Spiritual Coping and Adjustment in Siblings of Children with Cancer

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Background

Childhood Cancer

Approximately 12,000 US children are diagnosed with some form of cancer every year (Ries et al., 2006). While there are twelve major types of childhood cancers, leukemias and lymphomas as well as cancers of the brain and central nervous system make up more than half of all new diagnoses (National Cancer Institute, 2011). Other common cancers in children and adolescents include bone tumors (e.g., osteosarcoma, Ewing's sarcoma), soft tissue sarcomas (e.g., rhabdomyosarcoma), sympathetic nervous system tumors (e.g., neuroblastoma), renal tumors (e.g., Wilms' tumor), retinoblastoma, and germ cell tumors (National Cancer Institute, 2011).

Incidence rates of pediatric neoplasms have increased some over the last 20 years, rising from 11.5 cases per 100,000 children in 1975 to 14.8 cases in 100,000 children in 2005 (Ries et al., 2006). However, due to significant advances in treatment enabling multimodal treatment options (e.g., surgery, chemotherapy, radiation, bone marrow transplant etc.) over the last decades, 5-year survival rates for most types of childhood cancers now exceed 75% (Hewitt, Weiner, & Simone, 2003) and 3 out of 4 children diagnosed with a malignancy can be expected to survive their disease and treatment (Greenlee, Murray, Bolden, & Wingo, 2000).

As the paradigm of childhood cancer has shifted from all but death sentence and survival measured in weeks or months to an often highly curable disease and survival now being measured in years and/or a lifetime, the definition of “being cured from cancer” has been extended beyond merely physical outcomes and now encompasses health aspects within social, emotional, as well as psychological domains of functioning (Van Eys, 1999). This change in scope and focus transformed the field of pediatric psycho-oncology (Patenaude & Kupst, 2005) and subsequently brought about a great amount of work documenting and speaking to the far-reaching psychosocial impact of childhood cancer (Bleyer, 1990; Wakefield et al., 2010; Grootenhuis, & Last, 1997).

Bronfenbrenner’s social-ecological model (1979), also known as family systems approach, offers a suitable framework to depict the ripple effect childhood cancer has on patient and their families. The model conceptualizes an individual to be embedded within nested layers of social, cultural, and socio-historical systems and structures whose interactions and bi-directional influences shape and affect the individual’s development (Bronfenbrenner, 1989). The characteristics of these systems and environments (i.e., family environment, SES, social support network, neighborhood, school, community etc.) are thought to influence an individual’s adjustment and shape their functional outcomes throughout the course of their life. It underscores the power of environmental factors influencing and possibly moderating risk or protective factors for an individual especially in times of life challenges and stress.
The application of Bronfenbrenner’s model to pediatric psychology and specifically to the experience of childhood cancer has been supported (Kazak, Rourke, & Navsaria, 2009) and illustrates the far-reaching impact pediatric cancer has on multiple levels within those systems. However, the most direct impact is felt by the family (Kazak, Rourke, & Navsaria, 2009) as childhood cancer permeates multiple microsystems within the family environment and the many implications of having a child with cancer in the family are felt by every family member.

A diagnosis of cancer imposes many challenges on families and, despite the overall improvement in 5-year survival rates over the past few decades, it still constitutes a life-threatening illness requiring sustained and often vigorous treatment regiments. Sources of stress and burden associated with having a child with cancer in the family are multifaceted and differ by diagnosis, prognosis, and treatment stage (Rabineau, Mabe & Roger, 2008). Examples of stressors encompass the shock of diagnosis, fears the child may die, invasive and painful procedures, and the uncertainty regarding outcome of treatment, all of which can take a huge emotional toll on families. Moreover, the demands of cancer treatment, such as frequent clinic visits and inpatient stays, navigating the medical system, caring for the child with cancer at home, taking care of other family members’ needs, financial concerns etc., can cause additional strain (Alderfer et al., 2009). The impact of childhood cancer and its unique stressors on the affected children and their parents has received a lot of attention and is starting to be understood (Wakefield et al., 2010; Phibbs, 2007; Patenaude & Kupst, 2005; Alderfer & Kazak, 2006), however, much less attention has been devoted to understanding the effect of being the sibling of a child who is undergoing cancer treatment (Alderfer & Noll, 2006). Relationships between siblings are said to be among the most intense, enduring, and influential relationships in a person’s lifetime, with brothers and sisters exerting a powerful influence in shaping each other’s identities (Horwitz & Kazak, 1990). The impact of one sibling falling ill is immense on the others as that special relationship is disrupted and threatened.

**The Sibling Experience**

Brothers and sisters of children with cancer are often called the invisible siblings (Kreicbergs, 2010), a term that adequately recounts their experience as the focus and attention within the family shifts to attend to the needs of the sick child. In an attempt to gain a more accurate understanding of siblings’ adjustment research has increasingly moved to including siblings’ self-report (Houtzager, Grootenhuis, Caron, & Last, 2005) and away from relying on sibling proxies (i.e., parents) alone. Accuracy as well as agreement between proxy and child self-report has been found to vary as a function of symptom severity, the proxy’s own psychological state, and seems to be mediated by age and developmental level of the child (Verhulst & Van der Ende, 1991; Aschenbach, McConaughy & Howell, 1987; McConaughy, 1993).
Qualitative research, such as interviews and content analyses of sibling data, has been able to provide unique insights into the experience of childhood cancer, including the siblings’ own appraisals of potentially stressful situations resulting from having a brother or sister with cancer (Sloper, 2000). Overarching themes emerging across different qualitative studies highlight the profound impact of the illness on siblings, the many changes in their lives, the range of intense feelings they are dealing with, and the many unmet needs they are subsequently left with after diagnosis and during treatment (Wilkins & Woodgate, 2005).

The most prominent theme revolves around the many changes and associated losses in their lives due to events related to the illness. Siblings describe losses caused by changes in family routines and subsequently their own routine. With the parents attending to the sick child, taking him or her to appointments and staying overnight at the hospital, there is a marked decrease in quantity as well as quality of parental contact for siblings (Lähteenmäki, Sjöblom, Korhonen, & Samli, 2004; Brown, Oikler, Lavish, Keune, & Hutto, 2008) and an increase in time spent under the care of parental substitutes such as grandparents and neighbors (Barrera, 2000). Furthermore, due to the logistical demands of cancer treatment and increased absenteeism of at least one parent, siblings, and especially older teens, report taking on more chores and responsibility at home to alleviate burden on the parents (Barrera, Chung, Greenberg, & Fleming, 2002). Siblings also voice a loss of attention and status within the family citing the emotional unavailability of parents and the increased focus on the sick child as troublesome and difficult to deal with (Sargent et al., 1995; Shapiro & Brack, 1994). Younger teens in particular mention concerns about further adding to the burden of their parents and are cautious about upsetting them with their own worries about the disease (Barrera, Chung, Greenberg, & Fleming, 2002).

Another area of loss involves the relationship with the sick brother or sister. Siblings often feel like they lost the friendship and companionship of the sick child as the time spent together is reduced and different due to physical limitations/restrictions the sick child may have because of the disease and/or treatment (Sloper, 2000). They also state a change in the quality of the relationship, an increase in sibling rivalry (Kramer, 1984), and feelings of jealousy and resentment due to the attention centering on the sick child and preferential treatment given to him or her by parents and other people (Havermans & Eiser, 1994; McGrath, 2001). Lastly, siblings’ sense of self seems to undergo changes and be diminished as their life seems to revolve and be defined by their brother’s or sister’s illness (Sloper, 2000; Wilkins & Woodgate, 2005). The latter may partially be attributable to the overall loss of security and certainty children usually derive from being involved and embedded in a family with routines and schedules providing structure and security in children’s lives, all of which are undermined and profoundly challenged by the illness and treatment (Woodgate, 2006). Siblings also report the notion that they should
have been the one to get sick instead of their brother or sister and there seems to a tendency to see
themselves as ‘cut off’ from and not part of the cancer as it is experienced by their parents and the
affected child which contributes further to feeling lost and isolated within the family (Woodgate, 2006).

The emotional toll of the aforementioned changes and losses, compounded by a decreased sense
of self and less security and certainty in their lives, manifests itself in a lot of strong and potent feelings
experienced by the siblings (Wilkins & Woodgate, 2005; Sloper, 2000; Woodgate, 2006; Alderfer et al.,
2010). The most pervasive and enduring feeling reported by many siblings across different studies seems
to be sadness. Siblings report feeling sad due to the separation from their parents and the sibling and they
'mourn’ the loss of the life they used to have (Barrera, 2000; Wilkins & Woodgate, 2005; Sloper, 2000).
Seeing their parents struggle and their brother or sister suffer due to painful procedures and treatment side
effects may further add to their sadness (Woodgate, 2006). Siblings also report feeling lonely as the
family unit gets split apart to accommodate the demands of cancer treatment. They may feel left out of a
lot of treatment related events as those usually necessitate and involve the parents and the sick child
(Kramer, 1984). The separation from parents also means not being able to share their own worries and
thoughts they way they may have been used to before which further adds to their perception of being
alone within the cancer experience (Bendor, 1990).

Preferential treatment shown to the sick child by parents, friends, and other people may make
them feel rejected, unimportant, and abandoned. They may also feel resentful towards their parents and
the sick child, which may provoke anger and jealousy towards their brother or sister (Freeman, O’Dell, &
Meola, 2000; Bendor, 1990). A lot of siblings are also dealing with intense guilt for having these negative
feelings about what is happening to them and their family because of the cancer (Shapiro & Brack, 1994;
Kramer, 1984), while younger siblings’ guilt may result from the notion that something they did or said
may be to blame for their brother or sister’s cancer (Bendor, 1990).

Adjustment in Siblings of Children with Cancer

All of these feelings can be considered a normal reaction to the cancer as it is experienced by the
siblings (Wilkins & Woodgate, 2005). However, the multitude of feelings, repeated and prolonged
exposure to their respective triggers, and the many ensuing unmet needs siblings report give reason for
concern regarding their ability to adjust and thrive (Sahler et al., 1997).

Psychosocial adjustment of siblings of children with cancer has been investigated in several studies
looking at externalizing reactions (e.g., behavior disorders, disobedience, academic problems) as well as
internalizing reactions (e.g., depression, social loneliness, anxiety) (Hamama, Ronen, Feigin, 2000).
Three major constructs have received the most attention in an attempt to assess and describe internalized
reactions in siblings with a brother or sister with cancer (i.e., anxiety, depression, and more recently symptoms of post-traumatic stress).

The most disruptive and longest lasting internalized reaction to childhood cancer in siblings may be anxiety (Carpenter & Sahler, 1991). Siblings may experience symptoms of anxiety such as in response to the profound and rapid changes the illness is causing in their lives however, findings have been inconclusive. While there are a few studies reporting elevated anxiety scores in siblings of children with cancer (Barrera, Chung, Greenberg, & Fleming, 2002; Cuttini, Da Fre, Haupt, Deb, Baronci, & Tamaro, 2003), the majority seem to indicate siblings’ anxiety to be below clinical levels and thereby not significantly different from community controls (Alderfer et al., 2010). Associations with regard to age and gender as well as time since diagnosis, further reflecting the contradictory findings within this population, have been noted and reported on several occasions. Age has been implicated as a predictor of anxiety with some studies pointing towards younger siblings of both genders being at higher risk for anxiety problems than older siblings (Houtzager, Grootenhuis, & Last, 2001; Houtzager, Oort, Hoekstra-Weebers, Caron, Grootenhuis, & Last, 2004). However, gender patterns remain unclear as some studies report higher anxiety scores in younger as well as older boys and but not girls (Houtzager, Grootenhuis, & Last, 2001) while another study by the same researchers found older girls to experience elevated levels of anxiety (Houtzager et al., 2004). Older children may be more involved in the disease process (i.e., they may have to take on new and more responsibilities etc.) which may make them more susceptible to experience symptoms of anxiety (Houtzager et al., 2004). Time since diagnosis has been associated with anxiety with siblings reporting the most distress shortly after diagnosis with levels decreasing and stabilizing to near normal and often lower levels than what is found in reference data as time passed by (Lahteenmaaki, Sjoblom, Korhonen, & Salmi, 2004; Houtzager et al., 2003). Overall, however, results are still inconclusive as to what constitute consistent and reliable predictors and patterns of anxiety in siblings.

Depressive symptoms signify another area of psychosocial adjustment siblings of children with cancer may be at risk for. Due to the many changes caused by the cancer and the subsequent disruption of their lives, siblings may experience symptoms such as helplessness, loss of hope, they may lose interest in things they used to enjoy, and become more irritable and short-tempered. Several studies investigating depression in siblings of kids with cancer indicate the majority of siblings to experience non-clinical levels of depression (Alderfer et al., 2010; Lahteenmaaki, Sjoblom, Korhonen, & Salmi, 2004; Barrera, Fleming, & Kahn, 2004) with some studies even reporting lower levels than those found in community samples (Zeltzer, Chen, & Weiss, 1997). There are, however, a few studies documenting elevated symptoms of depression (Cuttini, Da Fre, Haupt, Deb, Baronci, & Tamaro, 2003; Mulrooney, Ness, &
Neglia, 2008) as well as reports of increased rates of symptoms in subsets of siblings (Barrera, Fliming, & Kahn, 2004) indicating some risk within this population.

The varied and often contradictory findings across studies looking at the constructs of anxiety and depression within the domain of psychosocial functioning (Houtzager, Grootenhuis, Hoekstra-Weebers, Caron, & Last, 2003) may be due to methodological differences (e.g., measures used, proxy report vs. sibling self-report, time since diagnosis, conceptualization of adjustment) as well as varying sample sizes. It seems that siblings endorse certain items on anxiety (e.g., feeling scared, frightened, not at all happy, feel like crying often) and depression measures (e.g., being worried about pains and aches, things never go well) more frequently and on a higher level than community controls, but overall their means on those measures do not stand out as being higher when compared with population norms (Lahtenmaaki, Sjoblom, Korhonen, Salmi, 2004). Another factor contributing to the lack of convergent findings may be due to siblings’ individual differences in the appraisal of the event (Hamama, Rogen, & Feigin, 2000) as well as age differences and age-related coping skills. Further, it has been postulated that applying constructs and using measures primarily focused on adjustment related psychological disorders may not accurately describe the experience of having a brother or sister with cancer (Alderfer, Labay, & Kazak, 2003).

There have been attempts to extend the approach of understanding the siblings’ experience beyond defining it in terms of psychopathology by focusing on the appraisal of having a brother or sister with cancer as potentially traumatic. Motivated by the inclusion in the fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV; American Psychiatric Association, 2000) and recognition of medical events such as injuries and life threatening illness as potentially traumatic events, there have been a few more recent studies applying a traumatic stress framework to capture the distress of being the sibling of a child with cancer (Alderfer, Labay & Kazak, 2003). The definition of a life threatening illness such as cancer as traumatic event is based on the premise that it constitutes a real or perceived threat to life and physical integrity to which individuals, including those indirectly exposed to the threat (i.e., family members) may respond with intense fear, horror, and helplessness making them susceptible to traumatic reactions (Kaplan, Kaal, Bradley, & Alderfer, under review).

Traumatic reactions are defined to fall into three categories 1) re-experiencing of the event due to upsetting thoughts, nightmares, and flashback, 2) avoidance of reminders of the event including not wanting to talk about it and avoiding reminders of it, and 3) experiencing symptoms of arousal such as irritability, being overly careful and jumpy (Foa, Johnson, Feeny, & Treadwell, 2001). Considering the many changes within the family after a diagnosis of cancer, resulting in a loss of security and certainty for siblings accompanied by fear the sibling may die, anxiety, and helplessness, as well as the physical
changes they are witnessing in their brother or sister due to the cancer and treatment (e.g., losing weight, hair, being in pain, looking severely ill), makes a traumatic stress model applicable to this population.

The largest empirical study to date studying post-traumatic stress reactions in siblings of cancer survivors (Alderfer, Labay, Kazak, 2003) found nearly half of their sample \(N = 78\) to experience mild and one third moderate to severe levels of post-traumatic stress (PTS) indicating higher rates than those found in community controls. Similar findings have been replicated in a few different studies. Packman et al. (1997) found one third of siblings of children who had undergone stem cell transplants to experience moderate to severe levels of PTS in response to the illness. In another study of participants of a summer camp for siblings of children with cancer, rates were similarly high with a little more than one third reporting moderate to severe cancer-related PTS (Packman, Fine, Chesterman, VanZutphen, Golan, & Amylon, 2004). Further, there is evidence pointing towards female siblings being at an increased risk for PTS (Alderfer, Labay, & Kazak, 2003), resembling trends reported for adult populations which indicate a higher risk of developing PTS in females (Breslau, 2009). Age differences, however, have not been reported on a consistent basis (Alderfer et al., 2010). While more research is needed to further replicate and explore patterns of PTS in siblings of children with cancer, current findings support a post-traumatic stress framework as a viable construct to capture the unique stress of living as the sibling of a child with cancer.

There have been calls within the field of pediatric psycho-oncology to focus more on factors promoting adjustment instead of exclusively relying on measures of psychopathology as they may be unsuitable and not specific enough to assess sibling adaptation and their cancer experience accurately (Houtzager, Grootenhuis, & Last, 1999). Few studies have looked at constructs such as self-control (Hamama, Rogen, & Feigin, 2000) and social support as variables which may buffer some of the stress and promote better adjustment in siblings. Barrera et al. (2004) reported perceived social support to be linked to symptoms of anxiety and depression with siblings who perceived greater social support through teachers, classmates, friends and family reporting lower levels. An area that has not been explored as much but might be important and predictive of sibling adjustment is appraisal and coping as it may play an important part in mediating the stressful impact of having a brother or sisters with cancer.

**Coping**

One way of conceptualizing coping is to look at it as a set of cognitive and behavioral responses to a stressor which are intended to reduce stress and achieve progress toward important life goals (Compas, Connor-Smith, Saltzman, Thomsen, & Wadsworth, 2001). Lazarus and Folkman (1984) postulated coping as an ongoing and constantly changing process in which the individual evaluates (i.e.,
appraises) an event on the basis of its perceived stressfulness and threat. This appraisal takes place in several stages in which the event is not only assessed in terms of its ‘stress factor’ but the individual also gauges his or her options as to what can and might be done to control the threat and how they may be equipped to cope with it. Applied to the cancer experience it may be said that siblings’ coping efforts are proportional to the perceived threat of the cancer as well as the effectiveness of the coping strategies they may have at their disposal to reduce the threat (Hamama, Ronen, & Feigin, 2000). Research on coping in siblings of children with cancer is very limited with only a few studies specifically addressing constructs thought to be coping and adjustment related (i.e., self-control) (Hamama, Ronen, & Feigin, 2000; Houtzager et al., 2004).

**Spirituality**

Spirituality has recently emerged as an interest in medicine and health care as a factor contributing to adjustment in people who are dealing with an illness. Religion and spiritual issues are important to children and adolescents with an estimated 95% believing in God, 85% stating religion as an important part of their life, and more than 50% attending religious services more than once a month (Cotton, Zebracki, Rosenthal, Tsevat, & Drotar, 2006). Religious/spiritual development in children is thought to follow similar patterns observed in general cognitive development (i.e., new developments advance in stages and build on skills mastered in previous stages) with children becoming able to think in more abstract religious and spiritual ways as they grow older (Fowler, 1981).

Definitions of spirituality and religion and the difference between the two are manifold and the terms often used interchangeably. The term ‘religion’ usually denotes a more formally organized system of beliefs and practices whereas ‘spirituality’ may refer more to an individual attempt to find and construct meaning in life (Sexson, 2004). The connecting factor and common denominator between both constructs, however, is the sacred which includes concepts such as God, the divine, an ultimate reality, or higher power people assign virtue or meaning to (Hill & Pargament, 2003). As such, both religious and spiritual traditions may provide a framework for understanding the world and to make sense of events in an individual’s life. Despite the central role of religion and spirituality in people’s lives, variables relating and associated with it remain understudied in health-related research (Hill & Pargament, 2003). Among the few studies investigating the construct within the health care field health behavior, mental health, and health outcomes in children and adolescents have received some attention as they are thought to be influenced by religiosity/spirituality (Cotton et al., 2006).

With regard to health behaviors linked to religiosity/spirituality, studies have found inverse associations between adolescents’ report of religiosity/spiritual connectedness and drug use, voluntary
sexual activity, and other high-risk behaviors (Holder, DuRant, Harris, Daniel, Obeidallah, & Goodman, 2000; Hodge, Cardenas, & Montoya, 2001). Religiosity/spirituality is also implicated in children’s and adolescents’ mental health linking higher religiosity/spirituality with lower levels of depression (Wright, Frost, & Wisecarver, 1993) and lower risk of suicide (Rew, Thomas, Horner, Resnick, & Beuhring, 2001). Research investigating religiosity/spirituality and physical health outcomes in children and adolescents, however, is very limited. The literature that does exist is often descriptive in nature speaking to heightened spiritual concerns and increased focus on spiritual matters in hospitalized children (Silber & Reilly, 1985). One study specifically focusing on children with cancer indicated that children and adolescents may use religiosity/spirituality as a way to cope with medical illness in ways similar to adults (Spilka, Zwartjes, & Zwartjes, 1991). Religious/spiritual coping as such has been defined as ‘as a search for significance or meaning in times of stress which relates to the sacred’ (Pargament, 1997).

Research on religious/spiritual coping in children with chronic illnesses is limited also as a result of measurement issues, however, there have been more recent studies investigating the construct in children dealing with different medical conditions such as asthma and sickle cell disease (Benmore, Pargament, & Pendleton, 2008; Cotton, Grossoehme, Rosenthal, McGrady, Roberts, Hines, Yi, & Tsvevat, 2009). Similarly as in adult populations results indicate two types of religious/spiritual coping (i.e., positive and negative religious/spiritual coping) which are linked to different outcomes on a variety of adjustment variables (Benmore, Pargament, & Pendleton, 2008). Positive religious/spiritual coping is thought to involve a positive reappraisal of the stressful event as well as the perception of spiritual support and connection to God or a religious community, whereas negative religious/spiritual coping is conceptualize to include negative reframing of the stressful event and an impression or idea of being punished resulting in discontent with God or the religious community (Benmore, Pargament, & Pendleton, 2008). Findings point towards a strong predictive function of religious/spiritual coping on perceived adjustment in children with those disclosing more use of negative religious/spiritual coping reporting poorer adjustment than those disclosing more positive religious/spiritual coping. Positive religious/spiritual coping however was also found to predict greater worry during the length of the hospitalization. Overall, religious/spiritual coping was found to predict over 50% of the variance in adjustment measures (Benmore, Pargament, & Pendleton, 2008). Kaal and Alderfer (2007), reported similar findings, reporting a positive correlation between use of religious/spiritual coping and adjustment related outcomes such as anxiety and post-traumatic stress in siblings of children with cancer. Given that religious/spiritual coping is such a new construct in pediatric populations, no associations between the construct and variables such as age, gender, or (where applicable) time since diagnosis have been examined or reported.
A distinction, not yet reported in children, between religious (i.e., more faith based) and existential coping (i.e., based on finding meaning and peace) has emerged in research investigating the construct in adult populations (Yanez, Stanton, Edmondson, Park, & Blank, 2009). Yanez et al. (2009) found existential coping (i.e., meaning and peace based) to be predictive of adjustment in a sample of breast cancer survivors, with participants engaging in more existential as opposed to religious coping reporting lower levels of cancer-related distress and improved mental health. No such distinctions have been investigated or reported in the child/pediatric literature so far.

Current Project

In light of these findings, the growing evidence of the importance of religiosity and spirituality in the health care field, and the scarce research on religious/spiritual coping, especially in children and adolescents, this project investigated the construct of spiritual coping in siblings of children with cancer. Assuming that children use and engage in religious/spiritual coping similarly to patterns reported in the adult literature (Spilka, Zwartjes, & Zwartjes, 1991), this project examined variables thought to be predictive of religious/spiritual coping in children. More specifically it examined age, gender and time since diagnosis in an attempt to explore associations with the levels of religious/spiritual coping reported by the siblings in this sample. In an attempt to investigate a trend reported in the adult literature only at this point, it also looked at the potentially different predictive functions of religious versus spiritual (i.e., existential) coping. Furthermore, the predictive nature of religious/spiritual coping itself was investigated by looking at associated adjustment outcomes as well as variables thought to moderate the association of religious/spiritual coping and outcomes such as anxiety, depression, and post-traumatic stress.

Aims and Hypotheses

The overall aim of this study was to examine religious/spiritual coping in siblings of children with cancer and to explore associations between religious/spiritual coping and adjustment related outcomes (i.e., anxiety, depression, and post-traumatic stress) as well as to investigate variables that may moderate the association between religious/spiritual coping and adjustment, such as age, gender, and time since diagnosis.

The first aim of the study was to examine religious/spiritual coping in siblings. It was hypothesized that older siblings would engage in more religious/spiritual coping as opposed to younger siblings. Similarly, it was expected that female siblings would engage in more religious/spiritual coping than male siblings. Time since diagnosis was thought to be predictive of religious/spiritual coping levels
with siblings closer to time of diagnosis reporting higher levels than siblings further out from diagnosis at the time of assessment.

The second aim was to examine the association between religious/spiritual coping and anxiety. It was hypothesized that religious/spiritual coping would be predictive of anxiety in siblings of children with cancer. More specifically, it was expected that siblings engaging in more religious/spiritual coping would report more symptoms of anxiety.

The third aim was to examine the association between religious/spiritual coping and symptoms of depression. It was hypothesized that religious/spiritual coping would be predictive of depression in this sample, with siblings engaging in more religious/spiritual coping presenting as more depressed.

The fourth aim was to examine the association between religious/spiritual coping and symptoms of post-traumatic stress. Specifically, it was expected that siblings engaging in more religious/spiritual coping would report more symptoms of post-traumatic stress.

The fifth aim of this study was to address whether time since diagnosis, age, and gender moderated the impact of religious/spiritual coping on adjustment related outcomes. It was hypothesized that the effect of religious/spiritual coping on adjustment related outcomes would differ with regard to age with older siblings disclosing higher levels of religious/spiritual coping reporting more anxiety, depression and symptoms of post-traumatic stress than younger siblings. Further, with regard to gender female siblings disclosing higher levels of religious/spiritual coping were expected to experience more anxiety, depression, symptoms of post-traumatic stress. Lastly, siblings whose brother or sister had been diagnosed more recently and who disclosed higher levels of religious coping were hypothesized to endorse more symptoms of anxiety, depression, and post-traumatic stress.

Method

Procedure

Following approval of the study by the Committee for the Protection of Human Subjects at a large northeastern pediatric oncology center in the United States, potential participants were identified via the institution’s Tumor Registry. Eligibility criteria for families included a) a child diagnosed with cancer or a brain tumor, still receiving treatment or, if off treatment, within two years of diagnosis b) at least one healthy child between the ages of 8 and 18, c) English speaking and d) residing within two hours of the treatment center. All healthy siblings in the family were invited and eligible to participate, however, one sibling’s data was randomly selected for data analyses. Siblings were defined as full biological, half-siblings, step- and adopted siblings residing in the same household as the child with cancer. Families were
excluded if a) the sibling had a chronic health condition requiring treatment by a pediatric specialist, or b) he or she had been diagnosed with a severe developmental disorder which prevented him or her from filling out questionnaires.

Parents of families believed to be eligible received a letter introducing the study. Trained study staff subsequently contacted the family to ascertain eligibility, explain the project, ensure interest in the project, as well as to answer any questions. Home visits were scheduled with families who were interested in participating, at which point informed consent and child assent was obtained for all participating family members. Siblings and at least one caregiver residing in the home (e.g., biological or step-parent) were asked to complete a battery of standardized assessments. Siblings independently completed questionnaires and, if necessary, items were read to younger siblings by research assistants. Home visits lasted approximately 1.5 hours and families were compensated for their time.

**Participant Characteristics**

As part of a program of research regarding siblings of children with cancer, 126 families participated (75% participation rate). The majority of the participating caregivers identified themselves as the sibling’s biological parent (96%; \( n = 121 \)), the remaining being 3.2% (\( n = 4 \)) step-mothers and .8% (\( n = 1 \)) grandmothers.

Mothers (\( n = 112 \)) were on average 40.5 years old (\( SD = 6.11 \)); 88% (\( n = 98 \)) were White and 82% (\( n = 92 \)) were married. Fathers (\( n = 14 \)) were on average 45.2 years old (\( SD = 5.8 \)); 92.3% (\( n = 12 \)) were White and 92.9% (\( n = 13 \)) were married. Roughly one fifth of families (21%) reported an annual income below $50,000, 43% between $50,000 and $100,000, and 35% over $100,000.

Participating siblings included 51.6% females (\( n = 65 \)). The mean age of siblings at time of data collection was 12.9 years (\( SD = 2.89 \)). According to parent report, the sample was 84.1% White (\( n = 106 \)), predominantly non-Hispanic (95.2%; \( n = 120 \)), with 11.1% African American (\( n = 14 \)), .8% Asian (\( n = 1 \)), and 3.2% (\( n = 4 \)) indicating to belong to another racial group or identifying as bi-racial. At the time of data collection, families were on average 15.8 months after diagnosis (\( SD = 7.32 \)). Diagnoses included 30.2% leukemias (\( n = 38 \)), 15.9% lymphomas (\( n = 20 \)), 13.5% brain tumors (\( n = 17 \)), and 38.1% other solid tumors (\( n = 48 \)).

**Measures**

*Demographic Form.* This form assessed background information about the parent and the participating sibling (e.g. age, race, ethnicity, education, marital status, SES, number of people residing in
It also provided information about the child with cancer, such as type of cancer, date of diagnosis, and kind of treatment received.

**Spiritual Coping.** The Children’s Spiritual Coping Scale (CSCS; Boeving & Finney, 2003) is a 22-item questionnaire assessing the respondents’ use of existential (e.g., “I know I have a place in the world.”) and religious (e.g., “God is with me.”) beliefs. The items are answered on a 5-point scale (0 = ‘never to 4 = ‘Always’). The scale provides two subscale scores for religious and existential coping as well as a total religious/spiritual coping score. The instructions and two of the items were modified to allow the measure to be applicable to siblings of children with cancer (e.g., “I think about what my cancer has taught me about life,” was changed to, “I think about what my brother’s/sister’s cancer has taught me about life.”). Coefficient alphas for the two subscales (religious and existential coping) in this sample were .95 and .89 respectively.

**Anxiety.** The Revised Children’s Manifest Anxiety Scale (RCMAS; Reynolds & Richmond, 1985) is a standardized self-report inventory assessing anxiety in children and adolescents from 6-19 years of age. Participants read 37 statements describing how people think or feel and are asked to indicate which applies to them by selecting ‘true’ or ‘false’ for each statement. The scale includes three subscales, Physiological Anxiety, Worry/Sensitivity, Social Concerns/Anxiety, and a Total Anxiety score which was used for the purpose of this project. The number of ‘true’ responses were counted and converted to age and gender-based T-scores ($M = 50$, $SD = 10$) with higher scores indicating higher levels of anxiety. The clinical range is defined as T-scores $> 70$. Raw scores were used for all analyses in this project except to summarize and describe anxiety levels. Test-retest reliability of the RCMAS over a nine months period has been demonstrated with a .68 correlation and adequate construct as well discriminate validity has been reported with other well established measures of anxiety (Reynolds, 1982). Among this sample coefficient alpha was .87.

**Depression.** The Child Depression Inventory (CDI-Short Form; Kovacs, 1992) is a short, 10-item self-report measure assessing behavioral and cognitive symptoms of depression in children ages 7 to 17. The participant is asked to pick one statement out of three for each item that best describes his or her for the past two weeks. Responses to items correspond to three levels of symptomatology with (0) indicating the absence of the symptom, (1) indicating a mild or probable symptom, and (2) signifying a definite symptom. Raw scores are converted to T-scores with a mean of 50 and standard deviation of 10 with higher scores indicating more depressive symptoms. The clinical range is defined as T-scores $\geq 70$. Raw scores were used for the purpose of this project except where sample characteristics were reported. The measure is widely used in clinical populations as well as for research purposes and the alpha reliability
Posttraumatic Stress. The Child PTSD Symptom Scale (CPSS; Foa, Johnson, Feeny, & Treadwell, 2001) is a 26-item self-report measure of posttraumatic stress symptoms for children ages 8 to 18. Its design mirrors the diagnostic criteria for PTSD as specified in the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV). For the purpose of this study, the instructions were modified to ensure siblings’ answers related to their brother or sister’s cancer (e.g., “When/since your brothers or sister was diagnosed with cancer...”). Further, two items were added to assess criterion A2 of the DSM-IV criteria for PTSD which postulates the experience of intense fear, helplessness and horror as a result of being exposed to a potentially traumatizing event. Symptom items are rated on a 4-point scale (0 = ‘not at all’ to 3 = ‘5 or more times a week’). The scale provides a symptoms severity score (range = 0-51) with higher scores representing more severe symptoms. Moderate to severe PTS was indicated by a cut-score of 11 or greater as recommended by the authors. Coefficient alpha in this sample was .89.

Statistical Approach

Descriptive statistics and independent sample t-tests were used to summarize sample characteristics and to compare gender differences in predictor (i.e., spiritual coping) as well as outcome variables (i.e., anxiety, depression, and post-traumatic stress). Simple linear regressions were performed to explore religious/spiritual coping in siblings using age, gender, and time since diagnosis as predictors. Similar analyses were conducted to examine the same set of predictors and the religious and existential coping subscales separately.

The first, second, and third hypothesis stating that spiritual coping predicts siblings’ anxiety, depression and post-traumatic stress scores were tested using simple linear regression models.

The fourth hypothesis, postulating that time since diagnosis, age, and gender moderate the impact of religious/spiritual coping on adjustment related outcomes was tested via three hierarchical regression models. To eliminate the problem of multicollinearity (Holmbeck, 1997) predictor and moderator variables were centered (i.e., the sample mean was subtracted from all individuals’ scores on the variable, producing a revised sample mean of zero) before testing the significance of the interaction term. The first step of each regression model examined religious/spiritual coping and the respective moderator variable (i.e., age, gender, and time since diagnosis). The second step of the regression model examined the significance of the interaction between the predictor and moderator variable. The simple effect of each moderator on spiritual coping was examined using post-hoc tests (Holmbeck, 2002). This was repeated
with age, gender, and time since diagnosis and spiritual coping for each of the three outcome variables (i.e., anxiety, depression, and post-traumatic stress symptoms).

Results

Anxiety, Depression, and Post-traumatic Stress in Siblings of Children with Cancer

Siblings reported mild to moderate anxiety \((M = 50.4, SD = 10.9; T\)-score range: 18 – 87) with only 5% falling into the clinical range of symptom severity (i.e., T-score \(\geq 70\)). Similarly, siblings reported depression scores in the mild to moderate range \((M = 48.2, SD = 9.0; T\)-score range: 39 – 90) with only 3% falling into the clinical range for self-reported depression symptom severity (i.e., T-score \(\geq 70\)). Siblings’ post-traumatic stress scores fell into the moderate to severe range \((M = 13.5, SD = 9.6; \text{score range: } 0 – 40\)), with sixty percent of the sample falling above the recommended cut-score of 11 indicating elevated levels of post-traumatic stress in this sample. Independent sample \(t\)-tests revealed no significant gender differences between male and female siblings in any of the outcome measures.

Religious/Spiritual Coping in Siblings of Children with Cancer

Siblings’ religious/spiritual coping scores ranged from 1 – 88 \((M = 54.2, SD = 19.6)\) indicating that the majority of siblings in this sample engaged and used religious/spiritual coping to varying degrees with only a few siblings reporting minimal to no religious/spiritual coping. Religious coping scores ranged from 0 – 36 \((M = 22.1, SD = 11.5)\), whereas existential coping ranged from 1 – 52 \((M = 32.3, SD = 10.7)\). Matched sample \(t\)-tests revealed a significant difference in scores for religious \((M = 22.1, SD = 11.5)\) and existential coping \((M = 32.3, SD = 10.8); t(119) = -10.14, p < .01\).

The first aim of the project was to examine and describe religious/spiritual coping in siblings of children with cancer with regard to age, gender, and time since diagnosis. It hypothesized that older siblings would report higher levels of religious/spiritual coping. Simple linear regression was computed to investigate whether age predicted total use of religious/spiritual coping. Results indicated age to significantly predicted reported use of religious/spiritual coping \((M = 54.2, SD = 19.6), F(1, 123) = 7.04, p < .01, \text{adjusted } R^2 = .04\). According to Cohen (1988) this is a negligible effect size. Contrary to what was hypothesized, this finding suggests religious/spiritual coping to decrease as sibling age increases. A similar trend was detected with regard to the religious but not the existential coping subscale. Simple linear regression analysis indicated age \((M = 12.9, SD = 2.89)\) to significantly predict religious coping \((M = 22.1, SD = 11.5)\) in siblings of children with cancer, \(F(1,118) = 9.62, p < .01, \text{adjusted } R^2 = .06\), with younger siblings reporting more religious coping than older siblings.
Contrary to what was hypothesized, gender did not predict religious/spiritual coping in siblings of children with cancer. Simple linear regression indicated no significant differences between male and female siblings in total religious/spiritual coping scores, \(F(1,124) = .59, p = .44\), or the respective subscales.

Time since diagnosis was hypothesized to predict religious/spiritual coping scores with less time passed since diagnosis equaling higher levels relative to levels in siblings further out from diagnosis. Simple linear regression computed to test this prediction revealed no significant differences in religious/spiritual coping scores between siblings closer as opposed to further out from date of diagnosis, \(F(1,124) = 1.28, p = .26\). Similar analyses for the two subscales (i.e., religious and existential coping) revealed no significant differences with regard to time since diagnosis either.

**Religious/Spiritual Coping and Adjustment Related Outcomes**

Another aim of this project was to examine religious/spiritual coping and adjustment related outcomes in siblings of children with cancer. It was hypothesized that higher levels of religious/spiritual coping would be predictive of higher scores in each of the outcome measures (i.e., anxiety, depression, and post-traumatic stress). Simple linear regressions were computed to investigate whether religious/spiritual coping predicted total scores on the RCMAS tapping into anxiety, the CDI measuring depression symptoms, and the CPSS assessing symptoms of post-traumatic stress in this sample. Contrary to what was hypothesized, analyses computed for the RCMAS and CDI revealed religious/spiritual coping to not predict anxiety and depression scores in this sample, \(F(1, 124) = 1.29, p = .25\) and \(F(1,124) = 2.08, p = .15\) respectively.

Results of a simple linear regression analysis computed to test the predictive function of total religious/spiritual coping (\(M = 54.2, SD = 19.6\)) on siblings’ post-traumatic stress scores (\(M = 13.4, SD = 9.6\)) approached significance, \(F(1, 124) = 3.66, p = .058\), adjusted \(R^2 = .02\) for the total score of religious/spiritual coping. The same analysis investigating the predictive function of existential coping (\(M = 32.3, SD = 10.7\)) revealed this subscale of the CSCS to be a significant predictor of symptoms of PTS (\(M = 13.6, SD = 9.6\)) in siblings of children with cancer, \(F(1, 123) = 4.46, p < .05\), adjusted \(R^2 = .02\). According to Cohen (1988) this is another negligible effect, indicating symptoms of post-traumatic stress to increase slightly with higher levels of existential coping.

**Age, Gender, and Time since Diagnosis as Moderators**

The last aim of this project was to examine whether variables such as age, gender, and time since diagnosis moderated the association of religious/spiritual coping and adjustment related outcomes (i.e.,
symptoms of anxiety, depression, and post-traumatic stress) in this sample. In other words, analyses were planned to examine whether age, gender, and time since diagnosis explained a unique portion of the variance between the predictor variable of religious/spiritual coping and outcome variables such as anxiety, depression, and post-traumatic stress experienced and reported by the siblings. Using a series of hierarchical regression models, variables entered in step one included religious/spiritual coping (i.e., total scale as well as each subscale in separate analyses) and the variables assumed to moderate the association between coping and adjustment related outcomes (i.e., age, gender, and time since diagnosis). Step two included the interaction term (e.g., religious/spiritual coping x age etc.).

There was one model in which interaction terms explained a significant portion of the variance in outcome scores. The model included depression scores as outcome and spiritual/religious coping as well as the two subscales and time since diagnosis as moderator. Results indicated all three different significant interaction terms between the CSCS and its two subscales and time since diagnosis to account for significant portions of depression scores \( p < .05 \) in this sample. Post-hoc probing revealed that the interaction remained significant for values between 18 and 48 months in time since diagnosis (range 4 – 48 months) for the total score. The same trend remained for the interaction involving the religious \( p < .05 \) and existential coping \( p < .05 \) subscales. Post-hoc probing revealed the interactions to remain significant for values between 17 and 48 months (religious coping x time since diagnosis) and 26-48 months (spiritual coping x time since diagnosis) respectively.

Discussion

The dramatic increase in survival rates in children diagnosed with a form of cancer over the past several decades has led to an extension of the concept of cure far beyond merely physical outcomes now including constructs of health including social, emotional, as well as psychological domains of functioning (Van Eys, 1999). The development of new treatments and subsequent evolution of the concept of cure within the medical community of pediatric oncology has transformed the field of pediatric psycho-oncology as well (Patenaude & Kupst, 2005). A great amount of work published over the last decades has been able to document the profound impact childhood cancer has on the family (Bleyer, 1990; Wakefield et al., 2010; Grootenhuis, & Last, 1997). Keeping a family systems approach in mind, which has been supported within the field of pediatric psychology (Kazak, Simms, & Rourke, 2002) and especially pediatric cancer, it can be said that the entire family is affected and will feel the impact of diagnosis and treatment. Much work has documented the stress and emotional strain of cancer on parents and the patients (Wakefield et al., 2010; Phibbs, 2007). Research on the effects a diagnosis of cancer has
on siblings of the child with cancer has not been quite as prolific and many unanswered questions remain as to the nature of impact, pattern of symptoms, and trajectory of adjustment of siblings who have a brother or sister with a neoplasm (Alderfer et al., 2009).

The purpose of the current study has been to further contribute to the body of knowledge concerning the impact of pediatric cancer on siblings of children with cancer. Aptly so, they are also sometimes called the ‘invisible siblings’, a term which may be said to epitomize the status and relative lack of attention they receive, both in their respective families and with regard to the amount of research devoted to finding out more about the impact of cancer on their lives and how to best support them throughout the experience of having a brother or sister with cancer.

The aims and hypotheses of this project were focused on investigating issues within this population which may have received little or no attention before in the literature in an attempt to further contribute to the field. As such the overall aim was to investigate patterns of psycho-social adjustment in siblings in constructs such as anxiety, depression, and symptoms of post-traumatic stress where evident in this population. Two of these constructs have received inconclusive and sometimes contradictory support in terms of their applicability within this population. However, siblings may be at risk for to experience symptoms of anxiety, depression, and PTS and assessment of these constructs remains an important issue in the literature and field (Alderfer et al., 2009). To extend and in an attempt to make an original contribution to the literature, the current project also looked at an under-researched construct in this population (i.e., coping, and more specifically religious/spiritual coping). The specific aim including religious/spiritual coping was to examine the unique role it may play in adjustment related outcomes. Furthermore, this study aimed its hypotheses to follow a call to investigate relevant moderators which may contribute to outcomes (Alderfer et al., 2009). The specific moderators looked at in the current study included variables which have produced inconclusive and contradictory findings in previous work as well as one variable which has previously been overlooked in research investigating the impact of cancer on siblings (i.e., age, gender, and time since diagnosis in particular, respectively).

The current project’s unique strengths lie in its rigorous design, use of validated and widely used measures, as well as outstanding sample size ($N = 126$) giving it enough power to detect moderate to large effect sizes (Cohen, 1988). Further, the heterogeneity in types of diagnosis included, representative of the catchment area and demographic distribution of pediatric neoplasms at a large northeastern pediatric oncology center in the United States, as well as the age range of siblings providing self-report make this study uniquely suited to contribute to the body of knowledge on adjustment in siblings of children with cancer in general, and to add evidence of a relatively new construct (i.e., religious/spiritual coping in particular) in this population to the field.
Consistent with the majority of the existing literature (Alderfer, 2009), this study did not detect clinical levels of anxiety and depression in siblings. The majority of scores fell into the mild to moderate range of symptoms for both outcomes with only a limited number of siblings reporting clinical levels of anxiety and depression symptoms. Further, also consistent with more recent research, siblings endorsed elevated levels of post-traumatic stress, with almost 60% of the sample falling above the cut-score indicating moderate to severe post-traumatic stress symptoms to be present in our sample at the time of assessment. This finding seems to further support the applicability of a traumatic stress framework to this population (Packman et al. 1997, 2004; Alderfer, Labay, & Kazak, 2003) which may be suited to capture the unique stress and impact of having a brother or sister with cancer. It may also allow to bridge the ‘gap’ between the rich and detailed insights into the cancer experience of siblings provided by qualitative research and the relative lack of significant findings regarding outcomes which one may expect to be of a maladaptive nature given the profound impact of the illness on siblings’ lives which have been revealed in interviews and the like provided by the siblings themselves. The construct of PTS may capture the traumatic nature of pediatric cancer in a way measures of psychopathology are not able to.

The overarching goal of this project, however, went beyond assessment of adjustment related outcomes. It was to investigate and describe religious/spiritual coping in siblings of children with cancer. The literature on coping in this population is very limited (Houtzager et al., 2004) with just a few studies describing constructs thought to be relevant to coping efforts in siblings (i.e., self control) (Hamama, Ronen, & Feigin, 2000). With little to no relevant previous research to compare the findings of this study to results are intended to describe religious/spiritual coping in this sample while references may be made to work exploring the construct in other pediatric populations (i.e., asthma and sickle cell disease) as well as in the adult literature where religious/spiritual coping has received more attention. Consistent with the previously reported widespread reach and importance of religion and spirituality in U.S. society, and in children and adolescents’ lives in particular (Cotton et al., 2006), the majority of siblings in this sample reported to engage in varying degrees of religious/spiritual coping with less than 2 % of siblings reporting scores between 1 and 10 (i.e., endorsing answer choices reflecting ‘never’ or ‘once in a while’ on most items). There seemed to be a trend to endorse existential coping items more frequently and/or with higher values than religiously based items, however, no patterns as to gender were detected in this sample with regard to a preference of religious or existential coping.

Contrary to what was hypothesized, older siblings seemed to engage less in religious/spiritual coping than younger siblings. The few studies including an assessment of coping in siblings of children with cancer do not report trends with regard to age. However, it may be that older siblings have more or other coping skills at their disposal due to advanced cognitive abilities which may allow them to rely
more on coping skills such as self-control (Hamama, Ronen, & Feigin, 2000) which presumably may require more executive function abilities than younger siblings’ cognitive development may allow for. The latter reasoning may also serve to explain the age trend detected with regard to younger siblings’ engagement in more religious than existential coping. Religiously based coping is thought to be tied to and representing a more concrete idea of God or the divine (Sexton, 2004) guiding and helping them through the experience of having a sick brother or sister as opposed to a more abstract ideas thought to represent existential coping. Time since diagnosis did not predict religious/spiritual coping in this sample. It is difficult to speculate about the reason why this finding did not support the hypothesis stated in this project with regard to time since diagnosis as this variable has not been investigated as a predictor (or moderator for that matter) in this population yet (Alderfer et al., 2009).

To date, psycho-social outcome research in siblings of children with cancer has been dominated by primarily being focused on assessing psychological disorders such as anxiety and depression as a result of the events of the illness and the stress and changes caused by it in the siblings’ lives (Houtzager, Grootenhuis, & Last, 1999). There have been calls, though, to focus more on factors promoting adjustment as opposed to focusing on pathology. Religious/spiritual coping may be said to be more leaning and moving towards an inclusion of a more resilient and positive constructs as it has ties and is often linked to constructs such as benefit finding or post-traumatic growth (Youngmee, Schulz, & Carver, 2007). This is especially salient for the existential or more spiritual side of the construct. In this project, however, the hypothesized direction of results and effects in the analyses involving the outcome measures, expected religious/spiritual coping to predict more distress (i.e., higher anxiety, depression, and symptoms of post-traumatic stress) as opposed to less. The direction of this prediction is based on the coping and stress model this project is based on (Lazarus & Folkman, 1984), which conceptualizes coping as an ongoing, dynamic process proportional in its size and strength of effort to the perceived stress of the event. Hence, higher religious/spiritual coping would indicate a perception of higher stress and threat due to having a brother or sister with cancer which might be associated with higher anxiety, depression, and symptoms of post-traumatic stress.

Analyses revealed only partial support for this prediction and way of conceptualizing coping as religious/spiritual coping did not predict levels of anxiety or depression in this sample. The lack of significant results may be attributable to the appraisal process siblings go through when they are assessing the threat caused by events associated with the illness. It may be an indicator that they may not perceive their brother or sister’s cancer as that threatening (Hamama, Ronen, & Feigin, 2000). The relatively low levels of anxiety and depression in this sample, replicated results generally found in this population, as the support of clinically significant levels of psychopathology are debated and not widely replicated within
the field. The lack of clinical levels in these adjustment related constructs may be indicative of less stress and therefore less need or necessity of a strong coping effort. Although, not supportive of the hypothesis of this project which postulated that coping is proportional to and therefore predictive of distress, this finding, along with the predominantly sub-clinical levels of anxiety and depression reported in the literature on this population, does seem to support the notion that the focus on psychopathology may not be the right approach to capture the experience of being a siblings of a child with cancer.

Measures assessing cancer-specific stress more specifically may reveal a more accurate picture of the threat childhood cancer is to siblings and what they are dealing with when their brother or sister receives a diagnosis of cancer (Sahler et al., 1997; Alderfer et al., 2009). However, there have also been reports supporting the notion that siblings (as well as their brothers and sisters, i.e., the cancer patients) may be under-reporting emotional and behavioral problems (Barrera, Fleming, & Kahn, 2004; Elkin, Phibbs, Mulhern, & Fairclough, 1997) in an effort to present themselves in a better light. This, one may speculate, could be motivated by an unspoken expectation requiring cancer patients to be strong and hopeful as opposed to angry and resentful. The associated adaptive style in children and especially in pediatric populations has been described as repressive adaptive and is associated with avoidant coping (Phibbs & Srivastva, 1997). Unfortunately, the scope and design of this project did not allow to assess and compare avoidant coping and religious/spiritual coping in this sample. More work is needed to elucidate the possibility of siblings of children with cancer to display this adaptive style which so far has mostly been observed in pediatric cancer patients themselves, not in their siblings.

Support of coping as predictor of stress was supported in this project, though, with regard to post-traumatic stress symptoms. While religious/spiritual coping in general was approaching significance in its ability to predict PTS symptoms in siblings, the existential coping subscale revealed to be a significant predictor of post-traumatic stress. Although effect size was small to negligible, this finding may be interpreted as further lending support to the relatively new direction of establishing the experience of living as a siblings of a child with cancer within a traumatic stress framework.

In an attempt to contribute and add to the knowledge base as well as following a call to include and investigate variables thought to be moderators of outcomes in siblings’ adjustment to pediatric cancer (Alderfer et al., 2009), this project examined age, gender, and time since diagnosis on the basis of their presumed potential to explain unique portions of variance in outcome variables such as anxiety, depression, and post-traumatic stress. Hierarchical regression analyses revealed significant interactions only between religious/spiritual coping total score and both subscales and time since diagnosis to explain some variance in depression scores in this sample. Post-hoc probing revealed direction as well as the significant values for time since diagnosis in this sample. Siblings who reported higher levels of overall
religious/spiritual coping and those who were further out from date of diagnosis were found to have lower depressions scores than those who were closer to date of diagnosis. This finding was significant for siblings whose brother or sister had been diagnosed between 18 to 48 months prior to the time of assessment. With regard to the subscales of religious and existential coping siblings who disclosed high levels of religious coping and who were 17 to 48 months out from diagnosis at the time of assessment were found to have lower depression scores than those who had disclosed lower religious coping scores. Similarly, existential coping remained significant for the interaction term between the values of 26 to 48 months.

This finding supports the overall notion that distress declines as more time passes after diagnosis, both in siblings (Houtzager et al., 2003), as well as in parents and patients (Wijnberg-Williams, Kamps, Klip & Hoekstra-Weebers, 2006). However, the combinations of religious/spiritual coping and time since diagnosis seems to have a unique role in it in this sample as time since diagnosis and religious/spiritual coping alone were not predictive of depression. The relative contribution of the two subscales, however, is difficult to interpret as both interactions were significant, with both subscales and time since diagnosis explaining roughly the same amount of unique variance in depression scores.

The findings of this project need to be considered within the relative limitations of the study. The cross-sectional nature of the design was not ideal to assess adjustment or coping as they are both conceptualizes as processes (Houtzager et al, 2003), signaling a trajectory over time necessitating a longitudinal design to be able to capture and describe said trajectory of adjustment patterns and associated coping styles. Furthermore, the lack of inclusion of a more cancer-specific stress measure to capture the unique stress of having a brother or sister with cancer limits the study’s ability to accurately describe adjustment related to childhood cancer. Anxiety and depression reported by siblings in this sample is assumed to be in response to the illness of their brother or sister but without being able to link cancer-specific stressors to outcomes such as anxiety and depression the distinct association between what the siblings report and in response to what remains unclear and susceptible to conjecture.

With regard to religious/spiritual coping, this project was not able to compare secular coping (i.e., non religious/spiritual coping) to non-secular coping to validate and compare the effectiveness of religious/spiritual coping relative to other types of coping. In that vein, there was also no assessment or differentiation between negative and positive religious coping and adjustment related outcomes possible due to the nature of the questionnaire used to assess religious/spiritual coping in this study. Nevertheless, this project was able to look and describe existential and religious coping separately, marking a unique contribution to the literature as the construct of coping and especially religious/spiritual coping is not well researched yet, especially in pediatric populations. More research is necessary to replicate and extend on
the findings of this project and to bring more attention and insight to the unique experience of living as a brother or sister with of a child with cancer.

Future directions of research should include a move towards conceptualizing siblings’ adjustment as variations in normal development and aim to include assessment of constructs thought to contribute towards positive adjustment, resilience, and growth in this population. The development of measures sensitive enough to pick up on subtle changes in adjustment as they are typical in siblings of children with cancer is also important in order to allow the field to gain a better understanding of the sibling experience. Lastly, research efforts should continue to investigate possible moderators of adjustment. This project was able to show the unique contribution of time since diagnosis on adjustment related outcome. Variables such as SES, type of diagnosis, as well as race have not been examined yet for their potential role in moderating adjustment outcomes in siblings of children with cancer. As with all clinical research, the ultimate goal motivating researchers and clinicians alike is and always should be to design studies whose outcomes are able to inform the development of interventions to identify and help those siblings who are at increased risk for adjustment related problems.
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