  change requires 42 participants to obtain a

moderate effect size ( $f^2 = 0.20$ ) at a 0.80 level of power and an alpha of 0.05 with 3 independent variables.

## Hypothesis 3.

A power analysis for finding a significant  $R^2$  change requires 42 participants to obtain a moderate effect size ( $f^2 = 0.20$ ) at a 0.80 level of power and an alpha of 0.05 with 3 independent variables.

#### Preliminary descriptive analyses.

Descriptive statistics (means and standard deviations) were calculated for all measures. Means and frequencies for demographic variables were computed for parents and child. Prior to conducting correlational and regression analyses, data were checked for outliers and normality was assessed. Scatterplots determined linearity and residual and predicted value plots confirmed a normal distribution of residuals. Data was also be tested for multicollinearity.

# Hypothesis 1.

Poorer relationship adjustment, measured as lower rates of relationship satisfaction, will be related to poorer emotional adjustment for siblings, controlling for time since diagnosis.

*Correlational Analyses:* The statistical significance and magnitude of the correlations between relationship adjustment and sibling emotional adjustment while controlling for time since diagnosis were examined to test the primary hypothesis of the study.

Correlations between sibling adjustment and age were examined to guide regression analyses. Additionally, a correlation matrix was produced that includes all variables in the study to guide the subsequent regression analysis. *Independent Samples T-test.* A t-test was conducted to examine whether sibling adjustment differed by gender. Sibling adjustment was entered as the test variable and gender was entered as the grouping variable. Siblings were grouped by male or female.

## Hypothesis 2.

Sibling gender will moderate the relationship between relationship adjustment and sibling emotional adjustment problems. Relationship distress will be related to reduced emotional functioning for female siblings compared to male siblings.

*Linear Multiple Regressions*. Linear multiple regression was used to examine gender as moderator of the association between relationship adjustment and sibling emotional adjustment while controlling for time since diagnosis. Time since diagnosis was entered at Step 1, marital adjustment was entered at Step 2, and the interaction term (relationship adjustment x gender) was entered at Step 3; sibling emotional adjustment was the outcome variable. Before entering the interaction term into the regression equation, the interaction term was centered and calculated. First, relationship adjustment was centered by subtracting each individual value from the mean value. Gender was not centered as it is not a continuous variable. The interaction term was calculated by multiplying the centered term for relationship adjustment by gender. The interaction was probed using the median split. Siblings were grouped by gender (male or female). The interaction was graphed (see Figure 4) and the trend lines were graphed based on these categories.

In order to account for potential non-independence of siblings from the same family, cluster robust standard errors were used to adjust for the clustering within families. Cluster robust standard errors is a post regression analysis that adjusts the standard error to adjust for

within group, or cluster, variance (Cameron & Miller, 2014). The variance for siblings from the same family will be more similar compared to siblings from different families. These similarities in variance may be due to the shared experiences of siblings from the same family or that data from siblings within the same family is reported by only the mother. For this reason, the error term needed to be expanded to account for correlations for siblings from the same families. Failing to account for similarities of siblings from the same family could increase the chance of a significant finding, and thus increase the chance of committing a type 1 error. Cluster robust standard errors account for correlation errors for with-in cluster correlations; in this case, correlation errors for siblings from the same family.

# Hypothesis 3.

Sibling age will moderate the relationship between relationship adjustment and sibling emotional adjustment problems. Younger siblings will have poorer emotional adjustment when parents have decreased relationship adjustment.

*Linear Multiple Regressions*. Linear multiple regression was used to examine age as a moderator of the association between relationship adjustment and sibling emotional adjustment while controlling for time since diagnosis. Time since diagnosis was entered at Step 1, relationship adjustment was entered at Step 2, and the interaction term (relationship adjustment x age) was entered at Step 3; sibling emotional adjustment was the outcome variable. Before entering the interaction term into the regression equation, the interaction term was centered and calculated. First, relationship adjustment was centered by subtracting each individual value from the mean value. Age was also centered by subtracting each individual value from the mean value. The interaction term was calculated by multiplying the centered term for relationship

adjustment by the centered term for age. The interaction was probed using the median split. Siblings were grouped into two different age categories (4-10 and 11-17) based on the median for sibling age. The interaction was graphed (see Figure 5) and the trend lines were graphed based on these age categories. As with hypothesis 2, in order to account for potential nonindependence of siblings from the same family, cluster robust standard errors were used to adjust for the clustering within families.

# Qualitative.

All observations tasks were video recorded, transcribed, and then imported into excel for analysis (Meyer & Avery, 2009). Analysis was conducted at two levels, within each case and across cases (Yin, 2014). Coding occurred in two phases, open coding and thematic development (Guetterman, Babchuk, Howell Smith & Stevens, 2017). In open coding, the data was coded by reading and interpreting each line of text at the descriptive-level (e.g., communication and partner support). Next, open codes were linked together to develop themes by aggregating similar codes (Yin, 2014). After coding and thematic development, a case study narrative was developed, composed of descriptions and themes, and themes across cases were analyzed (Yin, 2014). Each case narrative developed included a discussion of how the relevant themes were demonstrated by the particular couple. The case narrative included a discussion of sub-themes that appeared throughout the course of the interview and their relevance to the overall themes analyzed. Following the construction of each narrative, a discussion of similarities and differences between cases within each emerging theme was presented.

# RESULTS

#### QUANTITATIVE

#### Preliminary analyses.

Data reported by mothers for 49 siblings was analyzed. 30% of siblings were above the clinical cutoff score on the SDQ ( $\geq$ 14), compared to 11% of children in community samples (National Center for Health Statistics, 2001). The mean relationship satisfaction score for mothers was 22.04 (SD= 5.23); scores of 15 or lower suggest poorer relationship adjustment (Sharpley & Rogers, 1984). The mean time since diagnosis was 9 months (SD= 3.71). An independent samples t-test was conducted to examine whether sibling adjustment differs by gender. There was not a significant difference in emotional adjustment scores for males (M=10.11, SD=6.02) and females (M=12.16, SD=8.36); t(47)= -.88, p= .39.

Correlations between sibling adjustment and age were examined to guide regression analyses (see Table 2). Sibling emotional adjustment and age were negatively correlated (r= -.40, p<.01). Sibling emotional adjustment was not significantly correlated with time since diagnosis (r= -.14, p=.35). Relationship adjustment and time since diagnosis were not significantly correlated (r= 0.08, p=.61).

# Hypothesis 1.

Correlations between parental relationship adjustment and sibling emotional adjustment while controlling for time since diagnosis were conducted to test the primary hypothesis. Parental relationship adjustment and sibling emotional adjustment were negatively correlated; however, the correlation was not significant (r= -.23, p= .12).

# Hypothesis 2.

A Linear multiple regression was conducted to examine gender as moderator of the association between relationship adjustment and sibling emotional adjustment while controlling for time since diagnosis. The main effect of relationship adjustment while controlling for time since diagnosis was not significant,  $R^2 = .07$ , F(1,46)= 1.64, SE= 7.19, p=.21; and the main effect of gender was not significant,  $R^2 = .08$ , F(1,45)= 1.38, SE= 7.20, p=.26. The interaction between relationship adjustment and sibling gender was not significant,  $R^2 = .13$ , F(1,44)= 1.62, SE= 7.10, p=.17 (see Table 3). In order to account for potential non-dependence of siblings from the same families, a cluster robust standard error analysis was conducted post regression. The cluster robust standard error analysis provides an adjusted standard error for the t-statistic of the interaction effect. The cluster robust standard error for the interaction between relationship adjustment and significant, SE= 1.82, p=0.57.

# Hypothesis 3.

A Linear multiple regression was conducted to examine age as moderator of the association between relationship adjustment and sibling emotional adjustment while controlling for time since diagnosis. The main effect of relationship adjustment while controlling for time since diagnosis was not significant,  $R^2 = .07$ , F(1,46) = 1.64, SE= 7.19, p = .21. The main effect of age was significant,  $R^2 = .20$ , F(1,45) = 3.73, SE= 6.73, p < .01. The interaction between relationship adjustment and sibling age was not significant,  $R^2 = .20$ , F(1,45) = 3.73, SE= 6.73, p < .01. The interaction between relationship adjustment and sibling age was not significant,  $R^2 = .20$ , F(1,44) = 2.78, SE= 6.80, p = .70 (see Table 4). As with sibling gender, to account for potential non-dependence of siblings from the same families, a cluster robust standard error analysis was conducted post regression. The cluster robust standard error for the interaction between relationship adjustment and age was

not significant, SE= .18, p=0.57.

#### QUALITATIVE

Four couples completed the qualitative phase of the study. Data for two couples was used in the qualitative analysis. The analysis of two cases and across two cases yielded five themes related to relationship adjustment and sibling emotional adjustment: 1) Relationship adjustment, 2) Sibling adjustment, 3) Cancer stressors, 4) Roles, and 5) Parent emotional adjustment. The description of each theme in the context of two exemplar couples follows.

## Couple 1.

The first couple was a heterosexual married couple that consisted of the mother and father of the ill child. The mother had previously participated in the questionnaire phase of the study prior to participating in the observation phase. She was 33 years-old, non-Hispanic white, and completed a college degree. Her satisfaction score on the DAS was a 23, and she completed the questionnaires 5 months post-diagnosis. The couple's ill child was diagnosed with a brain tumor, specifically an ependymoma. Both parents discussed being involved in the medical care of the ill child and financial responsibilities of the household.

*Relationship Adjustment.* A subset of codes that encompassed various aspects of the relationship, such as partner communication, communication challenges, relationship distress, relationship cohesion, differing partner emotions, and mismatched coping styles. Couple 1's relationship was positively impacted by supporting each other during treatment which increased relationship closeness for the pair: *"I think it probably made us stronger. Even people have asked me, like oh my gosh what'd that do to your marriage? I think it could go one way or the other, and I think ours went in the right direction."* Both partners agreed that the diagnosis

positively impacted their relationship and mother specifically discussed partner support as a positive factor in the relationship: "We definitely lean on each other, and we both are very aware that we could not do this alone." Mother also cited increased partner communication as a result of the diagnosis: "I mean, it definitely forces us to communicate... not that we had a communication issue prior to cancer, but we definitely had to sit down like every Sunday, or I mean just yesterday with two weeks planned out."

*Sibling adjustment.* A subset of codes that encompassed various aspects of sibling emotional adjustment such as, sibling negative emotions and sibling perceptions of normality. The ill child's well sibling was only a year old at the time of the interview. Although couple 1 was unable to discuss sibling negative emotions or parenting the sibling in response to cancer in depth due to her age, the couple did discuss the sibling's perception of normality of cancer: *"That's been normal, doctor's visits... and [sibling] definitely doesn't know any different. She was born in the midst of all this chaos."* 

*Cancer stressors.* A subset of codes that were related to stressors that arise from having a child in treatment or in remission, such as, cancer decisions, economic decisions, financial challenges, cancer related fears, and family challenges. Couple 1 identified cancer related fears that occurred as a result of the experience of having a child in cancer treatment. These fears stemmed around setbacks in treatment or the well child also becoming ill: "*Yeah, that's what I think about, just if this same diagnosis happens [to sibling]*." The partner dyad also identified family challenges that were exacerbated by the diagnosis: *"I think the biggest challenge was having a baby while our baby was in treatment.*" Both parents also reported financial challenges related insurance and maneuvering through the insurance company's system.

*Roles.* A subset of codes that referred to various aspects of the partner's role within the relationship and the family in relation to cancer, such as parental roles, parenting disagreements, parenting, and parenting well-sibling. Couple 1 identified several role challenges related to the ill child's treatment. Both parents discussed challenges with integrating treatment responsibilities into their existing roles: *"This is what's going on with [child] and she has an appointment every day. You're going to do the MRI on Monday and I'm going to do the audiologist on Tuesday and she'll see radiation oncology on Friday... Every week everything has to be organized and scheduled." The dyad also discussed a division of parental roles within the household to accommodate the diagnosis: <i>"I think you're the brains and I'm the brawns. You take care of the insurance company and I take care of the dishes."* 

*Parent emotional adjustment.* A subset of codes related to the emotional adjustment of the parent in relation to cancer such as, outside support and coping challenges. Both partners discussed several negative emotions, such as anxiety and sadness, that were the consequence of the diagnosis: *"So yeah, fear, but also loss of control because you can't protect your daughter."* Both parents also cited outside support as an essential aspect of their emotional adjustment to the diagnosis: *"I told [friend] that I was terrified to talk to her for a long time just because I didn't want their reality to be our reality... I feel like they've been helpful though."* 

# Couple 2.

Couple 2 was a heterosexual married couple that consisted of a mother and father dyad. The mother in couple 2 had also previously completed the questionnaire phase prior to participation in the observation phase. Mother was 45 years-old, non-Hispanic white, and had completed a college degree. Her satisfaction score on the DAS was a 15. The couple's ill child was diagnosed with T-cell Acute Lymphoblastic Leukemia. According to their interview, the father in the dyad was primarily responsible for the medical care of the ill child and the mother was primarily responsible for the economic responsibilities of the household.

*Relationship Adjustment.* Couple 2's relationship adjustment was negatively impacted by differing emotions and coping styles between the partners. The mother in the dyad mentioned specifically noticing that she coped with the diagnosis and treatment differently than her partner: "Don't take this the wrong way, you like to wallow and kind of feel it from all sides to really get a grip on things. You have to get your head around it in a different way than I do. I would rather, 'okay, what can we do today, right now?'" Both partners also discussed communication challenges that negatively affected their relationship during treatment and at the time of the interview: "Well when I try to talk to you, you do things like you did earlier. You correct me or tell me not to ask that or don't go there or I don't want to talk about it. Because I didn't ask the right way, and that makes me not want to talk to you."

Although a cancer diagnosis caused distress, mother reported feeling more cohesion as a result: *"I think it's negatively impacted in a lot of ways, but it's also brought us closer in some ways too."* She also discussed feeling improvement in their relationship adjustment as a result of the cancer diagnosis: *"Well I have to say we weren't in the best place before this happened and we weren't where we're at now. Right? I feel like we were headed in a positive direction."* 

*Sibling adjustment.* Couple 2 discussed feelings of worry about the emotional well-being of the ill child's well sibling: "*My biggest worry right now is how do we… we have to have an outlet for [sibling].*" Mother was particularly concerned with the well-child negative emotions as a result of the cancer: "*[sibling] is feeling left out.*"

*Cancer stressors.* Both parents identified economic decisions and challenges that arose as a result of a cancer diagnosis: "*I want to know financially how we're [going to] make things better.*" Father also discussed cancer related decisions that were stressful for him: "*I think some of those positives are out of stuff that I pushed on him from reading about glutamine, boots, and working with PT about AFOs… Yeah I obsessed over those things, but it's the worst feeling in my mind right now that my son has a very significant disability in his hands and his feet and it's all because of the cancer."* 

*Roles.* Couple 2 identified several aspects of their roles that were related to pediatric cancer. For couple 2, mother was primarily responsible for the finances of the home, while father was primarily responsible for caring for the ill child. Both partners identified challenges related to their respective roles, with mother feeling unable to be home to help care for the child and father not wanting to be home all of the time: *"So me sitting at home kills me sometimes. It does. It's not always where I [want to] be."* Father also identified parenting related concerns as an important aspect of his and his partner's roles: *"We [got to] figure out what his schedule is [going to] be", as well as* challenges related to parenting the well sibling specifically: *"[sibling] not doing [seeing friends] right now, she needs help with that."* 

Parent emotional adjustment. Mother discussed feeling that both partners were engaging in coping challenges in response to cancer: "I think that in between where we're at is good, but I think both of us are not handling it in the best way... I spend too much time at work and you spend too much time reading online. That's how I see it." However, father did not agree with mother's perspective on their coping: "I'm not always online when you come home."

## **Cross Case Analysis.**

Five similar themes related to the participants' relationship adjustment and sibling emotional adjustment in pediatric cancer emerged in the analysis across X cases: 1) Relationship adjustment, 2) Sibling adjustment, 3) Cancer stressors, 4) Roles, and 5) Parent emotional adjustment. Despite commonalities across themes for both couples, the themes differed in number and similarity of the codes within each theme (see Table 5). Codes are displayed in Table 5 by couple in the order of most frequently discussed to least frequently discussed within each theme. Overall, there were more similarities across couples for Roles and Cancer stressors. Both couples cited parental roles and role challenges as major aspects of their overall roles in response to cancer. In terms of Cancer stressors, both couples identified financial related concerns as important cancer stressors. However, Couple 1 also focused on cancer related fears whereas Couple 2 focused on cancer decisions as relevant cancer stressors. Although the overall theme of relationship adjustment appeared in interviews with both couples, sub-themes varied by couple. While both couples identified aspects of communication as important to relationship adjustment, Couple 1 identified increased partner communication as a positive factor in their relationship adjustment, while Couple 2 identified communication challenges as a negative factor in their relationship adjustment. Couple 1 also identified more partner support and relationship cohesion compared to Couple 2, who identified more relationship distress in relation to cancer. Similarly, both couples had differing sub-themes for parent emotional adjustment. Couple 1 discussed parent emotional challenges related to cancer and the importance of outside support. Couple 2 focused on coping with cancer, in particular, mother's perception of coping challenges by both partners in response to cancer.

#### **POST-HOC EXPLORATORY ANALYSES**

Exploratory independent samples t-tests were conducted to explore differences in mother's relationship adjustment between married and non-married mothers, non-Hispanic white and Hispanic mothers, and mothers in high/medium and low socioeconomic groups. Sibling emotional adjustment was also compared based on socioeconomic group and between non-Hispanic white and Hispanic siblings.

There was not a significant difference in relationship adjustment scores for married mothers (M=22.33, SD=5.50) and unmarried mothers (M=20.78, SD=3.77); t(47)= -.80, p= .43, d= 0.23. There was not a significant difference in relationship adjustment scores for Hispanic mothers (M=22.79, SD=6.25) and non-Hispanic White mothers (M=21.05, SD=3.32); t(47)= 1.16, p= .25, d= 0.33. There was not a significant difference in relationship adjustment scores for Middle/High SES (>\$50,000) mothers (M=21.75, SD=6.60) and Low SES (≥ \$50,000) mothers (M=22.32, SD=3.56); t(47)= 0.38, p= .71, d= 0.11.

There was not a significant difference in emotional adjustment scores for Hispanic (M=12.39, SD=6.90) and non-Hispanic white siblings (M=9.76, SD=7.67); t(47)= 1.26, p= .21, d= 0.36. There was not a significant difference in emotional adjustment scores for Middle/High SES (>\$50,000) siblings (M=10.58, SD=6.55) and Low SES (≥ \$50,000) siblings (M=11.92, SD=8.01); t(47)= 0.64, p= .53, d= 0.19.

# DISCUSSION

The purpose of the current study was to examine the relationship between parental relationship adjustment and sibling emotional adjustment in pediatric cancer. A sequential explanatory mixed-methods approach was used to examine the primary research questions. Overall the findings of the present study suggest that mothers of pediatric cancer patients report levels of relationship adjustment that are consistent with means from normative data (Sharpley & Rogers, 1984). Given that participants completed the questionnaires on average 9 months post diagnosis, this finding is consistent with previous studies that suggest that parents of pediatric cancer patients experience the most relationship distress in earlier months of diagnosis, particularly around 3 months post-diagnosis (Katz et al., 2018). Additionally, qualitative interviews with couples suggest that couples may perceive relationship distress as a result of a cancer diagnosis, but when couples reported more communication plays an especially important role for these couples due to the additional responsibilities of a cancer diagnosis and the need to reorganize roles.

The present study found that 30% of siblings have elevated levels of emotional problems compared to only 11% of children in community samples who meet or exceed the clinical cut off, indicating that a significant subset of siblings in our sample exhibited more emotional problems than the general population (National Center for Health Statistics, 2001). Siblings did not differ in levels of emotional adjustment by gender. This finding is inconsistent with previous research that has found that female siblings tend to experience higher levels of anxiety and depressive symptoms compared to male siblings (Barrera, Fleming, & Khan, 2004; Houtzager et al., 2003). This discrepancy may be due to methodological differences between previous studies

and the current study, such as other studies using siblings and parents as informants and using longitudinal data to capture sibling perspectives across time. However, the current study found that younger siblings showed significantly higher levels of emotional distress compared to older siblings. This finding is consistent with previous research that showed that younger siblings experience more overall distress compared to older siblings (Long, Alderfer, Ewing, & Marsland 2013). Parents indicated in qualitative interviews that they see parenting the well sibling as a vital part of their roles and part of parenting the well child includes meeting their emotional needs; however, parents may be unable to truly prioritize the needs of the well child due to the various other responsibilities necessary to care for a child with cancer. Developmentally, older siblings may be better able to meet their own emotional and physical needs when compared to younger siblings. Due to the reorganization of roles and the prioritization of the ill child's treatment, it is possible that younger siblings rely more heavily on adults to meet their emotional needs, and thus feel more emotional distress when parents modify routines to meet the needs of the ill child. As such, age may be a potential protective factor for older siblings.

The first research question of this study aimed to determine whether parental relationship adjustment was related to sibling emotional adjustment while controlling for time since diagnosis. The findings indicate that contrary to Hypothesis 1, relationship adjustment and sibling emotional adjustment were not significantly related. These findings are not consistent with previous studies demonstrating that relationship adjustment can impact emotional adjustment in community youth (Camisasca, Miragoli, & Blasio, 2016; Low & Stocker, 2005; Oh, Lee, & Park, 2011). A reorganization of family roles and priorities are often necessary in the face of pediatric cancer. As such, parents report putting the needs of the relationship on hold to focus on the ill child (Clarke 2006; Nicholas et al. 2009; van Dongen-Melman, Zuuren, & Verhulst, 1998). This reorganization of priorities may be perceived as necessary for the partner dyad, thus parents may not perceive their decreased interactions and communication as dysfunctional during treatment. Additionally, siblings may not perceive relationship discord due to the other changes in routine and family functioning due to the diagnosis. The current study relied on mother report of sibling emotional adjustment; however, mothers may be focused on the needs of the ill child (Kars et al. 2008; McGrath 2005; Mercer & Ritchie 1997) and therefore may not fully perceive the emotional impact of pediatric cancer on siblings. Our qualitative findings suggest that parents of children with cancer perceive a normalization of the diagnosis by well siblings. This perceived normalization may mean siblings are less distressed by their parents' reduced partner relationship satisfaction because siblings perceive these changes as necessary in order to properly care for the ill child. Furthermore, a majority of the participants for the current study were of middle to high socioeconomic status which may be a protective factor for both better relationship adjustment and sibling emotional adjustment, as higher resourced families may perceive financial responsibilities of a cancer diagnosis as less stressful and may be better able to manage stressors related to cancer (McGrath et al. 2005; Mercer & Ritchie, 1997; Neil-Urban & Jones 2002). Previous research has shown that parents with higher economic stress and higher cumulative stress had poorer marital adjustment over time (Lavi et al., 2018).

The second research question aimed to establish whether gender was a moderator in the relationship between relationship adjustment and sibling emotional adjustment. The findings indicated that gender did not moderate the relationship between relationship adjustment and

sibling emotional adjustment. Although the interaction plot appeared to show that female siblings have higher emotional distress when relationship adjustment is low, this interaction effect was not statistically significant. Thus, it cannot be inferred that relationship adjustment affects male and female siblings' emotional adjustment differently.

Similarly, the third research question examined whether sibling age was a moderator in the relationship between relationship adjustment and sibling emotional adjustment. The findings demonstrated that age did not moderate the relationship between relationship adjustment and sibling emotional adjustment. Based on these results, siblings of all ages may be equally affected by parents' relationship adjustment. The results of the current study were inconsistent with previous research with community samples that demonstrated that females and younger siblings exhibit poorer emotional adjustment in response to relationship distress (Hess & Camara, 1979; Mahoney, Jouriles, & Scavone, 1997).

The qualitative findings highlight several factors related to parent relationship adjustment, sibling emotional adjustment, family functioning, and parent mental health for couples facing a pediatric cancer diagnosis. Specific aspects of relationship adjustment that were described by couples included communication and communication difficulties, partner support, relationship cohesion, and relationship distress. Qualitative findings suggest that couples that reported communication as an influential factor in their adjustment to cancer also discussed partner support and relationship cohesion more often, and those that focused more on communication difficulties reported relationship distress more often. This suggests that when couples communicate and are more supportive of each other during treatment, relationship distress is less apparent in the relationship. These sub-themes are consistent with previous findings which suggest that partner communication is often put on hold during treatment and mothers report feeling insufficient emotional support from their partners (Bjork et al. 2005; McGrath 2001a, b; Mercer & Ritchie 1997).

Partners' roles were also seen as an important factor in couples' adjustment to a cancer diagnosis. Couples indicated role challenges as a stressor related to a cancer diagnosis. These role challenges were seen as necessary in order to adjust to a cancer diagnosis, which is consistent with previous studies which show that couples often reorganize roles within the household to meet the needs of the ill child (Mercer & Ritchie, 1997). Couples also cited their parental roles as an important part of their overall role in the family. Parental roles included parenting decisions for the ill child as well as the well siblings.

Mothers and fathers also identified financial challenges and cancer related decisions as cancer related stressors that impacted their relationship. Parents also expressed aspects of their own emotional adjustment that impacted their relationship with their partner. While all couples identified parent emotional challenges in response to cancer, couples who identified parent poor emotional adjustment more often discussed relationship distress and communication challenges. This is consistent with the original Family Stress model in which parent emotional problems and partner conflict and withdrawal are related in the face of an economic, or in this case cancer, stressor (Conger et al., 2000). Although not as apparent during the qualitative interviews, sibling emotional adjustment was noted as a relevant factor for the family's overall adjustment to cancer. Both mothers and fathers noted sibling negative emotions in response to cancer. These findings are consistent with quantitative findings that suggest that a large subset of siblings exhibit clinically elevated emotional symptoms.

Fathers specifically identified parenting as an essential part of their roles. Both fathers addressed indicated seeing parenting decisions about the ill child's treatment and parenting decisions for the well sibling as important responsibilities within the family. Further, consistent with past research that demonstrates that fathers are primarily responsible for the well sibling (Nicholas, Gearing, McNeil, Fung, Lucchetta, & Selkirk, 2009), my qualitative findings show that fathers perceived the well sibling's overall emotional wellbeing as an important part of sibling adjustment. This finding provides more depth to the understanding of fathers' roles in parenting the well sibling. Not only are fathers responsible for the physical needs of the well siblings, but they are also responsible for the siblings' emotional needs. Further, the reorganization of roles for the participating families included fathers having more responsibility with the ill child's treatment than what previous studies suggest. Fathers were either primarily responsible for the ill child's care while mothers were primarily responsible for the economic responsibilities of the household, or fathers shared in the medical caretaker role with mothers, often accompanying mothers to appointments. This reorganization of roles is different to what previous literature demonstrates in which mothers are primarily responsible for the ill child (Kars et al. 2008; McGrath 2005; Mercer & Ritchie 1997), indicating that while traditionally the medical caretaker role is taken by mothers and the financial caretaker role is taken by fathers, these roles are not strictly limited to one gender. These findings show the importance of considering fathers' perspective in illness related stressors, as fathers may be more involved in the medical care than previously thought.

#### LIMITATIONS, STRENGTHS, AND FUTURE DIRECTIONS

## Limitations.

The current study has a number of limitations that should be noted. First, all measures included in the quantitative phase of the study are mother report. Due to recruitment taking place at DCMC during the patient's appointment time, it is not likely that siblings would be present and able to participate. Patient appointments take place during typical business hours, during which time siblings would likely be at school. Mother report of siblings may not capture the full extent of a sibling's experience with pediatric cancer. Mothers may over or under report sibling emotional problems (Sourander, Halstela, & Helenius, 1999). Similarly, mother report does not allow for information on siblings' own perceptions of their parents' relationship functioning. As such, mothers may have underreported the extent to which siblings perceive parent relationship distress and how it affects their emotional adjustment. In addition, sibling functioning was not asked about specifically in the qualitative interviews. Rather, the interview asked couples how the diagnosis has affected their overall family functioning. This may have deterred couples from discussing siblings specifically, and thus did not provide more qualitative information regarding siblings. Providing questions about sibling functioning more specifically may have better allowed couples to discuss the emotional needs of siblings further.

Further, the study sample did not include father data in quantitative analysis. Due to the reorganization of roles in response to a cancer diagnosis, mothers are more likely to be in charge of the ill child's care while fathers are in charge of taking care of other members of the family and the finances (Nicholas et al. 2009). Thus, fathers are less likely to be present at the ill child's appointment and less likely to agree to participate due to other time commitments. This reorganization is supported by the small number of fathers enrolled in the larger study compared

to mothers (see Figure 3). A lack of father participation would mean less data on father perspectives of the partner relationship. Further, fathers may be more likely to spend time with the well siblings compared to mothers and be more aware of siblings' emotional adjustment problems compared to mothers. Potential differences between mothers and fathers were not be able to be examined.

The sample included only non-Hispanic White and Hispanic parents. Though White and Hispanic children have the highest incidence rates for childhood cancer (National Cancer Institute, 2015), a lack of representation of other races and ethnicities could limit the generalizability of findings. Potential differences by race/ethnicity were not able to be examined due to a lack of African American and Asian participants. Similarly, the majority of the sample was married. The generalizability of findings may be limited due to the lack of participants in non-married relationships. Although studies show that married and non-married co-habiting couples are similar in terms of relationship roles and are comparable when examining overall relationship adjustment (Copen, Daniels, & Mosher, 2013), a cancer diagnosis may affect non-married couples, and the relationship between partner and sibling adjustment, differently than married couples. These potential differences were not able to be examined due to the underrepresentation of non-married participants in the sample.

Overall relationship satisfaction was used to capture the level of relationship adjustment. While relationship satisfaction is typically used as a way to capture relationship adjustment (Long & Marsland, 2011), our qualitative findings and previous studies suggest that there are other constructs, such as communication and partner support, that are important to the construct of relationship adjustment (Spanier, 1976). For example, qualitative findings suggest that partner communication may be more important that overall relationship satisfaction. This may be especially true in the context of pediatric cancer given the logistical and emotional challenges couples may face when communicating about their child's cancer. Our qualitative findings suggest that communication is an important aspect of the couple relationship in order to meet the needs of the family and the needs of the child's treatment. As such, our use of relationship satisfaction may not have been comprehensive in capturing overall relationship adjustment.

# Strengths.

Despite these limitations, the current research is strengthened by a number of factors. The study used case narrative design to further expand upon quantitative results. The qualitative analysis allowed for the consideration of the father perspective. Qualitative findings also allowed for more in-depth analysis into the multiple components of relationship adjustment. These findings were used to shed light and provide further explanation of the quantitative findings. The combination of quantitative and qualitative results provided a larger picture of the impact of pediatric cancer on relationship adjustment and sibling emotional adjustment.

The use of cluster robust standard error analysis allowed data to be analyzed for dependent samples. In this case, siblings from the same families have dependencies that may influence results. Thus, cluster robust standard error analysis best accounted for the potential dependencies between siblings from the same families.

The current study used measures that have been validated for the constructs of interest. The use of validated measures ensures that the constructs in questions are being captured. Inclusion of a Spanish protocol allowed participants to choose to participate in the language that was most comfortable for them. It also allowed for the inclusion of families that might not be captured if the protocol was only available in English. Additionally, those measures that have not been validated in Spanish were translated then back translated to ensure consistency with the English versions. By including Spanish speaking families in the study, we expanded current literature by adding the unique experiences Spanish-speaking families might have compared to English-speaking families. For example, Spanish-speaking families may experience a language barrier with the medical providers and staff at the clinic. This may limit their ability to fully comprehend the information about their child's diagnosis and increase stress related to cancer due to this limited understanding. It is important to include the perspectives of culturally diverse families, specifically families whose primary language is not English, because it allows clinicians to better intervene during times of distress using culturally sensitive approaches to treatment.

While our study was unable to compare differences across ethnicities due to a limited sample of African American and Asian participants, the high percentage of Hispanic participants allows us to understand relationship and sibling emotional adjustment among families which are usually examined in the context of health disparities. Our quantitative sample included over 60% of Hispanic mothers, and post-hoc exploratory analysis did not find significant differences between Hispanic and non-Hispanic white mothers for relationship adjustment and sibling emotional adjustment. This indicates that there may be protective factors/strengths among Hispanic families that help maintain normative levels of relationship adjustment and sibling emotional adjustment, despite known health disparities within pediatric cancer (Lim, Bhatia, Robinson, & Yang, 2014). Studies have shown that Hispanic pediatric cancer patients with high levels of assimilation exhibit more emotional problems compared to those with lower levels of

assimilation (Tobin et al., 2018). Among Hispanic families in the United States, family, community, and cultural traditions have been shown to be strengths and protective factors for a variety of presenting concerns and families across socio-economic statuses (Mogro-Wilson, 2011). It is possible that like cancer patients, these protective factors extend to siblings and result in normative levels of emotional adjustment in response to cancer. Further religion is known to be an influential resource for Hispanic families in the face of stressors and an important factor within the partner relationship (Sanchez, Dillon, Ruffin, & De La Rosa, 2012). One study found that church attendance among Hispanic couples was related to higher relationship satisfaction (Stinson et al., 2017). Couples' strong reliance on religion as a coping mechanism may help maintain healthy levels of emotional adjustment even within the context of a stressful event such as pediatric cancer. This may be a possible reason why we did not find significantly lower levels of relationship adjustment within our sample.

# **Clinical Implications.**

The results of this study have direct implications for clinicians working with families of pediatric cancer patients. Although previous research and the findings of the current study suggest that siblings of cancer patients have elevated emotional symptoms when compared to peers in the general population, few studies have looked at effective interventions for siblings. Barlow & Ellard (2004) found that interventions incorporating cognitive-behavior techniques and focused on family functioning helped reduce symptoms of emotional distress in children and adolescents with chronic disease. Though the study did not involve siblings, the results of the proposed study may provide support for the incorporation of siblings in family interventions. A study by Kazak et al. (2004) looked at the effects of a cognitive-behavioral and family therapy

approach for the reduction of posttraumatic stress symptoms for cancer survivors and their families. The primary aim of the study was to look at the effectiveness of the intervention for survivors and their parents. However, researchers elected to include siblings for exploratory purposes. The results of the study did not show significant differences between siblings in the treatment group and siblings in the control group. However, the study did find individual family members in the treatment group had a greater decrease in posttraumatic stress scores from time 1 to time 2 than individuals in the control group. Though the intervention did not find significant results for siblings, the results of the study provide preliminary evidence for the effectiveness of combining CBT and family therapy for families of cancer survivors. A qualitative study by Barrera et al. (2018) found that siblings perceived having a sibling support group as highly important in order to cope with the illness.

Future research should examine the effectiveness of marital interventions on the reduction of sibling emotional problems, for both siblings of patients in active treatment and siblings of cancer survivors. Researchers should consider various recruitment strategies for siblings, including online and school recruitment, in order to expand the opportunity for participation for siblings. Clinicians working with families of cancer patients should consider including siblings in psychotherapy treatment, or referring siblings for individual treatment to manage emotional symptoms. Clinicians should consider sibling specific groups as previous findings have shown that siblings of cancer patients may benefit emotionally from their own intervention groups. Interventions for siblings should be offered at flexible times, such as after school or on the weekends, in order to minimize further disruptions to the sibling's life. In keeping with the psychosocial standards of care presented by Gerhardt, Lehmann, Long, &

Alderfer (2015), when clinicians are unable to provide services to siblings directly, clinicians should inform parents of the emotional needs of siblings and how to best meet these needs. Similarly, interventions geared toward siblings should include a parent component to support siblings' needs. A parent component would be especially important for younger siblings as supported by our findings that younger siblings exhibit significantly more emotional problems than older siblings. Further, clinicians should consider screening siblings for emotional problems and sibling age as a potential risk factor for poorer emotional adjustment.

Clinicians should also consider possible protective factors for families of Latino/Hispanic origin when providing services to cancer patients and their family. Consideration of these factors may reduce barriers to mental health services for these families and increase the involvement of families within these services. In particular, clinicians should consider how family, community, and cultural factors may be strengths of the family and include these in treatment planning. The lack of elevation in emotional symptoms and relationship distress among our Hispanic sample further demonstrates that regardless of the health disparities faced by Hispanic families within pediatric cancer, there are protective factors that promote emotional and relationship resilience within these families.

Additionally, clinicians and researchers should consider various strategies in order to increase the inclusion of fathers and address the unique stressors fathers experience. Jones et al. (2010) suggests several strategies for increased inclusion of fathers including, flexible meeting times with health care teams and clinicians in order to allow fathers an opportunity to attend important meetings about care. Similarly, researchers should consider flexible hours when recruiting and enrolling fathers in order to increase the likelihood of enrollment in studies. Jones

et al. (2010) also suggests providing video/audio-taped meetings or the ability to teleconference with providers. Researchers should consider various methods of study completion, such as phone, web-based, etc. to allow fathers to choose a study completion method that best fits with their schedules. Clinicians and researchers should also obtain information directly from fathers, rather than relying on mothers' assessments of fathers' availability and interest in treatment and research (Jones et al., 2010). Finally, Jones et al. (2010) suggests providing support in the form of groups or individual support for fathers in order to assist with emotional and everyday stressors of pediatric cancer.

## **Directions for Future Research.**

Future research should gather sibling reports of emotional adjustment and perceptions of relationship adjustment between parents, both quantitatively and qualitatively. Incorporating data from siblings themselves may expand on our findings and provide further insight into siblings' emotional experiences in response to pediatric cancer. Previous research shows that children's perceptions of inter-parental conflict are related to children's reported distress and emotional adjustment (Grych & Fincham, 1993). Exploring siblings' perceptions of parental conflict may provide further information about the factors contributing to emotional adjustment in families of pediatric cancer patients. Similarly, future studies should gather father reports of relationship adjustment and sibling emotional adjustment. Gathering father data would allow us to compare differences between mothers and fathers' perceptions of relationship adjustment and sibling emotionally, future studies may wish to examine other possible predictor variables, such as patient age or diagnosis type, and gather sibling, mother, and father data across multiple time points to further understand sibling emotional adjustment in response to pediatric cancer and the role of time since diagnosis in marital adjustment and sibling emotional adjustment.

# Conclusion

The current study sought to understand the relationship between parental relationship adjustment and sibling emotional adjustment in pediatric cancer. Sibling age was found to be significantly related to sibling emotional adjustment. Relationship adjustment and sibling emotional adjustment were not significantly related, and sibling age and gender did not moderate the relationship between relationship adjustment and sibling emotional adjustment. Qualitative findings highlighted five themes among couples of pediatric cancer patients: relationship adjustment, sibling adjustment, roles, cancer stressors, and parent emotional adjustment. There were no significant differences in relationship adjustment and sibling emotional adjustment between low SES families and middle/high SES families, and between Hispanic families and non-Hispanic white families. These findings have implications for clinicians working with cancer patients and their families. Clinicians should provide interventions for siblings of cancer patients, and consider including parents, specifically for younger siblings. Additionally, clinicians should consider possible strengths of Hispanic families that can be integrated into treatment. Finally, researchers and clinicians should consider various strategies for increased inclusion of fathers in research and in interventions.

# Appendix

Table 1.

Frequencies of Diagnosis for Patient

	Percent
1. Any Leukemia	37
2. Any Lymphoma	14
3. Any Brain Tumor	29
4. Any Other Solid Tumor	20

# Table 2.

		Mean	SD	1	2	3	4
5.	Sibling emotional Adjustment	11.27	7.29	-	22	40**	14
6.	Relationship Adjustment	22.04	5.23		-	.10	.08
7.	Sibling Age	10.35	3.50			-	
8.	Time Since Diagnosis (months)	9	3.71				-

Descriptives and Correlations for Relationship adjustment, Sibling emotional Adjustment, Age, and Time Since Diagnosis

\*\**p* < 0.01.

Table 3.

Predicting Sibling Emotional Adjustment by Gender

Predictor	β	r
Relationship Adjustment	32	.23
Gender	2.33	.28
Relationship Adjustment x Gender	67	.35

\**p* ≤ .01
## Table 4.

Predicting Sibling Emotional Adjustment by Age

Predictor	β	r
Relationship Adjustment	32	.23
Age	73*	.45*
Relationship Adjustment x Age	02	.45
* <i>p</i> ≤ .01		

## Table 5.

Themes and Sub-Themes Act	ross Cases

Themes	Codes by Theme		
	Couple 1	Couple 2	
Relationship	Partner Communication	Relationship Distress	
Adjustment	Relationship Cohesion	Communication Challenges	
	Partner Support	Mismatched Coping Styles	
		Differing Partner Emotions	
		Relationship Cohesion	
		Improved Relationship Adjustment	
Sibling Adjustment	Sibling Perception of Normality	Sibling Negative Emotions	
		Child Well-being	
<b>Cancer Stressors</b>	Cancer Related Fears	Economic Decisions	
	Financial Challenges	Financial Challenges	
	Family Challenges	Cancer Decisions	
Roles	Parental Roles	Parental Roles	
	Role Challenges	Role Challenges	
Parent Emotional	Parent Emotional Challenges	Coping Challenges	
Adjustment	Outside Support		

Codes are organized in order of most prevalent by each couple's discussion.



Figure 1a. The Family Stress Model. Reprinted from "A family process model of economic hardship and adjustment of early adolescent boys" by R.D. Conger, K.J. Conger, G.H. Elder, F.O. Simons and L.B Whitbeck, 1992, Child Development, 63, p. 526-541.



Figure 1b. The adapted Family Stress model



*Figure 2*. Statistical model



*Figure 3*. Participant Enrollment



Figure 4. Relationship Adjustment x Gender



Figure 5. Relationship Adjustment x Age

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