# SOCIOECONOMIC STATUS AND ACCESS TO RESOURCES AS PREDICTORS OF SIBLING HOPE AND SIBLING COPING WITH PEDIATRIC CANCER-RELATED STRESSORS

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# **DEDICATION**

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by

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#### **Abstract**

Although most siblings of pediatric cancer patients adjust well to cancer diagnosis and treatment course, some siblings demonstrate significant adjustment difficulties. One question is whether these siblings may also be at risk for reduced hope and poor coping, especially if family roles and routines are particularly disrupted during cancer treatment. This study will examine the degree to which sociodemographic variables (i.e., socioeconomic status and access to resources) predict pediatric cancer patients' siblings' hope and coping. Data were obtained from siblings of pediatric oncology patients and their parents at a large pediatric cancer treatment center using paper-and-pencil questionnaires, telephone/in-person structured interviews, and internet-based questionnaires. I hypothesized a direct relation between sociodemographic variables and sibling hope. I also hypothesized a direct relation between sociodemographic variables and adaptive coping and an inverse relation between sociodemographic variables and maladaptive coping. Both hypotheses were partially supported; sociodemographics as a whole did not significantly predict hope or adaptive coping, but did account for 5% and 10% of the variance, respectively. Sociodemographics did not significantly predict internalizing/externalizing coping or avoidant coping. To rule out superfluous findings, more research on the predictive value of income is needed. Future studies should also further examine other components of socioeconomic status and access to resources on sibling adjustment to pediatric cancer diagnosis and treatment. Life disruption variables significantly predicted all outcome variables, indicating that life disruption plays an important role in sibling adjustment. Providers should be aware of the impact of life disruption and find ways to care for siblings and families to ensure they experience as little disruption as possible.

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# LIST OF ABBREVIATIONS

CHS – The Children's Hope Scale

SRCS – Self-Report Coping Scale

#### **CHAPTER ONE**

#### Introduction

Researchers in recent years have devoted increased attention to healthy siblings' adjustment to pediatric cancer (Carpenter, Sahler, & Davis, 1990; Sidhu, Passmore, & Baker, 2006). Most extant studies suggest the majority of siblings adjust well to cancer diagnosis and treatment (for review see, Alderfer et al., 2010), with a small subset of siblings experiencing improvements in family closeness and increased maturity, independence, and empathy over the course of a brother's or sister's treatment (for review see, Alderfer et al., 2010). Yet, findings also suggest a subset of siblings experience significant adjustment difficulties, such as maladaptive behavior, anxiety, social stress, and somatization (Sidhu et al., 2006).

Regarding specific outcomes of pediatric cancer diagnosis and treatment, Alderfer and colleagues (2010) found that many siblings of pediatric cancer patients experience loss of parental attention, diminished family and community support, disruption in academic achievement, increased disruptive behavior, and diminished quality of life following a brother's or sister's cancer diagnosis. Perhaps not surprisingly, extant studies propose a number of family, sociodemographic (i.e., socioeconomic status and access to resources), individual, and illness-specific factors predict sibling adjustment to pediatric cancer (Cohen, Friedrich, Jaworski, Copeland, & Pendergrass, 1994; Sloper & While, 1996). Although scholars have long recognized the role of hope in predicting psychosocial adjustment (e.g., goal attainment; Bernardo, 2010), researchers have only recently begun evaluating hope among pediatric cancer patients and their families (e.g., Barerra et al., 2013; Germann et al., 2015). Studies consistently demonstrate links between parents' hope and their own adjustment (Kylma & Juvakka, 2012); however, no

published studies have empirically evaluated siblings' hope during a brother's or sister's cancer treatment.

Although some studies have identified sibling coping as a predictor of siblings' overall quality of life and adjustment, few studies have evaluated predictors of siblings' adaptive and maladaptive coping. Of those studies that have evaluated coping, most find that siblings are at risk of using maladaptive coping strategies throughout cancer treatment (for review see, Alderfer et al., 2010; Cohen et al., 1994). These strategies include internalizing, externalizing, and avoidant coping (Cohen et al., 1994). One question is the extent to which sociodemographics could impact siblings' hope and coping strategies for managing illness-related stressors.

As detailed in the sections that follow, previous research has demonstrated links between sociodemographics and sibling coping (Sloper & While, 1996). However, this literature is limited in that researchers have not consistently operationalized or assessed socioeconomic status or family access to resources in the same ways. The current study is designed to fill research gaps by utilizing a more nuanced conceptualization of sociodemographics that includes variables designed to proxy both socioeconomic status and families' access to resources. In the current study, I evaluated sociodemographic variables as predictors of siblings' hope and their coping strategies for managing pediatric cancer-related stressors. Because socioeconomic status and access to resources have been linked with improved adjustment in patients in previous studies (Cohen et al., 1994; Ryan, Eddington, Hullmann, & Ramsey, 2013), I hypothesized sociodemographic variables (i.e., variables measuring socioeconomic status and access to resources) would positively predict sibling hope after controlling for sibling age, sibling gender, and cancer-related life disruption (i.e., number of nights the patient has spent in the hospital over the past year, number of hospital admissions since diagnosis, relapse status). I also hypothesized

sociodemographics would predict sibling coping after controlling for sibling age, sibling gender, and cancer-related life disruption. Specifically, I predicted socioeconomic status and access to resources associated with cancer treatment would positively predict adaptive coping and negatively predict maladaptive coping.

#### **CHAPTER TWO**

#### **Review of the Literature**

#### **Sibling Adjustment to Pediatric Cancer**

Pediatric cancer impacts both the ill child's and family members' stress levels and acts as a major life disruption (Horwitz & Kazak, 1990). Although patients' and parents' adjustment to pediatric cancer has been well studied (for review see, Alderfer et al., 2010), researchers have only recently begun elucidating the effects of pediatric cancer on healthy siblings' concurrent and long term adjustment. Some scholars suggest siblings may be at more risk than other family members because healthy siblings' needs are often least adequately met (Murray, 1995; Murray, 2000). One potential source of stress after pediatric cancer diagnosis is a change in family dynamics (e.g., family roles, routines, power structure). Research shows healthy sibling(s) receive less parental attention than patients because of family financial strain, decreased family activities, and prioritization of the ill child's needs (Cohen et al., 1994; for review see, Houtzager, Grootenhuis, & Last, 1999; McGrath, Paton, & Huff, 2005; Woodgate, 2006). Many families also experience challenges maintaining equilibrium (i.e., balance of each family members' responsibilities). Mothers often spend extended time in the hospital, thereby disrupting parents' and siblings' daily lives (for review see, Long & Marsland, 2011; Mercer & Richie, 1997). A review of the literature shows many siblings adjust well to family system changes, but a significant subset of siblings are at risk for adjustment problems (Alderfer, Laybay, & Kazak, 2003; Alderfer & Noll, 2005). Concurrent and long-term sibling adjustment problems can include vulnerability to emotional problems, low self-esteem, anxious and depressive symptoms, externalizing symptoms (e.g., behavioral problems), posttraumatic stress symptoms, and decreased quality of life (for review see, Alderfer et al., 2010; Houtzager, Oort, HoeskstraWeebers, Caron, Grootenhuis, & Last, 2004; Nolbris, Enskar, & Hellstrom, 2007; Sloper & While, 1996; Woodgate, 2006). Although more research is needed to explain variance in sibling outcomes, adjustment predictors could distinguish the subset of siblings who are at risk.

In the sections that follow, I will first review sibling outcomes associated with pediatric cancer treatment. Then, given links between children's adjustment and their ability to cope effectively with stressful life events (Houtzager, Oort, et al., 2004), I will review risk factors for sibling adjustment problems. Next, I will review extant literature on siblings' hope and coping during pediatric cancer. Finally, I will review the role of sociodemographics in sibling adjustment and will discuss the present study.

## **Pediatric Cancer Adjustment Outcomes for Healthy Siblings**

Numerous qualitative and quantitative studies indicate a range of positive and negative sibling outcomes following cancer diagnosis and treatment. A recent review of sibling adjustment by Alderfer et al. (2010) reveals that siblings frequently report loss of attention, diminished family and community support, disrupted academic achievement, behavior changes, and diminished quality of life after a brother's or sister's cancer diagnosis and during treatment. Other studies have found that siblings can be left without sufficient emotional and instrumental support, often perceive being marginalized from the family, may have lower self-esteem, may experience increased anxiety, may have more health risks (e.g., sleeping problems, eating problems, somatic complaints, neglected health problems), and frequently feel lonely (e.g., Barrera, Fleming, & Khan, 2004; Houtzager, Grootenhuis, & Last, 2001; Sloper, 2000; Zeltzer et al., 1999) throughout and after cancer treatment.

Most research evaluating sibling outcomes during pediatric cancer treatment have focused on sibling quality of life as an outcome. For example, B. A. Houtzager worked with

several groups of researchers to examine quality of life in siblings over the course of pediatric cancer treatment (Houtzager, Grootenhuis, Caron & Last, 2004; Houtzager, Grootenhuis, Hoekstra-Weebers, Caron, & Last, 2003; Houtzager, Grootenhuis, Hoekstra-Weebers, & Last, 2005; Houtzager, Oort, et al., 2004). In a seminal study, Houtzager and colleagues administered the Dutch Children's AZL/TNO (Academisch Ziekenhuis Leiden/Toegepast-Natuurwetenschappelijk Onderzoek) Quality of Life Questionnaire (DuCATQoL; Vogels et al., 2000) and the Cognitive Coping Strategies Scale for Siblings (Grootenhuis & Last, 2001) to 83 siblings at one month and at six months post diagnosis to assess overall self-reported quality of life and coping. At both time points, siblings reported more emotional problems than population norms. At one month post-diagnosis, siblings' quality of life remained significantly diminished compared to norms, but improved at 6 months and two years post-diagnosis. Like other areas of adjustment, preexisting psychopathologies also can predict quality of life diminishment severity (Alderfer, et al., 2010). No studies have examined siblings' hope when they have a brother or sister undergoing cancer treatment. However, because hope can moderate adjustment outcomes for patients and parents (e.g., Barrera et al., 2013; Germann et al., 2015; McClement & Chochinov, 2008), hope may be an important predictor of sibling adjustment to pediatric cancer.

#### **Predictors of Sibling Adjustment to Pediatric Cancer**

Family predictors of sibling adjustment. Family systems theory suggests family members' adjustment to stressful life events is interrelated (Becvar & Becvar, 2013). For example, family members can be affected by one family member's experience of distress.

Consistent with family systems theory, a growing body of research reveals clear links between parent coping and siblings' ability to adjust to pediatric cancer (e.g., Sloper & While, 1996; Zeltzer et al., 1996).

Given the link between parent coping and siblings' ability to adjust to pediatric cancer, it is important to understand correlates of parent distress during pediatric cancer. A recent review on family adjustment to childhood cancer (Long & Marsland, 2011) found that parent distress is often correlated with lower family supportiveness, higher family conflict, lower family satisfaction, poorer communication, and lower family cohesion. Specific to siblings, evidence suggests that mothers' own health concerns and poor sense of well-being positively predict siblings' low social competence, behavior problems, and somatization during a brother's or sister's cancer treatment (Houtzager, Grootenhuis & Last, 2001; Sloper & While, 1996; Zeltzer et al., 1996). When mothers of children with cancer show symptoms of depression or anxiety, healthy siblings are more likely to demonstrate psychosocial problems, including internalizing coping (Robinson, Gerhardt, Vannatta, & Noll, 2007).

Because most studies on associations between parent and sibling adjustment to pediatric cancer include only or predominately mothers, fathers' role in sibling adjustment to pediatric cancer is not well understood (for review see, Long & Marsland, 2011). Only one study has compared mothers' and fathers' roles in sibling adjustment to pediatric cancer (Long, Marsland, & Alderfer, 2015). Long and colleagues distributed questionnaires to families (186 mothers, 70 fathers, and 209 siblings) and found that higher sibling-reported psychological control by mothers and fathers predicted greater sibling distress. Sibling distress may also be predicted by lower father-reported acceptance (Long, Marsland, & Alderfer, 2015). Although fathers' unique impact on healthy siblings' adjustment has not been studied, some studies have demonstrated that fathers' adjustment may explain unique variance in pediatric cancer patients' adjustment. One study found that younger children and boys showed more vulnerability to anxiety and distress when fathers were distressed, concluding that fathers' adjustment plays a significant role

in the well-being of children with pediatric cancer (Robinson et al., 2007). Other studies have included fathers in samples of caregivers but have not found any clear links to sibling adjustment, likely resulting from so few fathers participating, and subsequent poor statistical power (for review see, Long & Marsland, 2011; Robinson et al., 2007).

Family systems are comprised of a number of relational (e.g., parent-child relationship quality), individual (e.g., each family member's adjustment), and resource-related (e.g., social support) constructs (Becvar & Becvar, 2013). Extent of family system disruption during pediatric cancer treatment is one of the strongest predictors of psychosocial distress among pediatric oncology patients' siblings (for review see, Long & Marsland, 2011; Houtzager, Oort, et al., 2004). Family system disruption can present in a number of ways. For example, parents whose ill child has particularly extensive disease or poor prognosis are likely to spend more days in the hospital and in turn experience a greater shift in family roles and routines. Alternatively, in twoparent households, one parent may choose to discontinue employment during pediatric cancer treatment to improve caregiver availability for the ill child's medical needs. Related to family system disruption, two family system constructs most largely studied in the pediatric oncology population are family cohesion and adaptability (Cohen et al., 1994; Houtzager, Oort, et al., 2004). Family cohesion refers to closeness and mutual involvement in the family system (Kazak & Barakat, 1997). Other components of family cohesion include family rituals (Santos, Crespo, Canavarro, & Kazak, 2015), alliances (Long, Marsland, & Alderfer, 2015; Olson, Russell, & Sprenkle, 1983), sense of shared responsibility, enjoyment of family time and relationships (Long, Marsland, & Alderfer, 2015; Olson et al., 1983), emotional bonding, appropriate boundaries between parent and child, collective decision making, mutual interests, and shared recreation (Olson et al., 1983). Published research provides inconsistent findings regarding

family cohesion during pediatric cancer. Whereas some studies have found improved family cohesion to be an unanticipated benefit of enduring pediatric cancer (Long, Marsland, & Alderfer, 2015), other studies have found lower levels of family cohesion in pediatric oncology families compared to healthy samples (Cohen et al., 1994; Houtzager et al., 2004). One explanation for discrepant findings could be that only a specific subset of families are at risk for low cohesion when a distressing situation arises (for review see, Long & Marsland, 2011); however, studies have yet to evaluate predictors of family cohesion in the pediatric cancer population. A review by Houtzager et al. (1999) revealed several sibling-specific outcomes related to lower family cohesion during pediatric cancer treatment: lower adaptability, externalizing problems, and poor social competence. Family cohesion is also inversely associated with siblings' anxiety and insecurity, and positively associated with siblings' quality of life (Houtzager, Oort, et al., 2004; Santos et al., 2015).

Distinct from family cohesion (Houtzager, Oort, et al., 2004), family adaptability is the tendency for a family system to change its power structure, role relations, and relationship rules in response to situational and developmental stress (Olson et al., 1983). When a child is diagnosed with cancer, family routine often is compromised and the family system is forced to adapt (Fiese et al., 2002). One way mothers and fathers adapt to pediatric cancer is by splitting roles and responsibilities to maintain "household equilibrium" (i.e., to keep the family running smoothly; McCubbin, Balling, Possin, Frierdich, & Bryne, 2002). For example, fathers often take more time to care for the rest of the family at home compared to their previous involvement, while mothers frequently attend hospital appointments and care for the sick child's needs more so than fathers (Long, Marsland, & Alderfer, 2015; Prchal & Landolt, 2012). Families are forced to continuously adjust to changing demands over the cancer treatment trajectory. Researchers

have found the most pronounced family disruptions occur at initial diagnosis and early treatment stages, with consistent scheduling and a family's perception of normalcy generally not emerging until a year after diagnosis depending on variations in patient functioning (Harrington, Kimball, & Bean, 2009; McGrath et al., 2005).

Pediatric cancer research offers differing conclusions regarding the degree of family adaptability most predictive of optimal sibling adjustment. Two studies using the Family Adaptability and Cohesion Evaluation Scales (FACES II; Olson, Portner, & Bell, 1985) to obtain parent report of family adaptability found that high levels of adaptability were correlated with more favorable sibling outcomes (e.g., less internalizing and externalizing coping, fewer behavioral problems; Cohen et al., 1994; Horwitz & Kazak, 1990). Other studies found high levels of family adaptability are associated with sibling adjustment problems including loneliness, anxiety, lower quality of life, behavioral-emotional problems, and feelings of insecurity (Houtzager et al., 1999). Some scholars conclude that moderate levels of family adaptability may provide an ideal milieu for optimal sibling adjustment outcomes during pediatric cancer (Olson et al., 1983). Another possibility is that associations between family adaptability and family members' adjustment outcomes are moderated by family cohesion, such that strong family cohesion could act as a protective factor when family adaptability exceeds optimal levels (Houtzager et al., 2003). For example, some scholars have posited that, when a family's adaptability exceeds optimal levels, the family is likely to experience instability in power structure and role relations. Scholars suggest this kind of change can cause perceptions of chaos and result in poor outcomes for family members, with family cohesion partially mitigating these risks (Houtzager et al., 2003). Researchers have yet to empirically evaluate these relations.

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Consistent with findings explicating the importance of family cohesion and the role of family adaptability in sibling adjustment, the socio-ecological theory suggests an individual's adjustment depends not only on personal characteristics, but also on social constructs (e.g., family adjustment, peer and outside support) and available resources (e.g., financial means, time spent with parent(s), communication outlets; Robinson et al., 2007). Inherent in the Socio-Ecological Model is not only the importance of family influence, but also the importance of the larger social and community context with which an individual interacts. Following socioecological theory rationale, research investigating sibling adjustment to pediatric cancer finds social support from the family (e.g., parents) and the community (e.g., teachers, classmates, friends, other school related support) can have a significant positive impact on sibling adjustment (Alderfer et al., 2003; Barrera et al., 2004; for review see, Long & Marsland, 2011). Yet, although a number of studies document increased social and community support immediately following a child's cancer diagnosis (Mascara, 2003; Wallander & Varni, 1998), several studies have found siblings perceive themselves as having low social support (Alderfer et al., 2003; Alderfer & Hodges, 2010; Barrera et al., 2004; Mascara, 2003) and limited peer socialization (Murray, 2000) further into the treatment course. In line with sibling perceptions, several studies reveal that siblings' health concerns are often overlooked and that financial burdens limit resources for healthy siblings' needs (Zeltzer et al., 1996). Given that several studies document clear links between social support and siblings' psychosocial outcomes, siblings' lack of perceived support and limited family resources could place siblings at risk for adjustment problems.

**Social predictors of sibling adjustment.** Adjustment is effort to change one's behavior to conform to the needs of an environmental change or effort to change the environment to

conform to the needs of the individual (Aggarwal, 2014). Siblings' social support appears to predict adjustment to cancer-related stressors in a number of domains, including internalizing and externalizing symptoms and academic performance. For example, higher perceived social support is related to fewer depressive and anxious symptoms, fewer behavioral problems (Barrera al., 2004), and higher self-esteem (Wallander & Varni, 1998). In the most comprehensive study on sibling support to date, Alderfer and Hodges (2010) visited the homes of 161 families of pediatric cancer patients and administered batteries (Child Behavior Checklist, Revised Children's Manifest Anxiety Scale, Children's Depression Inventory – Short Form, Children's Post Traumatic Stress Scale, Child and Adolescent Social Support Scale, and Academic Competence Evaluation Scales) to assess internalizing (e.g., depressive) and externalizing (e.g., behavioral problems) symptoms, child competencies, and multi-faceted social support. Alderfer and Hodges' (2010) findings suggest siblings perceive friends as giving the most valuable social support followed by teachers and parents; however, different sources of support were uniquely related to sibling outcomes. Parent, friend, classmate, and other school support (i.e., other than teachers and classmates) were inversely related to sibling self-reported depression. Friend, classmate, and other school support also negatively predicted rule-breaking behavior and attention problems. Further, school support from peers and counselors was negatively associated with symptoms on problems scales and support from a close friend predicted better academic motivation and improved reading, math, and critical thinking skills.

Medical predictors of sibling adjustment. The risk and resilience model expands social-ecological theory, highlighting the role of disease and disability, interpersonal factors, psychosocial stressors, and stress processing factors in predicting an individual's psychosocial outcomes (Wallander & Varni, 1998). Wallander and Varni's (1998) tested a model of social-

ecological theory and empirically identified risk (i.e., disease and disability parameters, functional dependence, and psychosocial stressors) and resilience (i.e., intrapersonal factors such as competence, problem-solving ability, social-ecological factors, and stress-processing) factors that impact child adjustment to pediatric cancer. In testing this model (Wallander & Varni, 1998), findings indicated that maladjustment is positively related to patient medical severity and psychosocial stress and negatively related to the ill sibling's access to appropriate healthcare. Research demonstrates that siblings' insufficient knowledge about the diagnosis and treatment process (e.g., knowing few details of their brother's or sister's diagnosis and/or having little understanding of the treatment process) adversely affects sibling adjustment during pediatric cancer (Nolbris & Ahlstrom, 2014). Uncertainty may stem from siblings' limited knowledge and may correlate with siblings' maladaptive coping and adjustment problems (Bally et al., 2014; Long, Marsland, Write, & Hinds, 2015). Although specific oncological diagnoses and prognoses, in themselves, do not appear to significantly impact sibling adjustment, number of days the patient spends in the hospital can be inversely related to sibling adjustment, perhaps because of greater disruption in the family system (Grootenhuis & Last, 2007; Houtzager, Oort, et al., 2004; Long, Marsland, & Alderfer, 2015; Mack et al., 2007).

Individual predictors of sibling adjustment. Healthy siblings' individual characteristics (e.g., coping, premorbid adjustment problems) have a significant influence on siblings' adjustment to pediatric cancer (Cohen et al., 1994). No studies have prospectively examined siblings' psychosocial functioning prior to cancer diagnosis, but research findings suggests siblings who have preexisting psychological comorbidities or life stress are at especially heightened risk for adjustment difficulties after a brother's or sister's cancer diagnosis (e.g. Barbarin et al., 1995). The cancer experience can exacerbate preexisting conditions because of

cancer-related stress and increased risk for psychosocial problems in siblings, ill patients, and other family members. As explained by Santrock (2014), cognitive developmental theory proposes that adjustment depends largely on an individual's cognitive abilities and developmental level. Consistent with cognitive developmental theory, scholars propose the impact of pediatric cancer on sibling adjustment varies to a great extent based on a sibling's developmental level, cognitive abilities, and emotional capacities (Murray, 2000; Zeltzer et al., 1996). Current literature is inconclusive about the role of sibling age in adjustment outcomes, but some studies suggest adolescents are at greater risk for adjustment problems (e.g., health risks, depression, anxiety) than preschool- or latency-aged siblings (Houtzager et al., 1999; Zeltzer et al. 1996). Contradicting evidence purports younger children are at more risk for psychosocial distress (Long, Alderfer, Ewing, & Marsland, 2013; Rudolph & Hammond, 1999).

Discrepant findings regarding the moderating role of sibling age may result from different conceptualization, operationalization, and assessment methods among studies. For example, some studies use parent report of distress (e.g., Rudolph & Hammond, 1999), and others use sibling report (e.g., Long et al., 2013). Additionally, many published studies measure different kinds of distress (e.g., a mixture of depression, anxiety, perceived stress, post-traumatic stress, treatment intensity, and contextual threat; Long et al., 2013). Although direct links between age and sibling outcomes remain unclear, previous research indicates age mediates multiple risk factors. For example, one study identified the following risk factors related to age: vulnerability to peer distress, independent (i.e., fateful) vs. dependent (i.e., controllable) stressors, interpersonal (e.g., sibling-child conflict) vs. non-interpersonal (e.g., academic failure) stress, etc. (Rudolph & Hammond, 1999). Research remains needed to clarify and better understand mechanisms of variations in siblings' stress outcomes across age groups.

Cognitive ability buffers the negative effects of cancer diagnosis and treatment (Ownsworth, Dwan, Chambers, Walker, & Shum, 2014). Adults with cancer were found to have higher emotional well-being and fewer neurological problems when they had higher pre-morbid cognitive abilities (Ownsworth et al., 2014). Similarly, children with neurofibromatosis type-1 have less behavioral and social problems when cognitive ability is higher (Huijbregts & Sonneville, 2011). Long, Marsland, Wright, et al. (2015) proposed siblings' cognitive abilities aid in redefining their conceptualization of cancer and security, in turn positively influencing adjustment. Although no research to date has evaluated cognitive ability as a predictor of sibling adjustment, due to the similarity in patient and sibling experience of cancer diagnosis and treatment, it is likely cognitive ability also plays a role in sibling adaptation.

Cancer diagnosis and treatment can illicit many sibling emotions such as intrusive worry, jealousy, and aversion (Prchal & Landolt, 2005). Emotional functioning is one such variable that could influence how well a sibling adjusts to cancer-related stressors. Children who develop adaptive coping strategies in response to their negative emotions are more likely to positively adapt to cancer diagnosis and treatment (Prchal & Landolt, 2005). Another study found siblings who reported strong negative emotions did poorer in school and were more likely to cope using avoidance (Long, Marsland, Wright, et al., 2015). It is clear that emotional functioning plays a role in how siblings adjust to pediatric cancer, but more research is needed to clearly define the predictive value of emotional functioning.

Pediatric cancer adjustment literature has, to some extent, also evaluated sibling gender and birth order as adjustment predictors. Some scholars suggest girls and older siblings are more likely to take on responsibility for their sick brother or sister and in turn may experience more distress (Houtzager, Oort, et al., 2004; Murray, 2000). Consistently, two studies by the same

research group found sisters of pediatric cancer patients demonstrated more posttraumatic stress symptoms, anxiety, loneliness, insecurity, lower quality of life, and lower self-esteem compared to their healthy brothers (Houtzager et al., 2003; Houtzager et al., 2005). Yet, notably, some studies also show that brothers are more vulnerable to internalizing problems and independent distress as compared to sisters (Robinson et al., 2007; Rudolph et al., 1999). Further, still another study found no significant links between gender and sibling adjustment to pediatric cancer (Grootenhuis & Last, 2001). One possibility is that age and gender play a complex role in predicting sibling risk for psychosocial adjustment problems, possibly because of changes in development across life stages. More research is needed to determine the parameters within which age and gender predict sibling adjustment outcomes.

#### Hope

The construct of hope has no universal conceptualization, but the majority of pediatric cancer literature uses Snyder's (2002) definition: "the belief that one can find pathways to desired goals and become motivated to use those pathways." Hope has also been defined in other ways. Averill and colleagues (1990) suggested hope is thought-guided emotion (i.e., hope is an emotional state resulting from an individual's thoughts about goals and their ability to obtain goals) and is most useful for motivating behavior when a goal is important, under some personal control, moderately probable, and socially acceptable. Johnson (2007) defined hope as involving 10 different attributes, including positive outcome expectancy, individual characteristics (e.g., level of optimism, determination), spirituality, goal setting and attainment, physical comfort, and problem-solving. One study by Bernardo (2010) aimed to expand the hope construct by evaluating whether locus-of-hope is a dimension of hope in college students. He hypothesized two broad categories of hope: (1) internal locus-of-hope, which refers to the individual

perceiving he or she is the principle agent for goal-attainment, and (2) external locus-of-hope, which refers to perceptions that external forces limit or facilitate goal attainment. Bernardo further specified that external locus-of-hope could be subdivided into beliefs about family, peer, and spiritual influences. Using factor analysis and confirmatory factor analysis to test and validate his hypothesized models of locus-of-hope dimension, Bernardo demonstrated that internal and external locus-of-hope dimensions are driven by both individual pursuit and beliefs about external agents.

Despite multiple definitions of hope, scholars generally conceptualize hope as containing two broad dimensions: pathways and agency (Snyder, 2002; Snyder, Rand, & Sigmon, 2001). Pathways are the different ways an individual believes he or she can achieve his or her goals; to attain goals, an individual needs to view him or herself as capable of generating workable routes to identified goals (Snyder, 2002). Agency involves believing that one can investigate, change, and achieve goals he or she identifies (Snyder, 2002). Agency helps a person apply the requisite motivation to the best pathway available. Agency-directed thinking allows an individual to internally motivate him or herself to begin and continue pursuing a specific goal.

Despite being a similar construct, hope is distinct from problem-solving. Although hope and problem-solving both focus on goal setting and attainment, problem-solving involves only pathway thinking, whereas hope includes agency-directed cognitions (Snyder, 2002). Additionally, problem-solving theory does not encompass emotional experiences, whereas hope theory asserts emotions result from and motivate goal pursuit success (Snyder, 2002). Despite being distinct constructs, studies document positive correlations between problem-solving and hope (Felder, 2004; Snyder, Harris, et al., 2001).

## **Hope during Pediatric Cancer**

No studies have evaluated healthy siblings' hope in the pediatric oncology population; however, studies describing hope in pediatric oncology patients and parents could shed light on sibling experiences because of similarities between parent and sibling stressors (e.g., family role disruption, worry about the ill child's health). Generally, researchers have found hope plays a moderating role between cancer diagnosis/treatment and wellbeing for both pediatric oncology patients and their parents (Germann et al., 2015; Mack et al., 2007). One recent study found hope is positively related to pediatric cancer patients' quality of life (Germann et al., 2015). Other studies have found hope is inversely related to psychological distress among pediatric oncology parents (Mack et al., 2007; McClement & Chochinov, 2008; Snyder, Rand, et al., 1997) and positively predicts parents' quality of life and adjustment after a child's cancer diagnosis (Barrera et al., 2013).

Several studies document fluctuations in parental hope over their child's cancer trajectory, with parents' perceptions of child prognosis proving the most salient predictor (Bally et al., 2014; Barrera et al., 2013; Brunston, Mings, & Mackie, 1995; Granek, et al., 2013; Mack et al., 2007; Rustoen, Cooper, & Miaskowski, 2011). For example, if a child's prognosis is objectively poor, a parent's hope is likely to be lower than if a child's prognosis is good (Mack, et al., 2007). Consistent with these findings, parents of pediatric cancer patients generally report that the nature of their hope covaries with their child's health status, including the ill child's response to medical treatment and coping (Bally et al., 2014; Barrera et al. 2013). For example, as a child's prognosis improves, parents' hope level increases and shifts from hope for wellbeing in the moment toward hope for a cure (Bally et al., 2013).

Hope can be characterized as present-oriented or future-oriented. Whereas parents tend to focus on future-oriented hope (e.g., hope for a cure, hope for high school graduation) when children are doing medically well, parents tend to focus on present-oriented hope (e.g., hope for no suffering) as probability for a cure dwindles (Granek et al., 2013). Conversely, parents often report shifting their attention from hoping for a miracle to hoping for their child's future as the child's prognosis improves (Granek et al., 2013). Notably, even when their child's prognosis is poor, parents maintain hope in a variety of ways. Common themes for hope maintenance include accepting reality, establishing control, restructuring hope (e.g., moving from hoping for a cure to hoping for better quality of life), and using purposive positive thinking (e.g., choosing to think positively despite stressors; Bally et al., 2014). Parents of pediatric cancer patients also report maintaining hope by preparing for the worst and hoping for the best (Bally et al., 2014).

## **Predictors of Hope during Pediatric Cancer**

There are no existing studies that evaluate predictors of hope in pediatric cancer patients' siblings. Parental factors are particularly influential on siblings' adaptation to pediatric cancer (Sloper & While, 1996); therefore, because researchers have yet to evaluate predictors of sibling hope, this manuscript will examine predictors of parental hope. For parents of cancer patients, psychosocial support (Barrera et al., 2013), maintenance of family rituals and roles (Barrera et al., 2013), and strong spirituality (Bernardo, 2010) positively predict parental hope. In contrast, physical and emotional depletion (Bernardo, 2010), negative cognitive style (Barrera et al., 2013), maladaptive coping (Bernardo, 2010), external locus-of-control (Bernardo, 2010; Brunston et al., 1995), and negative perceptions of the child's prognosis (Mack et al., 2007) negatively predict parental hope. Parents' understanding of the child's medical illness may moderate links between poor child prognosis and parent hope, although the nature of these

relations remains unclear. One study found parents report difficulty maintaining hope when they know too much about their child's poor prognosis, possibly because it is difficult for parents to hope for a good outcome while worrying about potentially poor outcomes (Barrera et al., 2013). Conversely, another study found parents report higher levels of hope when prognostic disclosure from the medical team was greater (Mack et al., 2007). One possibility is that that a moderate level of prognostic disclosure and understanding is most beneficial to parents, as it is for children (McClement & Chochinov, 2008); however, no studies have empirically evaluated this notion.

Research regarding the association between sociodemographic variables and hope is limited in cancer literature. The only two findings elucidating sociodemographic variables' influence on hope are mixed with regard to the nature of relations. One study found that lower socioeconomic status was associated with lower hope in adults with cancer (Brunston et al., 1995), but a more recent study found socioeconomic status did not predict adolescent hope level from a healthy sample (Guse & Vermask, 2011). One explanation for discrepant findings could be the differing populations and measures of socioeconomic status included in these studies. Guse and Vermask (2011) studied a population of adolescents in South Africa and used the subjects' self-perceived socioeconomic status through a biographical questionnaire, whereas Brunston et al. (1995) examined a population of adults with cancer and used income, occupational status, educational attainment, and perceived unmet needs to operationalize socioeconomic status.

### Coping

#### **Coping Definition and Theory**

One variable that could influence sibling hope is the way in which siblings cope with a brother's or sister's cancer. It is also possible that coping could influence the way in which

siblings experience hope. Coping can be defined as cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the individuals' resources (Lazarus, 1993). Simply put, coping strategies are a person's cognitive and behavioral efforts to manage psychological distress. Coping strategies can be adaptive or maladaptive, successful or unsuccessful (Lazarus, 1993). Adaptive coping strategies are those that are related to good psychosocial outcomes, whereas maladaptive strategies are related to poor psychosocial outcomes and even further distress (Folkman & Lazarus, 1988). Adaptive coping strategies include problem-solving (i.e., a search for a solution to the problem; Lazarus, 1993; Folkman & Lazarus, 1988) and support-seeking (i.e., actively seeking support from family, friends, peers, or others; Lazarus, 1993; Long, Marsland, Wright, et al., 2015; Prchal & Landolt, 2012). Maladaptive coping strategies include internalizing (i.e., inward response to distress; for review see, Houtzager et al., 1999), externalizing (i.e., outward expressions of distress; for example, disruptive behavior; Sidhu et al., 2006), and avoidance (i.e., avoiding distress or cognitions/situations that may lead to distress; Last et al., 1998; Long & Marsland, 2011). Although avoidance is widely accepted as a maladaptive coping strategy, avoidance does not always lead to poor outcomes in pediatric cancer patients (Aldridge & Roesch, 2007). In general, avoidant coping appears to predict lower distress for pediatric cancer patients when stressors are unavoidable and of short duration (e.g., during port access; Windich-Biermeier, Sjoberg, Dale, Eshelman, & Guzzetta, 2007). Researchers have yet to evaluate whether avoidant coping is universally maladaptive or if avoidance could be helpful in some scenarios for siblings of cancer patients.

#### **Coping during Pediatric Cancer**

The majority (60-75%) of pediatric cancer patients' siblings experience positive psychosocial outcomes during and following the pediatric cancer experience and thus theoretically utilize adaptive coping strategies to manage cancer-related stressors (Cohen et al., 1994; Houtzager et al., 2005; Long et al., 2015). Siblings' adaptive coping strategies frequently include seeking information about their brother's or sister's diagnosis, problem-solving, and seeking emotional support from family and/or friends (Prchal & Landolt, 2012). Despite most cancer patients' healthy siblings utilizing adaptive coping responses, a significant subset of pediatric cancer patients' siblings remains at risk for maladaptive coping (Cohen et al., 1994; Houtzager et al., 2005). For example, some siblings utilize avoidance by refusing to discuss their cancer-diagnosed brother or sister, some avoid people likely to trigger thoughts about their brother's or sister's cancer, and some attempt to circumvent family conversation about the diagnosis (Prchal & Landolt, 2012). Many healthy siblings also report decreased involvement in social activities during their brother's or sister's cancer treatment (Prchal & Landolt, 2012). Moreover, some siblings demonstrate internalizing coping during a brother's or sister's cancer treatment (Sidhu et al., 2006). Common sibling internalizing coping correlates include somatization (e.g., stomachaches) and feelings of social isolation (for review see Alderfer et al., 2010; Houtzager et al., 1999; Sidhu et al, 2006). Some siblings of children with cancer also use externalizing coping in school and at home to cope with their distress (Houtzager et al., 2005). Some siblings do not report symptoms of distress, perhaps in an effort to protect parents from additional strain or to avoid additional conversation about stressors (Prchal & Landolt, 2012). A variety of variables influence siblings' coping styles. In the sections that follow, I will discuss predictors of coping strategies in the pediatric cancer population and I will further explicate the significant influence of socioeconomic status on coping and hope.

## **Predictors of Sibling Coping during Pediatric Cancer**

Family and social predictors of coping strategies. Most notably, parental use of effective problem-solving and communication within the family facilitates adaptive coping styles in siblings of children with cancer (Cohen et al., 1994). When parents model and communicate effective problem-solving, siblings of children with chronic illnesses are more likely to engage in effective problem-solving behaviors as well (Giallo & Gavidia-Payne, 2006). In contrast, siblings from families with communication problems are more likely to demonstrate disruptive behavior (i.e., externalizing; Cohen et al., 1994), internalize hostility and guilt (Bendor, 1990), and feel less competent in support seeking (Cohen et al., 1994). Additionally, siblings may also model parent coping in negative ways, as parental depression has been linked with siblings' increased internalizing coping, increased externalizing coping, and decreased support seeking coping behaviors (Cohen et al., 1994).

Parental attention, family cohesion and adaptability, and community resources are also associated with sibling coping during pediatric cancer. Siblings' and parents' satisfaction with their community support positively affects the likelihood that siblings will seek support and feel competent in doing so (Cohen et al., 1994), thus illustrating the need for substantial support throughout cancer treatment. Siblings with less perceived social support are more likely to report increased behavior problems (externalizing) and anxious symptoms (internalizing; Barrera et al., 2004). Additionally, siblings' perceptions of decreased parental attention are associated with increased internalizing symptoms (Bendor, 1990; Cohen et al., 1994). Loss of parental attention could be detrimental to the support pediatric cancer patient's siblings perceive.

**Individual predictors of coping strategies.** Social-ecological theory suggests that the cancer experience must be viewed in the context of an individual's interactions with others and

with their social and environmental systems (Kupst, 1994). In this model, individuals are at the center of complex concentric circles, representing settings with bidirectional influences on the child (Kazak, 1989). Siblings' support systems, parents' behavior, peers, and relationships all play roles in how siblings experience a brother's or sister's cancer. In accordance with social-ecological theory, siblings' individual characteristics (e.g., social competence, coping style, psychopathology; Barbarin et al., 1995; Cohen et al., 1994) may be predictive of their coping strategies for managing pediatric cancer (Cohen et al., 1994). Preexisting interpersonal problems or psychopathology are the strongest predictors of siblings' maladaptive coping strategies (Barbarin et al., 1995). Specifically, pediatric cancer patients' siblings who display anxious and depressive symptoms prior to a brother's or sister's diagnosis are more likely to internalize or externalize their cancer-related stress (Barbarin et al., 1995). Further, siblings' premorbid perceived low social competence and low self-esteem predict increased internalizing and decreased support seeking in siblings of pediatric cancer patients (Cohen et al., 1994).

Age also plays a role in sibling coping, although directionality is inconclusive. Some studies report older children engage in more internalizing (Houtzager et al., 2015; Packman et al., 1997) and support seeking (Cohen et al., 1994) than younger siblings; other studies report younger siblings engage in more externalizing than older siblings (Cohen et al., 1994; Zeltzer et al., 1996) and for longer periods of time (Houtzager et al., 2015). Adolescents report greater variance in coping strategies (Madan-Swain, Sexson, Brown, & Ragab, 1993), but it remains unclear whether younger or older children engage in maladaptive coping strategies more often (Alderfer et al., 2010; for review see, Houtzager et al., 1999). One possible explanation for discrepant findings could be the different qualitative and quantitative measures used to identify coping strategies. It is likely that younger children would appear to respond differently than older

children in different methods of assessment (e.g., open-ended questions through an interview versus multiple choice or prompting). Alternatively, the findings could differ because of the specific coping strategies being tested. For example, Cohen and colleagues (1994) assessed anxious and depressive symptoms to identify internalizing behaviors in siblings; Houtzager, Grootenhuis et al., (2004) assessed for anxiety and emotional reactions to identify internalizing behaviors. Further, findings could differ because many studies have failed to take birth order into account (Houtzager et al., 2003; Maiden-Swain et al., 1993). Given shifting family roles and the likelihood that older siblings could assume responsibility over some caretaking functions for younger healthy siblings, it is likely older siblings' experience of distress differs from siblings who are younger than the child with cancer. Additional research is needed to clearly define relations between age and maladaptive sibling coping. One area of study to consider is evaluating coping differences in latency stage versus adolescent siblings. Another interesting question is the extent to which birth order influences sibling coping, as birth order could have implications for sibling household responsibilities and family role.

Medical predictors of coping strategies. Time since diagnosis is a well-studied predictor of sibling coping (Cohen et al., 1994). Specifically, more sibling internalizing and externalizing coping behaviors are seen in the weeks immediately following diagnosis (Houtzager et al., 2003). Patient prognosis also predicts sibling coping (Sidhu et al., 2006). Higher risk diagnoses are positively correlated with siblings' use of maladaptive coping strategies, such as internalizing anxious symptoms (Sidhu et al., 2006), likely exacerbated by increased parent distress and family disruption (Giallo & Gavidia-Payne, 2014). Yet, withholding information about prognosis may not be beneficial; several studies document positive relations between siblings' increased prognostic knowledge and adaptive coping

(Nolbris, & Ahlstrom, 2014; Prchal & Landolt, 2015; Sidhu, et al., 2006). Further, siblings with more information about their brothers' or sisters' diagnosis (whether high or low risk) report a decrease in somatic symptoms (Nolbris & Ahlstrom, 2014), lower fear, lower anxiety, and more problem-solving coping compared to before they had information regarding the diagnosis (Sidhu et al., 2006).

Socioeconomic status as a predictor of coping strategies. Few pediatric cancer studies have examined socioeconomic status as a predictor of sibling coping. One study found higher family income negatively predicts siblings' internalizing and externalizing coping, and positively predicts siblings' support-seeking behaviors (Cohen et al., 1994). Siblings' coping may also be predicted by the amount of resources available to the family. Specifically, when a family does not have a car and has fewer financial resources, siblings are more likely to demonstrate negative behavior changes (e.g., externalizing coping) throughout a brother's or sister's cancer treatment (Sloper & While, 1996). Additionally, siblings in higher socioeconomic groups tend to better cope with cancer-related disruption and communicate more effectively than siblings in lower socioeconomic groups (Barbarin et al., 1995). One explanation for links between socioeconomic status and sibling coping could be the mediating role of parental stress. One study found that financial risk and indicators of limited financial resources, such as qualifying for Medicaid, are risk factors for parental stress (Karlson, Faith, Pierce, Elkin, & Megason, 2013), which, as previously noted, can impact sibling coping (Cohen et al., 1994). Further research is needed to explicate the effects of other measures of socioeconomic status on sibling coping strategies.

# The Role of Socioeconomic Status on Family Functioning in Pediatric Cancer

Although research investigating the influence of socioeconomic status on siblings' coping and hope during pediatric cancer is scarce, the influence of socioeconomic status on pediatric

cancer patients' family functioning is well studied. Siblings from families with fewer resources are at risk for insufficient social support (Barbarin et al., 1995), more psychosocial distress, and maladaptive coping (Giallo & Gavidia-Payne, 2006; Karlson et al., 2013). Furthermore, siblings are at greater risk for psychosocial problems when there are more children in the home, when their caregivers have lower education, and when there is greater family financial difficulty (Karlson et al., 2013). Low socioeconomic status is also associated with siblings' feelings of increased vulnerability (i.e., susceptibility to illness or death) and stress in the child-parent relationship (Ryan et al., 2013). Parents with fewer resources may be more likely to devote increased time and effort to obtaining help and resources, in turn leaving pediatric cancer patients' siblings with fewer opportunities to communicate and obtain emotional support.

Because researchers have yet to converge on a standard operational definition of socioeconomic status and studies have utilized a variety of measures to proxy socioeconomic status, more research is needed to clearly evaluate the additive effects of income, family education, access to resources, and neighborhood/family chaos on family adjustment.

# **The Current Study**

Although many studies demonstrate most siblings adjust well to their brother's or sister's cancer diagnosis and treatment (e.g., Murray, 1995; Murray, 2000), research also demonstrates some siblings are at risk for maladjustment and maladaptive coping (e.g., Long, Marsland, & Alderfer, 2015; Santos et al., 2015). Examples of siblings' maladaptive coping can include internalizing, externalizing, and avoidant behaviors. Because parents are at risk for low hope (Mack et al., 2007; McClement & Chochinov, 2008; Snyder, Rand, et al., 1997), siblings may also be at risk. Although one study did find a relation between parents' income and sibling adjustment (Sloper & While, 1996), studies have yet to evaluate other sociodemographic

characteristics and siblings' hope and coping during pediatric cancer. This study will begin filling research gaps by evaluating direct relations between sociodemographic variables and sibling hope and coping. This study also contributes to previous literature by considering a number of sociodemographic variables that proxy both socioeconomic status and the family's access to resources.

Hypothesis 1: Sociodemographic variables that may serve as a proxy for socioeconomic status (i.e., parent education level, household income) and/or siblings' access to adequate resources (i.e., number of adults in the home, number of children in the home; see data analytic plan) will positively predict sibling hope after controlling for (a) sibling age and gender, and (b) life disruption (i.e., number of nights spent in the hospital over the past year, number of hospital admissions since diagnosis, relapse status) associated with the brother's or sister's cancer.

Hypothesis 2: Sociodemographic variables that serve as proxies for socioeconomic status and/or siblings' access to adequate resources will predict sibling coping after controlling for (a) sibling age and gender, and (b) life disruption associated with the brother's or sister's cancer. Specifically, I hypothesized a direct relation between socioeconomic status/access to resources and adaptive coping (Hypothesis 2A) and an inverse relation between socioeconomic status/access to resources and maladaptive coping (Hypothesis 2B). Consistent with previous literature (Folkman & Lazarus, 1988; Long, Marsland, & Alderfer, 2015), I conceptualized support seeking and problem-solving as adaptive coping and I conceptualized internalizing and externalizing as maladaptive coping for this hypothesis. Because avoidant coping is cited as adaptive or maladaptive in pediatric oncology research literature (Aldridge & Roesch, 2007; Windich-Biermeier et al., 2007), I made no specific hypothesis regarding relations between sociodemographics and avoidant coping.

#### **CHAPTER THREE**

#### Method

### **Participants**

Participants were siblings of pediatric cancer patients (*n*=92, 44.2% male, Age *M*(*SD*) = 12.21(3.70)) and their parent or caregiver (herein "parent/s;" *n*=74). Parents were asked to identify the pediatric cancer patient's nearest-age sibling who (a) was at least 7 years of age, and (b) lived in the patient's home at the time of the study. Only siblings who parents identified as nearest in age to the cancer patient, at least 7 years of age, and cohabitating with the pediatric cancer patient were recruited for this study. This approach is consistent with previous literature in which siblings are selected for comparison if both siblings live in the home and comprise the sibling dyad in which siblings are closest in age (Cohen et al., 1994; Faith, Elledge, Newgent, & Cavell, 2015; Zeltzer et al., 1996). Siblings with significant cognitive deficits or learning disorders that precluded their ability to provide assent and complete study materials were excluded from this study. Assessment of cognitive deficits was based on whether the child or parent said the child could not provide assent or complete study materials. This was an exclusion criterion but no siblings were excluded for this reason. Families were recruited from a large pediatric cancer treatment center in the southern United States.

A variety of principle diagnoses were recorded in our sample (See Table 1). A small number (22%) of siblings had a sick brother or sister who had relapsed. 93.4% of participants' brothers or sisters with cancer had received chemotherapy treatment, 7.7% of ill brothers and sisters received a bone marrow transplant, and 31.9% of the healthy siblings in the sample had a psychiatric diagnosis. Regarding recruitment location, 12.1% of participants were recruited while their brother or sister was undergoing inpatient hospitalization, whereas 87.9% were recruited

while their brother or sister attended an outpatient oncology clinic visit. Only 5.3% of siblings had a medical problem of their own per parent report.

Regarding insurance status, 53.9% of the ill brothers and sisters had Medicaid insurance. Regarding primary language, 19.8% of siblings' parents reported Spanish as their primary language and 16.7% of siblings reported Spanish as their primary language (measures were available in English and in Spanish). Regarding parents who completed the demographic questionnaire, 78.4% were the siblings' mother, 16.2% were the siblings' father, and 5.4% were other family member guardians (18 siblings (19.6% of the sibling sample) did not have a parent or guardian fill out a demographic form). Regarding race, 74.1% of parents identified as white, 20.7% identified as black, and 5.2% identified as other or multiracial. Regarding ethnicity, 37.1% of parents identified as Hispanic. Regarding language of measure completion, 19.8% of parents and 16.7% of siblings chose to complete measures in Spanish. Per parent report, 71.2% of siblings were white, 20.3% were black, 8.5% were other or multiracial, and 38.2% were Hispanic.

With regard to parent education, 14.5% of parents reported attaining less than a high school diploma or GED, 34.2% reported having a high school diploma or GED, 14.5% reported having some college education, 23.7% reported having a bachelor's degree, and 13.1% reported having completed a graduate degree. With regard to income, 27.1% of parents reported an annual household income  $\leq$  \$20,000, 14.8% reported an annual household income of \$20,001-\$40,000, 17.5% reported an annual household income of \$40,001-\$60,000, 9.5% reported an annual household income of \$60,001-\$80,000, and 31.1% reported an annual household income  $\geq$  \$80,001. Demographic information is summarized in Table 1.

# Measures

# The Children's Hope Scale

The Children's Hope Scale (CHS; Snyder et al., 1997) is a widely used 6-item self-report scale designed to assess children's hope. Items are rated on a 6-point Likert-type scale (1 = *None of the time*, 6 = *All of the time*). The CHS contains two subscales to reflect children's agency thinking (e.g., "I am doing just as well as other kids my age") and pathway thinking (e.g., "Even when others want to quit, I know I can find ways to solve the problem"), respectively, with three items loading on each scale. The CHS has demonstrated strong construct validity (Valle, Huebner, & Suldo, 2004), convergent validity (Snyder et al., 1997), factor structure, discriminant validity, internal consistency, and test-retest reliability (Snyder et al., 1997; Valle et al., 2004) in previous studies. The CHS has been used with children as young as 7 years of age (Snyder et al., 1997) and as old as 17 years of age (Snyder et al., 1997; Venning, Elliot, Whitford, & Honnor, 2007). Internal consistency in this study was .72 for Pathways, .53 for Agency, and .71 for the total score. Because internal consistency for the Agency subscale was below acceptable levels (Tang, Cui, & Babenko, 2014), all subsequent analyses use the composite total hope score (α= .71).

# **Self-Report Coping Scale**

The Self-Report Coping Scale (SRCS; Causey & Dubow, 1992) is designed to assess children's self-reported coping strategies. The SRCS contains five subscales corresponding to support seeking, problem-solving, internalizing, externalizing, and avoidant coping behaviors. Children respond to each item on a 5-point Likert-type scale (1 = *Never*, 5 = *Always*). The SRCS has demonstrated good internal consistency, strong factor structure, and good test-retest reliability (Causey & Dubow, 1992; Kochenderfer-Ladd & Skinner, 2002) in previous studies. Kochenderfer-Ladd and Skinner (2002) modified the SRCS by asking children to respond to

coping items in response to the vignette, "When I have a problem with another kid at school, I..." For the current study, children were asked to respond to SRCS items in response to the vignette, "Imagine you or your brother/sister is very sick and has to go to the hospital. I would..." Consistent with Kochenderfer-Ladd and Skinner (2002), a manipulation check was conducted by asking children to report how sad, angry, embarrassed, and scared they would feel based on the vignette. The manipulation check items were rated on a 5-point scale (1 = *Not at all*, 5 = *Very much*). Further information about psychometrics of this measure is presented in the Preliminary Analyses section of this manuscript.

## **Sociodemographics**

Parents completed a sociodemographic questionnaire that included parent education level, household income, primary language spoken in the home, number of adults in the home, and number of children in the home. We also abstracted data from the electronic medical record to obtain additional information about the brother's or sister's medical diagnosis and treatment course.

#### **Procedure**

Data for this study were collected as part of a larger study examining the role of emotion socialization in cancer patients' and their siblings' functioning. Parent consent and sibling assent were obtained in accordance with UT Southwestern Medical Center IRB standards. Research personnel approached parents to participate in the larger emotion socialization study during pediatric cancer patients' outpatient oncology clinic visits or inpatient hospital admissions.

Parents who consented to participate were asked to identify the pediatric cancer patient's nearestage, cohabitating sibling who was at least 7 years old. Research personnel then invited the identified sibling to participate in this study and obtained sibling assent if the sibling's age was

greater than or equal to 13 years. Participating parents and siblings were given the option to complete study materials via paper-and-pencil, via structured interview over the phone/in person, or via an online survey. Regarding completion method, 29.7% (n=19) of siblings completed the survey via paper-and-pencil, 67.2% completed the survey by structured interview (telephone or in-person; n=43), and 3.1% (n=2) completed the online survey. All study measures were available in English and Spanish. Regarding translation into Spanish, English measures were forward and backward translated into Spanish by native Spanish speakers and were validated by certified Spanish language experts at the large academic hospital in which this study was completed. Spanish interpreters were available for the consent/assent process and for structured interview questionnaire administration. Participants were not financially compensated for participation in this study.

#### **CHAPTER FOUR**

#### **Results**

## **Preliminary Analyses**

SPSS (Version 23) was used for all analyses except where otherwise noted (i.e., post hoc power analyses). Data were screened for multivariate normal distribution, linearity, and outliers. Variables with non-normal distribution were transformed to allow parametric tests. Outliers were recoded to the next most extreme participant score on the scale.

Because a new vignette was added to the SRCS for this study, siblings were asked to rate anger, fear, sadness, and embarrassment in response to the vignette (1 = "not at all" 2 = "just a little," 3 = "sort of," 4 = "A lot," 5 = "very much"). I conducted a manipulation check of the SRCS vignette by examining frequencies of scores for siblings' self-reported negative emotions in response to the vignette. The vignette was determined to successfully manipulate if at least 75% of respondents responded at a value of "3" or higher for at least one of the negative emotions assessed. Regarding the manipulation check, 81.4% of siblings rated "Scared" as 3 or above, 79.2% rated "Sad" as 3 or above, 34.2% of siblings rated "Angry" as 3 or above, and 7.2% rated "Embarrassed" as 3 or above; thus, the vignette was determined to successfully manipulate participants' mood state.

Because of the added vignette and because the SRCS has never been used in published research with the pediatric oncology population, preliminary analyses also included examining reliability of the SRCS subscales to ensure adequate psychometric integrity prior to primary analyses. The five coping subscales as designed (Causey & Dubow, 1992) and as used with previous healthy samples (e.g., Lyons, Heubner, & Hills, 2016) yielded poor to adequate reliability estimates in my sample (Cronbach's alpha coefficients = .34-.76), suggesting the

SRCS five-factor solution may not have adequately characterized sibling responses in my data. Given poor reliability of some original SRCS subscales, I conducted exploratory factor analysis to determine whether a different factor solution better characterized my data. The items of the SRCS were subjected to exploratory factor analysis using varimax rotation. Inspection of the scree plot revealed a clear break after the third factor. The three-factor solution explained a total of 38.78% of the variance, with the first factor contributing 15.44%, the second factor contributing 12.23%, and the third factor contributing 11.11% of explained variance. Items that did not exhibit a factor loading  $\geq$  .30 (one item) were excluded. For cross-loading items to be included in a factor, the item must not have loaded on more than one item  $\geq .30$  and the absolute value of factor loading differences must have been > .15. Using these criteria, four cross-loading items were excluded. The content of each factor, its name, and the number of items loading on it were as follows: adaptive coping (11 items), internalizing/externalizing coping (six items), and avoidant coping (six items). Factor loadings are shown in Table 3. Item loadings were used to form subscale arithmetic average scores based on each exploratory factor. Reliabilities for the new subscales ranged from .71- .81 (with removal of one item from the avoidant coping subscale; See Table 3).

I conducted chi-square tests to determine whether siblings differed by ethnicity on whether they chose to complete questionnaires via paper-and-pencil or structured interview. Internet administration was not included in this analysis because only two participants completed internet surveys. Method of completion did not vary by ethnicity ( $x^2 = 2.35$ , p = .31, df = 2). I used one-way between groups analysis of variance to determine whether siblings' hope or coping differed by method of survey completion. Neither hope (F = 2.37, p = .13), adaptive coping (F = 2.37).

1.99, p = .16), internalizing/externalizing coping (F = .11, p = .75), nor avoidant coping (F = .61, p = .44) differed by completion method.

To determine which life disruption variables should be included in primary analyses as covariates, I examined bivariate correlations between life disruption variables (i.e., number of nights the patient sibling spent in the hospital over the past year, number of hospital admissions the patient sibling had since diagnosis, and patient siblings' relapse status) and outcome variables. Only life disruption variables that correlated with an outcome variable  $(p \le .10)$  were included as covariates for analyses predicting that outcome variable. The correlation between relapse and sibling adaptive coping and between relapse and internalizing/externalizing coping approached statistical significance (r = .19, p = .07; r = -.22, p = .07, respectively). The ill child's number of hospital admits since diagnosis was significantly correlated with both sibling hope (r = .21, p = .05) and sibling avoidant coping (r = .53, p = .02). Because only two life disruption variables were correlated with outcome variables, I used these variables as individual covariates in subsequent analyses instead of creating an index of life disruption. Aside from life disruption variables, sibling age was significantly correlated with sibling hope (r = .37, p < .01)and the correlation between sibling age and sibling avoidant coping approached significance (r =-.22, p = .06). The correlation between sibling gender and sibling hope approached significance (r = .19, p = .10). Age and gender were only included as covariates in subsequent analyses where the correlation between age/gender and the outcome variable of interest was statistically significant or approached statistical significance (p < .10).

### **Primary Analyses**

Hypothesis 1: Socioeconomic status and siblings' access to resources will positively predict sibling hope after controlling for (a) sibling age and gender (where sibling age and

gender significantly correlated with the outcome variable), and (b) life disruption associated with the brother's or sister's cancer (where life disruption variables significantly correlate with hope).

I performed a hierarchical regression analysis to examine the role of sociodemographic variables in predicting sibling hope after controlling for sibling age/gender and life disruption. Regression analyses are summarized in Table 4. Covariates were included in regression analyses if they demonstrated statistically significant or approached statistically significant (p = .10) bivariate correlations with the dependent variable (See Preliminary Analyses section of this manuscript). Regression main effects were considered statistically significant where  $p \le .05$ . Although the data analytic plan included examination of effect sizes of main effects based on Cohen's recommendations ( $d \ge 0.2 =$  small effect size,  $d \ge 0.5 =$  medium effect size,  $d \ge 0.8 =$  large effect size; Cohen, 1969), effect sizes were not examined in any analyses that follow because there were no statistically significant main effects of primary variables.

Order of entry of predictors was as follows: (Step 1) sibling age and gender, (Step 2) life disruption variables that significantly correlated with sibling hope (i.e., number of hospital admissions since diagnosis), and (Step 3) sociodemographic variables (i.e., number of adults in the home, number of the children in home, household income, parent education level). Regression analysis indicated sociodemographics were not a statistically significant predictor of hope after controlling for sibling age/gender and life disruption; however sociodemographics did explain an additional 5% of the variance in sibling hope when added to the model. Sibling age/gender and life disruption explained significant variance in sibling hope, accounting for 16.3% and 6% of variance, respectively.

I conducted a post-hoc power analysis using G\*Power 3.1 (Faul, Erdfelder, Buchner & Lang, 2009) to determine observed power for Hypothesis 1 testing. Observed power was considered adequate if power exceeded .80 (Faul et al., 2009). Assuming medium effect size, observed power for Hypothesis 1 testing was .84.

Hypothesis 2: Socioeconomic status and siblings' access to adequate resources will predict sibling coping after controlling for (a) sibling age and gender (where sibling age and gender significantly correlate with the outcome variable), and (b) life disruption associated with the brother's or sister's cancer (where life disruption variables significantly correlate with the outcome variable). (Hypothesis 2A): Data will reveal a direct relation between socioeconomic status/access to resources and adaptive coping. (Hypothesis 2B): Data will reveal an inverse relation between socioeconomic status/access to resources and maladaptive coping.

I used hierarchical regression analyses to examine the role of sociodemographic variables in predicting sibling coping after controlling for sibling age/gender and life disruption. Regression analyses are summarized in Table 4. Covariates were included in regression analyses if they demonstrated statistically significant or approached statistically significant ( $p \le .10$ ) bivariate correlations with the dependent variable (See Preliminary Analyses section of this manuscript). Regression main effects were considered statistically significant where  $p \le .05$ .

Order of entry for the regression analysis predicting adaptive coping was as follows:

(Step 1) life disruption variables that significantly correlated with adaptive coping (i.e., relapse status) and (Step 2) sociodemographic variables (i.e., number of adults in the home, number of children in the home, household income, and parent education level). Sibling age and gender were not included as potential covariates because these variables were not significantly

correlated with adaptive coping. Regression analysis revealed sociodemographics, as a set, did not significantly predict adaptive coping; however, sociodemographics did explain 10% additional variance in adaptive coping. No individual predictors emerged as significant, but income approached significance as an individual predictor. Relapse status, when entered into the model, only approached significance in explaining additional variance in adaptive coping (5% additional variance explained); however, relapse status did emerge as a significant individual predictor in the full model.

Order of entry for the regression analysis predicting internalizing/externalizing coping was as follows: (Step 1) life disruption variables that significantly correlated with the internalizing/externalizing coping index (i.e., relapse status), and (Step 2) sociodemographic variables (i.e., number of adults in the home, number of children in the home, household income, and parent education level). Age and gender were not included as covariates because these variables were not significantly correlated with the internalizing/externalizing coping index. Sociodemographic variables did not predict internalizing/externalizing coping. Relapse status was a significant step in the internalizing/externalizing coping model, explaining 5.8% of additional variance; however, relapse status only approached significance as an individual predictor in the full model.

Order of entry for the regression analysis predicting avoidant coping was as follows:

(Step 1) sibling age, (Step 2) life disruption variables that significantly correlated with avoidant coping (i.e., number of hospital admissions since diagnosis), and (Step 3) sociodemographic variables (i.e., number of adults in the home, number of children in the home, household income, and parent education level). Sociodemographics did not significantly predict avoidant coping after controlling for covariates. Number of hospital admissions since diagnosis significantly

predicted avoidant coping and explained 11.2% of variance in the model. Age, as a step in the model, did not explain significant additional variance in avoidant coping; however, age did emerge as a significant individual predictor in the full model.

### **CHAPTER FIVE**

### **DISCUSSION**

This study examined sociodemographic variables as potential predictors of sibling hope and sibling coping with cancer-related stressors as a first step toward understanding how socioeconomic status and access to resources affect siblings' adjustment to cancer treatment. Based on extant literature, I hypothesized a direct relation between socioeconomic status/access to resources and sibling hope (Hypothesis 1) and adaptive coping (Hypothesis 2A). I also hypothesized an inverse relation between socioeconomic status/access to resources and sibling maladaptive coping (Hypothesis 2B). In keeping with the academic exercise component of a master's thesis project, because this is the first study of its kind, and because our sample was relatively small, text that follows will discuss statistically significant findings but will also cautiously interpret findings that only approached statistical significance.

Sociodemographics, as a set, did not significantly predict sibling hope, explaining only 4.8% of the variance in sibling hope. Interestingly, extant literature is not consistent with my findings; several studies report income and financial resources significantly, directly predict family and sibling psychosocial adjustment to cancer-related stressors (Cohen et al., 1994; Karlson et al., 2013; McConnell, Breikreuz, & Savage, 2011). Despite these findings and the theoretical links between income and sibling hope, my data is not suggestive of links between household income or other proxies for socioeconomic status and sibling hope. Hope as an adjustment outcome has not been well researched in the pediatric cancer population or in pediatric cancer patients' siblings; therefore, additional studies are warranted to expand our understanding of factors that influence sibling hope during pediatric cancer treatment.

Although sociodemographics did not significantly predict sibling coping, sociodemographics explained 10% of the variance in siblings' adaptive coping, partially supporting my hypothesis and indicating sociodemographics may play a role in sibling coping that would be better elucidated with a larger sample size. Additionally, income approached significance as a negative individual predictor of adaptive coping. Although this finding must be interpreted with extreme caution given that the finding only approached statistical significance, the nature of this finding is surprising; siblings with higher household income were marginally less likely to cope adaptively. This finding contradicts findings from previous research on pediatric cancer populations, as past researchers have found direct links between socioeconomic status/access to resources and coping behaviors (Cohen et al., 1994; Ryan et al., 2013; Sloper & While, 1996). Past research has also demonstrated high socioeconomic status is directly related to positive psychosocial outcomes in parents and in children after cancer diagnosis and during treatment (Ryan et al., 2013). Ryan et al. (2013) proposed that income may be more influential on child and family outcomes during pediatric cancer than overall economic status because income is subject to greater fluctuations year to year compared to overall economic status, especially given significant medical care costs associated with childhood illness (Ryan et al., 2013). Research conducted with pediatric oncology samples also suggests income is directly related to parental stress (Kupst, 1994; Ryan et al., 2013). Thus, given links between parent stress and child adjustment difficulties during pediatric cancer (Robinson et al., 2007), it is surprising that my data revealed marginally significant inverse relations between household income and siblings' adaptive coping.

A possible explanation for my findings, although counterintuitive and requiring further study, is that siblings with low socioeconomic status may enter into the cancer experience with

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more adaptive coping strategies they previously learned to cope with stress that comes with low socioeconomic status. Siblings who have a history of low socioeconomic status may have previous experience managing family role and income disruption, thus buffering them from some of the stressors tied to pediatric cancer. A further possible explanation for my finding is that parents who have lower socioeconomic status and less access to resources have learned adaptive coping styles (i.e., support seeking and problem-solving) as a function of need and therefore model those behaviors for healthy siblings. Again, it is important to interpret these possible explanations with extreme caution, as my findings were only marginally statistically significant and we did not collect data on pre-cancer coping or parent stress or coping. Further study is needed to understand ways in which families with low and high socioeconomic status approach emotion-laden stressors at cancer outset to better understand the role of socioeconomics in predicting sibling functioning during pediatric cancer. Additional research is also needed to elucidate the potential role of other mediators of relations between sociodemographics and sibling coping with pediatric cancer.

Although not a component of my hypotheses, an interesting finding from this study is the predictive value of life disruption variables. Our consistent findings that sociodemographic variables did not significantly predict sibling hope or coping after controlling for life disruption are congruent with past scholars' suppositions that the degree of family life disruption is the most important risk factor for poor sibling adjustment (Sloper & While, 1996). Indeed, I found that life disruption variables positively predicted all forms of sibling coping, such that number of ill-child hospital admits since diagnosis positively predicted sibling avoidant coping and ill-child relapse status positively predicted sibling adaptive coping and sibling internalizing/externalizing coping. Number of ill-child hospital admits since diagnosis also positively predicted sibling

hope. It is possible that life disruption variables are a more salient predictor of sibling adjustment to cancer-related stress compared to other sociodemographic variables. Regarding findings that life disruption predicts a variety of coping responses, it could also be that siblings with a high degree of cancer-related life disruption tend to rely on a larger variety of coping responses as they make adjustments to manage cancer-related stress. Interestingly, posthoc examination of bivariate correlations did not support this potential explanation; relapse status did correlate with number of coping indices for which siblings scored at or above the mean (r = .21, p = .04), but in the direction that siblings whose ill sister or brother had relapsed tended to demonstrate fewer coping indices on which they scored at or above the mean. Number of hospital admissions since diagnosis was not correlated with number of coping indices on which siblings scored at or above the mean (r = -.16, p = .14).

Of particular interest is my finding that siblings who have had more cancer-related life disruption are more likely to cope using internalizing/externalizing or avoidant strategies without regard to either their socioeconomic status or their access to resources. In some ways, these findings are promising, as these findings indicate maintaining family routines and consistency may be the most straightforward prevention strategy for pediatric cancer families irrespective of sociodemographics. Further research is needed to clarify the role of life disruption in sibling adjustment to pediatric cancer, including longitudinal study to examine the trajectory of sibling coping responses across cancer treatment and life disruption course.

My findings that sociodemographics, in general, did not predict sibling hope and coping is somewhat surprising given increased stressors likely to co-occur with limited financial and other resources during pediatric cancer. One explanation for my lack of significant findings could harken to the complex nature of socioeconomics. That is, because socioeconomic status is

a complex and nuanced construct, no single indicator of socioeconomic status can provide a clear picture of the impact on adjustment to pediatric cancer (Ryan et al., 2013). Examination of additional socioeconomic variables is necessary to adequately understand the impact of socioeconomic status on sibling adjustment. Despite my attempt to adequately capture socioeconomic status and access to resources by including a number of variables, it remains possible that other variables that more closely proxy community and/or household characteristics (e.g., crime or number of broken windows in the community, number of times the family has moved over the past 5 years, employment status) could more strongly predict sibling hope and coping.

Another possible explanation for my lack of findings related to links between sociodemographics and sibling hope/coping is that other variables may moderate the predictive value of sociodemographic variables on sibling hope and coping. Explained differently, it could be that untested moderator variables suppressed significant main effects in my data (Allen, 1997; Frazier, Tix, & Barron, 2004). One potential moderator variable could be siblings' perceived support from parents. A number of studies in pediatric cancer document the importance of parental support in predicting sibling outcomes (Santos et al., 2015); thus although low socioeconomic status and poor access to resources could place siblings at risk for low hope and maladaptive coping, parental support could mitigate this risk. Other possible moderating variables include parent mental health, parental coping, parent behavior modeling, parental support, parenting behavior, parenting goals regarding children's positive and negative emotions, sibling perceived social support, and sibling relationship quality. Further study is needed to better understand predictors of sibling hope and coping and ways in which sociodemographics

may interact with sibling, parent, and community characteristics to predict sibling adjustment outcomes during pediatric cancer.

Yet another explanation for my lack of significant findings could be my limited assessment of access to resources. My study only used number of children in the home and number of adults in the home as measures of access to resources, and these variables may not have truly captured the nature of resource access for families affected by pediatric cancer. Future studies should consider additional access to resources factors, including religious community involvement, family social support, parental access/perceived access to governmental assistance and other financial assistance, community sidewalk connectivity indicating community rural/suburban/urban nature, community crime rate, and other neighborhood characteristics.

# **Strengths and Limitations**

This study had a variety of strengths. An important strength is the representative spread in siblings' age, gender, and ethnicity in my sample. My sample was representative of the United States population with regard to ethnicity and therefore may provide a reasonable snapshot of sibling hope and coping across major United States ethnic groups. A large spread in age helps us understand functioning at different ages of childhood and a relatively evenly-distributed spread in gender allows for better generalization across genders. Despite the previously noted room for expansion on variables used to proxy socioeconomic status and access to resources, this study also utilized a variety of sociodemographic variables as potential predictor variables, providing a more nuanced look at the impact of sociodemographics on sibling adjustment compared to previous studies (Kunin-Batson, A., Kadan-Lottick, N., & Neglia, J. P., 2014; Sloper & While, 1996). Lastly, this study included a relatively large number of siblings compared to many previous studies in pediatric oncology (for review see, Alderfer et al., 2010). Because of the

fragility of this population, it is often difficult for researchers to recruit large samples of pediatric cancer patients and their families (Grootenhuis & Last, 2004), especially with sibling studies (Faith et al., 2015; Mascara, 2003).

Findings from this study must be considered within the scope of important limitations. Although the large variation of pediatric cancer diagnoses in this study enhances generalizability, including pediatric cancers with great disparities in prognosis, treatment length and rigor, and comorbid disability, correlates may have limited my ability to detect significant relations between sociodemographics and sibling hope/coping among specific illness groups. The nature of my sample may also have limited generalizability of my findings in some ways. The majority of siblings in this study came from two-parent homes (78.9%), which, in addition to limiting generalizability to single parent households, may also have limited the extent to which families truly perceived a lack of caregiver resources in rearing siblings during pediatric cancer treatment. Also notable, single parents tend to experience greater stress than parents in two-caregiver households (Mullins et al., 2010), and parental psychosocial stress is directly related to sibling adaptation (Santos et al., 2015). Therefore, our limited number of single parent households may have contributed to lack of statistically significant findings. Adding to sample bias, 31.1% of parents in this study reported an annual household income > \$80,001 and an additional 9.5% reported an annual household income >\$70,001, which is well above the national average household income of \$51,939 (U.S. Census, 2014).

Although I considered a variety of socioeconomic and resource access variables, I did not assess all aspects of sociodemographics. For example, I did not assess degree of community support, parent and sibling perceived access to resources, rural/suburban/urban nature of communities, neighborhood crime rate, or family religious community involvement. My data

also revealed some psychometric limitations within some measures. The hope and coping scales both demonstrated lower than optimal reliability statistics (Cronbach's alpha = .71 and .34 -.76, respectively), instigating exploratory factor analysis for the coping scale. Poor psychometric properties of the Self Report Coping Scale in this study could reflect that this study was the first to use the Self Report Coping Scale with cancer populations and with the added vignette depicting hospitalization. We addressed potential concern about the vignette by ensuring we were eliciting negative emotion; however, the vignette may have elicited sibling responses that are not representative of siblings' overall coping style. Also possible is that strategies siblings utilize in the context of hospitalization differ from strategies they use to manage other daily stressors because of the acuity of hospitalization.

An additional limitation is the current study did not control for sibling dyad composition variables, including sibling age difference, birth order, or dyad gender composition. Sibling dyad composition variables have be found to be predicative of adjustment (Whiteman, Solmeyer, & McHale, 2015) and health behaviors (Senguttuvan, Whiteman, Jensen, & Alexander, 2014; Whiteman, Jensen, Mustillo, & Maggs, 2016;) in healthy sibling populations, indicating these variables could be significant predictors or correlates of sibling hope and coping in the pediatric oncology population.

Finally, this study utilized only self-report data to assess siblings' hope and coping. Although hope is often viewed as an internal state and therefore may be best assessed by self-report (Bryant & Harrison, 2015), several parent-report measures of child coping are available (e.g., Achenbach & Edelbrock, 1983; Reynolds & Kamphaus, 1992; Walker, 1988) and may have contributed to a more thorough assessment of sibling coping behavior. Utilizing only sibling self-report of sibling functioning and attending to pragmatics of sibling data collection

also limited my ability to administer measures of sibling behavior problems, psychopathology, social functioning, and engagement in extra-curricular activities. Relatedly, this study did not consider the potential roles of family support, culture/acculturation, parents' emotion socialization goals, or parenting style in moderating links between sociodemographics and sibling hope/coping.

## **Future Directions**

In the future, more variables should be considered in measuring socioeconomic status and sociodemographics to better understand how sociodemographics as a whole impact sibling hope and coping. It could be that other sociodemographic variables, other than the ones used in this study, are better at predicting hope/coping in siblings of children with cancer. Future studies may need to separately examine income, education, and access to resources to get a better picture of each indicator and related outcomes.

It may also be interesting to assess siblings' perceived social support in relation to sociodemographics and sibling hope and coping. Past literature explicates the importance of social support in relation to child adjustment to pediatric cancer (for review see, Long & Marsland, 2011); thus it could be that siblings' perceived social support moderates relations between sociodemographics and sibling hope/coping. Other moderating variables to assess in future studies include parent stress, parent perceived social support, family support, parenting styles, parents' emotion socialization goals and practices, single-parent versus two-parent home status, and/or sibling perceptions of socioeconomic status and access to resources.

This study only examined parent reported variables of socioeconomic status and access to resources; this study did not examine siblings' perceptions of their socioeconomic status or their knowledge about access to resources. It could be that sociodemographic variables' relation to

adaptation to cancer-related stressors is stronger when siblings perceive socioeconomic status and fewer resources available to the family. Future studies could assess the extent to which siblings are knowledgeable about family sociodemographics and explicate child beliefs of socioeconomic status and access to resources. Further, studies could also examine parent and child stress related to socioeconomic status and access to resources.

Regarding measurement of coping, it is still unclear whether the SRCS is a reliable measure with the added hospital vignette. Future studies should further examine psychometrics of the SRCS with pediatric cancer patients and their siblings, especially with patients and siblings older than 17 years. It would be valuable to validate this measure with a larger sample size to allow for validation of a coping measure in the pediatric cancer population. It is also important to validate the SRCS with older siblings; a study examining coping styles of older siblings may be necessary to fully understand if there are differences between older and younger siblings' coping styles.

Pediatric cancer patients have a wide range of diagnoses, treatment regimens, and prognoses. The current study limited my ability to detect significant relations between sociodemographics and sibling hope/coping among specific illness groups. Future studies should identify how different diagnoses impact sibling hope and coping, especially in regard to socioeconomic impact and life disruption possibility.

The current study examined the relation between sociodemographics and sibling hope and sibling coping at only one time point; inclusion criteria included patient diagnosis having occurred at least six weeks prior to study recruitment. As indicated by extant literature (for review see, Alderfer et al., 2010; Houtzager, Grootenhuis, et al., 2004), the initial six weeks after diagnosis is a time when parents, patients, and siblings feel the most psychosocial distress

compared to six months and two years post-diagnosis. A longitudinal study examining relations between socioeconomic status/access to resources and sibling hope and sibling coping would shed light on sibling experiences over time. Few studies have longitudinally examined siblings' coping strategies and no studies have examined longitudinal impact of socioeconomic status and access to resources on siblings' experience of pediatric cancer, making such a study a potentially important contribution to the literature.

## **Clinical Implications**

Maintenance of family roles and routines is an important clinical implication to consider. My findings provided evidence of a significant relation between life disruption and sibling hope and coping; thus providers should be aware of family relations, roles, and routines and do their best to provide support when life gets chaotic for the family. It may be important for families to be given appropriate resources to preserve family roles, structure, and regular schedule when medically appropriate and possible. My findings suggest it may also be important for providers and parents to be aware of life disruptions' impact on siblings and to provide sibling support through community referrals (if needed), discuss siblings' feelings surrounding cancer-related stress, and model adaptive coping behaviors for siblings.

Regarding socioeconomic status and access to resources, my results do not warrant clear clinical implications. Although statistically insignificant relations were found in my study, past research shows clear links between income and parent stress during pediatric cancer treatment (Cohen et al., 1994); thus, healthy siblings may also be affected. Clinical providers should be aware of the financial strain placed on families during cancer treatment and provide psychosocial support when necessary.

This study offered a nuanced explication of sociodemographics and the relation between socioeconomic status/access to resources and sibling hope and coping. Findings differed from extant literature as sociodemographics did not significantly predict sibling hope, adaptive coping, internalizing/externalizing coping, or avoidant coping. Although my findings warrant caution in interpretation because of this study's limitations, it could be that sociodemographics do not play a strong role in sibling hope and coping after accounting for life disruption. Interestingly, analyses revealed life disruption variables were a more salient predictor of sibling hope and coping. More research is needed to expand understanding of the relation between sociodemographics and sibling adaptation and to further investigate the role of life disruption variables on sibling adaptation to pediatric cancer.

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Table 1

Participant demographics

		Sibling	<u>Parent</u>
Demographic variabl	e	n (%)	n (%)
Age in years	≤17	89(96.7%)	
	>17	3(3.3%)	
Gender	Male	34(44.2%)	
	Female	43(55.8%)	
Medical problem (sibling)		4(5.3%)	
Caregiver relation to sibling	Father		12(16.2%)
	Mother		58(78.4%)
	Other		4(5.4%)
No. of parents in home	Two-parent		60(78.9%)
	One-parent		16(21.1%)
Measure completion language	English	76(83.3%)	74(80.2%)
	Spanish	16(16.7%)	18(19.8%)
Race	White	42(71.2%)	43(74.1%)
	Black	12(20.3%)	12(20.7%)
Mult	iracial/Other	5(8.5%)	3(5.2%)
Ethnicity	Hispanic	26(38.2%)	26(37.1%)
Ν	Von-Hispanic	42(61.8%)	44(62.9%)
			(continued)

Table 1 (Cont'd)

Participant demographics

		Sibling	Parent
D	emographic variable	n (%)	n (%)
Income	≤ \$20,000		20(27.1%)
	\$20,001-\$40,000		11(14.8%)
	\$40,001-\$60,000		13(17.5%)
	\$60,001-\$80,000		7(9.5%)
	≥ \$80,001		23(31.1%)
Education	>High school/GED		11(14.5%)
	High school/GED		26(34.2%)
	Some college		11(14.5%)
	Bachelor degree		18(23.7%)
	Graduate degree		10(13.1%)
			(continued)

Table 1 (Cont'd)

Participant demographics

Disease characteristics of cancer patients			
	Patient		
Demographic variable	n (%)		
Medicaid	48(53.9%)		
Relapse	20(22%)		
Chemotherapy treatment	85(93.4%)		
Bone marrow transplant	7(7.7%)		
Psychiatric diagnosis	29(31.9%)		
Family recruited inpatient	11(12%)		
Family recruited outpatient	81(88%)		
Cancer diagnosis categories Blood cancers	42(45.7%)		
CNS tumors	27 (29.3%)		
Non-CNS tumors	6 (6.5%)		
Other	17 (18.5%)		

*Note*: Percentages based on valid percent excluding missing values. Demographic data not available where parents declined completing all or portions of the demographic form and data not extractable from the ill child's medical record.

Table 2

Means, Standard Deviations, and Reliabilities for Primary Variables

	M	CD	-
Total hope	<u>M</u> 4.32	.83	<u>α</u> .70
Adaptive coping	3.10	.74	.79
Internalizing/externalizing coping	1.74	.78	.79
Avoidant coping	1.84	.78	.72

Table 3

Factor loadings for the Self-Report Coping Scale

	Factor and item	1	2	3
1.	Know there are things I can do to make it better	.624		
	Ask someone who has had this problem	.624		
	Ask a friend for advice	.617		
	Get help from a family member	.612		
	Ask a family member for advice	.610		
	Change something so things will work out	.610		
	Get help from a friend	.606		
	Do something to make up for it	.601		
	Decide on one way to deal with the problem	.570		
	Talk to somebody about how it made me feel	.482		
	Try to understand why this happened to me	.472	.302	336
	Worry too much about it	.346	.346	
	Talk to my teacher about it	.302		
2.	Take it out on others because I feel sad or angry		.753	
	Get mad and throw or hit something		.747	
	Yell to let off steam		.733	
	Get mad at myself		.592	
	Cry about it		.514	310
	Become so upset that I can't talk to anyone		.499	.370
			(cor	ntinued)

Table 3 (Cont'd)

Factor Loadings for the Self-Report Coping Scale

	Factor and item	1	2	3
	Worry that others will think badly of me		.466	
	Just feel sorry for myself		.422	
3.	Tell myself it doesn't matter			.756
	Forget the whole thing			.727
	Forget the whole thing			.121
	Refuse to think about it			.659
	Say I don't care			.613
	Make believe nothing happened			.516
	Ignore it when people say something about it			.489
	Try extra hard to keep this from happening again			

*Note*: Item factor loadings shown only when loadings  $\geq$  .30. Items in bold were included in the subscale score.

Table 4

Regression Analyses Predicting Sibling Hope and Coping

Predictor variables	β	$R^2\Delta$	F∆
<u>Total</u>	hope		
Age	.35**	.16	6.64**
Gender	.19+		
No. hospital admissions since diagnosis	.24*	.06	4.79*
No. children in the home	.09	.05	.40
No. adults in the home	12		
Household income	03		
Parent education	.17		
<u>Adaptiv</u>	e coping		
Relapse	.25*	.05	3.31+
No. children in the home	.04	.10	2.01
No. adults in the home	.12		
Household income	27+		
Parent education	05		
			(4:4)

(continued)

Table 1 (Cont'd)

Predictor variables	β	$R^2\Delta$	FΔ			
Internalizing/externalizing coping						
Relapse	.23+	.06	4.32*			
No. children in the home	04	.01	.22			
No. adults in the home	001					
Household income	06					
Parent education	.20					
Avoidan	t coping					
Age	25*	.03	2.35			
No. hospital admissions since diagnosis	.33**	.11	9.04**			
No. children in the home	08	.01	.89			
No. adults in the home	.03					
Household income	10					
Parent education	.04					

 $p \le .10. p \le .05. p \le .01.$ 

#### Appendix A

#### Child Hope Scale

### Questions about your goals

Directions: The six sentences below describe how children think about themselves and how they do things in general. Read each sentence carefully. For each sentence, Please think about how you are in most situations. Place a check mark in the circle that describes YOU best. For example, place a check (,/) in the circle above "None of the time," if this describes you. Or, if you are this way "All of the time," check this circle. Please answer every question by putting a check in one of the circles. There are no right or wrong answers.

1.	I think I am	doing pretty we	ell			
	O	O	O	O	O	O
	None of	A little of	Some of	A lot of	Most of	$All\ of$
	the time	the time	the time	the time	the time	the time
2.	I can think	of many ways to	get the things	s in life that are	e most importar	nt to me
	O	O	О	O	O	O
	None of	A little of	Some of	A lot of	Most of	All of
	the time	the time	the time	the time	the time	the time
3.	I am doing	just as well as o	ther kids my a	.ge		
	0	O	О	О	O	O
	None of	A little of	Some of	A lot of	Most of	All of
	the time	the time	the time	the time	the time	the time
4.	When I hav	e a problem, I c	an come up w	ith lots of ways	s to solve it	
	O	O	O	O	O	O
	None of	A little of	Some of	A lot of	Most of	$All\ of$
	the time	the time	the time	the time	the time	the time
5.	I think the t	hings I have do	ne in the past v	will help me in	the future	
	O	O	O	Ō	O	O
	None of	A little of	Some of	A lot of	Most of	$All \ of$
	the time	the time	the time	the time	the time	the time
6.	Even when	others want to	quit, I know th	at I can find wa	ays to solve the	problem
	O	O	O	O	O	O
	None of	A little of	Some of	A lot of	Most of	$All\ of$
	the time	the time	the time	the time	the time	the time

# Appendix B

## Self-Report Coping Scale

## **My Emotions**

Imagine you or your brother/sister is very sick and has to go to the hospital.

Now we want to know how you would feel in this situation. How much would you feel...

	Not at all	Just a little	Sort of	A lot	Very much
Angry					
Scared					
Embarrassed					
Sad					

We also want to know what you would do if you  $\underline{or}$  your brother/sister was very sick and had to go to the hospital. I would...

	Never	Rarely	Sometimes	Often	Always
1.) Ask a family member for advice					
2.) Know there are things I can do to make it					
better					
3.) Tell myself it doesn't matter					
4.) Worry too much about it					
5.) Get mad and throw or hit something					
6.) Talk to somebody about how it made me					
feel					
7.) Change something so things will work					
out					

8.) Forget the whole thing			
9.) Become so upset that I can't talk to			
anyone			
10.) Curse out loud			
11.) Get help from a family member			

	Never	Rarely	Sometimes	Often	Always
12.) Try extra hard to keep this from happening again					
13.) Make believe nothing happened					
14.) Cry about it					
15.)Yell to let off steam					
16.) Ask a friend for advice					
17.) Do something to make up for it					
18.) Refuse to think about it					
19.) Just feel sorry for myself					
20.) Take it out on others because I feel sad or angry					
21.) Try to think of different ways to solve it					
22.) Tell a friend or family member what happened					
23.) Do something to take my mind off of it					

24.) Go off by myself			
25.) Go over in my mind what to do or say			
26.) Ask someone who has had this problem			
27.) Get help from a friend			
28.) Say I don't care			
29.) Worry that others will think badly me			

Never	Rarely	Sometimes	Often	Always
	Never	Never Rarely	Never Rarely Sometimes	Never Rarely Sometimes Often

#### **BIOGRAPHICAL SKETCH**

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EDUCATION/TRAINING			
INSTITUTION AND	DEGREE	YEAR	FIELD OF STUDY
LOCATION	DEGREE	ILAK	THEED OF STOD I
The University of North Texas	B.S.	2014	Psychology
The University of Texas	M.C.R.C.	2016	Clinical Rehabilitation
Southwestern School of Health			Counseling
Professions			

#### **Positions and Employment**

2014-2016	Research assistant under Melissa Faith, Ph.D., ABPP.
2012-2014	Research assistant under Zina Trost, Ph. D.

2012-2014 Research assistant under Heidimarie Blumenthal, Ph. D.

## **Clinical Experience**

2016-2016	Clinical intern at Children's Health, Oncology Department
2015-2016	Counseling and assessment intern at University Rehabilitation Services
2015-2016	Clinical intern at Eugene McDermott Center for Pain Management

#### **Presentations and Publications**

2016	Prindiville, K., Tarkenton, T. R., Frazee, L. A., El-Behadi, A. F., Pastrana, F.,
	Faith, M. A. (2015). Relations between patient and sibling coping and perceptions
	of sibling relationship quality in the pediatric oncology population.
2016	Frazee, L. A., Tarkenton, T. R., <b>Prindiville, K.</b> , El-Behadli, A. F., Pastrana, F., &
	Faith, M. A. (2015) Pediatric cancer treatment-related life disruptions as
	predictors of sibling relationship quality and sibling hope during pediatric cancer.
2016	El-Behadli, A. F., Lazarus, M., Frazee, L. A., Tarkenton, T. R., Prindiville, K., &
	Faith, M. A. (2015) Changes in social adjustment, sickle cell-specific adjustment,
	and emotional wellbeing following a summer camp for youth with sickle cell
	disease.
2014	Guck, A., Nowlin, A., Acord, K., <b>Prindiville, K. A.</b> , and Trost, Z. (2014) The
	influence of observational learning on appraisals of painful and threatening aspect
	of activity among healthy individuals.

# **Professional Memberships**

2016 International Association of Rehabilitation Professionals