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Spirituality and Depression in Parents with Children in Oncology or Hematology Treatment

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Abstract

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M.A., Lindenwood University, 1999
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Dissertation Submitted in Partial Fulfillment
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Abstract

The psychological burden of cancer treatment affects not only child patients but also their parents. There is extensive literature on the positive influence of spirituality on the cancer patient. But there is a gap in the literature on the potential healing influence of spirituality on the parent of the cancer or hematology patient. The purpose of this study was to examine the relationship between spirituality and parents' levels of depression and anxiety during their child's hematological or oncology treatment. Using the transtheoretical model of change, a purposive sample of 48 parents of children undergoing cancer or hematology treatment completed a demographic form and the Daily Spiritual Experience Scale (DSES), which was used to divide participants into two groups, spiritual and nonspiritual, based on their median scores. Participants then completed the Beck Depression Inventory (BDI) and the Beck Anxiety Inventory (BAI), which were used as indices of psychological resiliency. These data were analyzed using independent samples *t* tests and ANOVA to determine if scores on the DSES predicted a difference between groups on both the BDI and the BAI. No significant effects were found. In order to clearly identify the role spirituality plays in mediating resiliency for coping with a life-threatening illness, more precise operational definitions and measures for the construct of psychological resiliency are needed. Implications for positive social change include a better understanding of the role spirituality plays in improved psychological resilience in times of medical crisis. Implementing such programs will lead to social change in the manner in which we counsel and approach parents facing this crisis.

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Dedication

This dissertation is dedicated to the many, many parents that have had to endure one of the greatest challenges of their lives. Fighting cancer and blood related illnesses is extremely overwhelming. Thank you for fighting for your children, fighting for your family, and fighting for a cure.

This dissertation is also dedicated to the entire staff at Pediatric Oncology and Hematology. The devotion and commitment of Drs. Bergamini and Hanson is indescribable. In addition, the sacrifice of Jill Turec for every child and every family that she encounters is beyond words. Thank you for being a warrior for all of them. You are an inspiration to us all!

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Most importantly, I would like to proverbially drop to my knees and give the most humble thanks and gratitude to my family. Julie, you have been my greatest fan, my greatest encourager, and my best friend. Mitch and Evan, thank you for your support. You both have encouraged me from day one. I could not have done this without your patience and tolerance of me. Lastly, my mom, in-laws, brothers, sisters, nieces, and nephews have all encouraged me along the way. I am greatly blessed!

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CHAPTER 1: Introduction to the study

Introduction

Everyday, parents all over the world learn that their child may have cancer. There becomes a confluence of emotions for parents to come to terms with their own emotions and the logical process of getting help for their child. Parents are typically referred by their pediatrician to a pediatric specialist. These physicians treat illnesses such as sickle cell anemia, thalassemia, leukemia, lymphoma, and bleeding and immunodeficiency disorders such as hemophilia and combined immunodeficiency syndrome or autoimmune idiopathic thrombocytopenic purpura (Dana-Farber, 2009). In addition, these same specialists are trained in solid tumors like brain tumors, soft-tissue tumors, and bone tumors (Dana-Farber, 2009). Due to the complexity for physicians to understand both pediatric medicine and blood-related illnesses it became necessary for pediatricians to specialize in both oncology and hematology, as there can be a very natural relationship between the two disciplines. According McBride (2002), many times physicians are the first professionals to recognize the psychological distress of their patients ,. When it comes to the traumatic distress of chronic illnesses and a diagnosis of cancer, physicians find that depression and anxiety are very common . But this can become an opportunity to inquire about a family or child's spiritual beliefs because, according to McBride (2002), found that people who are spiritual can refocus their internal and emotional priorities, which, in turn can have an immediate impact on depression and anxiety. Cardella and Friedlander (2004) referred to this refocusing as spiritual coping and claimed that it could offer a sense of security. This study will investigate how spirituality

contributes to building psychological resilience (self-evaluated levels of depression and anxiety). If early detection of medical problems is vital then it might be just as beneficial for parents to understand how their own spiritual awareness may be an early detection of their own psychological wellness (Cardella & Friedlander, 2004).

The staff at the American Cancer Society ([ACS]; 2009) recognizes the emotional distress that any parent can experience on hearing that their child is diagnosed with cancer. Common reactions include shock, denial, anxiety, guilt, depression, and anger, all of which can have a range of intensity, consistency, and duration (ACS, 2009). Seeking guidance from spiritual advisors, such as pastors, preachers, or rabbis, can improve overall emotional functioning (ACS, 2009). Understanding what influences this overall emotional functioning is difficult. As will be discussed later, parents are faced with variables such as (a) the initial shock of an oncology and hematological diagnosis and (b) the ongoing emotional journey both during and after treatment (Norberg, Lindbald, & Boman, 2006).

Background

Due to advances in scientific research and in the evolution of medical technology, children and adolescents with cancer and blood related illnesses can live and prosper as adults is a reality. What complicates this reality is the understanding that living with a chronic illness or the fear that a chronic illness will reappear can leave parents in a state of perpetual uncertainty (Cardella & Friedlander, 2004). It is this uncertainty that can add to a parent's levels of depression and anxiety. It is commonly believed that individuals handle the diagnosis and treatment of cancer and blood-related illnesses

differently (Beck, 2007; Cardella & Friedlander, 2004; Sormanti & August, 1997). The scholarly literature is consistent about the role spirituality plays in helping people cope with, and accept, these illnesses. There is considerable research on the role of spirituality in adults with cancer (Cole, Hopkins, Tisak, Steel, & Carr, 2008) and on how parents deal with the death of a child diagnosed with cancer (Sormanti & August). However, there is little research on how parents deal with their child's diagnosis and treatment of cancer or blood-related illnesses (Cardella & Friedlander, 2004).

Pargament, Cole, Van de Creek, Belavich, Brant, and Perez, (2000) investigated how spirituality has influenced traumatic events in individuals' lives, including postwar integration into society, natural disasters, and healthcare issues. Five areas of relevance for the use of spirituality were identified: (a) spiritual collaboration, that is, seeking control in problem solving through a partnership with God; (b) religious surrender, that is,turning control over to God; (c) direct intercession, that is, the request for divine intervention through miraculous healing or miracles; (d) passive spiritual deferral, that is, waiting on God's timing; and, (e) religious coping, that is,the belief that God will provide the tools and resources needed to solve problems. This study will continue the work of Pargament et al. by trying to understand how spirituality contributes to building psychological resilience (self-evaluated levels of depression and anxiety).

Statement of the Problem

The psychological burden of cancer treatment affects not only child patients but also their parents. There is extensive literature on the positive influence of spirituality on the cancer patient (Cole, Hopkins, Tisak, Steel, & Carr, 2008). But there is a gap in the

literature on the potential healing influence of spirituality on the parent of the cancer or hematology patient. This study sought to better understand the overall role of spirituality and whether it had an effect on depression and anxiety with respect to gender of parent and length of treatment.

Nature of the Study

For the purpose of this study, the construct of spirituality was defined by the Daily Spiritual Experience Scale (DSES); participants that scored above the mean were defined as spiritual; those participants that scored below the mean were categorized as non-spiritual (B. Robbins, personal communication, August 16, 2010). This quantitative study will be rooted in the transtheoretical model of change and the role it plays in understanding attitudes about medical beliefs (Cancer Prevention and Research Center, 2008).

Purpose of the Study

The purpose of this study was to determine whether or not spirituality has an effect on depression and anxiety in parents whose children are undergoing either oncology or hematological treatment. After taking the Daily Spiritual Experience Scale (DSES), parents were divided into two groups. The psychological factors identified will include a comparison of test scores on the Beck Depression Inventory and the Beck Anxiety Inventory

Research Questions and Hypotheses

The following research questions and hypotheses were developed from the review of current literature on spirituality and its role with individuals experiencing traumatic events relative to oncology and hematology treatment.

Research Question 1

What is the nature of the relationship between parents' spirituality level in regards to levels of depression and anxiety as measured by the Beck Depression Inventory and Beck Anxiety Inventory for parents whose child is undergoing oncology and/or hematological treatment?

Null Hypothesis #1

There will be no difference in depression and anxiety scores among the two groups of parents.

Non-Directional Hypothesis #1

There will be a difference in depression and anxiety scores among the two groups of participants.

Research Question #2

Does duration of treatment (DOT) have an effect on parents' depression and anxiety as measured by the Beck Depression Inventory and Beck Anxiety Inventory?

Null Hypothesis #2

DOT will have no effect on parents' depression and anxiety as measured by the Beck Depression Inventory and Beck Anxiety Inventory.

Non-Directional Hypothesis #2

DOT will have an effect on parents' depression and anxiety as measured by the Beck Depression Inventory and Beck Anxiety Inventory.

Research Question #3

Does gender of parent have an effect on parents' depression and anxiety as measured by the Beck Depression Inventory and Beck Anxiety Inventory?

Null Hypothesis #3

Gender of parent will have no effect on parents' depression and anxiety as measured by the Beck Depression Inventory and Beck Anxiety Inventory.

Non-Directional Hypothesis #3

Gender of parent will have an effect on parents' depression and anxiety as measured by the Beck Depression Inventory and Beck Anxiety Inventory.

Research Question #4

Does parents' spiritual level and duration of treatment have an effect on parents' depression and anxiety as measured by the Beck Depression Inventory and Beck Anxiety Inventory?

Null Hypothesis #4

Parents' spiritual level and duration of treatment will have no effect on parent's depression and anxiety as measured by the Beck Depression Inventory and Beck Anxiety Inventory.

Non-Directional Hypothesis #4

Parents' spiritual level and duration of treatment will have an effect on parents' depression and anxiety as measured by the Beck Depression Inventory and Beck Anxiety Inventory.

Research Question #5

Does spiritual level and gender of parent have an effect on parents' depression and anxiety as measured by the Beck Depression Inventory and Beck Anxiety Inventory?

Null hypothesis #5

Spiritual level and gender of parent will have no effect on parent's depression and anxiety as measured by the Beck Depression Inventory and Beck Anxiety Inventory.

Non-Directional Hypothesis #5

Spiritual level and gender of parent will have an effect on parents' depression and anxiety as measured by the Beck Depression Inventory and Beck Anxiety Inventory.

Theoretical Framework

The transtheoretical model of change (TTM) is designed primarily for assessing the ability for behavioral change regarding one's health (Cancer Prevention and Research Center, 2008). This model helps identify the stages of change and offers a blueprint for future change. The TTM focuses on a person's ability to accept a situation and the momentum it takes to change perspective of the situation (Cancer Prevention and

Research Center, 2008). The purposeful position of change takes place on an emotional, cognitive level, and behavioral level. The concept of change involves a dimension of time (Cancer Prevention and Research Center, 2008). The change that takes place over time, in regards to psychological resilience, can be positive or negative (Cancer Prevention and Research Center, 2008). Spirituality is also a construct that evolves over time that can take place on an emotional, cognitive, and behavioral level.

Researchers have defined the construct of spirituality in a number of ways. Marler and Hadaway (2002) and Mytko and Knight (1999) suggested that often times individuals use the terms religion and spirituality synonymously. It is important to delineate some differences between the two terms in order to focus on the direction of what spirituality means in this dissertation. Mytoko and Knight noted in a Gallop poll that 95% of Americans, "believe in God" (p. 440). It is also important to understand that there are major differences in believing in God and the interpersonal nature of spirituality. Mytoko and Knight wrote that spirituality tends to encompass a sense of "wholeness, transcendence, connection, joy, and peace" (p. 440). Marler and Hadaway found that individuals describing themselves as being religious were more likely to be involved in an organized faith and participating in consistent activities such as worship, study, and socializing. Spirituality is more thoroughly defined in chapter 2.

For the purpose of this study, participants took the Daily Spiritual Experience Scale (DSES), parents were then divided into two groups. Based on the median score of the DSES, participants who scored above the median were placed in the one category while participants who score below the median were placed in the other category.

Definition of Terms

Operational definitions of terms, jargon, and special word uses are provided:

Agnostic: An agnostic is one who is not committed to believing in either the existence or the nonexistence of God or a god (Edwords, 2007).

Atheist: An atheist is an individual or group that has a disbelief in the existence of deity (Smith-Stoner, 2007).

Autoimmune Idiopathic Thrombocytopenic Purpura (ITP): TP is an autoimmune disorder that causes low platelet counts. In addition, with this disorder the body produces antibodies that fight against his or her own tissue (Kuga et al., 2001).

Buddhism: Buddhism is a religious teaching from Buddha concentrating on the natural suffering in life and self-purification from mental and moral self-purification (Keown, 2005).

Christianity: Christianity is a religion based on the teachings of Jesus Christ, derived from the Bible as a holy and inspired written word of God, and comprised of Easter and Roman Catholic and Protestant parishioners (Gregory, 2008).

Hemophilia: Hemophilia is a deficiency in coagulation of factor IX in the blood that results in prolonged bleeding (Pritchard & Page, 2008).

Hinduism: Hinduism is the dominant religion of India focusing on dharma and the results of ritual and social observances and often mystical practices (Lahiri & Bacus, 2004).

Islam: Islam is a Muslim religion with the belief in Allah as God and as Muhammad as a prophet (Dien, 2007).

Judaism: Judaism is a religion developed by the ancient Hebrews based on one true God with whom was revealed to iconic individuals such as Abraham and Moses. These religious values have been captured on a religious book called the Torah (Rainbow, 2008).

Leukemia: Leukemia is cancer of the blood and bone marrow (Traunecker, Mallucci, Grundy, Pizer, & Saran, 2008).

Lymphoma: Lymphoma is cancerous tumors within the lymphoid system (Book, 2008).

Necrotic: Necrotic is a word synonymous with death. In other words, necrotic tissue is dead tissue (Nusem & Morgan, 2006).

Pediatric Oncologist/Hematologist: A pediatric hematologist/oncologist is a specialist who treats children and adolescents with blood diseases or cancer. They are specially trained to work with young patients as well as in both hematology (the study of blood) and oncology (the study of cancer) in children. Pediatric hematologist/oncologists are medical doctors who have completed 4 years of medical school. In addition, they must have: (1) completed 3 years of residency training in pediatrics and (2) completed 3 years of specialized training in pediatric hematology/oncology (Dana-Farber, 2009).

Psychological resiliencies: Psychological resilience refers to an individual's capacity to withstand stressors and not manifest psychology dysfunction, such as mental illness or persistent negative mood (Neill, 2006). In addition, psychological resiliencies were defined by the following delineation: The Beck Depression Inventory interprets depression using the following scoring: A grand sum of between a 17-29 indicates

moderate depression while a grand sum of between a 30-63 indicates severe depression. The Beck Anxiety Inventory interprets anxiety using the following scoring: A grand sum of between a 22-35 indicates moderate anxiety while a grand sum that exceeds 36 indicates severe anxiety. For the sake of this study the sum from the Beck Depression Inventory scores and Beck Anxiety Inventory scores were combined. A combined grand sum of between a 0- 37 indicated psychological resilience.

Severe Combined Immunodeficiency Syndrome: This syndrome is a combined deficiency of the body's two major factors: antibodies and T-cells (Cossu et. al., 2002).

Sickle cell Anemia: Sickle cell anemia is a genetic disorder, primarily affecting African Americans, comprised of irregular formed hemoglobin cells (a type of protein in red blood cells that carries oxygen to tissues within the body) causing tissue and organ damage (Day, 2004).

Thalassemia: Thalassemia is a genetic disorder primarily affecting individuals of African, Middle East and Southeast Asia. These individuals typically experience compromised hemoglobin cells causing chronic anemia (low red blood cell count)(Rahim, Kaikhaei, Zandian & Hoseini, 2008).

Assumptions and Limitations

Based on informed consent letters that were signed by each participant it is important to qualify the following assumptions: First, it was assumed that each participant willingly engaged in each of the three questionnaires – Daily Spiritual Experience Scale (Underwood, 2006), Beck Depression Inventory (Arbisi, 1993) and Beck Anxiety Inventory (Dowd, 2004) and that their responses would be truthful and an

accurate representation of themselves. Secondly, participants who initially agreed to participate in the study but found the ongoing questions too difficult to complete due to the emotional investment and connection to their own personal situations were encouraged to decline any further participation without penalty. Every participant that started the study completed the study. Since there were no participants that asked to be excluded or asked if they could withdraw from this study, it is assumed that all participants were willing participants. Lastly, it is also assumed, based on prior reports, implementations, and current uses, that the two measures of testing (BDI & BAI) were appropriately understood by the participants.

The bounds of this study are limited to that of the defined population. The ability to generalize the design of this study to use in other populations is surely limited. The current versions of the BDI and BAI are for adult use only. There are versions of the BDI for adolescent use but were not used in this study. The use of the Daily Spiritual Experience Scale is for adults. Another limitation is the inability to control for situational factors (e.g., any number of events that could be taking place at the time of participation). One of these situation factors is socioeconomic status (SES). The weak economy at the time of data collection, paired with SES, could have directly influenced levels of stress and anxiety (Feldman & Steptoe, 2004). A second limitation was not knowing the existing support system for each participant, the healthiness of that support system and its effect on level of depression and anxiety. Other limitations and confounding variables were ethnicity, number of additional children parents have, and other compounding

health related issues within the family. These are discussed in greater length in chapter 5 as recommendations for further study.

Significance

As discussed in chapter 2, many factors lead to stress in both pediatric-oncology patients and their parents. In most cases, parents are the frontline defenders and encouragers for their children who are going through treatment. Parents have an amazing role to set the tone for onset of their child's treatment. It is important to understand what contributes to a parent's increased or decreased ability to handle the ongoing stressors they are enduring while their children go through their treatment. The more parents understand their own psychological makeup, the more effective they can become in meeting their child's emotional and psychological needs. This study will contribute to scholarly research in helping to identify if spiritual individuals are more psychologically resilient compared to nonspiritual individuals. If so, the spiritual identity of parents needs to be better understood in order to help educate individuals regarding spirituality as a valid complimentary and alternative form of medicine.

Summary

Treating pediatric cancer and blood-related illnesses encompasses many different factors: ongoing research, the use of leading-edge technologies, financial constraints, and sacrifice of many different healthcare professionals. One constant in the aforementioned factors is the idea that individuals and families who are being treated have no influence on the growth and development of those factors. The findings of this study will promote positive social change by investigating one attribute in which individuals do have control

over, that is, the ability to produce more insight into the relationship between spirituality and its possible effect on levels of depression and anxiety for the parent while their child undergoes oncology or hematological treatment.

Chapter 2 looks at a highly underrepresented population relative to pediatric cancer and oncology treatment – the parent. In addition, the physical, emotional, and mental effects on parents are identified. Spirituality as a construct is better understood. Lastly, the need for normalcy in a parent's life is identified

Chapter 3 describes the methodology used to study all of the research questions; discusses the use of a factorial ANOVA as a valid means to analyze the possible relationship between spirituality and psychological factors, such as depression and anxiety; includes a full description of the setting and sample population, background on measurements, data collection and analysis, and ethical considerations.

Chapter 4 will describe the results of the study and outline the specific statistical results and their correlation to the original research questions.

Chapter 5 will summarize the interpretation of the findings, the implications for social change, limitations, and the need for further recommendations for ongoing research.

CHAPTER 2: LITERATURE REVIEW

Introduction

The purpose of this literature review is to emphasize past research in the areas of spirituality, a better understanding of the physical, emotional, mental, and relational needs of parents as they watch their child go through oncology or hematology treatment, and the importance of normalcy in a family's life. There is a tremendous amount of research in the role of spirituality in cancer patients (Kaplar, Wachholtz, & O'Brien, 2004; Ramondetta & Sills, 2004). However, there is a lack of information on how traumatic medical events affect parents and the role spirituality plays on the parent of a child undergoing treatment (Nolan et al., 2006). How a parent responds to his or her child's treatment is crucial in not only how it effects the parent but also in how the child undergoing treatment perceives the systemic nature of his support system. It can be a delicate emotional and relational dance between the parent and child (Krupski et al., 2006).

Literature Search Strategy

The peer-reviewed articles used for this literature review were obtained through the following electronic databases: Academic Search Premier, PsycARTICLES, PsycINFO, and SocINDEX. The following keywords were used: Spirituality and cancer, kids with cancer, cancer and psychological distress, parents of kids with cancer, complimentary and alternative forms of medicine, religion versus spirituality,

This chapter sufficiently addresses the importance of understanding the psychological stressors that parents go through while their children are being treated for cancer or blood-related illnesses. Parents as a highly underrepresented population relative

to pediatric cancer and oncology treatment is addressed. Spirituality as a construct is better understood. The need for normalcy in a parent's life is identified. Lastly, the traumatic nature of this experience is reviewed with a more thorough understanding of the physical effects, emotional effects, mental effects, and relational effects of this journey.

The foundation of this research was established through the theoretical framework of the transtheoretical model of change (TMC) (Cancer Prevention and Research Center, 2008). The premise of this model emphasizes the importance of understanding how traumatic medical-events can affect individuals on an emotional, cognitive, and behavioral level. The TMC focuses on one's ability to accept a situation and the momentum it takes for one to change his or her perspective of the situation. There is no doubt that the concept of change involves a dimension of time. The change that takes place over time, in regards to psychological resiliencies, can either be positive or negative. Clearly, the desire is of the former position while the TMC looks to identify either.

Understanding the Importance of Spirituality

Oftentimes, spirituality plays an extremely important role in giving meaning, offering comfort, and encouraging hope in everyday life experiences (Oman, Flinders, & Thoresen; McConnell, 2008). A recent poll by Gallup (as cited in Oman, Flinders & Thoresen, 2008) indicated the importance of spirituality: 32% of those polled said that religion was "extremely important" while another 32% indicated it was "very important." This same research by Gallup reported that 80% of U.S. college students have an interest

in spirituality while searching for its meaning in their lives. These findings have led researchers, over the most recent past, to consider the importance of assimilating spirituality into other areas of one's life (Oman, Flinders, & Thoresen, 2008). Because of the importance that spirituality has on the human spirit it has been suggested that spiritual and religion affiliations should be assessed even in medical care (McConnell, 2008). Therefore, even the Joint Commission on Accreditation of Health Care Organizations (JCAHO) mandates a spirituality and/or religious assessment for individuals admitted to the hospital (McConnell, 2008).

Towards an Understanding of Spirituality

Bateson (as cited in Piedmont, 2001) believed that the study of spirituality was at least 30 years behind what was happening in the field, and researchers have offered a diverse range of definitions of this construct. By contrast, in most scholarly situations individuals can typically agree on one definition of religion (Koenig, 2009). Koenig states that religion is generally believed to be more about, "beliefs, practices, and rituals related to the sacred." (p. 284). Koenig (2009) continues by adding that religion, in most situations, is an organized event that is practiced in a community setting. Spirituality is something completely different from religion. Spirituality is vital to human nature, an almost symbiotic relationship with all other forms of life (Moberg, 2008). Spirituality is more of a personal decision made by individuals on their own terms, "free from allegiance to religion." (p. 285). Due to the personal nature of spirituality it is typically a part of one's expression of the way they think and feel (Krok, 2008). Krok goes on to make it perfectly clear that spirituality is not a dichotomous thing: it is not like one is

either spiritual or not spiritual. Underwood (2006) agrees and goes on to add that spirituality has an evolutionary component within each individual. Therefore, it is common to watch one's spiritual maturity evolve. Spirituality is also based on an internalized continuum (Underwood, 2006). It is not a binary construct; meaning, it is not about being present or absent (Krok, 2008). It is more of a latent construct: meaning that spirituality is a something unseen and more often an underlying entity of one's personal identification (Krok, 2008).

Because there are so many attributes to spirituality (van der Steen, 2009) the definition, itself, is based on more than the physical features of one's behaviors (going to church, outwardly prayer, etc.). Instead, spirituality is based on a perception, which is hard to objectively see (Ellison & Fan, 2008). Peterman, et al. (as cited in Ellison & Fan, 2008) elaborates on this topic by stating that defining spirituality is more of a real-time measure of well being or one's perception of the quality of their life.

The Transcendent Nature of Spirituality

Attributes of spirituality include both theistic variables (e.g., feeling God's presence or having a sense of personal intimacy with God) and non-theistic variables (e.g. feeling connected to all of life (Underwood, 2006 and Underwood & Tersi, 2002). It is because of these attributes that spirituality is often seen as being transcendent. Piedmont (2001) describes spiritual transcendence as, "the capacity of individuals to stand outside of their immediate sense of time and place to view life from a larger, more objective perspective" (p. 5). Putting it a different way: spirituality is an individual's effort to construe a broad sense of personal meaning in the lives they lead (Piedmont). It

is also believed that with this higher spiritual transcendence, or maturity, comes a greater ability to reduce levels of depression and anxiety and the ability to have more sufficient support systems (Underwood & Teresi, 2002). For the purpose of this study, the definition of spirituality is a combination of past definitions by Underwood (2006) and that of Krok (2008): Spirituality is an evolutionary component, based on a continuum, that is not seen but is only understood by each individual and often an underlying entity of one's personal identification.

An Underrepresented Population

The past 50 years has provided research regarding certain mental stressors that parents may go through in traumatic situations with their children (Sormanti & August, 1997). In addition, there is little information that helps clarify what those mental stressors are and little information to help parents understand the full effects of this overall stress. (Sormanti & August, 1997). Stating it a different way: parents do endure stress when their kids are diagnosed with a chronic or terminal illness but it is not always well understood. Clearly, what one finds or appreciates as normal stress may become slightly subjective. There are so many unknown factors for parents when they hear their children have cancer or a blood related illness. The ability to teach parents how to advocate for themselves could be crucial (Sormanti & August, 1997). Traumatic incidents for parents do not have to just include death; sometimes knowing how to live through traumatic experiences is just as important. (Schneider & Mannell, 2006).

Rationale for the Study

So much of the literature has focused on the role spirituality plays on the identified patient but very little research has focused on the parent or caregiver of the child who is going through cancer or hematology treatment (Schneider & Manell, 2006). In a world where the term cancer represents many different definitions, due to the complexity of cancer's many forms, parents may have a natural tendency to feel as though the situation is out of control. When parents are confronted with so many uncontrolled variables, numerous options for treatment regimens and varying prognoses it becomes easy to lose hope. It is because of this hopelessness that a fuller understanding of the role spirituality plays on the psychology of parents is crucial for researchers to understand (Schneider & Manell).

The Parents' Point of View

Childhood cancer has been on the increase. Desmeules (as cited in Clarke, 2004) noted that in 1995 nearly 1 in 900 children were being diagnosed with cancer. Mangano (as cited in Clarke, 2004) found a 3% increase per year in diagnosis during the previous 15 years. When a child is diagnosed with cancer an immediate entourage of individuals is put into place to care for the identified patient: doctors, nurses, physical therapists, psychologists, and a slew of ancillary support personnel like home healthcare workers, educational tutors, and dieticians (Clarke, 2004). Immediately, parents find themselves in a situation that Eiser (as cited in Clarke, 2004) referred to as a lifetime of uncertainty. It is this uncertainty that becomes a part of the overall grieving process for parents. The active treatment of cancer (e.g., chemotherapy, radiation, lumbar punctures, bone marrow

transplants, numerous labs, and many admissions to the hospital) usually takes multiple years. There may also be many years of inactive treatment (e.g., follow-up CT scans, lab review, and long-term applications of physical healing) that make the overall experience of cancer treatment a life-changing experience (Streisand, Kazak, & Tercyak, 2003). This life-changing experience necessitates an immediate transition where parents find themselves feeling lost, confused and angry (Norberg et al., 2006).

Most parents are not wired to know how to handle the news that their child has cancer. In fact, it is common for parents to experience many new emotional experiences for which they are not prepared and to which they are uncertain how to respond (Norberg, et al., 2006). Parents experience one of the most paradoxical moments in parenting: seeing their child in extreme pain; seeing their child with breathing tubes in his or her mouth; witnessing long bouts of little to no appetite; vomiting, diarrhea, and literally hundreds of needle sticks without the ability to eliminate or reduce the fear and pain their child is experiencing – thus, the feeling of hopelessness ensues (Clarke, 2004). It becomes easy for parents to feel alone and although the support of family, friends, and the church can be extremely helpful we still find parents needing more mental and emotional support in dealing with what appears to be a never-ending slew of unknowns and unpredictable scenarios (Bragadottir, 2008).

A New Meaning of Stress

The first thing that every parent who has a child with cancer realizes is that every day is a different day and each day comes with its own set of complications (Steisand, Kazak, & Tercyak, 2003). With the systemic nature of how families operate it is difficult

to keep these medical and emotional stressors from affecting the entire family system. In extensive research, Streisand, et al., 2003 wanted to look at how having a child with cancer effected the family and if it mattered as to whether the child was directly in treatment or post treatment. Specific areas of functioning that were evaluated were: communication, affective responsiveness, affective involvement, behavioral control, and general functioning. It is probably not too surprising to know that families who were active in treatment tended to experience higher levels of stress which was associated with the five areas that were studied. One of the highest correlations in Streisand et al. between stress and family functioning was behavioral control. This meant that the more stress parents experienced the more likely there was behavioral chaos with their other children. Again, Steisand et al. (2003) helped outline what behavioral control was: the inability to follow through with consequences to other children when specific family rules were broken or overlooked. The important element to understand here is how systemic this can become. When there is a breakdown within the general hierarchy of family structure regarding rules, the breakdown in unmet expectations can lead to frustration. This relational frustration, if not dealt with in a positive and healthy way, can ultimately lead to resentment. It is within this resentment stage that a total relational collapse is possible. When parents scored higher on what the researchers referred to as resiliency scales (e.g., humor, spirituality, prosocial family values, cognitive competency, behavioral and social skills, emotional stability, creativity, and talent) they were more likely to counteract the stress and rely on prior determined parenting plans (Steisand, et al., 2003). Realizing the vital role of stress and its ability to have such a large impact on

family functioning it seems relevant to better understand what parents experience as a result of their child's new diagnosis.

The Need to Focus on the Parent

According to Neimeyer and Hogan (2007) there are three disciplines that have greatly added to the research of grieving and bereavement: psychology, medicine, and social work. Although there is a lot for which to be grateful in this pursuit of knowledge, these three disciplines vary greatly in their research methodology and therefore have arrived at differing opinions making it even more difficult to offer healthier solutions in the area of grief therapy (Neimeyer & Hogan, 2007). In the past, medical social-workers have attempted to help families deal with childhood cancers and have also tried to identify families that are in need of more purposeful psychological-interventions. Over the past ten years many hospitals have implemented what is referred to as a collaborative health-care approach (Schaible, Thomlinson, & Susan, 2004). So, in addition to medical social-workers, psychologists, psychiatrists, neurologists, physical therapists, educational therapists, and art therapists all have taken a role in identifying specific families that might be in need of more purposeful psychological interventions (Schaible et al., 2004).

The Need to Find Normalcy

Many families whose children are being treated for cancer see the need to maintain some semblance of normalcy (McGrath, 2001). This normalcy includes being able to keep schedules as intact as possible, keeping up with school schedules, sport schedules, and interacting with friends. Yet anyone who has ever undergone cancer treatment knows that consistency in daily schedules can be an arduous task at best. In

fact, in McGrath's (2001) research, he found a significant number of families that either considered or actually moved their home temporarily or permanently to be closer to the medical facility in which they were receiving treatment. The shorter travel time allowed more family time and the actuality of trying to find family balance. As stated earlier in this section, families require the need for normalcy. This includes not only the parents, but siblings of the identified patient, and the identified patient as well (McGrath, 2001). Children with cancer want to be seen by their peers as normal. Because they have cancer does not mean that all other areas of their life should go unattended. This means that children want to get back to school; they want to be back in scouts, and they want to play any sports that are tolerable considering their current levels of treatment (McGrath, 2001).

So what happens when normalcy cannot be attained or the new levels of normalcy are not enough for families? What do families experience? It is common, right or wrong, healthy or unhealthy, for parents to correlate death with cancer (Penkman, Scott-Lane, & Pelletier, 2006). Sometimes this is a catastrophic response by parents who may not be educated in the survival rates of specific childhood cancers. Regardless, the pending thoughts of death to their child can loom subconsciously for many parents (Penkman et al., 2006). Research has suggested the long-term effects for parents whose children have cancer is undetermined (Patterson, Holm, & Gurney, 2004). The family systems approach to family therapy indicates that families do not operate independently; what happens to one family member has automatic effects on each of its members (Patterson).

Understanding Oncology and Hematology Treatment

The average person would probably not have difficulty believing that oncology and hematology treatments can be extensive and life changing. Yet, the fact is, until a parent has had to go through it they truly do not know what the journey entails. How these extensive treatments effect the parents of a child who is going through these exhaustive treatments is a completely different picture. As described, earlier the full understanding of what treatment means can, in some ways, be nearly limitless. Parents can be overwhelmed by doctor visits, blood work, transfusions, and surgeries. A common surgical procedure includes introducing devices like a peripherally inserted central catheter (PIC) line to continually administer medications in lieu of being stuck with an intravenous (IV) needle multiple times per week or month. Other surgeries require the removal of cancerous tumors or the removal of spinal fluid and bone marrow to be tested to determine their component strengths (Frojd, Lampic, Larsson, Birgegard, & Essen, 2007). Additionally, parents seem to be most aware of the common forms of treatment: chemotherapy and radiation. These are all just the beginnings of a list that give the reader a glimpse of what patients with cancer and blood-related illnesses go through at any given time.

It is important to understand how the previous paragraph pertains to the parent. One very important aspect to consider here is that all of the treatment-related elements listed above have one very specific thing in common: They are treatments that are visible. These treatments are tangible because they are things that are physically being done. What about the things that cannot be seen? The elements that tend to be listed as patient

subjectivity include (a) the unreliability of the source or (b) the differing internal levels of emotion that individuals go through (Wang, 2008). The next few portions of this paper delineate the less tangible effects that parents experience including physical effects, emotional effects, mental effects, and lastly relational effects.

Physical Effects

One of the most common side effects that many parents experience is exhaustion (Chaudhuri & Behan, 2004). Parents often comment about their frustration with feeling so tired – especially because they may not have been overly active physically. This exhaustion frequently feels impossible to conquer. Technically, it is not really exhaustion that they are experiencing; it is fatigue. Wang (2008) described fatigue as a series of emotions complicated by varying degrees of motivation and drive, fear and anger, and memory. Fatigue is not a result of overexertion (as described above), but more about what is happening in the brain. Chaudhuri and Behan (2004) describe fatigue as a difficulty in ability to maintain voluntary activities and as an inability in completion of any task requiring self-motivation and internal cues. It has been proposed that this depletion of internal focus or control starts in the basal ganglia and is also believed to be precipitated by emotional distress (Chaudhuri & Behan, 2004). It is not a far stretch to assume that many parents are under an insurmountable degree of distress.

Fatigue has systemic effects as well. It is believed that fatigue plays a part in self-regulating pain management, sleep patterns, depression, and a decreased immune system (Wang, 2008). Fatigue within cancer patients is very common: More than 60% of cancer patients experience clinical fatigue as a side effect to cancer treatment (Losito, Murphy,

& Thomas, 2006). Knowing how difficult fatigue can be for kids is important but the amount of distress that parents can be under at any given time is also a relevant factor in determining parent-related fatigue as well. Fatigue in parents is likely to reduce their physical levels of activity that, again, has systemic results in changes in sleep habits and appetite (Leahy, 2008). Chronic stress has been linked to heart disease (Stanley & Burrows, 2008), arthritis (Bergsten, Bergman, Fridlund, Alfredsson et al., 2009), and sleep disorders (Bates, 2004). Lastly, just to come full circle, there also seems to be some link between low levels of physical activity and instances of adults being diagnosed with colorectal cancers as well (Harriss et al., 2007). The rationale for parents to stay active has been well archived in past research.

Emotional Effects

The previous section described how much impact fatigue could have on the physical well-being of the parent. Fatigue can be a result of emotional dysregulation and understanding the full ramifications of parents' emotional state of mind is crucial. This self-regulation has been studied by Leventhal, Brissette, and Leventhal (2003). Their research postulates that understanding this emotional self-regulation of information has a direct impact on the ability for individuals to deal and cope with chronic or terminal illnesses. Cameron and Jago (2008) believed that distressing information about illness evokes two different responses: first, there is a cognitive process of trying to disseminate the reality or objectivity of information and then, secondly, there is the emotional process of trying to find the subjective information regulating anxiety and fear. Anxiety and fear can be used in proactive way in terms of finding motivation to filter levels of overall

distress (Cameron & Jago, 2008). It is when anxiety and fear become too much that individuals start to shut down, become paralyzed by their intense emotions and start to feel helpless (Cameron & Jago). The idea of self-regulation of emotions asserts that individuals can be proactive as long as they can be aware of their internal, emotional state of mind and through these observations they add healthy solutions (e.g., the use of spirituality) to help off-set the extreme emotional-states that tend to be paralyzing (Cameron & Jago). One very important aspect to insert here is the notion that even if self-regulation does not come naturally to parents it can still be learned. Schoo (2008) postulated the importance of learning to evaluate our internal states of emotion so that we can proactively insert healthier solutions.

One of the most powerful aspects of emotional attachment for adults is communication. It is believed that communication is one of key leading components that will determine if a couple stays happily married or unhappily married (Rogge et al., 2006). Poor communication has also been considered one of the leading variables in causing divorce (Rogge et al., 2006). If this is the case, then understanding how traumatic illness affects parents' communication is vital. First, it is extremely important to understand that if communication within a family is poor before the diagnosis of cancer the reality after the diagnosis will not make it easier. The comments by Schoo (2008), listed in the preceding paragraph, come into play – the importance of being able to self-evaluate is paramount. The family dynamic of nearly any family is automatically changed after the diagnosis of cancer (Harzold & Sparks, 2006). One common response tends to be avoidance and through this avoidance comes a series of uncertainties often

times leaving many family members feeling disengaged, feeling alone, and building resentment (Harzold & Sparks). Maybe one of the most valid reasons as to why communication is so important is the process of being able to encode and decode information regarding the treatment a patient with cancer must endure (Harzold & Sparks). In this case, communication can becomes the fulcrum for parents that may offset the intense emotional state of being by reaching out to their spouses, extended family members, and peers.

Finding perspective is very important in dealing with childhood cancers. Stiller and Draper (as cited in Maurice-Stam, Oort, Last, & Grootenhuis, 2008) found that the 5-year survival rate for children diagnosed with cancer in European countries is currently more than 70% compared to 30% from the 1960s. Sometimes, this perspective reminds the parents that just because their child has successfully completed cancer and/or hematological treatment there is still the possibility of one major component: relapse (Maurice-Stam et al., 2008). Their research indicated that even one year post-treatment approximately 34% of mothers and 36% of fathers had higher than expected levels of distress. Continued research by Maurice-Stam, et al. (2008) listed the importance of certain variables that tend to determine overall emotional-reaction ability by observing demographics, medical variables, and psychosocial variables such as coping abilities, social support systems, and overall family functioning. The assertion here being that family location and income, access to healthcare and ancillary medical necessities, severity of medical treatment needed to begin with, and current cognitive and psychological skills all play a part in an individual's ability to cope with their child's

cancer post treatment. Interestingly enough, the same research indicated that psychosocial functioning, more than medical variables, was a better indicator of emotional functioning (Maurice-Stam, et al., 2008). A continued understanding of what adds to or detracts from one's psychosocial functioning is paramount.

Earlier the topic of communication was addressed in regards to the importance of getting accurate information to make informed decisions. A series of communications leads to conversations. Nabati (2008) found that conversations can sometimes help negotiate our emotions and outlined five core communicative applications: (a) appreciation, (b) affiliation, (c) autonomy, (d) status, and (e) role. Nabati (2008) continued by stating how important the first two applications truly are: An individual needs to believe he or she has been heard and needs his or her feelings validated. The importance here is to focus on the fact that communication leads to conversations with others and through these conversations mothers and fathers may be able to formulate their emotional connection to what is happening to them and that their child's treatment is extremely important.

Mental Effects

Research has shown that the systemic nature of childhood cancers can be psychologically traumatic for parents, affecting them in various ways (Merrill, Justin, Alder, et al., 2007). Lower self-esteem, a decreased ability to handle stress, and mood disturbances are prevalent with many parents. Recent research by Merrill et al. (2007) showed that even the medical workup that is needed to rule out cancer can cause parents to experience certain levels of depression and anxiety. Once they realize that the world in

which they were all coexisting has somehow changed its orbital path, the distress parents go through, often produces maladaptive coping strategies (Frank, Brown, Blount, & Bunke, 2001). Wyn (as cited in Merrill, et al., 2007) reminded the reader that, generalizations aside, mothers tend to be the predominant caretaker of children with cancer. This caretaker definition includes the mother being the primary individual that takes her child for treatments, meets with medical professionals to discuss treatment options, etc. It does not necessarily imply that fathers are not involved; just less involved typically referring to the fact that fathers feel the need to maintain their income to cover an unimaginable amount of medical bills (Frank et al., 2001).

Some research indicates that levels of depression and anxiety are highly correlated to actual prognosis (Zabora et al., 2001). Meaning, depending on the particular diagnosis and the prognosis, there can be varying levels of depression and anxiety. Research by Hagedoorn, Sanderman, Bolks, Tuinstra, and Coyne (2008) postulated that these emotional connections can also be more difficult for mothers than fathers. Hagedoorn et al. attributed this to the highly researched correlation between women's state of being and the well being of others. The way partners react to highly stressful medical events leads to another unique component: How cancer affects relationships.

Relational Effects

There is no doubt that in the past 50 years the more favorable prognosis of cancer has dramatically changed the interpretation of having cancer. Even 50 years ago the term cancer typically meant a prognosis of death; with today's technology, world-renowned

doctors, and continued research in cancer treatment the word cancer no longer has to imply death (Hagedoorn et al., 2008). As stated in the prior paragraph there appears to be a difference in women's reactions to cancer and that of men. Hagedoorn et al. (2008) looked at the importance of gender and found that women, regardless of whether or not they were the parent or the patient, had higher levels of distress than that of men. Looking at these data one might conclude that mothers are more likely to have higher levels of distress than fathers when it comes to the treatment of their children. If so, then a better understanding of how this kind of stress affects relationships is greatly needed.

Understanding the importance of family intervention is paramount; this includes parents and siblings according to Svavarsdottir and Sigurdardottir (2005). The more a family is involved in the treatment of a child the more likely the whole family feels connected, well informed, and in unity. When families can express their distress in a way that is not only healthy but also in a way that allows a new and authentic type of thinking, then the concept of mental and emotional processing can help alleviate the distress (Svavarsdottir & Sigurdardottir, 2005). Information from these same researchers found that numerous factors come into play as to how well families handle traumatic stress: length of marriage; strength of support systems; financial security; and, if appropriate, how dual-income families handle the tandem of working full or part-time and spend adequate time with their child during any number of treatment phases. One major conclusion regarding how having a child with cancer affects a marriage comes down to the art of communication among the partners.

Spirituality in Terms of Coping

The social impact of spirituality has had a long-standing history of usefulness in different settings: For example, Alcoholics Anonymous (AA) has always indicated a specific connection to God and a higher power (Redman, 2008). Oftentimes, spirituality blends a helpful and useful sense of healthier coping skills and strategies (Redman, 2008). Sometimes these coping skills are a part of the everyday interactions of individuals. Idler and Kasl (as cited in Redman, 2008) found that individuals who draw relief and solace from their own spirituality are more likely to see positive possibilities and opportunities in what appears to be negative situations. Individuals who can draw deeper meaning and satisfaction from life's difficult moments are more likely to not be negatively impacted by traumatic situations as well (Redman, 2008). According to Redman (2008), the opposite can be true, too: individuals who have difficulty drawing meaning from difficult events may have more difficulty acclimating to changes in life.

Research has also shown how spirituality can have a positive effect on many individuals who are going through medical difficulties. Earlier, the discussion of AA brought about the importance of spirituality. Research has shown that spirituality also has an effect on depressive symptoms with women going through post partum depression: One study indicated that over 19 percent of women might suffer from post partum depression within the first three months after delivery (Mann, McKeown, Bacon, Vesselinov, & Bush, 2008). This same study showed that women who had strong religious and spiritual beliefs were more likely to be protected from post partum depression than women who had no affiliation with either religion or spirituality. In

another study by Giaquinto and Spiridigliozzi (2007) nearly 40%of hospitalized individuals reported that their spiritual faith was their most important factor in their physical healing. This same research indicated that individuals who were spiritual were more likely to experience decreased levels of anger, fear, and stress – all of which decreased levels of hypertension. Koenig (2009) indicates that the identification of one's spirituality is paramount in promoting positive mental health as well.

If one of the most important factors for individuals who are going through a traumatic situation is to find meaning then spirituality can oftentimes lend a helping hand (Peres, Moreira-Almeida, Nasello, & Koenig, 2007). Their research indicated that spirituality fostered a new type of resiliency for individuals who experienced traumatic events. More important, spirituality gave a sense of hope in what had been deemed hopeless. It is also believed that spirituality has the ability for individuals to find perspective in the midst of emotional trauma (Park 2007). The blending of one's psychology and spirituality becomes a most intriguing element of one's overall mental health (Parsons, 2010). It is crucial to understand the connection between spirituality, perspective, healing, and the resuming of one's daily life (Krok, 2008; Vis & Boynton, 2008).

Cancer and Spirituality

There has been past research in terms of understanding how spirituality can influence an adult who is going through cancer (Rinaldis, Pakenham, Lynch, & Aitken, 2009; Gullatte, Brawley, Kinney, Powe, & Mooney, 2010; Sigal, Ouimet, Margolese, Panarello, Stibernik, & Bescec, 2008). Whether in terms of colorectal cancer (Rinaldis,

Pakenham, Lynch, & Aitken, 2009) or breast cancer (Gullatte, Brawley, Kinney, Powe, & Mooney, 2009), spirituality becomes a very common tool or strategy used in dealing with the distress that cancer treatment brings. Spirituality has even shown to reduce the most extreme anxiety in individuals diagnosed with cancer – facing the possibility of death (Sigal et al. 2008).

It is important to try and understand how spirituality can effect individuals who are stressed over loved one's health concerns. For example, Sanders, Ott, Kelber, and Noonan (2008) studied the caretakers of individuals who were afflicted with either Alzheimer's or dementia. First off, their research indicated high levels of stress, burden, and depression in caregivers. According to Sanders et al. (2008) caretakers experience prolonged grief with symptoms of, "bitterness, emotional numbness, shock, diminished sense of self, mistrust of others, trouble accepting loss, and avoidance" (p. 496). One cannot avoid the obvious emotional toll that a caregiver must experience. Their research concluded that spirituality was indeed a helpful adjunct in reducing levels of grief for these caretakers.

A parent would never consider themselves as a caretaker to their child in the way that someone might see himself or herself when taking care of an individual who is struggling with Alzheimer's or dementia. Most parents see it as part of their job: to take care of their child who has any type of chronic or terminal disease (Mackenzie, Carlson, Munoz, & Speca, 2007) as either an honor or an obligation. The same research by Mackenzie indicated that when individuals can use a sort of "mindfulness based stress reduction" (MBSR) they tend to experience overall less stress. Sigal, et al. (2008)

conclude in their research that to understand all of the psychological and environmental factors that contribute to the overall wellbeing of cancer patients is to better understand all of the distressing factors involved. This type of research includes the need to better understand all coping mechanisms, including how spirituality of parents might benefit in their overall psychological wellbeing as well.

Summary

The systemic effect of having a child with cancer can nearly be endless. One major focus is the adaptability of the parents. Detmar (2005) described how communication with the parents is not only essential but is also paramount. Schwab (1998) agreed that there is a lot of research indicating that traumatic illness typically negatively affects marriages, but included that newer research tends to indicate that many times traumatic illness of a child can paradoxically brings couples together as well. It can be through highly stressful events that communication produces a heightened level of awareness in both partners. Old assumptions from Schiff (as cited in Schwab, 1998) predicted that nearly 80%-90% of marriages were in distress just months after the diagnosis of their child with many ending in divorce. What Schwab (1998) discovered was that there were very few actual scholarly sources used in Schiff's study rendering it biased and useless information. Moreover, the diagnosis of any traumatic illness of a child tends to magnify already developed pathologic interactions of a couple: Therefore, communication becomes the foundational element in relational connection (Schwab, 1998). Couples with poor communication-styles need to understand the differences between avoidance of traumatic situations, in which intervention counseling can directly

help, and the pathological patterns that may have existed prior to the diagnoses (Rogge et al., 2006). It becomes that latter situation where communication among family members can be just as necrotic as the actual cancer.

A parents' reaction to their child having cancer or blood related illnesses can be psychologically systemic (Cameron & Jago, 2008). Through this chronic time of distress parents' levels of depression and anxiety can fluctuate (Merrill et al., 2007). Although research has been thorough studying how spirituality can influence a parent's mental health, research has yet to demonstrate how spirituality can influence a parent whose child is being treated. The design for this study was chosen based upon a careful review of existing psychological literature in the areas of spiritual awareness and psychological factors of depression and anxiety. The desire is that the information gathered in this study will contribute to existing literature on this topic and will enhance social change initiatives through a better understanding of the relationship between spirituality and the hope it instills within parents to reduce psychological factors such as depression and anxiety. The variable of spirituality as a form of complimentary and alternative medicine may be a largely underappreciated attribute on the individual level but also on the overall effectiveness on a community level as well.

Chapter 3 discusses the methodology, setting, sample, instrumentation, and analyses that were used in the study.

Chapter 3: Research Method

Introduction

This chapter includes a description of this study's design, sample, instrumentation, data analysis, and ethical considerations. An overview of the study's design includes a rationale for why this particular research design was selected. The sample characteristics and size are presented along with a description of the instrumentation. The data collection process and analysis is also discussed. The purpose of this study was to examine the relationship between spirituality and parents' levels of depression and anxiety during their child's hematological or oncology treatment.

Research Design and Approach

This quantitative study used a correlational approach to investigate the independent variables of depression and anxiety with the dependent variable of spirituality. Through a combination of *t* tests, ANOVA, and linear analysis, this study sought out the correlations between the dependent and indepent variables. The correlational approach is appropriate because it helps explain the relationship between how participants' perceive their own level of spirituality and their own self-reported levels of depression and anxiety.

Setting and Sample

Participants

Participants were not randomly assigned to a specific group; instead, participants took the DSES, and based on their answers, were be put into one of two categories: Based on the median score of the DSES, participants who scored above the median were placed

in the one category while participants who scored below the median were placed in the other category. The participants were gathered through a form of convenience sampling from a large medical center in St. Louis, Missouri. A list of patients was obtained from the Child Life Specialist at the Pediatric Hematology and Oncology office. Current patients included any patient who was still receiving some level of treatment or therapy ranging, for example, from intense treatment (concurrent chemotherapy and radiation treatment) to medication management treatment (preventative intravenous immunoglobulin - IVIG therapy for conditions of immune deficiency and autoimmune disease in hematology patients). Permission was received from the head pediatric oncologist to conduct the study through his office (see Appendix A). Participants were selected for the following reasons: (a) the population was accessible; (b) they were not minors and could voluntarily participate; and, (c) their experiences directly related to the purpose of this research. Participants of these individuals were first contacted by a Child Life specialist within the Pediatric Hematology and Oncology practice and notified of the research. All families were sent the survey, questionnaires, and psychological resilience scales. Individuals were reminded that all participation is voluntary and their right to withdraw at any time from the study.

Procedures

A power analysis revealed that for a two-tailed test $p < .05$, to detect an effect size of .30 with a power analysis of at least .80, the study required a sample of at least 15-20 participants in each category. Written information describing the study a well as an informed consent form was either mailed or handed out directly to individuals. The

informed consent form included a brief background of information regarding the study, the procedures for participation, confidentiality, the purpose of volunteering for this study, and ethical guidelines. A copy of the implied consent is provided in Appendix B. An email address was provided so that any additional questions regarding participation can be directed to the researcher and the chair of this dissertation. All parents who do not have access to a computer will have direct access to multiple computers from the physician's office in order to send emails. According to the Child Life Specialists, there were no requests to correspond via email. Individuals interested in participating in this research read an implied consent form.

Willing participants received in the mail or were given a packet of information including an instruction sheet detailing the packet contents and specific completion date information. A demographic sheet included information regarding gender, age, marital status, and educational background. A copy of the demographic questionnaire is provided in Appendix C. Also included in the packet were the three testing instruments, Daily Spiritual Experience Scale, Beck Depression Inventory, and Beck Anxiety Inventory. Completed scales were either mailed back to the physician's office or handed back directly upon completion. As stated earlier, a Child Life Specialist helped direct the distribution of testing measurements whether in the office or through the mail.

Participants were also made aware that the results will be made available upon request. When doing research it becomes equally important for the researcher to promote, "accuracy, honestly, and truthfulness" and to allow the results of finalized research to be available for participants to view (Fisher, 2003, p. 250).

Instrumentation

Demographics.

The demographic sheet included information regarding gender, age, marital status, family income, and educational background.

Daily Spiritual Experience Scale

More and more, spirituality is gaining credibility in the world of scholarly healthcare research (Underwood, 2006). The Daily Spiritual Experience Scale (DSES) had its origination back in 1995 when the National Institute of Aging and the Fetzer Institute cosponsored a meeting with the National Institute of Health in order to develop a "…measurement of religious and spiritual variables that could be used in health studies" (Underwood & Teresi, 2002, p. 22). It was not until 2002 until the DSES came to its final inception (Underwood, 2006). The DSES is a sixteen-item self-report intended to measure "mundane" (p. 2) spiritual experiences (Underwood). The intention is not to measure the supernatural or dramatic experiences of near death, seeing visions, or hearing voices. It does measure "how beliefs and understandings are part of moment-to-moment features of life from a spiritual or religious perspective" (p. 2). One of the key components set out by the DSES was to combine, or bridge the gap, between spirituality and religion. The DSES does not measure spirituality inasmuch measure the subjective experiences that form into everyday life experiences (Loustalot, Wyatt, Boss, May, & McDyess, 2006; Underwood, 2006).

This 16-item questionnaire uses a modified Likert-scale scoring system. The Test-retest reliability was generally stable over a short period of time: Not unexpectedly

though, over time the degree to which the degree of stress is elicited could change therefore giving a direct change to the score (Underwood & Teresi, 2002). According to the authors, interrater reliability is of no concern since the measurement is self-administered, internal consistency reliability using the Cronbach's alpha were very high, .95. There is also a six-item version of the DSES in use that was not evaluated or used in this study. Recent research using the DSES shows an extremely positive association between the DSES and psychological well-being; meaning, the higher correlation with daily spiritual experiences translates to lower stress and higher levels of comfort and feeling loved (Ellison & Fan, 2008). The high internal consistency estimates for the DSES suggest that the items do function together to accurately measure the spiritual experience construct (Ellison & Fan, Underwood, 2006). A previous study using the DSES studied African-American subjects only. Again, criterion validity, represented by concurrent validity, was assessed using ANOVA methods: In addition, stability, internal consistency, and equivalence were all positively assessed (Loustalot, Wyatt, Boss, May, & McDyess, 2006).

Beck Depression Inventory

The original purpose of the Beck Depression Inventory (BDI) was to monitor the depressive symptoms of mental health inpatients over a period of time; since then, the BDI-II has been used in outpatient settings as well (Arbisi, 1993; Gregory, 2007). The basic premise of evaluating for depression is broken down into three categories: Negative attitudes towards self; performance impairment, and somatic (bodily) disturbance (Arbisi). The BDI has only had two alterations in over 45 years. The first changes came

in 1987 with the BDI-IA that mostly had to do with changing the biased language of the questions relative to gender. The current form of the BDI-II reflects the sensitivity to depression and the many attributes of the disease (Arbisi, 1993).

The BDI-II consists of 21 questions that are self-administered and usually takes less than 10 minutes to complete (Arbisi, 1993). Because the BDI-II can be used in multiple settings the scoring for the BDI-II is relatively different for the general population compared to individuals who have been diagnosed as clinically depressed (Arbisi, 1993). Although the interpretation of the data appears basic in nature it is to be fully evaluated by professionals (Arbisi, 1993).

The validity of the BDI-II has been broken down into content validity (do the items of the test measure what is to be measured) and supported by clinicians regarding the depressive symptoms present by psychiatric patients; concurrent validity (the measure of which a test concurs with existing standards) - more than 35 studies have shown concurrent validity between the BDI and other measures of depression supported by the Hamilton Depression Scale (Gregory, 2007) and the Minnesota Multiphasic Personality Inventory – D (Gregory, 2007); and, construct validity (the degree to which a test can measure and internal construct or variable) has been shown to be relative to medical conditions, anxiety, stress, loneliness, sleep patterns, alcoholism, suicidal behaviors, etcetera (Arbisi, 1993).

The reliability of the BDI-II has been established through internal consistency in over 25 studies with differing populations – the reliability and validity of the BD-II has

been consistent with more than 90% of clinician's ratings of depression as well (Gregory, 2007).

There are some drawbacks to the BDI-II. Most noticeable is the fact that test takers can easily alter their responses in ways to either further their own agenda or to confuse the test giver (Arbisi, 1993). In most cases if this occurs then the proper diagnosis of depression may be of only one concern from the client. The majority of individuals who take the BDI-II want the assessment done and therefore are more willing to be as honest as they can (Gregroy, 2007).

Not only is the BDI-II easy to administer, but the feasibility of the test makes it one of the most widely used instrument in identifying symptoms and onset of depression (Arbisi, 1993).

Beck Anxiety Inventory

Unlike the BDI, the Beck Anxiety Inventory (BAI) originally was designed to be used in outpatient mental health settings (Dowd, 2004). According to Dowd, the design of the BAI identified four types of anxiety symptoms: (a) neurophysiological, (b) subjective, (c), panic, and (d) autonomic symptoms. All of these were surmised after an exhaustive study from three prior anxiety measurement tools: The Anxiety Check List, The PDR Checklist, and the Situational Anxiety Check List were all compressed to form the BAI (Gregory, 2007).

The BAI consists of 21 self-administered questions and usually completed in less than 10 minutes (Dowd, 2004). According to Beck (as cited in Dowd, 2004), there are two demographics that any test administer must take into consideration: (a) gender and

(b) age. Women have been found to be more anxious than men while younger individuals tended to be more anxious than older people. Therefore, the authors of the BAI have suggested adjusting scores based on interpretation.

The validity of the BAI is thorough in regards to content, concurrent, construct, discriminate, and factorial validity (Dowd, 2004). In addition, the internal consistency reliability coefficients are equally as strong, scoring between .85 and .94 (Dowd, 2004). Test-retest reliability data showed a coefficient of .75 over one week.

Obvious drawbacks to the BAI are the gender and age variable concerns and the subjective manner in which the tester is to take that into consideration. Secondly, although the BAI is highly respected among mental-health professionals, longer term studies have not been completed on the BAI (Dowd, 2004).

Analysis

This study employed a correlational research design using an analysis of variance (*ANOVA*). With the use of multivariate analysis the instruments used in this study allowed for the data to be analyzed through regression analyses. The research questions and hypotheses are listed again for review.

Research Question #1

What is the nature of the relationship between parents' spirituality level in regards to levels of depression and anxiety as measured by the Beck Depression Inventory and Beck Anxiety Inventory for parents whose child is undergoing oncology and/or hematological treatment?

Null Hypothesis #1

There will be no difference in depression and anxiety scores among the two groups of parents.

Non-Directional Hypothesis #1

There will be a difference in depression and anxiety scores among the two groups of participants.

Research Question #2

Does duration of treatment (DOT) have an effect on parents' depression and anxiety as measured by the Beck Depression Inventory and Beck Anxiety Inventory?

Null Hypothesis #2

DOT will have no effect on parents' depression and anxiety as measured by the Beck Depression Inventory and Beck Anxiety Inventory.

Non-Directional Hypothesis #2

DOT will have an effect on parents' depression and anxiety as measured by the Beck Depression Inventory and Beck Anxiety Inventory.

Research Question #3

Does gender of parent have an effect on parents' depression and anxiety as measured by the Beck Depression Inventory and Beck Anxiety Inventory?

Null Hypothesis #3

Gender of parent will have no effect on parents' depression and anxiety as measured by the Beck Depression Inventory and Beck Anxiety Inventory.

Non-Directional Hypothesis #3

Gender of parent will have an effect on parents' depression and anxiety as measured by the Beck Depression Inventory and Beck Anxiety Inventory.

Research Question #4

Does spiritual level and length of treatment have an effect on parents' depression and anxiety as measured by the Beck Depression Inventory and Beck Anxiety Inventory?

Null Hypothesis #4

Parents' spiritual level and duration of treatment will have no effect on parent's depression and anxiety as measured by the Beck Depression Inventory and Beck Anxiety Inventory.

Non-Directional Hypothesis #4

Parents' spiritual level and duration of treatment will have an effect on parents' depression and anxiety as measured by the Beck Depression Inventory and Beck Anxiety Inventory.

Research Question #5

Does spiritual level and gender of parent have an effect on parents' depression and anxiety as measured by the Beck Depression Inventory and Beck Anxiety Inventory?

Null hypothesis #5

Spiritual level and gender of parent will have no effect on parent's depression and anxiety as measured by the Beck Depression Inventory and Beck Anxiety Inventory.

Non-Directional Hypothesis #5

Spiritual level and gender of parent will have an effect on parents' depression and anxiety as measured by the Beck Depression Inventory and Beck Anxiety Inventory.

The instruments were scored and the data was analyzed by using SYSTAT Softward Inc. (2007). Separate linear regressions were run for each individual parent score on the BDI and BAI. Gender, age, marital status, family income, and educational background were treated as possible variables included in the regression models. A 2x2 analysis of variance (*ANOVA*) will be used to determine if there are significant differences in mean depression and anxiety scores between males and females along with those identifying themselves as either (a) spiritual or (b) not spiritual.

Descriptive statistics are included and the recorded data from all of the test measurements divided by gender and by spiritual identification. Additional information will be gathered regarding age, marital status, and educational background.

Ethical Considerations

Each participant was reminded of the possible emotional intensity of this study. Regardless of the researcher's intentions or the participant's availability, participating in this research can possibly bring about many unresolved emotions and feelings about what they are experiencing as parents and how parents feel about what their kids are experiencing while going through treatment. A post-study support group was available for any participants that felt the need for continued therapeutic processing. Participants were notified that they were free to withdraw from the study at any time without penalty. No participants indicated such a need. Clearly, a participant's decision to participate or

withdraw has no effect on their child's continued treatment. All recorded research data will be stored at the researchers office. Information will be securely kept for a period of five years at which time the data will be destroyed by a local document disposal company.

Chapter 3 outlined the setting and sampling procedures used to obtain data, gave a description of the participants and procedures used during the data collection stage, and described in detail the three main testing measurements: Daily Spiritual Experience Scale, Beck Depression Inventory, and Beck Anxiety Inventory.

Chapter 4 will explain the results of data collection and interpret the analysis with a descriptive breakdown of each research question.

CHAPTER 4: RESULTS

Introduction

The purpose of this study was to examine the relationship between spirituality and parents' levels of depression and anxiety during their child's oncology or hematology treatment. The construct of spirituality was defined by the Daily Spiritual Experience Scale (DSES); participants that scored above the mean were defined as spiritual; those participants that scored below the mean were categorized as non-spiritual (B. Robbins, personal communication, August 16, 2010). Five nondirectional hypotheses were tested using a number of different statistical applications. This chapter summarizes the descriptive statistics for this study and presents the results of the inferential tests.

Sample Demographics

Over a 4-week period in March of 2011, 50 research packets were either handed out or mailed to all participants via a Child Life Specialist at a major metropolitan hospital in St. Louis, MO. Some of the packets were mailed to participants because they were not scheduled for in-office treatment for another 4 to 6 weeks. Of the 50 research packets that were handed out or mailed, 48 (96%) were returned to the Child Life Specialist. 10 (20%) of the packets were mailed, while 40 (80%) were handed out to participants. Of the 10 packets that were mailed out, 8 (80%) were returned. Of the 40 packets that were handed out, 40 (100%) were returned. Of those who responded, 18 respondents (38%) were male and 30 respondents (62%) were female. Table 1 summarizes the demographic characteristics of the study sample.

Table 1
Demographic Characteristics of Study Sample (N= 48)

Characteristic	*N*	%
Age Bracket		
20-29	1	.021
30-39	18	.375
40-49	22	.458
50-59	4	.083
60-79	3	.063
Diagnosis		
Cancer	39	.813
Blood Related Illness	9	.187
Duration of Treatment		
0-6 months	15	.313
7-12 months	6	.124
13-18 months	3	.062
19-24 months	9	.188
Greater than 24 months	15	.313
Level of Treatment		
Current Chemo	17	.354
Maintenance Chemo	12	.250
Non-Cancer IVIG	7	.145
Off Treatment < 6 months	8	.168
Off Treatment > 6 months	4	.083
Educational Background		
No High School Diploma	2	.042
High School Diploma	3	.063
Some College Credit	13	.270
Trade School	2	.042
Undergraduate Degree	17	.354
Graduate Degree	11	.229

The greatest numbers of participants were between the ages of 30 and 49 (83%). More participants' children were being treated for cancer (81%) than blood-related illnesses (19%). The duration of treatment results was an inverted bell curve with the largest numbers at each end: Less than 6 months (31%) and greater than 2 years (31%) respectively. With respect to level of treatment, the majority had a child on either a current chemotherapy treatment schedule (35%) or maintenance chemotherapy treatment (25%). The vast majority of participants had either some college experience (27%) or had a college degree (35%). There were a high percentage of graduate degrees as well (23%).

Analysis

Hypothesis 1

The first hypothesis predicted that participants who scored as *spiritual* on the Daily Spiritual Experience Scale (DSES) would have different (i.e., lower) levels of depression and anxiety scores on the Beck Depression Inventory (BDI) and Beck Anxiety Inventory (BAI) than participants who scored as *nonspiritual*. To test this hypothesis two independent samples *t*-tests were used. There were no significant mean differences between the two groups in regards to level of spirituality and depression. Spiritual participants had a BDI scores with a mean of 8.35 ($M = 8.35$; $SD = 6.13$) while non-spiritual participants had BDI scores with a mean of 10.84 ($M = 10.84$; $SD = 7.40$) thus, indicating no difference in levels of depression, $t_1(46) = -1.271$, $p > 0.21$. There were also no significant mean differences between groups in regards to level of spirituality and

anxiety. Spiritual participants had BAI scores with a mean of 6.69 ($M = 6.69$; $SD = 6.52$) while non-spiritual participants had BAI scores with a mean of 5.74 ($M = 5.74$; $SD = 7.75$) thus, indicating no difference in levels of anxiety, $t_2(46) = 0.459$, $p > 0.65$.

Hypothesis 2

The second hypothesis predicted that duration of treatment (DOT) would have an effect on participants' depression and anxiety as measured by the BDI and BAI. To test this hypothesis a Pearson correlation was used. The degree of linear correlation between two variables is measured by using the Pearson product moment correlation (Gravetter & Wallnau, 2007). BDI scores ($M = 9.33$; $SD = 6.70$) approached significance with DOT ($M = 30.40$; $SD = 48.04$). Although the data showed a trend toward a correlation between DOT and depression, the null was accepted, $r_1 = 1.909$, $p > 0.06$. In simple terms, as duration of treatment increased there was not a significant increase in levels of depression. Similarly, there was no correlation between BAI scores ($M = 6.31$; $SD = 6.97$) and DOT ($M = 30.40$; $SD = 48.04$), $r_2 = 1.19$, $p > 0.24$. As duration of treatment increased there was not a significant increase in levels of anxiety.

Given the variability of the DOT ($M = 30.40$; $SD = 48.04$), a follow-up Factorial ANOVA for duration by BDI and for duration by BAI was conducted to test for significant mean differences between groups using five levels of DOT (see Table 2). Neither ANOVA was significant; $F_1(4, 43) = 0.947$, $p > 0.446$; $F_2(4, 43) = 1.091$, $p > 0.373$ (BDI & BAI respectively).

Table 2

Frequency Distribution for Duration of Treatment Across Five Levels

Duration	Frequency (*f*)	Cumulative (*f*)	Percent (%)	Cumulative %
0 – 6	15	15	31.25	31.25
7 – 12	6	21	12.50	43.75
13 – 18	3	24	6.25	50.00
19 – 24	9	33	18.75	68.75
>24	15	48	31.25	100.00

Note. Duration was measured in months.

Hypothesis 3

The third hypothesis predicted that the gender of the participant would have an effect on levels of depression and anxiety as measured by the BDI and BAI. To test this hypothesis two independent samples *t* test were conducted. There was no significant difference between groups in regards to gender and depression. Male participants (N = 18) had a BDI with a mean of 9.78 (M = 9.78; SD = 7.54) while female participants (N = 30) had a BDI with a mean of 9.07 (M = 9.07; SD = 6.27) thus, indicating no difference in mean levels of depression across gender, $t_1(46) = 0.353$, $p > 0.73$. There was also no significance between groups in regards to gender and anxiety. Male participants (N = 18) had a BAI with a mean of 8.28 (M = 8.28; SD = 7.83) while female participants (N = 30) had a BAI with a mean of 5.13(M = 5.13; SD = 6.24) thus, indicating no gender difference in mean levels of anxiety, $t_2(46) = 1.54$, $p > 0.13$. Although not statistically significant, male participants had higher means of both depression and anxiety over their female counterparts.

Hypothesis 4

The fourth hypothesis predicted that participants' spiritual level and duration of treatment (DOT) would have an effect on their levels of depression and anxiety as scored by the BDI and BAI. The data were analyzed by using two 2 x 5 factorial ANOVAs (spiritual and DOT by BDI and spiritual and DOT by BAI). Neither ANOVA was significant, $F_1(8,39) = 0.76$, $p>0.64$; $F_2(8,39) = 0.62$, $p > 0.75$ (BDI and BAI respectively).

Hypothesis 5

The last hypothesis predicted that participants' spiritual level and gender would have an effect on their levels of depression and anxiety as scored by the BDI and BAI. A 2 x 2 factorial ANOVA was conducted for each dependent variable. Again, the data failed to show any main or interaction effects between spirituality and gender on BDI scores, $F_1(1,44) = 0.96$, $p > 0.33$; or on spirituality and gender on BAI scores, $F_2(1,44) = 0.41$ $p > 0.52$.

Summary

None of the analyses showed statistically significant relationships with the dependent measures of the BDI and BAI. Therefore, none of the research hypotheses were supported.

Chapter 5 summarizes the study and presents conclusions about the findings;, it also discusses the limitations of this study, the social change implications of the findings, and recommendations for future research.

CHAPTER 5: CONCLUSION

Introduction

This study was conducted in order to better understand the relationship between spirituality and parents' levels of depression and anxiety during their child's oncology or hematology treatment. nature of possible group differences between spirituality and scored levels of depression and anxiety. In particular, it assessed the spiritual levels of individuals and the corresponding levels of depression and anxiety that those individuals experienced while their child was undergoing oncology or hematology treatment based on level of spirituality. The stress of treatment can have a systemic effect on the mental health of an individual (Clark, 2004). Since depression and anxiety have a direct influence on levels of stress it is vital to understand any possible variables or factors that could help reduce those levels of depression and anxiety. Therefore, it was appropriate to look at the mean differences between spirituality and depression and anxiety.

Summary and Interpretation of Findings

Research has demonstrated that spirituality can have a positive or healing influence on adults going through cancer treatment (Ramondetta & Sills, 2004), and adolescents going through cancer or blood illness treatment (Kaplar, Wachholtz, & O'Brien, 2004). Yet, past studies have had a limited understanding when it comes to the influence spirituality can have on the mental health of a parent whose child is undergoing cancer or blood illness treatment (Nolan et al., 2006).

In this study, adults whose child was being treated for cancer or blood related illnesses were evaluated in numerous ways: First, their level of spirituality was

determined with the DSES. Participants were then put into either the categories spiritual or non-spiritual category based on their score above or below the mean of the group. Then each group answered a series of demographic questions, and completed both the Beck Depression Inventory (BDI) and Beck Anxiety Inventory (BAI). It was predicted that spirituality would have a negative effect on the depression and anxiety scores(i.e., scores would be lower on the BDI and BAI).

As discussed in Chapter 2, this research was grounded in the transtheoretical model of change (TMC), which postulates that traumatic medical events can have an impact on behaviors and emotions (Cancer Prevention and Research Center, 2008). The benefit of TMC is that it can improve the ability to accept a situation and develop the momentum it takes to change perspective on it. In conjunction with the TMC model, it is possible that a person's ability to accept a situation and change perspective on it may be independent of the spiritual background.

The findings of this study indicated that level of spirituality had no significant effect on levels of depression and anxiety. Although DOT approached significance ($p >$ .06), it was not significant at the 95% confidence interval. Because DOT had a very large range in this study, the power may have been lowered, resulting in a failure to detect significant differences between groups.

Spirituality and Levels of Depression and Anxiety

Oman, Flinders, and Thoresen (2008) indicated that 64% of individuals considered spirituality either *very important* or *extremely important*. McConnell (2008) went on to state that spirituality should be assessed even more in medical settings to

understand its impact on psychological well-being. Hypothesis 1 examined the mean differences between spiritual levels and levels of depression and anxiety. There was no significant relationship between levels of spirituality and levels of depression and anxiety. Research has indicated a correlation between depression and anxiety (Baram & Bilgel, 2008; Cheng-Cheng, 2006). Although it was not one of the research questions, data from this research also showed a positive correlation between depression and anxiety among the participants, r (48) = .602, p < 0.001 (r_2 = 0.363), indicating a reliable relationship between these two variables.

Duration of Treatment and Levels of Depression and Anxiety

Hypothesis 2 examined the relationship between duration of treatment and levels of depression and anxiety. Past research has indicted a correlation between duration of treatment and levels of depression with the adult population (Hopko, Robertson, & Colman, 2008). But very little is known about how duration of treatment for a child can affect levels of depression and anxiety in the parent. The results approached significance (r1 = 1.909, p > 0.06) indicating that with more power, a significant effect may have been found. In short, as duration of treatment increased there was an increase in levels of depression and anxiety as well. Hopko, Robertson, and Colman (2008) indicated that there could be a number of reasons why levels of depression and anxiety increase over the duration of treatment: support system levels can change leaving parents feeling more alone or abandoned; educational backgrounds can have an effect as the more parents do not understand regarding their child's treatment or have the cognitive ability to understand the terminology the more discouraged they may become over time; the type

of cancer and type of treatment may be discouraging as time goes on for parents who see other family come to treatment after them and finish entire protocols before them, and the unknown fact of what the parents' mental health status was prior to their child's treatment can be very important.

Gender of Parent and Levels of Depression and Anxiety

Hypothesis 3 examined the relationship between gender of parent and levels of depression and anxiety. Over the past 20 years more and more hospitals and treatment centers have implemented collaborative medial approaches – the use of holistic adjuncts like psychologists, psychiatrists, acupuncture, massage therapy, and music therapy to help with ongoing treatment care (Neimeyer & Hogan, 2007). Yet, there is very little research on how these complimentary and alternative forms of medicine can aid the parent.

The results from this analysis showed no significant differences in levels of depression and anxiety between male parents and female parents. It is possible that had the Ns of each group been more equal, a significant effect would have been found. Carter, Mikan, and Simpson (2007) showed that gender of caregiver could have an effect on levels of depression and anxiety with long term cancer patients when the patient is an adult. Yet, there is very little research to address this construct when the cancer or hematological patient is a child. Past research by Hagedoorn, et al (2008) indicated that females tended to have higher levels of emotional distress compared to males in terms of dealing with medical trauma. This research did not indicate this. There are a number of possibilities that could have contributed to these paradoxical findings. First, it is possible

that whether or not the female was single, married, or divorced may have led to skewed results. In addition, it is possible that the educational level of the females may lead to an increase in mental health functioning in terms of dealing with emotional distress. Both of these aspects would be recommended for future research.

Spiritual Level Combined with Duration of Treatment and Levels of Depression and Anxiety

Hypothesis 4 examined the relationship between the combined factors of spiritual levels and duration of treatment and levels of depression and anxiety. The 2 x 5 factorial analysis showed no significant differences in levels between groups. Prior to the research being conducted, it was hypothesized that the combined variables would have an even great influence on the possible relationship with depression and anxiety. A scholar practitioner would deduce that if levels of spirituality and depression and anxiety were non-significant; and, levels of spirituality and duration of treatment was non-significant so would the combined variables of spirituality and duration of treatment be non-significant. In other words, if no main effects were found, then it is not surprising that no interaction effects were found either. Unfortunately, the data to these subsets was not known prior to this study.

Spiritual Level Combined with Gender and Levels of Depression and Anxiety

This last hypothesis examined the relationship between the combined factors of spiritual level and gender and scored levels of depression and anxiety. The 2 x 2 factorial analysis showed no significant differences in levels between groups. Prior to the research being conducted, it was hypothesized that the combined variables would have an even

greater influence on the possible relationship with depression and anxiety. Combined with the literature review indicating that females tended to score higher on distress levels than males made this combined variable even more interesting. Again, because no significant main effects were found with these variables, it is logical that no interaction effects were found. As stated with the previous hypothesis, the data to these subsets was not known and only reiterated what was determined by the individual factors by themselves.

Again, the purpose of this study was to determine whether or not spirituality had an effect on depression and anxiety in parents whose children were undergoing either oncology or hematological treatment. None of the analysis showed significant relationships with the independent measures of the BDI and BAI. Therefore, none of the research hypotheses were supported. There were several limitations of this study, not the least of which is that the overall N of the project may have been too low. The other critical constraint of the study is that the BDI and BAI may not have been appropriate measures of the construct of psychological resilience. Perhaps neither the BDI nor the BAI were robust measures for this particular sample to indicate a statistically significant relationship.

Nonsignificant Findings Reviewed

Nonsignificant findings are still quite significant (E. Galaif, personal communication, August 18, 2011). It is important to try and interpret the nonsignificant findings as it helps future researchers ask different scholarly questions. The construct of spirituality can be a very difficult construct to operationally define (Krok, 2008). There

can be a myriad of definitions, expectations, and understanding of what spirituality means to each individual. It could also be important to better understand if there are additional buffers, other than just spirituality, that quite possibly protected the participants from scoring higher on the BDI and BAI. Variables such as closeness and participation from extended family and coworkers could be very powerful and supportive in terms of dealing with emotional distress. The age of the participant may have an additional perspective in terms of how they have handled past emotional distress. Younger participants may not have had to endure as many emotionally difficult situations as that over their older counterparts, and therefore not have the emotional coping skills and strategies that are learned over time. In addition, both the physical health and the mental health of the participant can be factors that make individuals more resilient in terms of coping with stress. This is talked about in greater detail in the confounders section.

One possible reason why there were no significant results can be related to the confounders of this study.

Confounders

There are many possible confusing or perplexing variables that may have led to a lack of significance in the research findings. One particular confounder to this study is that there is no known information regarding if the participants had other children and if any of these children had medical complications. Dealing with a single child may be viewed as easier in terms of being able to redirect so much focus on the only child and not feeling torn or guilty in trying to still emotionally connect and parent additional siblings. Also, the mental status of the participants prior to their child starting cancer or

other blood related illness treatment was not known. Weissman (2007) indicated that at any given time nearly 10% of the population suffers from depression. If that were the case for this particular study, one would assume that nearly five of the participants were struggling with depression. It might be helpful to have a more thorough mental health exam for participants to get a more accurate metal health baseline. It is also important to address additional confounders to this research. The broad definition of spirituality, along with the broad descriptions used in the DSES, can limit the true nature of how an individual defines spirituality in their own lives. Another confounder in this research was marital status. It is very difficult to know how single parents respond to this kind of stress related to those participants who are married. Having a partner to emotionally lean on can be very helpful. This might explain the paradoxical results with gender in terms of males actually scoring slightly higher on levels of depression and anxiety compared to females in this particular study. Personal researcher bias can be very strong especially when the topic of spirituality is such a personal matter. Regardless of how objective this researcher proposed to be during his research, the nature of his own spirituality is very personal and subjective. Self-report bias can be prevalent as well. Even though this researcher never handed out or mailed any of the packets it is possible that participants answered questions the way they thought this researcher would want them to. It is also possible that participants elevated their educational status on the demographic questionnaire as to not feel embarrassed or inadequate in regards to their educational background and possibly even their age.

Implications for Social Change

Past research and past exploration has provided many forms of vital information. Individuals and/or groups can look back and learn from history's mistakes, marvel at her achievements, and most of all - pioneer change for the future. One of the most important aspects of being a scholar practitioner is the quest for scientific discovery. Many times this quest for discovery comes from chance happenings. Take for instance the discovery of penicillin, x-rays, and plastic. All of which were discovered by accident. Scholarly research starts with a plan and gives indication for either an acceptance for that initial plan or the realization for continued work. This particular study ventured to understand the interaction between levels of spirituality and scored levels of depression and anxiety. The medical model greatly supports the use of research to improve the quality of patient care, to find cures for disease, and to prolong life itself. Figuratively, this research hoped for the same.

As indicated in chapter 1, being diagnosed with cancer is no longer an automatic death sentence. Not only is the pediatric population being diagnosed with cancer or blood related illnesses at a greater rate, but the treatment being used, and the cures for cancer are allowing the pediatric population to beat one of the most deadliest diseases known to this population. Chapter 2 discussed the importance of understanding the underrepresented population of adults whose child is being treated for cancer or blood related illnesses. The more the medical community understands how to meet the systemic needs of parents it is possible that the medical journey of the child can be positively affected. Social change implications include the need for more precise

measures of psychological resilience to extend our knowledge about the role of spirituality in the face of life-threatening illness. The implications for positive social change include the fact that the more parents understand their own psychological makeup, the more effective they can become in meeting their child's emotional and psychological needs.

Recommendations for Action

Spirituality is a complimentary and alternative form of medicine. There is no doubt that spiritual assessments are being used in both the hospital setting and primary care setting. Spirituality has been ignored when it comes to the parent of the identified patient. No matter what this research concluded, the need for spiritual assessments will remain, will be fine-tuned, and will be extremely useful. This study set out to promote positive social change initiative through a better understanding and possible relationship between spirituality in a healthcare setting and psychological factors such as depression and anxiety. Although there were no correlations between spirituality and depression and anxiety, much was learned about the absolute importance of continued research in this area. Past research indicates that spirituality is important to most people. The more research indicates to what extent spirituality is important to parents who are going through extremely stressful times while their child is going through cancer or blood illness treatment might greatly add to the research indicating that complimentary and alternative forms of medicine are highly significant forms of overall treatment. Future research could focus on the role of spirituality as a complimentary form of medical treatment for medical caregivers in terms of other mental health issues such as insomnia

and obsessive-compulsive disorder.

Limitations

By nature, the definition of spirituality, the purpose of spirituality, and the practice of spirituality are very personal concepts that may not be quantifiable given their subjective nature. Most individuals are very private about their spirituality and see spirituality as a personal matter. There are many ways to operationally define spirituality (religious definitions, humanistic definitions, and new age or eclectic definitions). One limitation to this study was the broad definition of spirituality: Spirituality is an evolutionary component, based on a continuum that is not seen but is only understood by each individual and often an underlying entity of one's personal identification. (Underwood, 2006; Krok, 2008). It may be beneficial to narrow the specific definition for future research.

Another limitation to this study was the sample size. There were not equal ends with some of the variables. Take duration of treatment (DOT) for example. Although the cutoff variables appeared to be equal there was still a very wide rang of treatment time for individuals that were treated for greater than 24 months. The general principles of the generalized adaptation syndrome state that the longer individuals are under stress the harder it is for their body and mind to recover (Derevenco, 2009; Tache & Brunnhuber, 2009). The assumption here is that parents who have children in longer term treatment (greater than 2 years) could very well respond to stressful situations differently than parents whose children were only in treatment for less than two years. A

larger sample size could help equalize the distribution and better understand the longer term effects of depression and anxiety on the parent.

In addition to limited sample size would be the sampling method used. Convenience sampling was used for this study. There were other large pediatric oncology and hematology practices in the area that refused any research to be conducted by outside researchers. Stating it a different way, they only allowed practitioners on staff from their facility to conduct research. This greatly reduced the sampling procedures. Therefore, convenience sampling was the most cost effective and time effective form of sampling. The hospital where the research took place is in a middle class part of the county where socioeconomic status is not as likely to represent the general population. Random sampling across different counties and even different parts of the United States would help represent different religious and spiritual affiliations along with better ethic representation.

Future Recommendations

Even though it might be clear that there is a correlation between depression and anxiety the variables of depression and anxiety may not be good indicators of what makes an individual more or less psychologically resilient. Future research could focus on other measurable variables such as sleep patterns, appetite changes, closeness in relationships, and mood changes. It could also be imperative to better understand if there are other unknown confounding variables that quite possibly protected the participants from scoring higher on the BDI and BAI.

In conclusion, this study could become a springboard for much-needed continued research. It is vital to better understand what parents of children going through oncology or hematology treatment are going through in order to better assist them in handling what is happening with their children. Spirituality was the dependent variable in this study, but future studies could use other dependent variables as well and then measure levels of depression and anxiety: marital status, family income, and emotional support systems to name a few.

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Appendix A – Letter of Cooperation

Pediatric Cancer and Hematology Center
XXXXXXXXXXXX
XXXXXXXXXXXX
XXXXXXXXXXXX
XXXXXXXXXXXX
XXXXXXXXXXXX

12/03/10

Dear Kurt Soell,

Based on my review of your research proposal, I give permission for you to conduct the study entitled "Spirituality and Depression in Parents with Children in Oncology or Hematology Treatment" within the Pediatric Cancer and Hematology Center. As part of this study, I authorize you to (1) use XXXXXX, our Child Life Specialist, to mail out all research questionnaires and (2) leave research packets in our office to be picked up directly. Individuals' participation will be voluntary and at their own discretion. We reserve the right to withdraw from the study at any time if our circumstances change.

I confirm that I am authorized to approve research in this setting.

I understand that the data collected will remain entirely confidential and may not be provided to anyone outside of the research team without permission from the Walden University IRB.

Sincerely,

XXXXXXXXXXXX

Appendix B – Implied Consent Form

You are invited to participate in a research study of how spirituality has an effect on depression and anxiety of parents whose child is being treated for cancer or blood related illnesses. Any parent whose child is receiving any level of therapy (ongoing chemotherapy treatment, maintenance chemotherapy, non-cancerous blood disorders requiring ongoing IVIG treatment, or children who require off treatment aftercare via yearly or semi-annual checkups) will be encouraged to participate. The purpose will be to discover possible correlations with anxiety and depression based on one's spiritual assessment. This form is part of a process called "implied consent" to allow you to understand this study before deciding whether to take part.

This study is being conducted by a researcher named Kurt Soell who is a doctoral student at Walden University.

Background Information:

The purpose of this study is to examine the relationship between spirituality and parents' levels of depression and anxiety during their child's hematological or oncology treatment.

Procedures:

If you agree to be in this study, you will be asked to:

Fill out demographic sheet.

Complete the Daily Spiritual Experience Scale (DSES).

Complete the Beck Depression Inventory (BDI).

Complete the Beck Anxiety Inventory (BAI).

Return one demographic sheet and three test measurements with supplied self addressed stamped envelope back to Kurt Soell.

The total time to fill out the demographic sheet and three questionnaires should take less than 15 minutes.

Voluntary Nature of the Study:

Your participation in this study is voluntary. This means that everyone will respect your decision of whether or not you want to be in the study. No one at Pediatric Cancer and Hematology Center will treat you differently if you decide not to be in the study. If you decide to join the study now, you can still change your mind during the study. If you feel stressed during the study you may stop at any time.

Risks and Benefits of Being in the Study:

Each participant should be reminded of the possible emotional intensity of this study. Regardless of the researcher's intentions or the participant's availability, participating in this research can possibly bring about many unresolved emotions and feelings about what they are experiencing as parents and how parents feel about what their kids are experiencing while going through treatment.

The desire is that the information gathered in this study will contribute to existing literature on this topic and will enhance social change initiatives through a better understanding of the relationship between spirituality and the hope it instills within parents to reduce psychological factors such as depression and anxiety. The variable of

spirituality as a form of complimentary and alternative medicine may be a largely underappreciated attribute on the individual level but also on the overall effectiveness on a community level as well.

As the participation of this study could bring about strong emotions, if any participant needs additional outpatient counseling they may contact XXXXXXXXXX.

Compensation:

There is no compensation for participation in this study.

Confidentiality:

Any information you provide will be kept anonymous. The researcher will not use your information for any purposes outside of this research project. Also, the researcher will not include your name or anything else that could identify you in any reports of the study.

Contacts and Questions:

You may ask any questions you have now. Or if you have questions later, you may contact the researcher via phone (xxx-xxx-xxxx) and/or email (xxxx.xxxx@waldenu.edu). If you want to talk privately about your rights as a participant, you can call Dr. Leilani Endicott. She is the Walden University representative who can discuss this with you. Her phone number is 1-800-925-3368, extension 1210. Walden University's approval number for this study 01-24-11-0189991 and it expires on January 23, 2012.

Participants may keep this implied consent form for their own records.

Statement of Consent:

I have read the above information and I understand the study well enough to make a decision about my involvement. By returning the enclosed documents I am indicating my agreement to the terms described above.

Appendix C – Demographic Sheet

Parent Demographic Information
(please have each parent fill out their own demographic sheet)

Gender of Parent:	Male Female
Age of Parent:	_____
Marital Status of Parent:	Single Married Separated/Divorced Widow/Widower
Specific Diagnosis of Child:	_____
Date of Child's Diagnosis:	_____
Level of Current Treatment: (please circle)	Currently Undergoing Chemotherapy Currently Undergoing Maintenance Chemotherapy Non-cancerous Blood Disorder Requiring Regular IVIG Treatment Off Treatment (with check-ups) less than six months Off Treatment (with check-ups) greater than six months
Educational Background of this Parent: (please circle)	Did Not Graduate from High School High School Graduate Some College Credit Trade School Undergraduate Degree Graduate Degree Other: _____

Curriculum Vitae

KURT D. SOELL, MA, LPC, NCC
St. John's Mercy Medical Center, 607 South New Ballas Rd., Suite 1430 St. Louis, MO 63141
314-504-8388 – office / 314-251-4565 - fax

EDUCATION: **Walden University – Minneapolis, MN 2006 – Present**
PhD Student – General Psychology – Education Track
Current GPA: 4.0
Anticipated Graduation Date: 08/11

The Haelan Center – St. Louis, MO 1999-2003
Post Graduate Training
Clinical Counseling – Staffing/Professional Orientation

Lindenwood University, St. Charles, MO 1996-1999
Master of Arts in Counseling Psychology
GPA: 4.0
Member of Chi Sigma Iota – National Honor Society
Student Member of American Counseling Association

University of Missouri – Columbia, MO 1985-1989
Bachelors of Science in Human Enviornmental Sciences
Deans List
1987 - Lieutenant Governor – Residential Living

WORK EXPERIENCE:

3/02 – Present **Kurt D. Soell, MA, LPC, LLC – Owner, St. Louis, MO**
Private Practice - Psychotherapist
Individual, couples and family therapy
Work with specific schools, and judiciary groups for treatment planning
Teaching Instructor for Family Practice Residents at St. John's Mercy Medical (2002 & 2003)
Community Education for parents, teachers & organizations

12/99 – 3/02 **Sports and Family, Inc., - Partner, St. Louis, MO**
Private Practice - Psychotherapist
Individual, couples and family therapy
Sports psych consulting with individuals & teams
Public lecturing with leagues, coaches, & parents

3/99 - 6/01 **St. John's Mercy Medical Center, St. Louis, MO**
Intake Counselor - Access Center
Psychiatric intake for the hospital and emergency room
Recommend behavioral health treatment options for patients
Worked directly with Managed Care Companies

Referral source for community

6/96 – 3/99 **St. John's Mercy Medical Center, St. Louis, MO**
Psychiatric Technician – Inpatient/Outpatient Psych
Assisted medical team with daily orders & procedures
Developed and implemented programming for group therapy activities
Worked with families for discharge planning
Responsible for treatment plans for patients
Worked with patients and Psychiatrists to develop goals

1/98 – 8/98 **Logos School, St. Louis, MO**
Adolescent Therapist (Intern)
150+ counseling hours, including individual, family & group therapy
Aided in treatment planning, crisis prevention/intervention, individualized educational plans (IEPs), and consultation with other therapists

AFFILIATIONS:
Licensed Professional Counselor
Licensed by the State of Missouri
Nationally Certified Counselor
Certified by the National Board of Certified Counselors
Medical Staff - Allied Health Professional – St. John's Mercy Medical Center
Member for Association for the Advancement of Applied Sports Psychology
Monthly contributor in *Parenting Network Newsletter*
Periodic contributor to *West County Kids* in the St. Louis County Journals