

Interpersonal Relationships of Children & Adolescents with Cancer

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**Abstract**

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Interpersonal relationships are a central and critical aspect of children's socioemotional development and contribute to later wellbeing. When a child or adolescent is diagnosed with cancer, problems may arise in family and peer relationships and negatively affect adjustment. Given that these youth are at risk for poor psychosocial outcomes, understanding how social relationships change after diagnosis, influence one another, and contribute to patient wellbeing is needed to inform prevention and intervention efforts. Toward this goal, the current series of studies examines how family and peer relationships are affected when a child or adolescent has cancer.

In Study 1, associations between cancer-related stressors and sibling conflict were examined longitudinally across the first year of treatment. Families (N=103) included a child with cancer and at least one sibling. Primary caregivers completed monthly questionnaires throughout the first year of treatment assessing stress and sibling conflict. Using multilevel modeling, we explored if changes in stress resulted in concurrent changes in conflict within an individual

family and whether greater average stress affected the trajectory of conflict between families. Results indicated that higher average levels of cancer-related stress, general life stress, and financial stress were associated with higher sibling conflict over time. No stressors were associated with concurrent changes in conflict. Results suggested that some stressors contribute to increases in sibling conflict during the first year of treatment.

In Study 2, spillover between marital adjustment and parent-child conflict was examined across Months 1, 6, and 12 post-diagnosis. Primary caregivers (N = 117) completed self-report questionnaires assessing marital adjustment and parent-child conflict in the past month. Cross-lagged panel models were then used to assess whether associations existed and whether these associations were unidirectional or bidirectional in nature. Results indicated that a unidirectional model of spillover from the marital to the parent-child relationship best explained the data. In terms of specific temporal patterns, lower marital adjustment soon after diagnosis was associated with an increase in parent-child conflict 6 months later. Targeting marital problems soon after diagnosis may prevent conflict from developing in the parent-child relationship.

In Study 3, the experience of peer relationships during cancer treatment was assessed using perspectives of both adolescents with cancer and their peers. Patients aged 12-19 (n = 14) and peers (n = 2) completed semi-structured interviews and patients completed self-report questionnaires on social support, social functioning and psychological adjustment. Results indicated that patients valued communication with peers and perceived changes in their relationships. Patients discussed instances of support by friends and offered advice for other teens with cancer. Mothers and same-sex friends provided the most support for patients. Patients' social functioning and psychological adjustment were high on average, similar to US norms, and

moderately associated. Helping adolescents maintain close peer relationships may attenuate developmental disruption and negative psychosocial impact of cancer.

Taken together, these studies demonstrate that interpersonal relationships are impacted when a child has cancer. Developing interventions targeting marital and sibling relationship quality soon after diagnosis may serve a preventative purpose and promote family wellbeing. Bolstering peer support may be especially valuable for adolescents with cancer, which could be accomplished through teaching patients to seek support and teaching peers about support provision, cancer treatment, and coping skills. Methodological limitations related to sampling bias, measurement, and generalizability are discussed. Future directions for this work involve further descriptive research and intervention development.

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## CHAPTER 1 | Introduction

### 1.1 Background

Substantial advances have been made in the treatment and prognosis of childhood cancers. Forty years ago, 58% of children diagnosed with cancer survived five years or more. Today, that rate has risen to nearly 85% (Siegel, Miller & Jemal, 2016). With this improvement in survival has come an increased focus on the psychosocial aspects of pediatric cancer treatment and survivorship. In recent decades, the burgeoning field of pediatric psycho-oncology has sought to understand how the cancer experience affects children's current and later quality of life, psychological adjustment, social functioning and developmental milestones.

In the past decade, there has been a rapidly growing awareness of the unique needs of adolescents with cancer. Adolescents with cancer are considered part of the adolescent and young adult (AYA) patient population - a high-risk subgroup distinct from younger and older patients. As defined by the National Cancer Institute (NCI), AYAs are individuals diagnosed with cancer during the ages of 15-39 years (Ries et al., 2008). This delineation of AYAs as a unique subpopulation was spurred by a Progress Review Group (PRG) established by the National Cancer Institute (NCI) and Lance Armstrong Foundation (LAF) in 2006, which published a report detailing research imperatives to "close the gap" between AYAs with cancer and other patient groups (Adolescent & Young Adult Oncology PRG, 2006). This report acknowledged a number of disparities between AYAs and both younger and older patients, including little to no improvement in survival rates despite marked improvements for children and older adults, and poorer psychosocial outcomes and quality of life during treatment and survivorship. Since then, AYA psycho-oncology has emerged as a sub-specialty in which

researchers aim to understand and address the unique psychosocial needs of adolescents and young adults during and after cancer treatment.

As pediatric psycho-oncology has grown as a discipline, focus has expanded beyond the patient to examine other individuals or systems that are affected when a child or adolescent is diagnosed with cancer, such as the family. Applying a family systems perspective, Kazak (1989) argued that one cannot study children with serious illness without considering their place within the family and how family members and their relationships reciprocally affect one another. Since then, researchers have explored how cancer affects psychological adjustment of caregivers and siblings (Alderfer et al., 2010; Pai et al., 2007; Vrijmoet-Wiersma et al., 2008); quality of family relationships (Hoekstra-Weebers et al., 1998; Katz et al., 2018; Katz et al., 2010; Orbuch et al., 2005); and other aspects of family functioning, such as cohesiveness or conflict (Hullmann et al., 2010; Long & Marsland, 2011; Varni et al., 1996).

Together, this body of research has sought to understand how pediatric cancer affects psychosocial adjustment of child and adolescent patients and their families with the applied goal of lessening negative outcomes through prevention and intervention efforts. While a growing body of work has examined psychosocial adjustment of child and adolescents with cancer, their caregivers, and their siblings, substantially less work has focused on interpersonal relationships of children and adolescents with cancer. Given that interpersonal relationships with family members and peers are a central aspect of children's socioemotional development, understanding how these relationships are affected by pediatric cancer is critical. Quality of family relationships, including the marital relationship, parent-child relationship, and sibling relationship, contribute to child wellbeing both concurrently and over time (Brody et al., 1998). Beyond the family, peer relationships are an essential part of daily life and major context for

development, particularly for adolescents (Brown & Larson, 2009; Smetana, Campione-Barr & Metzger, 2006; Steinberg & Morris, 2001). In addition to their contributions to developmental outcomes, these relationships also provide social support to patients, which has been linked to less distress in children undergoing treatment and in survivors (McCarthy et al., 2016, Corey et al., 2008).

Many unanswered questions remain regarding cancer's effects on children's relationships. Though a small body of work has examined family relationships, most studies have focused on the marital relationship (for a review, see Van Schoors et al., 2016). To date, few have examined parent-child relationships, and none have examined sibling relationships. Additionally, no studies have examined how dyadic family relationships interrelate, or how problems in one subsystem (i.e., the marital relationship) may affect other relationships in the family. As children affect and are affected by the environment of the family as a whole, considering quality of all family relationships and how they affect one another is needed. Lastly, few studies have considered cancer's effects on peer relationships. Particularly for adolescents with cancer, for whom peer relationships are equally proximal and more salient than family relationships, deficits in peer socialization may be a major unexplored contributor to psychosocial adjustment during and after treatment.

In order to create effective interventions to support patients and their families, it is critical to comprehensively understand how the experience of pediatric cancer affects interpersonal relationships. Toward this goal, this series of three studies aims to examine the effects of pediatric cancer on relationships of youth with cancer during the first-year post-diagnosis. Two studies focus on family relationships of children with cancer and the third focuses on peer relationships of adolescents with cancer. We first provide a general introduction in which we

review existing research on: 1) individual psychosocial adjustment of children and adolescents with cancer and their family members, and 2) family and peer relationships during pediatric cancer treatment and survivorship. Next, for each study, we describe aims, methods, results, and a brief study-specific discussion. Lastly, we offer a general discussion describing collective conclusions, broader methodological limitations affecting some or all of the present studies, clinical applications, and directions for future research.

## **1.2 Psychosocial Adjustment of Patients and Family Members**

To understand how children's interpersonal relationships are influenced by cancer, it is important to consider how cancer affects individual adjustment of both patients and their family members. A large body of literature has examined this topic, focusing on psychological and social adjustment of children with cancer; adolescents with cancer; caregivers of children with cancer; and siblings of children with cancer.

**Children & adolescents with cancer.** Evidence suggests that at least a subset of children with cancer are at risk for poor psychosocial adjustment during and after treatment. While a number of studies have suggested that many children with cancer do not report substantial distress, a growing body of evidence suggests that a subset of children are at-risk for psychological adjustment outcomes, particularly soon after diagnosis (Katz et al., 2018b; Sawyer et al., 2000). A recent meta-analysis suggested that across studies, children with cancer typically report a moderate elevation in internalizing symptoms when compared to population norms (Pinquart & Shen, 2011). Additionally, two studies have found that while on average symptoms are not elevated, clinically-relevant symptoms of anxiety and depression are higher than expected among children with cancer when compared to age-matched population norms (Kunin-

Batson et al., 2016; Myers et al., 2014). Thus, some children with cancer may be at risk for maladjustment, particularly during the first year of treatment.

Compared to children, adolescents with cancer are at higher risk for poor psychosocial adjustment both during treatment and survivorship (Bleyer, 2007). Adolescents are part of the AYA (adolescent and young adult) patient population and are rarely studied separately from young adult patients. Among AYAs, clinically significant psychological distress during and after cancer treatment is common (Mor, Aleen & Malin, 1994; Pendley, Dahlquist & Dreyer, 1997; Samsom-Daly & Wakefield, 2013; Zebrack et al., 2014; Zebrack, Mills & Weitzman, 2007). In a longitudinal study of 152 AYAs, Zebrack and colleagues (2014) found that 35% of newly diagnosed AYAs reported clinically significant distress at some point during the first two years post-diagnosis. In a sample of young AYAs (15-25 years) in Australia, McCarthy and colleagues (2016) found that 48% of AYAs scored above the clinical cutoff for PTSS, and 31% scored in the moderate-to-severe range for anxiety and depression. Among AYA cancer survivors (i.e., survivors who were diagnosed as an adolescent or young adult), rates of psychological distress remain high (for a review, see Barnett et al., 2016).

AYAs with cancer also report problems in social functioning compared to non-ill peers (Husson et al., 2017; Warner et al., 2016). AYAs report poorer social quality of life compared to controls, struggle to maintain peer and romantic relationships, and report deficits in peer support (Geue et al., 2014; Warner et al., 2016). In one longitudinal study, social functioning of AYAs with cancer was lower relative to controls at diagnosis and one- and two-year follow-up (Husson et al., 2017). After treatment, AYA survivors are less likely to participate in peer activities (Pendley et al., 1997) or achieve social milestones like living independently, finding an intimate partner, or being employed (Eiser, Penn, Katz & Barr, 2009; La Greca & Harrison, 2005;

Richardson, Nelson & Meeske, 1999). To understand and address these disparities, recent work has focused on examining how the unique developmental context of adolescence and young adulthood may place AYAs at risk. Critically, these disparate psychosocial outcomes may be largely attributed to disruptions in important developmental processes occurring at this point in the lifespan, as the demands of cancer are often in contrast to the developmental goals of adolescence (Docherty, Kayle, Maslow & Santacroce, 2015; Morgan et al., 2010).

**Caregivers & siblings.** Second only to patients themselves, the most focus has been given to examining psychological adjustment of caregivers. Psychological distress is common among caregivers (Pai et al., 2007; others) and has been associated with poor child and caregiver outcomes (Trask et al., 2003; Robinson et al., 2006; Pierce et al., 2016; Poder et al., 2010; Landolt et al., 2012). Caregivers of children on treatment report elevations in distress compared to both control samples and caregivers of children off-treatment (Yeh, 2002, Santacroce, 2002; Von Essen, Sjoden & Mattsson, 2004), with the highest rates reported around the time of diagnosis (Compas et al., 2015; Allen, Newman & Souhami, 1997; Yeh, 2002; Santacroce, 2002). Fewer studies have examined clinically significant levels of distress among caregivers, yielding mixed findings. Across differing times since diagnosis, estimates of clinically-relevant or moderate-to-severe depressive symptoms have varied greatly, ranging from 14-65% for mothers and 9-50% for fathers (Allen et al., 1997; Barrera et al., 2004; Bonner et al., 2007; Compas et al, 2015; Frank et al., 2001; Iqbal & Siddiqui, 2002). In one study examining rates of clinical symptoms over time, more than 50% of primary caregivers met criteria at diagnosis and 30% at one-year post-diagnosis (Katz et al., 2018).

A growing body of research has focused on siblings of children with cancer, with most examining siblings' subjective experiences of cancer and their psychosocial adjustment

outcomes. Siblings report both positive and negative experiences related to their brother's or sister's cancer. In terms of negative experiences, qualitative work has identified themes of changing lives, intense feelings, unmet needs, loss, and fear of death (Walker, 1988; for a review see Wilkins & Woodgate, 2005). Siblings also report feeling increased isolation, differential attention, and rivalry as parents focus on the ill-child (Sargent et al., 1995). However, in terms of positive experiences, siblings report being more sensitive to others' needs, more compassionate, or more protective of the ill-sibling (Heffernan & Zanelli, 1997; Nolbris, Enskar, & Hellstrom, 2007; Sargent et al., 1995).

In terms of psychosocial adjustment, some siblings experience adjustment problems after their brother's or sister's diagnosis. For example, some siblings report poorer academic performance and social functioning (Cohen et al., 1994; Labay & Walco, 2004), and more externalizing and internalizing symptoms (Cohen et al., 1994; Sloper, 1996), particularly in the first months following diagnosis (Houtzager et al., 2004). However, some siblings of children with cancer do not show significantly more adjustment difficulties or behavior problems compared to controls (Alderfer et al., 2010; Horwitz & Kazak, 1990; Labay & Walco, 2004), and some may also show higher levels of prosocial behavior compared to siblings of non-ill children (Horwitz & Kazak, 1990).

### **1.3 Pediatric Cancer & Interpersonal Relationships**

Interpersonal relationships are a critical component of child and adolescent development, though are understudied among youth with cancer. In healthy populations, high quality relationships with parents, siblings, and peers are the primary context for socialization, provide long-term social and instrumental support, and have been linked to positive developmental outcomes (Brody, 1998; Brown & Larson, 2009; Katz & Gottman, 1997). In contrast, conflict in

these relationships may contribute to psychosocial problems, both concurrently and over time (Carson & Parke, 1996; Davies & Cummings, 1994; Kim et al., 2007). Considering that the risk for poor adjustment is elevated among children and adolescents who have undergone cancer treatment, a clear understanding of how pediatric cancer affects interpersonal relationships is needed to promote high quality relationships, social support, and positive psychosocial adjustment.

**Family relationships.** Within the child development literature, family functioning has long been recognized as a strong predictor of child adjustment. In particular, while close family relationships are associated with positive developmental outcomes, family conflict may be especially harmful to children (Cummings, Davies & Campbell, 2000; Katz & Gottman, 1995). When a child is diagnosed with cancer, families may experience increases in conflict as all family members cope with the diagnosis, readjust family roles, and adapt to lifestyle changes to accommodate the child's treatment (Long & Marsland, 2011; Lavee, 2005; Pai et al., 2007; Van Schoors et al., 2015). Though general family functioning has been linked to children's psychological adjustment both in non-ill children (Katz & Gottman, 1993) and children with cancer (Van Schoors et al., 2017), only a small number of studies to date have examined how specific dyadic relationships within the family are affected by pediatric cancer.

Most studies examining dyadic family relationships in the context of pediatric cancer have focused on the marital relationship. Among healthy populations, it has been widely established that high levels of interparental conflict negatively affect children's psychological adjustment. Interparental conflict may threaten children's emotional security (Davies & Cummings, 1994) thereby eliciting problems regulating emotional arousal (Katz, Kramer & Gottman, 1992), or lead to deficits in parental warmth, engagement, or attunement (Gerard,

Krishnakumar & Buehler, 2006; Katz & Gottman, 1997). Children who experience high levels of interparental conflict are more likely to have a variety of adjustment problems, including externalizing and internalizing symptoms (Grych & Fincham, 1990; Katz & Gottman, 1993).

To date, evidence has been mixed regarding the effect of cancer on marital conflict. Burns, Peloquin, and Sultan (2016) found that about 25% of mothers and 21% of fathers reported significant marital distress at diagnosis, and 36% of mothers and 43% of fathers reported significant distress after 2 years. Similarly, Dahlquist and colleagues (1993) found that about 25% of couples reported significant marital distress shortly after their child's diagnosis. Fife, Norton, and Groom (1987) found that on average, marital satisfaction was lower than the well-adjusted range. In contrast, other work with parents of children with cancer has suggested no differences compared to families with healthy children (Larson, Wittrock & Sandgren, 1994; Leventhal-Belfer, Bakker & Russo, 1993). A recent systematic review reported that many couples fare well after their child's diagnosis, but a subset decline in general marital adjustment and satisfaction particularly in the first-year post-diagnosis (Van Schoors et al., 2016).

Fewer studies have focused on parent-child relationships during treatment despite their key role in children's socioemotional development and robust contribution to children's psychosocial adjustment outcomes. From infancy, attachment theorists posit that a secure parent-child attachment relationship helps infants regulate distress and develop an internal working model that will influence their expectations for future interpersonal relationships (Bowlby, 2008). During childhood, close, warm, and emotionally-attuned parent-child relationships help children learn to effectively regulate their own emotional states (Katz & Gottman, 1995), are associated with better psychological adjustment (Darling & Steinberg, 1993; Khaleque, 2012; Steinberg, 2001), and may buffer children from the deleterious effects of interparental conflict

(Katz & Gottman, 1997). In contrast, conflictual parent-child relationships are associated with higher risk for psychopathology in childhood and adolescence and predict poorer social competency with siblings and peers (Burt et al., 2003; Carson & Parke, 1996). To date, two studies have examined the parent-child relationship in the context of pediatric cancer. Describing patterns of parent-child conflict, Katz and colleagues (2018a) reported low levels of parent-child conflict among young children during the first year of treatment, though Marine and Miller (1998) found that adolescents with cancer reported higher conflict with both mothers and fathers compared to a non-cancer sample.

Relative to other family relationships and aspects of family functioning, almost no focus has been given to sibling relationships among children with cancer. Sibling relationships are often the longest in one's life, making them a unique and valuable source of lifelong social and instrumental support. They are also a primary context for socialization for many children, as children spend more time with their siblings than with peers or parents (Brody, 1998; McHale & Crouter, 1996). Among typically developing children, sibling relationship quality has been associated with adjustment outcomes. Positive sibling relationships have been associated with fewer adjustment difficulties concurrently and over time (Kim, McHale, Crouter & Osgood, 2007; Pike, Coldwell & Dunn, 2005), while high levels of sibling conflict have been associated with depressed mood, anxiety, and delinquent behavior (Kim et al., 2007).

For children in highly stressful contexts such as having a sibling with a chronic illness, typical sibling socialization processes may be disrupted, and sibling relationship quality may suffer (Conger, Stocker & McGuire, 2009). To our knowledge, only two quantitative studies have examined sibling conflict among families of children with cancer. Labay and Walco (2004) found that perceptions of sibling conflict were similar between the ill-children and their healthy

siblings, and less conflict was reported as the age of the healthy sibling increased. In this study, sibling conflict did not predict adjustment. Among adolescents with cancer, sibling conflict levels did not differ from a healthy comparison sample (Marine & Miller, 1998). Both of these studies used a cross-sectional design in which conflict was measured once during active treatment at a broad range of times since diagnosis. As such, these findings do not elucidate how sibling conflict may vary over time, and, given the older average ages of the children with cancer in these samples, cannot be generalized to younger children. These studies also do not assess the influence of specific aspects of the cancer experience or mechanisms by which it may affect sibling relationships.

Finally, in addition to a lack of focus on dyadic family relationships, no studies to date have considered how family relationships influence one another in the context of cancer. From a family systems perspective, family relationships are closely intertwined and reciprocally affect one another over time (Fincham, Grych, & Osborne, 1994). For example, in families of healthy children, Engfer's *spillover hypothesis* (1988) has been widely applied to examine patterns of influence between marital and parent-child relationships (e.g., Gerard, Krishnakumar & Buehler, 2006; Katz & Gottman, 1996). According to Engfer (1988), patterns of interaction and emotional displays in one subsystem (e.g., the marital relationship) may propagate similar patterns in other subsystems (e.g., the parent-child relationship). Given widespread support for this hypothesis among families with healthy children (Cox, Paley & Harter, 2001; Erel & Burman, 1995), this framework may also be of utility in understanding similar cascades in families of children with cancer. Doing so may provide useful insights to appropriately time and target interventions to prevent negative downstream effects on family relationships and child wellbeing.

**Peer relationships.** An additional overlooked aspect of interpersonal relationships of youth with cancer has been relationships with peers, which may be especially important for adolescents with cancer. While peer relationships play a major role in the daily lives of young people, they are particularly salient and developmentally-relevant for adolescents (Brown & Larson, 2009; Smetana, Campione-Barr & Metzger, 2006). Among healthy populations, quality of peer relationships during adolescence has been shown to predict both concurrent and later psychosocial functioning more so than at younger ages (Burk & Laursen, 2005; Buhrmester, 1990). Peer acceptance has been associated with wellbeing, such that adolescents who are more accepted tend to have fewer emotional and behavioral problems and better self-esteem, both concurrently and later in development (Brown & Larson, 2009). Adolescents report that friends are often the source of their happiest experiences (French & Conrad, 2001), and those with closer friendships have been shown to have higher interpersonal competence, less hostility and internalizing symptoms, and higher self-esteem (Buhrmester, 1990). High quality peer relationships may also protect adolescents from social anxiety (La Greca & Harrison, 2005) and buffer negative effects of adversity (Gauze, Bukowski, Aquan-Assee, & Sippola, 1996).

Cancer treatment removes adolescents from their peer group and social environment at a time when peer interaction is an essential developmental context and peer relationships are a major contributor to wellbeing (Morgan et al., 2010). While it is understood many adolescents with cancer do not experience normative peer socialization due to isolation from their peer group (Treadgold & Kuperberg, 2010), little is known about their peer relationships during and after treatment or how they change across the cancer trajectory. While no studies to date have focused on relationships with non-ill peers (or peers who do not have cancer) specifically, a small body

of qualitative literature has provided some description of peer relationships among adolescents and AYAs with cancer through describing unmet needs or life situation in this population.

Adolescents with cancer perceive that they have lost friends due to cancer. In a mixed-method study of adolescents with cancer, patients described “learning who your real friends are” during treatment (Enskar et al., 1997). They felt that early in treatment they became closer with their best friends, who visited them frequently and provided helpful and support. However, when facing a lengthy treatment course, adolescents also described losing friends over time as friends “kept their distance”. Similarly, through a focus group with six adolescents with cancer, Palmer and colleagues (2007) found that nearly all patients described losing friends, often due to misconceptions about their illness. They felt that their friends perceived that they couldn’t “do the basics” or that they were stigmatized due to their illness. In an older study of 27 adolescents who had undergone an amputation due to cancer, experiences with friends were primarily negative (Tebbi et al., 1987). More than half the sample described perceiving that their friends felt sorry for them and nearly half described friends avoiding them or drifting away. Finally, in addition to friends avoiding them, adolescents with cancer may also lose friends due to their own withdrawal from social interaction. In a small study of adolescents within one-year of diagnosis, Larouche and Chin-Peuckert (2006) found that patients described avoiding friends and social situations themselves during treatment, primarily due to concerns about their physical appearance or not wanting their friends to see them while they are sick.

A small body of mixed-method literature has focused on the role of peer support during treatment and survivorship. Studies examining social support during treatment have found that adolescents rate friends as a primary source of support, second or equal to support from parents (Kyngas et al., 2001; Ritchie, 2001; Trask et al., 2003; Woodgate, 2006), and describe peer

support a primary coping strategy (Kyngas et al., 2001). In a study focusing on perceived social support among adolescents with cancer, Woodgate (2006) found that many adolescents talked about the unique value of a “best friend” who knew them prior to diagnosis, with 75% of the sample describing their best friend as their primary supportive relationships. Many felt their best friend provided support through “being there”, a theme that encompassed feeling their friends were there for them, keeping them from feeling lonely, and helping them stay positive. In a similar study describing emotional support among adolescents with cancer, Ritchie (2001) found that nearly half the sample rated friends as their primary source of support. Friends also supported patients by helping them feel normal, as interacting with friends made them feel connected to school and social activities. Finally, adolescents with cancer have described peers providing support through acting as “peer shield” from unwanted attention when they went out in public (Larouche & Chin-Peuckert, 2006).

While adolescents with cancer clearly perceive peer support as important, it is unclear whether peer support is perceived to be satisfactory or whether it is associated with wellbeing. Among adolescents on treatment, Marine and Miller (1998) found no differences in amount of perceived peer support between patients and healthy controls and no relation between perceived support and distress. In contrast, in a larger study of AYAs on treatment, Corey and colleagues (2008) found that more peer support was associated with less depressed mood and less anxiety, even after adjusting for age, gender, and time since diagnosis. Among survivors, evidence has also been mixed. While two studies to date have found peer support to be adequate or comparable to controls (Nichols, 1995; Haluska Hesse & Nagy, 2002), a review of social support among AYA survivors found that across seventeen studies the majority reported peer support to be less than satisfactory (Jones et al., 2011).

Taken together, this body of literature suggests that while peer support is critical for AYAs during treatment and survivorship, peer relationships often suffer due to cancer. However, many research gaps remain in this area that limit current understanding of why, how, and the extent to which peer relationships are affected by cancer. Ultimately, a better understanding of adolescents' peer relationships during cancer treatment is needed to develop interventions aimed at bolstering peer relationship quality and support during treatment, which may in turn reduce deficits in social functioning and mental health through survivorship. To date, no studies have specifically aimed to examine relationships between adolescents with cancer and non-ill peers during treatment. Thus, many unanswered questions remain regarding these relationships and their contribution to later adjustment.

#### **1.4 Current Studies**

The current series of studies aims to address knowledge gaps and inform intervention development by examining how interpersonal relationships are affected when a child or adolescent has cancer. The first two studies focus on family relationships of young children during the first year of treatment using a longitudinal approach. Studies of family adjustment to pediatric cancer have highlighted the importance of studying families during the first year of treatment, when both stress and distress are often highest and most variable due to the dynamic nature of cancer treatment (Houtzager et al., 2004; Pai et al., 2007; Sawyer et al., 2000). Study 1 is among the first studies to address the sibling relationship, examining how cancer-related stressors affect sibling conflict over time. Study 2 applies a family systems perspective to examine how quality of family relationships reciprocally affect one another over time, specifically examining spillover between marital adjustment and parent-child conflict. Study 3 extends beyond the family to examine peer relationships of adolescents newly diagnosed with

cancer. As virtually no studies have focused on peer relationship quality within this population, this study used a mixed-method approach including both qualitative interviews and self-report questionnaires. This study aims to describe both patient and peer perspectives of their friendships during the first year of treatment and examine relations between social functioning and adjustment.

## **CHAPTER 2 | Stress & Sibling Conflict During Pediatric Cancer Treatment (Study 1)**

Sibling relationships are an important aspect of development, provide long-term social support, and influence children's concurrent and later adjustment (Brody, 1998). Thus, it is important to understand how these relationships are affected when a child has cancer. One way in which cancer might influence the sibling relationship is via stress associated with diagnosis and treatment. Pediatric cancer is a highly stressful experience for all family members, including siblings (Long & Marsland, 2011; McCaffrey, 2006). Families often must reorganize roles, as one parent typically becomes the primary caregiver for the child with cancer while the other cares for siblings, the home, and provides for the family economically. Siblings may fear for their ill brother or sister, feel isolated from parents, or struggle with changes as the family environment shifts to accommodate treatment (Wilkins & Woodgate, 2005). Families also may experience financial stress or material hardship during this time (Bona et al., 2014), causing changes to the daily life of siblings.

These many stressors may impact interaction patterns between siblings. For example, long absences to receive treatment may result in decreased opportunity for communication or interaction between siblings (Breyer, Kunin, Kalish, & Patenaude, 1993), thus lessening intimacy or bonding opportunities. Moreover, when siblings do interact, the child with cancer may not be physically or psychologically capable of engaging in interaction or play with their sibling (Katz, Leary, Breiger & Friedman, 2011). Siblings may also experience differential treatment as parents focus on the child with cancer (Sargent et al., 1995), thus increasing feelings of rivalry or antagonism. Thus, the goal of the current study was to examine how stress associated with pediatric cancer influences sibling conflict through the first year of treatment. To do so, this

study assessed parent-perceived stressors and sibling conflict monthly through the first year of treatment to examine the relationship between stress and conflict over time.

Using a longitudinal framework, we conceptualize the relationship between stress and sibling conflict in two ways. First, we are interested in investigating how an individual family is affected by monthly changes in their usual stress levels. While pediatric cancer is a chronically stressful experience, the amount of stress at a given time likely changes based on factors such as progression through treatment regimens and time since diagnosis. As such, sibling conflict may also differ over time as a function of variation in stress, as conflict may be higher when a given family's stress is higher than their typical level. To address this question, we will examine how deviations in stress from a family's typical level are related to concurrent increases or decreases in sibling conflict levels (i.e., a within-families effect). We predict that as stress increases from a family's typical level, sibling conflict will also increase.

Second, we are interested in investigating how average amount of stress relates to sibling conflict over time. When a child has cancer, it is likely that all families may be experiencing more stress than prior to diagnosis, but there is likely to be variability between families in their average stress levels over the course of treatment. Thus, the pattern of conflict over time may differ depending on the average amount of stress a given family experiences. To address this question, we will examine how families differ from one another in their average stress levels over time and how that relates to their sibling conflict trajectory (i.e., a between-families effect). We also predict that higher average level of stress will be associated with higher sibling conflict.

Finally, we will explore the hypothesis there may be differential effects of stress on the sibling relationship based on the type of stress the family is experiencing. To do this, we will separately assess the influence of five sources of stress on conflict, including general life stress,

cancer treatment related stress, economic stress, assessment of life threat, and treatment intensity. For each stressor, we will examine both within-family and between-family effects. Due to the exploratory nature of this question, we do not offer any specific hypotheses regarding whether certain types of stress are more strongly associated with sibling relationship quality than others.

## 2.1 Method

### Participants

Families in the current study were part of a larger study examining pediatric cancer and family adjustment ( $N = 159$ ). Families were included in the present analyses ( $N = 103$ ) if they reported having at least one sibling within five years of age of the child with cancer. Children with cancer were ages 2-17 ( $M_{\text{age}} = 6.36$  years,  $SD_{\text{age}} = 3.51$ , 52% male) and families had on average 2.6 children ( $SD = .76$ ). While the majority of children with cancer were ages 2-10, twelve adolescents were included. The majority of children with cancer were identified as White/Caucasian (85.6%) by the primary caregiver, with the remaining identified as Black/African-American (5.2%), Asian (1.0%), or other (8.2%). 15.5% of participants identified as ethnically Hispanic. The majority of children with cancer were diagnosed with leukemia (35.9%), followed by lymphoma (10.7%) or a sarcoma (9.7%), a Wilm's tumor (11.7%), a neuroblastoma (3.9%), or another form of cancer (7.8%). The remaining 20.4% of the children with cancer were diagnosed with a CNS tumor. On average, families had less than one inpatient admission per month, with the average number of admissions declining over time. Number of admissions were highest during the first month ( $M = 1.94$ ,  $SD = 1.21$ ), and lowest during the 12<sup>th</sup> month ( $M = .09$ ,  $SD = .29$ ).

Among families who provided demographic information on healthy siblings ( $N = 128$ ), 55.3% of children with cancer had one sibling, 28.2% had two siblings, 9.7% had three siblings,

5.8% had four siblings, and 1.0% had six siblings. Siblings ranged in age from 10 months to 25 years of age ( $M_{\text{age}} = 8.34$ ,  $SD = 5.61$ ); 61.2% of children had one or more older siblings, 58.3% had one or more younger siblings, and 5.8% had one or more siblings of the same age (twin or step-sibling). Families were asked to identify the primary and secondary caregivers for the child with cancer, and the relationship status between the caregivers. For primary caregivers, 85.9% identified a mother, 12.1% a father, 1.0% a grandmother, and 1.0% a stepmother. Relationship status of caregiver dyads included 77.5% married, 14.7% non-romantically involved, and 7.8% romantically involved but not married. Primary caregivers were on average 35.7 years old ( $SD = 7.4$ ) and the majority were White/Caucasian (81.6%). The majority of primary caregivers had completed college (60.8%). Median annual family income was between \$60,000-\$69,000. While this sample is representative of the population of the two urban clinics from which they were drawn, relative to the broader population of families of children with cancer in the United States it likely over-represents high SES, White/Caucasian families with highly educated caregivers.

### **Procedure**

Participants were recruited as part of a larger study from two children's hospitals in urban areas of the Northwest and Southeast United States and were approached within two weeks of diagnosis. Families were eligible if they had a child 2-17 years old recently diagnosed with cancer and spoke English. Of 502 eligible families across both sites, 309 were approached, 176 enrolled, with 159 completing at least one study component. Common reasons eligible families were not approached were that they had been recruited to another study or did not consent to be approached because they felt too overwhelmed, or because physicians did not approve of approach (e.g., because the child was too ill) or were unable to approach within the study window. Of the families approached who did not enroll, common reasons for refusal were due to

either excessive time-required or no reason was given. All study procedures were approved by the Institutional Review Boards at all participating institutions. Consent was attained from the primary caregiver at the time of enrollment. Data were collected over a twelve-month period beginning with an initial home visit, followed by 12 monthly questionnaire packets distributed through the mail completed by primary caregivers. The initial (Month 1) packet was received 1.6 months post-diagnosis on average. After the initial questionnaire packet (82.3%), the highest proportion of primary caregivers were retained at Month 6 (67.5%), and the lowest at Month 2 (5%). See Table 1 for sample size at each month, and Supplemental Figure 1 for patterns of data obtained from all eligible families at each time point. Number of completed packets was not associated with any demographic variables, and missing data was accounted for in all analyses.

### **Measures**

**Sibling conflict.** Sibling conflict was measured via primary caregiver report using the conflict subscale of the Sibling Relationship Questionnaire (SRQ; Furman & Buhrmester, 1985). Nine items assessing frequency of sibling conflict in the past month were rated 1 (hardly at all) – 5 (extremely much), with higher scores indicating greater frequency of conflict. Frequency of contact between siblings was also measured using one item in which response options assessed approximate number of days siblings interacted in the past month. To minimize participant burden, in families with two or more siblings, primary caregivers were instructed to complete the questionnaire thinking about the ill child's relationship with siblings in general rather than his or her relationship to an individual sibling. In our sample Cronbach's alpha ranged from .91 - .99 with an average of .95 across time points.

**General life stress.** General life stress was assessed via primary caregiver report using an adapted version of the Negative Life Events Scale for Children (Sandler, Ramirez & Reynolds,

1986). This index was originally adapted by Lengua and Long (2002) for use with parent-report. Eighteen items from this 29-item adaptation were used in the current study based on negative events that were most relevant to families of children with cancer. Removed items included those that were obviously true for a cancer population (e.g., “your child suffered serious illness or injury”), as well as items that were assessed in other parts of the overall study (e.g., items related to inter-parental relationships). Eighteen items assessed a range of moderate to severe negative life events (e.g., “you or your partner lost a job”, “a relative or close family friend died”) in the past month. Items were rated for whether or not it occurred and if it did occur how upsetting it was for the child with cancer. This yielded two measures at each of the twelve time points: a summed frequency count score and difficulty for child score. Frequencies score had a possible range of 0-18, with higher scores reflecting greater frequency; difficulty for child scores ranged from 0-54, with higher scores representing more difficulty for the child with cancer. In prior studies, this measure is associated with measures of psychological adjustment and symptomatology (Lengua & Long, 2002; Sandler et al., 1986). As we are not concerned with shared item variance given that this index is intended to be composite of stressful events rather than a scale, internal consistency reliability information is not provided.

**Cancer-related stress.** Cancer-related stress was assessed via primary caregiver report using the Treatment-Related Events Questionnaire. This measure was developed for this study based on qualitative work examining stressors among children with cancer (McCaffrey, 2006). See Supplemental Figure 2 for full measure. This 24-item scale used a similar format to the Negative Life Events Scale for Children to assess caregiver-reported treatment stressors (e.g., long hospital stays) and procedures (e.g., lumbar punctures) in the past month. Each item was rated 1 (never) – 5 (very often) for how frequently it occurred, and 1 (not at all) – 5 (extremely)

for how difficult it was for the child. Two cancer-related stress scores were computed, one for frequency and one for difficulty, with higher scores reflecting greater frequency and difficulty. Cronbach's alpha ranged from .77-.94, with an average of .91 across time points for the frequency score, and .77-.94 with an average of .89 across time points for the difficulty score.

**Financial stress.** Financial stress was measured via primary caregiver report using the Economics in My Family Questionnaire (EIMF; Barrera, Caples, & Tein, 2001). This 10-item scale yields an overall financial strain score ranging from 1-39, with higher scores reflecting more strain. Cronbach's alpha ranged from .83-.91, with an average of .88 across time points.

**Life threat and treatment intensity.** Perceptions of the child's life threat and treatment intensity were assessed via primary caregiver using the Assessment of Life Threat and Treatment Intensity Questionnaire (ALTTIQ; Stuber et al., 1997). The ALTTIQ has been used widely in studies of pediatric cancer. This 4-item scale included two questions assessing perceived life threat and two questions assessing perceived treatment intensity. Possible scores ranged from 2-10 for each subscale, with higher scores reflecting more life threat or treatment intensity. For Perceived Life Threat, Spearman-Brown reliability coefficients ranged from .66-.84, with an average of .77 across time points. For Perceived Treatment Intensity, coefficients ranged from .52-.91, with an average of .78 across time points.

### **Data Analytic Strategy**

Given the wide age range of the patients in the sample (2-17 years), all analyses were conducted with and without the inclusion of the families of 12 adolescents with cancer in the sample to ensure that adolescent data did not change patterns observed amongst the younger children. There was no substantial difference in estimates or pattern of results across any stress variable, and therefore results with the full sample are reported.

To examine change in sibling conflict over time, we estimated growth curve models with a Multilevel Modeling (MLM) approach using the Maximum Likelihood estimator (ML) in SPSS 18.0. Multilevel models are appropriate for examining non-independent data (e.g., repeated measures), and can be used to model both within-family trajectories of conflict over time (Level-1 effects) as well as between-family differences in trajectories (Level-2 effects). Although some families did not have data at each time point (see Table 1), MLM handles missing data well by allowing trajectories to be estimated from different numbers of observations per family. Thus, families who were missing data at any time points were still included in the models as long as they had any follow up data. Additionally, there was no correlation between number of missing data points and initial levels of sibling conflict. Power analyses suggested that the current study had sufficient power (.80) to detect small regression effects ( $b = .10 - .15$ ) and power approaching 1.0 to detect moderate ( $b = .30$ ) to large effects within a multilevel framework. While many families did not have complete data, average cluster size (i.e., number of observations per family) are not important for power of these tests (Snijders, 2005).

We first estimated an unconditional linear growth model. This model estimated an intercept parameter, representing the level of sibling conflict at the 12-month follow-up, as well as a linear time parameter, which represents the rate of change over time in sibling conflict and the direction of such change. Time was coded from -11, Baseline, to 0, with each code representing the two-week window in which data was received for each month of the 12-month follow-up. This approximately corresponded to time since diagnosis. We then tested random effects to examine whether there were between-family differences in the trajectory of conflict, and to indicate whether sufficient variance existed between families to test potential predictors

(i.e., stress variables) that may have accounted for these within-family differences in conflict over time. Improvement in model fit was measured via  $-2LL$  differences.

To test the effects of predictors (i.e. stress) on sibling conflict, we followed the recommendations of Enders & Tofighi (2007) to center Level 1 and Level 2 predictors. We used centering within cluster at Level 1 to assess within-family effects and grand mean centering at Level 2 to assess between-family effects. To obtain within-family effects, each observation was subtracted from a given family's mean level across all observations over time. This score reflects a family's deviation from their own mean level of stress at a given time point, and its effect on the outcome explains why a family might differ from their expected trajectory of conflict at a given time point. At Level 2, or the between-families level, grand-mean centering was used by deviating each family's mean level of the predictor from the average of all families' means. This score reflects each family's average level of stress over time, and its effects reflect how between-family differences in average stress levels across time influence level of sibling conflict at the intercept, in this case the final time point. We also tested two interactions: (1) an interaction between the between-families score and time, reflecting how differences in average stress levels were related to change over time in sibling conflict, and (2) a cross-level interaction, or the interaction between the within- and between-family effects. This score tested whether the within-family effect differed depending on a family's average level of stress over time.

## 2.2 Results

For fit statistics, see Table 2. The initial growth model indicated that on average sibling conflict changed in a linear fashion over time across the sample, and there were between-family differences in both the rate of change and ending point of sibling conflict. In the final model, there was a linear effect of time ( $b = .02, p = .04$ ). The average final level of sibling conflict

between families was 2.39 (possible range = 1-5). Thus, while sibling conflict increased slightly across time levels were not elevated compared to the population, assuming that this construct is normally distributed. However, random effects for both the slope and intercept parameters indicated that variability existed between families in both the ending point and rate of change. Thus, assessing whether families' stress levels could explain some of this variability in trajectories of conflict was justified.

For each stress variable, we tested the effects of both within- and between-family predictors, as well as two interaction terms. We also controlled for frequency of contact with sibling(s) in the past month for all models. In all models, more sibling contact was significantly associated with more conflict. For results of all predictor models including covariates, see Table 2. Non-significant interactions were removed from the final models for parsimony.

**General life stress.** Higher average frequency of general life stress across the first year of treatment relative to other families (i.e., a between-families effect) was associated with higher levels of sibling conflict at the end of the first year of treatment ( $b = .21$ ,  $SE = .08$ ,  $p = .02$ ). A similar pattern was found for the effects of difficulty of general life stress and sibling conflict. That is, for families for whom stressful events were, on average, more difficult for the child with cancer across all time points relative to other families, sibling conflict was higher at the final time point ( $b = .10$ ,  $SE = .03$ ,  $p = .001$ ). However, monthly fluctuations in general life stress were unrelated to concurrent sibling conflict levels (i.e., a within-families effect), and average stress levels did not affect the rate of change of sibling conflict over time.

**Cancer-related stress.** Families who on average had a higher frequency ( $b = .01$ ,  $SE = .01$ ,  $p = .02$ ) and difficulty ( $b = .02$ ,  $SE = .01$ ,  $p = .02$ ) of cancer-related stressors relative to other families across time had higher sibling conflict at the end of the first year of treatment. However,

monthly fluctuations in cancer-related stress were unrelated to concurrent levels sibling conflict, and average stress levels did not affect the rate of change.

**Financial stress.** Families who had higher average financial stress relative to other families across time had higher sibling conflict at the end of the first year of treatment ( $b = .03$ ,  $SE = .01$ ,  $p = .02$ ). However, monthly fluctuations in financial stress were unrelated to sibling conflict, and average financial stress levels did not affect the rate of change.

**Life threat and treatment intensity.** There were no effects for within- or between-family predictors.

### 2.3 Discussion

The current study is the first to empirically examine the relationship between caregiver perceptions of stress and sibling conflict over time in families where a child has been recently diagnosed with cancer. We assessed the impact of stress both at the within- and between-families levels to understand how stress concurrently affects sibling conflict within an individual family, as well as how average stress levels affect the trajectory of conflict over time.

Results showed a between-families effect for general life stressors, cancer-related stressors, and economic stress, such that higher average levels of stress compared to other families predicted higher levels of caregiver-perceived sibling conflict. While no quantitative studies to date have directly assessed the relationship between stress and sibling conflict in families where a child has cancer, this finding is in accordance with some literature reporting higher sibling conflict in other stressful family circumstances, such as when one sibling is developmentally delayed (Gamble & McHale, 1989). However, research on sibling conflict in other disease or disability groups is scant, and comparisons should be considered in light of

relevant differences between illness characteristics or historical context that may affect sibling interactions.

From a family systems perspective, stressful experiences such as those associated with pediatric illness may directly or indirectly influence all family members and their relationships with one another (Kazak, Rourke & Crump, 2003). In the case of prolonged stress, psychological resources of family members may become exhausted and stress may then spillover into family relationships. For example, stressed parents may be less available or able to scaffold sibling interactions, leading to more conflict between siblings over time as smaller conflicts go unresolved. Parents dealing with stress may also be more likely to engage in differential parenting practices between siblings (Crouter, McHale & Tucker, 1999). Indeed, studies indicate that siblings commonly perceive differential treatment from parents when their brother or sister has cancer (Wilkins & Woodgate, 2005), which may contribute to conflict. Finally, children in families who experience continuous stress may also be more reactive to minor stressors resulting in greater conflict with their siblings (Nixon & Cummings, 1999).

Higher average levels of stress compared to other families predicted higher conflict across three of the five sources of stress, suggesting that during a highly stressful time such as when a child has cancer, the specific type of stressor may be less relevant than overall amount of stress. After diagnosis and during treatment, the family may already be so taxed that they are less able to cope with the stressor adaptively regardless of its source. However, while each of these stressors may affect sibling conflict, the mechanism may differ depending on the stressor. For example, some stressors, such as loss of a job or financial concerns, may affect parents more directly than children and thus affect sibling relationships via a decline in parenting quality. Other stressors, such as treatment procedures, may directly affect the ill child and their healthy

siblings' abilities to regulate their own emotions and behavior. Future research may elucidate these mechanisms by examining parenting behavior and children's emotion regulation as buffers between stress and sibling conflict. Importantly, a body of qualitative research has identified increases in family closeness and cohesion after a child's cancer diagnosis (Brody & Simmons, 2007; Long & Marsland, 2011; Woodgate 2006). Thus, while stress may influence sibling conflict, it may also bring the family closer and strengthen other aspects of the sibling relationship, such as warmth or closeness. Future research assessing both positive and negative qualities of sibling relationships is thus needed to comprehensively understand the effect of cancer on sibling relationships.

It was notable that no stress predictors affected sibling conflict at the within-family level. Given that there was sufficient variance at this level to examine predictors, the lack of within-family effects suggests that stress does not account for these within-family differences. One possible explanation is that monthly fluctuations in stress do not affect concurrent sibling conflict because it takes longer than one month for the effects of a short-term increase in stress to spill over into family relationships. A second possibility is that temporary fluctuations in stress do not affect sibling conflict as long as average levels of stress remain low. For example, in the context of cancer treatment, if a family has one month in which the child has a few more stressful treatment procedures than usual this may not affect the sibling relationship, provided most other months do not involve many stressful procedures. In contrast, if the child has many stressful procedures every month, the continued stress may then eventually spillover into the sibling relationship.

Taken together, results suggested that families reporting higher stress compared to other families also reported higher levels of sibling conflict. Thus, families dealing with more stress

may experience elevated levels of sibling conflict that may then negatively influence adjustment of both the child with cancer and their siblings (Kim et al., 2007; Stocker, Burwell & Briggs, 2002). For these families especially, maintaining positive sibling relationships and minimizing conflict during pediatric cancer treatment may be particularly important. High quality sibling relationships may provide a unique source of long-term social support for survivors who are at risk for encountering continued challenges into adolescence and adulthood. For example, many survivors of childhood cancer will encounter late effects, or long-term sequelae of treatment that may range from mild to life-threatening (Nathan et al., 2007; Oeffinger et al., 2000). Thus, a sibling may be a valuable source of emotional and instrumental support in the case of late effects during adolescence or adulthood. Moreover, close sibling relationships may also be protective for the siblings of children with cancer themselves, given that a subset of siblings encounter poor adjustment outcomes such as post-traumatic stress or emotional distress (Alderfer et al., 2010; Labay & Walco, 2004). Taken together, these findings highlight the importance of maintaining high quality relationships for children with cancer and their healthy siblings alike.

This study has a number of strengths. First, few studies to date have examined sibling conflict among children with cancer. Identifying both the trajectory of conflict and how it is affected by stress is the first step to understanding how the sibling relationship may influence adjustment for children with cancer and their siblings. Second, the longitudinal, month-to-month design is a novel approach in pediatric psycho-oncology research and allowed us to not only examine change in sibling conflict over time, but also to examine the effect of stress both relative to individual families' typical levels and on average between all families. Third, this study also utilizes a relatively large sample for this population, thereby increasing statistical power.

The current study had a number of limitations that are important to note, primarily related to measurement of sibling conflict. First, future research may benefit from examining composition of sibling dyads in more detail. The current study assessed conflict between the child with cancer and their siblings in general rather than individual dyads, so estimates of conflict likely reflected average amounts of sibling in which the child with cancer was involved. More variability may have been observed if parents had reported on individual dyads or the most conflictual dyad (e.g., the child with cancer and brother or sister with whom they had the most conflict). While all families had at least one sibling with five years of age of the child with cancer, assessments of conflict may have potentially included siblings not living in the home or those substantially older or younger than the child with cancer. While frequency of contact between siblings was controlled for analytically to account for these differences, different patterns may still exist between siblings close in age or living in the home compared to those more removed from the child with cancer. The current study also did not obtain data regarding sibling gender. Thus, future work examining specificity such as gender composition of dyads, birth order, or age difference may be useful to inform whether stress differentially affects conflict based on these factors. For example, Labay and Walco (2004) found that less conflict was reported as the age of the healthy sibling increased. It is possible that older siblings are better able to cope during stressful times, and thus stress may be less likely to spill over into the sibling relationship.

Future research may also contribute to our knowledge of sibling conflict by using observational measures, or self-reports from the child with cancer and their siblings rather than solely caregiver report to better capture the children's experiences and improve validity. The Sibling Relationship Questionnaire used to assess sibling conflict in this study was originally

developed for child self-report rather than caregiver report. Though the SRQ has been used with parent report in other studies (e.g., Fullerton et al., 2017), comparisons to other studies using child self-report may be limited. Importantly, because the primary caregiver completed both the conflict and stress measures in the current study, single reporter bias may have influenced the findings such that highly stressed caregivers may have been more likely to perceive or notice conflict in the sibling relationship, or conversely stressed caregivers may not notice sibling conflict and thus underreport. It is ultimately important to note that these findings only speak to caregivers' perceptions of conflict and don't necessarily reflect objective levels, as factors such as caregiver psychological distress or trait negative affect may influence perceptions of both stressors and sibling conflict.

Due to their unique nature, lifelong importance, and links to later adjustment, sibling relationships are important to understand and protect for all individuals but may be particularly valuable for pediatric cancer survivors. Studies that focus on describing and explaining changes in the family during pediatric cancer may ultimately help identify ways to minimize additional challenges and promote positive outcomes for children with cancer and their families.

### CHAPTER 3 | Patterns of Spillover in Family Relationships (Study 2)

While many families exhibit resilient outcomes in the face of a child's cancer diagnosis and treatment, a number of studies have suggested that a subset of families experience marital distress and increased parent-child conflict after a child's diagnosis (Van Schoors et al., 2015). However, no studies to date have examined how these family subsystems influence one another over time in the context of cancer. Applying Engfer's *spillover hypothesis* (1988), this study aims to understand how spillover between the marital and parent-child relationship operates in the context of pediatric cancer in order to inform intervention and prevention efforts.

Understanding how spillover between the marital and parent-child relationship operates in the context of pediatric cancer may inform intervention and prevention efforts in a number of ways. First, if spillover is occurring over time, early intervention may be useful to prevent such cascades from unfolding. Second, understanding the direction of spillover would allow for interventions to be appropriately targeted, thereby minimizing burden on families. For example, if the quality of the marital relationship affects the parent-child relationship rather than the reverse, targeting the marital relationship early could prevent this spillover without need to involve the child. During treatment, families experience high stress and significant demands on their time (McCaffrey, 2006). Likewise, providers often have limited resources to implement supportive services for families. Identifying whether and how these relationships influence one another over time could inform the development of appropriately targeted interventions that would be maximally effective while minimizing burden on families and providers.

While spillover between family relationships has not been addressed among families in which a child has cancer or another chronic illness, research on healthy families has identified three potential patterns or directions of spillover between marital and parent-child relationships.

First, much work to date has found evidence of spillover from the marriage to the parent-child relationship, suggesting that discord or dissatisfaction in the marriage may lead to troubled parent-child relationships (Erel & Burman, 1995; Gerard, Krishnakumar & Buehler, 2006; Cox et al., 2001). Fewer studies have examined the second direction of influence, namely whether conflict parent-child relationship may spill over into the marital relationship. Some have found evidence for this direction (Jenkins et al., 2005; VanderValk et al., 2007) while others have not (Almeida, Wethington & Chandler, 1999; Erel & Burman, 1995). Only two studies have considered and found support for a third direction of influence - reciprocal and/or transactional pathways. In other words, that spillover may occur in both directions simultaneously, or may occur from one subsystem to another and in turn back to the subsystem in which the conflict originated (Margolin, Christensen & John, 1996; Sears et al., 2016).

Using three time points through the first year of pediatric cancer treatment, the current study aimed to address two research questions: (1) Is spillover occurring between the marital and parent-child relationships during the first-year post-diagnosis, and if so, is this spillover unidirectional or bidirectional? (2) Do any specific patterns exist regarding how this cascade unfolds over time? We predict that there will be spillover between the marital and parent-child dyads and that it will be bidirectional in nature, meaning marital and parent-child relationships will influence one another over time.

### **3.1 Method**

#### **Participants**

Families were part of a larger study examining pediatric cancer and family adjustment ( $N = 159$ ). Families in the current study ( $N = 117$ ) were those with a child 2-10 ( $M = 5.42$  years,  $SD = 2.59$ ) who was recently diagnosed with cancer, and primary and secondary caregivers who

were married (90.6%) or romantically involved (9.4%). Most children with cancer were identified as White/Caucasian (87.4%) by the primary caregiver, with the remaining identified as Black/African-American (2.7%), Asian (1.8%), American Indian (.9%), or other (7.2%). Additionally, 18.0% of participants identified as ethnically Hispanic. Children were diagnosed with leukemia (40.2%), lymphoma (11.1%), sarcoma (9.4%), Wilm's tumor (7.7%), neuroblastoma (3.4%), or another form of cancer (6.8%). The remaining 21.4% of the children were diagnosed with a CNS tumor. Families were asked to self-identify the primary caregiver based on who spent the most time with the child with cancer. Most families identified the mother (86.3%). Primary caregivers were on average 35.04 years old ( $SD = 7.32$ ), White/Caucasian (91.7%), and had completed college (58.0%). For married caregivers, the average length of marriage was 9.32 years ( $SD = 5.55$ ). Median annual family income was between \$70,000-\$79,000.

## **Procedure**

Participating families were recruited through two hospitals in urban areas of the northwestern and southeastern United States and approached within two weeks of diagnosis. Eligible participants were identified through a new diagnosis registry within each hospital and approached either by a provider during a clinic appointment for outpatient families or by a nurse for inpatient families. To be considered eligible, families needed to be newly diagnosed with cancer, be English-speaking, and have no history of developmental delay. Across both sites, of the 502 eligible families, 209 were approached, 176 enrolled, and 159 completed at least one study component. A greater number of families were eligible, approached and enrolled at the northwestern site, though rate of decline was also higher (44% vs. 22%). Primary reasons that eligible families were not approached included: a) physician did not consent to approach because

child was too ill; b) families were recruited by a competing study; and c) at the northwestern site, there was difficulty completing an IRB-required two-step approach process within the study window. Of the families approached who did not enroll, common reasons for refusal were excessive time required or no reason was given (e.g., family did not respond to calls or letters from study team). Consent was attained from the self-identified primary caregiver and assent from the child with cancer. No children died while on study, and all families remained eligible for the duration of the study.

Data were collected over a twelve-month period via questionnaire packets completed by primary caregivers and returned through the mail. The initial (Time 1) packet was received 1.5 months post-diagnosis on average ( $SD = 0.79$ ) and was intended to assess family relationships within the past month (e.g., the first month after diagnosis). The Time 2 packet was sent 6-months after receipt of the Time 1 questionnaires. Caregivers had a two-week window to return the packet after this date. If it was not received within that window, data was considered missing for that month. The same procedure was used for Time 3 (e.g., packet was sent 12-months after receipt of Time 1). Completion of each time point was not necessary to remain eligible for the next time point. While all families remained eligible through the duration of the study, some families did not complete data at each time point. Specifically, 97.5% of families completed questionnaires at Time 1, 80% at Time 2, and 58.4% at Time 3. Missing data was accounted for in all analyses (see data analytic strategy). For the current study, these time points were selected to represent relevant phases of the first year of treatment to capture the dynamic experience of families over time. Specifically, the first month after diagnosis is often a highly stressful time for families during which parents may be exhibiting high levels of distress and conflict may be more likely to arise (Pai et al., 2007); at six months post-diagnosis, life may be less chaotic as the

family has adjusted to a new lifestyle accommodating treatment; finally, the 12<sup>th</sup> month represents the end of the first year of treatment, when some families may be transitioning to survivorship. For additional information regarding study procedures, see [citation removed]. Study procedures received IRB approval from all participating institutions.

## Measures

**Demographic and Medical Information.** Demographic information was collected from families via primary caregiver report questionnaires included in the initial questionnaire packet. Questionnaires assessed child and family information, including age and ethnicity of child with cancer and caregivers, caregivers' relationships to the child with cancer, caregiver marital status, length of marriage, family income, and number and age of siblings. Diagnosis and treatment intensity information were extracted from medical records by research assistants. Treatment intensity was coded using the Intensity of Treatment Rating (ITR-3, Kazak et al., 2012). This measure provides a treatment intensity score of 1 (least intensive) – 4 (most intensive) based on diagnosis, stage/level of disease, and number or type of treatment modalities.

**Marital adjustment.** Marital adjustment was assessed through primary caregiver report using the Dyadic Adjustment Scale (DAS; Spanier, 1976). The DAS is a well-validated 35-item self-report questionnaire used to assess marital adjustment. This measure yields an overall dyadic adjustment score computed as the sum of all items, with higher scores indicating better adjustment. Wood, Crane, and Law (2005) established ranges for mildly distressed (96-107), moderately distressed (80-95.9), and severely distressed (<80) couples. Couples scoring greater than 107 are considered to be in the happily married range. This measure has been shown to reliably predict marital distress among parents of chronically-ill children (Walker, Manion,

Cloutier & Johnson, 1992). Cronbach's alpha was high throughout the study period (.96 at Time 1, .96 at Time 2, and .97 at Time 3).

**Parent-child conflict.** The conflict subscale of the Parenting Questionnaire (Fauchier & Margolin, 2004) was used to assess parent-child conflict between the primary caregiver and the child with cancer via primary caregiver report. Six items assessing parent-child conflict in the past month (e.g., "I easily lose my temper with my child", "My child and I disagree and quarrel") were rated on a 5-point scale and summed to form a total score, with higher scores indicating higher levels of conflict. Concurrent validity for this scale has been demonstrated by Fauchier and Margolin (2004) through comparison to the Parent-Child Conflict Tactics Scale (PCCTS), which has been validated for use with children ranging from infancy through adolescence (Straus et al., 2007). In our sample, Cronbach's alpha was acceptable across time points (.82 at Time 1, .78 at Time 2, and .81 at Time 3).

### **Data Analytic Strategy**

**Cross-lagged models.** To test associations between marital and parent-child relationships, manifest variable cross-lagged models were used with each construct measured at three time points (see Figure 1 for full theoretical models). Cross-lagged models were selected due to their ability to test interrelations between constructs over time, and compare multiple directions of influence between dyads over time. Although cross-lagged models have faced some criticism in that they are not an appropriate method for assessing change within a construct over time (e.g., Rogosa, 1980), they are a useful tool for examining questions concerned with patterns of influence between constructs (Selig & Little, 2012). As such, they are appropriate for the current study. Models included the following paths: cross-lagged structural paths, whose regression coefficients reflect the extent to which one construct predicts another (i.e.,  $X_1$

predicting  $Y_2$ ); autoregressive paths, which reflect stability in a single construct over time (i.e.,  $X_1$  predicting  $X_2$ ); and estimates of residual covariance between exogenous constructs, which assesses whether changes in one variable not accounted for by the model are associated with concurrent changes in another. In other words, this assumes that two variables measured simultaneously share at least one unmeasured cause as a function of time (Kline, 2016).

Autoregressive and cross-lagged paths are estimated controlling for the other, in other words testing whether one construct predicts *change* in another (i.e.,  $X_1$  predicting  $Y_2$ , controlling for  $Y_1$ ).

**Missing data.** To account for missing data, Full Information Maximum Likelihood (FIML) in R was used to estimate model parameters, supplemented with auxiliary correlates to improve estimation with missing data (Graham, 2003). Auxiliary correlates are variables included in the model that may account for missingness, though are not considered part of the substantive model. Correlates were selected using a data-driven approach, as follows: missingness across the study period was correlated with family demographic variables (e.g., child gender, number of children in family), treatment variables (e.g., treatment intensity, frequency of treatment events), and T1 variables representing initial levels of stress and family functioning after diagnosis (e.g., economic stress, parenting strain, sibling conflict). Any variable that was correlated with missingness at  $\pm 0.1$  or greater was selected as an auxiliary correlate (van Buuren et al., 1999). This resulted in four auxiliary correlates: number of children in the family, economic strain, frequency of parenting stress related to medical care, and sibling competitiveness. Using the spider method, these variables were (1) correlated with all exogenous variables (T1 marital adjustment and parent-child conflict), (2) correlated with residuals of all

outcomes (T2 and T3 for both constructs), and (3) correlated with residuals of all other auxiliary correlates (Graham, 2003).

**Testing the research questions.** To test the first research question, four nested model comparisons were conducted to assess direction of spillover between family dyads – specifically, to compare models of unidirectional vs. bidirectional influence (see Figure 1 for a depiction of each model). First, a baseline model of independence was established that included only autoregressive paths (no cross-lagged paths; Model A). This model suggests that each family dyad has no relation with the other over time and was used as a basis for comparison for subsequent models positing different patterns of relations between dyads. Cross-lagged paths were then added to compare three models to the baseline model: 1) a model representing unidirectional spillover from marital adjustment to parent-child conflict over time (Model B); 2) a model representing unidirectional spillover from parent-child conflict to marital adjustment over time (Model C); and 3) a model representing spillover in both directions, in which all cross-lagged paths were included (Model D). Model D was also compared to both Models B and C to determine whether a model representing bidirectional influence fit better than either model fit representing unidirectional influence. Model fit comparisons were done via chi-square difference tests, comparisons of the Root Mean Square Error Approximation (RMSEA), Comparative Fit Index (CFI), and Aikake Information Criteria (AIC). To address the second research question regarding how these relations specifically unfold over time, path coefficients were then interpreted from the best fitting model (Model E). To assess change in influence between constructs over time, path coefficients were not constrained.

## 3.2 Results

### Preliminary Analyses

Means, standard deviations, and correlations for study variables are displayed in Table 3. All correlations were in the expected directions. Results from independent samples *t*-tests or ANOVAS revealed no differences between any study variables based on recruitment site or demographic variables of diagnosis or child gender. Across all time points, mean marital adjustment scores were within the normal range (scored  $\geq 107$ ), though 16.2% of couples scored in the distressed range at Time 1, 15.4% at Time 2, and 8.5% at Time 3. However, few couples (<2%) were considered highly distressed (scored < 80) at any time point. Parent-child conflict ranged from 8.54-9.06, which corresponds with a low to average level on a scale ranging from 0 to 30. Because of substantial attrition, families with any missing data were compared to those with no missing data. Results suggested no differences between groups on gender, age of child, diagnosis, or initial parent-child conflict scores. Because marital adjustment at Time 1 was associated with number of missing data points ( $r = -.26, p = .01$ ), initial marital adjustment was included as a predictor in all models.

### Cross-Lagged Panel Models

**Unidirectional versus bidirectional patterns of spillover.** Nested model comparisons were used to test the hypothesis that a bidirectional rather than unidirectional relationship exists between marital adjustment and parent-child conflict during the first year of treatment. Results of each model and model fit comparisons are presented in Table 4, and a graphical depiction of each model is presented in Figure 1. As predicted, based on comparisons of fit indices, the bidirectional model in which all autoregressive and reciprocal paths in *both* directions were included (Figure 1: Model D) had better fit compared to the baseline model (Figure 1: Model A),

and the parent-child conflict to marital unidirectional model (Figure 1: Model C). Based on the chi-square difference test, the bidirectional model did not have significantly better fit compared to the marital adjustment to parent-child conflict unidirectional model (Figure 1: Model B). In addition, while the RMSEA value was slightly improved in the bidirectional model, comparing CFI and AIC fit indices also suggested no appreciable difference between models. Thus, it was concluded that the bidirectional model provided no appreciable improvement in fit and the more parsimonious marital to parent-child unidirectional model was retained. In summary, model fit comparisons indicated partial support for our first hypothesis such that spillover does occur between the marital and parent-child relationships during the first year of treatment (as indicated by comparisons to the baseline model), though it is best characterized as unidirectional (from the marital to the parent-child relationship) rather than bidirectional.

**Temporal patterns of spillover.** Path coefficients from the retained marital to parent-child unidirectional model were then interpreted to determine specific temporal patterns of spillover. This model showed good fit to the data, ( $\chi^2(9) = 12.18, p = .20$ ; CFI = .99; RMSEA = .05; see Figure 2). All 1<sup>st</sup>-order autoregressive paths were strong, as expected, meaning that previous levels of a construct predicted itself at later time points. Cross-lagged path estimates indicated that lower marital adjustment at T1 predicted higher parent-child conflict at T2 ( $\beta = -.21, SE = .01, p = .01$ ). No other cross-lagged paths were significant. Thus, the second hypothesis that marital adjustment drives patterns of spillover was supported such that poorer marital adjustment soon after diagnosis predicts an increase in parent-child conflict 6 months later.

### 3.3 Discussion

While some existing evidence suggests that some families experience conflict or strain in family relationships after a child's cancer diagnosis, particularly within the marital relationship

(Burns et al. 2016; Dahlquist et al, 1993; Katz et al., 2018), no studies to date have temporally examined how change in the marital relationships affects other family relationships in the context of cancer. The current study applied a spillover framework to the study of interrelations between family subsystems in families of children with cancer to test whether and how the marital and parent-child relationships influence one another during treatment and the direction and timing of such effects in order to inform intervention development.

Most couples in the current study scored in the happily married range ( $> 107$ ) at each time point, and parent-child conflict was low on average across time points given the range of the scale. Results suggested that spillover is occurring, and it is driven by the marital relationship, as the model of unidirectional influence from the marital to the parent-child relationship best explained the data. This is aligned with most extant literature among families of non-ill children (for a review, see Erel & Burman, 1995), suggesting that quality of the marital relationships may influence conflict between parents and children both in typical contexts and in unique contexts such as pediatric cancer.

In terms of temporal patterns of spillover, results suggest that marital adjustment soon after diagnosis may spillover into the parent-child relationship in the first 6 months post-diagnosis. Specifically, lower marital adjustment during the first month post-diagnosis may be associated with an increase in parent-child conflict at 6 months. Interestingly, this pattern was not repeated between marital adjustment at 6 months and parent-child conflict at 12 months in the current study, suggesting that problems in the marriage soon after diagnosis may be uniquely indicative of later issues in family functioning. This highlights the importance of early identification of at-risk families and considering appropriate timing of intervention.

The effects of stress on the family may be one mechanism to explain spillover from the marital to the parent-child relationship in families of children with cancer. During treatment, families face numerous and prolonged stressors (McCaffrey, 2006), and coping resources of both parents and children are taxed. This may be especially pronounced around the time of diagnosis (Pai et al., 2007). Thus, for parents, marital quality may suffer in the face of stress (Sheeran, Marvin & Pianta, 1997), and this loss of a supportive partner may further exacerbate the effects of stress and make emotion regulation or coping more difficult (Gottman & Katz, 1989). Stressed parents may also be more likely to use ineffective parenting strategies, potentially leading to greater conflict with children (Webster-Stratton, 1990).

This study has strengths and limitations that may inform future work. First, as observed rates of parent-child conflict were low, parents may be reluctant to report on conflict with their child with cancer which may have resulted in an underestimation of parent-child conflict. The measure used to assess parent-child conflict has also not been validated for use with pediatric samples. Second, some limitations related to the quantitative methods used in the current study should be considered. Use of Full Information Maximum Likelihood (FIML) as an estimation procedure assumes that any missing data is MAR (Missing at Random). While efforts were made in all models to account for missing data (e.g., inclusion of auxiliary correlate variables), data may have been MNAR (missing not at random) as suggested by the negative correlation between marital adjustment and missing data. If so, these may have resulted in biased estimates. Cross-lagged models also do not account for intra-individual change. As such, findings from the current study should not be used for inferences related to trajectories of change in these constructs over time (e.g., increases, decreases or stability in marital adjustment). Strengths of this study include its prospective design and use of statistical methodology allowing for assessment of bidirectional

effects rather than solely unidirectional processes. Finally, to our knowledge this is the first study to examine spillover between the marital and parent-child dyads in the context of pediatric cancer.

Given the well-established negative effects of family conflict on children's adjustment, identifying appropriate, efficient, and effective ways to minimize conflict and preserve quality of family relationships during pediatric cancer treatment is needed. To do so, it is first necessary to understand when and with whom to intervene to aid prevention efforts and minimize burden on families. Based on results from the current study, the marital relationship may be the optimal point of intervention in early months post-diagnosis to prevent later spillover. In the context of cancer, the maintaining supportive and protective family relationships may serve to both support family members coping with the child's diagnosis and ultimately protect the children from the deleterious effects of family conflict.

## **CHAPTER 4 | Peer Relationships Among Adolescents with Cancer (Study 3)**

Peer relationships play a central role adolescent development and are a major source of social support for adolescents with cancer. The current study aims to address gaps in current understanding of peer relationships and support among adolescents receiving treatment for cancer by describing relationships between adolescents with cancer and their non-ill peers during treatment and examining relations between peer support, social functioning and psychosocial wellbeing. This study also aims to better understand peer relationships during cancer treatment from peer perspectives, as to date little is known about their experience.

The current study aims to address four unanswered questions. First, a general description of peer relationships and peer interaction during treatment is needed, including relationship qualities, changes in relationships due to cancer, and factors that are perceived to promote or inhibit peer relationships during treatment. Second, while prior studies have clearly demonstrated the importance of peer support, a more specific understanding of peer support during treatment is needed to identify targetable behaviors or relationship qualities. Little is known about how adolescent patients subjectively define peer support or what specific behaviors are perceived as supportive during treatment. Third, no studies to date examining social functioning of adolescents with cancer have obtained peer reports of relationship quality. To comprehensively understand peer relationships during cancer treatment, perspectives of both adolescent patients and their peers are needed. As peers may encounter unique challenges or stressors during the treatment process that impact relationship quality or their ability to provide support to the patient, their perspectives may yield critical insights about why some friendships deteriorate during treatment and others are strengthened. In particular, perspectives of peers who have remained supportive may highlight factors that help them weather the challenges of having a

friend with cancer. Finally, few studies have examined associations between peer-specific social functioning and psychological adjustment, which is needed to identify targetable outcomes for interventions.

To address these deficits, the current study uses a mixed-method approach to describe relationships between adolescents with cancer and non-ill peers utilizing both patient and peer reports. This study will address three aims using interview and questionnaire data. Aims 1 and 2 will be examined using a qualitative approach and Aim 3 will be examined using a quantitative approach. Given the dearth of research in this area and the descriptive and exploratory nature of this study, no specific hypotheses are offered.

**Aim 1.** To describe patient perceptions of peer relationships during treatment, including how their relationships have changed since diagnosis, factors that promote or inhibit their relationships, and their experiences with support from peers.

**Aim 2.** To describe the experience of having a friend with cancer from peers' perspectives, including how their relationship has changed, factors that promote or inhibit their relationship, and their experience providing support and coping with their friends' cancer.

**Aim 3.** To examine patient-reported social support, social functioning, and psychological adjustment.

**a.** To examine degree of support provision and negative interaction with peers versus other relationships (i.e., family members, romantic partners).

**b.** To examine levels of social functioning (i.e., quality of peer interactions, loneliness) and psychological adjustment (i.e., anxiety, depression) of patients within the first-year post-diagnosis and compare to US population norms.

**c.** To examine associations between social functioning and psychological adjustment.

## 4.1 Method

### Participants

**Patient participants.** The current study aimed to recruit a total of 30 adolescents with cancer. To be considered eligible, patient participants were required to be 13-18 years-old and 3-6 months post-diagnosis at the time of enrollment. Additional inclusion criteria included receiving care at Seattle Children's Hospital and ability to speak and write in English. Parents of participants under age 18 were also required to speak and write in English in order to provide consent. Only patients receiving treatment for a new cancer diagnosis were eligible due to potential systematic differences in patient experiences when cancer has occurred before. Thus, exclusion criteria included having a secondary or relapsed cancer diagnosis, a diagnosis that did not involve any active treatment, or any history of developmental delay.

After two months of data collection, the decision was made to expand two inclusion criteria for patient participants due to slow enrollment rates and limitations identified in preliminary data. First, the eligible age range was expanded from 13-18 to 12-20 years old. Youth within this age range are still considered to be adolescents and this modification allowed for more patients to be eligible over the course of the study. Second, the required time since diagnosis was expanded from 3-6 months to 3-12 months. The 3-6-month post-diagnosis period was originally selected as the optimal time for studying peer relationships during treatment, as previous research has suggested a pattern in which peers remain close around the time of diagnosis but subsequently become more distant (Enskar, 1998). This phase was thus intended in order to capture this drop-off period in which most patients are still on active treatment, but sufficient time has passed since diagnosis for change or reorganization of peer relationships to have begun. However, preliminary interview data suggested that this time frame was potentially

too soon after diagnosis, as patients had not yet experienced any changes to their peer relationships or struggled to reflect on any changes that had occurred.

See Table 5 for complete sample demographic information. The final sample of patient participants was 14 (47% of target enrollment). Patients were majority female (64%), with ages ranging from 12 to 17 years ( $M_{\text{age}} = 14.8$ ;  $SD = 1.8$ ). The majority were diagnosed with leukemia (43%), followed by lymphoma (36%), sarcoma (14%), and CNS-tumor (7%). Time since diagnosis was 6.3 months on average ( $SD = 3.2$  months). The majority of patients identified themselves as White/Caucasian (76%), followed by Asian (31%) and American Indian (8%). The majority identified as non-Hispanic (92%). No participants were only children, and the median number of siblings was one. Most patients were currently attending school (62%), and most were mostly living at home during treatment (69%).

**Peer participants.** The current study aimed to recruit a total of 30 peers of adolescents with cancer. To be eligible, peer participants were required to be nominated by an enrolled patient, within 3-years of age of the patient and able to speak and write in English. Parents of peer participants under age 18 were also required to speak and write in English in order to provide consent. Immediate family members (i.e., siblings) were not considered to be eligible peer participants due to potential differences in the nature of family relationships compared to peer relationships. While patients were able to nominate peers of any gender to allow for mixed-gender friend dyads, peers could not be currently romantically involved with the patient. Though romantic relationships are often a major source of support for adolescents (Furman & Buhrmester, 1992), the nature of these relationships and how they are affected by cancer is likely different compared to platonic friendships. Lastly, peers with a personal history of cancer (i.e., have or have had cancer themselves) were not considered eligible, as their response to the

patient's diagnosis may have been systematically different from those without a previous personal cancer experience.

The final sample of peer participants was 2 (7% of target enrollment). One participant identified as female, and the other as male. Ages were 13 and 15 years, and both peers were within 3 years of age as the co-participating patient. As peers did not complete demographic information questionnaires, no other demographic data was obtained.

### **Procedure**

See Figure 3 for a summary of recruitment procedures and information. All study procedures were approved by the University of Washington Institutional Review Board. This study was considered "Not More than Minimal Risk" and received both a waiver of written consent and a full waiver of HIPAA authorization. This study was designed to utilize primarily digital means of data collection in order to examine feasibility of these methods for a larger study. These methods included using RedCap for distribution of consent documents and questionnaires, using both email and phone communication regarding scheduling and reminders, and conducting interviews via phone rather than in-person.

**Patient participants.** Potentially eligible patients were identified by the primary investigator through a list of new diagnoses distributed by Seattle Children's Hospital and through reviewing upcoming appointments in the Hematology/Oncology Clinic. After potential patient participants were identified, the PI screened their medical record to confirm eligibility and access contact information.

Eligible patients were then recruited through a passive, opt-out recruitment method that has been successfully used in prior studies conducted at SCH with an enrollment rate of 60-70% (Rosenberg et al., 2018). Letters describing the study were mailed to parents of eligible

participants under 18 or directly to patients over 18. The letter provided a brief summary of the study and a telephone number to call within 10-days of receipt if the patient did not wish to be contacted for recruitment. If patients did not opt-out, they were contacted via phone by the PI or an undergraduate research assistant. For patients under 18, a parent was first provided brief information about the study and then asked for permission to share information about the study with their child. If permission was given, the child was provided detailed information about the study aims and procedures and asked for verbal assent. If verbal assent was provided, the parent was then provided additional detail about the study and asked for verbal permission for their child to participate. For patients 18 and over, the patient was contacted directly, provided with detailed information about the study, and asked for verbal consent. If assent/consent was given, potential participants were then emailed an Information Statement via RedCap describing all study procedures, compensation and potential risks and benefits. At the end of the document, patients were asked to check a box indicating their willingness to participate and for those under 18 a parent was asked to check a box indicating their permission. Once this form was complete, patients were considered enrolled.

Over a 5-month period, a total of 61 potentially eligible patients were identified and screened, with 36 identified as eligible. The most common reasons patients were not eligible were: did not have a new cancer diagnosis (n = 7; 28%); language for care was not English (n = 7; 28%); were not receiving active treatment (n = 6, 24%); were not receiving care at Seattle Children's (n = 4; 16%); or were developmentally delayed (n = 1, 4%). Of the 36 eligible patients, 34 were approached by the study team. Two patients were not approached due to inability to obtain correct contact information (i.e., contact information listed in medical record was not correct). Of the 34 patients approached by the study team, 14 enrolled in the study

representing a 41% enrollment rate. Ten patients (53% of those who were approached but did not enroll) were deemed a passive decline, meaning the study team was unable to contact the patient or parent after 5 attempts. On the 5<sup>th</sup> attempt, the team member left a voicemail for the family to inform them that they would no longer be contacted but were still welcome to contact the study team if they were interested. The remaining reasons for decline were patient was not interested (26%), patient had too much on their plate already (16%), or patient did feel comfortable with the topic (5%). No patients opted-out of recruitment after receiving the initial letter.

Once enrolled, patients were first asked to complete a battery of questionnaires distributed via RedCap. This survey included five measures assessing social support, social functioning, and psychological adjustment. This survey required approximately 20 minutes to complete. The survey also included a demographic information sheet and a peer nomination form in which peers were asked to list the initials of up to three friends with whom they planned to share information about the study.

Once questionnaire responses were received, patients were asked to participate in a one-on-one semi-structured interview about their peer relationships. Interviews were conducted via phone and recorded using a digital voice recorder. At the end of the interview, patients were asked if they had shared any information about this study with their friends or if they planned to do so. Once the interview was complete, patients were mailed a \$20 gift card to Amazon. Participants were given a three-month window from the time of enrollment to complete all study components. If all study components were not completed within this window, the participant was informed that they would be unenrolled from the study if they did not complete all study components in the next 7-days. If a patient died while on study, they were automatically unenrolled. All enrolled participants completed at least one study component, with 86%

completing both components (questionnaires, interview) and 14% completing one component. No patients were unenrolled from the study.

**Peer participants.** To recruit peers, a snowball sampling method was used to protect families' privacy. Patient participants were emailed a flyer about the study and asked to share it with up to three friends who may be interested in participating. Patient participants were reminded that they were not required to share this flyer with their friends, and that their friends' willingness to participate would not affect their participation. The flyer provided brief information about the study and instructions for interested peers to contact the study team directly via phone. For peers under 18, the flyer requested that a parent contact the study team first. Peers 18 or older were able to contact the study team independently. As no studies to date have recruited peers of adolescents with cancer, this study aimed to test feasibility of this method for accessing peer populations based on number of peers who contacted the study team.

Once an interested peer contacted the study team, they were provided detailed information about the study via phone following similar procedures to patient participants. After verbal assent/consent was provided by the peer, they were asked questions to confirm eligibility. Once eligibility was confirmed, parental permission was obtained for peers under 18. Peers were then emailed an information statement via RedCap describing all study procedures, compensation, and risks and benefits, and asked to check appropriate boxes to indicate assent/consent and parent permission when under 18. A total of two peers contacted the study team, both were recruited and enrolled in the study, and both completed all study components.

Once enrolled, peers were asked to participate in a one-on-one semi-structured interview about their experience of having a friend with cancer. Interviews were conducted via phone and recorded using a digital voice recorder. Upon completion of the interview, peers were mailed a

\$15 Amazon gift card. If the patient associated with a peer died prior to the peer completing their interview, the peer was informed that they would be unenrolled from the study but will still be compensated. As no patients died on study, no peers were unenrolled.

## **Measures**

**Demographic & treatment-related information.** Patient diagnosis and diagnosis date were obtained from medical records during screening. All other information was obtained through a self-report demographic information sheet included as part of the questionnaire survey. Patients were asked to identify their age and gender using open-ended responses. They were also asked to identify their race (Caucasian, African American, Asian, Pacific Islander, American Indian, or Other) and ethnicity (Hispanic, non-Hispanic). If the “Other” ethnicity category was selected, they were provided an open-ended response option to specify. Patients were also asked to report about their schooling. They were asked if they were currently attending school (Yes, No, No, but I plan to return after treatment) and their grade level (7<sup>th</sup> grade – college). Finally, they were asked how many siblings they had (0 – 4 or more) and if they had mostly been living at home during treatment (Yes, No). If they had not mostly been living at home during treatment, they were provided with an open-ended question to specify where they had been living.

**Perceived social support.** The shortened version of Network of Relationships Inventory – Social Provision Version (NRI-SPV; Furman & Buhrmester, 1985) was used to describe relative degree of support obtained from different relationships for patients. The shortened version was adapted from the full 30-item questionnaire by the measure developers and was selected for this study to reduce participant burden. Respondents are first asked to list the relationships about whom they will answer questions. For the current study, the following options were included: a mother/mother figure, father/father figure, sibling, romantic partner,

closest friend, and an extra friend. Thirteen items assess positive and negative relationship features for each relationship: seven items assessing positive relationship features (i.e., “How much does this person help you figure out or fix things?”) and six items assess negative relationship features (i.e., “How much do you and this person get annoyed with each other’s behavior?”). Response options range from 1 (little or none) – 5 (the most). Scores are then averaged within each domain to form a support factor score and a negative interaction factor score for each individual, with scores ranging from 1-5. A final question asks respondents to specify which of the individuals they listed is their “best friend”. To assess reliability, Cronbach’s alpha was calculated for each dimension within each relationship except for significant others as only 2 respondents provided data for this relationship. Reliability was adequate across all dimensions (see Table 6 for all estimates).

**Peer interactions.** Patients’ peer interactions were measured using the Neuro-QOL Pediatric Social Relations – Interactions with Peers Scale, Short Form v.1.0 (Lai et al., 2012). This 8-item self-report measure assesses quality and satisfaction with peer interactions in the past week, with items such as “I felt close to my friends”, and “I felt comfortable talking to my friends”. Response options range from 1 (never) to 5 (almost always). Scores for each item are summed to form a total score, with higher numbers indicating more positive peer interactions. Total scores were converted to a T-distribution based on the United States population to allow norm comparisons. Reliability was high in the current sample (Cronbach’s alpha = .95).

**Loneliness.** Patient perceived loneliness was measured using the Loneliness-Fixed Form scale for ages 8-17 from the NIH Toolbox Item Bank v2.0 (Gershon et al., 2013). This 7-item self-report measure assesses frequency of feelings of loneliness in the past month, with items such as “I feel that I have nobody to talk to” and “I feel left out”. Response options range from 1

(never) to 5 (always). Scores for each item are summed to form a total score, with higher numbers indicating more perceived loneliness. Total scores were converted to a T-distribution based on the United States population, thus allowing norm comparisons. Reliability was high in the current sample (Cronbach's alpha = .88).

**Patient depressive symptoms.** Patient participants' depressive symptoms were measured using the short form of the PROMIS Pediatric Depressive Symptoms Scale v2.0 (Quinn et al., 2014). This 8-item self-report measure assesses frequency of depressive symptoms in the past week, with items such as "I could not stop feeling sad" and "I felt like everything in my life went wrong". Response options range from 1 (never) to 5 (almost always). Scores for each item are summed to form a total score, with higher numbers indicating more depressive symptoms. Total scores were converted to a T-distribution based on the United States population, thus allowing norm comparisons. Reliability was high in the current sample (Cronbach's alpha = .96).

**Patient anxiety symptoms.** Patient participants' anxiety symptoms were measured using the short form of the PROMIS Pediatric Anxiety Scale v2.0 (Quinn et al., 2014). This 8-item self-report measure assesses frequency of anxiety symptoms in the past week, with items such as "I felt like something awful might happen" and "I worried about what could happen to me". Response options range from 1 (never) to 5 (almost always). Scores for each item are summed to form a total score, with higher numbers indicating more anxiety symptoms. Total scores can be converted to a T-distribution based on the United States population to allow norm comparisons. Reliability was high in the current sample (Cronbach's alpha = .91).

**Semi-structured interviews.** Individual semi-structured interviews with patients and peers were conducted by the primary investigator and one undergraduate research assistant. Interviews were digitally audio recorded and transcribed verbatim by two trained undergraduate

research assistants. Interviews were conducted using a specific guide of open-ended questions and participants were invited to fully elaborate on their responses. Interviews lasted approximately 10-20 minutes each. For the patient and peer participant interview guides, see Tables 7 and 8, respectively.

### **Data Analytic Strategy**

**Aim 1.** The first aim of this study was to describe patient experiences of peer relationships during cancer treatment. Analysis of interview data was guided by a multi-step process of inductive concept analysis using methods adapted from grounded theory interviews. All interviews were coded by the PI. ATLAS.ti 8 Windows was used to manage data and analysis and provide an audit trail.

The coding process involved five steps, each maintaining the respondents' exact words:

- 1) All text from transcribed interviews were unitized using Microsoft Word. Each unit was a direct quotation of a complete idea that includes both a noun and a verb, whether implicit or explicit;
- 2) Each unit of data was then open-coded using a code that starts with a gerund. Codes were derived verbatim from words used by the interviewee (e.g., feeling scared, being thankful);
- 3) The open codes were organized into an initial set of categories with descriptions that clearly differentiate each category;
- 4) Constant comparative analysis (Hsieh & Shannon, 2005; Vaismoradi, Turunen & Bondas, 2013) was then used to verify the distinctions between the categories and verify the accuracy of fit between each unit of analysis in each category; and
- 5) The refined set of categories was then grouped into higher order domains. Trustworthiness of results was protected through formal peer debriefing between the PI and a peer debriefer (i.e., Dr. Walker). Three comparisons were made in the debriefing process: 1) a comparison between all categories, including an examination of distinctions between categories to verify their

uniqueness and non-overlapping characteristics; 2) a comparison of the adequacy of fit between each verbatim quote and the category; and 3) a comparison of each verbatim quote with all other categories and descriptions to confirm the correct placement of the quote within the categories. Disagreements between the primary coder and peer debriefer were resolved during this process.

**Aim 2.** The second aim of this study was to describe the experience of having a friend with cancer from peers' perspectives. Because an insufficient number of peer interviews were obtained to reach saturation ( $n = 2$ ), the full coding process could not be completed with the peer interviews in order to address Aim 2. Instead, narratives were created for each peer interview.

**Aim 3.** The third aim of this study was to quantitatively examine patient-reported social support, social functioning, and psychological adjustment, and associations between these factors. Given the small sample size and thus insufficient statistical power, all quantitative analyses were descriptive in nature and intended only to suggest trends to be tested by future research. No inferential statistics were used; thus results are discussed in terms of differences in direction and magnitude rather than statistical significance.

Aim 3a was to examine and compare the degree of support obtained from different interpersonal relationships, including parents, siblings, peers, and significant others. To do so, the support and negative interaction factor scores on the NRI-SPV were used to describe general levels of support and conflict in each relationship and compared to determine which relationship(s) provide the highest degree of support for patients and which had the most negative interactions with patients.

Aim 3b was to describe levels of social functioning and psychological adjustment in the current sample and compare these levels to population norms. To do so, raw scores were converted to T-scores using US-population normed conversions provided by the measure

developers. Descriptive statistics were then examined for each social functioning and psychological adjustment measure and distributions were then compared to US population norms for each measure. To further describe levels of social functioning and adjustment based on individual characteristics, differences in mean T-scores were compared based on demographic characteristics of gender (male, female), ethnicity (white, non-white), age group (<15, 15+), and number of siblings. Mean T-scores were also compared based on four relevant treatment characteristics, including: 1) diagnosis group (leukemia, lymphoma, other diagnoses), 2) time since diagnosis (<6 months, 6-12 months), 3) living at home during treatment vs. not living at home during treatment, and 4) currently attending school vs. not currently attending school.

Aim 3c was to examine associations between social functioning and psychological adjustment. To do so, Pearson product-moment correlations were used to describe bivariate associations between peer interaction quality, loneliness, depression, and anxiety. Correlation coefficients between each pair of constructs were examined only for magnitude and directionality, not statistical significance.

## 4.2 Results

### **Aim 1. Patient Descriptions of Peer Relationships**

#### **Domain 1: Catching Up**

Adolescents with cancer described staying connected with their friends through talking frequently, using technology, and spending time together. They described trying to stay up to date on things they were missing at school and what was happening in their friends' lives.

**Talking a lot.** Adolescents described being in touch with their friends frequently. As one participant described, “[I talk to my friends] pretty much almost every day.” Referencing his two

closest friends, one participant said, *“Those two have been very like in touch. Just like all the time.”*

**Hanging out together.** Adolescents described seeing their friends and spending time with one another. One participant noted, *“I still get to them [friends], so that’s good. Um, well, we just mostly, like, hang out and just talk”*. Another described having friends come visit, saying, *“Yeah well, like when I’m still – when I’m inpatient and they come, I don’t know, we don’t like do a lot. But we just kinda hang out and just kinda go with my daily stuff that I do – like walk around halls. And we might play some games together or do a craft together or something.”*

**Keeping me updated.** Most conversations between adolescents with cancer and their friends involved discussing what had been happening at school and in their friends’ lives. One participant described catching up on the things she was missing at school, *“Um, [we talk] about school, like what’s going on in their lives, just kind of trying to, like, catch up. And like, know the things that I’m kind of, like, missing while being at home so much”*. Similarly, another said, *“or if we’re talking about them, then just how school’s been. Like, they try to keep me updated on how school is going. Like, you know, all the drama.”*

**Texting & Facetiming.** Adolescents with cancer frequently described using text messaging and video-chat platforms to stay in contact. As one participant described using FaceTime and texting often, *“I FaceTime them, and they always text me at least once a day. [I use Facetime] At least once a day.”* One participant felt that having access to these technologies helped him stay connected to his friends without his parents’ having to intervene, saying, *“Yeah. Them getting the iPad and all of them having Apple products we can talk on [has helped me stay close]. Easy! Yeah, it’s a lot easier than trying to get parents to call and then get kids on the phone and have the parent sitting right next to you hearing every word.”*

**Using social media.** Patients commonly communicated with friends through social media. For example, one participant described, *“It was easy to stay in touch with like – yeah,*

*definitely like social media. I didn't really see them that often like in person. Like, mainly like Instagram and Snapchat.*" Another noted, *"We're sending memes back and forth"*.

**Online gaming.** A few adolescents described using online gaming to stay in contact with friends. As one participant noted, *"Definitely videogames. Like even in the hospital, we brought a Play Station from home, and I was able to stay connected every day. We'd always just hang out together. So, it was nice being able to keep myself entertained with them."*

## **Domain 2: Shifting Relationships**

Adolescents with cancer perceived that their peer relationships had changed in various ways since they were diagnosed. They describe friends being more distant, remaining close, growing closer, and reorganizing such that some became closer while others became further.

**Being more distant.** Adolescents perceived that their friendships became less close since they were diagnosed. As one participant described, *"I feel like me and my friends have gotten, like, a little bit more distant just because we don't see each other, like, every single day like we did last year."* They described not feeling connected with their friends, as one participant noted, *"It's just, they don't really, like, hit me up. If, like, I hit them up, they like aren't really down to come and hang out, I'd say."*

**Growing closer.** Conversely, some adolescents felt that their friendships were strengthened and became closer since they were diagnosed. As one participant described, *"They've probably gotten a little bit closer. I know that like a lot of them are always thinking about me and like care about me, so I've probably just gotten a little closer with them in general."* Another participant noted positive changes in his friendships,

*"Well, it's not like- it changed. Well, like, yeah, it did, but like, not in a bad way, you know what I mean? Like, it changed to a good way, cause like, we like, care more about each other, stuff like that... Mm, I feel, yeah, I think it's the time we spend together, you know? Like, and the things we say to each other. Just stuff like that."*

**Remaining close.** Some adolescents did not perceive changes to their relationships and felt their relationships had stayed as close as before they were diagnosed. As one described, *“Like, it didn’t change. It’s been, like, consistent and always open and caring.”* Similarly, another adolescent noted, *“Yeah, I don’t know. I don’t think any of them would have like – I don’t think any of us have really like gotten worse.”*

**Getting closer and further.** Some adolescents perceived that their closest friendships had shifted, as some friends had become closer while others had drifted apart. One adolescent reflected, *“Um, I don’t know, cause I talk to some other friends more than I would’ve before and then the ones that I would’ve talked to before, I don’t talk to as much anymore.”*

### **Domain 3: Being Hard to Stay Close**

Adolescents with cancer found it challenging to maintain their relationships due to being far away from their friends, having to be on their own time frame or schedule due to treatment, and at times not feeling well enough to engage with friends.

**Being far away.** Many adolescents felt that distance was a major challenge to their friendships. As one participant described, *“I would say that I’m so far away from all of them [is the hardest part]. Like all my friends are at home and are like two streets away when I’m being treated somewhere else...I get really lonely.”* Another teen felt that distance had contributed to changes in their friendships, saying, *“[my friendships changed] a little bit. I feel like we’re not as close, cause of the distance.”*

**Having my own time frame.** A major challenge for staying close with friends was feeling like they couldn’t do the things they used to with their friends, or that they couldn’t be on their friends’ schedules because of treatment. As one teen described,

*“Um, mostly just having everything have to be like, within my own time frame. Like I said, after chemo, there would be days where I wouldn’t be able to go and see more than two people, or like, I wouldn’t be able to go outside and like go into crowded areas. So, I wouldn’t be able to, like, um, like go to a party or like, go to, like, a group, you know? And hang out. Yeah, not, not being able to be on their time, so when they’re able to do things and having everything be on my time is more like what made it hard.”*

**Not feeling up for it.** Patients felt that another barrier to their friendships was not feeling well. One participant described struggling early in treatment when she felt particularly unwell, saying, *“Um, I’d say it was a little more hard in the beginning when I really wasn’t feeling good because I didn’t really want to, like, do a lot or, like, text or anything.”* Another described often feeling that she didn’t have the energy to do things with friends,

*“Well, that sometimes I just don’t feel like, like going and do stuff- going, you know, out. Sometimes I just, like, stay home and they want to go and do something, I just don’t feel like going. Yeah, I just feel like I don’t have an excuse not to. It’s just, I don’t have as much, like, energy as I used to.”*

#### **Domain 4: Finding Your ‘Real’ Friends**

Adolescents discussed how their cancer experience had influenced their perceptions of their friendships. They felt that cancer had showed them how close their relationships really were, in both positive and negative ways. Some observed that their friends did not want to be involved once they were diagnosed and considered reasons for this and some felt worried about how they would fit in with their friends after treatment.

**Showing me how close they really are.** Adolescents re-evaluated their friendships after diagnosis based on who was there for them and who was not. As one participant said, *“I mean, if your friends are your real friends, then they’ll support you.”* For some, this led to negative realizations that their friendships weren’t as close as they thought. One participant reflected,

*“I think it definitely showed me how close they really are, you know? Like, me and my friends, like, we- we were always super, super close before this, so like, we would always say, like, ‘Oh yeah, we’ve always got each other’s backs’, you know, ‘Hundred percent, whatever you go through, I’ll be- I’ll have your back one hundred percent and be there for you.’ And then, like,*

*something like this happens, and it kind of shows like how little they are there for you. And, like how it's mostly just like trying to have a good time and not really, like, um, like a 'you thing', you know?"*

Conversely, some also described being surprised by friends who were expectedly supportive. For example, one participant described a friend visiting him during chemotherapy,

*"and like, one of them... I've known her since, like, second grade... in the middle of the day, she, like, went to one of my chemos and that was really cool. And kind of showed me, like, 'oh wow'. Like, cause I – I didn't really realize, like, that me and her – that she even, like saw me as a friend anymore let alone cared about me to come see me, so that was pretty surprising."*

**Not wanting to get involved.** Some adolescents felt that their friends had not wanted to be there to support them due to discomfort with cancer. They felt that their friends didn't know how to deal with their cancer, as one participant described,

*"I think that, um, when you go through things like this, people don't want to like, have convos – or like, they don't want to, like, involve themselves just because they haven't, either they haven't dealt with something like this before or don't know how to deal with stuff like that."*

Reflecting on why his friends not been there for him, a participant said,

*"Cause like, it's easy to think, 'Oh I have cancer. They have no reason not to be supportive'. But I mean, everybody has their own life and their own perception of own things and stuff and they don't really know what do to be supportive."*

**Worrying how I'll fit in.** Some adolescents expressed concerns about returning to school after cancer and being uncertain about the state of their friendships. Some were worried that social life had changed while they were gone,

*"Well, a lot of stuff at school has changed, like, friendships have shifted and stuff, and like, and I haven't been there. I was a little bit, um, like, a little bit worried that when, like I'd go back to school I wouldn't really know, like, exactly where I would, like, fit in anymore."*

They also wondered if their friends would treat them the same after their cancer, *"I'm more worried about whether they'll treat me differently, you know? Well, I'm worried that people might think that I'm more fragile and like, can't like – I don't know, just like different."*

## **Domain 5. Talking about Cancer**

Adolescents had mixed experiences discussing cancer with their friends. Some described talking to their friends about cancer and their experience, though most expressed a reticence toward the conversation.

**Telling them about my cancer experience.** A few adolescents discussed cancer with their friends. One participant said, *“we’ll talk about just how I’ve been doing. Yeah. Just like the experience with it [cancer]... I’ve told them like the science behind it, so they’re all kind of educated on what it’s like.”* Another described talking about cancer with a friend, *“Um, one of my friend’s mom also had cancer. So, I just talk about, yeah, we just talk about how, like, it- like, the different types, how I’m doing, like, my health.”*

**Not wanting to talk about cancer.** Most adolescents did not feel comfortable discussing cancer with their friends. Some felt the conversation didn’t arise naturally or that they only discussed it when their friends asked. Others felt more notable discomfort with the subject. As one participant noted, *“Um, it’s just personal, and you always have your privacy. And I don’t want to talk about it”*. Another described preferring not to talk about cancer because he didn’t feel it had affected him substantially, *“I kind of actually don’t like saying I have cancer, just because, I’m not, you know, on bad chemo and I’m not really sick.”*

### **Domain 6: Feeling Supported**

Most adolescents with cancer felt supported by their friends. They defined support as their friends being there for them, checking in with them frequently, being patient and understanding, and showing their support through gifts and public gestures.

**Being there for me.** Adolescents defined support as knowing that they could rely on their friends no matter what. As one teen summarized, *“I mean, no matter what happens, they’re*

*still going to be there*". Many adolescents described instances in which their friends told them they would be there for them if there was anything they needed. As one teen described,

*"Well, all of them just keep saying that- they just say, like, 'if you ever', you know, 'if you ever need someone for a bone marrow biopsy, you know, I'm there'. I mean, I know that's obviously not how it works, but you know, they're- they'd be willing to- to do that. Like, they're saying if it ever comes down to that, you know, 'I would if I could'."*

**Checking in on me.** Many adolescents felt that their friends demonstrated their support by asking how they were doing and coming to see them. When asked how he would support a friend with cancer, another teen said, *"Just check in on them, like, every day. Like, at least send a text."* One teen felt that her friends checking in showed that were thinking about her, saying,

*"Well I say that it's probably just like sometimes someone will message me and that will just probably [feel supportive], and if we're like talking more, like if we're messaging more that would probably make me think they're actually thinking about me here, rather than never saying anything."*

Coming to visit was also perceived as supportive. One teen noted the importance of friends' visiting, saying,

*"Supportive would mean to me or whatever, like, if a friend was fully supportive, they'd just, like, want to spend time with me, because that's really all I, like – at the moment – that is what I'm looking for, just because, like, I've been so distant from people."*

**Being understanding.** Some adolescents talked about friends supporting them by being patient and agreeable. One participant described,

*"All of my friends just being, like, understanding more than I thought they would be, you know, of like, how I act, like my emotional instability, I guess. Like, they would be, like, understanding that I just had, like, a lot going on, you know?"*

Another felt her friends showed support by being agreeable, saying, *"Okay, well, it feels good, and like, they show that, like, they support me, and they care about me because, like, they agree on, like, whatever choice- choice I'm like- you know decisions and stuff like that?"*

**Showing their support.** Adolescents with cancer described friends' demonstrating support through gifts and public gestures. They enjoyed receiving gifts from their friends, as one girl described, *"But also, um like, like receiving the gift baskets from them, just like, that kind of helped me know that they're still, like, thinking about me and they hadn't, like, forgotten about me or anything."* A number of adolescents also described times when their friends made public gestures of support, which meant a lot to them. For example, *"When this all went down, she made this Google post thing, like, 'Hey, my friend recently got leukemia...'. And like, I read through it, and it was, like super nice. It was saying, 'Go support her', yeah."*

### **Domain 7: Helping Me Get Through It**

When asked what advice they would give to another teen with cancer, adolescents felt that keeping up with communication, finding support from friends and family, and staying positive had been most helpful for them.

**Keeping up with communication.** The most common advice for other teens with cancer was to try to stay in touch with friends. As one participant stated, *"Just try to at least kind of stay in touch with them, tell them what you're doing. If they like – tell them about treatment, or if they ask, let them know. That's kind of the only way I know"*. Others emphasized the importance of being willing to reach out oneself, saying,

*"Even if your friends don't, like, text you, then reach out to them because they will be, like, more than happy to talk to you I would guess. And so, just make sure if you want to stay really close with your friends, you just, like, keep talking to them."*

**Finding support.** Some adolescents had advice for other teens with cancer about seeking support from friends and family. Some described expecting support from friends, particularly for those with worse types of cancer, *"I think the worse it is, obviously the more concerned their friends are gonna be... if it's bad, I mean, they should expect a lot of support."* Others

recommended seeking support from family, saying, “*The number one thing that you should push is for, uh, kids to learn how to get close with their family... that’s kind of important because those are the people that are going to be in your life every day.*”

**Staying positive.** Adolescents advised other teens with cancer to maintain an optimistic attitude and think about the future. As one participant stated, “*Just to be, like, always positive and think about, I don’t know, like, think of the future and stuff like that. Never think about, you know, ‘I have cancer,’ and all, ‘I’m going to die one day’.*”

## **Aim 2. Peer Experiences of Having a Friend with Cancer**

As only two peers enrolled and provided interview data, there was not sufficient data to complete the coding process or reach saturation. Instead, narratives of each interview are provided.

**Peer Interview 1:** When asked what it had been like for her to have a friend with cancer, the first thing she shared was that she often felt distressed because she could not be there for her friend with cancer more frequently. She struggled with wanting to see her more but being unable to because her friend was at the hospital and she had to go to school. They had been close friends since they were young, and she felt that despite their separation they had remained close and still had the same connection. They communicated often, and she tried to see her friend at least twice per month. She worried about her friend and often thought about what she was going through. She described an instance of visiting her friend at the hospital and seeing “*this thing that’s basically a hole in her chest*”, which was very hard to see and made her feel worried.

She felt that communicating often had helped their friendship stay close. She participated in marches for cancer research with her other friends, and had her mom send pictures to her friend with cancer’s mom so that her friend would know they were supporting her. She felt that a

major challenge to staying close was that her friend could get sick really easily, so they had to make sure they were in clean places when they saw each other. She thought there should be a special, sanitary place at the hospital where teens with cancer could spend time with their friends and where they could all meet up and do activities together. She didn't feel worried about their friendship. She enjoyed it when her friend got to come to school to visit and described a time her friend came to school to give a presentation about her cancer story. She felt that her friend was well-supported, and it made her feel good to see so many people showing their support for her.

She recalled feeling very emotional when her friend was first diagnosed and it being hard to understand. She still noticed her absence at school, particularly because she felt their friend group had dissolved without her friend there to bring them together. She recalled many memories with her friend and missed her but reminded herself to look forward to her return to school the following year. Though her friend with cancer was usually the one who helped her when she was feeling upset, she felt was able to get help from other friends too. She felt that thinking positively helped her cope, especially when she heard bad news. She advised other teens who have a friend with cancer to try to stay positive, be there for their friend with cancer, and give them help and comfort.

In the end, she viewed the situation as an opportunity for growth. She reflected on the day her friend first told her about her diagnosis, how unexpected it was, and recalled not even realizing what cancer was at the time. She acknowledged that many friendships go through rough times and believed most important thing was to stay positive. She felt amazed by her friend's ability to stay positive despite everything she was going through, and this inspired her to be positive herself, saying *"throughout everything she smiles, and is just really positive about the whole thing. It's really amazing to me."*

**Peer Interview 2:** He felt that things had been very different since his friend was diagnosed. Mostly it felt strange to not see him every day since they had been such close friends. Though he was only able to see his friend in-person once every few weeks, they talked everyday through playing games on their PlayStation 4 (PS4). His friend always kept him up to date on everything that was going on, and he felt like this frequent contact had kept them pretty close. Aside from not seeing one another, their friendship felt the same to him as before.

When they talked, he usually told his friend about everything that had been going on at school. They also discussed his friend's treatment, which was sometimes hard for him to hear about. He felt it was especially hard to hear about chemotherapy and to think of what his friend was going through, and he often felt badly for him. He felt the hardest part of his friend having cancer was not being able to see each other as often. He recalled when his friend had gone through a bone marrow transplant and how difficult it had been to go such a long time without seeing him. He felt that being in contact every day through their PS4s had helped them to stay close and helped his friend stay connected with their friend group, but he also thought it would help to see each other more often. However, he didn't feel worried about their friendship because they talked so often. He believed that cancer had tested their friendship and ultimately brought them closer together.

Personally, he felt this experience had opened his eyes because he hadn't previously dealt with something so serious and, in some ways, it still felt surreal and difficult to believe. He played sports often and doing so helped keep his mind off of things. However, he felt that talking with his friend through their video games was the most helpful way of coping. His advice to another teen who has a friend with cancer was to see and talk to their friend as much as possible. He felt that frequent contact was important because it had both helped him cope and helped his

friend with cancer, “*you know, so they can talk to someone.*” To support his friend, he always told him to keep his head up, “*There’s a light at the end of the tunnel. It – it’s gonna get better.*”

### **Aim 3. Examining Patient-Reported Social Support, Social Functioning, and Psychological Adjustment**

#### **Social Support Provision by Peers & Family**

To examine degree of support provision and negative interaction with peers versus other relationships (i.e., family members, romantic partners), NRI support and negative interaction factor scores were compared by relationship.

Average support scores were high for most relationships, ranging between 2.58 and 4.06 (see Figure 4). On average, the greatest degree of support was received from mothers ( $M = 4.06$ ,  $SD = .81$ ) followed by same-sex friends ( $M = 3.84$ ,  $SD = .90$ ). The lowest degree of support was received from significant others ( $M = 2.58$ ,  $SD = .12$ ), though only two participants reported on a significant other. To further examine relative degree of support from each relationship, a rank order was calculated for each respondent based on their average support score for each individual (see Figure 5). Mothers were most commonly ranked as the greatest source of support ( $n = 6$ ), followed by fathers ( $n = 4$ ) and siblings ( $n = 4$ ). Same-sex friends were most commonly ranked second ( $n = 8$ ), followed by fathers ( $n = 4$ ). Siblings were most commonly ranked third ( $n = 4$ ) and other-sex friends were most commonly ranked fourth ( $n = 4$ ).

Average negative interaction scores were lower relative to support scores, ranging between 1.12-2.14 across relationships (see Figure 6). On average, the greatest degree of negative interaction was with mothers ( $M = 2.14$ ,  $SD = 1.08$ ) followed by siblings ( $M = 1.90$ ,  $SD = .55$ ). Negative interactions with same-sex and other-sex friends tended to be low ( $M = 1.33$ ,  $M = 1.12$ , respectively). To further examine relative degree of negative interactions from each

relationship, a rank order was calculated for each respondent based on their average negative interaction score for each individual (see Figure 7). Siblings were most commonly ranked as the highest source of negative interaction ( $n = 8$ ), followed by mothers ( $n = 4$ ). Mothers were most commonly ranked second ( $n = 7$ ), followed by fathers ( $n = 4$ ). Fathers and same-sex friends were most commonly ranked third ( $n = 4$ ) and same-sex and other sex friends were most commonly ranked fourth ( $n = 4$ ).

### **Levels of Social Functioning & Psychological Adjustment**

To describe levels of social functioning and psychological adjustment, descriptive statistics were examined for peer interactions quality, loneliness, anxiety, and depression measures (see Table 9). All scores were converted to population-normed T-scores with a mean of 50 and standard deviation of 10 using conversion tables provided by the measure developers.

For mean comparisons based on demographic variables, the following groupings were used: for gender, means were compared between males ( $n = 3$ ) and females ( $n = 9$ ). For age, means were compared between younger adolescents (<15 years;  $n = 4$ ) and older adolescents (15+ years;  $n = 8$ ). For race, means were compared between those who identified as White/Caucasian ( $n = 9$ ), and those who identified as other races ( $n = 3$ ). As only three survey respondents identified as other races, more nuanced comparisons within the “other race” category could not be made. No respondents were only children; thus, for number of siblings, correlation coefficients were calculated between number of siblings and each variable of interest. All descriptive statistics for these comparisons are provided in Table 10.

For mean comparisons based on treatment-related variables, the following groupings were used: for diagnosis, means were compared between leukemias, lymphomas, and other diagnoses (i.e., sarcomas, CNS tumors). As only two survey respondents were diagnosed with a

sarcoma and CNS tumor, respectively, more nuanced comparisons within the “other diagnoses” group could not be made. For time since diagnosis, means were compared between patients 3-6 months ( $n = 7$ ) and 6-12 months post-diagnosis ( $n = 5$ ). For living situation, means were compared between adolescents living at home during treatment ( $n = 9$ ) vs. those not living at home ( $n = 3$ ). Last, comparisons were made between patients currently attending school ( $n = 8$ ) and those not attending school ( $n = 4$ ). All descriptive statistics for these comparisons are provided in Table 11.

**Peer interaction quality.** The average level of self-reported peer interaction quality was 47.63 ( $SD = 10.09$ ). Thus, peer interaction quality in the current sample was distributed similarly to population norms for this measure ( $M = 50.00$ ,  $SD = 10.00$ ). Peer interaction quality was similar between males and females (48.90 vs. 47.07). Younger adolescents reported higher interaction quality than older adolescents (51.10 vs. 46.09), and patients who identified as other races reported higher interaction quality than those who identified as White/Caucasian (54.33 vs. 45.62). There was a weak negative correlation between number of siblings and interaction quality such that patients with more siblings tended to report lower peer interaction quality ( $r = -0.40$ ).

Adolescents diagnosed with leukemia reported the highest levels of peer interaction quality ( $M = 51.80$ ), with lower levels reported by those diagnosed with lymphoma ( $M = 44.52$ ) and other diagnoses ( $M = 42.90$ ). Patients who were 6-12 post-diagnosis reported higher levels than those 3-6 months post-diagnosis (51.80 vs. 45.03). Patients currently attending school reported lower levels than those not attending school (45.44 vs. 51.14), and levels were similar between patients living at home and patients not living at home during treatment (47.30 vs. 48.38).

**Loneliness.** The average level of self-reported loneliness was 53.25 (SD = 8.75). Thus, loneliness in the current sample was distributed similarly to population norms for this measure (M = 50.00, SD = 10.00). Average loneliness was similar between males and females (54.55 vs. 52.67). Older adolescents reported higher levels of loneliness than younger adolescents (55.00 vs. 49.30). Patients who identified as White/Caucasian reported higher loneliness than those who identified as other races (54.16 vs. 50.20). There was a moderate positive correlation between number of siblings and loneliness such that patients with more siblings tended to report more loneliness ( $r = 0.53$ ).

Higher levels of loneliness were reported by patients diagnosed with lymphoma (M = 55.96) or other diagnoses (M = 54.05) compared to those diagnosed with leukemia (M = 50.76). Patients who were 6-12 post-diagnosis reported higher loneliness than those 3-6 months post-diagnosis (55.03 vs. 50.40). Patients currently attending school reported higher loneliness than those not currently attending school (54.76 vs. 50.82), and patients not living at home during treatment reported higher loneliness than those living at home (56.50 vs. 51.80).

**Anxiety.** The average level of self-reported anxiety was 45.04 (SD = 10.65). Thus, average anxiety symptoms in the current sample were slightly lower than population norms for this measure (M = 50.00, SD = 10.00). Females reported slightly more anxiety than males (46.48 vs. 41.80). Older adolescents reported higher levels of anxiety than younger adolescents (47.76 vs. 38.90). Patients who identified as other races reported higher anxiety than those who identified as White/Caucasian (49.03 vs. 43.84). There was a moderate positive correlation between number of siblings and anxiety such that patients with more siblings tended to report more anxiety ( $r = 0.47$ ).

Adolescents diagnosed with lymphoma reported the highest levels of anxiety ( $M = 49.48$ ) with lower levels reported by those diagnosed with leukemia ( $M = 42.72$ ) and other diagnoses ( $M = 40.90$ ). Patients who were 6-12 post-diagnosis reported higher anxiety than those 3-6 months post-diagnosis (48.30 vs. 43.00). Patients currently attending school reported higher anxiety than those not attending school (49.84 vs. 37.36), and levels of anxiety were similar between patients living at home during treatment and those not living at home (44.31 vs. 46.68).

**Depression.** The average level of self-reported depression was 48.07 ( $SD = 11.49$ ). Thus, depressive symptoms in the current sample were distributed similarly to population norms for this measure ( $M = 50.00$ ,  $SD = 10.00$ ). Average depression was similar between males and females (48.13 vs. 48.04). Older adolescents reported higher levels of depression than younger adolescents (51.39 vs. 40.60). Patients who identified as White/Caucasian reported slightly higher depression than those who identified as other races (48.78 vs. 45.70). There was a moderate positive correlation between number of siblings and depression such that patients with more siblings tended to report more depression ( $r = 0.53$ ).

Adolescents diagnosed with lymphoma reported the highest levels of depression ( $M = 54.10$ ) with lower levels reported by those diagnosed with leukemia ( $M = 43.73$ ) and other diagnoses ( $M = 46.00$ ). Depression was similar between adolescents 3-6 months and 6-12 months post-diagnosis (48.59 vs. 47.24). Patients currently attending school reported higher depression than those not attending school (52.77 vs. 40.56). Depression was similar between patients living at home during treatment and those not living at home (48.73 vs. 48.67).

### **Associations Between Social Functioning & Psychosocial Adjustment**

Associations between social functioning constructs (peer interaction, loneliness) and psychological adjustment (anxiety, depression) were examined using Pearson product-moment

correlations. Due to the small sample size, correlations were examined for direction and magnitude rather than statistical significance. Correlation coefficients are presented in Table 12. All correlations were in the expected direction.

Peer interaction quality had strong, negative correlation with loneliness ( $r = -0.68$ ), a moderate negative correlation with anxiety ( $r = -0.50$ ), and a strong negative correlation with depression ( $r = -0.79$ ). In other words, those who reported better peer interactions also tended to report less loneliness, and lower anxiety and depression. Similarly, loneliness had a moderate positive relationship with anxiety ( $r = 0.58$ ) and a strong positive relationship with depression ( $r = 0.79$ ). Thus, those who reported more loneliness also tended to report higher anxiety and depression. As expected, there was a strong, positive correlation between anxiety and depression ( $r = 0.84$ ), such that those who reported higher anxiety also tended to report higher depression.

### **4.3 Discussion**

The first aim of this study was to describe adolescents' perceptions of their relationships with non-ill peers during the first year after cancer diagnosis. Seven domains emerged from patient interviews: catching up, shifting relationships, being hard to stay close, finding your 'real' friends, getting through it, feeling supported, and talking about cancer. The second aim of this study was to describe the experience of having a friend with cancer from peers' perspectives. Though only two peers provided interview data, their narratives had a number of overlapping themes. Both peers were distressed by being separated from their friend with cancer, though both also noted the importance of frequent communication to help them stay close. Both worried about their friend with cancer. They were upset by learning about their friends' treatment and thinking of what they were going through. They acknowledged that they hadn't been through

something like this before. Both ultimately viewed the experience as a challenge to their friendship and an opportunity to bring them closer.

While literature on peer relationships during cancer treatment has been very limited, results of the current study echo themes identified in previous qualitative research. The current study found that adolescents perceived both positive and negative changes in their relationships due to cancer. Other studies qualitative studies have similarly identified themes of becoming closer with a best friend but sensing that friends have drifted over time (Enskar et al., 1997; Tebbi et al., 1987). Adolescents in the current study felt these changes had made them reevaluate their relationships and identify their ‘real’ friends. This echoes a very similar sentiment to “learning who your real friends are”, as described by Enskar and colleagues (1997). Some adolescents in the current study believed that their friends did not want to be involved once they were diagnosed. This again describes a similar experience to one described by Enskar et al. in which teens reported that friends had “kept their distance” since their diagnosis. Adolescents in the current study also defined support as their friends “being there” for them and many noted the importance of staying in touch with friends. These themes are very similar to those described by Woodgate (2006) in her paper, “The Importance of Being There.” She describes friends supporting teens with cancer by preventing loneliness, helping them feel like they have a life, providing comfort, and helping them to think positively, each of which was also described by adolescents in the current study.

The third aim of this study was to quantitatively examine patients’ self-reported social support, social functioning, and psychological adjustment. Across relationships, patient-perceived social support was generally high. On average, mothers provided the greatest degree of support (as indexed by the average support score of any relationship across respondents) and

were mostly frequently rated as the primary source of support (as indexed by receiving the highest support score relative to other relationships within respondents). Same-sex friends provided the second greatest degree of support and were most frequently rated as the second highest source of support relative to other relationships. These findings provide further evidence that most adolescents with cancer experience sufficient levels of general social support (Marine & Miller, 1998; Haluska et al., 2002; Nichols, 1995). They also clearly align with prior research demonstrating that mothers are typically the greatest source of support for adolescents with cancer, followed by peers (Kyngas et al., 2001; Ritchie, 2001; Trask et al., 2003; Woodgate, 2006).

Across relationships, negative interactions were generally low. Despite being scored the highest in support provision, mothers also had the highest negative interaction scores across individuals. However, within individuals, siblings were most frequently rated as the greatest source of negative interactions. While negative interactions in interpersonal and familial relationships have not been examined extensively among adolescents with cancer, these findings mirror normative adolescent literature and suggest developmentally expected behavior. Conflict with parents – and particularly mothers – is common during adolescence and can be characterized as a form of individuation and autonomy-seeking (Steinberg & Morris, 2008). For adolescents with cancer, there simply may be more opportunities for both support and conflict with mothers during treatment. As mothers are often the primary caregiver when a child has cancer, patients are likely interacting with their mothers more frequently than other individuals. Frequent negative interactions with siblings are also developmentally normative. Conflict between siblings, even at high frequency or intensity, is typical throughout childhood and

adolescence and provides an important socialization opportunity as siblings learn to navigate interpersonal conflict (Brody, 1998).

Social functioning and psychological adjustment were similar when compared to US norms for youth 8-17 years-old, suggesting that adolescents with cancer may not experience marked deficits in these domains during the first-year post-diagnosis. This finding contrasts prior literature suggesting that average social functioning is lower than US norms (Husson et al., 2017) and that psychological adjustment is poor among AYAs with cancer (for a review, see Samsom-Daly & Wakefield, 2013). However, most prior studies in these areas have included a broader age range, and few have specifically examined an adolescent sample. For example, while Husson and colleagues (2017) found that social functioning was lower than norms at diagnosis and one- and two-year follow up, their sample ranged from 14-39 years-old and was compared to norms for individuals 18-44 years-old. Additionally, age-related differences in psychological adjustment within the AYA group are understudied, and existing evidence is mixed. Some studies have demonstrated higher risk among those diagnosed at younger ages (Smith et al., 2013; Zebrack et al., 2014), while others have found emerging and young adults to be at higher risk. For example, Kim and Yi (2013) identified better adjustment in adolescents (15-19) compared to both emerging adult (20-25) and young adult (26+) groups. It is possible that older adolescents and young adults with cancer may be more likely to experience greater social functioning deficits and psychological adjustment problems compared to adolescents due to developmental factors. For example, younger adolescents may experience less overall life disruption due to cancer as they are often able to transition back into school after treatment. In contrast, older adolescents may feel left behind as their peers move away or leave for college,

and young adults who have already moved away from home prior to diagnosis may be forced to return home and leave their peer environment in order to receive treatment.

Differences in social functioning and psychological adjustment were examined based on demographic and treatment-related factors, revealing a number of notable patterns. In contrast to prior literature identifying female gender as a risk factor for poor psychosocial functioning in the broader AYA population (McCarthy et al., 2016; Phillips-Salimi & Andrykowski, 2013; Warner et al., 2016), males and females scored similarly on all constructs. This discrepancy may be an artifact of the small sample size in the current analysis. However, it may also be due to the lower age of the sample relative to other studies of AYAs, as gender differences in anxiety and depression do not typically emerge until approximately age 14 and tend to become more pronounced in later adolescence (Salk et al., 2017; Wade et al., 2002). Some differences were identified based on age and race. On average, older adolescents (15+ years) reported lower peer interaction quality and higher loneliness compared to younger adolescents (<15), though differences were not substantial (< .5 SD). Additionally, older adolescents (15+ years) reported notably higher anxiety and depressive symptoms (+1 SD) compared to younger adolescents (<15 years). This finding further suggests a need for future research to explore age-related differences in adjustment within the AYA age range, as older adolescents may be at increased risk for negative psychosocial outcomes. White/Caucasian adolescents reported lower peer interaction quality and higher loneliness compared to other race adolescents. However, this difference is difficult to interpret given that only three participants (23%) identified as other races.

There was a moderate correlation between both social functioning and number of siblings and psychological adjustment and number of siblings, suggesting that adolescents with more siblings tended to report lower peer interaction quality, higher loneliness, and higher anxiety and

depression. While no studies to date have looked at relations between family structure and psychosocial adjustment in this population, one explanation may be that having more children in the family causes increased stress for parents during treatment, which may then affect the wellbeing of the adolescent with cancer either directly or through parents' mental health. However, many mechanisms could explain this relation, and no conclusions regarding causality or directionality can be drawn based on these associations. Thus, future research is needed to explore any association between number of siblings, social functioning, and psychological adjustment.

Differences based on treatment-related factors were also explored, including diagnosis, time since diagnosis, whether or not adolescents primarily lived at home during treatment, and whether or not adolescents were currently enrolled in school. Adolescents diagnosed with lymphoma reported notably higher anxiety and depression compared to those diagnosed with leukemia or other diagnoses. This pattern is not consistent with prior literature, which has identified sarcomas and CNS malignancies as diagnoses that have been consistently associated with greater psychological distress and lower quality of life (Sansom-Daley & Wakefield, 2013). Thus, this difference is difficult to interpret and may be an artifact of the small sample size in the current analysis.

Though living at home during treatment did not appear to be associated with differences in social functioning or adjustment, adolescents who reported currently attending school reported lower peer interaction quality, higher loneliness, and higher anxiety and depression compared to those not currently attending school. This finding contrasts prior literature examining the relevance of school attendance, most of which has suggested that school disruption is associated with risk for distress (Kwak et al., 2013; Yanez et al., 2013; Zebrack et al., 2014). However,

Yanez and colleagues (2013) suggest that this association may develop in later months post-diagnosis as AYAs transition to survivorship, potentially explaining why this trend was not demonstrated in the current sample. Interestingly, time since diagnosis did not appear to be consistently associated with differences in social functioning or adjustment. Evidence has been mixed regarding the effect of time since diagnosis on AYA adjustment, with some studies suggesting that distress is maintained over time (Kwak et al., 2013b) and others suggesting that distress increases after the first year of treatment (Yanez et al., 2013). Importantly, effects of time since diagnosis on psychosocial adjustment may vary greatly based on diagnosis and treatment course. As the current study was not sufficiently powered to further stratify participants based on both time since diagnosis and diagnosis group, it is difficult to disentangle these effects.

Methodological limitations related to recruitment may have impacted study enrollment rates. The enrollment rate in the current study was lower than expected, and lower than similar studies conducted within this institution. This was primarily due to “passive declines”, or instances where the family was not able to be reached after repeated attempts. A number of factors may explain this difference. First, recruitment procedures may have affected ability to contact families and willingness to enroll. While families were initially contacted with an opt-out letter addressed from a physician at Seattle Children’s Hospital (SCH), recruitment calls were made using a phone number associated with the University of Washington, not SCH. Thus, families may have been less likely to answer calls from an unknown number. In addition, all approaches were conducted via phone rather than in-person. Other studies using in-person approaches at SCH have yielded higher enrollment rates (i.e., Rosenberg et al., 2018), suggesting that adolescents and caregivers may be more likely to consent if approached in-person. Future

research on this topic may benefit from using hospital-associated phone numbers to contact potential participants and in-person approaches to mitigate this issue. Second, the potentially sensitive nature of the study topic may have also influenced ability to contact potential participants and their willingness to enroll. While only one eligible participant explicitly stated their reason for decline as discomfort with the topic, it is possible that others felt uncomfortable with the idea of discussing their peer relationships and thus chose not to answer or return calls from the study team.

A notable limitation of the current study was the snowball method used to recruit peers. During the recruitment call, potential patient participants were informed that an optional component of the study was to share a flyer about the study with up to three peers who may be interested in participating. The flyer provided a brief summary of the study aims and asked peers to contact the study team directly if they were interested in participating. This flyer was provided as a PDF via email to participating adolescents and/or their parents. Patients were also asked to provide the initials of the friends they intended to share the flyer with as part of their survey. While 50% of patients completed this portion of the survey, peer enrollment rates were very low (5%). Thus, this method was not feasible. Given the multiple steps necessary for a peer to enroll using this method, there were many opportunities for break-down. It is possible the patients who enrolled understood this component was optional and did not intend to share the flyer. Patients or their parents may have intended to share the flyer but forgotten to do so given the many competing demands of cancer treatment. Last, patients may have shared the flyer and peers then either forgot to follow-up with the study team or were not interested in participating.

Future research aiming to study peer perspectives should select an alternative recruitment method. One possibility may be enrolling patient/peer dyads rather than first enrolling patients

and allowing peer participation to be optional. This latter method was used in the current study so that patients could participate even if they were not close to their friends or did not have a friend who was interested in participating. Another alternative may be to obtain patient permission to approach peers through their school. Teachers could be asked to distribute flyers to classmates, who would then be asked to contact the study team directly. However, patients may be less likely to feel comfortable with this method and this may only be feasible for younger adolescents who are enrolled in school. Lastly, studies could use a similar snowball method but include more frequent reminders to participants about sharing the study flyer and following-up with friends if they had shared it already. However, this would potentially increase participant burden or cause discomfort among those who did not want to have a peer participate.

For recruitment, consent, and data collection, the current study used exclusively phone and online methods rather than in-person. As previously mentioned, not using in-person approaches may have negatively affected enrollment rates. However, all families who provided verbal consent via phone were able to complete the online consent forms with minimal issues. Once a participant was enrolled, all contact was via phone or email, including scheduling and reminders, and surveys were distributed exclusively via email through RedCap. Many participants expressed a preference for email contact, and though given the option to receive surveys via mail, all participants opted to complete surveys online. Lastly, qualitative interviews were also conducted via phone rather than in-person. Given the high rates of study completion over a relatively brief period (5 months), these methods appear to be feasible for consent and data collection purposes.

Though using online/phone methods rather than in-person may have contributed to lower enrollment rates, they may have promoted enrollment and participation for some participants.

First, a number of eligible participants were no longer staying locally by the time they were contacted (i.e., those off-treatment), so in-person approaches and/or interviews may not have been possible for these families and limited their ability or willingness to participate. In addition, during consent conferences, some adolescents expressed liking that they were able to complete the study on their own time and that they didn't have to return to the hospital to participate. Lastly, using these methods minimized burden on the study team by allowing staff to conduct study activities when and where they were able, thus reducing staffing needs. Ultimately, future research may benefit from using a combination of in-person and remote contact methods to promote higher enrollment rates and reduce burden on both participating families and study teams.

Results of the current study demonstrated that adolescents with cancer perceive peer relationships to be important and that these relationships are a primary source of support. They strive to stay connected to their friends and their social world during treatment and feel that cancer has changed their relationships for better and for worse. They want their friends to be there for them, to check in often and visit as much as they can. These findings highlight the critical role of peer relationships in the lives of adolescents with cancer. They provide further evidence that the quality of these relationships may be an overlooked contributor to psychosocial outcomes for these at-risk youth. If so, addressing patients' social connection and support needs may lessen developmental disruption and promote better psychological adjustment for adolescents with cancer.

## CHAPTER 5 | General Discussion

The present series of studies examined how interpersonal relationships are affected when a child or adolescent is diagnosed with cancer. The first two studies examined family relationships among children with cancer. The first study focused on the sibling relationship and tested whether various cancer-related stressors were associated with levels of sibling conflict over the first year of treatment. The second study examined how conflict in family relationships interrelate by examining patterns of spillover between marital adjustment and parent-child conflict. The last study examined peer relationships of adolescents with cancer using qualitative methods to describe patient and peer experiences of friendships during the first year of treatment.

### 5.1 Summary of Findings

Taken together, these studies demonstrate that interpersonal relationships are impacted when a child has cancer. First, cancer may negatively affect sibling relationship quality. In Study 1, families who experienced more stressors over time relative to other families also reported more conflict between the child with cancer and their siblings. Similarly, in Study 3, adolescents with cancer reported that sibling relationships were their primary source of negative interactions compared to other family members and peers. While some sibling conflict is typical among children, elevated conflict is not and may place children at risk for poor adjustment outcomes (Kim et al., 2007; Pike et al., 2005)

Second, results suggested that these changes in dyadic relationships do not occur in isolation, as problems in one relationship, such as the marriage, can have effects on other relationships within the family, such as the parent-child relationship. From a family systems perspective, each relationship within the family both affects and is affected by other relationships and the dynamics within the family as a whole (Feinberg, Solmeyer & McHale, 2012). Thus, it is

not surprising that a major stressor such as a child's cancer diagnosis has downstream effects on each family relationship, and that problems in one relationship contribute to problems in others.

Third, the present studies suggested that peer relationships are also affected by cancer in both positive and negative ways. Adolescents with cancer described changes in their relationships, as they grew closer to some friends and became further from others. They discussed a desire to stay connected with peers and their life from before cancer and described experiences of support from friends. This strong desire to stay connected with peers is developmentally expected given the salience of these relationships during adolescents. Furthermore, it is not surprising that peer support is impactful for adolescents with cancer as close peer relationships are associated with wellbeing among this age group.

These findings advance current understanding of interpersonal relationships among children and adolescents with cancer. Study 1 is among the first to focus on sibling relationships in this population, providing both description of change in sibling relationship quality over time and how this trajectory is affected when families are dealing with high levels of prolonged stress. Study 2 is the first to examine interrelations between family relationships rather than adjustment of family members, thereby contributing to current understanding of family dynamics during treatment and suggesting intervention targets beyond individual adjustment. Lastly, Study 3 provides novel description of adolescents' relationships with non-ill peers during treatment and provides initial evidence that peer support may be protective for these at-risk youth.

## **5.2 Clinical Applications**

The present studies provide a number of insights that can be applied in clinical settings or inform future research. First, results highlight need for family-level screening and interventions that consider the family as a system rather than focusing on the individual adjustment of family

members. In terms of screening, it may be beneficial for social work teams to routinely assess family functioning and conflict levels to identify families in need of intervention. Providing marital counseling in the early months after diagnosis may be maximally effective in helping to minimize later problems in the family, including parent-child relationship. Such intervention would be particularly beneficial to couples that experience marital distress in the first months after diagnosis (Katz et al., 2016), though could also serve a preventative function by supporting happily married couples as they navigate the myriad challenges and stressors inherent in cancer treatment. Promoting sibling relationship quality may also be important for some families, particularly those dealing with high levels of stress. This could be accomplished by applying existing treatments such as the *More Fun with Sisters and Brothers* program (Kennedy & Kramer, 2008). This program focuses on fostering emotion regulation skills in order to help siblings navigate negative emotional interactions more effectively. As emotion regulation may be challenging during treatment, fostering these skills may help ameliorate sibling relationship concerns.

Second, given that peer support is highly valuable for adolescents with cancer, providers and parents should strive to help adolescents maintain their peer relationships during treatment to the extent possible. For instance, a major takeaway from Study 3 was that adolescents with cancer desire to stay connected with friends through frequent communications and visits. Both patients and peers noted the importance of frequent communication to maintain their friendship, stay updated on each other's lives, and cope with the challenges of cancer. Patients may benefit from parental encouragement to reach out to their friends or set aside special times during the day for talking to friends. As expected for this age group, both patients and peers described using a number of technological methods to stay in touch, including texting, FaceTime, social media,

and online gaming. Parents can aid in support through providing their children with access to smartphones, tablets, or videogames when possible. In addition, hospitals should ensure that adolescent patients have access to wireless internet in their hospital rooms and provide necessary technology for staying in contact. As both patients and peers noted that not being able to see one another was a major hardship, parents can help promote these interactions through arranging and prioritizing visits with friends. Having teen-friendly spaces in the hospital may also help mitigate these challenges by providing a sanitary space for adolescents to spend time with their peers when they visit.

Psychoeducation and skill-building around social support may be useful for both adolescents with cancer and their peers. For patients, this may involve help thinking through which individuals provide support for them, what kind of behaviors feel supportive to them, and what they can do to seek the support they need from their friends and family. They may benefit from learning how other teens with cancer have sought support and maintained their relationships, which may encourage them to stay connected. For example, many patients advised other teens with cancer to make the effort to stay in touch with friends themselves even if they haven't heard from them, because they felt keeping up with communication was critical. Peers may likewise benefit from some psychoeducation on this topic. As one teen with cancer noted, some friends may not know what to do to be supportive. Learning how they can support their friend and understanding what behaviors are perceived as supportive may help address this issue.

Additionally, peers described feeling confused about their friends' diagnosis and treatment. For example, one peer described not knowing what leukemia was when her friend first told her, and later feeling scared and worried when she visited the hospital and saw her friend's port. Thus, education around cancer and treatment may help peers better understand their friends' diagnosis

and know what to expect when they see them. Peers also described strong emotions and worry regarding their friends' cancer, which suggests they may also benefit from psychoeducation around stress management and coping.

### **5.3 Methodological Limitations**

Across studies there were some methodological limitations related to recruitment methods, attrition and measurement. First, in each study systematic differences may have existed between participants who enrolled versus those who did not. For instance, some families did not consent to be approached by the study team and some who were approached did not enroll due to feeling overwhelmed, because the child was too ill, or because the child was uncomfortable with the subject matter. Thus, these families may have systematically differed relative to those who enrolled in their stress levels, degree of family conflict, or degree of difficulty with peer relationships. Particularly for Study 3, it is also possible that those who enrolled may have been more likely to have had positive experiences with their interpersonal relationships during treatment whereas those who did not may have been less interested in sharing their experiences. This may have led to an underestimation of the degree to which relationships had been negatively affected since the child was diagnosed.

Second, concerns with attrition were present in Study 1 and Study 2, as missing data was substantial at later time points. While missing data was accounted for analytically in both studies to the extent possible, non-random missing data may still have affected results. For example, factors such as overall family functioning or disease prognosis may have contributed to a families' likelihood to complete questionnaires and may also be related to different patterns of conflict in each family subsystem. Additionally, when stress or conflict was higher in a given month families may have been less likely to complete questionnaires leading to underreporting

of stress or conflict levels. In terms of feasibility, assessing families on a monthly basis during the first year of cancer treatment may be excessively burdensome.

Third, issues related to measurement may have influenced results. For Study 1 and Study 2, all measures were completed by the primary caregiver. Thus, these studies had risk of single-reporter bias such that stressed caregivers or those struggling with their own psychological adjustment may be more likely to notice or be more sensitive to problems in family relationships. Using multiple reporters for questionnaire data or using observational methods to assess family conflict may mitigate this concern in future work.

Finally, generalizability of findings may be limited by the homogenous nature of these samples. The majority of participants across studies were recruited from Seattle Children's Hospital, which serves a relatively racially homogenous population compared to other geographic regions in the U.S. Indeed, for Study 1 and Study 2, our samples were majority White/Caucasian with a high average income and caregiver education level. Thus, it is unclear whether these findings would generalize to non-White or lower income families, or those living in other geographic regions.

#### **5.4 Future Directions**

While these studies advance current understanding of interpersonal relationships of children and adolescents with cancer, many unanswered questions remain regarding how relationships are affected by cancer, how quality of relationships are interrelated, and how relationships influence adjustment. Critically, future research is also needed to develop and test interventions to promote relationship quality and support during and after treatment.

Continued longitudinal research is needed to examine how interpersonal relationships change across the cancer trajectory and understand factors that influence this trajectory. While the

current series of studies focused on relationships during the first-year post-diagnosis, it is also important to understand if and how these relationships continue to be affected after treatment has ended. For instance, relationship problems that are exacerbated by stress, such as sibling conflict, may remediate naturally once the family is no longer experiencing high levels of stress associated with treatment. In contrast, some relationships may continue to degrade. Adolescents with cancer who became distant from peers during treatment may struggle to rebuild these relationships or develop new ones once they have transitioned back into school (Jones et al., 2011). Future research should also consider how cancer's effect on interpersonal relationships could vary based on diagnosis or disease status. For instance, the present studies focused solely on children and adolescents with new cancer diagnoses. Relapsed or refractory disease, which often means more aggressive treatment and a poorer prognosis, may have different or more pronounced effects on family and peer relationships compared to a new diagnosis. Relatedly, examining how relationship quality varies based on diagnosis or treatment course may also be useful in identifying at-risk families or patients.

We also lack a clear understanding of how interpersonal relationships relate to one another in this population. While Study 2 suggested a link between the marital and parent-child relationships, no studies to date have examined how quality of other family relationships influences the sibling relationship or how family and peer relationships are interrelated. Among families of healthy children and adolescents, evidence suggests that parent-child relationship quality may influence peer relationships such that children who have conflictual relationships with parents tend to have poorer peer socialization skills (Elicker, England, & Sroufe, 2016), and those with highly connected parent-child relationships tend to be more accepted by peers and

have more friends (Clark & Ladd, 2000). Understanding which relationships are most likely to affect others or drive problematic cascades may further refine targets for intervention.

An important next step for research in this area is to understand how relationship quality is associated with patient and family adjustment outcomes in the context of cancer. While the current studies further understanding of how relationships are impacted by cancer, it remains unclear how this impact affects the wellbeing of child with cancer or their family members. For instance, while sibling relationships have been found to predict adjustment among normative samples (Kim et al., 2007), few studies have examined this link among children with cancer. Likewise, the link between marital conflict and child maladjustment has been well-established in the normative literature (Davies & Cummings, 1994; Grych & Fincham, 1990; Katz & Gottman, 1993) but has yet to be examined in pediatric samples. Given the unique stressors the family experiences when a child has cancer and related elevations in risk for maladjustment of family members, associations between family conflict and adjustment may operate differently in this context. Identifying risk or protective factors within the family may be fruitful for informing and targeting intervention efforts.

In a similar vein, the link between peer support and psychosocial adjustment in adolescents with cancer remains understudied. While social support more broadly has been linked to better adjustment outcomes in this population (Corey et al., 2008; McCarthy et al., 2016), few studies have looked at peer support specifically. In addition, no theoretical models have been developed to explain how peer relationship quality, social support, and adjustment may be linked. For example, results from the Study 3 suggest that adolescents with cancer perceive that staying connected to peers during treatment is critical. Patients felt that frequent communication helped them maintain their friendships and felt that friends reaching out was a

demonstration of support. In contrast, those who did not talk to their friends often felt their friendships had become more distant and reevaluated how supportive or close their relationship had been. Based on these findings, one potential mechanism may be that communication with peers contributes to perceptions of peer support, which then contributes to better patient adjustment. As adolescents with cancer are at substantially elevated risk for negative psychological outcomes and social functioning deficits and this risk is maintained long after treatment has ended (Husson et al., 2017; Sansom-Daly & Wakefield, 2013; Warner et al., 2016), understanding the etiology of these outcomes and identifying protective factors such as peer support may identify needed intervention targets.

Finally, a critical future direction for this work is to develop and test interventions to promote high quality relationships and social support for youth with cancer. While some evidence-based psychosocial interventions exist for children with cancer and their families, the majority focus on survivors rather than those receiving treatment (Kazak, 2005). Of those that are designed to be delivered during treatment, most focus on individual adjustment of patients and caregivers through teaching skills such as stress management and coping (Kazak et al., 2005; Rosenberg et al., 2018; Yi-Frazier et al., 2017). In contrast, few interventions exist to date that directly target family relationship quality, and fewer have been tested as Randomized-Controlled Trials (RCTs). In a notable exception, Kazak and colleagues (2005) developed and tested the *Surviving Cancer Competency Intervention Program* for families of both newly diagnosed children and adolescent survivors. This intervention is designed for caregivers, and uses an interpersonal focus to help caregivers cope, normalize their experience, and focus on the family's strengths (Kazak et al., 2004; Kazak et al., 2005). While this intervention does not explicitly

target family conflict, it may provide a useful foundation on which to build future family-based interventions.

Regarding peer relationships, one simple method of intervention to bolster peer support may be to disseminate information about support provision to peers themselves. In Study 3, patients described many ways in which their friends demonstrated their support, including checking in with them frequently, visiting them, sending them gifts, and engaging in public displays of support (i.e., making an online post). This information may be useful for peers, particularly for those who are unsure of what they can do to support their friend with cancer. Thus, determining how best to disseminate this information is a critical first step. Given that many of the support behaviors described in the current study are fairly straightforward (i.e., checking in every day, talking through things, sending gifts), face-to-face or individual intervention may not be necessary for most peers. An alternative option may be to develop a guide for teens supporting a friend with cancer. Such a guide could be disseminated by providers, patients, parents or other peers. As adolescents today are considered “technology natives”, with 95% of US teens owning a smartphone and 45% reporting that they use the internet “almost constantly” (Pew Research Center, 2018), an online format for such a guide may be more developmentally appropriate than a traditional book or pamphlet. Furthermore, more adolescents report using YouTube compared to any other online platform, with 85% endorsing use and 32% reporting that it is their most used platform (Pew Research Center, 2018). Thus, creating a video guide that can be easily accessed and shared via YouTube may be one promising future direction for disseminating this information.

## **5.5 Conclusion**

The current studies provide novel insights regarding the effects of pediatric cancer on family and peer relationships which can be used to inform future descriptive research and intervention development. These studies highlight that in order to understand how cancer affects child outcomes and provide comprehensive psychosocial care, it is critical to consider how the cancer experience interacts with the developmental and ecological context of the child. Family and peer relationships are among the most proximal contexts for socioemotional development, and both affect and are affected by child wellbeing. Thus, while protecting the quality of these relationships is important for all children, it is even more essential for youth with cancer to prevent negative psychosocial outcomes and promote wellbeing during treatment and through survivorship.

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**Table 1.** Descriptive Information for Sibling Conflict and Stress Predictors

	T1	T2	T3	T4	T5	T6	T7	T8	T9	T10	T11	T12
<b>Construct (possible range)</b>												
<b>Sibling Conflict (1-5)</b>												
<b>n</b>	91	5	43	64	63	70	49	53	53	50	16	59
<b>M</b>	2.27	1.80	2.39	2.37	2.37	2.40	2.27	2.22	2.44	2.55	1.90	2.43
<b>SD</b>	.89	.65	.99	1.00	.85	.90	.86	.90	.96	1.09	.67	.90
<b>General Life Stress: Frequency (0-18)</b>												
<b>M</b>	3.03	1.71	2.35	2.09	1.81	1.62	1.55	1.72	1.47	1.72	1.61	1.51
<b>SD</b>	(1.78)	(1.50)	(1.48)	(1.53)	(1.50)	(1.49)	(1.40)	(1.38)	(1.44)	(1.39)	(1.51)	(1.54)
<b>General Life Stress: Difficulty (0-54)</b>												
<b>M</b>	5.98	2.87	4.12	3.61	3.30	2.79	2.78	2.76	2.43	2.86	2.71	2.52
<b>SD</b>	(4.48)	(2.61)	(3.12)	(2.78)	(3.11)	(2.76)	(2.76)	(2.50)	(2.57)	(2.62)	(2.95)	(2.50)
<b>Cancer-Related Stress: Frequency (24-120)</b>												
<b>M</b>	72.58	56.80	68.67	44.00	62.04	59.58	55.85	55.27	49.08	38.92	39.58	42.80
<b>SD</b>	(16.03 )	(26.41 )	(16.73 )	(14.85 )	(19.72 )	(18.25 )	(19.86 )	(21.44 )	(19.85 )	(15.84 )	(19.91 )	(16.59 )
<b>Cancer-Related Stress: Difficulty (24-120)</b>												
<b>M</b>	53.47	50.40	49.89	61.31	47.27	44.23	42.00	42.04	37.56	43.50	35.36	37.67
<b>SD</b>	(15.81 )	(15.57 )	(17.32 )	(18.07 )	(18.41 )	(16.41 )	(15.30 )	(16.30 )	(15.56 )	(17.67 )	(18.61 )	(16.93 )
<b>Financial Strain (1-39)</b>												
<b>M</b>	19.58	21.43	19.31	18.25	17.86	17.72	17.82	18.64	17.83	18.24	17.50	17.97
<b>SD</b>	(7.01)	(5.71)	(5.83)	(6.85)	(6.99)	(6.99)	(7.64)	(6.97)	(7.80)	(6.92)	(7.69)	(7.42)
<b>Treatment Intensity (2-10)</b>												
<b>M</b>	7.7852	7.57	7.90	7.61	8.03	7.55	8.13	7.87	7.44	7.56	7.78	7.44
<b>SD</b>	(1.65)	(2.15)	(1.48)	(1.70)	(1.99)	(1.97)	(1.61)	(2.10)	(2.55)	(2.42)	(2.23)	(2.14)
<b>Life Threat (2-10)</b>												
<b>M</b>	7.37	5.57	7.30	7.11	7.32	6.73	7.01	6.94	6.69	7.30	7.35	6.98
<b>SD</b>	(2.20)	(2.50)	(2.37)	(2.19)	(2.20)	(2.46)	(2.25)	(2.53)	(2.48)	(2.59)	(2.40)	(2.42)

**Table 2.** Building the Multilevel Growth Model and Final Parameter Estimates

<b>Building the Multilvel Growth Model</b>				
		<b>Fully Fixed</b>	<b>Random Intercept</b>	<b>Fully Random</b>
<b>Model Fit</b>				
-2 Restricted Log Likelihood		1659.82	1178.72	1165.94
AIC		1661.82	1182.72	1173.94
BIC		1666.24	1191.56	1191.62
<b>Fixed Effects</b>				
Intercept		2.40 (.07)***	2.49 (.09)***	2.49 (.10)***
Linear Slope		.01 (.01)	.02 (.01)**	.02 (.01)*
<b>Variance Components</b>				
Intercept			.57 (.09)***	.66 (.01)***
Linear Slope				.01 (<.01)*
<b>Stress Predictors: Final Model Parameter Estimates</b>				
	<b>Intercept</b>	<b>Within-Families Effect</b>	<b>Between-Families Effect</b>	<b>Sibling Contact</b>
<b>General Life Stress</b>				
Frequency	1.96 (.18)***	.02 (.02)	.21 (.08)*	.10 (.03)***
Difficulty	1.98 (.18)***	.01 (.01)	.10 (.03)***	.10 (.03)***
<b>Treatment Related Stress</b>				
Frequency	1.94 (.18)***	<.01 (.01)	.01 (.01)*	.10 (.03)***
Difficulty	1.90 (.19)***	.002 (.002)	.02 (.01)*	.12 (.03)***
<b>Financial Stress</b>				
Financial Strain	1.91 (.18)***	.01 (.01) <sup>+</sup>	.03 (.01)*	.12 (.03)***
<b>Assessment of Life Threat/Treatment Intensity</b>				
Life Threat	1.86 (.18)***	.01 (.02)	.05 (.04)	.12 (.03)***
Treatment Intensity	1.87 (.19)***	.02 (.02)	.04 (.05)	.12 (.03)***

*Note.* All non-significant interaction terms were dropped from final models for parsimony. <sup>+</sup> = <.10; \* = <.05, \*\* = <.01, \*\*\* = <.001. AIC = Akaike Information Criteria; BIC = Bayesian Information Criteria; “Sibling Contact” reflects estimates for covariate of amount of contact between siblings.

**Table 3.** Observed Variable Means, Standard Deviations, and Correlations

Variable	1.	2.	3.	4.	5.	6.	7.
1. T1 Marital Adjustment	--						
2. T2 Marital Adjustment	.72***	--					
3. T3 Marital Adjustment	.74***	.80**	--				
4. T1 Parent-Child Conflict	-.18	-.16	-.38**	--			
5. T2 Parent-Child Conflict	-.33**	-.33**	-.53**	.59***	--		
6. T3 Parent-Child Conflict	-.24	-.38**	-.33*	.41**	.74***	--	
7. Tx Intensity	-.05	-.12	-.14	-.13	.09	.02	--
<i>N</i>	96	74	57	104	81	61	
<i>M</i>	123.26	122.87	125.75	8.54	9.06	8.82	2.56
<i>SD</i>	20.56	22.78	22.02	2.59	2.86	2.96	0.71

*Note.*  $N = 117$ . For marital adjustment, higher scores represent better adjustment. Scores  $\leq 107$  indicate marital distress. For parent-child conflict, higher scores represent more conflict. For treatment intensity, higher scores represent more intensive treatment. \* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$ .

**Table 4.** Model Fit and Fit Comparisons

<b>Model Fit Information</b>				
	$\chi^2$ (df)	RMSEA	CFI	AIC
A. Baseline	18.18 (11)	.07	0.97	5628.4
<b>B. Marital → Parent-Child</b>	<b>12.18 (9)</b>	<b>.05</b>	<b>0.99</b>	<b>5626.4</b>
C. Parent-Child → Marital	13.46 (9)	.06	0.98	5627.7
D. Bidirectional	7.53 (7)	.02	0.99	5625.7
<b>Nested Model Fit Comparisons</b>				
	$\chi^2_{dif}$ (df <sub>dif</sub> )			
A vs. B	6.00 (2)*			
A vs. C	4.73 (2)			
A vs. D	10.65 (4)*			
B vs. C	1.28 (0)***			
B vs. D	4.65 (2)			
C vs. D	5.93 (2) <sup>+</sup>			

*Note.* <sup>+</sup> $p = .05$ , \* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$ . RMSEA = Root Mean Square Error Approximation; CFI = Comparative Fit Index. AIC = Aikake Information Criteria. Final model in **bold**.

**Table 5.** Sample Demographic Information

	<b>Patients (n = 14)</b>	<b>Peers (n = 2)</b>
	n (%)	n (%)
Gender		
Female	9 (64%)	1 (50%)
Male	5 (36%)	1 (50%)
Age (years)		
M (SD)	14.8 (1.8)	14.0 (1.0)
12	2 (14%)	
13	2 (14%)	1 (50%)
14	1 (7%)	
15	5 (35%)	1 (50%)
17	4 (28%)	
Diagnosis Group		
Leukemia	6 (43%)	
Lymphoma	5 (36%)	
Sarcoma	2 (14%)	
CNS-Tumor	1 (7%)	
<b>Patient Sample Self-Reported Demographic Information (n = 13)</b>		
Time Since Diagnosis (months)		
M (SD)	6.3 (3.2)	
Race		
White/Caucasian	10 (76%)	
Asian	4 (31%)	
American Indian	1 (8%)	
Ethnicity		
Hispanic	1 (8%)	
Non-Hispanic	12 (92%)	
Currently Attending School		
Yes	8 (62%)	
No	5 (38%)	
Living at Home During Treatment		
Yes	9 (69%)	
No	4 (31%)	
Number of Siblings		
Median	1	
1	7 (54%)	
2	5 (39%)	
4+	1 (8%)	

**Table 6.** Reliability Estimates for NRI Social Support Provision Scale

	Mother	Father	Sibling	SO	SS Friend	OS Friend	Extra Friend
Support $\alpha$	.78	.80	.88	NA	.83	.89	.78
Negative Interaction $\alpha$	.98	.97	.88	NA	.96	.89	.73

*Note.*  $\alpha$  = Cronbach's Alpha; SO = significant others; SS = same-sex; OS = other-sex

**Table 7. Semi-Structured Interview Guide for Patient Participants**

**Relationship Qualities & Communication**

So, first just tell me a little bit about your friendships right now. *[Can prompt if needed: Who are your closest friends?]*

How would you describe your friendships since you were diagnosed?

How often do you see your friends right now?

When you see them, what do you usually do together?

How often do you talk to your friends right now?

How do you communicate mostly? (in person, phone, text, social media?)

When you talk to them, what do you talk about?

Do you ever talk to them about cancer?

**Changes in Relationships**

How have your friendships changed since your diagnosis?

Do you feel as close to your friends as you did before?

Are your closest friends now the same as before you were diagnosed? *[if needed, prompt further: why? What changed?]*

Some teens say they feel like they've become closer with some friends and more distant with others – has that been true for you?

**Support**

How supported do you feel by your friends right now?

What does it mean for a friend to be supportive for you right now?

Can you tell me a story about something a friend did for you since your diagnosis that was really supportive or helpful for you?

Based on your experience, if you had a friend with cancer what would you do to help support them?

**Challenges & Resources**

What has been the hardest part about staying close with your friends during treatment?

Has there been anything that has helped you stay close to your friends during your treatment?

Is there anything you are worried or concerned about regarding your friendships?

What advice would you give another teen with cancer about their friendships? Are there any changes they should expect or anything you think they should know that might help them?

Last, I want to see if there is anything I didn't ask you about that you would like to share. As someone who is trying to understand what friendships are like for teens with cancer, is there anything else that you think it would be important for me to know?

**Table 8. Semi-Structured Interview Guide for Peer Participants**

**Relationship Qualities**

What has it been like for you to have a friend with cancer?

How would you describe your friendship with [patient] right now?

How long have you known [patient]?

How has your friendship with [patient] changed since [he/she] was diagnosed?

**Challenges & Resources**

What have been the hardest parts about having a friend cancer? *[prompt if needed: Can you tell me more about that? Can you tell me a story about that?]*

What has helped you stay close to [patient] right now?

Is there anything that has made it hard stay close to [patient]? *[follow-up, if needed: is there anything that makes it hard to see [patient], to stay in contact with [patient]?]*

Can you think of anything good that has come from this experience? *[prompt, if needed: Good things for your friendship? Good things for you personally?]*

**Coping**

How do you think having a friend with cancer has affected you personally?

What helps you cope right now? *[clarify, if needed: when you're feeling upset, how do you get through it? Is there anything that you do?]*

What advice would you give to another teen who just found out their friend has cancer?

Last, I want to see if there is anything I didn't ask you about that you would like to share. Is there anything else that you think it would be important for me to know?

**Table 9.** Descriptive Statistics for Social Functioning & Psychological Adjustment

	Peer Interactions	Loneliness	Anxiety	Depression
M	47.63	53.25	45.04	48.07
SD	10.09	8.75	10.65	11.49
Range	29.40-64.50	38.50-67.60	33.50-66.90	35.20-71.40

**Table 10.** Mean Comparisons by Demographic Variables

	Peer Interactions M (SD)	Loneliness M (SD)	Anxiety M (SD)	Depression M (SD)
Gender				
Male (n = 4)	48.90 (14.16)	54.55 (9.69)	41.80 (9.33)	48.13 (16.08)
Female (n = 9)	47.07 (8.75)	52.67 (8.87)	46.48 (11.40)	48.04 (10.05)
Race				
White/Caucasian (n = 10)	45.62 (10.66)	54.16 (9.61)	43.84 (9.03)	48.78 (12.34)
Other Races (n=3)	54.33 (3.58)	50.20 (5.20)	49.03 (16.82)	45.70 (9.76)
Age				
< 15 (n = 4)	51.10 (5.11)	49.30 (9.90)	38.90 (10.80)	40.60 (10.80)
>= 15 (n = 9)	46.09 (11.60)	55.00 (8.19)	47.76 (9.96)	51.39 (10.68)
Number of Siblings*	$r = -.40$	$r = .53$	$r = .47$	$r = .53$

*Note.* \*Bivariate correlation between number of siblings and each variable

**Table 11.** Mean Comparisons by Treatment-Related Variables

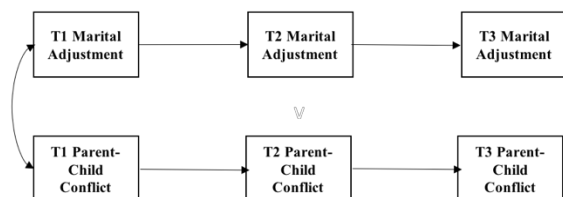
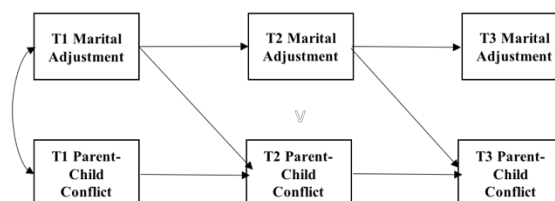
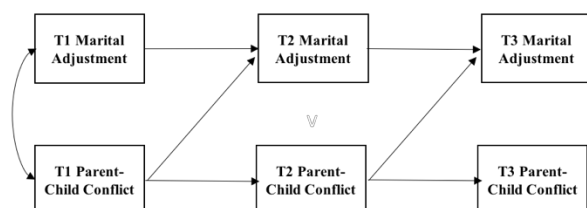
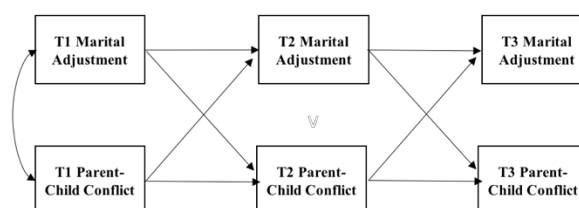
	Peer Interactions M (SD)	Loneliness M (SD)	Anxiety M (SD)	Depression M (SD)
<b>Diagnosis</b>				
Leukemia (n = 6)	51.80 (7.79)	50.76 (8.48)	42.72 (13.23)	43.73 (10.08)
Lymphoma (n = 5)	44.52 (9.47)	55.96 (8.96)	49.48 (7.28)	54.10 (11.61)
Other (n = 2)	42.90 (19.09)	54.05 (12.70)	40.90 (10.47)	46.00 (15.27)
<b>Time Since Diagnosis</b>				
3-6 mo (n = 8)	45.03 (10.47)	55.03 (9.39)	43.00 (7.82)	48.59 (12.49)
6-12 mo (n = 5)	51.80 (8.87)	50.40 (7.71)	48.30 (14.56)	47.24 (11.03)
<b>Living at Home During Treatment</b>				
No (n = 4)	48.38 (5.60)	56.50 (4.67)	46.68 (14.84)	46.73 (10.56)
Yes (n = 9)	47.30 (11.86)	51.80 (9.96)	44.31 (9.26)	48.67 (12.44)
<b>Currently Attending School</b>				
No (n = 5)	51.14 (8.85)	50.82 (9.47)	37.36 (6.42)	40.56 (9.35)
Yes (n = 8)	45.44 (10.76)	54.76 (8.57)	49.84 (10.12)	52.77 (10.53)

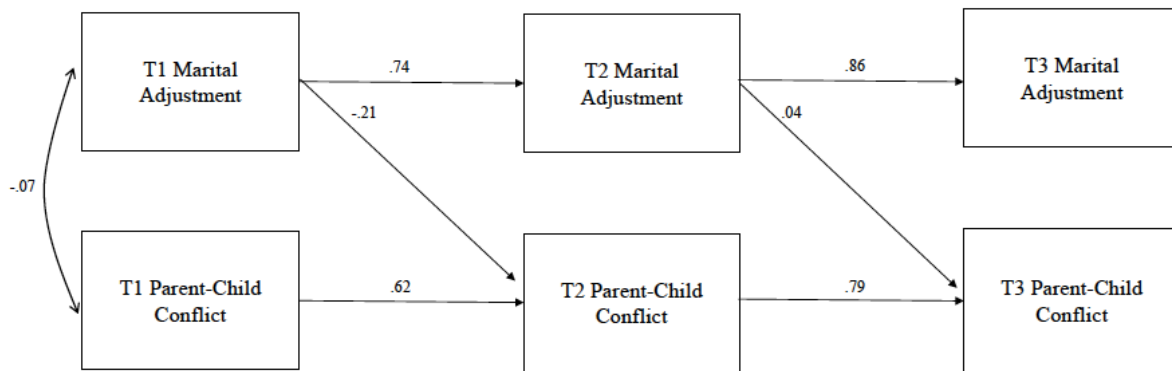
**Table 12.** Bivariate Associations between Social Functioning & Psychological Adjustment

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	1.	2.	3.	4.
1. Peer Interaction Quality	--			
2. Loneliness	-0.68	--		
3. Anxiety	-0.50	0.58	--	
4. Depression	-0.79	0.79	0.84	--

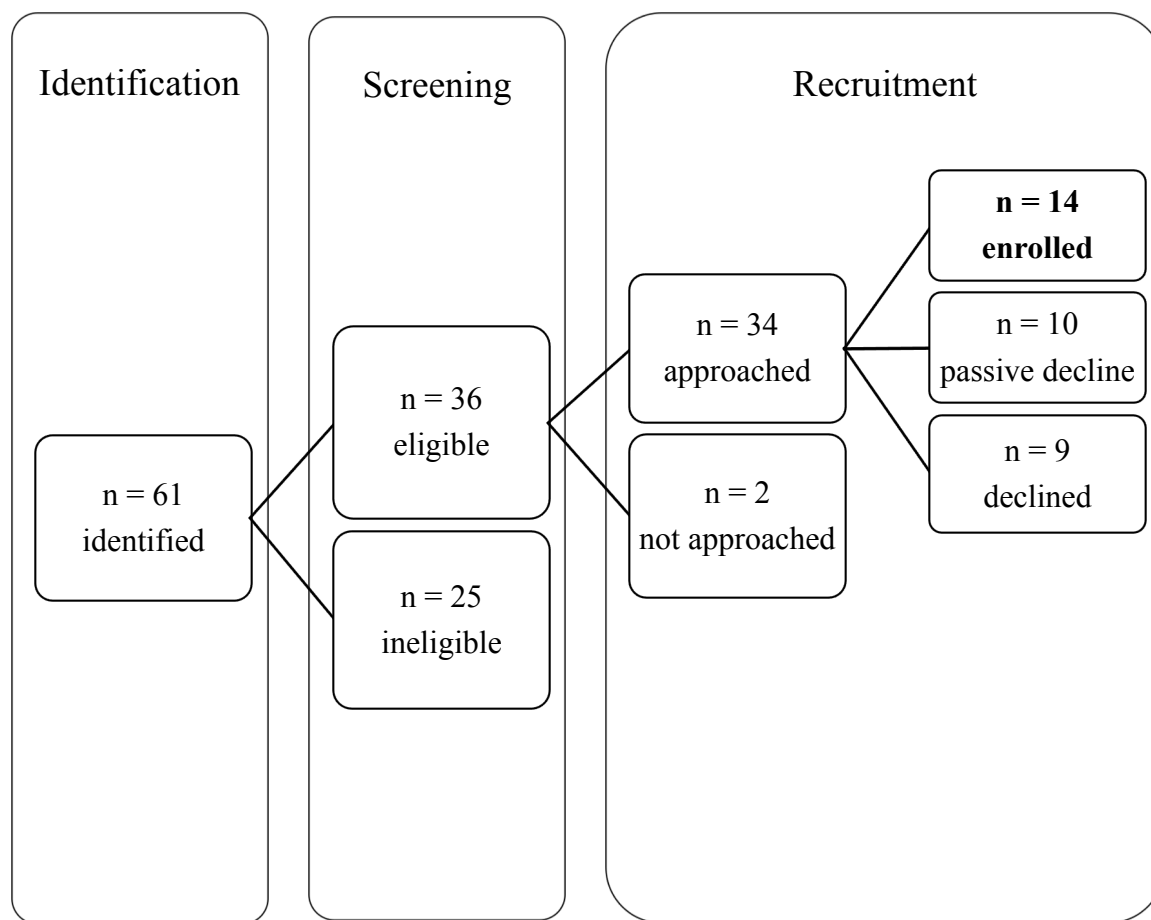
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**(A) Baseline Model of Independence****(B) Marital Adjustment → Parent-Child Conflict Unidirectional Model****(C) Parent-Child Conflict → Marital Adjustment Unidirectional Model****(D) Fully Reciprocal Model****Figure 1.** Theoretical models for unidirectional vs. reciprocal nested model comparisons.

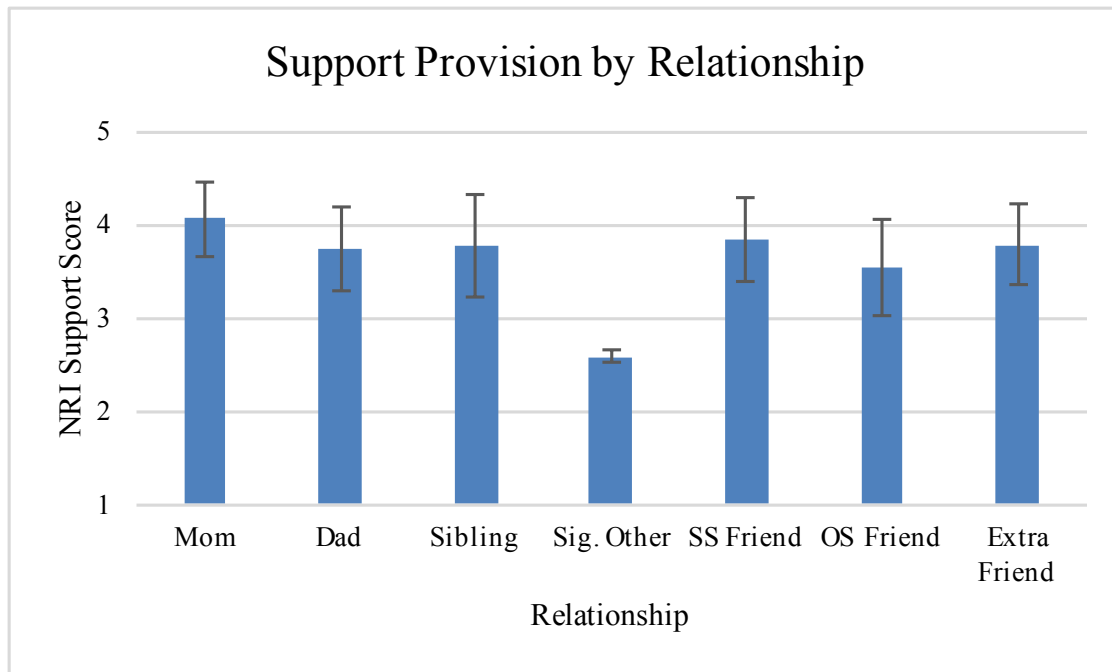


**Figure 2.** Final substantive model with standardized path estimates.

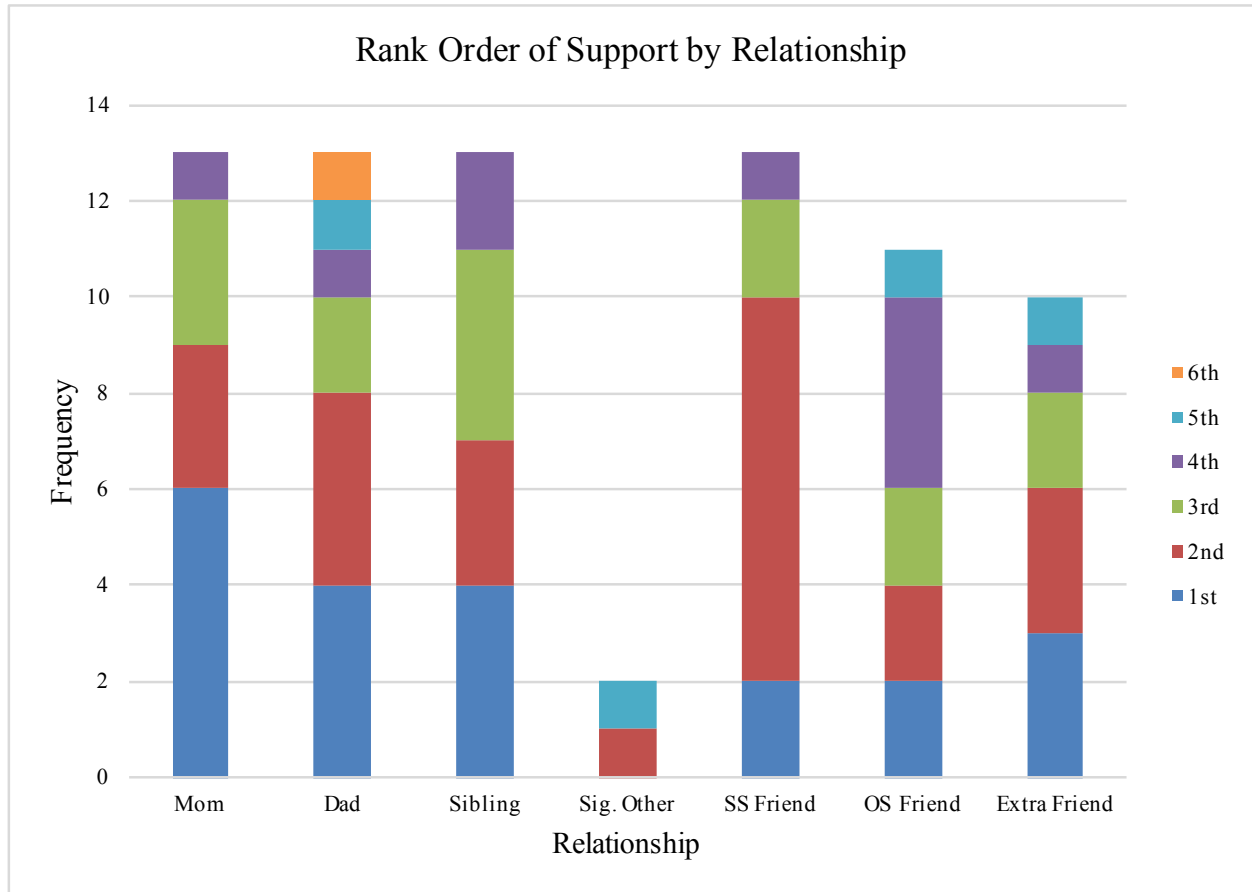
$\chi^2(9) = 12.18, p = .12$ ; CFI = .99; RMSEA = .05. Auxiliary correlates were included but are not depicted for clarity (see Data Analytic Strategy for more information).



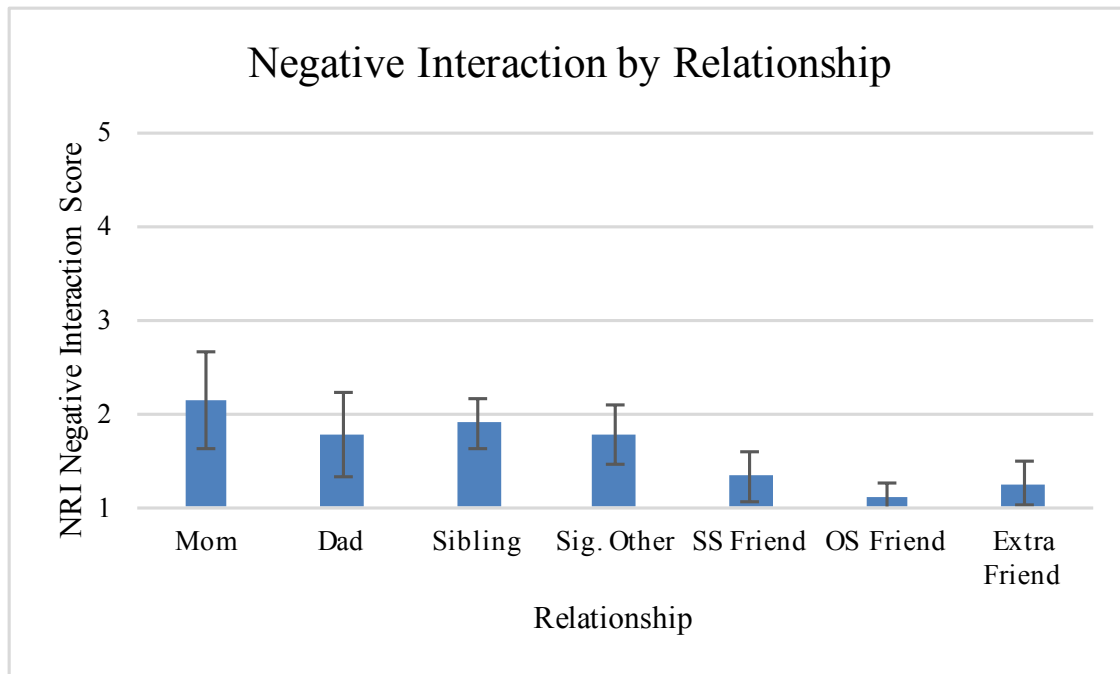
**Figure 3.** Summary of Patient Recruitment Procedures



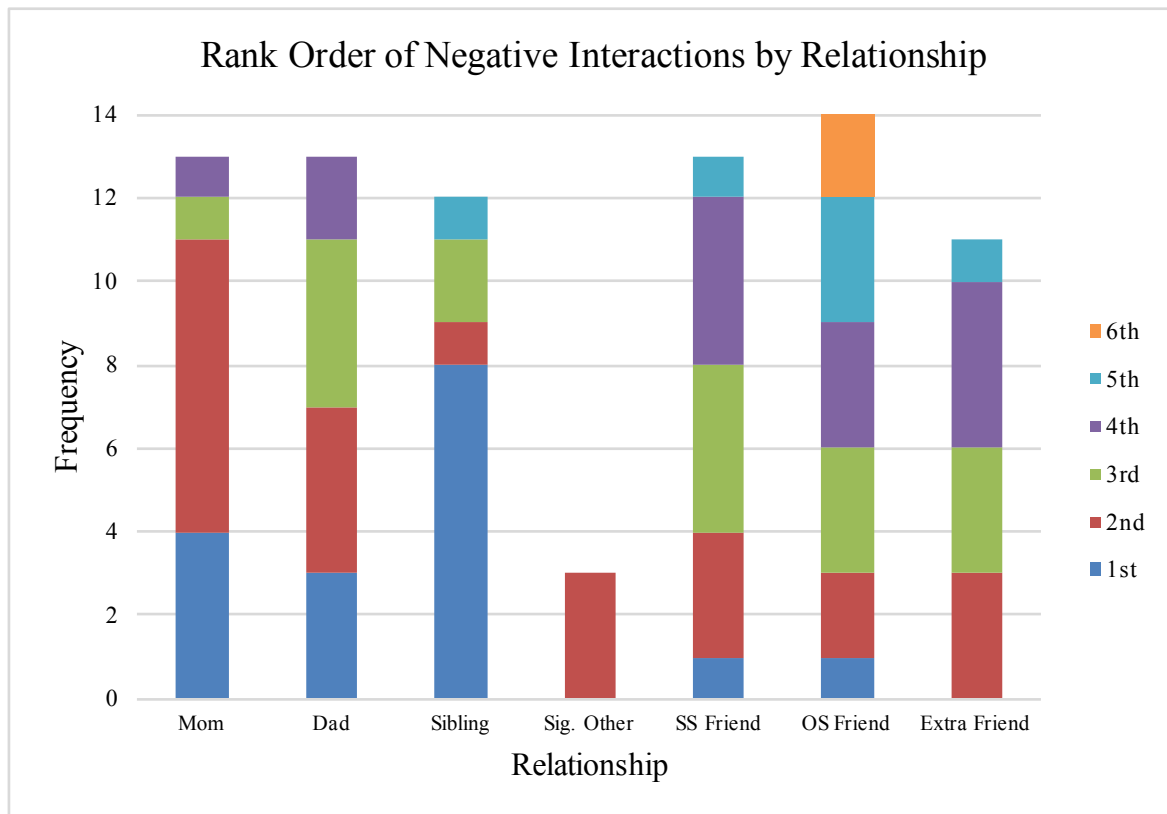
**Figure 4.** NRI Support Provision by Relationship



**Figure 5.** Rank Order of Support by Relationship



**Figure 6.** NRI Negative Interaction by Relationship



**Figure 7.** Rank Order of Negative Interactions by Relationship