

The Development of a Children's Spirituality Measure and  
The Exploration of the Role of Spirituality in the Lives of  
Childhood Cancer Survivors and a Healthy Comparison Group

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### Abstract

Previous researchers exploring children's spirituality have often used narrow measures that do not account for the significant spiritual experiences of children in a diverse context. Although researchers have shown that spirituality can sometimes arise in response to illness, it is recognized that its value often goes beyond coping with immediate adversity. In Study 1, a children's spirituality measure was developed (i.e., Children's Spiritual Lives). A factor analysis revealed three main factors including Comfort (Factor 1), Omnipresence (Factor 2), and Duality (Factor 3). The newly developed measure, along with the established Spiritual Well-Being Scale, was used in Study 2 and its purpose was threefold: (a) to describe spirituality in childhood cancer survivors compared to a healthy comparison group, (b) to explore the effect of spirituality on psychological health and coping compared to a healthy comparison group, and (c) to determine whether parent-child<sub>cancer</sub> dyads scores on spirituality and psychological health measures were more highly correlated than parent-child<sub>healthy</sub> dyads of their healthy peers. The results revealed that there were significant differences between children's reported spirituality in relation to health history (i.e., cancer, healthy). Several spirituality factors and subscales were significantly higher in the childhood cancer survivor group than in the healthy comparison group. Health history was found to significantly moderate the relationship between spirituality and outcome variables, such as depression and anxiety. That is, some spirituality factors and subscales predicted lower depression and anxiety scores in the childhood cancer survivor group. The results also revealed that parent-child dyads<sub>cancer</sub> had more highly correlated scores than parent-child dyads<sub>healthy</sub> on both the Depression subscale and the Existential Well-Being subscale, whereas parent-child dyads<sub>healthy</sub> had more highly correlated scores than parent-child dyads<sub>cancer</sub> on the Duality factor. These results have implications for professionals providing

therapeutic interventions to childhood cancer survivors in both pediatric and school settings.

*Keywords:* spirituality, children, cancer, survivors, psychological health

## Résumé

Auparavant, les chercheurs qui ont étudié la spiritualité de l'enfant ont surtout utilisé des mesures étroites (e.g., présence à l'église) qui ne tiennent pas compte de la diversité contextuelle dans laquelle les enfants ont des expériences spirituelles significatives. Plusieurs chercheurs ont démontré que ces expériences spirituelles peuvent survenir en réponse à la maladie. Cependant, il est important de remarquer que la valeur véhiculée par la spiritualité surpasse fréquemment la simple capacité de faire face à l'adversité dans l'immédiat. Suite à l'étude 1, un indicateur de spiritualité de l'enfant a été développé (Vie Spirituelle de l'Enfant). Une analyse exploratoire des facteurs a révélé 3 facteurs : le confort, l'omniprésence, et la dualité. Cette nouvelle mesure a été utilisée dans l'étude 2 afin de répondre aux trois objectifs suivants: (a) décrire la spiritualité chez des survivants du cancer et chez un groupe de comparaison en santé; (b) examiner l'impact de la spiritualité sur la santé psychologique et sur l'adaptation; (c) déterminer si la relation dyades parent-enfant<sub>cancer</sub> avec les mesures de spiritualité et de santé psychologique était davantage corrélée comparativement au dyade parent-enfant<sub>en santé</sub> du groupe de pairs en santé. Les résultats des études présentent des différences significatives en ce qui a trait à la spiritualité des enfants rapportée en relation aux antécédents de santé de ceux-ci (e.g. survivant du cancer, en santé). Les sous-échelles de spiritualité confort, omniprésence, et religion sont considérablement plus élevées auprès du groupe d'enfants ayant survécu au cancer comparativement au groupe en santé. D'ailleurs, les antécédents de santé se présentent comme une variable modératrice entre la spiritualité et les variables de résultats telles l'anxiété et la dépression. Les résultats démontrent aussi que la dyade parent-enfant<sub>cancer</sub> détient une plus forte corrélation que le dyade parent-enfant<sub>en santé</sub> sur les variables de résultats de dépression et de spiritualité existentielle tandis que le dyade parent-enfant<sub>en santé</sub> détient une plus forte corrélation

que le dyade parent-enfant<sub>cancer</sub> avec la variable de résultat de dualité. Ces conclusions ont des répercussions importantes sur les professionnels de la santé qui interviennent auprès d'enfants qui ont le cancer.

*Mots-clés:* la spiritualité, les enfants, le cancer, les survivants, la santé psychologique

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Finally and most importantly, I am indebted to the families and children that participated in this study. I am thankful for their time, candor, and willingness to help advance research in this area of study. This dissertation is dedicated to all the childhood cancer survivors who took part in this study. In a special way, this study is also dedicated to the children I worked with who fought cancer with bravery and now rest in peace. I will never forget their valiant voices singing "Boom, boom, boom, even brighter than the moon, moon, moon. It's always been inside of you, you, you, and now it's time to let it through-ough-ough".

## **Preface**

I, Kelsey Moore, am the primary author of this dissertation. As its primary author, I conceptualized this study and have written the dissertation in its entirety. My doctoral supervisor, Dr. Victoria Talwar, played an integral role in the supervision of this project. Dr. Jacob Burack, Dr. Sandra Bosacki, and Dr. Linda Moxley-Haegert served as my doctoral committee, approving the dissertation's theoretical frameworks, methodology, and proposed statistical analyses at the proposal defense stage of this research. Sarwat Qaseem, Andrea Too, and Cheryl Gabbay assisted primarily in participant recruitment and data entry. Dr. Carlos Gomez-Garibello served in the capacity of statistics consultant, assisting with the conceptualization and execution of statistical analyses. Louis Vigneault translated the abstract into French. The Talwar Research Team at McGill University assisted in the data collection for both Study 1 and Study 2. Dr. Moxley-Haegert played an integral role in recruiting childhood cancer survivors, which allowed me to organize and carry-out home visits. Editorial recognition goes to Donald Bidd, Steven Bidd, and Brohan Moore. This dissertation contains original scholarship and distinct contributions to the field of children's spirituality through the development of a new measure of children's spirituality and its use with childhood cancer survivors. The study was approved by the McGill Research Ethics Board at McGill University and the Montreal Children's Hospital. This dissertation was funded by both the Canadian Institute of Health Research (CIHR) Doctoral Award and the Social Sciences and Humanities Research Council (SSHRC) Seed Grant.



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### **Introduction**

In pediatric settings, children and their parents often seek religious or spiritual support from health care providers as they attempt to find meaning in life-threatening illness (e.g., Barnes, Plotnikoff, Fox, & Pendleton, 2000; Kamper, Van Cleve, & Savedra, 2010; Lima et al., 2013; VandeCreek, Grosseohme, Ragsdale, McHenry, & Thurston, 2007). Children's spirituality is a topic of "direct relevance to pediatric practice, and child well-being" (Barnes et al., 2000, p. 900) as their spiritual beliefs can shape their understanding and experience of illness. For instance, religiosity and spirituality can provide children with positive coping strategies, such as finding meaning and purpose in the midst of trauma or illness (Lima et al., 2013; Walker, Reese, Hughes, & Troskie, 2010). Furthermore, some researchers have extended their studies beyond children facing immediate adversity. For instance, Morse and O'Rourke (2009) reviewed research in which spirituality was explored beyond the initial stage of a childhood cancer diagnosis and throughout the stages of cancer survivorship.

More Canadian children are surviving cancer due to innovations in medical technology and treatment protocols (Canadian Cancer Society, 2014). As a result, more researchers are investigating possible factors, such as spirituality, that may promote children's well-being beyond a cancer diagnosis and into survivorship (e.g., Hendricks-Ferguson, 2008; Morse & O'Rourke, 2009). According to Morse and O'Rourke (2009), "understanding the spiritual needs of children and adolescents is vital to supporting their well-being and providing the best possible care throughout various phases of survivorship" (p. 146). A greater awareness of spirituality and its relation to psychological health and coping strategies can strengthen the health care professional's therapeutic interventions with childhood cancer survivors as their spiritual needs may differ from their peers due to their history of illness (Moore, Talwar, & Moxley-Haegert,

2015; Smith, & McSherry, 2004).

Some researchers have placed a greater emphasis on the positive outcomes that follow a childhood cancer diagnosis as opposed to highlighting negative psycho-social sequelae (e.g., Parry, 2003). For instance, Zebrack et al. (2012) used the Post-traumatic Growth Inventory (PTGI) to measure perceived positive impact (e.g., spiritual change, new appreciation for life) in 6425 young adults who survived cancer as children. They found that these survivors were more likely to report perceptions of positive growth when compared to their healthy siblings. Similarly, Parry and Chesler (2005) found that a childhood cancer experience led to positive psychosocial outcomes in 50 young adults. In their qualitative study, they used the term *psycho-spiritual growth* to capture the deeply rooted changes reported in the participants' interviews; such changes were often existential or spiritual in nature. Zebrack et al. (2012) and Parry and Chesler (2005) both observed spiritual growth at long-term follow-up with these childhood cancer survivors. Other researchers, however, place more importance on spirituality as a protective factor that serves as a resiliency resource (Reutter & Bigatti, 2014).

Miller (2013) found that spirituality is one of the most robust protective factors against depression, especially throughout the period of adolescence. Spirituality, defined as the valued and dynamic relationship with a higher power, was shown to be a protective factor against depression in both adolescence and adulthood. Therefore, a better understanding of the role of spirituality in the lives of childhood cancer survivors and its relation with psychological health and coping could highlight potential sources of positive growth and protective factors for children facing the hardship of a cancer diagnosis. However, spirituality in relation to a childhood cancer diagnosis has often not been explored in childhood, but in later periods of life such as adolescence and adulthood. Moreover, researchers who have examined children's

spirituality have tended to use measures that are oriented towards adults or focused solely on religious practice (e.g., Houskamp, Fisher, & Stuber, 2004), which do not adequately account for the complexity of children's spiritual thoughts and ideas. Child-oriented measures that extend beyond religious practices would yield a richer study of children's spirituality and its implication for supporting health care professionals.

In addition, despite playing an integral role in their spiritual development, parents' perspectives of their child's spiritual lives are not well understood. Many researchers propose that parent-child conversations can shape children's moral (e.g., Recchia & Wainryd, 2014) and spiritual (e.g., Boyatzis & Janicki, 2003; Renaud, Engarhos, Schleifer, & Talwar, 2014) understanding. Thus, understanding how parents view their child's spiritual life is needed to better comprehend the dynamic of spirituality in the parent-child context. Because illness may prompt the discussion of spiritual themes (Cotton, Zebracki, Rosenthal, Tsevat, & Drotar, 2006), childhood cancer survivors may have more opportunities to have meaningful exchanges about such topics with their parents. When children are ill, parents often place more importance on relationships (e.g., family relationships, spiritual relationships) that promote recovery, rather than an emphasis on achievements (e.g., achieving high grades at school) that require optimal health. Thus, parent-child conversation during this time may shift from typical discussions about a child's achievements to discussions about spiritual concepts (e.g., Thayer, 2009), which may subsequently lead to parents' greater understanding of their child's spiritual ideas.

These parents may also engage in more conversations about their child's thoughts and feelings, given that a serious medical diagnosis can prompt complex emotions and discussion about illness (e.g., Eiser & Morse, 2001). Due to the compelling nature of medical situations, parents of childhood cancer survivors may have had more discussions with their children about

their psychological health, when compared to parents and children who may not have had such an experience. Taken together, parents of childhood cancer survivors may have more accurate perceptions of their children's spiritual lives and psychological well-being than parents of children who have not experienced a grave medical illness.

Thus, the research presented in this dissertation is comprised of two related studies in which children's spirituality was explored in the lives of childhood cancer survivors and in a healthy comparison group. In Study 1, a new children's spirituality measure (i.e., Children's Spiritual Lives) was developed with Canadian children and an exploratory factor analysis was conducted. The objectives of Study 2 were: (a) to describe spirituality in childhood cancer survivors compared to a healthy comparison group, (b) to explore the effect of spirituality on psychological health (i.e., depression, anxiety) and coping (i.e., positive and negative) in childhood cancer survivors compared to a healthy comparison group, and (c) to determine whether parent-child<sub>cancer</sub> dyads have more highly correlated scores on measures of spirituality and psychological health than parent-child<sub>healthy</sub> dyads. These two studies are connected, as the newly developed measure from Study 1 was used to explore children's spirituality in Study 2.



## Chapter 1: Review of the Literature

To ensure the appropriate scope, the main objectives in this literature review were to: (a) provide an overview of the concepts of *religiosity* and *spirituality*, (b) review the literature on children's spiritual development, (c) explore the quantitative measures of children's spirituality, (d) examine research on school age children's spirituality, (e) describe the research on pediatric cancer survivorship and its relation with spirituality, psychological health, and coping, (f) highlight the parent-child context and its relevance to children's spirituality and psychological health, and (g) present the theoretical and conceptual underpinnings that provided the impetus for the current study.

### Religiosity and Spirituality

William James (1902/1961), a seminal figure of the late nineteenth century, is renowned for his influence in philosophy, physiology, and psychology. Highly esteemed for his contributions in the psychology of religion, James conceived of human experience as the means to understand spirituality. Instead of focusing on institutional religion, James connected religion with spirituality, viewing religion as the "feelings, acts, and experiences of individual men in their solitude [...] in relation to whatever they may consider the divine" (p. 42). He advanced the notion that religions often use similar terms such as *divinity* or *transcendence* despite differences in practices and traditions. Currently, most researchers agree that both religiosity and spirituality transcend common human experience. This was evident in a review of 73 articles published between 1991 and 2000 on the conceptualization of spirituality in health literature by Chiu, Emblen, Van Hofwegen, Sawatzky, and Meyerhoff (2004), who found that connectedness, transcendence, energy, and existential reality were observed across cultures and creeds.

Defining the concepts of religiosity and spirituality has challenged researchers in this field of study and thus, there is no one single definition in the literature. According to Hart (2003), defining spirituality is like “trying to hold water in our hands” (p.8). In a similar vein, Oman (2013) notes that, despite the growth in research on religiosity and spirituality in the past decade, a consensus on these terms has yet to be achieved. Hill and Pargament (2003) suggest that both constructs are multifaceted in their own right; however, they caution against polarizing these concepts, as they both unfold within similar social contexts. Further, certain understandings of spirituality encompass the definition of religiosity and vice versa (e.g., Benson, Roehlkepartain, & Rude, 2003). Thus, these terms will be briefly discussed in order to highlight trends in their conceptualization in the literature and to clarify how these concepts were operationalized in the current study.

Certain broad themes can be identified among cited definitions. When examining these concepts more quantitatively, researchers are often challenged to operationalize these terms based on precedents in the literature. For example, in their study, Reutter and Bigatti (2014) operationalized these terms by describing spirituality as internal, subjective, and private and religiosity as institutional, visible, and tied to a public community. In a study by Ubani and Tirri (2006) of Finnish pre-adolescents, the majority of participants associated religion with institutional features (e.g., traditions, religious practices) whereas they associated spirituality with broad transcendent or humanistic qualities (e.g., individual beliefs, values). Benson et al. (2003) consider spirituality as an individual's journey toward self-transcendence and the relationship with a sacred higher power. Similarly, Stanard, Sandhu, and Painter (2000) propose that spirituality is a deeply personal experience, making it broader concept than religiosity, since it is not directly connected to a community or institution.

Pargament, Tarakeshwar, Ellison, and Wulff (2001) propose an alternative method to conceptualize these terms. They put forward a distal-proximal model to represent the essence of these concepts. In their model, distal dimensions of religiosity and spirituality include individual practices, which have been traditionally deemed as religious (e.g., frequency of church attendance). In contrast, proximal dimensions of religiosity and spirituality include practices closely related to well-being (e.g., finding comfort in a relationship with a higher power, using spirituality to cope with adversity). Although this model was developed for adults, Cotton et al. (2006) reviewed several studies in which proximal aspects of spirituality (e.g., religious and spiritual coping) were associated with positive outcomes in adolescents.

In this dissertation, the concepts of religiosity and spirituality will be differentiated based on the broad precedents and patterns found in the literature. Given that the objective of this research is to examine spirituality in children living in a pluralistic Canadian context, ubiquitous spiritual characteristics (e.g., relationship with a higher power, purpose and meaning in life, spirit-body dualism; Barrett, 2011) that transcend cultures and creeds are of particular relevance. The intention is not to be reductive in relation to spirituality, but to explore broader spiritual experiences that appear across religious groups. In particular, the relationship with the sacred is of specific importance, as it is often deemed the most robust protective factor against negative psychological symptoms, such as depression (e.g., Miller, 2013). Fisher (2012) also found that a relationship with a higher power plays an integral role in spiritual well-being. Based on his review of 22 studies, he found that a relationship with the sacred accounted for the most variance in spiritual well-being. Thus, because one of the main objectives of this study is to examine spirituality in relation to psychological health outcomes and coping strategies, exploring the relationship with the transcendent is especially germane.

### **Children's Spiritual Development**

As expressed by Oser, Scarlette, and Bucher (2006) "there is no one theory of pure spiritual development" (p. 943). James Fowler (1981) proposed the most prominent and widely accepted faith-development theory. Based on discontinuous stages of spiritual development, this theory is presented in relation to Jean Piaget's theory of cognitive development, Erik Erikson's theory of psycho-social development, and Laurence Kohlberg's theory of moral development. Fowler models his ideas regarding spiritual development within the context of these developmental frameworks. For instance, in each of these frameworks, children are acknowledged as having the capacity to progress from concrete to abstract thinking as they mature. Fowler situates the stages of spiritual development within these developmental models, suggesting that, as children mature, they have an increased ability to become more aware and engaged with their spirituality.

In a move away from Fowler's spiritual developmental framework, proponents of the "spiritual child movement" (Oser et al., 2006, p. 968) distanced themselves from traditional stage-structural theories, which were deemed "too cognitive" (Oser et al., 2006, p. 969). Similarly, Hart (2003) argues that Jean Piaget's work "has been hugely influential in shaping how psychologists and educators view children. However, there is increasing evidence that he was both right and also quite wrong, or at least, incomplete" (p.92). Hart proposes that the stages of spiritual development are more fluid than were once understood, since children often have the ability to understand complex issues, but may struggle to express themselves. Although children are often perceived as egocentric or unable to take another's perspective, Hart emphasizes children's seemingly innate ability to recognize complex issues, such as injustice, suffering, and compassion. Based on his anthropological studies and interviews of hundreds of

children and adults about their spiritual childhood experiences, Hart argues that children often ask existential questions and have the ability for “deep metaphysical reflection” (p. 9). He proposes that children are “natural mystics” (p. 49) who express “wonder and awe” (p. 91). Although spirituality is often considered at the “top of the developmental ladder” (p. 9) and only fully realized by passing through a series of discontinuous stages, Hart argues that spirituality is more accessible throughout development.

Kelemen (2004) also digresses from traditional developmental theory and proposes that children are innate theists. From this perspective, children naturally view the world and their existence within the context of intelligent design. Similarly, Barrett and Richert (2003) propose a *preparedness hypothesis*, which challenges the anthropomorphist view that children cannot think abstractly until they develop and mature. They suggest that children have cognitive biases that enable them to contemplate the metaphysical characteristics of God. After reviewing several studies geared towards cognitive-cultural foundations of spiritual development, Johnson and Boyatzis (2006) propose that research, such as that by Barrett and Richert, provides grounds to suggest that children are naturally spiritual from an early age.

Woolley and Phelps (2001) also suggest that children may have a more sophisticated understanding of prayer than was once understood. They juxtapose children's beliefs in prayers with their beliefs in wishing and found that “not only do children believe thinking to be involved in praying, but their beliefs in the efficacy of this form of mental-physical causality increase with age rather than decrease, as is the case with wishing” (p. 160-161). Even from an early age, children have been found to have ideas about spirituality. For instance, Vaden and Woolley (2011) found that young children (4-6 years) who explained events in a story by using spiritual concepts rated the stories and characters as more believable. Similarly, Richert and Harris

(2008) found that children (6-12 years) could understand the concept of the soul as a supernatural agent that connects them to a higher power, and that even very young children (4 years-old) could show an understanding of dualism. In summary, these researchers all suggest that children, even from an early age, may have more profound and meaningful thoughts about spirituality than was once thought.

A more complex understanding of children's spiritual development can also be derived from research about children's interactions with their parents and their environment. Boyatzis (2012) proposes a social-ecology model to better understand children's varied contexts and how these factors shape their religious and spiritual development. More specifically, he frames spiritual development within the context of Bronfenbrenner's (1979) ecological model as well as transactional models of development (Kuczynski, 2003; Sameroff, 1975). Drawing on Bronfenbrenner's ecological model of microsystems (e.g., school, religious group) and macrosystems (e.g., cultural landscape and ideology), Boyatzis (2012) proposes that children's relationship with the divine emerges prior to "religious socialization" (p.153) and is subsequently shaped by the way in which it is cultivated in their environment. Adopting the perspective that spirituality is not imposed on children by their parents, he proposes that parent-child interactions are multidirectional in nature and that these complex exchanges shape children's spiritual development. In turn, the development of spirituality in children is understood as a fluid and dynamic interaction between children, their parents, and their environment. As a result, researchers have begun to explore, both theoretically and empirically, the development of spirituality not only in relation to interactions with others and their environment, but also in relation to the self (e.g., gender development).

### **Spiritual Development and Gender**

Spiritual development in relation to gender has been explored both theoretically and empirically. In exploring pre-adolescents' gender and spirituality from a theoretical perspective, Bosacki, Moore, Talwar, and Park-Saltzman (2011) argued that spiritual and gender development is a dynamic and complex process that is tightly interwoven with children's sense of self, which includes mind, body, and spirit. Other researchers have examined gender and spirituality more empirically. For example, in adolescent girls, higher relational spirituality was related to decreased depressive symptomology (Desrosiers & Miller, 2007) and participation in a religious group or organization was linked to a lesser likelihood of depression (Miller & Gur, 2002). In general, spirituality among adult women has been more strongly related to salutary psychological outcomes (e.g., Ellison, Finch, Ryan, & Salinas, 2009). The relation between spirituality, gender, and psychological outcomes is perhaps better understood in adolescence and adulthood, as most measures used to explore spirituality are geared towards these populations in contrast to children.

### **Measuring Spirituality**

**Challenges in measure development.** In general, researchers have developed measures mainly oriented to members of Judeo-Christian traditions (Roehlkepartain, Benson, Ebstyne King, & Wagener, 2006). Hill (2013) proposes that most spirituality measures have been developed in the United States and are often deliberately, or unintentionally, rooted in Christian traditions. Canada could benefit from a spirituality measure that represents a broad and pluralistic population. However, the lack of sustained research in developing such a measure is problematic. As summarized by Hill, experts in the area of measure development have discussed both the strengths and limitations of developing overarching broad measures of spirituality

versus more focused measures of specific religious traditions. The main challenge, as outlined by Hill, is to then use these measures in studies with appropriate populations to achieve validity and reliability. Sustained research and longitudinal data are necessary to better understand the strengths and weaknesses of both types of spirituality measures (i.e., concepts specific to a religious group versus broad concepts that transcend religious groups).

Researchers also struggle with the specific terminology to use when referring to the supernatural in their spirituality measures. Underwood and Teresi (2002) found that when they used a spirituality measure with adult participants, the term *God* was the most easily understood across religious and spiritual groups. They suggest that “those outside the Judeo-Christian orientation, including Muslims, people from indigenous religious perspectives, and agnostics, were generally comfortable with the word, being able to translate it into their concept of the divine” (p. 24). They found that questions, in which the term God was used were not problematic in their factor analysis, which led them to conclude that this term may be appropriate to use across religious groups. Evidently, in recent years researchers have begun to invest in the development of spirituality measures and have discussed the nuances of item development. However, researchers have tended to place more focus on the development of these measures for adult populations (e.g., Houskamp et al., 2004; Cotton, McGrady, & Rosenthal, 2010).

**Adult spirituality measures.** In a systematic review, Monod et al. (2011) identified 35 measures of adult spirituality. These measures were classified into various groupings, such as spiritual well-being, spiritual coping, spiritual needs, and general spirituality. Although they found several promising measures, Monod et al. expressed concerns about the lack of published data on these measures' psychometrics. One of the most established and frequently used measures noted in this review is the Spiritual Well-Being Scale. Developed by Paloutzian and



Ellison (1982), this measure has been used outside of North America with a wide variety of faiths, making it a more appropriate measure to use with diverse populations. Although it was developed and standardized for adults, this measure has been used occasionally in pediatric settings with children facing illness (Cotton et al., 2009; Hendricks-Ferguson, 2008; Winkfield, 2009). In a review, Cotton et al. (2010) found that the Spiritual Well-Being Scale was one of the most commonly used questionnaires with adolescents. Nevertheless, they concluded that many measures used with adolescents are adult-based and thus may be developmentally inappropriate.

**Children's spirituality measures.** Despite a recent proliferation of spirituality measures, most of these measures are geared towards adults (Monod et al., 2011). In the early 2000s, Fisher (2004) reported finding only one measure designed specifically for children, which was in an unpublished doctoral dissertation. As a result, Fisher developed a children's spirituality measure (i.e., Feeling Good Living Life questionnaire) to provide educators with a tool to efficiently assess the role of spirituality in the lives of children in school. More recently, Fisher (2009) reviewed all known spirituality measures for children and adolescents. In his review of approximately 30 multi-item measures, he identified very few published measures that were specifically developed for school age children (7-11 years). The Multidimensional Life Satisfaction Scale for Children (primary school age; Huebner, 1994), Feeling Good Living Life (5-12 years; Fisher, 2004), Spiritual and Religious Thriving in Adolescents (9-15 years; Dowling et al., 2004), and the Benefit Finding Scale for Children (7-18 years; Phipps, Long, & Ogden, 2007) are all published scales that have been subjected to factor analysis and have been used with school-age children.

Fisher's (2004) Feeling Good Living Life questionnaire, however, is the only aforementioned scale that includes items pertaining to children's relationship with the

transcendent. Since Fisher's (2009) review, there has been a small handful of newly developed children's spirituality measures (e.g., Sifers, Warren, & Jackson, 2012; Stoyles, Stanford, Caputi, Keating, & Hyde, 2012). For instance, Stoyles et al. (2012) developed the Children's Sensitivity Scale for Children, which does not include any questions pertaining a child's relationship with the transcendent, but is centered on children's ability to reflect about themselves and the world. Sifers et al. (2012) used a diverse sample to develop and validate a Youth Spirituality Scale for children (7-14 years). The measure was piloted and showed signs of validity and reliability, but is still in the stages of requiring further validation. Although, Sifers et al. (2012) reported participants' cultural backgrounds, they did not report the participants' various religious and spiritual orientations. In sum, there are no known spirituality measures that have been developed for school-age children from a diversity of religious and spiritual backgrounds in Canada.

### **Spirituality in School Age Children**

Due to the limited number of spirituality measures for children, researchers often opt for more qualitative approaches in studying children's spirituality. For example, Mountain (2005) conducted semi-structured interviews with 60 primary school children from diverse faith orientations and showed that children tend to perceive prayer as a positive activity. Despite the religious and cultural diversity among the children, prayer was considered a valuable form of spiritual engagement among most participants, especially in the midst of difficult moments. These children expressed the view that the thoughts and words used in prayer helped them identify and express feelings. Similarly, Bamford and Lagatutta (2010) also explored the role of prayer in the lives of children. When controlling for religious and spiritual backgrounds, they found that 8 year-olds believed that prayer could alleviate negative emotions, whereas children between 4 and 6 years old tended to believe that only positive emotions were associated with

prayer. In a questionnaire-based study, Holder, Coleman, and Wallace (2010) explored the role of prayer in relation to emotions. More specifically, they explored spirituality in relation to happiness. They found that spirituality was a predictor of happiness in children (8-12 years, 51% female) especially with those children who expressed personal dimensions of spirituality (i.e., sense of meaning in life) and communal dimensions (i.e., close interpersonal relationships).

### **Spirituality and Illness**

Other researchers have investigated more specifically the role of religiosity and spirituality in the midst of various childhood illnesses (e.g., asthma, inflammatory bowel disease, cystic fibrosis). Overall, religiosity and spirituality appear to be related in varying degrees to positive psychological and coping outcomes in children with illness (e.g., Cotton et al., 2009; Cotton et al., 2012; Pendleton, Cavalli, Pargament, & Nasr, 2002). Given that cancer is the leading cause of death in childhood (Canadian Cancer Society, 2014), researchers have begun to extend their study of spirituality in the context of children's cancer experiences. Currently, the highest incidence of cancer in children is between birth and 5 years-old (Canadian Cancer Society, 2014). Thus, many children will receive cancer diagnoses as toddlers and complete primary treatment by the time they begin school. The experience of childhood cancer survivors, however, is typically only studied once these survivors have become adolescents or adults (Morse & O'Rourke, 2009). In order to promote earlier and more effective interventions with young children who have survived cancer, researchers should aim to better understand factors that may promote psychological health and positive coping strategies during childhood, rather than focusing primarily on adolescence or adulthood. Even with an early childhood cancer diagnosis, children's cancer experience cannot be overlooked, given that even very young children may understand the severity of their diagnoses and potentially fatal outcomes

(Bluebond-Langner, 1978; Pai et al., 2007).

Bluebond-Langner's (1978) influential ethnographic work in the field of pediatric cancer illustrates how even very young children are affected by a cancer diagnosis. Her dissertation-based book, *The Private Worlds of Dying Children*, is highly cited in the literature on children's understanding of death. Through her interviews and observations in pediatric oncology, she suggests that children often become aware of their illness and prognosis through indirect and nuanced interactive processes. Over the course of nine months, 40 children (3-9 years) with leukemia displayed an understanding of the gravity of their illness, even when their parents chose not to disclose their illness and prognosis to them. Bluebond-Langner argues that children in pediatric settings are often socialized by to appear unaware of their terminal illness in order to protect their parents. Her findings contradict traditional developmental theory as she argues that children have more competence in dealing with these complex issues than they are often given credit.

Woodgate and Degner (2003) suggest that Bluebond-Langner's findings "reinforced how the acquisition of information about the self is increased through the illness experience; experience as opposed to age may be more valuable to a child's understanding of illness" (p. 104). Similar to those children studied by Bluebond-Langner, childhood cancer survivors also faced the prospect of their own mortality and may have contemplated spiritual and existential ideas, as these concepts often emerge in relation to death (Renaud et al., 2014). Thus, spiritual and existential perspectives, and its relation with psychological outcomes and coping should be more thoroughly explored in the lives of childhood cancer survivors.

### **Cancer Survivorship, Psychological Outcomes, Coping, and Spirituality**

The term *cancer survivor* has many definitions. The definition adopted by Feuerstein

(2008) and the *Journal of Cancer Survivorship* describes cancer survivors as “populations and individuals with a diagnosis of cancer who have completed primary treatment for cancer [...] these survivors have completed primary treatment or the major aspects of treatment and either desire or need to get on with their lives” (pp. 6-7). According to Zebrack and Zeltzer (2003), cancer survivorship is a “concept used by many health care professionals, researchers, and cancer patients to understand not only the physical but also the social, psychological, and spiritual/existential impact of cancer on one’s life and for the remainder of one’s life” (p. 198). Other researchers adopt broader definitions. For example, Leigh (1992) describes cancer survivorship as any stage of an individual’s cancer journey, even at the time of diagnosis. Many cancer patients declare themselves cancer survivors at the moment of diagnosis. However, in the current study, the term cancer survivorship refers to children at least 6 months post-diagnosis who have completed major aspects of their treatment (e.g., primary induction).

**Psychological outcomes.** Eiser, Hill, and Vance (2000) explored the psychological consequences of surviving childhood cancer. In their review of 20 studies specifically examining children and adolescents, they found no significant differences in measures of depression, anxiety, or self-esteem when they compared these results to matched controls or comparison groups. However, a small subset of survivors (i.e., children with a history of bone tumors) tended to have poorer overall outcomes.

Speechley, Barrera, Shaw, Morrison, and Maunsell (2006) examined parent-reported quality of life in 800 children and adolescents (6-16 years). They found that health-related quality of life was overall poorer in long-term cancer survivors (i.e., more than 5 years) when compared to a health comparison group. However, psychological outcomes of these two groups were not clinically significant. Howard Sharp, Rowe, Russell, Long and Phipps (2014) shifted

from the parent perspective to the child's point of view, and used child-report measures with 255 survivors (8-17 years). They concluded that healthy status (i.e., cancer, healthy) accounted for negligible variance in children's overall functioning. Instead, they found that children's disposition (i.e., five-factor personality measure) was a better predictor of psychological outcomes (e.g., depression, anxiety). In a study examining social support received at a camp for children with cancer, Conrad and Altmaier (2009) explored psychological health and well-being of 25 children (9-18 years) and their parents. Following the week-long camp experience, parents completed the Child Behavior Checklist and children completed a Social Support questionnaire. Children's adjustment, as reported by parents, was not different from normative populations and no relation was found between parents' reported adjustment and children's perceived support.

When these survivors enter young adulthood, however, more discrepancies emerge between them and their healthy peers on several outcome measures (e.g., Zeltzer et al., 2009). Zeltzer et al. (2009) propose that these differences are likely due to small sample sizes, numerous outcomes measured (e.g., psychological health, health-related well-being, coping strategies), and varied comparison groups. In general, it appears from this research that childhood cancer survivors are comparable to their healthy peers with respect to psychological outcomes. However, Speechley et al. (2006) acknowledge that psychological consequences of childhood cancer survivors are often only examined in adulthood; thus, children's psychological outcomes are still not well understood. As a result, factors that may promote psychological well-being and adaptive coping strategies following such a diagnosis in childhood warrant further exploration (e.g., Wenninger, et al., 2013).

**Coping.** In an exploratory study by Sposito et al. (2015), 10 children (7-12 years) participated in semi-structured interviews while in the process of undergoing chemotherapy.

Among the many themes identified in the transcripts, one key theme that emerged was children's ability to find support through their religious convictions. The researchers found that children's praying and participation in religious services helped them in coping with their illness. Although Sposito et al. examined coping in the midst of chemotherapy treatments, they highlighted the importance of considering coping across various stages of the cancer experience. In another study with school-age children (6-12 years,  $n=15$ ), Hildenbrand, Alderfer, Deatrick, and Marsac (2014) explored parent-child coping in pediatric cancer. They found that both parents and children frequently used avoidance strategies to cope with cancer and treatment. Conversely, some researchers have found that parents and children do not adopt avoidance coping approaches but use more approach-oriented coping. For instance, in the study by Hildenbrand, Clawson, Alderfer, and Marsac (2011), 15 parent-child dyads (6-12 years) took part in semi-structured interviews. The researchers found that parents encouraged approach-oriented coping (e.g., cognitive restricting, relaxation) as opposed to avoidance coping; distraction was noted as the only avoidance coping strategy used. In general, Kupst and Bingen (2006) underline that coping, and its relationship with other factors, is still not well understood in pediatric cancer populations, as the results are sometimes inconsistent. Thus, they recommend that researchers should continue to clarify the relation between coping and other factors that may promote well-being.

**Survivorship and spirituality.** Previous researchers have suggested that spirituality may serve as a protective factor for children, adolescents, and adults. However, this relation is not clearly understood due to methodological issues and imprecise self-report measures (e.g., Benson, Scales, Sesma, & Roehlkepartain, 2005). With respect to children with a history of cancer, most researchers have examined spirituality by using qualitative methods. In a review by Morse and O'Rourke (2009), 10 studies concerning cancer survivors' spirituality were discussed.

Overall, Morse and O'Rourke found common and overarching themes across the studies, which included the presence of (a) hope, (b) understanding, meaning and coping, (c) spiritual well-being, and (d) finding a sense of spirit throughout the cancer experience. However, of their reviewed studies, many included adolescent and adult participants who survived a childhood cancer diagnosis, as opposed to school-age children who survived a childhood cancer diagnosis.

In a longitudinal study, Kamper et al. (2010) asked 60 children and adolescents (6-17 years) with advanced cancer to respond to a spiritual quality of life questionnaire every two weeks over a period of five months. Seventy-eight percent of children reported engaging in some type of activity that made them feel close to God and 59 percent of children reported praying to God for a sense of normalcy. Kamper et al. concluded that health care professionals who are more attuned to children's spirituality throughout their cancer experience can enhance the quality of children's care. In another longitudinal study, Woodgate and Degner (2003) explored families' sense of spirituality throughout the cancer experience using a qualitative design with 39 children and adolescents (4-18 years) and their families. From their analysis of the interviews, they found that children and families engaged in a *keeping the spirit alive* discourse in the midst of suffering and illness. Families often referred to the *spirit* as something that the cancer could not destroy. Although the spirit was vulnerable during the difficult cancer experience, the families relied on the spirit to get them through the experience and worked together towards keeping the spirit alive even in times of adversity.

Other researchers have used individual interviews with children and adolescents to explore spiritual concepts. Through semi-structured interviews with adolescent cancer survivors (11-18 years), Weekes and Kagan (1994) found that adolescents appeared to find meaning, purpose, and benefits throughout their cancer care experience. Specifically, they interviewed



adolescents at four different time points (i.e., before completing chemotherapy, upon completing chemotherapy, three months post-chemotherapy completion, six months post-chemotherapy completion) and noted differences in the participants' coping before and after treatment. For example, adolescents used more positive thinking and avoided thinking about treatments before chemotherapy completion, whereas they used negotiation and selective forgetting after chemotherapy completion.

Hendricks-Ferguson (2008) also explored the relation between spiritual well-being and phases of survivorship experienced by adolescents (13-21 years). The phases of survivorship were organized into four main time points (a) one year since diagnosis, (b) one-two years since diagnosis, (c) two-three years since diagnosis, and (d) three or more years since diagnosis. In using the Spiritual Well-Being Scale, Hendricks-Ferguson found that overall spiritual well-being (i.e., Religious Well-Being subscale and Existential Well-Being subscale) was greater at the first two time points. Adolescents also reported higher scores for Existential Well-Being (i.e., sense of meaning and purpose in life) at the first time point compared to the third time point. Hendricks-Ferguson found that spirituality may be more germane in the beginning stages of a cancer diagnosis, but suggests that future researchers should investigate spiritual well-being across various phases of survivorship.

In an earlier study also conducted by Hendricks-Ferguson (2006), gender and age were explored in relation to spirituality and hope in adolescents (13-20 years) with cancer. The Hopefulness Scale for Adolescents and the Spiritual Well-Being Scale were used. Hendricks-Ferguson found that adolescent girls had higher levels of both religious and existential well-being. Higher levels of hope were also found in early adolescent girls. As made evident by these findings, there may be some differences between males and females with respect to

religious and existential well-being in adolescents and thus gender differences should be considered when examining spirituality.

Parry and Chesler (2005) also used a qualitative approach to understand the cancer survivor experience. In using *thriving theory* as a guiding framework, Parry and Chesler conducted in-depth interviews with 50 childhood cancer survivors as young adults (17-29 years) and examined themes related to thriving. Parry and Chesler propose that thriving consists of two main components (a) the presence of hardship or adversity, and (b) positive growth or adaptation in response to the adverse experience. Thus, they were attentive to themes such as positive change in the cancer survivor's narratives. A compelling finding was the "meta-narrative" (p. 1065) of *psycho-spiritual growth* that emerged in many of the transcripts. According to Parry and Chesler, the participants discussed more spiritual and existential dimensions of growth (e.g., finding meaning and purpose in illness) as opposed to traditional religious dimensions of growth (e.g., religious services).

Although some researchers have made efforts to explore the role of spirituality in the lives of childhood cancer survivors qualitatively, quantitative studies have been far less common. Few researchers have examined spirituality and its role in the childhood cancer experience, despite some researchers suggesting that it is an important dimension to consider in pediatric care (e.g., Kamper et al., 2010). With respect to adults, several researchers have shown that the incorporation of spirituality into their cancer care appears to improve their overall cancer experience (e.g; Balboni et al., 2007; Ferrell, 2007; Skalla & McCoy, 2006). Puchalski (2012) suggests that: "inquiring about a cancer patient's spirituality also correlates with a whole-person healthcare model that shifts care from a focus on disease cure to one that addresses how an individual cancer patient defines wellness in the context of the disease experience" (p. 51).

However, in pediatric settings, some argue that health care professionals afford children few opportunities to express their wishes about their care (e.g., Seller, 2010).

Robert Coles (1990), a prominent child psychiatrist renowned for his writings on spirituality and morality, argued that adults often do not seriously acknowledge the real impact children's beliefs can have on how they understand their experiences. Coles interviewed, at length, over 500 children (8-12 years) from different religious and spiritual backgrounds and was a strong proponent of the notion that children have dynamic spiritual lives. Coles, Because of seminal works, including his book entitled *The Spiritual Life of Children*, researchers have begun to consider more seriously the role of spirituality in the lives of children following a life-threatening experience. In his investigation of children faced with adversity (e.g., pain, accidents, illness), Coles found that children from a diversity of faith backgrounds were able to reflect on how the experience affected their lives and their spirituality, a finding that does not correspond to the common perception of most adults.

### **Parents' Perceptions of Children's Spirituality**

Given that parents may play an integral role in children's spiritual development (Boyatzis, 2012), there is a need to understand how parents view their child's spirituality. Some researchers have explored how parents and children talk about topics (e.g., death) in which supernatural concepts may arise (e.g., Talwar, 2009). Renaud et al. (2014) found that parents talked to very young children (2-7 years,  $n=140$ ) about abstract topics such as death and afterlife. Overall, Renaud et al. found that parent-child conversation about death were first initiated when children were toddlers (i.e., 3 years-old) and parents who provided spiritual explanations about death (e.g., continued existence after death) tended to feel more satisfied with their conversations.

In a similar vein, Boyatzis and Janicki (2003) conducted a study examining parent-child conversations about abstract concepts, such as religious and spiritual understandings. They examined parent-child communication about Christian religious topics during a two-week span. Parents were asked to keep a diary chronicling their children's (3-12 years) conversations related to religious topics. Boyatzis and Janicki (2003) found that parents relied on open-ended questions as a method of religious inquiry and seldom explored their children's religious perspectives. They also noted that children engaged in religious conversations as frequently as their parents, emphasizing "the need for researchers to view children as active participants in religious socialization rather than as more passive recipients of parental influences" (p. 252).

Although Eiser and Morse (2001) did not examine parent-child conversations about spiritual concepts, they systematically reviewed parent-child ratings children's quality of life. They found that reports by parents and chronically ill children were more positively correlated than reports by parents and healthy children. Notably, more observable quality of life factors (i.e., health) had greater parent-child agreement than less evident quality of life factors (i.e., emotional, social). Nonetheless, the higher positive correlation on the quality of life measure suggests that parents of chronically ill children may be more aware of their children's overall well-being due to their challenging medical circumstance. Because illness can potentially prompt more discussions about spirituality and overall well-being, parents of children with an illness may be more attuned to their child's spiritual lives and psychological health than parents of healthy children. Although the parent-child context provides a framework to better understand children's spirituality, guiding theories in this field of research are also helpful when exploring the role of children's spirituality following a cancer diagnosis.

### **Theoretical Frameworks**

Given that most findings on childhood cancer survivors' spirituality have been exploratory in nature, and thereby limited, two theoretical frameworks were used to help interpret and discuss this dissertation's findings. Of particular interest are theories of post-traumatic growth (PTG) and resilience. Tedeschi and Calhoun (2004) describe post-traumatic growth (PTG) as the phenomenon of a positive psychological change, which can result from an individual's struggle with difficult circumstances. The construct of PTG builds on the notion that positive outcomes can emerge from experiences of suffering and distress. Positive outcomes associated with PTG may include a greater appreciation for life, changes in priorities, more intimate relationships, a greater sense of personal strength, and spiritual growth (Tedeschi & Calhoun, 2004). Researchers such as Linley and Joseph (2004) found that religiosity was associated with post-traumatic growth, particularly in situations where adults used religious coping to derive meaning from a traumatic event. Harris et al. (2008) found that PTG was reported after adults received spiritual support whereas Yanez et al. (2009) reported that women with breast cancer were more likely to report PTG if they highly identified with a religious faith.

Given the higher-level, reflective nature of such processes, Tedeschi and Calhoun (2004) acknowledge that PTG may be less applicable to children than to adults and adolescents. McElheran et al. (2012) therefore proposed a revised model, which considers the unique development needs of children. Given this framework for PTG, specific activities and individual characteristics are considered to make growth more likely following a major life crisis. For example, deliberate cognitive processing and disclosure in the context of stable and consistent social support may facilitate growth. Such activities are seen to be conducive to growth because they contribute to a meaning-making and narrative development process by which the survivor

can makes sense of the adverse event.

According to Tedeschi and Calhoun (2004), PTG is qualitatively different from the concept of resilience. PTG refers to deeper transformations in one's fundamental outlook and sense of self rather than a toughness or ability to thrive in the face of adversity. Given this distinction, Tedeschi and Calhoun note that survivors with high levels of resilience and coping may in fact report relatively little growth if their struggle with the aftermath of trauma is minimal. Some researchers suggest that religion and spirituality can promote resilience by helping individuals find a sense of meaning in hardship, thus protecting them from harmful feelings of distress. Spirituality is often viewed as a protective factor, because it may contribute to the consolidation of personal values (Van Dyke & Elias, 2007) and equip individuals with adaptive coping strategies (Smith, Pargament, Brant, & Oliver, 2000). In sum, both the resilience and PTG approaches provide firm ground to speculate that (a) spirituality may serve as a protective factor for children following cancer diagnosis and treatment, and/or (b) children may experience spiritual growth following a cancer diagnosis and treatment.

### **Rationale and Original Contribution**

Researchers exploring children's spirituality have tended to use narrow measures (e.g., religious service attendance) that do not account for the spiritual and religious experiences of children in a diverse context (Houskamp et al., 2004). This fact is especially germane to Canada, which is a very heterogeneous with respect to spiritual and religious practices. In Canada, Christianity is the predominant religion with approximately 22 million adherents from different denominations. There are over one million adherents to Islam. Sikhism and Hinduism each have approximately half a million adherents whereas Judaism and Buddhism each have approximately 400,000 observers (Statistics Canada, 2013). Despite increases in religious and

spiritual diversity and the interactions of faith groups in pluralistic contexts, most measures of spirituality used in North America are often derived from Christian-based ideologies (Roehlkepartain et al., 2006). As such, these measures inadequately reflect the variety of religious and spiritual identities, which are present in North American society (Moberg, 2002). Researchers, such as Cotton, Larkin, Hoopes, Cromer, and Rosenthal (2005), challenge the research community to extend its investigation beyond religious service attendance to include more transcendent concepts of spirituality. In response to this challenge, in Study 1 of this dissertation, the main objective was to develop a spirituality measure for children from diverse backgrounds in order to capture overarching dimensions of children's spiritual lives.

With a child-oriented measure developed for Canadian children in a heterogeneous culture, spirituality could be more fully explored in relation to psychological health and coping strategies. More specifically, spirituality can be examined more quantitatively in the lives in the lives of children who have survived a serious illness, such as cancer. Indeed, medical advances have resulted in children surviving once fatal cancer diagnoses. It is a fact, however, that strategies and practices to provide appropriate psychological support and interventions with this newly emerging population have not evolved as quickly as medical technology (Zebrack & Zeltzer, 2003). As a result, Zebrack and Zeltzer (2003) argue that "success in pediatric oncology requires that researchers and health care professionals attend to the psychosocial and behavioral consequences of treatment and to the quality of life of these survivors" (p. 198). This study therefore makes a unique and original contribution, as spirituality will be explored as a factor that can promote psychological health and positive coping in this emerging population.

### **The Current Study**

In this study, references to children's health history were abbreviated by using subscript

convention. Childhood cancer survivors were identified as Children<sub>cancer</sub>, whereas children with a healthy medical history were identified as Children<sub>healthy</sub>. In Study 1, a children's spirituality measure was developed and an exploratory factor analysis was conducted. The purpose of Study 2 was threefold: (a) to describe spirituality in childhood cancer survivors compared to a healthy comparison group, (b) to explore the effect of spirituality on psychological health and coping compared to a healthy comparison group, and (c) to determine whether parent-child<sub>cancer</sub> dyads have more highly correlated scores on measures of spirituality and psychological health than parent-child<sub>healthy</sub> dyads. These two studies are interconnected, given that Study 2 uses the newly developed measure from Study 1 to explore children's spirituality.

### **Study 1: Objectives and Hypotheses**

**Objective 1.** In Study 1, a children's spirituality measure was developed with children from diverse religious, spiritual, and cultural backgrounds living in a pluralistic context. An exploratory factor analysis was conducted; no hypotheses were warranted for Objective 1.

### **Study 2: Objectives and Hypotheses**

**Objective 2.** To describe spirituality in childhood cancer survivors compared to a healthy comparison group. Children's reported spirituality will be examined in relation to gender (i.e., female, male) and health history (i.e., cancer, healthy).

**Hypothesis 2a.** It is hypothesized that childhood cancer survivors will show higher levels of spirituality than children in a healthy comparison group. Because few researchers have investigated the role of gender in children's spirituality, the examination of gender will be exploratory and thus no hypothesis is warranted.

**Objective 3.** To explore the effect of spirituality on psychological health (i.e., depression, anxiety) and coping strategies (i.e., positive, negative) in childhood cancer survivors



and a healthy comparison group. Based on previous research and theory, the following hypotheses were proposed.

**Hypothesis 3a.** Spirituality, when moderated by health history, will be a predictor of lower depression scores (i.e., higher levels of reported spirituality will predict lower depression scores for childhood cancer survivors).

**Hypothesis 3b.** Spirituality, when moderated by health history, will be a predictor of lower anxiety scores (i.e., higher levels of reported spirituality will predict lower anxiety scores for childhood cancer survivors)

**Hypothesis 3c.** Spirituality, when moderated by health history, will be a predictor of lower negative coping scores (i.e., higher levels of reported spirituality will predict lower negative coping strategies for childhood cancer survivors).

**Hypothesis 3d.** Spirituality, when moderated by health history, will be a predictor of positive coping strategies (i.e., higher levels of reported spirituality will predict positive coping strategies for childhood cancer survivors).

**Objective 4.** To determine whether parent-child dyads<sub>cancer</sub> reported spiritual and psychological health (i.e., depression, anxiety) scores are more highly correlated than those scores of parent-child dyads<sub>healthy</sub>.

**Hypothesis 4a.** It is predicted that parent-child<sub>cancer</sub> dyads will have more highly correlated scores on spirituality measures and psychological health measures (i.e., depression, anxiety) than parent-child dyads<sub>healthy</sub>.

## Chapter 2: Methods

The methodologies for Study 1 and Study 2 are described here separately. In Study 1, children from a diversity of faith orientations were asked to complete a children's spirituality measure. In Study 2, parents and children (i.e., cancer, healthy) were asked to complete a series of questionnaires examining spirituality, psychological health (i.e., depression, anxiety), and coping strategies (i.e., positive and negative).

### Study 1

**Purpose.** The purpose of Study 1 was to develop a children's spirituality measure (Appendix L). This measure was based primarily on a qualitative study conducted by Moore, Talwar, and Bosacki (2012). Given that open-ended questions tend to yield a more comprehensive understanding of spirituality (Houskamp et al., 2004), these researchers interviewed children ( $n = 64$ ; 6-11 years, 50% female) from different religious and cultural backgrounds concerning their spiritual thoughts, beliefs, and experiences. Regardless of the children's religious background, six overarching themes emerged. The most salient coded responses were developed into 64 items for the initial development of the Children's Spiritual Lives measure.

**Participants.** Ethics approval was obtained from McGill University (Appendix N). A total of a 368 children (7-11 years, 54 % female;  $M = 9.2$  years,  $SD = 18.44$ ) from diverse faith and cultural backgrounds participated in the study (see Table 1). Three hundred is the recommended number of participants for conducting factor analysis (DeVellis, 1991). Participants were recruited primarily through the McGill Infant Research Group and the Talwar Child Development Research Lab databases of past participants (Appendix G). Because a primary goal of this research was to develop a spirituality measure for children from diverse

cultural, religious, and spiritual orientations, advertisements were placed in magazines and newspapers (e.g., Montreal Families Magazine) to attract a diverse sample. Advertisements were also widely distributed to religious and spiritual centers (Appendix J). An effort was made to recruit a sample that was representative of the diverse religious backgrounds found in Canadian society (Statistics Canada, 2013).

**Materials and procedure.** Participants were invited to the Talwar Child Development Research Lab at McGill University to participate in the study. Parents were asked to sign a Consent Form (Appendix C) and complete a brief Demographic Questionnaire (Appendix E) with questions pertaining to their cultural background, socio-economic status, and religious affiliation. Parents were asked to rate the level of religiosity and spirituality in their family (i.e., very religious/spiritual, somewhat religious/spiritual, not at all religious/spiritual). Parents were also asked to report how often they frequent a place of worship (i.e., not at all, once a year, 3-4 times per year, once a month, once a week).

Children's assent (Appendix D) was obtained before completing the initial version of the Children's Spiritual Lives (Appendix L) measure. Children were asked to complete the questionnaire by answering questions relating to spirituality on a five-point Likert scale ranging from *strongly disagree* to *strongly agree*. The questionnaire was read aloud to children. Consistent with Ubani and Tirri (2006) and Cotton et al. (2005) the term *God* was used in the measure's items, but children were encouraged to use their preferred term for a higher power. In order to be respectful to certain traditions that do not write the word *God*, this term was presented as *G-d* on this spirituality measure. Children received a prize (e.g., a small toy of a value of five dollars) for their participation.

Table 1

*Parent-Reported Demographics and Religious and Spiritual Information*

Variable		Frequency (%)
How Religious	Not Religious	77 (20.9)
	Somewhat Religious	190 (51.6)
	Very Religious	90 (24.5)
	Not Identified	11 (3.0)
How Spiritual	Not Spiritual	51 (13.9)
	Somewhat Spiritual	216 (58.7)
	Very Spiritual	83 (22.6)
	Not Identified	18 (4.9)
Place of Worship Attendance	Not at all	90 (24.5)
	Once a week	111 (30.2)
	Once a month	58 (15.8)
	3-4 times a year	69 (18.8)
	Once a year	35 (9.5)
	Not Identified	5 (1.4)
Religious Affiliation*	Catholic	138 (37.5)
	No Religion	52 (14.1)
	Muslim	48 (13.0)
	Jewish	48 (13.0)
	Hindu	23 (6.2)
	Christian (no denomination)	14 (3.8)
	Eastern Orthodox	12 (3.3)
	Protestant	11 (3.0)
	Anglican	11 (3.0)
	United	11 (3.0)
	Baptist	5 (1.4)
	Presbyterian	9 (2.4)
	Greek Orthodox	6 (1.6)

	Baha'i	4 (1.1)
	Wiccan	1 (0.3)
	Sikh	1 (0.3)
	Buddhism	1 (.03)
	Evangelical	1(.03)
	Pentecostal	1 (.03)
	Lutheran	1 (.03)
Cultural Group**	North American	146 (39.7)
	South American	16 (4.4)
	European	245 (66.6)
	Oceanian	0 (0.0)
	African	14 (3.8)
	Asian	88 (24.0)
Languages Spoken	One	110 (29.9)
	Two	144 (39.1)
	Three or more	114 (31.0)
Income	< 40 000	50 (13.6)
	40 000 – 50 000	13 (3.5)
	50 000- 59 000	28 (7.6)
	60 000- 69 000	24 (6.5)
	70 000- 79 000	21 (5.7)
	80 000 or more	135 (36.7)
	Not reported	97 (26.4)

*Note.* \*Approximately 10 percent of parents reported more than one religious affiliation. For example, one parent reported that their family was Catholic and Muslim.

\*\*Approximately sixty percent of parents reported more than one affiliated cultural group. For example, one parent reported that their family was Filipino, Canadian, and Irish. Reported groups included: French, Scottish, Greek, Korea, Irish, Polish, English, Canadian, German, Dutch, Italian, Jewish, Romanian, Chinese, Mexican, Belgium, Cherokee Indian, Welsh, American, South Asian, Ukrainian, Indian, African American, Afghani, Lebanese, Swedish, Danish, Portuguese, South African, Finnish, Pakistani, Arab, Egyptian, Persian, Czech, Spanish, French-Canadian, Filipino, English.

## Study 2

**Purpose.** The purpose of Study 2 was threefold: (a) to describe spirituality in childhood cancer survivors compared to a healthy comparison group, (b) to explore spirituality in relation to psychological health and coping in cancer survivors compared to a healthy comparison group, and (c) to determine whether parent-child<sub>cancer</sub> dyads had more highly correlated scores on measures of spirituality and psychological health than parent-child<sub>healthy</sub> dyads.

**Participants.** A total of 69 school-age participants (7-11 years) were recruited. Forty-three healthy comparison children ( $M_{\text{age in months}} = 112.42$ ,  $SD = 17.69$ , 56% females) and 26 childhood cancer survivors ( $M_{\text{age in months}} = 121.58$ ,  $SD = 24.17$ , 50% females) participated. Inclusion criteria for the healthy parent-child dyads included no history of life-threatening illness or trauma for the child, which was determined by a screening parent-report Medical History Questionnaire (Appendix F). Sixteen cases were excluded from the healthy comparison group due to missing data. Inclusion criteria for the childhood cancer survivor-parent dyads included children who had already undergone primary cancer treatment (e.g., primary induction) and were at least six months post-diagnosis. Four parents from the cancer survivor group who originally expressed interest in participating later declined for various reasons (e.g., death in the family, child did not want to participate, family too busy with medical follow-ups). Four other parents from the cancer survivor group expressed interest in participating, but their children did not meet the inclusion criteria (e.g., child was too young to participate). The age at the time of diagnosis ranged from 9 months to 128 months-old ( $M_{\text{age at diagnosis}} = 59.77$  months,  $SD = 34.26$ ). The length of active treatment (e.g., chemotherapy, radiation, surgery) ranged from 3 months to 48 months ( $M_{\text{length of treatment}} = 25.04$  months,  $SD = 17.33$ ). See Tables 2 and 3 for parent-reported demographic information and cancer history information. Notably, over 90 percent of parent

respondents were mothers in both the childhood cancer survivor group and in the healthy comparison group.

Table 2

*Parent-Reported Demographics and Religious and Spiritual Information*

Variable		Healthy (%)	Cancer Survivor (%)
Gender	Male	19 (44.2)	13 (50)
	Female	24 (55.8)	13 (50)
Parent Respondent	Mother	39 (90.7)	24 (92.3)
	Father	4 (9.3)	2 (7.7)
How Religious	Not at all	16 (37.2)	6 (23.1)
	Somewhat	21 (48.8)	17 (65.4)
	Very	6 (14.0)	3 (11.5)
How Spiritual	Not at all	9 (20.9)	1 (3.8)
	Somewhat	24 (55.8)	19 (73.1)
	Very	10 (23.3)	6 (23.1)
Place of Worship	Once a week	7 (16.3)	4 (15.4)
Attendance	Once a month	6 (14.0)	4 (15.4)
	3-4 times/year	15 (34.9)	5 (19.2)
	Once a year	8 (18.6)	7 (26.9)
	Not at all	7 (16.3)	6 (23.1)
Religious Group*	Christianity	34 (79.1)	16 (61.5)
	Judaism	5 (11.6)	3 (11.5)
	Islam	2 (4.7)	3 (11.5)
	Hinduism	4 (9.3)	1 (3.8)
	None	10 (23.2)	3 (11.5)
Cultural Group**	North American	27 (62.8)	11 (42.3)
	South American	4 (9.3)	2 (7.7)
	European	31 (72.1)	16 (61.5)
	Oceanian	0 (0.0)	0 (0.0)
	African	0 (0.0)	0 (0.0)
	Asian	7 (16.3)	8 (30.8)
Languages Spoken	One	11 (25.6)	2 (7.7)
	Two	17 (39.5)	11 (42.3)



	Three or more	15 (34.8)	13 (50.0)
Family Income***	< 40 000	0 (0.0)	13 (50.0)
	40 000 – 50 000	3 (7.0)	1 (3.8)
	50 000- 59 000	4 (9.3)	0 (0.0)
	60 000- 69 000	5 (11.6)	0 (0.0)
	70 000- 79 000	1 (2.3)	2 (7.7)
	80 000 or more	29 (67.4)	8 (30.8)
	Not reported	1 (2.3)	2 (7.7)

*Note.* \*Approximately 25 percent of parents indicated affiliation with more than one religion. For example, one parent identified their family as Hindu, Roman Catholic, and No Religion.

\*\*More than 60 percent of parents identified with more than one cultural group. For example, one parent identified their family as Canadian, French, Italian, and Chinese. Reported groups included: Canadian, Italian, Lebanese, Iranian, Jewish, Filipino, Asian, Slovenian, German, Croatian, Armenian, South Asian, Vietnamese, Chinese, Romanian, French, Latin, Trinidadian, Polish, American, Scottish, English, First Nation, Irish, Indian, West-Indian, Dutch, Russian, Greek, Mexican, Black, Indian, East-Indian, and Spanish.

\*\*\* Parents typically take leave from their jobs following the cancer diagnosis of a child and experience a loss of income (see Limburg, Shaw, & McBride, 2008). Thus, their income may be lower than expected.

Table 3

*Parent-Reported Cancer Diagnosis, Cancer Status, and Interference with Daily Life*

Variables		Frequency (%)
Type of Cancer	Leukemia (AML, ALL)	15 (57.7)
	Ewing's Sarcoma	3 (11.5)
	Wilms Tumor	2 (7.7)
	Optic Nerve Glioma	2 (7.7)
	Lymphoma	1 (3.8)
	Neuroblastoma	1 (3.8)
	Bilateral Retinoblastoma	1 (3.8)
	Rhabdomyosarcoma	1 (3.8)
Current Status	Terminated Treatment	20 (77.0)
	Maintenance Treatment	5 (19.2)
	Active Treatment	1 (3.8)
Interference with Daily Life	No longer interferes	13 (50.0)
	Sometimes interferes	10 (38.5)
	Always interferes	3 (11.54)

The GPower calculator version 3.1 was used to compute the sample size given the effect size, alpha, and the desired power. A priori power analysis showed that a sample size of approximately 24 in each group was sufficient when using multiple analyses of variance to detect a clinically significant difference at 0.05, with an effect size of 0.25, and power of 0.80. These calculations were grounded in Cohen's (1992) statistical guidelines and were based on the assumption that the measurements on the scale are normally distributed. To conduct a linear multiple regression, with an effect size of 0.15, significant difference of 0.05, and power of 0.80, an overall total of 55 participants was needed. According to Harrell (2001), "in many situations a fitted regression model is likely to be reliable when the number of predictors (or candidate predictors if using variable selection)  $p$  is less than  $m/10$  or  $m/20$ , where  $m$  is the limiting sample size" (p. 61). Thus, the current sample size ( $n=69$ ) is appropriate for the proposed analyses.

**Materials and procedure.** Ethics approval was obtained from the Montreal Children's Hospital (Appendix O) and McGill University (Appendix N). The healthy comparison group of children was recruited primarily through the McGill Infant Research Group and the Talwar Child Development Research Lab database of past participants. Childhood cancer survivors were recruited through the Montreal Children's Hospital (Appendix K). An oncology staff member approached parents of identified children (i.e., in person, on the phone) and asked them if they would be interested in hearing more details about a study concerning childhood cancer survivors and spirituality. If the parents expressed interest, a research assistant contacted them. The nature of the study was fully described to parents over the phone when initial contact was made, so that parents could make an informed decision about whether they would like to participate (Appendix G). While the healthy comparison children participated in the research at the Talwar Research Lab, a researcher travelled to the homes of childhood cancer survivors to ensure a safe research

environment, because some children were immuno-compromised.

On some questionnaires, parents and children were asked to answer some sensitive questions. In rare cases where parents or children answered items on any measures that raised clinical concern, survivors were referred to the psychologist at the Montreal Children's Hospital. On one occasion, a childhood cancer survivor endorsed a measure item (e.g., self-harm item) that prompted the researcher to refer this child to the hospital's psychologist. On five occasions, healthy children endorsed a measure item that prompted the researcher to provide parents with a resource handout with information for counselling services offered by the McGill Psychoeducational and Counselling Clinic in the Faculty of Education and other services in the Montreal area (Appendix I). All parents were given a general information letter about the research upon study completion (Appendix H).

**Parent and child measures.** All parents completed a Consent Form (Appendix A), a Demographic Questionnaire (Appendix E), and a Medical History Questionnaire (Appendix F). Parents completed a questionnaire, which examined children's psychological health (i.e., Behavior Assessment System for Children—Second Edition). Parents were asked to complete questionnaires pertaining to spirituality from their child's point of view (i.e., Spiritual Well-Being Scale, Children's Spiritual Lives). Parents were instructed to answer all spirituality questions as if they *were* their school-age son or daughter. They were asked not to discuss their answers with their child until both parent and child completed the study. Assent was obtained from children before administering any measures (Appendix B, Appendix D). All children were asked to complete a questionnaire that examined their psychological health (i.e., Behavior Assessment System for Children Second Edition). Children were also asked to complete two questionnaires that measured their spirituality (i.e., Spiritual Well-Being Scale, Children's

Spiritual Lives) and a questionnaire related to personal coping strategies (i.e., Kidcope-Younger Version). Questionnaires were read aloud to children. The study took approximately one-hour.

***Kidcope-Younger Version.*** The Kidcope-Younger Version is a 15-item measure that assesses children's coping strategies. This measure has been shown to correlate highly with other widely used coping questionnaires for children (Spirito, Stark, & Williams, 1988) and has also been used with children who have cancer (e.g., Rodgers et al., 2012). When completing this questionnaire, children were asked to identify a situation not related to illness that they found stressful (e.g., "I did poorly on a spelling test", "I had a fight with my sister", "I was upset and the teacher said she does not listen to tattle-tales") and identify particular coping strategies they used, some of which were positive and others negative. According to Spirito et al., 1988, reliability of the Kidcope-Younger Version was determined with test-retest correlations. Correlations ranging from 0.56 to 0.75 were obtained when children were asked to report their coping on the same reported situation 3 days apart. Correlations ranging from 0.41 to 0.83 were obtained when children were asked to report their coping three to seven days apart. In a study by Cheng and Chan (2003), a two-factor model using the Kidcope-Younger Version was established. The Negative Coping factor consisted of seven questionnaire items including: distraction, social withdrawal, self-criticism, blaming others, wishful thinking, resignation, and negative emotional regulation. The Positive Coping factor consisted of four questionnaire items including: cognitive restructuring, problem-solving, social support, and positive emotional regulation.

***Behavior Assessment System for Children—second edition (BASC—2).*** This measure has been used to assess behavioral, social, and emotional problems in children (Reynolds & Kamphaus, 2004). It is an appropriate measure to use in the current study, since it has been used

with both healthy and chronically ill children to explore factors such as depression and anxiety (Pinquart & Shen, 2011). Higher scores obtained on this measure are indicative of more problematic outcomes (e.g., high levels of depression and anxiety). The Depression and Anxiety subscales were chosen as the outcome measures due to the focus on the relation between spirituality and psychological health. In both general and clinical samples, internal consistency has coefficient alpha reliabilities at approximately 0.90 range for the composite scales, and reliabilities in the 0.80 range for individual scales across all forms (i.e., Parent, Teacher, and Self-Report). Test-retest reliabilities were calculated for all forms (i.e., Parent, Teacher, and Self-Report) and had correlations in 0.80 range for composite scores and between the 0.70-0.80 range for individual scales across all age groups (Reynolds & Kamphaus, 2004).

***Spiritual Well-Being Scale (SWBS).*** This scale measures overall spiritual well-being, which is comprised of a Religious Well-Being subscale (e.g., relationship with God), and an Existential Well-Being subscale (e.g., sense of purpose and meaning in life). The 20-item measure uses a six-point Likert scale, (e.g., 1 = *strongly agree*, 6 = *strongly disagree*). For the overall scale, scores range from 20 to 120 points; each subscale ranges from 10 to 60 points. In all cases, higher scores are indicative of greater levels of well-being. According to Cotton et al. (2009), who used the measure in a study of adolescents with and without inflammatory bowel disease, “the reliability and validity of the full scale are well established, and the measure has been used widely in various samples, including adolescents” (p. 487). According to Bufford, Paloutzian, and Ellison (1991) this scale and subscales have good reliability. Internal consistency coefficients range from 0.82-0.94 for the Religious-Well-Being subscale, 0.78-0.86 for the Existential Well-Being subscale, and 0.89-0.94 for the scale. Reliability between 1-10 weeks of testing ranges from 0.82 to 0.99. Although this scale has not been used with children

as young as 7-years-old, it is considered the most widely used measure of adult and adolescent spirituality, and it was chosen to complement the Children's Spiritual Lives measure as it uses a similar structure and has items relating to a relationship with a higher power.

***Children's Spiritual Lives.*** This measure was developed by Moore, Talwar, and Bosacki (2014) and was largely based on a qualitative study by Moore et al. (2012). The most salient coded responses were developed into 64 items for the initial version of the Children's Spiritual Lives (Appendix L) measures. An exploratory factor analysis revealed three main factors, which reduced the measure from 64 questions to 31 questions (see Moore et al., 2014). The revised scale was used in Study 2 (Appendix M).

### Chapter 3: Analyses and Results

#### Study 1

**Objective 1.** A measure of children's spirituality was developed with children from diverse religious, spiritual, and cultural backgrounds living in a pluralistic context. To meet Objective 1, an exploratory factor analysis was conducted to determine the factors in which the items clustered ( DeVellis, 1991).

**Initial item development.** A pool of items related to children's spirituality was created. This pool consisted of 64 items that were largely based on themes that emerged in a qualitative study in which children's diverse ideas of spirituality were explored (Moore et al., 2012). Items were also generated from theoretically based logic, past literature, and questions adapted from existing adult spirituality measures. Following item development, these items were reviewed and amended for clarity and theoretical relevance by expert researchers in developmental and educational psychology.

**Exploratory factor analysis.** A factor analysis is typically used to examine the inter-correlations between large numbers of items and to reduce the items into smaller groups known as factors (Tabachnick & Fidell, 2013). In the current factor analysis, the reported factors contain correlated variables that measure similar underlying dimensions in the data that are interpretable in a theoretical sense. Given the fact that some participants did not answer all 64 items (11% of the total number of observations), the pattern for the missing values was examined using the multiple imputation option in SPSS version 2.0. The results suggested that the missing values did not follow a pattern; thus, missing data fell into the Missing Completely at Random (MCAR) category. In order to address the problem of missing observations, multiple imputations were computed. The generator Mersenne Twister was used as the option that fits



best to impute MCAR. This process yielded five datasets with no missing values. The examination of these five datasets suggested that there were no differences across them; for that reason, the first imputation was used for the current factor analysis. A principal component analysis was run with Varimax extraction and Kaiser normalizations. Factor solutions were considered in the rotated matrix based on the following criteria: (a) Eigenvalues of 1.0 or greater, and (b) factor loadings greater than 0.3 (Comrey & Lee, 1992). The rotated solution included 12 factors. Items and loadings on three factors are presented in Table 4. Thirty-three items were eliminated, as they did not load onto these factors.

**Description of factors.** Although 12 factors emerged, three factors that showed the strongest factor loadings and that could be interpreted in a theoretical sense were chosen. Factor 1 (i.e., Comfort) includes 15 items that focus on God as source of support and comfort. Items range from seeking help or new ideas from God to talking or praying to God to feel happy or comforted. Factor 2 (i.e., Omnipresence) includes eight items that concern the ubiquity of God. These items are centered on themes of God being able to hear and see everyone as an omnipresent being and creator of the world. Factor 3 (i.e., Duality) includes four items and encompasses the notion of dualism that is, having a soul or a spirit apart from the body (see Table 4). A fourth factor was initially included in the measure, but was later eliminated, as it was not interpretable in a theoretical sense.

Table 4

*Factor Loadings for Exploratory Factor Analysis with Varimax Rotation*

Factor 1 (Comfort)	
I pray to G-d or talk to G-d when I feel sad	.84
When I want to feel better, I talk or pray to G-d	.81
I ask G-d for help	.76
When I pray to G-d or talk to G-d I feel better about things	.76
G-d helps me by making me feel strong	.75
G-d helps me by making me think of new ideas	.74
I pray to G-d or talk to G-d when I feel sad or worried about something	.73
G-d helps me by giving me advice	.72
I pray to G-d because I want to thank G-d for all of the good things in my life	.71
When I think about G-d, I feel happy	.71
G-d can make people feel better	.69
I pray to G-d or talk to G-d when someone is sick or when someone dies	.69
G-d keeps people company when they feel sad and lonely	.63
G-d listens to my thoughts and wishes	.68
I make wishes to G-d and the wishes come true	.58
% Variance	22.70
Eigenvalues	14.52
Cronbach's Alpha	.96
Skewness	.78
Kurtosis	-.04

<hr/> Factor 2 (Omnipresence) <hr/>	
G-d always knows how I feel, even without talking	.45
G-d is everywhere in the world and watches over everybody	.50
G-d created all the people in the world and knows all of them	.46
I think G-d listens to everyone	.50
It is impossible for G-d to watch over everybody (reversed item)	.63
There are too many in the world for G-d to know all of them (reversed item)	.62
There are too many people in the world for G-d to listen to (reversed item)	.68
G-d will never know what I am thinking to myself (reversed item)	.57
<hr/>	
% Variance	8.66
Eigenvalues	5.54
Cronbach's Alpha	.91
Skewness	.79
Kurtosis	-.05
<hr/>	
Factor 3 (Duality) <hr/>	
Every person has a body and something inside them, like a soul or spirit	.78
People do not have a soul or a spirit (reversed item)	.66
Everyone has a body, but having a soul or a spirit is fake (reversed item)	.66
I think that people have something like a soul or a spirit that lives inside them	.64
<hr/>	
% Variance	5.62
Eigenvalues	3.60

Cronbach's Alpha	.81
Skewness	1.06
Kurtosis	1.24

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## Study 2

**Hypotheses.** To test Hypothesis 2a, that childhood cancer survivors will show higher levels of spirituality than their healthy peers, several multivariate analyses of variance (MANOVA) were computed. To test the Hypotheses (i.e., 3a, 3b, 3c, 3d) that spirituality will predict lower (a) depression, (b) anxiety, (c) negative coping, and higher (d) positive coping in the childhood cancer survivor group, moderator analyses were conducted. To test Hypothesis 4a, a series of Pearson correlations were computed in order to examine the relation between parent and child reports on spirituality, depression, and anxiety. More specifically, examining whether or not parents of childhood cancer survivors had more highly correlated scores with their children's spirituality, depression, and anxiety scores than parents of healthy children was explored using Fisher's Z transformations.

**Assumptions, correlations, and differences on measures.** All presented analyses were performed using SPSS, version 20.0. Assumptions of normality and parametric statistics (i.e., linearity, outliers) were examined and no violations were detected. Because participants were from a range of religious, spiritual, and cultural backgrounds, descriptive statistics were reported (see Table 1, Table 2, and Table 3). See Table 5 for correlations between cognitive measures and Table 6 for any differences on measures between health history (i.e., cancer, healthy).

Table 5

*Correlations Between Variables*

Variable	1	2	3	4	5	6	7	8	9
1. Comfort		.60**	.25*	.69**	.20	.28*	-.03	-	-
2. Omnipresence	.81**		.47**	.57**	.36**	.20	-.10	-	-
3. Duality	.65**	.68**		.29*	.34**	.01	-.15	-	-
4. Religious	.83**	.80**	.69**		.28*	.14	-.14	-	-
5. Existential	.51**	.40**	.47**	.54**		.05	-.28*	-	-
6. Anxiety	-.31**	-.32**	-.25*	-.22	-.17		.36**	-	-
7. Depression	-.22	-.12	-.13	-.27*	-.44**	.49**		-	-
8. Positive Coping	.48**	.25*	.20	.28*	.41**	-.12	-.18		-
9. Negative Coping	-.11	-.06	-.16	-.03	-.12	.06	.22	-.09	

*Note.* Parents are above the main diagonal and children are below the main diagonal.

\* $p < .05$ , \*\* $p < .01$

Table 6

*Differences in Variables Between Healthy and Cancer Group for Parents and Children*

Variable		Group		<i>t</i>
		Healthy <i>M</i> ( <i>SD</i> )	Cancer <i>M</i> ( <i>SD</i> )	
Anxiety	Parent	51.47 (10.37)	53.54 (10.29)	-.81
	Child	48.65 (8.62)	46.62 (8.48)	.96
Depression	Parent	50.74 (9.92)	49.42 (9.63)	.54
	Child	45.12 (6.42)	45.27 (10.03)	-.07
Coping	Positive	3.05 (1.03)	3.04 (.92)	.05
	Negative	2.03 (.84)	2.58 (.76)	-2.69**

\* $p < .05$ , \*\*  $p < .01$

**Objective 2.** In order to test Hypothesis 2a, that childhood cancer survivors would have higher scores on spirituality measures than their healthy peers, several multivariate analyses of variance were computed. Children's reported spirituality (i.e., Children's Spiritual Lives, Spiritual Well-Being Scale) was examined in relation to health history (i.e., healthy, cancer) and gender (i.e., male, female). In both analyses, age and parents' reports of the family's religiosity and spirituality (i.e., very, somewhat, not at all) were all entered as covariates.

With regards to the Children's Spiritual Lives (i.e., Factor 1 [Comfort] Factor 2 [Omnipresence] and Factor [Duality]) as the outcome measure, there was a significant difference with respect to gender, Wilks'  $\lambda = .871$ ,  $F(3, 60) = 2.96$ ,  $p = .040$ . However, this was likely a spurious finding as there were no between-subject effects; thus, there was a probable weak multivariate effect, which was not detected in the univariate analyses (Tabachnick & Fidell, 2013). There was a significant difference between health history, Wilks'  $\lambda = .803$ ,  $F(3, 60) = 4.91$ ,  $p = .004$ . Between-subjects analyses showed that the Comfort factor,  $F(1, 62) = 4.81$ ,  $p = .032$  ( $M_{\text{cancer}} = 4.04$ ,  $SD_{\text{cancer}} = .83$ ;  $M_{\text{healthy}} = 3.54$ ,  $SD_{\text{healthy}} = 1.00$ ) and the Omnipresence factor,  $F(1, 62) = 13.40$ ,  $p = .001$  ( $M_{\text{cancer}} = 4.48$ ,  $SD_{\text{cancer}} = .67$ ;  $M_{\text{healthy}} = 3.72$ ,  $SD_{\text{healthy}} = .99$ ) accounted for this significant difference between groups; the Duality factor was not significant. Parents' reports of their family's religiosity was found to be a significant covariate Wilks  $\lambda = .852$ ,  $F(3, 60) = 3.48$ ,  $p = .021$ . Age and parents' reports of their family's spirituality were not significant covariates.

With regards to the Spiritual Well-Being Scale (i.e., Existential Well-Being subscale, Religious Well-Being subscale) as the outcome measure, no significant differences were found with respect to gender. However, there were significant differences between health history, Wilks'  $\lambda = .881$ ,  $F(2, 61) = 4.12$ ,  $p = .021$ . Between-subjects analyses revealed that the



Religious Well-Being subscale,  $F(1, 62) = 5.82, p = .019$  ( $M_{\text{cancer}} = 49.69, SD_{\text{cancer}} = 9.72; M_{\text{healthy}} = 42.72, SD_{\text{healthy}} = 13.17$ ) accounted for this significant difference between groups, whereas the Existential Well-Being subscale was not significant. Age was a significant covariate, Wilks'  $\lambda = .871, F(2, 61) = 4.53, p = .015$ . Parents' reports of their family's religiosity and spirituality were not significant covariates. Thus, Hypothesis 2a was supported, as childhood cancer survivors had higher scores on some of the spirituality factors and subscales (i.e., Comfort and Omnipresence factors, Religious Well-Being subscale) than their healthy peers. See Table 7 and Table 8 for a summary of the results.

Table 7

*Between-Subjects Effects of Children's Health History and Gender on Spirituality in Relation to Comfort, Omnipresence, and Duality Factors*

Variables	Children's Spiritual Lives Factors					
	Comfort		Omnipresence		Duality	
	<i>M (SD)</i>	<i>F</i>	<i>M (SD)</i>	<i>F</i>	<i>M (SD)</i>	<i>F</i>
Healthy	3.54 (1.00)	4.81*	3.72 (.99)	13.40**	4.26 (.66)	1.90
Cancer	4.04 (.83)		4.48 (.67)		4.50 (.70)	
Male	3.67 (.97)	.20	3.81 (.97)	2.42	4.28 (.74)	.67
Female	3.78 (.97)		4.17 (.92)		4.41 (.63)	

\* $p < .05$ . \*\* $p < .01$

Table 8

*Between-Subject Effects on Children's Health History and Gender on Religious and Existential Well-Being Scales*

Variables	Spiritual Well-Being Subscales			
	Existential		Religious	
	<i>M (SD)</i>	<i>F</i>	<i>M (SD)</i>	<i>F</i>
Healthy	49.33 (7.64)	.01	42.71 (13.17)	5.82*
Cancer	50.12 (7.58)		49.69 (9.72)	
Male	49.53 (7.05)	.69	45.81 (10.72)	.05
Female	49.70 (8.09)		44.95 (13.80)	

\* $p < .05$ . \*\* $p < .01$

**Objective 3.** In order to test Hypotheses 3a, 3b, 3c, and 3d moderator analyses were conducted. It was hypothesized that spirituality, when moderated by health history, would predict lower scores on the (a) Depression subscale, (b) Anxiety subscale, (c) Negative Coping factor, and higher scores on (d) Positive Coping factor in the childhood cancer survivor group. Spirituality, as measured by the Children's Spiritual Lives measure (i.e., Comfort, Omnipresence, Duality factors) and Spiritual Well-Being Scale (Existential Well-Being and Religious Well-Being subscales) were the predictors. The moderator was health history (i.e., cancer, healthy). Age and parents' reports of the family's religiosity and spirituality (i.e., very, somewhat, not at all) were entered as covariates.

With respect to the Children's Spirituality Lives (i.e., Comfort, Omnipresent, Duality factors) as the predictor of the Depression subscale, the Comfort factor was significant,  $F(6, 62) = 2.43, p = .036$ . Higher scores on the Comfort factor predicted lower Depression subscale scores ( $M = 45.17, SD = 7.91$ ). This significant relationship was moderated by health history; that is, only childhood cancer survivors showed this significant relationship (see Figure 1). Omnipresent and Duality factors were not significant predictors of the Depression subscale. With respect to the Spiritual Well-Being Scale as the predictor (i.e., Religious Well-Being and Existential Well-Being subscale), the Religious Well-Being subscale was significant  $F(6, 62) = 3.23, p = .008$ . Higher scores on the Religious Well-Being subscale predicted lower Depression subscale scores ( $M = 45.17, SD = 7.91$ ). This significant relationship was moderated by health history; that is, this relationship was only significant for childhood cancer survivors (see Figure 2). See Table 9 for a summary of results.

With respect to the Children's Spiritual Lives measure (i.e., Comfort, Omnipresence, Duality factors) as the predictor of the Anxiety subscale, there were no significant results. With

respect to the Spiritual Well-Being Scale, the Religious Well-Being subscale was a significant predictor of the Anxiety subscale  $F(6, 62) = 3.66, p = .004$ . Higher scores on the Religious Well-Being subscale predicted lower Anxiety subscale scores ( $M = 47.88, SD = 8.56$ ), which was moderated by health history. That is, this relationship was only significant for childhood cancer survivors (see Figure 3). The Existential Well-Being subscale as a predictor of the Anxiety subscale was not significant. See Table 9 for a summary of results.

Neither the Children's Spirituality Lives measure (i.e., Comfort, Omnipresent, Duality factors) nor the Spiritual Well-Being Scale (i.e., Religious Well-Being and Existential Well-Being subscales) predicted Positive or Negative Coping factors when moderated by health history. Notably, a simple comparison  $t$  test revealed that there were significant differences between groups (i.e., healthy, cancer) with respect to negative coping. Childhood cancer survivors had higher negative coping scores than their healthy comparison group (see Table 5). There were no other significant results.

Thus, Hypotheses 3a and 3b were supported, as some measures of spirituality predicted lower levels of depression and anxiety for the childhood cancer survivor group whereas the relationship was not found with respect to the healthy comparison group. However, Hypotheses 3c and 3d were not confirmed, as spirituality had no significant relation with positive or negative coping when moderated by health history.

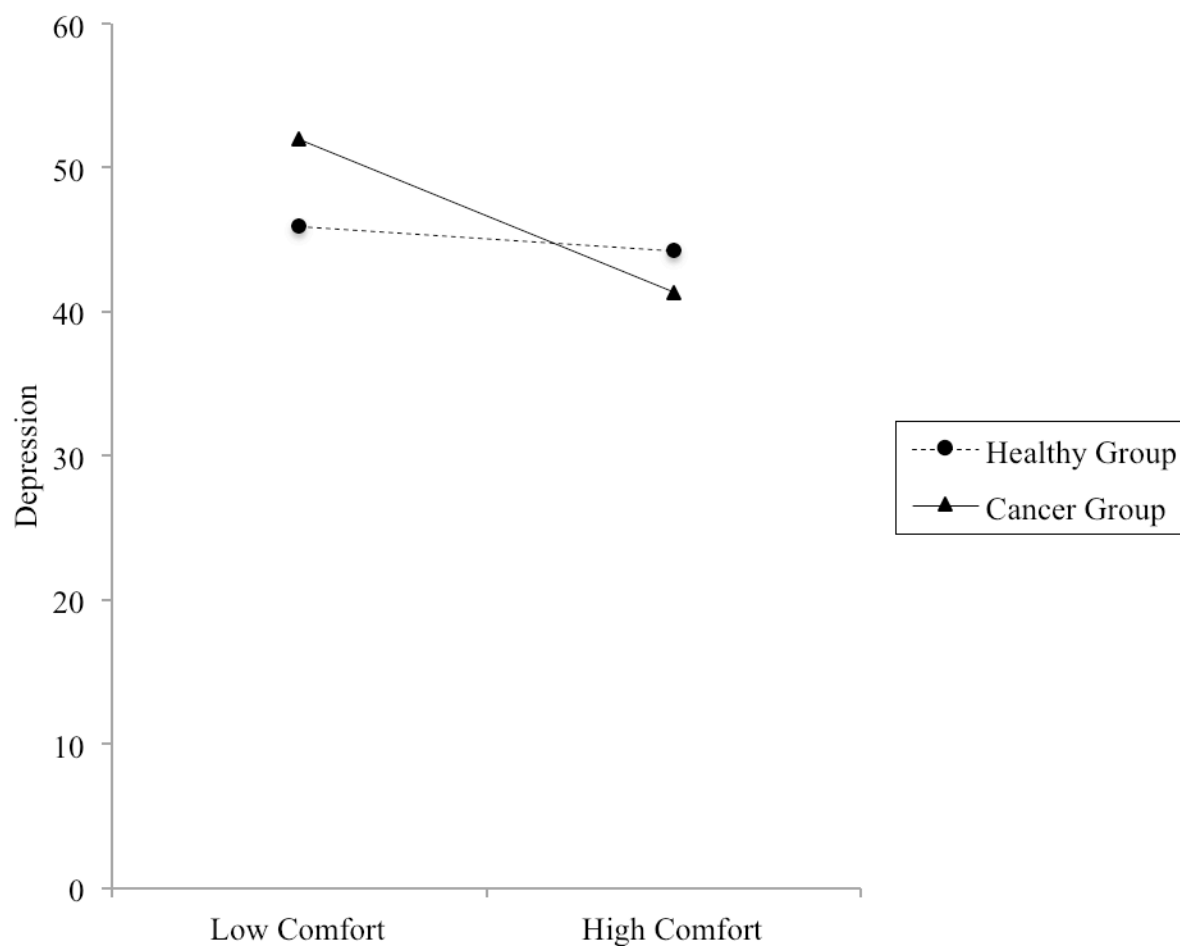
Table 9

*Regression Equations for the Prediction of Depression and Anxiety from Spirituality Measures*

Variable	$R^2$	$B$	$SE\ B$	$\beta$	$t$
Depression					
Age	.19	.06	.05	.20	1.27
How Religious*		3.74	1.81	.18	2.07*
How Spiritual		-2.88	1.87	-.18	-1.54
Comfort		-.90	1.33	.11	-.67
Group*		18.71	8.87	1.26	2.11*
Comfort Group*		-4.61	2.21	1.32	-2.08*
Overall $F(6, 62) = 2.43^*$					
Age	.24	.05	.05	.37	.10
How Religious		3.11	1.66	.02	1.88
How Spiritual		-2.06	1.88	-.08	-1.10
Religious Well-Being		-.06	.10	-.11	-.57
Group**		25.13	8.65	1.51	2.91**
Religious Group**		-.50	.18	-1.51	-2.88**
Overall $F(6, 62) = 3.23^{**}$					
Anxiety					
Age	.26	.16	.05	.20	3.21**

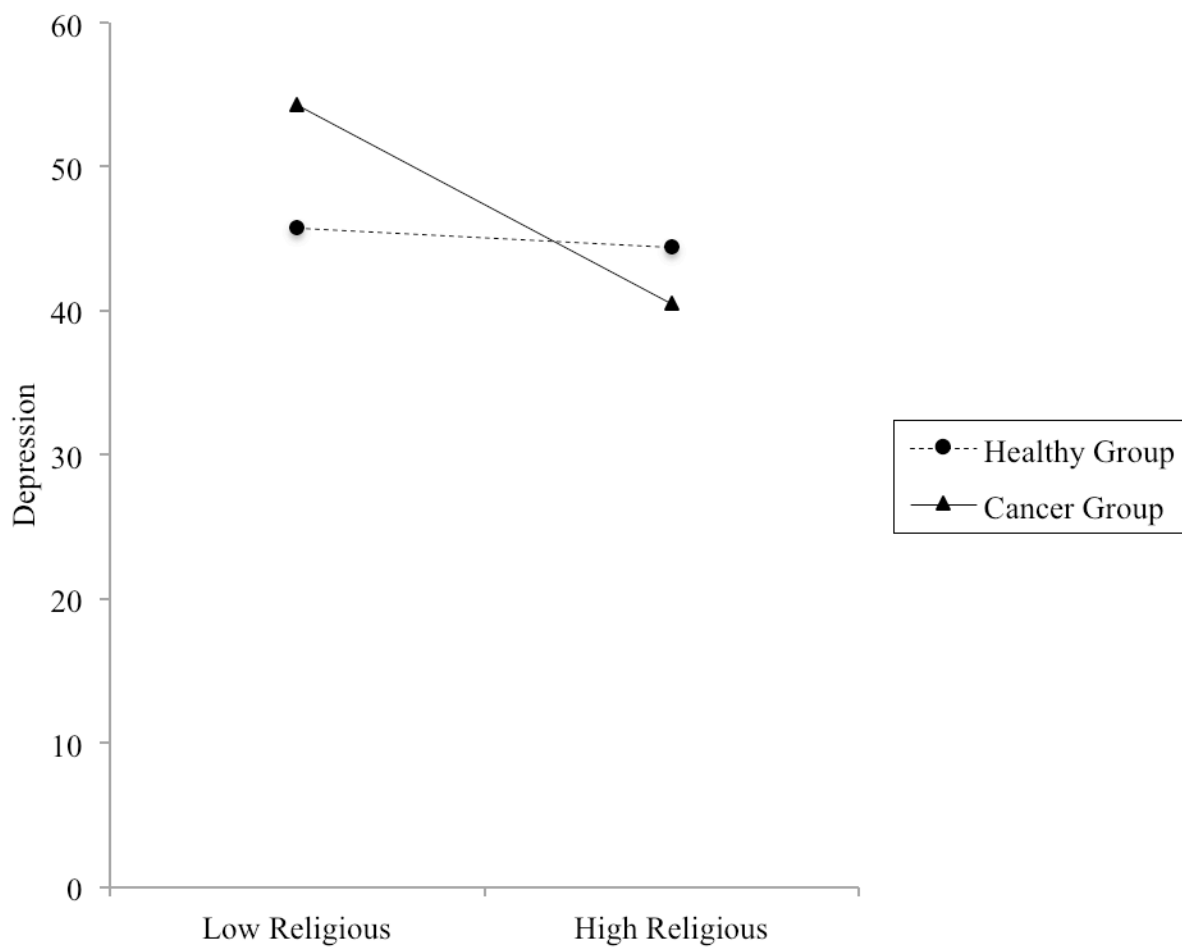
How Religious	.34	1.77	.18	.19
How Spiritual	-1.23	1.99	-.18	-.61
Religious Well-Being	.06	.10	-.04	.54
Group*	19.48	9.22	1.24	2.11*
Religious Group*	-.47	.19	-1.39	-2.50*
$F(6, 62) = 3.66^{**}$				

\*  $p < .05$ , \*\* $p < .01$



*Figure 1.* Plot of the moderating effect of health history on the relationship between the Comfort factor (Children's Spiritual Lives) and the Depression subscale.





*Figure 2.* Plot of the moderating effect of health history on the relationship between Religious Well-Being Subscale (Spiritual Well-Being Scale) and the Depression subscale.

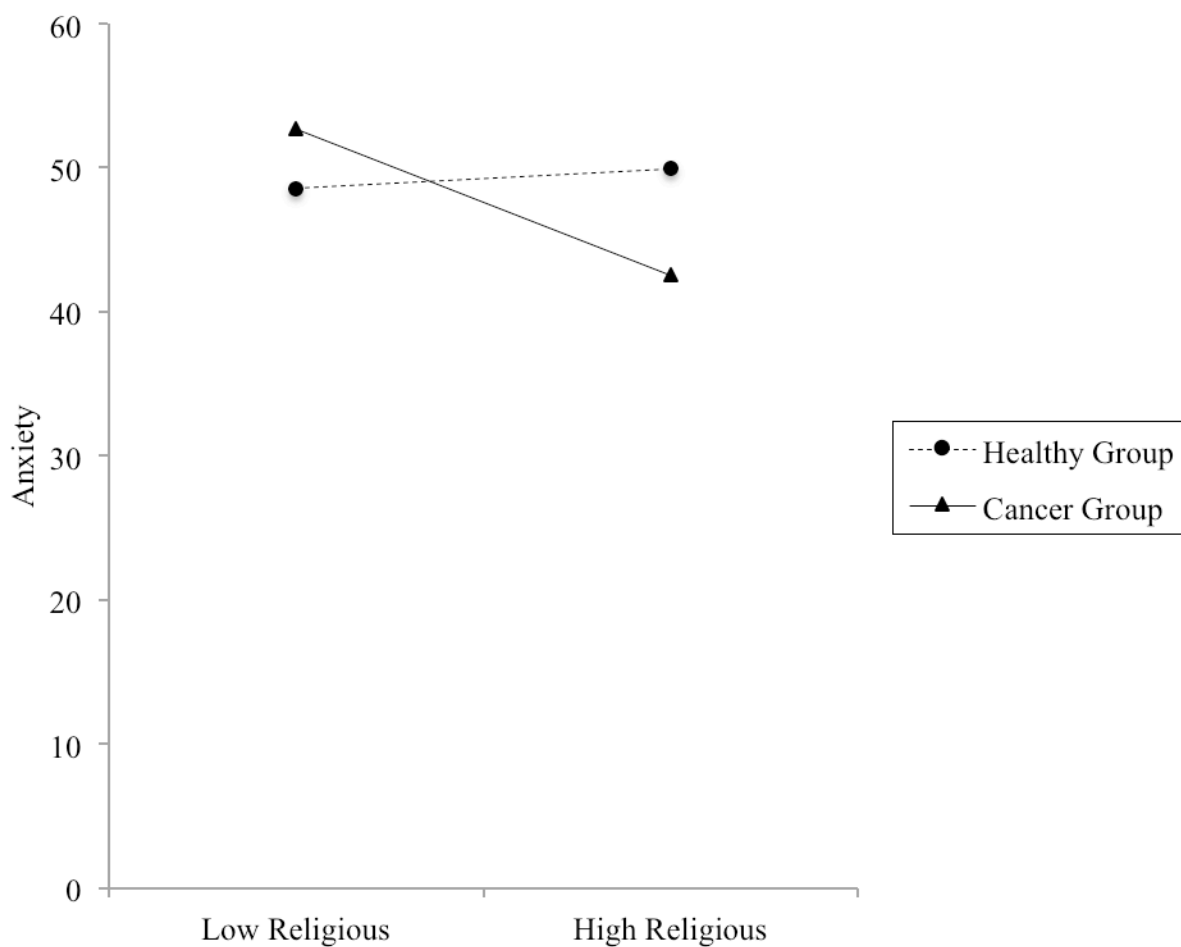


Figure 3. Plot of the moderating effect of health history on the relationship between Religious Well-Being Subscale (Spiritual Well-Being Scale) and the Anxiety subscale.

**Objective 4.** To test Hypothesis 4a, a series of Pearson correlations were computed. It was hypothesized that parents of childhood cancer survivors would be better raters of their child's spiritual lives and psychological well-being (i.e., depression, anxiety) than parents of children in the healthy comparison group. Examining whether or not parents of childhood cancer survivors had more highly correlated scores with their children's spirituality, depression, and anxiety scores versus parents of healthy children was explored using Fisher's  $Z$  transformations. Fisher's  $Z$  transformation tests were used to detect differences between correlations of the same two variables in two independent groups (Snedecor & Cochran, 1980). That is, parent-child dyads in the cancer survivor group and in the healthy comparison group were compared on the same measures.

The results revealed that the correlations between parent-child dyads<sub>cancer</sub> ( $r = .576$ ) were significantly higher than correlations between parent-child dyads<sub>healthy</sub> ( $r = -.134$ ) on the Depression subscale ( $z = -6.31$ ). The correlations between parent-child dyads<sub>cancer</sub> ( $r = .584$ ) were significantly higher than correlations between parent-child dyads<sub>healthy</sub> ( $r = .380$ ) on the Existential Well-Being subscale ( $z = -2.47$ ). Parent-child dyads<sub>healthy</sub> ( $r = .314$ ) were significantly more correlated than parent-child dyads<sub>cancer</sub> ( $r = .161$ ) on the Duality factor ( $z = 2.08$ ). There were no other significant differences. Thus, Hypothesis 4a was partially supported, as parent-child dyads<sub>cancer</sub> had more significantly correlated scores than parent-child<sub>healthy</sub> on the Existential Well-Being subscale of spirituality and on the Depression subscale. However, parent-child dyads<sub>healthy</sub> had significantly more correlated scores than parent-child<sub>cancer</sub> on the Duality factor. See Table 10 for a summary of results.

Table 10

*Correlations Between Parent-Child Dyads and Fisher's Z score*

Variables	Parent-Child Dyad Correlations		Z
	Healthy <i>r</i>	Cancer <i>r</i>	
Comfort	.38	.43	-.78
Omnipresence	.66	.68	-.48
Duality	.31	.16	2.08*
Religious	.61	.51	1.90
Existential	.38	.58	-3.62*
Anxiety	.05	.17	-1.69
Depression	-.13	.58	6.73*

\*Z&gt;1.96

### **Chapter 4: General Discussion**

The main objective of Study 1 was to develop a measure of children's spirituality that would allow for rigorous investigation of spirituality in a multi-faith context. An exploratory factor analysis revealed items that clustered together to create three interpretable factors (i.e., Comfort, Omnipresence, Duality). The purpose of Study 2 was threefold: (a) to describe spirituality in childhood cancer survivors compared to a healthy comparison group, (b) to explore spirituality in relation to psychological health and coping in childhood cancer survivors compared to a healthy comparison group, and (c) to determine whether parent-child<sub>cancer</sub> dyads have more highly correlated scores on measures of spirituality and psychological health than parent-child<sub>healthy</sub> dyads. In turn, the main objectives of this discussion are to (a) highlight this research's unique contribution to the field of children's spirituality, (b) summarize this study's results in relation to the literature and theories of post-traumatic growth and resilience, (c) discuss implications for psychologists, (d) outline some of the main limitations of this study, and finally, (e) conclude by providing suggestions for future research in this area of scholarship.

#### **Original Contribution**

In this dissertation, a measure for evaluating children's spirituality was developed and used with children with and without a history of cancer. This newly developed measure for school-age Canadian children makes a significant contribution to the limited repertoire of scales used with children. In using this scale, it was made evident that children with a history of cancer had higher scores on some measures of spirituality than their healthy comparison peers. Moreover, health history was found to significantly moderate the relation between spirituality and outcome variables, such as depression and anxiety. Thus, by using a healthy comparison group, it can be suggested that spirituality plays an important role in the lives of children who

have experienced a life-threatening illness, such as cancer. Now that more children are surviving cancer diagnoses, applying such research in clinical practice could strengthen supportive services and interventions for this population. The contributions of this research extend beyond this area of scholarship and into clinical practice. More specifically, these findings have a range of practical implications for psychologists in pediatric and school settings, which will be discussed here in further detail.

### **Discussion of Findings**

**Measure development.** The Children's Spiritual Lives measure is a newly developed measure that draws on three main factors (i.e., Comfort, Omnipresence, Duality). Based on the results from Study 2, it appears that the Comfort factor may be beginning to show indications of convergent validity with the Religious Well-Being subscale on the Spiritual Well-Being Scale. For instance, there were significant differences between health history (i.e., healthy, cancer) on both the Comfort factor and the Religious Well-Being subscale. In addition, both the Comfort factor and the Religious Well-Being subscale were predictors of lower scores on the Depression subscale in the cancer survivor group. These converging results were anticipated, given that both measures are indicators of an individual's personal relationship with a higher power. Notably, the subscale's label *Religious Well-Being* could be misleading. As previously described, this subscale does not in fact embody the religious conceptualizations used in research (e.g., church attendance, adherence to doctrine), but reflects more relational spiritual dimensions (e.g., personal relationship with a higher power).

The development of this measure makes a significant contribution to this field of research, given that few measures have been developed specifically for a school-age population living in a diverse urban setting in Canada. As previously mentioned, this measure is deeply

rooted in children's narratives (Moore et al., 2012). Unlike the Spiritual Well-Being Scale that uses adult oriented language, the Children's Spiritual Lives measure was developed specifically for Canadian school-aged children and grounded in their perspectives. In line with Hill (2013), who discusses measure development and validation, this measure should be further validated with a population similar to the one for which it was developed. Confirmatory factor analyses will need to be carried out to better establish this measure's validity (e.g., construct validity) and reliability (e.g., test-retest reliability). Furthermore, each item should be reviewed with respect to the phrasing and terminology used in order to ensure the measure is as child-oriented as possible. Once the scale has more reliable and valid psychometrics, its use, specifically with populations such as childhood cancer survivors, should be more thoroughly evaluated. This was clearly the initial stage of measure development and future research is needed for its refinement.

**Health history differences.** Differences in children's reported spirituality on the Children's Spiritual Lives measure and the Spiritual Well-Being Scale were examined in relation to health history (i.e., cancer, healthy) and gender (i.e., male, female). With respect to health history, childhood cancer survivors had significantly higher spirituality scores on the Comfort and Omnipresence factors and on the Religious Well-Being subscale than their healthy comparison peers; these factors and subscale all draw on a similar construct (i.e., relationship with a higher power, thoughts related to a higher power). The newly developed factors of Comfort and Omnipresence measure the closeness of the relationship children have with God as well as the ubiquitous nature of God. Items on this subscale include "I pray to God or talk to God when I feel sad", "God always knows how I feel, even without talking" and "I think God listens to everyone". Similarly, on the Religious Well-Being subscale, questions revolve around God's love, care, and concern. Examples of items on this scale include "I believe God loves me

and cares about me” and “My relationship with God helps me not to feel so lonely”. Based on these findings, children who have cancer may be more likely to rely on God as a source of comfort, support, and companionship than their healthy comparison peers.

Consistent with Kamper et al. (2010), children in the current study may also draw on their spiritual resources to feel close to God throughout their cancer experience. In the current study, children prayed to God for help, strength, and comfort (i.e., Comfort factor). Moreover, they felt that God was always ubiquitous and always listening (i.e., Omnipresence factor). Similarly, the majority of pediatric cancer patients in the study by Kamper et al. indicated wanting to feel close to God and praying to God for help (i.e., wanting to feel *normal*). It can be speculated that children in the current study used their relationship with God to make sense of adversity (Coles, 1990), to cope during difficult times (Woodgate & Degner, 2003), and to better identify and express their feelings (Mountain, 2005). As made evident by Bamford and Lagatutta (2010), children in the current study may have also understood that a relationship with a higher power could alleviate negative feelings, and thus they may have used their relationship with God to reduce negative psychological outcomes by expressing their feelings.

**Spirituality and gender.** Although there was an overall indication of a significant difference with respect to gender on the Children's Spiritual Lives measure, this was likely a spurious finding. As described earlier in this study, there were no differences found with respect to gender on any of the measure's factors. Similarly, the body of research on children's spirituality for this age range (7-11 years) has been mostly qualitative in nature, and it is therefore difficult to draw conclusions from this study about gender differences. Some researchers have found a more robust relationship between spirituality and psychological health for females following physical maturation (Miller & Gur, 2002). Adolescent and adult females



may have a stronger connection to their relational spirituality following puberty (Desrosiers & Miller, 2007), which has been linked to less depressive symptomology. Because spiritual and gender development is a dynamic and complex process that is tightly interwoven with children's sense of self (Bosacki et al., 2011), continued exploration of gender differences is necessary to better understand how children relate to their spiritual selves throughout development.

**Spirituality and psychological health.** As prognoses continue to improve with medical advances, the number of childhood cancer survivors continues to grow (Canadian Cancer Society, 2014). Although new and effective medical treatments continue to emerge, researchers have only begun to explore the post-treatment needs of children. Zebrack and Zeltzer (2003) acknowledge that qualitative studies provide the field with a necessary foundation to better understand childhood cancer survivors' spiritual experiences. However, they also recognize that these studies have small sample sizes and often do not use a healthy comparison group. The findings in the current study show spirituality having a salutary relation with psychological health outcomes. Thus, the current study contributes substantively to the research given that its results generally align with the findings of qualitative studies (e.g., Kamper et al., 2010; Morse & O'Rourke, 2009; Woodgate & Degner, 2003), but add a much-needed quantitative perspective by using spirituality measures and a healthy comparison group. In this study, links were made between childhood cancer survivors' spirituality and lower depression and anxiety scores, something that has been implied in qualitative research, but never explored quantitatively with school-age children. Certainly, more research is needed to explore other explanatory models that could account for the relationship between spirituality and psychological health. Because few researchers have explored children's spirituality by using quantitative methods, the impact of other factors on this relationship remains largely unexplored.

**Resilience and post-traumatic growth.** Gleaned from these compelling findings, spirituality may likely serve as a significant protective factor against depression and anxiety for children who have endured a cancer diagnosis and treatment, whereas it may not play the same role in the lives of children who have never experienced a cancer diagnosis. Although spirituality can be viewed as a protective factor in the context of resilience, it can also be viewed within the framework of post-traumatic growth (PTG). For instance, childhood cancer survivors may identify more strongly with spiritual concepts due to spiritual growth following their traumatic cancer experience; this spiritual growth may then result in better management of depressed and anxious feelings. It can also be inferred that positive spiritual growth may take place in the lives of childhood cancer survivors, and that this spiritual growth in turn serves as a buffer from symptoms of depression and anxiety. There may not be a clear answer as to whether or not these children experienced psycho-spiritual growth or used their existing spiritual resources to cope with their illness. However, these theoretical frameworks can continue to serve as a foundation to better conceptualize what may be occurring in the lives of children who have experienced cancer.

Both resilience and PTG frameworks can provide researchers and clinicians with a lens to better understand childhood cancer survivors' spirituality. Other guiding frameworks that should be considered in light of these results are the ecological (Bronfenbrenner, 1979) as well as transactional models of development (Kuczynski, 2003; Sameroff, 1975). It can be conjectured that childhood cancer survivors may have had more opportunities to engage in discourse with their parents about spiritual concepts in an environment that fosters more meaningful spiritual exchanges (e.g., praying before a medical procedure, discussing spiritual issues with a pastoral care worker, experiencing the loss of a fellow patient). Thus, children's exchanges with their

proximal (e.g., parents) and distal (e.g., hospital community) environment during a cancer experience may shape their spiritual growth and how children may draw on spiritual resources throughout their experience.

**Spirituality and coping.** When completing the Kidcope-Younger Version questionnaire, children were asked to identify a situation not related to illness (e.g., “I did poorly on a spelling test”, “I had a fight with my sister”, “I was upset because the teacher told me she does not listen to tattle-tales”) and how they coped with that particular situation. Although a qualitative analysis of children’s identified situations was not conducted, most situations that children reported concerned a relational problem (e.g., fight with friend; teacher-student quarrel; parent-child disagreement). Both positive and negative coping scores were not related to children’s spirituality in the moderation analyses. In fact, childhood cancer survivors had similar scores to their healthy comparison group with respect to positive coping strategies. However, there were significant differences between groups (i.e., healthy, cancer) with respect to negative coping. A simple statistical comparison revealed that childhood cancer survivors had higher negative coping scores than their healthy comparison group.

Because of frequent hospitalizations, children with a cancer diagnosis frequently miss school and their social interactions are often limited to family and hospital staff (Vance & Eiser, 2002). When children enter into various phases of survivorship, however, they slowly integrate back into their social networks and have to navigate nuanced social relationships. Thus, childhood cancer survivors may have positive coping strategies (e.g., cognitive restructuring, problem solving, social support) which are similar to their healthy peers, but due to their lack of experience relative to their peers in navigating social situations, they may likely resort more often to negative coping strategies (e.g., blaming others, wishful thinking, social withdrawal)

when dealing with problems in various relationships. Further investigation exploring why childhood cancer survivors may use more negative coping strategies when dealing with interpersonal problems is warranted to better support these children into survivorship.

**Parent-child dyads.** Parents' understanding of their child's spirituality was also of interest in this study. As evidenced by the results, parent-child dyads in the childhood cancer survivor group had more highly correlated scores than healthy parent-child dyads on Depression and Existential Well-Being subscales. With respect to the Depression subscale, it can be suggested that parents who have shared their children's cancer experience through exchanges with their children may be more aware of their children's depressive thoughts, or lack thereof. It can also be conjectured that these parent-child dyads may have had more discussions about such topics due to their circumstances. Children undergoing cancer treatments often interact with social workers, psychologists, and other professionals who encourage children to talk about their positive, as well as negative feelings. Thus, parents of childhood cancer survivors may have had many opportunities to discuss their children's feelings throughout the cancer treatment process, possibly making these parent-child dyads more open to these conversations through the cancer survivorship experience compared to healthy parent-child dyads.

Parent-child dyads of childhood cancer survivors also had more highly correlated scores on the Existential Well-Being subscale. The questions comprising this subscale include children's thoughts about purpose and meaning in life. Some of the items on this measure include, "I believe there is some real purpose for my life", "I don't enjoy much about life", and "I feel that life is a positive experience". Certainly, parents and children who have journeyed together through a cancer diagnosis, treatment, and into survivorship, spend a great deal of time together. Consistent with Thayer (2009), children who are ill are often unable to continue with

their regular range of activities during their treatment, and thus the focus of the parent-child relationship may shift from concerns about achievement to a greater emphasis on relationships and trying to find meaning in adversity. Parents and children may have more time to discuss these more meaning-oriented topics that might not have surfaced had their children not been diagnosed with a life-threatening illness such as cancer.

Healthy parent-child dyads, in fact, had more highly correlated scores than parent-child dyads of cancer survivors on only one measure; this was found on the Duality factor. It is possible that parent-child dyads with childhood cancer survivors do not have as many conversations about duality, because it concerns the idea of soul and spirit. These concepts may evoke potentially stressful conversations about the afterlife and life beyond the body. For example, one item on the Duality subscale was "Every person has a body and something inside of them like a soul or a spirit". The idea of a soul or spirit may evoke feelings of mortality. The thought of mortality may be too much of an anguishing prospect for childhood cancer survivors and their parents, given that this was likely a major concern at the time of diagnosis. Thus, it is reasonable to consider that concepts related to the soul and spirit may not be frequently broached. In turn, parents and children may engage in mutual pretenses (Bluebond-Langner, 1978) when it comes to ideas of the soul, afterlife, and the possibility of death. Parents and children may both be thinking about such distressing outcomes, but do not discuss such topics to protect each other from emotional distress. These results can be used as a springboard to further investigate parent-child conversations about such concepts in the midst of illness.

### **Implications**

Given that the findings of this research have significant potential for clinical practice, implications for both pediatric hospital psychologists and school psychologists will be discussed.

Although clinical psychologists in pediatric settings have frequent contact with childhood cancer survivors during maintenance treatments and follow-up appointments, school psychologists play an integral role in the reintegration of these children into schools. Based on the results of this research and intervention frameworks, supportive approaches and strengthen future treatment for this population will be discussed.

**Pediatric clinical psychologists.** Moore et al. (2015) proposed an approach in which psychologists and interdisciplinary treatment teams can better understand children's spirituality in hospital settings. According to Moore et al. there is a need for a therapeutic framework to guide psychologists and to inform interdisciplinary teams' understanding of spirituality in children in pediatric contexts. They suggest that narrative therapy's *definitional ceremonies* (Myerhoff, 1978, 1982; White & Epston 1990; White, 2007) can provide an appropriate therapeutic model for psychologists to encourage and strengthen children's spiritual narratives, facilitate interdisciplinary teams' understanding of children's spirituality in coping with illness, and contribute to more holistic and effective care. They argue that a children's spiritual narrative may play an important role in their perception of illness and treatment and that children should be given an opportunity to voice their spiritual stories in pediatric contexts.

Post-traumatic growth (PTG) is another framework that can help inform and guide psychologists' interventions in treating childhood cancer survivors in pediatric settings. With a focus on strengths, meaning-making, and understanding one's identity in relation to adversity, notions of PTG cannot be underestimated in the attempt to understand and support the healing process. A deeper awareness of the potential of PTG for psychologists and other professionals can aid childhood cancer survivors in finding hope in their difficult circumstances. As Tedeschi and Calhoun (2004) discuss, the positive psychological outcomes associated with PTG are

typically not sought out consciously by the patient, but emerge from their struggle to cope and adapt to their adverse circumstances. Thus, psychologists should be mindful that children could be unaware of the positive psychological or psycho-spiritual growth in their lives. In turn, psychologists can make children more aware of their positive growth by reflecting their narratives back at them in the context of supportive counseling or therapy. Thus, using the PTG framework along with narrative therapeutic approaches as described by Moore et al. (2015), may be especially appropriate in supporting childhood cancer survivors in pediatric settings.

**School psychologists.** Upon reintegrating into the school system following treatment, a child's primary supportive community shifts from a pediatric hospital context to a school setting. Childhood cancer survivors typically have a pattern of missing many school days due to treatments, procedures, and compromised immunity. Upon returning to school post-treatment, these children are faced with many challenges. In addition to having missed opportunities to be taught grade-level curriculum with their peers, they are returning to a classroom in which other students have developed and deepened their friendships. Maintaining friendships outside of the hospital is often difficult for childhood cancer patients due to frequent absences from school and compromised immunity. They may also return to school with physical markers of their cancer experience (e.g., fatigue, hair loss). These children may then feel ostracized, given their absence from the school environment due to medical treatments (Hildenbrand et al., 2011; Vance & Eiser, 2002).

As a result, childhood cancer survivors often need additional support from their teacher or school psychologist in order to adjust to the school routine. Clearly, school psychologists would benefit significantly from understanding the role spirituality can play in the lives of children, given that they are the professionals supporting and interacting with these children

following hospital discharge. As students, these childhood cancer survivors may be more likely to draw on spirituality to reduce depressive symptoms and anxiety that can result from social, academic, and familial challenges. As a result of their experience with cancer, these children may confront adversity in their lives with a very different perspective than their healthy peers. Their perception of adverse life events may be more deeply rooted in their sense of meaning and purpose and life and their experience of a relationship with a higher power. Thus, school psychologists should remain open to children's spiritual narratives and draw upon their spiritual strengths in the context of counseling and therapy. It may also be helpful for teachers to be aware of the value a particular child may place on his or her spirituality throughout the cancer experience. Although spirituality may not be integral to every cancer survivor's well-being, it is clear from the current research that it may have a salutary relationship with depression and anxiety. Thus, spirituality should be given serious attention when there exist indicators of its value in psychological support.

### **Limitations**

**Developmental factors.** Given the diverging theories on children's spiritual development, a closer examination of its developmental trajectory would be of great value. However, in this dissertation, greater emphasis was placed on the role that a negative life experience may have on the relation between spirituality and other factors (i.e., psychological health, coping). Profound experiences, such as a cancer diagnosis, should not be overlooked as an integral part of spiritual development. Thus, the objectives and hypotheses proposed in this dissertation centered on health history as a moderator of spirituality, as opposed to age. Age was not examined for a number of reasons (e.g., small sample size, focus on health history as opposed to age). Future research using a more developmentally oriented methodology could



inform our understanding of children's spirituality across a larger span of childhood. Certainly, the data may be more informative with a focus on a developmental progression issues including age at diagnosis, age at which the questionnaire was administered, length of treatment, and time between diagnosis and completion of treatment.

**Measure development.** The current study had several limitations. With respect to the development of the Children's Spiritual Lives measure in Study 1, many of the questions in this newly developed scale pertained to children's relationship with God, given that is what emerged from a qualitative study by Moore et al. (2012). However, more questions oriented towards children's broader spiritual experiences might have allowed for deeper insight into children's spiritual lives and existential thoughts. In this vein, Hart (2003) warned against only examining children's spirituality through a "God-talk" (p. 214) lens and argued that broad spiritual experiences should also be thoroughly explored (e.g., supernatural experiences). Children's spiritual lives and supernatural experiences are often harmfully ignored, which prompted Hart to write extensively on the integral role spirituality plays in the lives of children. Although ignoring children's spiritual lives may be detrimental, overemphasizing children's spiritual experiences may inadvertently put pressure and stress on children to clearly articulate their complex spiritual experiences.

Hart concludes that the more we know and understand about children's spirituality, the less likely those interacting with children will repress, shame, pathologize, or under-over emphasize children's spiritual experiences. Thus, the measure developed in this research is intended to be used as part of a holistic evaluation (i.e., discussion with child) of children's spirituality in pediatric settings, so as to promote a more complete understanding of children's spirituality and its full potential in the healing process. Notably, a limitation of using a broad

measure of spirituality is that it may obscure important differences between religious groups. In the future, analyses used to examine trends across within and between religious groups could be explored to better understand the measure's strengths and weaknesses.

**Exploratory analyses.** Because the newly developed measure has not yet been validated by a confirmatory factor analysis, it is a limitation that all analyses described in this study that use this measure are exploratory in nature. Continued exploration of the scale's strengths and weaknesses is warranted to ensure that it is appropriate to use with children from a diversity of faith and cultural backgrounds living in a pluralistic society. Although this measure is meant to be used with children from a wide variety of faith orientations, a better understanding of which factors are strongest or weakest in different faith groups would be helpful in future phases of the measure's development. In addition, it is important to note that the Spiritual-Well-Being Scale used in the current study is an adult-oriented measure. Although it has been used with some child and adolescent populations, there are limitations in using such a measure with children (e.g., some difficult language).

**Inclusion criteria.** Another limitation concerns the issue of inclusion criteria for the childhood cancer survivor participants. Given the challenges in recruiting childhood cancer survivors, the inclusion criterion concerning the number of years post-diagnosis was broad. Childhood cancer survivors with several different types of cancer at different stages of survivorship participated in this study. With a larger sample size, different types of cancer across stages of survivorship could have been explored. Certainly, examining children's understanding of spirituality across survivorship from a more developmental perspective could provide insights into the evolution of spirituality from childhood into adolescence and adulthood. Notably, children who survive cancer may have a much more positive report of spirituality than

those children who receive a more negative prognosis (e.g., palliative) or children who suffer permanent consequences (e.g., loss of a limb). Childhood cancer survivors who have fewer physiological consequences may have an overarching feeling of gratitude for their survivorship, whereas children with an incurable cancer or impairing or permanent consequences from their cancer treatment may have a less positive report of spirituality. Researchers could explore these possible differences by refining inclusion criteria.

**Socio-economic status.** It is important to acknowledge that parents of children in the healthy comparison group tended to report higher income levels than parents of childhood cancer survivors. Researchers have shown that parents typically take leave from their jobs when their child is diagnosed with cancer and thus experience a loss of income (Limburg et al., 2008). Income levels may thus be comparable between these two groups prior to a diagnosis of cancer. Conversely, it is possible that parents of childhood cancer survivors from lower socio-economic status were more spiritually oriented and more willing to participate in this research study. Yet, given the low refusal rate in this study, this was likely not the case. Future researchers should seek to understand if there is any relation between the families' socio-economic status and spirituality. Appropriate statistical analyses could be used to more closely examine the role of socio-economic status, as well as other demographic variables, in relation to spirituality.

### **Future Directions**

**Spiritual dissonance.** Some researchers have explored negative consequences resulting from the adherence to specific religious or spiritual beliefs (e.g., Wagener & Maloney, 2006). Negative consequences can also arise when families rely on religious or spiritual healing instead of medical interventions (Asser & Swan, 1998). Parents and children may also call into question their religious or spiritual beliefs during painful and traumatizing medical treatments. As a

result, these children and parents may discontinue spiritual or religious practices, as they may appear to be too much in contradiction with such a difficult life situation. Indeed, children's religious and spiritual communities play an important role in how particular traditions are interpreted and how they will influence children's lives (Barnes et al., 2000). Consistent with Boyatzis (2012), it is helpful to understand children's spirituality within a social-ecological context to better understand how children and their families will understand, dialogue, and express their spirituality, whether that be positively or negatively. Researchers should also explore spirituality in the lives of those children and families who identify as being agnostic and atheist, and how those beliefs are manifested throughout children's cancer experiences.

**Siblings of survivors.** The research concerning siblings of childhood cancer survivors has often remained on the periphery, but is now becoming an area of keen professional interest (Alderfer et al., 2010; Barrera, Fleming, & Khan, 2004; Lima et al., 2013). In fact, many pediatric hospital settings (e.g., Montreal Children's Hospital) recognize the needs of siblings of children with cancer and offer support groups for them to share thoughts and feelings. Siblings of childhood cancer survivors are a population that deserves much further investigation given the importance of the family dimension in a pediatric context. Examining differences between childhood cancer survivors and their siblings' understanding of spirituality would be a unique way of exploring the impact of illness on the family system given that many environmental factors could be controlled. As a result, the role of spirituality in the lives of children facing a direct threat to their mortality, as well as with their siblings, who indirectly experience the trauma of a diagnosis, could be better understood.

**Existing interventions.** A future direction for research with important implications for psychologists would be to closely examine the types of interventions (e.g., psychotherapy,

medical play, group therapy, pastoral support) childhood cancer survivors receive over the course of their treatments. It would be important to determine if there is any link between the type of intervention received and its relation between spirituality. Interventions that support spiritual expression (e.g., narrative therapy practices) could be more closely examined in relation to psychological health. Children could also be interviewed to better understand how they perceive these interventions with respect to meeting their spiritual needs. Given this budding area of study, future researchers have many opportunities to investigate potential factors that may promote well-being throughout phases of childhood cancer survivorship.

### **Summary and Conclusion**

Researchers exploring children's spirituality have often used narrow measures that do not account for the significant spiritual experiences of children in a diverse context (e.g., Houskamp et al., 2004). Although researchers have shown that spirituality can sometimes arise in response to illness, it is recognized that its value often goes beyond coping with immediate adversity. In Study 1, a children's spirituality measure was developed (i.e., Children's Spiritual Lives). A factor analysis revealed three main factors, including Comfort (Factor 1), Omnipresence (Factor 2), and Duality (Factor 3). The newly developed measure, along with the established Spiritual Well-Being Scale, was used in Study 2 and its purpose was threefold: (a) to describe spirituality in childhood cancer survivors compared to a healthy peer group, (b) to explore the effect of spirituality on psychological health and coping compared to a healthy peer group, and (c) to determine if parent-child<sub>cancer</sub> dyads scores on spirituality and psychological health measures were more highly correlated than parent-child<sub>healthy</sub> dyads of their healthy peers.

The results revealed that there were significant differences between children's reported spirituality in relation to health history (i.e., healthy, cancer). Several spirituality factors and

subscales were significantly higher in the childhood cancer survivor group than in the healthy comparison group. Health history was found to significantly moderate the relationship between spirituality and outcome variables, such as depression and anxiety. That is, some spirituality factors and subscales predicted lower depression and anxiety in childhood cancer survivors. The results also revealed that parent-child dyads<sub>cancer</sub> had more highly correlated scores than parent-child dyads<sub>healthy</sub> on both Depression and Existential Well-Being subscales, whereas parent-child dyads<sub>healthy</sub> had more highly correlated scores than parent-child dyads<sub>cancer</sub> on the Duality factor.

As made evident by these results, children with a history of cancer had higher scores on some measures of spirituality than their healthy peers, suggesting that spirituality is likely relevant for children who have survived a serious illness. In using a healthy comparison group, it was discovered that spirituality plays a larger role in reducing depressive and anxious feelings in childhood cancer survivors than in a healthy comparison group. These results have significant implications for professionals, and more specifically psychologists, who provide therapeutic and supportive services to children who have survived a cancer diagnosis and treatment. The original findings of this research make a substantial contribution to the emerging body of research on childhood cancer survivors' spirituality and can serve to guide future research in this field and therapeutic interventions with this growing population.

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## Appendix A

### INFORMED CONSENT

**Title:** Examining the role of spirituality in the lives of pediatric cancer survivors

**Principal Investigator(s):** Dr. Linda Moxley-Haegert, Dr. Genevieve Janveau

**Sponsor/Funded By:** Canadian Institutes of Health Research Doctoral Award

“You” means “you/your child”.

#### Purpose and General information

The purpose of the study is to better understand children's ideas about spirituality and its role in their lives. The current study aims to examine children with and without a cancer diagnosis and their ideas of spirituality. In the current study, "spirituality" will be used in the broad sense, capturing children's ideas about a higher power. Children will be encouraged to use whatever word they choose to represent a "higher power". In this study, children's ideas about duality (that is, having a soul or a spirit that is separate from the body) are also of interest. In addition, children will also be asked about how they make meaning out of certain life experiences. We will also examine how children deal with problems and explore their thoughts and feelings about themselves and their friends. We will also look at children's overall ability to do normal daily activities, like taking a walk.

You will be asked to fill out some background information (e.g., cultural background, number of people in the home) and agree (e.g., sign a consent form) for your child to participate. You will also be asked to complete questionnaires related to your child's ideas of spirituality. You will also be asked to answer questions about your child's social life and feelings. You will be asked questions about how children deal with problems and some questions about your child's everyday activities, like taking a walk or playing with friends.

Your child will be asked to answer questionnaires concerning his/her ideas about spirituality. Your child will also be asked to complete questions that explore how he/she deals with problems and questions about his/her social life, thoughts, and feelings. Your child will also be asked about some normal daily activities that he/she does, like taking a walk or playing with friends. The study will take about one hour.

#### Study Procedures

Children will have the option of reading the questionnaires or having the questionnaires read to them by a research assistant. Parents and/or children can discontinue participation at any point in the study. Your child will complete these questionnaires with a trained Research Assistant. The



study can either be completed at your home with a Research Assistant, or at our research lab at McGill.

**Possible Risks and Discomforts**

This study presents minimal risks to participants. In some cases, children and parents may be reporting about stressful cases (e.g. struggles with living with cancer).

**Possible Benefits**

There is no direct benefit in participating in the current study, but your participation may further our understanding of children's spirituality and its relationship with children's thoughts, feelings, social life, and ability to deal with problems.

**Voluntary participation**

Your participation is voluntary and you should not feel any obligation. You may agree now and are free to withdraw from this study at any time. Refusal to join or withdrawal from the study will not affect your care at this hospital.

**Confidentiality**

All information obtained during the study will be kept confidential as required or permitted by law and will be kept for 7 years. Your personal identity will remain confidential, as a subject identification number will be used to identify you. All study data will be stored in the locked office of Talwar Research Lab at McGill, where only authorized researchers will have access.

Your name and other personal identifying information will not be used in any reports, presentations or publications.

If the results of this study are published, you will not be identified in any way. Your personal information will be kept strictly confidential except as required or permitted by law.

Representatives from Health Canada, the sponsor, and the McGill University Health Centre Research Ethics Office, may have access to your records as it pertains to this study. The research team will have access to your hospital records.

**Quality Assurance Program**

The MUHC Research Institute has implemented a Quality Assurance Program that includes active continuing review of research projects (on site visits) conducted within the establishment. Therefore, it must be noted that all human subject research conducted at the MUHC or elsewhere by its staff, is subject to MUHC Routine and Directed Quality Improvement Visits.

**Contact person**

Please contact Dr. Linda Moxley Haegert, 514 412 4400 extension: #22155 or Dr. Genevieve Janveau 514 412 4400 # 22157 if you have any questions or concerns about the study.

For additional information regarding your (child's) rights as a research subject, you may contact the hospital's Patient Representative (ombudsman), Patricia Boyer (514) 412-4400 ext. 22223, who is independent of the investigator, and works to protect patients' rights.

**Consent**

I have read this information and consent form and have had the opportunity to ask questions which have been answered to my satisfaction before signing my name. I acknowledge that I will receive a copy of the Information and Consent Form for future reference. I agree to (have my child) participate in the research study.

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Participant's name:

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Parent or legal guardian's printed name:

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Parent or legal guardian's signature:

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Relationship to child:

---

Date: (dd/month/yy)

---

Name of the person who obtained consent

---

Signature of the person who obtained consent

---

Date: (dd/month/yy)

**Appendix B****CHILD ASSENT FORM**

**Title:** Examining the role of spirituality in the lives of pediatric cancer survivors

**Principal Investigator(s):** Dr. Linda Moxley Haegert, Dr. Genevieve Janveau

**Sponsor/Funded By:** Canadian Institutes of Health Research Doctoral Award

You are invited to participate in a research study about children's ideas about spirituality and their thoughts and feelings about things in their life.

**What is This Study About?**

The purpose of the study is to better understand what kids think about spirituality and how they think and feel about different things in their lives.

Your participation will involve answering a few questions. Some of these questions are about spirituality. I am interested to know more about your thoughts about "God" (i.e., or appropriate term used by child). Other questions are more about thoughts and feelings that you have almost every day. I'll ask you about how you deal with hard times. I'll also ask you about some things you do everyday, like playing with friends or walking. Remember, you do not have to answer any questions that you don't want to and we can stop this study at anytime. Also, if you want to take a break, we can do that too! The study will take about one hour.

**What Are the Possible Risks and Discomforts?**

Some of the questions may make you feel sad or bring up old memories that are hard to think about.

**What Are the Possible Benefits?**

**There is no direct benefit in participating, but you may be helping us to better understand kids' thoughts and feelings about spirituality.**

**What Are My Options?**

Your participation is completely voluntary. You may agree now and are free to change your

mind at any time and no one will be mad at you. Refusal to join or withdrawal from the study will not affect your care at the Montreal Children's Hospital.

**Who Will Know What I Did?**

All information obtained during the study will be kept confidential. All printed data will be stored in a locked filing cabinet, in which only authorized experimenters will have access.

Your personal identity will remain confidential, as you will only be identified by a subject identification number. Your name and other personal identifying information will not be used in any reports, presentations or publications.

If the results of this study are published, you will not be identified in any way. Your personal information will be kept strictly confidential except as required or permitted by law. As required by Health Canada, and representatives of the McGill University Health Centre Research Board, may have access to your records as it pertains to this study. The research team will have access to your hospital records.

**Who Can I Contact if I Have Questions?**

If you have any questions, you can call Dr. Linda Moxley Haegert, 514 412 4400 extension: #22155 or Genevieve Janveau, 514 412 4400 extension #22157

**ASSENT:**

I have read this information and assent form and have had the opportunity to ask questions which have been answered to my satisfaction before signing my name.

I agree to participate in the research study.

Participant's name: \_\_\_\_\_

Participant's signature: \_\_\_\_\_

Date: (dd/month/yy) \_\_\_\_\_

Name of the person who explained the assent: \_\_\_\_\_

Signature of the person who explained the assent: \_\_\_\_\_

Date: (dd/month/yy) \_\_\_\_\_

## Appendix C

### MCGILL UNIVERSITY CONSENT

#### Study 1

Dear Parent/Legal Tutor,

We are members of the McGill Education Child Development Research Team. We are presently conducting a study and wonder if you would give permission for you and your child to participate. The purpose of the study is to examine children's spirituality and their conceptions of various themes related to spirituality.

**What would I/my child have to do?**

This study involves your child answering a questionnaire concerning spirituality (approximately 20 minutes). Children will rate statements on a scale from "strongly agree" to "strongly disagree" (e.g., I pray or talk to the divine when I'm sad or lonely, the divine listens to my thoughts and wishes, and I can ask the divine for help). Parents will also be asked to fill out some demographic information and sign a consent form (5 minutes). The entire study will take approximately 20-30 minutes.

**Is there anything else?**

Participation in this study is completely voluntary and you or your child may withdraw from the session at any time. The risks to participants are minimal. If, however, your child experiences any negative feelings during the procedure, we will stop the study immediately. You and your child are not required to answer any questions that make you uncomfortable or you do not wish to answer. While there are no expected benefits for individual children, it is expected that this research will help psychologists understand the role of spirituality in children's lives. The purpose of this study is to explore general patterns of responses among groups of children of different ages rather than the response of any particular child.

The results of the study will be shared at academic conferences and in peer-reviewed journals as well as on our website. In all cases, the responses of participants will be kept confidential and anonymous. All information and data collected will be protected for confidentiality by assigning a random identification code to each participant. Data will be kept in a locked cabinet at our McGill research lab which can only be accessed by our research team. If you have any questions or concerns about your/your child's rights or welfare as a participant in this study please contact the McGill Research Ethics Officer at 514-398-6831. If you have any concerns or questions, please contact Kelsey Moore (514) 554-9807 or kelsey.moore@mail.mcgill.ca

Sincerely,  
Kelsey Moore

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Yes, I, \_\_\_\_\_ agree to participate in the study and give permission for my child \_\_\_\_\_ to participate in the research as described above.

Signature of Parent/Legal Tutor: \_\_\_\_\_ Date: \_\_\_\_\_

Birth date of child: \_\_\_\_ / \_\_\_\_ / \_\_\_\_ (D/M/Y) Gender \_\_\_\_\_

## Study 2

Dear Parent/Legal Tutor,

We are members of the McGill Education Child Development Research Team. We are presently conducting a study and would like to know if you would give permission for you and your child to participate. The current study aims to examine the children with and without a cancer diagnosis and their conceptions of spirituality and their social-emotional well-being, quality of life, and coping.

### **What do I have to do?**

Before beginning the study, you will be asked if your child meets inclusion criteria. You will then be asked to fill out some demographic information (i.e., which include some questions related to religious practices) and give consent for your child to participate. You will also be asked to complete questionnaires related to your child's spirituality and their social-emotional wellbeing, coping, and quality of life.

### **What does my child have to do?**

This study involves your child answering questionnaires concerning spirituality and social-wellbeing, coping, and quality of life. On the spirituality questionnaires, children will rate statements related to their spiritual practices and God (i.e., or preferred word used for the divine) on a scale from "strongly agree" to "strongly disagree" (e.g., I pray or talk to God or "term used for the divine" when I'm sad or lonely). Children will also be asked to fill out questionnaires related to their social-emotional well-being, coping and their quality of life. The study will take between 45-60 minutes. Children will have the option of reading the measures or having the measures read to them by a research assistant.

### **Is there anything else?**

Participation in this study is completely voluntary and you or your child may withdraw from the session at any time. The risks to participants are minimal. You and your child are not required to answer any questions that make you uncomfortable or you do not wish to answer. While there are no expected benefits for individual children, it is expected that this research will help psychologists understand the role of spirituality in children's lives. The purpose of this study is to explore general patterns of responses among groups of children of different ages rather than the response of any particular child. Therefore, it is important that your child completes the questionnaire carefully and diligently.

If you or your child endorse any questions about self-harm, you will be notified and the researcher will give you a list of appropriate resources.

The results of the study will be shared at academic conferences and in peer-reviewed journals as well as on our website. In all cases, the responses of participants will be kept confidential and anonymous. All information and data collected will be protected for confidentiality by assigning a random identification code to each participant. Data will be kept in a locked cabinet at our McGill research lab which can only be accessed by our research team. No individual results will be presented—only aggregated data will be reported. If you have any questions or concerns

about your/your child's rights or welfare as a participant in this study please contact the McGill Research Ethics Officer at 514-398-6831.

If you have any concerns or questions about the current study, please contact Kelsey Moore (514) 554-9807 or [kelsey.moore@mail.mcgill.ca](mailto:kelsey.moore@mail.mcgill.ca)

Sincerely,  
Kelsey Moore, Dr. Victoria Talwar

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Yes. I, \_\_\_\_\_ agree to participate in the study and give permission for my child  
\_\_\_\_\_ to participate in the research as described above

Signature of Parent/Legal Tutor: \_\_\_\_\_ Date: \_\_\_\_\_

Birth date of child: \_\_\_\_ / \_\_\_\_ / \_\_\_\_ (D/M/Y) Child's Gender: \_\_\_\_\_

## Appendix D

### CHILD ASSENT

#### Study 1

Hello \_\_\_\_\_.

My name is \_\_\_\_\_, and I'm a researcher at McGill University. I'm doing a big project about what kids think about spirituality. Do you know what that word means? What do you think it means? Maybe your mom or dad can help us?

Remember! You do not have to answer any questions that you don't want to and we can stop this study at any time. Also, if you want to take a break we can do that too.

\_\_\_\_\_, do you still want to participate?

#### Study 2

Hello \_\_\_\_\_.

My name is \_\_\_\_\_, and I'm a researcher at McGill University. I'm doing a big research project about what kids think about **spirituality** and different ideas about **your feelings, how you deal with your feelings, and I will also ask questions about your life.**

In other words, I have a few questions that I want you to answer. Some of these questions are about spirituality. I am interested to know more about your thoughts about "**the divine**" (i.e., or appropriate term used by child). Other questions are more about **thoughts and feelings** that you have almost every day. I'll ask you questions about yourself, your friends, and your family. I'll also ask you about different emotions you have and what you think about things in your life.

Remember! You **do not** have to answer any questions that you don't want to and we can **stop** this study at anytime. Also, if you want to take a break, we can do that too!

\_\_\_\_\_, do you still want to participate in this study?



## Appendix E

**DEMOGRAPHIC QUESTIONNAIRE****Questionnaire for Parents**

(Adapted from the National Longitudinal Survey of Children,  
Statistics Canada Human Resources Development Canada)

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**Your answers will be kept strictly confidential and only used for statistical purposes. While participation is voluntary, your assistance is essential if the results are to be accurate. Thank you.**

---

1. What is your child or children's name, date of birth, and gender?

Child 1: Birth Year _____	Gender: Male   Female
Child 2: Birth Year _____	Gender: Male   Female
Child 3: Birth Year _____	Gender: Male   Female
Child 4: Birth Year _____	Gender: Male   Female

2. Please list a) the number of adults (18 years and older) living in your household \_\_\_\_\_

Relation to you: \_\_\_\_\_

b) The number of people 6-17 years of age in household \_\_\_\_\_

Relation to you: \_\_\_\_\_

c) The number of people younger than 6 years of age in household \_\_\_\_\_

Relation to you: \_\_\_\_\_

3. To which ethnic or cultural group(s) did your child or children's ancestors belong?

_____ Canadian	_____ American	_____ Chinese
_____ French	_____ Latin	_____ English
_____ Jewish	_____ Polish	_____ German
_____ Portuguese	_____ Scottish	_____ South Asian
_____ Irish	_____ Inuit/Eskimo	_____ Black (African American)
_____ Italian	_____ Mexican	_____ North American Indian
_____ Ukrainian	_____ Métis	_____ Dutch (Netherlands)

If ancestry is not listed please specify, \_\_\_\_\_

4. What, if any, is your child or children's religion?

_____ No religion	_____ Hindu
_____ Roman Catholic	_____ Jehovah's Witness
_____ United Church	_____ Sikh
_____ Anglican	_____ Presbyterian
_____ Lutheran	_____ Baptist
_____ Eastern Orthodox	_____ Jewish
_____ Islam (Muslim)	_____ Buddhist

If not listed please specify, \_\_\_\_\_

5. Do you think your family is \_\_\_\_\_ very religious?  
\_\_\_\_\_ Somewhat religious?  
\_\_\_\_\_ not religious at all?
6. Do you think your family is \_\_\_\_\_ very spiritual?  
\_\_\_\_\_ somewhat spiritual?  
\_\_\_\_\_ not spiritual at all?
7. Other than special occasions (such as weddings, funerals or baptisms), how often did your child or children attend religious services or meetings in the past 12 months?  
\_\_\_\_\_ At least once a week  
\_\_\_\_\_ At least once a month  
\_\_\_\_\_ At least 3 or 4 times a year  
\_\_\_\_\_ At least once a year  
\_\_\_\_\_ Not at all
8. Other than special occasions (such as weddings, funerals or baptisms), how often did your child or children attend religious services or meetings in the past 12 months?  
\_\_\_\_\_ At least once a week  
\_\_\_\_\_ At least once a month  
\_\_\_\_\_ At least 3 or 4 times a year  
\_\_\_\_\_ At least once a year  
\_\_\_\_\_ Not at all
9. Please list ALL languages spoken at home \_\_\_\_\_
10. What is your marital status?  
\_\_\_\_\_ Single (never married) \_\_\_\_\_ dating a significant other, not living together  
\_\_\_\_\_ living with significant other \_\_\_\_\_ married, since when (date: D/M/Y) \_\_\_\_\_  
\_\_\_\_\_ Common law \_\_\_\_\_ separated, since when (date: D/M/Y) \_\_\_\_\_  
\_\_\_\_\_ Divorced \_\_\_\_\_ widowed, since when (date: D/M/Y) \_\_\_\_\_
11. What is the highest level of education that you have attained?  
\_\_\_\_\_ High school diploma  
\_\_\_\_\_ some trade, technical or vocational school, or Business College  
\_\_\_\_\_ Some community college, CEGEP, or nursing school  
\_\_\_\_\_ Some University  
\_\_\_\_\_ Diploma or certificate from trade, technical or vocational school, or business school  
\_\_\_\_\_ Diploma or certificate from community college, CEGEP, or nursing school  
\_\_\_\_\_ Bachelor or undergraduate degree, or teacher's college (e.g. B.A., B. SC. LL.B.)  
\_\_\_\_\_ Master's (e.g. M.A., M.SC., M.ED.)  
\_\_\_\_\_ Degree in medicine, dentistry, veterinary medicine or optometry (e.g. M.D., D.D.S., D.M.D., D.V.M., O.D.)  
\_\_\_\_\_ Earned Doctorate (e.g. PH.D., D.SC. D.ED.)  
\_\_\_\_\_ if other please specify.

12. If applicable, what is the highest level of education that your partner has attained?

- ☐ High school diploma
- ☐ Some trade, technical or vocational school, or Business College
- ☐ Some community college, CEGEP, or nursing school
- ☐ Some University
- ☐ Diploma or certificate from trade, technical or vocational school, or business school
- ☐ Diploma or certificate from community college, CEGEP, or nursing school
- ☐ Bachelor or undergraduate degree, or teacher's college (e.g. B.A., B. SC. LL.B.)
- ☐ Master's (e.g. M.A., M.SC., M.ED.)
- ☐ Degree in medicine, dentistry, veterinary medicine or optometry (e.g. M.D., D.D.S., D.M.D., D.V.M., O.D.)
- ☐ Earned Doctorate (e.g. PH.D., D.SC. D.ED.)
- ☐ If other please specify.

13. What do you consider to be your current main activity?

- ☐ Caring for family
- ☐ working for pay or profit
- ☐ Caring for family and working for pay or profit
- ☐ recovering from illness/on disability
- ☐ looking for work
- ☐ Retired
- ☐ if other please specify.

14. If applicable, what do you consider to be your partner's current main activity?

- ☐ Caring for family
- ☐ Working for pay or profit
- ☐ Caring for family and working for pay or profit
- ☐ Recovering from illness/on disability
- ☐ Looking for work
- ☐ Retired
- ☐ If other please specify.

15. Can you estimate in which of the following groups your household income falls? Please specify.

- ☐ Less than \$20, 000
- ☐ Less than \$25, 000 (\$20, 000 to \$24, 999)
- ☐ \$25, 000 or more (\$25, 000 to \$29, 999)
- ☐ \$30, 000 or more (\$30, 000 to \$34, 999)
- ☐ \$35, 000 or more (\$35, 000 to \$39, 999)
- ☐ \$ 40, 000 or more
- ☐ Less than \$50, 000 (\$40, 000 to \$49, 999)
- ☐ \$50, 000 to \$59, 999
- ☐ \$60, 000 to \$ 69, 999
- ☐ \$ 70, 000 to \$ 79, 999
- ☐ \$ 80,000 or more
- ☐ No income

**Appendix F****MEDICAL HISTORY QUESTIONNAIRE****1. Does your child have a cancer diagnosis?**

- a) Yes → complete entire questionnaire
- b) No → skip to question 6

**2. When was your child diagnosed with cancer?**

Date(Day, Month, Year): \_\_\_\_\_ What is the diagnosis:

Approximately how long was your child's treatment: \_\_\_\_\_

Please provide any important treatment details:

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**3. Has your child had their primary induction?**

- a) Yes
- b) No

**4. What is the current stage of your child's cancer treatment?**

- a) my child is still in active treatment
- b) my child is in maintenance treatment (since (d/m/y): \_\_\_\_\_)
- c) my child has terminated treatment and has follow-up appointments (since (d/m/y): \_\_\_\_\_)

**5. Currently, my child illness:**

- a) always interferes with his/her daily life
- b) sometimes interferes with his/her daily life
- c) no longer interferes with his/her daily life

**6. Please describe your child's history of illnesses (including accidents, surgeries, and hospitalizations):**

- a) my child does not have a history of illness
- b) my child does have a history of illness. Please describe below.

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**7. Please describe any traumas in your child's life?**

- a) my child does not have a history of trauma
- b) my child does have a history of trauma. Please describe below.

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**8. Please describe any stressors in your child's life?**

- a) my child does not have any stressors in his/her life.
- b) my child does have stressors in his/her life. Please describe below.

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**9. Has any close family member had cancer or another serious illness?**

- a) my child does not have a family member with cancer
- b) my child does have a family member with cancer. Please describe below.

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**10. Has any close family member recently died?**

- a) my child does not have a family member recently die.
- b) my child does have a family who died recently. Please describe below.

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**Appendix G****RECRUITMENT PHONE SCRIPT**

Hello. My name is \_\_\_\_\_ and I am calling from the Talwar Child Development Research Lab at McGill University. I'm calling a) because you expressed interest in our study as you saw an advertisement.

We are presently conducting a study and wonder if you would give permission for you and your child to participate. We are looking at children's perceptions of spirituality and its relationship to social-emotional well being, coping, and quality of life in the lives of children with and without cancer.

**What do I have to do?**

You will be asked to fill out some demographic information and give consent for your child to participate. You will also be asked to complete a questionnaire related to your child's spirituality and their social-emotional wellbeing and quality of life.

**What does my child have to do?**

This study involves your child answering a questionnaire concerning spirituality and complete questionnaires related to their social-emotional well-being, coping, and their quality of life.

**Is there anything else?**

Participation in this study is completely voluntary and you or your child may withdraw from the session at any time. The risks to participants are minimal. You and your child are not required to answer any questions that make you uncomfortable or you do not wish to answer. The study will take approximately 45 minutes to one hour and your child will receive a certificate to Indigo (twenty dollar value) for participating. The study will take approximately one hour of your time.

**If interested...**

Great. We can schedule a time that is convenient for you to come to your house to conduct the study. We will also send you an information letter about the study upon study completion and a copy of the study consent form with our contact information!

**If not interested...**

That's no problem. Please feel free to contact the Talwar Child Development Research Lab if you have any questions. Thank you for your time.

## **Appendix H**

### **STUDY INFORMATION SHEET**

#### **Why are we doing this research?**

Children's perceptions of spirituality are viewed as constantly evolving as children develop (Coles, 1990; Fowler, 1981; Houskamp, Fisher, & Stuber, 2004). As the majority of research exploring spirituality has focused on adults and adolescents (French, Eisenberg, Vaughan, Purwono, & Suryanti, 2008) studies exploring children's spirituality and understanding of prayer remain sparse (Bamford & Lagatutta, 2010; Ream & Savin-Williams, 2003).

#### **Why examine spirituality and cancer:**

A cancer diagnosis during childhood can influence physical, psychological and behavioral development, peer acceptance, and family relationships (Suris, Michaud, & Viner, 2004). For some children, spirituality may play a significant positive role in their ability to cope and adjust to their illness. For others, it may play little or no role and for still others it may have a negative impact (e.g., fears of punishment) on their ability to cope with their illness. Therefore, the objective of the proposed research project is to examine the role of spirituality in the lives of children with and without a cancer diagnosis.

#### **What impact will this research have?**

The proposed research will contribute to the understanding of the role of spirituality in the lives of children with and without cancer. The study will also examine if there is a relationship between children's spirituality and their social and emotional wellbeing. Even more, the examination of parents' perspectives of spirituality will inform researchers whether or not parents' ideas of their child's spirituality are congruent with the child's actual spiritual life.

This research has a core focus on knowledge translation in academia in addition to having practical implications in clinical settings and aims to improve the health of Canadian children by providing more culturally, spiritually and religiously competent health services to children in the health care system. A core objective of this project is to improve the health of Canadian children through gaining a better understanding of the ways in which social, cultural, environmental, factors determine health status. A series of research reports will be submitted to Canadian and international journals in psychology and education. The findings will be disseminated at academic and professional conferences.

## Appendix I

### RESOURCES IN MONTREAL AREA

CSSM – Central Agency (514) 842 – 5141

Information and Referral Centre of Greater Montreal (514) 527 – 1375

O.C.C.O.Q. (514) 737 – 4715

O.P .Q. (514) 738 – 1223

O.P.T.S.Q. (514) 731-3925

**Lakeshore General Hospital** 160 Stillview Road

Pointe Claire, Quebec H9R 2Z2 Physician's Referrals: (514) 630 – 2010

**Montreal Children's Hospital**

2300 Tupper Avenue Montreal, Quebec H3H 1P3

Children and Adolescent Psychiatry: (514) 412 – 4400

**St. Mary's Hospital Centre** 5300 Cote-des-Neiges Montreal, Quebec H3T 1Y3

Outpatient Department: (514) 345 – 3584

**Montreal General Hospital** 1547 Pine Avenue West Montreal, Quebec H3G 1B3

Short and Long Term Units: (514) 934 – 8013

**Royal Victoria Hospital** 687 Pine Avenue West Montreal, Quebec H3A 1A1

Outpatient Clinic: (514) 842 – 1231 (Ext. 34284 / 34530)

**Ste. Justine's Hospital**

3175 Cote-Sainte-Catherine Montreal, Quebec H3T 1C5 Psychiatry Department: (514) 345 – 4695

**Douglas Hospital**

6875 LaSalle Blvd. Verdun, Quebec H4H 1R3

Psychotherapy: (514) 761 – 6131 (Ext. 2606)

**Allan Memorial Institute** 1025 Pine Avenue West Montreal, Quebec H3A 1A1

Intensive Psychotherapy: (514) 842 – 1231 (Ext. 35532 / 34530)

Child Psychiatry: (514) 843 – 1619

**Jewish Family Services / Social Service Centre**

5151 Cote Saint-Catherine, Suite 320

Montreal, Quebec H3W 1M6 (514) 340 – 0000, Child Services: 514- 340- 8222

**McGill Psychoeducational and Counselling Clinic**

3700 McTavish, 1B Montreal, Quebec H3A 1Y2 (514) 398 – 4641

(514) 398 – 4641

**The Odyssey Zone: Center for Creative and Play Therapists: 514- 485- 6556**

**Kids Help Phone: 1-800-668-6868**

**Canadian Mental Health Service: 1-866-482-2724**



Appendix J

MCGILL STUDY ADVERTISEMENT

THE TALWAR CHILD  
DEVELOPMENT RESEARCH TEAM



*DO YOU HAVE A CHILD BETWEEN THE AGES OF 7-11?*



WE ARE DOING **EXCITING** RESEARCH  
EXAMINING THE ROLE OF SPIRITUALITY IN  
THE LIVES OF CHILDREN



THE STUDY TAKES 60-90 MINUTES

CHILDREN WILL RECEIVE A GIFT CARD TO INDIGO AND A SMALL  
PRIZE

**INTERESTED?**

CONTACT TALWAR RESEARCH @ 514-398-8059

	514 398 8059	talwarresearch@gmail.com
	514 398 8059	talwarresearch@gmail.com
	514 398 8059	talwarresearch@gmail.com
	514 398 8059	talwarresearch@gmail.com
	514 398 8059	talwarresearch@gmail.com
	514 398 8059	talwarresearch@gmail.com
	514 398 8059	talwarresearch@gmail.com
	514 398 8059	talwarsearch@gmail.com
	514 398 8059	talwarresearch@gmail.com

## Appendix L

## (INITIAL) CHILDREN'S SPIRITUAL LIVES QUESTIONNAIRE

*Please answer the following questions. There are no right or wrong answers. If you do not use the word G-d, please replace G-d with the term you use (examples: Higher Power, Jesus, Allah, Baha'u'llah).*

1. When I think about G-d I feel happy

Strongly Agree	Agree	I do not Agree or Disagree	Disagree	Strongly Disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

2. Praying to G-d makes me feel worse when I am sad

Strongly Agree	Agree	I do not Agree or Disagree	Disagree	Strongly Disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

3. I ask G-d for help

Strongly Agree	Agree	I do not Agree or Disagree	Disagree	Strongly Disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

4. G-d's miracles are fake

Strongly Agree	Agree	I do not Agree or Disagree	Disagree	Strongly Disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

5. G-d created the world

Strongly Agree	Agree	I do not Agree or Disagree	Disagree	Strongly Disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

6. People are without spirit

Strongly Agree	Agree	I do not Agree or Disagree	Disagree	Strongly Disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

7. G-d listen to my thoughts and wishes

Strongly Agree	Agree	I do not Agree or Disagree	Disagree	Strongly Disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

8. I think boys like G-d more

Strongly Agree	Agree	I do not Agree or Disagree	Disagree	Strongly Disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

9. When I pray to G-d or talk to G-d, I feel better about things

Strongly Agree	Agree	I do not Agree or Disagree	Disagree	Strongly Disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

10. People still feel alone and scared even if they talk or pray to G-d

Strongly Agree	Agree	I do not Agree or Disagree	Disagree	Strongly Disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

11. G-d helps me with my problems by giving me advice

Strongly Agree	Agree	I do not Agree or Disagree	Disagree	Strongly Disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

12. The idea that G-d can make wishes come true is wrong

Strongly Agree	Agree	I do not Agree or Disagree	Disagree	Strongly Disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

13. G-d is everywhere in the world and watches over everybody

Strongly Agree	Agree	I do not Agree or Disagree	Disagree	Strongly Disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

14. Some people think G-d lives with spirits of dead people, I think G-d lives alone

Strongly Agree	Agree	I do not Agree or Disagree	Disagree	Strongly Disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

15. G-d always knows what I feel even without talking

Strongly Agree	Agree	I do not Agree or Disagree	Disagree	Strongly Disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

16. I think it is bad that different people pray to different G-ds

Strongly Agree	Agree	I do not Agree or Disagree	Disagree	Strongly Disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

17. Whenever I want to feel better, I talk or pray to G-d

Strongly Agree	Agree	I do not Agree or Disagree	Disagree	Strongly Disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

18. If someone is sick, I would talk to my family about it instead of talking to G-d

Strongly Agree	Agree	I do not Agree or Disagree	Disagree	Strongly Disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

19. G-d helps me by making me think of new ideas

Strongly Agree	Agree	I do not Agree or Disagree	Disagree	Strongly Disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

20. Praying to G-d about wishes is a waste of time

Strongly Agree	Agree	I do not Agree or Disagree	Disagree	Strongly Disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

21. G-d created all the people in the world and knows all of them

Strongly Agree	Agree	I do not Agree or Disagree	Disagree	Strongly Disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

22. It is impossible to live with G-d after you die

Strongly Agree	Agree	I do not Agree or Disagree	Disagree	Strongly Disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

23. I think that G-d listens to everyone

Strongly Agree	Agree	I do not Agree or Disagree	Disagree	Strongly Disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

24. I am sad that some people do not believe in G-d

Strongly Agree	Agree	I do not Agree or Disagree	Disagree	Strongly Disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

25. People have to make themselves happy without G-d

Strongly Agree	Agree	I do not Agree or Disagree	Disagree	Strongly Disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

26. I would rather talk to my family and friends about being sad instead of talking to G-d

Strongly Agree	Agree	I do not Agree or Disagree	Disagree	Strongly Disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

27. G-d helps me by making me feel strong

Strongly Agree	Agree	I do not Agree or Disagree	Disagree	Strongly Disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

28. Some people thank G-d for things, but I would never do that

Strongly Agree	Agree	I do not Agree or Disagree	Disagree	Strongly Disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

29. G-d created the world and everything in it

Strongly Agree	Agree	I do not Agree or Disagree	Disagree	Strongly Disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

30. Everyone has a body, but spirits are fake

Strongly Agree	Agree	I do not Agree or Disagree	Disagree	Strongly Disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

31. G-d listens all the time

Strongly Agree	Agree	I do not Agree or Disagree	Disagree	Strongly Disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

32. I feel bad when people make jokes about G-d

Strongly Agree	Agree	I do not Agree or Disagree	Disagree	Strongly Disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

33. I feel unhappy when I think about G-d

Strongly Agree	Agree	I do not Agree or Disagree	Disagree	Strongly Disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

34. I pray to G-d or talk to G-d when I feel sad or worried about something

Strongly Agree	Agree	I do not Agree or Disagree	Disagree	Strongly Disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

35. There is no point in asking G-d for help because you have to do things by yourself

Strongly Agree	Agree	I do not Agree or Disagree	Disagree	Strongly Disagree
----------------	-------	----------------------------	----------	-------------------

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
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36. G-d can do miracles—G-d can cure people and do things that are not humanly possible

Strongly Agree	Agree	I do not Agree or Disagree	Disagree	Strongly Disagree
----------------	-------	----------------------------	----------	-------------------

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
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37. The world was created by accident

Strongly Agree	Agree	I do not Agree or Disagree	Disagree	Strongly Disagree
----------------	-------	----------------------------	----------	-------------------

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
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38. I think that people have a soul or a spirit that lives inside them

Strongly Agree	Agree	I do not Agree or Disagree	Disagree	Strongly Disagree
----------------	-------	----------------------------	----------	-------------------

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
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39. G-d will never know my thoughts and wishes

Strongly Agree	Agree	I do not Agree or Disagree	Disagree	Strongly Disagree
----------------	-------	----------------------------	----------	-------------------

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
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40. I think girls like G-d more

Strongly Agree	Agree	I do not Agree or Disagree	Disagree	Strongly Disagree
----------------	-------	----------------------------	----------	-------------------

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
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41. Talking to G-d about my problems makes me feel worse

Strongly Agree	Agree	I do not Agree or Disagree	Disagree	Strongly Disagree
----------------	-------	----------------------------	----------	-------------------

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
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42. G-d keeps people company when they feel sad and lonely

Strongly Agree	Agree	I do not Agree or Disagree	Disagree	Strongly Disagree
----------------	-------	----------------------------	----------	-------------------

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
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43. I can solve problems without G-d helping me

Strongly Agree	Agree	I do not Agree or Disagree	Disagree	Strongly Disagree
----------------	-------	----------------------------	----------	-------------------

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
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44. I make wishes to G-d and the wishes come true

Strongly Agree	Agree	I do not Agree or Disagree	Disagree	Strongly Disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

45. It is impossible for G-d to watch over everybody

Strongly Agree	Agree	I do not Agree or Disagree	Disagree	Strongly Disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

46. When people die, their soul or spirit stays alive and lives with G-d

Strongly Agree	Agree	I do not Agree or Disagree	Disagree	Strongly Disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

47. G-d will never know what I am thinking to myself

Strongly Agree	Agree	I do not Agree or Disagree	Disagree	Strongly Disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

48. It is okay that people in different countries pray to different G-ds

Strongly Agree	Agree	I do not Agree or Disagree	Disagree	Strongly Disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

49. Talking or praying to G-d makes me feel worse about things

Strongly Agree	Agree	I do not Agree or Disagree	Disagree	Strongly Disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

50. I pray to G-d or talk to G-d when someone is sick or when someone dies

Strongly Agree	Agree	I do not Agree or Disagree	Disagree	Strongly Disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

51. I have my own thoughts and ideas without G-d's help

Strongly Agree	Agree	I do not Agree or Disagree	Disagree	Strongly Disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

52. A reason I pray or talk to G-d is to wish for things

Strongly Agree	Agree	I do not Agree or Disagree	Disagree	Strongly Disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



53. There are too many people in the world for G-d to know all of them

Strongly Agree	Agree	I do not Agree or Disagree	Disagree	Strongly Disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

54. I think spirits live with G-d

Strongly Agree	Agree	I do not Agree or Disagree	Disagree	Strongly Disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

55. There are too many people in the world for G-d to listen to

Strongly Agree	Agree	I do not Agree or Disagree	Disagree	Strongly Disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

56. I feel okay knowing that some people do not believe in G-d

Strongly Agree	Agree	I do not Agree or Disagree	Disagree	Strongly Disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

57. G-d can make people feel better

Strongly Agree	Agree	I do not Agree or Disagree	Disagree	Strongly Disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

58. I pray to G-d or talk to G-d when I feel sad

Strongly Agree	Agree	I do not Agree or Disagree	Disagree	Strongly Disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

59. I would never ask G-d to help me feel strong

Strongly Agree	Agree	I do not Agree or Disagree	Disagree	Strongly Disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

60. I pray to G-d or talk to G-d because I want to thank him for all of the good things in my life

Strongly Agree	Agree	I do not Agree or Disagree	Disagree	Strongly Disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

61. People created the world and everything in it

Strongly Agree	Agree	I do not Agree or Disagree	Disagree	Strongly Disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

62. Everyone has a body and a spirit

Strongly Agree	Agree	I do not Agree or Disagree	Disagree	Strongly Disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

63. G-d only listens to people when G-d feels like it

Strongly Agree	Agree	I do not Agree or Disagree	Disagree	Strongly Disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

64. Some people make jokes about G-d and that's okay

Strongly Agree	Agree	I do not Agree or Disagree	Disagree	Strongly Disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

## APPENDIX M

CHILDREN'S SPIRITUAL LIVES				
<p><i>Please answer the following questions. There are no right or wrong answers. If you feel that you cannot answer a question, you can skip it, but make sure you write SKIP next to it. Just try your best. If you do not use the word G-d, please replace G-d with the term you use (examples: Jesus, Allah, Baha'u'llah).</i></p>				
1. I pray to G-d or talk to G-d when I feel sad				
Strongly Agree  O	Agree  O	I do not Agree or Disagree  O	Disagree  O	Strongly Disagree  O
2. There is no point in asking G-d for help because you have to do things by yourself				
Strongly Agree  O	Agree  O	I do not Agree or Disagree  O	Disagree  O	Strongly Disagree  O
3. I ask G-d for help				
Strongly Agree  O	Agree  O	I do not Agree or Disagree  O	Disagree  O	Strongly Disagree  O
4. People have to make themselves happy without G-d in their life				
Strongly Agree  O	Agree  O	I do not Agree or Disagree  O	Disagree  O	Strongly Disagree  O
5. G-d helps me by making me feel strong				
Strongly Agree  O	Agree  O	I do not Agree or Disagree  O	Disagree  O	Strongly Disagree  O

6. I can solve my own problems without G-d's help				
Strongly Agree  O	Agree  O	I do not Agree or Disagree  O	Disagree  O	Strongly Disagree  O
7. I pray to G-d or talk to G-d when I feel sad or worried about something				
Strongly Agree  O	Agree  O	I do not Agree or Disagree  O	Disagree  O	Strongly Disagree  O
8. I have my own thoughts and ideas without G-d's help				
Strongly Agree  O	Agree  O	I do not Agree or Disagree  O	Disagree  O	Strongly Disagree  O
9. I pray to G-d or talk to G-d because I want to thank G-d for all of the good things in my life				
Strongly Agree  O	Agree  O	I do not Agree or Disagree  O	Disagree  O	Strongly Disagree  O
10. G-d listens to my thoughts and wishes				
Strongly Agree  O	Agree  O	I do not Agree or Disagree  O	Disagree  O	Strongly Disagree  O
11. G-d can make people feel better				
Strongly Agree  O	Agree  O	I do not Agree or Disagree  O	Disagree  O	Strongly Disagree  O
12. G-d always knows how I feel, even without talking				
Strongly Agree  O	Agree  O	I do not Agree or Disagree  O	Disagree  O	Strongly Disagree  O

13. G-d keeps people company when they feel sad and lonely				
Strongly Agree  O	Agree  O	I do not Agree or Disagree  O	Disagree  O	Strongly Disagree  O
14. When I think about G-d, I feel happy				
Strongly Agree  O	Agree  O	I do not Agree or Disagree  O	Disagree  O	Strongly Disagree  O
15. I make wishes to G-d and the wishes come true				
Strongly Agree  O	Agree  O	I do not Agree or Disagree  O	Disagree  O	Strongly Disagree  O
16. I pray to G-d or talk to G-d when someone is sick or when someone dies				
Strongly Agree  O	Agree  O	I do not Agree or Disagree  O	Disagree  O	Strongly Disagree  O
17. G-d is everywhere in the world and watches over everybody				
Strongly Agree  O	Agree  O	I do not Agree or Disagree  O	Disagree  O	Strongly Disagree  O
18. G-d will never know what I am thinking to myself				
Strongly Agree  O	Agree  O	I do not Agree or Disagree  O	Disagree  O	Strongly Disagree  O
19. I think G-d listens to everyone				
Strongly Agree  O	Agree  O	I do not Agree or Disagree  O	Disagree  O	Strongly Disagree  O

20. Every person has a body and something inside them, like a soul or spirit				
Strongly Agree  O	Agree  O	I do not Agree or Disagree  O	Disagree  O	Strongly Disagree  O
21. There are too many in the world for G-d to know all of them				
Strongly Agree  O	Agree  O	I do not Agree or Disagree  O	Disagree  O	Strongly Disagree  O
22. There are too many people in the world for G-d to listen to				
Strongly Agree  O	Agree  O	I do not Agree or Disagree  O	Disagree  O	Strongly Disagree  O
23. G-d created all the people in the world and knows all of them				
Strongly Agree  O	Agree  O	I do not Agree or Disagree  O	Disagree  O	Strongly Disagree  O
24. It is impossible for G-d to watch over everybody				
Strongly Agree  O	Agree  O	I do not Agree or Disagree  O	Disagree  O	Strongly Disagree  O
25. People do not have a soul or a spirit				
Strongly Agree  O	Agree  O	I do not Agree or Disagree  O	Disagree  O	Strongly Disagree  O
26. When I want to feel better, I talk or pray to G-d				
Strongly Agree  O	Agree  O	I do not Agree or Disagree  O	Disagree  O	Strongly Disagree  O

27. I think that people have something like a soul or a spirit, that lives inside them.				
Strongly Agree  O	Agree  O	I do not Agree or Disagree  O	Disagree  O	Strongly Disagree  O
28. G-d helps me by giving me advice				
Strongly Agree  O	Agree  O	I do not Agree or Disagree  O	Disagree  O	Strongly Disagree  O
29. G-d helps me by making me think of new ideas				
Strongly Agree  O	Agree  O	I do not Agree or Disagree  O	Disagree  O	Strongly Disagree  O
30. When I pray to G-d or talk to G-d I feel better about things				
Strongly Agree  O	Agree  O	I do not Agree or Disagree  O	Disagree  O	Strongly Disagree  O
31. Everyone has a body, but having a soul or a spirit is fake				
Strongly Agree  O	Agree  O	I do not Agree or Disagree  O	Disagree  O	Strongly Disagree  O

**Appendix N**

Research Ethics Board Office  
James Administration Bldg.  
845 Sherbrooke Street West, Rm 429  
Montreal, QC H3A 0G4

Tel: (514) 398-6831  
Fax: (514) 398-4644  
Website: [www.mcgill.ca/research/researchers/compliance/human/](http://www.mcgill.ca/research/researchers/compliance/human/)

**Research Ethics Board III**  
**Certificate of Ethical Acceptability of Research Involving Humans**

**REB File #:** 242-1213

**Project Title:** Spirituality and its relationship with social-emotional well-being

**Principal Investigator:** Kelsey Moore      **Department:** Educational&Counselling Psychology

**Status:** Ph.D. student      **Supervisor:** Prof. Victoria Talwar

**Approval Period:** February 18, 2014 – February 17, 2015

The REB-III reviewed and approved this project by full board review in accordance with the requirements of the McGill University Policy on the Ethical Conduct of Research Involving Human Participants and the Tri-Council Policy Statement: Ethical Conduct For Research Involving Humans.

Lynda McNeil  
Manager, Research Ethics

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\* All research involving human participants requires review on at least an annual basis. A Request for Renewal form should be submitted 2-3 weeks before the above expiry date.

\* When a project has been completed or terminated a Study Closure form must be submitted.

\* Should any modification or other unanticipated development occur before the next required review, the REB must be informed and any modification can't be initiated until approval is received.



## Appendix O



July 24, 2014

Dr. Linda Moxley Haegert  
MUHC - MCH  
4018 Ste Catherine Street

**Re: MUHC Authorization to Conduct Human Subjects Research 13-342-PED**

Dear Dr. Moxley Haegert:

We are writing to confirm that the study titled " *Examining the role of spirituality in the lives of pediatric cancer survivors* " was submitted for all institutional reviews required by McGill University Health Centre policy.

The PED Research Ethics Board (REB) has notified us that ethical approval to conduct your study has been provided.

Please refer to the MUHC Study Code **13-342-PED** in all future correspondence relating to this study.

**Important Note:**

You are required to advise the MUHC once the study has been initiated. Please complete the Study Status Report through the eReviews system to indicate the date the study became active.

In accordance with RI MUHC Policies (SOP-CR022), it is the investigator's responsibility to ensure that staff involved in the study has been certified to conduct clinical research. Research staff can register on the RI MUHC portal under the Clinical Research section. Should you have any questions, please do not hesitate to contact us at [qaclinicalresearch@muhc.mcgill.ca](mailto:qaclinicalresearch@muhc.mcgill.ca).

On behalf of the MUHC, we wish you every success with the conduct of the research.

Sincerely,

A handwritten signature in black ink, appearing to read 'Miguel Burnier'.

Miguel Burnier, MD, PhD  
General Director for Clinical Research  
The Research Institute of the McGill University Health Centre

Enclosures

cc: RI MUHC Study File  
REB Study File