

ST. STEPHEN'S COLLEGE

RELEASE FORM

NAME OF AUTHOR:

Leigh Amber Teghtmeyer

TITLE OF THESIS:

CLIMBING THE MOUNTAIN TOGETHER: DESCRIBING THE SPIRITUAL
EXPERIENCE OF COUPLES WHO HAVE A CHILD WITH CANCER

DEGREE:

MASTER OF PSYCHOTHERAPY AND SPIRITUALITY

YEAR DEGREE GRANTED: 2012

Permission is hereby granted to St. Stephen's College to reproduce single copies of this thesis and to lend or sell such copies for private, scholarly or scientific research purposes only. Where the thesis is converted to, or otherwise made available in digital form, St. Stephen's College will advise potential users of the thesis of these terms.

The author reserves all other publication and other rights in association with the copyright in the thesis, and except as herein before provided, neither the thesis nor any substantial portion thereof may be printed or otherwise reproduced in any material form whatsoever without the author's prior written permission.

Signature

ST. STEPHEN'S COLLEGE

CLIMBING THE MOUNTAIN TOGETHER: DESCRIBING THE SPIRITUAL
EXPERIENCE OF COUPLES WHO HAVE A CHILD WITH CANCER

By

Leigh Amber Tegtmeyer

A thesis submitted to the Faculty of St. Stephen's College
in partial fulfillment of the requirements for the degree of

MASTER OF PSYCHOTHERAPY AND SPIRITUALITY

Edmonton, Alberta
Convocation: November 5, 2012

ST. STEPHEN'S COLLEGE

MASTER OF PSYCHOTHERAPY AND SPIRITUALITY PROGRAM

The undersigned certify that they have read, and recommend to the Academic Senate of St. Stephen's College for acceptance, a thesis entitled *Full Title of Thesis* submitted by Full Name of Student in partial fulfillment of the requirements for the degree of Master of Psychotherapy and Spirituality.

Dr. Margaret DeJongberg, Thesis Supervisor

Dr. Rhea Plouffe, Internal Examiner

Dr. Karen Massey, External Examiner

Date: November 5, 2012

DEDICATION

I dedicate this to my Mom, Karen Mary Lee Teghtmeyer; to my Dad, Roger Henry Teghtmeyer; to my three brothers, Matthew, Patrick and Jonathan; and to my cousin Nancy, all of whom provided loving support before and during my Masters Degree.

ABSTRACT

The purpose of this study is to provide initial evidence to describe how spirituality is involved in the experience of couples who have a child with cancer. This study used an Interpretive Description (I.D.) method which was designed to study health and illness. The outcome is a description of an experience from the viewpoint of the people who have lived it. It is intended that such a description will allow for a greater understanding of how supportive interventions may improve adjustment and healing for the whole family. Three couples were recruited to participate in a 90 minute semi-structured, open-ended interview. Cycles of spiritual dwelling and spiritual seeking were identified as evidence of spiritual transformation in the couples. The strength, trust and reliability in the couple relationship were found to support the process of spiritual transformation.

Keywords: childhood cancer, spirituality, couples, spiritual seeking, spiritual dwelling

ACKNOWLEDGEMENTS

I would like to thank my thesis supervisor, Margaret deJongBerg, for all of the meetings, listening and support that she gave me throughout the writing of this thesis.

I would also like to thank all of the couples who gave me the honour of sharing their personal experiences with me.

TABLE OF CONTENTS

Chapter One: Introduction	1
Chapter Two: Literature Review	4
Chapter Three: Methodology	24
Chapter Four: Findings	41
Chapter Five: Discussion	73
Chapter Six: Conclusion	97
Bibliography	99
Appendix 1: Demographic Information	106
Appendix 2: Recruitment Newsletter Article	107
Appendix 3: Recruitment Email	108
Appendix 4: Participant Information Letter	109
Appendix 5: Consent Form	111
Appendix 6: Interview Guide	112

Chapter One: Introduction

In 2009, it was estimated that 1,300 children under the age of 19 would be newly diagnosed with cancer (Canadian Cancer Society [C.C.S.] Steering Committee, 2009). A cancer diagnosis in a child results in significant distress for the child who is diagnosed, the parents, siblings and to a lesser degree the extended family as well (Barbarin, Hughes, & Chestler 1985; Lavee & Mey-Dan, 2003; Murray, 2000; Patterson, Holm & Gurney, 2004; Sherman & Simonton, 2001). “Many families discover that their lives have been transformed in unanticipated ways by their experience with cancer- goals and priorities, identity or spiritual values may have shifted” (Shermon & Simonton 2001, p. 194). Studies have shown that the parents’ marital relationship can significantly affect not only how the child with cancer adjusts, but also how the whole family functions and how they cope psychologically (Cummings, 1994; Lavee & Mey-Dan, 2003; Varni, Katz, Colegrove & Dolgin, 1996). Although some research has shown that parental coping and the amount of distress experienced by parents during childhood cancer is lessened through spirituality (Cardella & Friedlander, 2004; Nicholas et al., 2009; Patterson et al., 2004; Schneider & Mannell, 2006), to date there has been no research that explores how spirituality functions within these couple relationships. This study will examine spirituality in the couple relationship. The focus on the couple relationship has been chosen with a perspective that the strength of the couple relationship has been found to provide a foundation of stability for the whole family (Clarke-Steffen 1997; Howes & Markham, 1989; Lavee & Mey-Dan 2003; Varni et al., 1996).

Research Question

In this qualitative study one specific area of couple functioning for families going through a childhood cancer diagnosis will be addressed, namely the couple's spirituality. With the goal of creating a description of the experience as a couple, the study will extract common themes and identify areas of exceptionality. It is intended that such a description will allow for a greater understanding of how supportive interventions may improve adjustment and healing for the whole family. The proposed question for research is:

How do couples describe their spiritual experience when their child is diagnosed and treated for cancer?

Sub-questions to include will be:

1. What is the couple's recollection of how they described spirituality before the cancer diagnosis?
2. How does the couple currently define spirituality?
3. Are there critical aspects of spirituality that are shared by the couple?
4. Do couples influence each other's spiritual journey and if so how?

Personal Interest in the Subject

My interest in the area of childhood cancer and its influence on the family comes from a combination of professional and educational experience. While working in peer support at the C.C.S., I provided psycho-social support to adults with cancer and parents of children with cancer. As I walked the journey with them, I discovered that once treatment was complete many individuals did not know how to assimilate the experience

because it was more profound than anything they had previously experienced. As well, clients told me about being confronted with their own mortality and the resulting emotional process that followed. The experiences described included times that were intensely isolated and other experiences that demonstrated human interpersonal connectedness.

Before this time I struggled to understand how couples endure the emotional challenges of having a child with cancer and, moreover, how it seemed that many developed stronger and closer family bonds because of it. Working with Moms and Dads in separate support groups, I heard the stories of personal struggle that occurred at the same time as they were attempting to support their partner and families. Many of my clients spoke about the ‘hidden gifts’ in the cancer journey, including such things as intensified relationships, increased trust and faith in their relationships, living in the moment, finding meaning in life, and re-evaluation of priorities. Without realizing it at the time, I learned that these positive outcomes are similar to what many describe as a spiritual transformation.

As a student in a pastoral counselling program, I was curious to know how my education and professional relationships with clients affect my personal-spiritual development. I have recently started to examine my own history of spirituality. I was never baptized in a faith tradition as an infant. My mother converted to the Baptist faith as a youth, and believed that her children should decide as adults whether they wanted to belong to a faith tradition. My father did not belong to a religious community, and although as children we would occasionally go to church with my Mom, my Dad never

attended with us. I grew up knowing that I believed in God, and knowing that God loves me. I recall that as a child I enjoyed singing in church and that it often brought tears to my eyes and gave me a feeling of inner peace. That, to me, was the experience of being in relationship with God. The inconsistency with which we attended church meant that I did not have a solid understanding of the Bible. I did not know how, or have the language needed to reflect upon the spiritual experiences I had.

As I began to research topics for my master's thesis, I knew that I wanted to follow my curiosity to explore how spiritual transformation occurs. I was interested to know more about spiritual development from both a personal perspective and also in relation to clients. As a result, I have chosen to combine my educational interest in family systems and individual development with my professional interest in psychosocial support for parents dealing with childhood cancer. I have chosen to research how spirituality functions within the couple relationship as each person attempts to process such a deep, meaningful and personal experience.

Chapter Two: Literature Review

Cancer is a serious illness that can lead to death, though recent statistics show that mortality rates are declining in all cancers including childhood cancer (C.C.S. Steering Committee, 2009). Indeed, most children who develop cancer now will survive the disease: "For all childhood cancer combined, the five-year observed survival proportions (OSP) was estimated to be 82%" (C.C.S. Steering Committee, 2009, p. 49). Even though survival rates continue to increase, the news of a cancer diagnosis in a child is devastating and the impact is extensive for every member of the family (Barbarin et al., 1985; Lavee

& Mey-Dan, 2003; Murray, 2000; Patterson et al., 2004; Sherman & Simonton, 2001).

While early studies concentrated solely on the child who is diagnosed, researchers have recently broadened the focus to include other family members. According to Patterson et al., (2004), 100% of families experience strain as a result of the cancer diagnosis, with the most significant response relating to the intense emotional reaction experienced by the parents. Emotional reactions included feelings of numbness, helplessness, fear of death and grief for the child's losses (Patterson et al., 2004). Clarke-Steffen (1997) demonstrate that the parents' reactions and attitudes determine the way a family responds to childhood cancer. Further results from a study by Lavee and Mey-Dan (2003) show that the parents' marital state has "major significance for functioning of the whole family, the psychological well-being of all family members, and the child's adjustment to the illness" (p.261). As much as managing diagnosis and treatment are difficult, the impact of childhood cancer does not end once treatment has concluded. While surviving the initial cancer, children may experience ongoing medical concerns related to heart, lungs, thyroid, kidneys, puberty, fertility, growth and development (Canadian Cancer Society, 2009). As survivorship increases, a growing number of families are faced with the challenge of returning to "normal" life after the diagnosis and treatment and have a growing need for ongoing support.

Impact on the Family

The stress of childhood cancer has a significant impact on the family because of the multiple areas of life that are affected and the intensity of emotion involved (Lindahl Norberg & Bowman, 2008; Patterson et al., 2004; Sherman & Simonton, 2001). Patterson

et al. (2004) studied the impact that childhood cancer has on the family and identified five major categories of strain: cancer-related strains; child strains; family strains; community strains; and health-care system strains. Each area of strain has significant impact on the parents, as they try to cope with multiple demands, emotions and needs of others. Further, these authors found that parents experience additional strain as a result of dealing with how others are managing. Some of these additional concerns include the parent-child relationship, sibling issues, conflicts in the extended family and avoidance from friends and the community (Patterson et al., 2004). These concerns may be classified as functional, practical and emotional stressors.

Functional stressors. The distress felt by one member of the family may impact other members of the family. Often family members will try to reduce the pain that their loved ones are feeling. This behaviour can lead to disrupted or stilted communication between family members (Sherman & Simonton, 2001). In an attempt to protect one another family members disguise their own distress or withhold information from one another. “Often, the result of these protective strategies is that family members are left feeling isolated at precisely the time when greater cohesion would be helpful” (Sherman & Simonton, 2001, p. 195).

Practical stressors. Parents also confront practical challenges and changes such as financial pressures, role changes, the need to make medical decisions and negotiate the medical system. These challenges and concerns extend beyond the cancer treatment, leaving an impact that may be felt for years (Patterson et al., 2004).

Emotional stressors. Lindahl Norberg & Bowman, 2008 studied post-traumatic

stress symptoms in parents of children diagnosed with cancer. They discovered a greater predominance of depression and anxiety in parents during the first years after diagnosis as compared to parents of children without the illness. The study found that the elevation in the father's anxiety can last for up to 5 years after diagnosis. Continued worries about cancer might include intruding thoughts about the child's cancer and the trauma that was experienced during treatment. Further, the study reported that approximately 10% of parents studied experienced a level of intrusive thoughts comparable to patients who suffered from Post-Traumatic Stress Disorder (Lindahl Norberg & Bowman, 2008).

Patterson et al. (2004) proposed a theoretical model wherein families attempt to balance the demands of a childhood cancer diagnosis with their capabilities. The adjustment phase of this model shows that in the beginning of the cancer journey families are frequently out of balance, with the demands out-weighting the resources. This balance is affected by situational meaning, family identity and world view. Their study suggested that there are a number of ways in which families make meaning out of their experience with childhood cancer, including "being positive and hopeful, believing in God and in doctors, viewing the circumstances of others as worse than their own, and blocking out what is too painful by denying the possibility of death or living only in the moment" (Patterson et al., 2004, p. 405).

While parents are impacted in many ways by the diagnosis of childhood cancer the vast majority cope with the stressors. This coping occurs in a number of ways including social support, information seeking, gaining medical understanding, spousal support, maintaining family cohesion and spirituality (Barbarin et al., 1985, Goldbeck, 2001).

Spirituality

The current study will focus on the role that spirituality plays as a coping mechanism for parents. Although most people fear the thought of dealing with a cancer diagnosis, surprisingly many families who have experienced it will say that there are positive aspects mixed in with the negative (Clarke-Steffen, 1997). Some of the positive effects of experiencing a journey with cancer are reported to be an increased meaning of life, a deepened religious faith and an increased closeness in relationships (Barbarin et al., 1985, Spilka, Zwartjes & Zwartjes, 1991, Clarke-Steffen, 1997, Patterson et al., 2004). These effects may be understood as dimensions of spirituality.

Aspects of spirituality. Many obstacles prevent spirituality from being researched from a scientific perspective. Defining and measuring spirituality is an extremely difficult task. Schneider and Mannell (2006) studied parents of children with cancer and the role of spirituality in coping. The outcomes showed that spirituality was experienced in unique and personal ways. The spiritual experience is often considered to be beyond words; people have difficulty describing it in a way that others can understand (Schneider & Mannell, 2006). This makes it challenging to find commonalities among experiences that result in a common definition of spirituality. It is necessary to explore unique personal definitions with individuals when researching spirituality. The definitions may include such constructs as hope, faith, self-transcendence, belief in a higher power, meaning of life, beliefs about death, as well as religious beliefs and practices (Efficace & Marrone, 2002; Mansager & Eckstein, 2002; Schneider & Mannell, 2006; Strang, Strang & Ternstedt, 2001; Woodgate & Degner, 2003).

Defining Spirituality. In much of the literature regarding spirituality and health, there is a separation between the concepts of religion and spirituality. This difference is explained well in the study of existential support for brain cancer patients by Strang, Strang and Ternestedt (2001):

Religion comes from the Latin *religio*, which means to tie together, where life is bound to or is governed by a God... For believers, a living faith in a God can function as an explanatory model for suffering and death, and create hope and security. "Spiritual" is derived from the Latin *spiritus*, which is to breathe or make living, and is ultimately a deep human dimension, irrespective of belief...

Spirituality can be described as a conviction that gives meaning to life, illness and death, and that guides the individual. (Strang et al., 2001, p.626)

For the purposes of this study, religion is defined as a tradition of faith pertaining to an organized group of people who all ascribe to the same set of beliefs and practices. Even though religion may be a part of spirituality, spirituality can encompass more than what is outlined in any specific organized religion. "While religion is commonly identified with organized and communal places of the sacred, spirituality is marked by the deeply personal experience of finding one's place in the world" (VanKatwyk, 2003, p.12).

Spirituality may also be described as that which is associated with the human spirit. Woodgate and Degner's (2003) study on keeping the spirit alive with children who had cancer and their families, described the characteristics of spirit as: 1) a mindset that reflects how one looked at life and helped them "get through the rough spots", 2) a force within the individual which created the will to persevere, 3) a passion for life and living,

4) a need to feel connected with others (p.110). Whether by positive mindset, a persevering will, a passion for life, a need to be connected with others, or any combination thereof, it seems that the spirit contributes to the way that children and families cope with the illness. “As long as the children were able to maintain their spirit to some degree, parents, children, and siblings were able to get through the cancer trajectory” (Woodgate & Degner, 2003, p.114). The theologian Paul Tillich (1963) describes spirit as the direct intervention of God within an individual. “Spirit is the mysterious substance; it is not a part of God. It is God Himself...God as present in communities and personalities, grasping them, inspiring them and transforming them” (p.84). One may wonder if developing a personal, intimate relationship with the Divine and allowing it to influence self and others is instrumental in coping.

Theological understanding of couple relationships.

How can communion grow out of solitude? We have seen that we can never reach the innermost center of another being. We are always alone, each for himself. But we can reach it in a movement that rises first to God and then returns from Him to another self. (Tillich, 1963, p. 24)

The purpose of this research is to understand how each individual in a couple grows and develops through the relationship with each other and through spirituality. To understand this, it is essential to first explore the theological beliefs about couples and relationships. In the book “Becoming Married” (1993), Anderson and Fite outline five themes in the theology of marriage. These themes include sacramentality, indissolubility, intentionality, fidelity and covenant. These themes reflect the commitment and love of

both individuals and a promise of God's grace in the relationship (Anderson & Fite, 1993). In a study on marriage and religious constructs, researchers found that couples who had perceptions of sacred qualities in the marriage and active participation in religion were less likely to engage in verbal aggression and stalemate strategies to handle marital conflict (Mahoney et al., 1999). Gerkin (1979) wrote that the covenant of marriage is strengthened with time: "In the beginning this covenant may be weak and fragile, easily broken apart by the conflicts of the partners' separate expectations and desires for the marriage" (p.306).

According to the theology of Anderson and Fite, the covenant is strengthened as long as the couple is able to maintain an equal distribution of power, continue to view each other with positive regard and allow for personal growth (1993). The marital covenant is strengthened and maintained by nurturing a hospitable environment in the marriage. "It is a context in which affirmation is unconditional and expectations are explicit. It is a holding environment in which there is freedom to have 'a room of one's own' and freedom to be together" (Anderson & Fite, 1993, p.157). The couple's capacity to create such a holding environment may be influenced by past interactions in their family of origin (Grant, 2001, Noffke & Hall, 2007, Sandage & Shults, 2007). Unfortunately, as Anderson and Fite (1993) point out, couples are not always conscious of how their unmet needs from childhood impact the expectations put upon their partner and the marriage itself.

Conceptual Framework

Relational Model of Spirituality

Shults and Sandage (2006) describe a relational model of spiritual transformation utilizing both psychological and theological resources in contemporary thought. “A relational model of spirituality highlights the reciprocal influence of spirituality and interpersonal relationships in human development” (p.263). The model is a combination of three components: the “three way model”; the crucible theory; and, attachment theory. Together with the theological understanding previously described, this model will provide a framework for exploring the complex relationship between two people as they struggle through the crisis of cancer in their child. The goal of this study is not to prove or disprove this theory, however the theory gives a starting point for listening to the couples’ experience. In Interpretive Description (I.D.) methodology, this is called theoretical scaffolding (Thorne et al., 2004, Thorne, 2008).

According to Sandage and Shults (2007), although spiritual development can bring about positive, healthy change for individuals the transformation often begins during a problematic period of struggle and darkness. Because the outcome is not always known, individuals rely on their sense of faith:

In the situation of crisis we are confronted with our human vulnerability, our finitude, the utter impossibility of our deepest hopes and wishes. Either persons must defend themselves against the contradiction with whatever human defense is possible, be that denial or heroic courage, or they must open themselves to the vulnerability of the unknown future, trusting in the power and care of God coming

out of the change and contingency of the unknown. (Gerkin, 1979, p.32)

A relational model of spirituality also accounts for the occasions where spirituality is not experienced as positive. Some individuals may go through periods in their lives where they feel resentment, rejection, abandonment, and anger towards God. The immediate response to a transition in spirituality may be increased suffering, while the individual is confronting painful realities. “ A relational and developmental view opens conceptual space for considering the wide variety of ways people relate to the sacred, including trust, disappointment, questioning, repair of conflict, avoidance, surrender and many others” (Sandage and Shults, 2007, p.263).

Three Ways Model. Shults and Sandage (2006) combine the knowledge of theology and psychology in order to outline a theory that would explain the process of spiritual transformation and still respect both traditions. The theological aspect of this model is based upon the classic Christian model of “three ways”: purgation, illumination and union. This “three ways” model has been described by various writers and theologians in history, and is explained more in depth by Benedict Groeshel (1989). “The spiritual journey (three ways model)...has been thus described by writers from different cultures through the centuries” (Groeshel, 1989, p. 87).

The “purgative” way is often initiated during a dark period in a person’s life. It can be a painful experience of realization, when one discovers that the way she is living her life is not bringing happiness and fulfillment. There is a sense that something is missing, and the person begins to see that some of her strivings and attachments are

bringing greater unhappiness. “One awakens into a new awareness that one’s way of life is tending toward death” (Shults & Sandage, 2006, p.27). This awakening leads the person to “purge” some of the aspects of her life which are unhealthy. Rhea Plouffe (2005) describes this process as a belief transition. When a crisis occurs, individuals are faced with a new experience that does not correspond with current beliefs and thus it may be the impetus to questioning entrenched belief systems. “The search for meaning draws them to the basic issues of life, to the core questions of their existence. As they try to make sense of their situation by taking a journey inward, reflecting on the spiritual aspects of life they often discover that their beliefs no longer resonate with their experience” (Plouffe 2005, p.4). Purgation or belief transitions require that the individual becomes open to sacrificing the attachment to worldly goods and ideas which may be foundational to identity and perception of the world. “Unhealthy attachment to particular things becomes idolatrous, blocking intimacy with the absolute Beauty of divine life, which can never be reduced to finite imagery” (Shults and Sandage, 2006, p. 147). The process of letting go can be quite painful and may cause some to turn back toward the comforts of what is known. Individuals who follow the purgative way become open to the influence of the “illuminative” way.

The “illuminative” way involves opening oneself to the influence of God. It requires that the person relinquish some control and allow the presence of God to shed light upon his life. “This illumination transforms persons as they come to understand, perceive, and interpret themselves and the world in the ‘light’ of the divine presence” (Shults & Sandage, 2006, p. 27). The individual may experience a sense of peace and joy

as he surrenders to the experience of God. There is a changed perception of knowing, where the person relinquishes his sense of personal knowing in the world and begins to trust in an all-knowing God. It becomes easier for the individual to separate from his worldly attachments, once he is able to trust in God's knowledge and let go of his fear of the unknown.

Through the process of illumination the individual is able to build a personal relationship with the Divine, and move forward in a united partnership. This joining with the divine is known as the "unitive" way. Through relationship with the divine, the individual comes to experience life in a new way. This unitive way is difficult to describe; "words fail and thoughts evaporate as one attempts to describe the experience of union with God which comes to the very few who arrive at this way of infused contemplation" (Groeschel, 1989, p. 86). One might suppose that there are a limitless number of ways in which to interact with an Infinite God.

According to Shults and Sandage (2006), the "three way" model has been interpreted for different societies and cultures throughout history. Their goal was to interpret the model in such a way as to make it palatable in current times. The strength of their framework is the combination of theology from the "three ways" model with the contemporary psychology of crucible and attachment theories.

Transforming Spirituality. The transformation model of Shults and Sandage (2006) incorporates purgation, illumination and union as stages of spiritual seeking. The model uses concepts from Schnarch's (1997) crucible theory of sex/couple therapy, wherein stress and crisis are emphasized as growth opportunities for couples. Schnarch

proposed that couples move through alternating cycles of comfort and growth. Shults and Sandage (2006) altered this model to account for a similar pattern in spirituality. In their model, spirituality is viewed as a balance between dwelling in beliefs and traditions that are comfortable and seeking new spiritual experiences. A transition requires that the individual step out of the comfortable space and willingly experience anxiety and discomfort in pursuit of growth.

“Spiritual dwelling” is described as a period of complacency and comfort coming from associating with a particular community of people with like-minded ideas and values, often within a religious tradition. Although spiritual dwelling may include a sense of safety and comfort, it can also lead to disappointment and denial. If one resides in spiritual dwelling for an extended period of time, then beliefs and behaviours may become patterned and rigid. Paul Tillich touched on this concept when he explained that God is infinitely near and far, thus we must experience both in order to fully know Him. “Sometimes when our awareness of Him has become shallow, habitual- not warm and not cold- when He has become too familiar to be exciting, too near to be felt in His infinite distance, then he becomes the absent God” (Tillich, 1963, p.88). According to the model, when persons are in a period of detachment or denial they have a choice to remain in the spiritual dwelling and live with the feelings of boredom and disappointment, or take a risk and move into a stage of seeking.

The first step away from spiritual dwelling toward seeking is a leap of faith. The leap of faith takes an individual out of their comfortable dwelling place and into the unknown. This first movement is what is described as awakening in the purgative way,

where an individual must confront their current ways of being and believing. “Spiritual seeking” is described as a period of questioning and searching for new spiritual experiences and understanding. The process of spiritual seeking is achieved through the three ways of purgation, illumination and union. This leads to spiritual maturity, increased commitment and trust. Seeking is exciting while at the same time scary; an individual must have a safe environment in which to tolerate the anxiety of seeking or else he or she will return to the familiarity of spiritual dwelling.

There is anxious arousal when one enters this realm, and the anxiety intensifies as one enters into Confrontation. Confrontation is equivalent to the purgative way, where one confronts the self with the reality of how they are living. Defense mechanisms are removed and the individual is awakened to truth. This leads to growth and questing. “A person might start authentically asking new spiritual questions, pray or meditate in a new way, or explore a different spiritual practice” (Shults and Sandage, 2006, p. 33). The quest may lead to the illuminative way, which is characterized by spiritual self-soothing. As persons enter into greater relation with the Divine, they develop new understanding of the self and a greater openness to Divine influence. Although they might experience greater anxiety in letting go of control and reliance on God’s wisdom, they are able to sooth this anxiety and comfort the self with increased personal growth and commitment. This commitment leads to trust and intimacy with God in the unitive way. In union with God, “capacities for love and compassion are intensified” (Shults and Sandage, 2006, p. 35). This intensification of the relationship with God can be experienced as spiritual maturity in the forms of wisdom, justice and freedom.

An individual requires a certain sense of security to risk taking a leap of faith. It is possible that the couples will not go in the direction of a spiritual transformation. Even after someone has taken a leap of faith, they are still able to turn back to spiritual dwelling if the anxiety and arousal of spiritual seeking is overwhelming. Shults and Sandage allow for various possibilities in their theory, including the individual's choice to opt out of spiritual growth and return to the comfort and safety of spiritual dwelling. It is also possible for an individual to continue questing which leads to wandering and the limnoid space, which is defined as "the terrain of seeking extraordinary experiences outside the boundaries of any transformative relational containment" (Sandage & Shults 2007, p.267). A person may remain in the path of wandering for many years or even a lifetime.

The Crucible. Shults and Sandage (2006) suggest that the tension between spiritual dwelling and seeking is essential for spiritual transformation to occur and furthermore, the transformation can only happen in the context of relationships between self, others and God. A crucible is described as a container which holds an intense transformation and is able to safely contain the reaction that happens inside. The crucible theory developed by Schnarch (1997) maintains that relational systems go through periods of change and growth as well as periods of relative stability. Schnarch speaks to the couple relationship as being a crucible which can either sustain the growth, return back to the comfort of stability or break under pressure. An underlying assumption of the model is that individuals will usually be at different stages of change. Thus as one member builds in anxiety and makes a choice to leave the comfort of dwelling for the

growth of seeking, the other member is left to decide whether to follow. “Marital partners rarely change in a synchronous fashion, meaning that one partner usually embraces the growth cycle before the other, who often initially feels controlled by the changes” (Shults & Sandage, 2006, p. 32). How the couples negotiate such a challenge can depend upon known patterns of interaction and may require significant change.

Image of God. Building off a foundation of influences such as Bowlby(1969), Winnicott (1971), Bowen (1966) and Kegan (1982) the relational theory of Sandage and Shults suggests that entrenched patterns of relating established in childhood may be realigned through safe relationship with significant others and in relationship with a higher being. “The extent to which the human self is centered in loving relationship and the rich integration with its component parts, directly influences its capacity for intimacy with God and neighbor; and... is deeply influence by the intimacy it achieves with both” (Grant, 2001, p. 107).

A number of theorists have related the concept of attachment to spiritual development by proposing that a person’s attachment style may have an impact upon their image of God (Kirkpatrick, 1999; Hall, 2004; Noffke & Hall, 2007). This may be related to the development of a person’s self-image, which if associated with a secure attachment develops as one who is worthy of love and protection (Bowlby 1973). Some studies have shown that a person who has secure attachments in adult relationships is more likely to have an image of God as loving and present (Hall, Brokaw, Edwards & Pike, 1998), whereas those “who tend to experience others as critical and to emotionally withdraw to protect themselves are more likely to experience God as critical and to emotionally

withdraw from God when this experience occurs” (Hall et al., 1998, p. 310). Results from a study by Kirkpatrick and Shaver (1990) suggest that when a person undergoes a transformation of attachment, it will affect all attachments with others and God.

From an Object Relations perspective, the image of God is developed in the transitional space between self and other (Winnicott 1971, Rizzuto 1979). Ana Marie Rizzuto (1979) discussed the development of God-image as a mirroring process wherein an individual’s psychic transformation is reflected in a changing representation of God. To reach religious maturity, an individual must develop a representation of God which corresponds with lived experience. “It has to do with the individual’s total psychic transformation and reworking in each stage of the life cycle. Those who are capable of mature religious belief renew their God representation to make it compatible with their emotional, conscious and unconscious situation” (Rizzuto 1979, p.46).

According to Rizzuto, this process begins in infancy when a child starts to begin to separate and individuate from the maternal representation. The resultant space between self and other is a transitional space where all opposites reside. Ulanov (2001) explains that there is a freedom when an individual plays in the transitional space, he or she can rest at ease without pressure of claiming or rejecting oppositional ideas. “The space of playing offers us rest from the daunting ego-task of trying to keep together outward reality and inward wishes and hopes...we need not reconcile these opposites or hold them in tension” (Ulanov 2001, p.15). With God as a transitional object that changes to reflect the current, ongoing and ever evolving reality, the individual is able to integrate different aspects of the self. “Like a mirror- or like a mother!- the subjective-objective God reflects

our ego back to us in the fullness of its identity, whether personal or social” (Ulanov 2001, p. 23). Thus the willingness to explore alternate images of God results in both psychic and spiritual transformation (Rizzuto 1979).

Spiritual Transformation

Spiritual dwelling and spiritual seeking parallel the concepts of conservation and transformation in Kenneth Pargament’s work on religion and coping (1999). Pargament begins with the assumption that all people seek significance in their lives and that events in life are interpreted through the significance that is assigned to them (p.91).

“Significance is, in part, a phenomenological construct involving feelings and beliefs associated with worth, importance and value. It embodies the experience of caring, attraction or attachment” (Pargament, 1999, p. 92). Pargament (1999) argues that when an individual encounters an event in life, they conduct a “primary appraisal” to understand the level of stress that the event will hold. The primary appraisal consists of evaluating the threat to the person’s well-being. A “secondary appraisal” is involved when an individual begins to account for the resources and burdens he has which will help or hinder the process of dealing with the event. Based upon these appraisals the individual must choose whether to utilize their current strategies of coping, or to endure the upheaval of transformation. “Faced with life-shaking events, the individual must also choose between profound change and the status quo” (Pargament, 1999, p.199).

Usually people will struggle to keep a hold of their current beliefs and values as much as they are able to. Pargament describes this as conservation of significance, which can be accomplished in two ways, either preservation or reconstruction. When

conservation is not successful in coping, one might turn to transformation. Spiritual transformation requires a more intensive change to the system of relating to the sacred, sometimes called “second order” change. “First order change is limited to one’s current set of coping skills, whereas second-order change involves a more complex systemic transformation that changes coping strategies and ways of relating to a system altogether” (Watzlawick, Weakland & Fisch, 1974 as cited in Sandage and Shults, 2007, p. 264). Second-order change requires intensive changes to both the person and how they relate to God, which can explain the resistance to transformation unless it is really essential. “Transformation is difficult. It requires a shift in direction from old destinations that no longer seem viable to new, more compelling ones” (Pargament, 1999, p. 235).

The crucible theory proposed by Shults and Sandage (2006) developed out of Winnicott’s (1971) concept of “holding environments”, which referred to the relational environment of caregivers that nurtures an infant’s development, and Robert Kegan’s (1982) “culture of embeddedness”, which extend the concept to life long development. Kegan’s theory proclaimed that human development goes through alternating cycles of integration and differentiation. These themes are enhanced by Shults and Sandage in relation to spirituality.

Shults and Sandage (2006) refer to the neo-Bowenian definition of differentiation, “the capacity to balance both autonomy and connection in close relationships” (p. 180). When persons are able to differentiate, they have the capacity to be intimately connected to another and can soothe their own anxiety during times of conflict. Differentiation is necessary to tolerate a change to the system, or second-order change, which may be

initiated when a partner begins a cycle of spiritual seeking. One must be able to self-soothe the anxiety felt in relation to the change in agreed upon belief systems, yet still maintain intimacy with the partner. The capacity to differentiate is related to earlier formative relationships and the attachment style one developed as an infant.

The culmination of the above concepts result in a number of implications for spiritual formation proposed by Shults and Sandage (2006). The first implication is that “spiritual formation is passed on relationally” (p.176). This suggests that the form of family and community relationships communicate ways of relating to the sacred. Relationships with caregivers facilitate internal representations which suggest the security and trust that one expects in relation to the Divine. The second implication is that “spiritual formation is facilitated through quality apprenticeship relationships with mentors, teachers and spiritual guides” (p.177). The idea here is that relational capacity of people who are seen as authority figures is of greater importance than the content of what is being taught. Third, “spiritual formation requires relationships with attachment figures and communities that can both hold on and let go” (p. 177) thus simulating the function of secure attachment. Leaders, teachers, clergy, therapists and other potential attachment figures cannot allow their own anxiety to intrude upon their ability to hold on during “dwelling” periods and let go during periods of exploration or “seeking”. The fourth implication is that “spiritual transformation is often generated through relationships with persons and communities that wisely and intentionally face contradiction and foster change” (p.178). This suggests that communities that are resistant to change, or try to protect and rescue the members from conflict and struggle, will inadvertently impede

their growth. Groups must encourage diversity and tolerate differences without large degrees of anxiety and stress. The last implication is that “spiritual formation and transformation are given rootedness by families, communities, and other social networks that generatively remain in place” (p.179). This implies that groups must remain in place and open to returning members. In other words, individuals and communities must be open to seeking behaviours such as questioning, leaving and differentiating. Communities of embeddedness must be responsive to both dwelling and seeking:

Spiritual dwelling provides attachment security, rootedness, stability, clarity of meaning and a shared sense of community. Spiritual seeking is oriented toward the freedom of exploring new uncharted territory described or dreamed by prophets, mystics and healers. Spiritual seeking is represented by the more fluid themes of the journey, pilgrimage, and quest. Spiritual dwelling offers security whereas spiritual seeking offers freedom from constraint (Shults & Sandage, 2006, p.185).

Chapter Three: Methodology

Studying spirituality and its function within couple relationships is a relatively unexplored phenomenon in the research field. This research is unique in its attempt to study the couple’s spirituality and relationship within a health context. A qualitative approach was required to explore the gap between what is known about spirituality and what is known about family adjustment to childhood cancer. It was important to hear the stories of the individuals who had been through it in order to understand their perspective of the experience. The method of interviewing with couples was chosen as most

appropriate for this initial exploration. This research can be considered a pilot study of a small sample size and results can then be applied to further study to extrapolate to a larger sample.

Initial Preparation

“The way in which a researcher responds, the follow-up questions asked, the researcher’s intonation, their eye contact and body language will profoundly impact the way in which a participant tells their story (or doesn’t as the case may be), and the way in which that story is heard and recorded by the researcher” (Swinton & Mowat, 2006, p.60). Initial preparation for this study involved the researcher preparing herself for the transition from the clinical role that she was accustomed to using with clients toward a researcher role which was focussed on collecting knowledge from the participants.

“Essentially you are taking on the role of someone who does not know, who has entered the study participants’ world in order to know, and who cannot bring that expertise into shaping the conversation as it unfolds” (Thorne, 2008, p. 110). This involved a sense of “unlearning” the skills of empathetic listening which had been so carefully studied and practised in counsellor training.

The unlearning involved allowing participants to talk about their experience and being sensitive to their emotion without losing focus on collecting data. A counsellor might validate the person’s emotions by acknowledging that others feel the same way, or using psycho-education in order to assist a client. Neither of these techniques would be appropriate in a research interview. While skills such as clarifying, summarizing, and being curious remain useful as a researcher, one must be careful not to reveal personal

bias by agreeing or disagreeing with the participants. “What qualitative research interviews ask you to do is suspend the idea that you know or understand- to prompt for further clarification or elaboration rather than to signal that you understand completely” (Thorne, 2008, p. 115).

This process of “unlearning” the counselling skills and taking on interviewer skills in preparation for the interviews was aided by documenting personal emotions in the personal reflective journal. Reflexivity is the process wherein the researcher reflects on her values, biases, ways of knowing, and learning. Even in initial preparations, the researcher used the reflective journal to document potential pitfalls and fears associated with the process of interviewing, which continued to increase awareness during the actual interviews.

Data from the literature

This study will use an Interpretive Description (I.D.) method which was designed to study health and illness. This methodology emerged from academic nursing research as a method which reflects clinical experience (Thorne, Reimer Kirkham & MacDonald-Emes, 1997). According to Thorne (2008), the clinician’s quest for knowledge is driven by the desire to understand the complexity of human circumstance while managing health difficulties. This method fits with the practice of pastoral counselling which includes spirituality as an aspect within the complexity of human experience. The pastoral counsellor is another professional included in clinical practice. The goal of an I.D. study is to extract knowledge so that it can be used to create innovations in clinical practice (Hunt, 2009) and improve standard of living (Thorne, 2008). Unlike traditional methods

of qualitative research where the final outcome is development of theory, in a clinical setting the theory is not as important as merely knowing that certain behaviours may occur (Thorne et al., 1997).

According to Thorne, Reimer Kirkham and O’Flynn-Magee (2004), the philosophical underpinnings of I.D. parallel a naturalistic orientation similar to that of Guba and Lincoln (1982). A naturalistic paradigm assumes that humans are active in the creation of knowledge; thus, reality is subjective and can be interpreted in a variety of ways. Reality is viewed as contextual, holistic and multifaceted. Furthermore, it holds that the researcher is an active participant in the creation of knowledge, influences and is influenced by the interaction with research participants. The goal of such research is to develop understanding of the individual case; “generalizations are impossible since phenomena are neither time- nor context-free” (Guba & Lincoln, 1982, p.238). Knowledge of an individual case may inform how other similar cases are perceived, however the specific context of each future case will be taken into account in order to understand unique differences.

While I.D. is founded in a history of qualitative social science methodology such as ethnography, phenomenology, and grounded theory, it is distinctly different from these methods (Thorne, 2008). The I.D. researcher is informed by professional involvement with a client, and uses this experience as a way to study what is happening. This contrasts the phenomenological approach which holds that bracketing is an essential element to isolating the influence of the researcher, and it is also different from the ethnographic researcher who is immersed in the fieldwork to a greater degree than is necessary in an

I.D. study (Thorne, 2008). Likewise, the level of saturation and depth of coding required for grounded theory is unnecessary in I.D. research, because the intention is not to find a theory to explain all cases. Using inductive reasoning, I.D. research identifies themes and patterns out of observations from individual cases. As with all naturalistic inquiry methodologies, one cannot enter into I.D. research holding onto a preconceived theory. “While theory may play some role in assisting you to come up with such heuristics, the ultimate purpose is not theorizing but rather illuminating insight” (Thorne, 2008, p. 169). The outcome is a description of an experience from the viewpoint of the people who have lived it and it is used to inform change in clinical settings given the new understanding (Thorne et al., 1997).

Interpretive description in pastoral counselling. While Thorne (2008) uses I.D. to learn about the behaviours that occur within a nursing setting, the purpose in a pastoral counselling setting is to discover what happens to human experience when space is opened to allow for the grace of God (Grant, 2001). VanKatwyk argued that spiritual care is best understood within a clinical environment: “Theological education moved to the clinic of the hospital in the development of clinical pastoral education in the 1920s, to study the human condition not through written texts but through ‘living human documents’” (VanKatwyk, 2003, p.21). For this study, it is assumed that increased knowledge of the couple experience can inform when and how professionals provide support to the families. Knowing more about spirituality and how the couple influences each other can enhance how spiritual support is given through professional involvement. “The kind of conceptual claim that you are striving toward is unlikely to be highly

abstract, original or metaphoric, but it is one that will powerfully capture the important elements within the clinical phenomenon in a manner that can be grasped, appreciated and remembered in the applied context” (Thorne, 2008, p. 169). If a couple is influencing each other spiritually this might result in developing an alternative approach to the family. The study may also reveal what happens when individuals do not consider a spiritual influence or experience it in a negative way. . If clinicians have an increased understanding about how couples could impact one another in a negative way, this may influence clinicians to alter their approach to prevent such an interaction. Results from this study may have implications in a number of professions dealing with psychosocial oncology such as nursing, pastoral care, counselling psychology and social work.

Data collection

In this study data included participant interviews, demographic information, field notes, and a personal research journal. This pilot study is an initial investigation into a phenomenon, thus interviewing was selected as the method of data collection in order to gain a preliminary understanding of the couples’ experience. Talking is considered essential to gain knowledge of the individuals’ unique experience because “there are aspects of any health or illness experience known only to the person going through it” (Thorne, 2008, p.126). Three couples were recruited for this study. Both partners were interviewed together in a semi-structured, open ended interview of approximately 90 minutes. In talking about the experience together, couples had an opportunity to reflect upon what the other partner said when considering their own response. A joint interview also gave an opportunity to observe behavioural interaction between partners.

Participants were asked to complete a questionnaire to chart demographic information (see appendix 1). The researcher wrote a personal research journal to allow for reflexivity and counter any personal bias in the research process (Glesne, 2006, Thorne et al., 1997). Reflexivity is necessary for the researcher to fully engage inductive reasoning and successfully distance herself from the initial theoretical framework (Thorne et al., 2004). Field notes included the date and time of interviews, the general context of the interview (where it took place), a three generation genogram of the family, a description of the topics covered and additional significant occurrences during the interview. The genogram was included so that the interviewer could develop an understanding of previous cancer experience in the family, as well as to provide a quick reference of the family structure.

Finding potential participants

Once ethics board approval was obtained, a number of strategies were initiated to recruit a convenience sample of participants. First, an article was written regarding the subject area, relevant research and the purpose of the study. This article was submitted for inclusion in local (Edmonton area) community newspapers, church newsletters and relevant organization newsletters (see Appendix 2). Due to ethical considerations, the researcher decided to include the information that the research was studying spirituality although it could deter people who do not self-define as religious or spiritual from volunteering to participate. The second method of recruitment was circulation of the newsletter article through personal and professional networks via email (see Appendix 3). An introduction email with the newsletter article as an attachment was sent to

professionals in the community, the St. Stephen's community and personal contacts. Lastly, participants were also recruited by word of mouth contact with other participants and community members who were familiar with the research study. All three couples were successfully recruited via the second method of sending emails through personal networks.

Selecting appropriate participants

Participants were selected if they were couples - married, common-law or same sex - who were the primary caregivers to a child who was diagnosed with cancer of any type that was currently in remission. The child with cancer must have been between the ages of birth to 18 years old at diagnosis. Inclusion criteria specified that the child had to be currently living at home and the parents must have been living together as a couple during the time of diagnosis and the time of interview. At least one of the parents had to be a biological or adoptive parent. All participants self-described as articulate and had the ability to conduct an interview in the English language. It was possible that couples could be the same sex, and they could be from a variety of socio-cultural and economic backgrounds. As exclusion criteria, foster parents were excluded from the study because it is unknown whether foster families have the same spiritual affect on one another, and if foster parents have the same hopes and dreams for the children. Couples who had a child with a recurrence of cancer, or a child who did not survive were excluded from the study. Couples who lost a child or had a child with a second cancer experience might have a more intensified spiritual experience which would be more appropriate to look at in a separate study.

Demographics

For this study a convenience sample of three couples were recruited to participate in 90 minute interviews. Each of the families had gone through an experience of having a child who was diagnosed and treated for cancer. All of the couples were married and living together at the time of diagnosis, and continued as such at the time of the interview. Participants names and the names of all family members have been changed to protect their anonymity.

Family #1. Bob and Harriet met over 20 years ago and have been married for 18 years. They have three children; Cory, Leslie, and Matthew. Leslie was diagnosed with Acute Lymphoblastic Leukemia in May 2002, at the age of 3.5 years. It has been 8 years since Leslie's diagnosis.

Family #2. Julie and Michael met 10 years ago and have been married for 8 years. Julie and Michael have three children; Bradley, Madison, and Gavin. Their eldest child Bradley was diagnosed with Acute Lymphoblastic Leukemia in January 2006 at the age of 3 years old. The youngest child, Gavin, was only one month old when Bradley was diagnosed and their daughter Madison was less than 2 years old. It has been 4 years since Bradley was diagnosed.

Family #3. Angela and Kevin met 20 years ago and have been married for 17 years. They have two children; Aaron and Neil. Aaron was diagnosed with Neuroblastoma in April 2001, at the age of 2.5 years. It has been 9 years since Aaron's diagnosis.

All of the participants were Caucasian, Canadian and had a family background

oriented in Christianity. All participants were in their mid-thirties to mid-forties with an age range of 36 to 46 years old.

Initial Contact

Initial contact occurred primarily through email or telephone. Participants contacted the researcher showing an interest in participating in the research study. The researcher responded to each participant with a phone call and reviewed the inclusion criteria to ensure participants were eligible for the study. Due to the fact that the interview involved both members of the couple, the interviewer asked if it was suitable to forward an email to explain the project, so that both members of the couple could review it and determine if they were still willing to participate. The Information Letter (see Appendix 4) was sent to participants via email and a phone call was made approximately one to two weeks later to confirm a date and location for the interview.

Informed Consent

An information letter was provided to each person prior to making an agreement to participate in the study. Potential participants were able to contact the researcher by phone or email to ask questions or discuss concerns. The information letter and consent form (see Appendix 5) were written at a grade six level of English literacy. Prior to the interviews, participants were informed in writing of their right to opt out at any time. At the beginning of each interview participants were told verbally that they could opt out at any time and their data would not be admissible. Participants were informed that they could notify the researcher within two weeks after the interview if they wanted to withdraw their data from the study. Due to the procedure of concurrent data collection

and analysis, participation could not be withdrawn at a later date as the data would be combined with data from other participants. If participants appeared to have discomfort during the interview they were asked if they still wanted to continue. The interviewer was careful not to push the participants to a place that they were not ready or willing to go.

Not all potential harm can be avoided, but it was reduced through informed consent, skill and sensitivity of interviewer, and referral to counselling resources. Prior to the interview, participants were informed of the risks and benefits of participation. They were also able to opt out at anytime in the research process. As someone who has worked with families and individuals affected by cancer before, the interviewer had developed sensitive interviewing skills. Although strong emotion was expressed during the interviews, the interviewer knew how to react and was not threatened or disturbed by their experience or emotion. Working with couples, it was possible that one partner could learn something about the other partner that they didn't already know and it had the potential to cause difficult. Resources for couple counselling were available. Participants were given resources for counselling support in their community for continued support after the interviews.

Data Collection

All couples were interviewed in their homes at a time that was convenient for the family and the researcher. In all cases, the children were present in the family home at the time of the interview, however they were preoccupied in other rooms of the house. Interviews took place in the family living room and discussion was suspended at any point that the children entered the room. Prior to beginning the interview, the researcher

took a few moments to develop rapport through social pleasantries and then proceeded to review confidentiality, risks and benefits of participation and the participants' right to opt out at any time. The following benefits were discussed with the participants:

1. You may feel better from sharing your story.
2. You may understand yourself, your partner and your family better regarding the experience with cancer.
3. You may experience a new closeness with your partner and/or a change in family relationships
4. You may have a new experience of spirituality.

The following risks were also discussed with participants:

1. You may learn new information about your partner that you didn't know before. This information could create discussion or disagreement in your relationship.
2. You may feel confused or overwhelmed with some of the feelings that you experience as a result of sharing your story.
3. You may not feel comfortable that you shared your story or have other feelings about telling someone about this personal event in your family's lives.

Participants were asked to read, complete and sign the consent form and to complete the demographic information. At this time the researcher joined with the couple to develop the family genogram. Although the genogram discussion was not included in the

transcripts, information revealed during the construction of the genograms aided the researcher in the writing of this thesis.

Recording the Data

Interviews were audio taped using both a digital audio recorder and also a tape cassette recorder as back-up. Participants were informed when the recorders were being turned on (and thus collecting data), and again when they were switched off at the end of the interview.

Confidentiality

Participants' names were changed to pseudonyms when audio data was transcribed to protect the anonymity of participants. All transcription was completed by the researcher herself and she is the only person who is aware of which pseudonym was used for which participant and family members. In order to maintain anonymity, data that was not influenced by special circumstance was reported in the most generic form possible in the writing of the thesis. For example, the written thesis only mentions the ages of siblings when it made a real difference to the results; otherwise it only reports that there are other children in the family. Demographic information was kept separately from all database information and database information was recorded by pseudonyms. All data was password protected on computer and paper copies were kept in a locked cabinet. This data will continue to be locked up until 2 years after the study is complete and then will be shredded or destroyed. All audio recordings were stored in the same manner and will be deleted and/or destroyed 2 years following completion.

Data Analysis

I.D. is founded in the philosophical belief that reality is socially constructed (Thorne, 2008), thus the researcher used both the methods of concurrent data collection and constant comparative analysis. The idea of a socially constructed reality implies that reality is changing and is influenced by people, rather than an objective reality that exists in a steady state (Thorne, 2008).

According to the I.D. method, data collection and analysis must occur concurrently in order to allow for inductive analysis. Inductive reasoning involves building knowledge starting with the basic pieces of data and moving toward broader categories. It is the opposite of deductive reasoning, which starts with a broad theory and then looks at the data to either prove or disprove the theory. With inductive analysis, each new piece of data is added to others, building upon what is known and creating further knowing. In order to ensure that the researcher remains open and does not become stuck in patterns of thinking, it is important to alternate data analysis with data collection.

“Usually, the positions or experiences that each participant or informant might represent cannot be known until data collection is well underway” (Thorne et al., 1997, p. 173).

This alternating process enabled the researcher to become submersed in the data before developing themes or categories.

“Interpretive description will inevitably require that the ongoing engagement with data be strategically employed to confirm, test, explore and expand on the conceptualizations that begin to form as soon as you enter the field” (Thorne, 2008, p.99).

The interviews were conducted a few weeks apart from one another. The transcribing

process was the initial stage of becoming submerged in the data. “Coding too meticulously, too early, or in too much minute detail can derail even the most enthusiastic analyst” (Thorne et al., 2004, p. 10). While the I.D. method does not prescribe a step-by-step process of data analysis, it does recommend techniques that “encourage repeated immersion in the data prior to beginning coding, classifying or creating linkages” (Thorne et al., 1997, p. 175).

Constant comparative analysis is an approach borrowed from grounded theory, “whereby you compare every piece of data with all others that may be similar or different from it in order to theorize all possible relations among data” (Glaser & Strauss, 1967 as cited by Thorne, 2008, p. 151). The researcher followed the recommendation of Thorne (2008), that methods of analysis should be considered as guides rather than a rigid rulebook of how to conduct analysis. A method outlined by Burnard (1991) was used as a guide for comparative analysis. According to Burnard (1991), the transcript is first read to get a general impression; during the second reading broad themes will be identified, and by the third reading patterns will start to emerge.

The researcher conducted interviews with a purposeful overlap between conducting the interviews, transcribing the data and reading the transcripts. Throughout this process, the researcher noted thoughts and connections in a personal research journal. Before interviewing the second couple, the researcher had already transcribed the first interview and started reading through the data. At the time of the interview with the third family, the researcher was already immersed in the data from the first two interviews and alert to themes and patterns which might emerge in the third. Although no coding had

been attempted, the researcher had already read the transcript for the first family three times and had also read the second family's transcript once. The researcher continued this alternating process until all interviews were transcribed, and every transcript was read three times. It was only at this point that coding began.

Coding. Every line of each transcript was numbered so as to allow the researcher to easily return to the transcript to find the context of what was said. Each transcript was read through and coded line by line with a brief description of the meaning. The coding process was completed manually, and transcripts were cut and pasted onto pages according to similar themes. A broad list of categories was created by gathering together similar themes. Repetitious or similar headings were removed and a final list was created. The researcher was careful to maintain the original meanings from the interview context as the coded items from all interviews were collected together.

The researcher asked a colleague and her thesis supervisor to read the transcripts and contribute their perceptions of patterns and themes. "By capitalizing on the tensions arising from the way that other people might read the same data, you paradoxically increase your sense of confidence by allowing yourself to understand and account for different perspectives" (Thorne 2008, p.162). Themes and categories were discussed and alternate assumptions and outliers were considered. The researcher was also careful to consider and discuss what was not being said or shown in the data. At this point, the researcher was ready to start the writing process, while maintaining an openness to return to the original transcripts or recordings to verify the original meaning and context. The researcher wrote up the findings interspersed with references to the literature, thus

comparing the new findings with previous works. “The method suggested here is one that stays close to the original material and yet allows for categories to be generated which allow the reader of a researcher report to ‘make sense’ of the data” (Burnard 1991, p.465).

Ethics

A number of ethical considerations have been made throughout the study to ensure informed consent, confidentiality, anonymity, and non-maleficence. These considerations have been outlined throughout this chapter.

Rigor

In this study scientific rigor involving the overall trustworthiness of the findings was ensured by the researcher through methods used throughout the process of research. Various safeguards were implemented throughout the research to ensure that validity was maintained. As suggested by Morse, Barrett, Mayan, Olson and Spiers (2002) the following verification strategies were used: methodological coherence; appropriate sample size; collecting and analyzing data concurrently; and, thinking theoretically. Methodological coherence means that the method used matches the research question. In this case Interpretive Description was selected as a method that is used within a health setting in order to produce a description of lived experiences which will then inform future clinical practice. A sample size of 3 couples allowed enough data for an initial pilot study and to make recommendations for further research. A larger sample would create more information than is manageable at the level of master’s thesis and a smaller sample would not provide enough information to allow for reliable analysis. The researcher alternated between data collection and data analysis to allow the researcher to think

theoretically and have a micro-macro perspective simultaneously. The researcher remained open and responsive, rather than clinging to previous assumptions. In order to achieve this openness the researcher recorded assumptions and reflections in a personal research journal, and continued to have discussions with her thesis supervisor and colleagues.

Chapter Four: Findings

A number of themes emerged from the descriptions that participants used to describe their spiritual experience. Influence of family, influence of friends and community members, discussion about beliefs, image of God, prayer, periods of stability and periods of growth were common themes in the descriptions.

Laying the Foundation

In order to gain an understanding of each individual's perspective of spirituality, relational patterns and view of the world, each participant was asked to describe their spiritual experience growing up. Participants described some common themes as being central to the development of spiritual beliefs such as the frequency of church attendance and prayer, family impacts such as parental influence and extended family involvement, as well as factors that changed or transitioned through their childhood and adolescence. These factors described each individual in unique and personal ways. Once their personal background was established, participants were asked what the important aspects of spirituality were as they came together as a couple. The responses from this question helped in understanding how two individuals combine individual perspectives to create shared meaning and an approach to life.

Couple #1: Harriet and Bob.

Harriet. Harriet is the youngest child in her family of origin, born 8 years after her three siblings. Harriet's father was a pastor in the Lutheran church. Unfortunately, Harriet never had the chance to meet her father because he died before she was born. In the face of the challenge of raising four children on her own, Harriet's mother maintained a strong faith: "My mom had just lost my Dad six months before, but she's an incredible, incredible woman of faith without a doubt." Harriet characterizes both her mother and the community that she grew up in as being genuine and authentic in their faith, which led her to feel secure in her Christian beliefs with little room for doubt or questioning. She maintained an image of a loving, relational God. "I actually went through very few times of doubting it. I always knew that God loved me and I always knew that he desired a relationship with me.

Bob. Bob grew up in a small northern Mennonite community in rural Canada. Bob was also the youngest child in his family, with 7 years between him and his next oldest sibling. He had six siblings and his eldest sister is 23 years older. Bob depicts his childhood home as one with no faith. "Even though we were in a Mennonite community, we had nothing to do with the church in any way." Bob's dad left the church after cutting off contact with his own father who was a Mennonite pastor. Today Bob has great love and respect for his father, even though in childhood Bob says his father was alcoholic and abusive.

From Bob's perspective, the experience with his father shaped his image of God. "So I think I saw God in a very similar fashion to what I saw my Dad and his behaviour.

So being a little bit controlling, being abusive, neglectful, a little aloof, not really caring about the individual needs of his family members.” His image of God and spirituality began to change when, as a teenager, Bob became involved in the church by attending with friends and neighbours. Bob was the first of his siblings to join a faith community.

Bob characterizes the transition to faith as immediate in some ways and long and arduous in others: “I think God is always working in our lives and some of that is a process and can sometimes take years, and it is sometimes painful.” Before coming to faith, Bob describes himself as having a mythical knowledge of spirituality with the idea that “good people go to Heaven and bad people go to hell.” As he grew in faith he describes a shift in paradigm which was strengthened when he met his future wife Harriet. Bob describes marriage as being an important factor in how he came to view spirituality:

Bob: And to me having the spirituality in my life is about relationship to God. One of the key factors in my life has been marriage, understanding relationship... She has accepted me the way I am with all my flaws and imperfections but she still loves me and I have never doubted that, I have never doubted her love for me. And that is kind of the way I see my relationship to God, even though I am a flawed human being I know that even if I screw up, or I mess up from time to time doesn't mean that he is going to abandon me.

Harriet and Bob joining as a couple. When Bob and Harriet met each other, they were both practicing faith in demonstrative ways. “He was travelling with a group and kind of putting his life on the line. Like both of us were kind of living by sponsorship,

which means you basically make no money. It was an active thing not a secondary thing.”

Harriet felt that it was essential to choose a partner who shared the same beliefs, indeed she doesn't believe they would be together if they did not “see eye to eye” on that. “My Christian faith is a very large core of who I am and to have to feel kind of split between serving God and serving someone I am married to is just not something I think I could live with.”

When they were joining as a couple, they expressed few differences between their beliefs, and the differences that did exist were relatively minor. In fact, Harriet says that she found fewer differences than she expected: “I had expected more gender role differences and there was far less of that, there wasn't really any of that actually, he did most of the cut and scrape.” The couple encountered divergent beliefs about baptism which became apparent when their children were born, and again Bob accommodated by choosing to have the children baptized as infants which aligned with Harriet's faith. According to Harriet, “actually it kind of worked itself out pretty easily too.”

Couple # 2: Julie and Michael.

Julie: The childhood home that Julie grew up in was focused more in athletic pursuits and less in formalized traditional religion. She had one older sister, one younger sister and a younger brother. She did not identify as being a member of a faith community when she was young, however she says that spirituality was present in the home. “We believed in Christ, and were Christians but we never went to church, and we never...made it too big of a deal really.” She portrayed her parents as being “very liberal” in their beliefs and not judgmental about the beliefs of others. Julie says that they

celebrated holidays and prayed together during times of hardship but for the most part “we were kind of left to our own devices as we were growing up.”

Michael. Michael characterized himself as having no spiritual beliefs yet he experienced spiritual influences during his childhood years. Michael is the oldest child and has one younger brother. His parents came from two different Christian backgrounds; his mother from Roman Catholic and his father from the Mormon Church of Jesus Christ of Latter-day Saints. Through his extended family, Michael had influences of both religions throughout his childhood. “On my mother’s side we would go to church when we were with her parents, on special days, and then conversely, the same on my father’s side.” Michael’s father left the church at the age of 18, but other members of the family are still practicing Mormons. For Michael, this meant that church and spirituality were more about the family relationships than the religious practice; it had more to do with “support system and structure, and just that family bonding.” He admits that it sounds a little confused and even though he doesn’t believe in a higher power, he knows that there has been spiritual influence through family members that he loves and cares about. “Do I believe in something greater? Hmm...I don’t think so, but it has certainly influenced our lives, my life.”

Julie and Michael coming together as a couple. From the beginning, Julie and Michael had a lot of independence in their relationship because they lived a long distance from each other before they moved in together. The couple sees this independence as a real strength in their relationship. They describe having many similarities in personality and beliefs; “I guess in our beliefs, for me I thought we had a lot of common beliefs,

similar beliefs in family and in ourselves, in our strength as a couple and as a family.”

Looking back, both agreed that there was no involvement of spirituality in the early days of their courtship. They agreed that they did not discuss spirituality very much as they were uniting as a couple.

Michael: you know we never, we never talked about church or...every once in a while we would get into those kind of discussions though

Julie: we would avoid it

The one notable exception was that they argued about spirituality after being together with Michael's extended family. It is interesting to note that Michael interpreted two of Julie's comments as criticism and the conversation was quickly redirected once he identified it as such:

Julie: his family, big families right- the Mormons, they have tons of kids. So we always end up fighting about something when we leave his family events. I mean he has first cousins that he doesn't even know. How do you have first cousins...sorry...

Michael: objectiveness hunny

Julie: I am sorry, so ya I can be critical of...

Michael: so no I don't think there is any spiritual interaction

Later in the interview, when Julie is discussing the Catholic school the kids attend, a comment is made about Catholics and Michael has a similar response:

Julie: I mean the Catholics can be a little narrow in that they only want you to see their side of religion but...

Michael: let's leave it at that

Julie: but the exposure at school, you know the kids have really kind of attached to it.

Couple # 3: Angela and Kevin.

Angela: Angela had a traditional, strict Catholic upbringing. Angela is the oldest child with one sister 14 months younger. Her family attended church every Sunday and every holiday. The family often prayed together at meals and talked about what they learned at mass. As a young child she was required to wear formal dress clothes to attend church. She remembers that her parents eased on this requirement as she entered her teen years, "so that we didn't mind going, there wasn't that resistance of having to get up in the mornings or whatever and get ready to go." Angela experienced a transition in her faith at the age of 19 when her mother died from an unexpected, rare disease. "I think we all regressed a bit in our practicing part of our faith. I think we all had to go through our circle of grieving as to how we coped and understanding why it happened." As a result, Angela moved away from the Catholic Church by exploring other churches and sought out pastoral counselling. It was not known to her at the time that her father was also seeking out other forms of spirituality and he became less strict in his practice as a result. Angela describes the shift as a change in her image of God and a change in how she practiced her faith.

Angela: To me, [I believe] God is a loving God, because we were raised to kind of fear God in our faith a little bit as we were younger. Whereas now... if I go to Church [it is] because I want to go to Church, not necessarily out of guilt or

whatever. So it was around that stage that I began to say ok these are my boundaries, these are my expectations, this is what I need and this is how I am going to go about it.

Through Angela's seeking and her father's seeking, there was a significant and reciprocal spiritual influence which her husband said also impacted him.

Kevin. Kevin was also raised in a Catholic home, but his parents were not as strict or formal in their practice. Kevin is the younger child; he has one older brother. He uses the term "occasional parishioners" to illustrate how his family attended church only on Christian holidays like Easter and Christmas. Prayer and grace before meals were uncommon in their home and Kevin believes that he had more religious exposure by attending a Catholic school than he did at home. Conversations about spirituality did not really occur in his childhood home. "We never did have any kind of sit down with Mom and Dad or say let's talk about God, let's talk about spirituality, you know forgiveness." His extended family, one uncle in particular, had a spiritual influence as Kevin recalls saying grace and attending church when he visited with that uncle; "he was an influence but, as growing up with my parents and stuff it was more casual."

As a teenager, Kevin started to explore spirituality on his own with the influence of friends and their families. In school, Kevin became an altar boy, which eventually extended to attending Sunday Mass even though his parents were not there. "So it was on my own sort of thing, which I didn't mind going to mass because the father was great, I liked the other kids because they were from my school, and interaction." Kevin recounted with pride that he is still able to remember the words and order of the mass

service from his experience as an altar boy.

Angela and Kevin coming together as a couple. In the very beginning of Angela and Kevin's relationship, spirituality and religious practice took a back seat to the every day practicalities of working full-time, shift work and living in different cities. From Kevin's recollection, they tried to make it work. "So the weekends and whatever, we wanted to spend as much time together as possible because we were separated for a week or two weeks, or whatever so if church was it, then I went to church to be with Angela." In addition to the impact that Angela had upon him, her family was also a great influence on Kevin's spirituality; "her family kind of influenced going to church and spirituality, having different conversations about spirituality whereas with my parents we didn't really have that."

At the beginning the couple had differences in the frequency of church attendance and prayer; Angela was more consistent with attending church regularly and praying each night before she went to sleep. Kevin met Angela a year before her Mom passed away, thus he was witness to the transition that she experienced during that period. As Angela questioned the tenets of the Catholic Church she eased in her practice and started to include other aspects of spirituality which were more aligned with Kevin's practice:

Angela: I guess in the Catholic Church it sometimes feels like, you have to go through the priest to get closer to God and you have to go to the church to be closer to God... I have come to the belief that you don't and you can be close to God if you want to be, in your own way... And of course to him that is just great.

Kevin: it is fantastic.

Angela: I didn't get that resistance from him because he sees I am exploring other avenues, and it is not that I don't believe in God, it is just that he can be approached differently.

While Angela explored new beliefs and practices, Kevin maintained strong support of her. "I would honestly say that he is much more accommodating in the sense of me exploring my spirituality ever since we have been together. And of course as I mentioned with my Mom dying I questioned a lot of things, and my belief system too." In return, Kevin received new knowledge and understanding of his own spiritual process and relationship with God. They started praying together, they developed an image of God who surrounds them in everything, and a realization that God has helpers to whom one can pray:

Kevin: You go to bed and we do our thank yous...and to us he is right there. He's right here...and also I think the other thing that changed is that we also have come to the conclusion that God has many helpers. He has many guides, He has many angels, and He has many saints; that we can call on them for help too.

Angela's father is a significant influence in their lives and their spiritual development. It was not known to them at the time, but her Dad was also exploring other avenues of spirituality. As the couple talked with her Dad, they all discovered new answers to their questioning. It was through open discussion that they all found new ways of relating to God:

Kevin: Angela's Dad is a very spiritual person. Like he has really changed since your Mom has passed away too. He has explored different things so it is good to

have those talks. It is not necessarily that I believe in them or not but it has helped understanding of different people's ways of thinking or why things happen the way they happen.

Living Through the Cancer Experience

Each individual entered the experience of the cancer diagnosis with a unique perspective of spirituality as shown in the descriptions of their experiences in childhood and coming together as a couple. While each couple entered the time of diagnosis from divergent aspects of spirituality, some common themes were identified in the experiences of all three couples. 1) All of the partners had a shared meaning of life that they developed with one another. 2) The importance they each placed on spirituality blended together to an agreed upon level that worked for their family. 3) Couples described a willingness to support each other during periods of stability and periods of change.

The next section discusses the descriptions of moving through the period of diagnosis and treatment. All of the descriptions of living through the cancer included experiences of faith during diagnosis, coping, hope, support from authentic people, prayer and meaning.

Handing it over to faith. All three couples spoke about not knowing what to do in such an unfamiliar situation and feeling a lack of control. When they had no idea of how to proceed, they sought out someone or something else to guide them. Couples described feeling helpless and out of control during the initial diagnosis period. Harriet illustrated a sense of shock as she tried to comprehend how to respond: "It was a little overwhelming right off the bat, because they said 'take her to the Children's Hospital, you will be spending the night, she probably has leukemia, make sure you don't take the

other kids with you'...I just went into survival mode.” For some families diagnosis happened quite rapidly with few symptoms that something was wrong with the child.

For family #2, Bradley’s symptoms progressed very quickly and he was not able to walk the day before his diagnosis. The progression of illness moved from normal to critical within a short period of time. As with other parents, they were in a state of shock when they received a diagnosis of cancer. Without having anything to compare the experience to, parents were left feeling a complete lack of control over the situation. As Julie explained: “I think I kind of put that into faith because it is out of your control. It is all out of your control so you have to put it all into someone else’s hands.”

Faith came in different ways for each of them, depending on the current circumstance and past experience. For Harriet and Bob, it meant giving up control to a higher power, Julie and Michael handed control over to the medical professionals, and for Angela and Kevin it was a combination of both. Harriet and Bob relied on the religious beliefs that they already held. They did not feel that the diagnosis shook their previous spirituality. “It wasn’t like my world was completely, like my belief system wasn’t torn down and restructured it just carried over into the world I was facing.” They turned to their spiritual beliefs as a way to make meaning out of what they were going through. Faith meant putting their beliefs into action. “It is not easy. Sometimes you have to take a step of faith in areas where you are not sure what is going to happen but you have to know that God is going to be there.” They spoke about reaching a realization that they needed to surrender their child to God. It was a very big step for Harriet, who identified that she was used to having control in her family life. “I had to surrender them into God’s

hands...they were His. I was just kind of taking care of them. That was a very big step for me.”

Julie and Michael focussed their faith in the doctors, nurses and entire medical system. Michael is a professional in the medical field so he was familiar with the surroundings: “My comfort zone is precisely the setting that we were in, dealing with doctors, dealing with surgeries and the medical mechanical side of it.” From the very beginning Michael had support from a doctor who was both a friend and a colleague. Very quickly after Bradley’s first exam, doctors were able to demonstrate their confidence and ability by providing a full understanding of the diagnosis:

Michael: He kind of fast tracked Bradley with his test and diagnosis. It was 36 hours from when they had the diagnosis and the first exam. They had it mapped down to the last genome. It was just kind of faith in the medical system and believing in what the people were doing and seeing what they were doing gave us the confidence.

Julie and Michael felt comfort in medicine and science, because it was something familiar and something they could trust. Even so, it was not an easy process for Julie and Michael to let go and put their faith into the doctors either: “Seeing the doctor with Bradley and thinking this person is saving your child’s life was really overwhelming for me, because you have to trust these people that you don’t know to save your child.” The family relied on guidance from the medical team. Julie gave an example of this when she expressed how the family made the decision between a central line (portacath) and a Hickman line, one of which needed to be temporarily inserted in Bradley to allow for

quick access of medications. She explained that it is one of the first things that you have to do when a child is diagnosed with cancer. Although she was provided with pamphlets and information about the medical devices decision she didn't feel prepared to make a decision and was grateful for the guidance she received from the doctor and surgeon.

"You just kind of hand it over for a while and hope that they are doing the right thing, and you are learning as fast as you can, reading everything that you can." Michael agreed that he was comforted by the expertise and personal touch of the medical team. "The surgeon came in, and remember, she took over like a quarterback. Not authoritatively, just confidence wise...and when they were rolling him away, we knew that he's ok."

Julie and Michael developed a strong trust in the medical professionals yet they still sensed that they needed something more and on occasion sought help from elsewhere. They appeared to have some ambiguity about their beliefs in science and spirituality. Julie had a difficult time to put her feelings into words: "I think I don't know if that is faith, it really uh, it is kind of, but it is kind of science too because it plays such a role." Michael showed some contradiction in his beliefs when his majority of responses indicated that he did not have spiritual beliefs, he did not believe in a higher power and yet surprised even himself when he admitted to praying when Bradley was first diagnosed. "I guess...I would say that I must have some sort of faith because I wouldn't have taken that trust or faith to hope for Bradley to get well or pray if you will, to ask someone else for help."

Angela and Kevin explained that they had faith in a higher power and the medical system when Aaron was first diagnosed. The type of cancer that Aaron experienced,

Neuroblastoma, has a relatively short period of active treatment with a long monitoring period of many years. It required surgery as the only treatment with no radiation or chemotherapy. They described faith as “leaving your life in God’s hands, it is allowing Him to do what He needs to do.” Similar to Harriet and Bob, this couple said they believe that God has a purpose and a plan. They did not assume that God wanted their child to have cancer, but they thought there was a reason for it. Just as they have a belief that there is a reason for everything to happen the way that it happens. “I am not saying that he is creating cancer but what I am saying is that we have been chosen to go through this for whatever reason.”

Kevin also expressed similar beliefs to Julie and Michael, when he mentioned how he let go of control and allowed the professionals to influence decisions about Bradley’s treatment. “Well they are the doctors, they decide more or less. We just wanted it gone so even when the surgeon says he might lose his kidney, we were like ‘you are the sight, you are the everything so do what you have to do.’” Whether through faith in spirituality, faith in medicine, or perhaps both, the couples were able to find hope and an ability to cope while going through their experience with cancer. As Kevin said, “faith gives you hope.”

Coping through treatment.

Hope. Hope took on a whole new meaning during crisis from what families had previously experienced. Once families were able to align themselves with something that could guide them through the process, they were able to have hope for a positive outcome. Michael explained, “however it evolved it gave you the belief that everything

was going to work out, everything was going to be ok, you are going to have hiccups, you are going to have speed bumps but you know what? (*sic*) It is a process, and this is the road map.” All of the couples agreed that hope was a crucial aspect of getting them through the treatment. Michael explained that “with respect to Bradley getting sick, hope was everything.” It allowed the families to cope with the difficult moments because they were able to see beyond the present day and look toward the future. Angela described hope as “a goal, it is something to look forward to, it is something to fall on.” Julie’s definition of hope was having a future of health and happiness for her children and other family members.

For some couples hope meant a belief in God and meaning beyond this life. Angela mentioned that her hope included believing that God would help guide her family through the rough spots, “not necessarily change what is going on, but just help us cope with what is going on.” The idea of eternal life was a comfort to Harriet and Bob early on in the cancer journey, when their daughter was first diagnosed. Bob stated that “hope means knowing for certain that there is more to this life than what the world has to offer...there is more to life than beyond this life.” Harriet found comfort in her hope for an eternal life: she spoke to God saying “even if this child doesn’t make it, I know that there is hope for her regardless. I know there is hope of heaven, I know there is hope of eternity”.

Bob and Harriet were the only couple who were able to talk about death in relation to their child’s life. It is interesting to note that when other couples were asked about their beliefs of death and the meaning of life, their answers referred to their own death.

Michael, Angela and Julie all responded with feelings surrounding their own death. One possibility for this response is that the subject of their child's death is still very sensitive and thus not a topic that was comfortable for discussion. Julie told how the concept of death really scared her, "especially the thought of me going before the kids or anything like that". Michael also shared the concern about how his death would affect his kids "I worry about what I would miss or what I haven't been able to convey to my children, to teach them or give them skills". For Angela, however, she is more comfortable now with the thought of her own death than she used to be. "I feel more comfortable in the sense that if I leave now then I can call on the spirit guides and so forth to help. And if I was to go, they could call me". Angela seems to have found comfort in her recently found belief that she can call upon spirits of those who have passed, like her mother. Thus, it seems that Angela also believes her children could still access her assistance if she were to die.

Support from authentic people. Support from others was frequently mentioned in these interviews as something that significantly impacted the couples' spiritual processes and how they coped with crisis. "It was more of a support network than anything on each of us. It was the people that came near to us that gave us the support and faith". This included the support from professionals in the medical system as well as family, friends, and the church community. The couples suggested that certain individuals understood their needs better than others. One commonality that extended throughout the descriptions of support was a sense that the individuals who understood their needs were authentic and genuinely cared. There was more hope and strength in coping when people appeared to believe on the inside what they were communicating on the outside. Couples felt less

trust, less comfort and less support from individuals who didn't appear authentic.

Authentic individuals provided practical support as well as emotional and spiritual support.

Practical support. Every couple talked about receiving support in the form of childcare, house cleaning, visits to the hospital, cards and emails. Family provided much of this support. As an example, Julie received a lot of support from her sisters and other family members who lived close by. Because it was difficult to care for all three small children, Julie and Michael were able to send their daughter to live with Julie's parents for a whole year when Bradley was in treatment. Kevin and Angela said they counted on their support network to bring them through the experience; "it was the fact that we got visitors to the hospital and here, we got food given to us, to help us through it." Harriet's mother was one of the primary supports for her family while Leslie was in the hospital and Harriet's mother stayed at home with the other children; "my Mom was a miracle, she came...we had so much support in that way."

Emotional Support. Michael and Julie had the unique experience of moving from the United States to Canada in the middle of Bradley's treatment. Because of their relocation, they experienced two different hospitals and medical systems. The approach was very different in each of the hospitals. Whether it is indicative of the different systems or not, it enabled the couple to contrast their experience in the United States with genuine, caring staff to the second hospital in Alberta that they portrayed as a cold and sterile environment. The approach in the U.S.A was to treat the whole family, rather than just treating the child; "the way they pursued it was genuine, it was comforting, it was

walking you through as much as you wanted to walk through it.” At this hospital they were allowed to join Bradley during his treatments, which provided comfort to both parent and child. Both Julie and Michael were tremendously upset when they discovered that they could not be with Bradley and hold his hand during the lumbar puncture (LP) procedures in the hospital in Canada. Not only was it disturbing that they could not be with their child, but they noticed a tremendous difference in their connection with the staff. “Like the nurses here are nice and they are good, but it wasn’t like it was in the U.S. They were more involved, more interactive, and they got attached.”

Spiritual support. From the perspective of the participants, people who are genuine in their beliefs seem more accepting and have an increased ability to comfort those who are going through crisis because their openness allowed others to receive without feeling threatened. Michael and Julie insinuated this when they allowed Michael’s grandmother to send a pastor from her church to pray over Bradley, even though they did not have any religious beliefs. Michael explains that “my grandmother is an amazing woman...for understanding everything that is outside of her religion. She’s really genuine.” This strikes a familiar chord as one recalls how Harriet described her Mom and the community of religious folk that she grew up with: “my Mom, she lived exactly what she said, and I thought ‘this is authentic, this is real’, and I grew up in it.”

Harriet expressed the emptiness she felt when people said things to try and make her feel better. She described their reactions as “empty platitudes” which were intended to increase her sense of hope. Harriet said that comments such as “she will be ok”, or “kids bounce back” felt empty because she found no reassurance in the sentiments. It didn’t

help her or Bob cope with the reality of what was happening to their child. “It was quite empty. You cannot tell me that. You cannot assure me by that and there is no way by saying it that you are giving me anymore hope that she is going to be fine.” However, Harriet did find comfort in the words and support that she received from her friends at church. Something different occurred with her friends who shared her faith, because instead of trying to take the reality away, they simply did what they could to support her during a difficult time.

For Angela and Kevin the spiritual support they received had a particular impact in respect to Angela’s Dad. His strong faith influenced how they were able to hold onto their faith during the crisis. Kevin frequently referred to the fact that talking was an important part of the spiritual process for him. He viewed the openness of communication as contributing to his ability to understand and develop in a spiritual way. Michael also agreed that talking was important for him and his processing of the experience: “Every time I talk about the situation it helps me deal with what was going on, deal with it then and after, you know I try. It just helps me.” It was helpful for these families to feel that other people were there to talk to and cared for them practically, emotionally and spiritually. “They were real for us, they felt our pain and they didn’t pretend that everything would just be ok magically.”

Prayer and meaning. Prayer was a reoccurring theme that participants talked about throughout the interviews. Prayer was frequently mentioned by all the participants as something that was offered to them by concerned family and friends. All of the couples said that their child was put onto prayer lists to be prayed for by groups of people. Angela

and Kevin said that their prayer as a couple and as a family had significantly increased during diagnosis and treatment. Harriet and Bob also spoke about praying together as a couple. Harriet explained that she prayed in different ways, sometimes as a conversation and other times almost a meditation or chant; “Lord have mercy, Christ have mercy.” Even Michael, who claimed to have no faith, had a conversation with God when his son was diagnosed, “I remember sitting there and hoping but I found myself, I guess praying or talking to God...or hoping that he would bring Bradley safely through this.”

Couples illustrated a connection between the practice of prayer and the meaning of events in life. Even though she has a difficult time expressing it, Julie felt that prayer would not necessarily change the outcome but that it could provide comfort if the worst were to happen. “People- if they pray harder would the child have survived 15 years ago? No, but would you have gotten through it in a different manner, I mean that is where faith...I mean good people die, good kids die.” There is some indication of how she associated spirituality with comfort and meaning when Julie spoke about a child who passed away. She saw another family turn to Buddhism in their grief and how it provided comfort to the family:

Julie: It is really weird and I just,(*sic*) you see him with the monks and stuff. I just can't imagine getting to that point. I was just sitting there imagining how that would feel... I found it really interesting at the funeral seeing that. You could kind of feel their energy and the comfort they took from that in the end. It was really, kind of...I don't know, just really enlightening.

Two couples associated their communication with God through prayer as

meaningful and believed that God communicates back to them through other people. Bob, Harriet, Angela and Kevin all had the belief that things do not happen in life due to coincidence, they believe that it is the work of God. “God must be working through that person, I don’t know how to explain it but this is just like perfect timing.” Bob and Harriet were able to provide extraordinary examples of situations that let them to believe that prayer was linked to the support they received from other people, that it was not just a coincidence. Harriet and Bob told about a moment when Bob was waiting for Leslie to get out of surgery:

Harriet: Bob was just sitting there and he was feeling so alone...he said ‘God I need someone to come along’ and who would you know but a friend comes up behind him and puts her hand on his shoulder and says “hi.”

Although they were not together at the moment when they learned of Leslie’s diagnosis, randomly they both had supportive others with them. Harriet was able to get support from the babysitter who just happened to be at home when she usually isn’t. Bob just happened to be sitting with clients, that he didn’t know previously, who identified themselves as Christians, held his hands and prayed with him. These couples felt that through their experience with cancer and with the support of others their spirituality was strengthened.

Transformation

All of these families were able to cope with the experience of cancer diagnosis and treatment of a child by using faith in doctors and God, hope, support from others and prayer. After going through the experience the families described changes they

experienced as a result of going through it. Couples explained that their experience led to strengthened faith, growth in the couple relationship, growth in strength of the family, witnessing their child's spirituality, and a desire to contribute to others.

Strengthened Faith. Couples reflected upon their experience and recognized an increase in spiritual strength and growth. They saw this development expressed through different ways such as a changed image of God, an increased love for their children, and a strengthened ability to cope. From their interpretation of God being involved in the small details, Harriet and Bob felt that their relationship with God changed. "For me, knowing God grew because I just saw him as so caring." Two couples mentioned that in some ways their faith was being challenged, and managing the pressure of a crisis helped to reaffirm their spirituality. Bob expressed that in some ways his faith became more real. Kevin and Angela stated that the experience reaffirmed their faith in God and everything that was important to them. "I think it has just affirmed everything, confirmed what we believe in: our beliefs, our desires, our wants, our needs- everything." From the experience and the confirmed faith in God, the families felt that they would be able to manage other crises that may occur in their lives. Harriet attributes the positive outcome for her family to God's mercy and grace:

Harriet: Grace is getting what we don't deserve as mercy is not getting what we do deserve. We are not owed anything...because we don't deserve good health, we don't deserve any of these things, these are not our rights as people...but God gives us so many things generously because of His mercy and His grace.

Michael and Julie appeared surprised by their spiritual growth. Julie was

emotionally moved when her husband disclosed that he spoke to God during their experience. She believes that her family continues to grow in spiritual ways, especially after learning that Michael prayed. “I think we are always growing spiritual wise. Especially with the kids being in, being exposed to more religion.”

Growth in couple relationship. Participants expressed that witnessing how their partner dealt with difficulties impacted their own personal growth. Harriet expressed this sentiment to Bob during the interview: “Anytime I see growth in you, it challenges me to grow too.” Couples described having greater reliance on each other, increased trust and respect for their partner and a stronger couple bond as a result.

Increased reliance, trust and respect. All of the couples spoke about changes in how they perceived and related to their partner as a result of the strong support they received. Harriet explained that her respect for Bob increased because of his consistent and reliable support. “My respect for you went up because he (sic) was such a strong support for me. Never once did he consider taking off and leaving it all behind, which anyone could have done but no he was just there.” Michael described that he relied on Julie to take care of the family and because she was extremely capable in that regard his trust in her was amplified. Kevin recollected that Angela influenced his spiritual growth as they discussed her reading, questioning and seeking. The couples achieved growth by spending time with each other and talking about their experiences. Angela

accredits her ability to freely explore spirituality to the fact that Kevin was supportive and understanding of her.

Kevin: She has influenced me more.

Angela: Well no. The fact that you supported me was a good thing.

Kevin: We had many talks.

Angela: and you didn't judge me, per se. You didn't lock me up somewhere like I was crazy.

Bob and Harriet recount that it was helpful when the hospital instructed them to create time for the couple relationship, when they could have easily ignored the importance of it during crisis. "One thing they said was that you have to take time for each other because we see about half of these cases end up in divorces, during treatment right, very high." With a high degree of stress, exhaustion and worry, couples are challenged to maintain a level of support for each other. According to Harriet, it was even more difficult because spouses can respond differently to the pressure. She recognized that knowing there would be different reactions was helpful; "it is not that someone's pain is more but they can show it in different ways right?"

Due to the circumstances of their lifestyle, Michael had to work away from home and was separated from his family at times during the cancer journey. Fortunately, the couple was able to stay connected by developing a common language for sharing the experience. Michael described that as a medical professional he needed to understand the specific details of Bradley's condition, and Julie was able to provide that to him in their telephone conversations. "She did such a great job of taking those objective look (*sic*) at

Bradley and the data...It helped me cope with stuff while I was away at work.” From the discussion in the interviews, it appeared that fathers have a harder time coping with their need to protect their child and the need to be away from the child due to work. Michael was visibly emotional as he shared the memory of not being there when his son was diagnosed: “I felt guilty because I wasn’t there for him when he started getting sick. So I have a tough time coping with that sometimes.” It was through relying on Julie in this way, and her care of the children that he “found a different level of trust” with her. Julie also explained that it was related to their level of independency and each person “playing the role that we needed to play to get through it.”

Stronger couple bond. Despite the challenge of it all, couples felt a strong bond as a result of surviving the experience. Kevin and Angela characterize it as being more “in-tune” with one another. They chose their vows, their shared beliefs and knowing the goodness in each other. “We are just tighter because of it, we both understand each other better, we both agree with the space where we are at now, there is not that resistance sometimes like there used to be.”

It changed us. Angela and Kevin describe a previous experience of spiritual transformation which affected how they were able to deal with their son’s cancer diagnosis. When Angela’s mother died, Angela began a journey of questioning her spiritual beliefs. “It was a big turning point when my Mom died when I was 19. I think we all kind of regressed a bit in our practicing part of our faith”. She described a process of moving away from her faith tradition and exploring other avenues of spirituality, including different religions, different churches, and pastoral counselling. “I just kind of

explored it to see where did it fit in my life and did I want it as part of my life, which I do, so that wasn't really a question but I thought about it". Angela described that this experience of seeking other modes of spirituality had a reciprocal effect on the people in her life. Her husband, Kevin, and her father were both affected by her seeking and their participation and conversations also affected her.

Kevin: You influenced me, because you were seeking. I wasn't really a seeker, you were a seeker so you influenced me.

Angela: and Dad did.

Kevin: and your Dad. It happens everyday now, we sit down to a Sunday dinner with her Dad and...have a talk.

Angela describes that she was seeking comfort, which she could no longer find in the religious tradition that she grew up in. She admits that the process deepened when their son Aaron got sick.

From their description, it would seem that the journey with cancer does not end when the treatment is complete. Once active treatment ends there is often a period of monitoring which may be less obvious as a threat but is still anxiety provoking for families. Kevin described that his son had a long monitoring period that gradually reduced but lasted for years after the original diagnosis. "When he was first diagnosed whenever he got sick, whenever he fell and hurt himself, if he was cold and clammy or looked pale, the whole thing just starts up in your mind. I think it took a long time for us. After about the third or fourth year I started to feel more comfortable that we are on the way."

Time to transform. These couples agreed that emotional and spiritual processing occurs once the cancer threat has diminished. Harriet described her emotional release came when she created a scrapbook of pictures and memories, “I cried more during the scrapbook than I did during the event, during the treatment because I was just kind of, you know, doing what you have to do.”

It is important to note here that these couples were in different points of their journey when interviewed. All of the children in these families had completed their treatment and yet for Michael and Julie the experience was more recent than for the others. The family is still in a monitoring period: “It was really nerve wracking wasn’t it? Like it still is, I still sit in the office when he comes back with his blood counts. It will be two years (since treatment ended).” Michael admitted that he felt the interview itself was part of his processing. At the beginning of the interview he said that he thought it would bring a sense of “closure” for him. By the end of the interview he thought that, because the interview brought up a lot of things for them, the couple would continue to discuss and process it. “You get so guarded at the moment and with Bradley and his treatment, and what is going on with the family unit that you forget about the emotional side of it, that you kind of turn off. Turn off or suppress it.” By talking about his experience, Michael showed some transition during the interview process. Michael was affected because the interview introduced the idea of spirituality in relation to the cancer experience, something he didn’t consciously consider previously. Michael intimated that the discussion in our interview started a process of reconsidering how he perceived God:

Michael: I am guarded a bit in saying that I think there is something else out there,

because I found myself searching for hope in something else there, and I never thought about it until you came and started asking questions...so, I, maybe I am a little confused I guess within myself.

A Stronger Family. Couples were able to see the effect of their strength and coping when the family as a whole feels closer, stronger, focussed and confident. Their love for each other grew deeper and the value of spending time together as a family increased for all of the families. Kevin and Angela measure the closeness of their family by describing how the boys call the parents when they are not home on time. “We enjoy each other, we enjoy the company...we are comfortable where we are at, we are in-tune to our beliefs and spiritually we are all in tune.” They emphasize the importance of family, not only within their immediate family but also with other families that they spend time with. Michael illustrated the bonds of his family through the faith that they have in one another: “how close we are, like he knows when he is not well that he is in complete perfect hands, like he has got that level of confidence or faith and belief in us.” Harriet describes how in their family the love grew deeper and they were all better for the experience: “I don’t think you can go through tough times without growing in some respect you either get bitter or better...either you harden or you grow more...and you grew deeper in your love for your kids, even though you already loved your kids very much.”

Child’s spirituality. Apparently it was not only the adults in these families who experienced a growth in faith; all of the couples expressed that their children exhibited signs of spiritual development as well. The children showed an increased

interest in religion and spirituality at some point during or following their cancer treatment. Kevin said that Aaron insists on praying together every night before bed “he holds us accountable because sometimes you just want to go to bed, we are tired right? No we have to do prayers”.

Harriet described how at the age of four Leslie asked for crosses from their pastor and she gave them to the other children at the hospital; “So she took them to the hospital and she was handing them out, and she was just saying ‘Jesus loves you and I hope you know that’.”

During the interview, Julie revealed to Michael that Bradley asked her if he could be baptized:

Julie: did I tell you that Bradley wants to be baptized?

Michael: no

Julie: he came home from school and at certain ages I guess they do communion and he is at that age. He says “mom I want to do communion” I was like “geez, oh I don’t know if you can if your parents aren’t catholic.” But it was pretty cute. I think it was communion, you will have to ask him.

Harriet felt that faith helped her daughter to cope with the experience. “The one thing that was really kind of cool was watching our own kids spiritually grow through all of this. I mean even Leslie at age 3, oh what a sweetie. Just to see her faith completely there, and just being ok about everything”.

All of the parents remained open to their children’s spiritual exploration. Michael and Julie inadvertently supported their children’s spirituality when

enrolling them in a Catholic school which happened to be the closest school to their home. Julie was a bit surprised when Michael agreed to the school, but he admits that it has been beneficial for the children. Michael supports whatever is best for his kids:

Michael: We wanted to give them the skills to have them make their own decisions and give them guidance to what they thought was right to do and to experience. Some of the stuff in the Catholic school, they just broaden. You can see them develop more, just spiritually and religiously.

It was an unexpected result when they saw how much of an impact it had upon Bradley. His class at school had a portacath party when the medical device was finally removed because it was no longer required for treatment. For Julie this reinforced her original intention; “so for me getting them into the Catholic school it was a part of that, letting them explore faith and religion.”

Kevin and Angela felt that the children experienced spirituality to a greater degree than either of them had when they were young. The difference was attributed to Aaron’s experience with cancer and also to their openness as parents. “They have even asked questions, and I tell them what I believe, you know and I am comfortable with it, whereas I was never taught that as a kid.” Once again the concept of talking emerges as significant in spiritual development.

Parents noticed that children had creative ways of coping with cancer and they were also affected by how the parents approached cancer treatment. At the age of four, Leslie used her understanding of spirituality to get through surgery when she asked her

parents “if God wanted to heal me in zero seconds he could right?” Harriet felt Leslie’s faith was unquestioned, which may have been in part due to Bob’s reaction to the cancer: “I really appreciated about Bob was that he never wavered as far as, going to church as a family was still an important thing. Keeping things as normal as possible.” Both parents thought that Leslie came out of her cancer experience as a stronger person. “Leslie came out better for it- you see it in lots of ways. I have seen her character...she is a strong person, she is a relational person.”

Keeping things normal for Julie and Michael meant that during his last year of maintenance treatment they allowed Bradley to go to school, play hockey and make his own decisions. At an early stage they agreed as a couple that they would tell him as much of what was going on as they could: “we were honest and up front but still guarded right because he was a three-year-old but give him the choice of everything that is happening to him.” Michael believed that this choice contributed to Bradley’s maturity in dealing with the cancer and the strengths that he has maintained following the treatment. “He is so smart, but that level of independence and his ability to experience, just, I guess, helped make meaning for it.” The child’s development may have been impacted by the enhanced strength of the couple that grew out of their influence of one another.

Contributing to others. The couples recognized that they were fortunate for the support that they had and desire to use their strength to help others. They saw the contrast between the experience of their family and others they met at the hospitals. They told stories of other kids who were in the hospital for cancer treatment and were dealing with family breakdown. Some of the kids were dealing with parents who were getting

divorced, others who had no visitors and were coping all on their own. These families described how they would provide support to the other kids who were in hospital: “and you talk to them and hear about the stories, my parents are splitting up and whatever...there were some pretty sad stories. I am grateful the way that we were able to manage through everything the way that we did.” After everything that they had been through and coming out stronger in the end, these families turned their focus to helping others.

All of the families talked about encouraging their children to become good people and contributing to society. It was important to all of these parents to raise their children to be good human beings who contribute to the good of society. It was so important to Michael that he described it as being his meaning of life; “I don’t really have an idea of meaning of life other than providing or instilling the children, our kids, to have a chance to be wonderful people and contributors.” The parents saw purpose in giving back to others and making the world a better place. Michael explained how he encourages his kids to “contribute in anyway they can to anything that they do, to themselves, to other people and just to cherish everything they have, just take everything in and give everything back.”

Chapter Five: Discussion

The data from this research confirms previous theories and research in the area of coping with childhood cancer and preliminary evidence to support the theory of transformational spirituality by Shults and Sandage (2006). The results from this study indicate that spirituality is a personally defined process which, along with other methods,

increases the ability of the couple to get through the experience of childhood cancer (Cardella & Friedlander, 2004, Nichols et al., 2009, Patterson et al., 2004, Schneider & Mannell, 2006). This study is also consistent with previous research which finds that the whole family is able to adjust to the cancer experience as a result of the parent's ability to cope with the cancer experience (Clarke-Steffen, 1997, Cummings, 1994, Howes & Markham, 1989, Lavee & Mey-Dan, 2003, Varni et al., 1996). The data also provides preliminary evidence that supports Shults and Sandage's (2006) framework of transforming spirituality. Descriptions provided by participants are concurrent with the theory that spirituality is relational and spiritual transformation occurs within a process of alternating cycles of spiritual dwelling and spiritual seeking.

Confirming Evidence on Coping and Spirituality

Spirituality is unique and personal. Previous research has shown that spirituality is shown in personal ways that are unique to the individual and frequently difficult to express in ways that are understood by others (Schneider & Mannell, 2006). This is confirmed by the results of this study which show that all of the individuals reported different meanings to the term spirituality. The three couples presented in this study reflect the edges of the continuum of spirituality with couple #1 who identified strongly with Christian doctrine, couple #3 who identified as non-religious, and couple #2 in the middle of the spectrum. Harriet and Bob were more likely to refer to Christian and biblical meanings, whereas Kevin and Angela talked about spirit guides, angels, communion with nature and openness to other religions. Michael and Julie frequently lost their words when trying to describe their meaning of spirituality; they were unable to

express the meaning of some of the events that they experienced. “If one has definite religious beliefs and is equipped by church and family to express religious impulses in conventional terms, religious expression comes more easily, as Jung pointed out” (Groeschel 1989, p.4).

The couples who grew up with faith, maintained the ability to express their experience in those terms, whereas for Michael and Julie there was an allegiance to the language of science and some resistance to spirituality and religion. The results were consistent with research by Schneider and Mannell (2006) which reported that “not all parents defined spirituality from a purely religious perspective... most parents recognized that it [spirituality] had a secular component as well, and both these perspectives were reportedly helpful” (p.18). Results show that couples were able to cope in numerous ways, which included spirituality.

Methods of Coping. Methods of coping described by participants in this study included seeking medical information and understanding, receiving support from others, reliable spousal support and spirituality. These results provide support for previous studies which showed similar methods of coping as positively affecting quality of life and emotional health (Barbarin et al., 1985, Goldbeck, 2001, Patterson et al., 2004, Woodgate & Degner, 2003).

Information seeking and medical understanding. The study by Patterson et al. (2004) found that 27% of parents studied used “seeking information about cancer” as a coping behaviour in dealing with childhood cancer. This result has been replicated in the current study where 1 out of 3 couples reported significant coping associated with seeking

medical information. While the other two couples may have slightly indicated the support from medical professionals, Michael and Julie indicated that their understanding and participation in the medical process was essential to their coping. Julie described that the more information and guidance she was given by medical staff, the more she was able to cope with what was going on. Michael expressed that as a medical professional himself, it gave him comfort to be able to participate in his son's care. This family also indicated that the perceived authenticity of medical staff significantly affected their ability to cope.

Social support from authentic people. Social support may come from a variety of people from different contexts such as hospital, church, family or school, and may take different forms such as practical, emotional or spiritual support (Patterson et al., 2004, Woodgate & Degner, 2003). The current study revealed that social support was offered from extended family, friends and neighbours, church members, schools and medical staff. The participants in this study also identified that support was more conducive to coping when it was provided by individuals who were perceived as being authentic and genuine. This finding corresponds to Shults and Sandage's (2006) concept of "true" persons: "Whether truth is "in" a person (eg., Gen, 42:16) is judged by his or her trustworthiness and fidelity. "True" persons are identified by the way they manifest faithfulness, the way in which they identify with others" (Shults and Sandage, 2006, p.71). According to Shults and Sandage (2006), true persons provide spiritual support through relational interaction with others. These true people may be seen as providing a holding environment for the process that families are going through. Practical and

emotional support was found to have a greater impact when offered by authentic individuals likely because they were able to mirror the experience back to the individual:

Just as a baby who is held, handled and presented with real objects by a devoted parent turns out to be a baby who is easy to manage... so an adult able to live from a true self makes a good citizen who helps fill the outer world with inner creation and cover the hard blows of fate with creative projections that bring meaning to suffering (Ulanov 2001, p.47).

Practical support. Tasks such as cooking, babysitting, house cleaning, and medical care were all described in this study as practical support that families received during the cancer treatment. This practical support provided relief to the parents as they were coping with other emotional and physical needs of the child with cancer as well as the rest of the family. The participants indicated that practical support was usually provided by family, close friends, church members and medical professionals. Harriet and Bob described that the practical support they received allowed them to have time together as a couple and to give more support to their children.

Julie and Michael had a difficult time adjusting to the second hospital where their son received treatment, because, although the same medical treatments were given they did not feel the same care from the medical team. This couple expressed that they felt the difference between the two hospitals had to do with the genuine caring of the professionals in the first hospital and a lack of compassion for family members in the second. This finding is paralleled in previous research by Patterson et al. (2004), where a majority of parents reported that dealing with health-care teams was the cause of strain

for them. Their findings revealed that “in most instances, strains with health-care providers were potentially avoidable, particularly with better provider training on ways to communicate with these families” (Patterson et al., 2004, p.404). From this example it is easy to see that practical support is more helpful when provided in tandem with emotional and spiritual support.

Emotional support. Results from this study show support for research which says that both seeking and giving emotional support is beneficial as a way of coping (Patterson et al. 2004). Emotional support was received by participants in the form of cards, gifts, telephone calls, visits to the hospital and visits at home. Two couples reported that they assisted other children and families who did not have emotional support. This outcome provides evidence for what Patterson et al. (2004) described as “the paradox of social support”, in that giving support to others can be as beneficial as receiving it.

Spiritual support. Results from this research show that spiritual support was offered from others in many ways, including individual prayers, prayer lists, and asking clergy to visit the child in hospital. It can be argued that spiritual support is present in all of the previous forms of support; through the lens of a relational model of spirituality, God is seen as working through genuine human connectedness (Shults and Sandage, 2006). “We are tempted to think of persons as *being* spiritual (or not), and then ask whether they are *acting* in ways that use their metaphysical weight to provide space and time for those who are struggling to find community. However, the reformative pneumatology we have been outlining can help us understand that our way of being-present to others in space and time *is* our spirituality” (Shults & Sandage, 2006, p.142).

Spousal support. The data revealed by participants in this study was consistent with previous research which indicates that spousal support is the most important source of social support (Barbarin et al. 1985). Kevin and Angela illustrated that talking about their beliefs and experience was an important factor in providing support for one another. Through discussion they were able to ask questions and influence each other as they exchanged new ideas and beliefs about spirituality. This result is consistent with results found by Lavee and Mey-Dan (2003) which found an “increase in satisfaction with marital communication and a more positive attitude toward the spouse” (p. 260). Harriet expressed that Bob provided reliable support and she would not have known what to do if he had reacted differently.

The study by Barbarin et al. (1985) revealed that parents were likely to use symmetrical styles of coping; husbands and wives were more likely to use the same methods of coping rather than using methods that differed from their partner. Similar results were found in the data from the couples in this study. Participants expressed that the support of their partner was essential to “getting through” the diagnosis, treatment and monitoring phases of the cancer journey. Michael and Julie stated that a common language of objectivity was developed between them and served to increase the sense of support and trust between them. The observed interaction during interviews paralleled the words that were spoken; the couples frequently showed behaviours that indicated they agreed with one another such as nodding, smiling, touching and verbal confirmation of agreed upon beliefs and approaches.

These supportive behaviours described by the couples studied fit with the concept

of crucible as described by Shults and Sandage (2006), wherein the support from the partner assists in tolerating anxiety and promoting spiritual growth. This will be discussed in more depth later in the discussion section; for now however, it is important to note that the supportive interaction between couples led to greater coping through spirituality.

Coping is aided by spirituality. The results from this study are concurrent with previous research which showed a child's adjustment and psychological well-being is affected by the parent's reactions, attitudes and interactions with each other (Cummings, 1994, Varni et al. 1996, Clarke-Steffen, 1997, Lavee & May-Dan, 2003). The couples studied provided data to support earlier research which suggested a journey with cancer may have some positive outcomes such as an increased meaning of life, deepened religious faith and increased closeness in relationships (Barbarin et al., 1985, Clarke-Steffen, 1997, Patterson et al. 2004). These outcomes are consistent with the definition of spirituality used in this study "a conviction that gives meaning to life, illness and death, and that guides the individual" (Strang et al. 2001, p.626). The study participants described these outcomes as occurring with their children and the family as a whole, which demonstrates the impact of the parents' coping.

Increased meaning of life. Many research studies have provided evidence that assigning meaning to the experience of cancer is an important aspect of coping (Nichols et al., 2009, Patterson et al. 2004, Sherman & Simonton, 2001, Woodgate & Degner, 2003). Patterson et al. (2004) suggested that the balance between demands and resources is influenced by the meaning that families attribute to the experience in addition to their world view and perspective. Although the reactions of the couples in this study varied to

some degree, they all described that they had hope that they would get through it, once they discovered their faith in spirituality or faith in doctors and science. The families described increased meaning of life after the treatment phase was concluded. Increased meaning included aspects such as newly aligned priorities, increased emphasis on family, increased emphasis on focusing on relationships with other people and “giving back” to the community.

Deepened religious faith. The couples described that their faith as individuals, as couples and as a family was strengthened as a result of going through the cancer experience. Couples #1 and #3 reported that their spiritual beliefs were re-affirmed after being tested during the experience. They did not believe that God gave their child cancer as a test but rather it was an experience in life that in the end brought them more in-line with their faith. Harriet stated that she felt their belief system grew stronger as a result of being tested. After going through the experience the couples described that their faith was more present in their day-to-day living. Couple #2 described that they were surprised to notice the spiritual growth in themselves, each other and their children. This couple reported that their spirituality continues to be questioned and strengthened.

Increased closeness of relationships. Concurrent with previous research, the couples in this study expressed having closer relationships with each other and with their children as a result of going through the cancer experience (Barbarin et al, 1985, Spilka et al. 1991, Woodgate & Degner, 2003). All of the participants involved in this study spoke of having strengthened family relationships after the cancer experience. This parallels results found in other studies. “Most informants indicated that the quality of their

marriage or their family life improved since diagnosis of their child's illness" (Barbarin et al., 1985, p.475). Michael expressed that he felt his son held unwavering trust in his parents' ability to take care of him, which contributed to the closeness and confidence of the whole family. Angela and Kevin provided detailed examples of how their family enjoys spending time together and long for one another when they are apart. They described how the family prays together and the couple shares spiritual experiences both within the church community and through discussions with one another at home. Harriet described that she witnessed Bob's love for his children grow greater through the experience.

Results from the study by Barbarin et al. (1985) showed that 55% of participants experienced a positive increase in their attitude toward their spouse as a result of going through the cancer experience. The results of this research showed that all of the couples experienced a greater closeness and trust in their partner after seeing what they were able to endure during the cancer treatment.

These outcomes of increased meaning of life, deepened religious faith and increased closeness in family relationships parallel the outcomes that can be expected from a spiritual transformation. This shows initial support for the theoretical framework of Shults and Sandage (2006) as proposed in this thesis.

Preliminary Evidence: Support of Spiritual Transformation.

This study provided some preliminary support for Shults and Sandage's (2006) relational theory of spiritual transformation. There is evidence to support that relational systems cycle through periods of growth alternating with periods of stability. These cycles

were described as occurring prior to pairing together as a couple and continued to occur in the couple relationship.

Spiritual dwelling. The results of this study show evidence that spiritual beliefs provide comfort, stability and meaning to individuals. This is consistent with Shults and Sandage's (2006) concept of spiritual dwelling. Spiritual dwelling means that individuals adhere to a system of beliefs that is comfortable and usually occur within a context of community with others (Shults & Sandage, 2006). "Spiritual dwelling provides attachment security, rootedness, stability, clarity of meaning, and a shared sense of community" (Shults & Sandage, 2006, p. 185). Individuals in this study described periods of spiritual dwelling associated with family and religious communities as they were growing up and in adulthood. These periods were also interspersed with times of growth and seeking.

Attachment security. Study participants expressed that they had times in their lives when they felt a sense of safety and security associated with spiritual communities, traditions and beliefs. Harriet spoke about her mother and her religious community as providing an environment of authenticity and care. She described that this environment led to her belief in God without a doubt and she never questioned His love for her. This is consistent with Kirkpatrick's (1999) description of secure attachment with God: "the religious person proceeds with faith that God will be available to protect and comfort him or her when danger threatens; at other times, the mere knowledge of God's presence and accessibility allows him or her to approach the problems and difficulties of daily life with confidence" (p.6).

Michael described the feeling of security and attachment when he spoke about going to church with his grandmother as a child and later when Bradley was in the hospital, Michael admitted that it helped him too when his grandmother arranged for the bishops to pray over his son. From an Object Relations perspective, the security that Michael experienced may be seen as a result of the holding environment that the bishops provided. “Connection to this antecedent fund of knowing, holding, and cherishing the being of persons is precisely what a chaplain in a hospital brings to patients...Only the chaplain, medically useless, will conserve the true self of a patient by holding it in attention and being present to it” (Ulanov 2001, p.48).

Rootedness and stability. Michael described that his association with religion was about family connectedness, or in other words, it gave him a sense of rootedness. Bob illustrated the opposite experience when as a young child he was isolated from spirituality and God due to his father’s detachment from extended family and religious community. Bob turned this around when as a teenager he went into a cycle of spiritual seeking and became the first person in his immediate family to join his religious community. Julie mentioned that her family turned to religion and prayer during special occasions and times of hardship.

Clarity of meaning. For all of these couples, the partners appeared to hold shared meanings prior to the cancer diagnosis. While they were coming together as couples there was agreement on their belief systems, which showed comfort and stability in the couple relationships.

Harriet and Bob identified that they both had a strong Christian faith prior to

coming together as a couple and this was a priority for each of them as they chose a marriage partner. They shared beliefs about fundamental Christian tenets such as beliefs in Jesus Christ as saviour, the bible as the authority and God's love, forgiveness and grace.

Both Michael and Julie described their childhood as being influenced by spirituality but not having a significant religious focus, which carried on into the shared meaning as a couple. Michael appeared to have some difficulty to pinpoint exactly what spirituality meant to him as a child, except to say that it was about family connection, support and structure. The couple shared beliefs in being independent and strong as a family.

Spiritual beliefs were important to both Kevin and Angela from the beginning of their courtship, although their practice of religion differed. At an early point in their relationship, Angela experienced a transformation from doctrine of the church to trusting more in her personal experience. This brought her more inline with Kevin's religious practice. They developed shared beliefs about experiencing God in everyday occurrences and talking about spirituality.

Shared sense of community. The results from this study show that some religious communities provide a sense of shared meaning and support. These communities may be viewed as an example of holding environments (Winnicott, 1965) or crucibles (Shults & Sandage.. Harriet said that she grew up in a religious community that provided genuine care and support. Michael described going to church as being about family connection however he did not express the sense that he felt shared community with the larger

congregation. Kevin and Angela describe that while they sometimes experience a sense of community within the church, they do not feel dependant upon this to feel a relationship with God.

The shared sense of community was described in terms of religious community but it was also found in family relationships. A good example of this is Angela's father and the reciprocal influence that was experienced between him, Angela and Kevin. These dynamic relationships between the three people showed a sense of community during spiritual dwelling but it also could be considered a crucible or holding environment that maintained its support during the periods of spiritual seeking.

The body of Christ offers a community whose members imaginatively hold one another in being...we can hold the other in our attention or in our prayers without resentment because we were held without resentment as a child; we internalized such holding and have it always ready to offer to others.(Ulanov 2001, p.47)

The Couple as Crucible: A sense of security to take a leap of faith. The evidence presented in this study show support that the couple relationship is a crucible which may hold the spiritual transformation personally experienced by partners. "The crucible metaphor suggests the resiliency and non-reactivity of the container is essential to the transformative process" (Sandage & Shults, 2007, p. 265). The couples in this study presented descriptions of their relationships as having qualities which were able to endure the experiences and changes of both partners. These qualities have been outlined earlier in the discussion and include strength, trust, reliability, and stability. Securely attached individuals may assess their relationship with their partner, others and God as being

resources for which to deal with the stresses that are associated with dealing with the functional, practical and emotional stressors (Sherman & Simonton, 2001).

Recent research by Hart, Limke, and Budd (2010) suggests that in order to achieve spiritual growth, individuals must experience their attachment figures (including God) without fear of abandonment (p.126). Bob and Harriet both described an image of God as loving and present, neither of them feared that God would abandon them. Bob equates this security of relationship with God with the security he feels in relationship with his wife. Harriet expressed a feeling of security in knowing that Bob did not question supporting her and the children and he never considered leaving his family during the crisis. This security is required in order to soothe anxiety when partners may be going through different periods of spiritual growth.

Shults and Sandage (2006) identify that individuals must be able to soothe their own anxiety in order to allow the seeking process of another without impeding the other person's growth. The ability of these couples to soothe one another was demonstrated both in their verbal descriptions of the experience and also in the non-verbal communication expressed during the interviews. Angela depicted her experience of seeking out new spiritual practices while her husband Kevin was supportive rather than resistant to her exploration of different avenues. Harriet and Bob identified that it was easier to support one another once they realized that their partner expresses pain in a different way. Michael and Julie displayed outward signs of soothing anxiety such as giving their partner a tissue, stroking their hand and empathetic looks during the interview. These signs of soothing demonstrate the capability of the couple relationship to

contain the reactions involved in spiritual seeking.

Spiritual seeking.

Cancer pushed them into seeking. All of the couples in this study spoke about feelings of shock and loss of control during the initial diagnosis of cancer. At the initial diagnosis these families described feelings of helplessness. They explained that they did not have previous experiences that compared to this one, they did not know how to proceed, and nothing they have experienced before could prepare them for what to do in this situation.

The results from this study correspond with Pargament's (1997) theory that a primary and secondary appraisal is conducted when individuals are faced with a threat. The primary analysis anticipates their belief system's ability to manage the threat and the secondary analysis takes into account the resources and deficits in dealing with the threat. When confronting the diagnosis of cancer in their child, the couples showed that it was a great threat to their current belief system as demonstrated by feelings of being out of control.

This is also consistent with the theoretical model proposed by Patterson et al. (2004), which suggest that the beginning of the cancer journey is marked by an adjustment phase when families are off-balance because their resources are outweighed by the demands. Without knowing what to do, the families just held onto survival, they did whatever they needed to for their child to survive and for the whole family to get through it. A secondary appraisal includes accounting for both resources and burdens which would help or hinder their capacity for dealing with the threat. The result of these

appraisals may affect whether one decides that their current system of beliefs can sustain the impact of the cancer journey or whether it requires transformation. Pargament (1997) defined this world perspective and system of beliefs as the orienting systems. “Depending on the character of this system, it may be a help or hindrance in the coping process, for orienting systems are made up not only of resources but of burdens as well” (Pargament, 1997, p. 100). If accommodation is possible within the current system this would be defined by Pargament (1999) as coping or primary change.

Even when the couples in this study were overwhelmed with emotion and exhaustion, there was something that carried them through and gave them the ability to support their child. This parallels Woodgate and Degner’s (2003) second characteristic of spirit which is “a force within the individual which created the will to persevere.” Harriet described that she was in “survival mode” when she received the word that Leslie had Leukemia. One of the ways which Patterson et al. (2004) suggested that families can regain this balance was through belief in God and in doctors. The results of this study found that two families coped through their belief in God and the third family found their coping ability in their belief in doctors and medicine. With their will to move forward in life and to create future for their children, they found hope and the ability to cope.

The transformational spirituality model of Shults and Sandage (2006) suggests that the first step or “leap of faith” can result in a period of seeking further spiritual development, or if the anxiety is too great the individual may return to the safe haven of dwelling. Harriet and Bob described hope as being something more than just wishing that things were going to turn out alright. Harriet recognized that when she had no power to

change the situation, she relied on God's grace and mercy. Accepting the lack of control is a first step, which may or may not (if the anxiety is too great) lead to spiritual transformation. "Our attempts to use our own finite power to control the future, to secure our own life against the threat of death, are pervaded by anxiety about our relation to the Good. Recognizing our own powerlessness opens up to a transforming intimacy with God, upon whose grace our creaturely agency is wholly dependent" (Shults and Sandage 2006, p. 110). It is a "leap of faith" which brings the individual away from that which is known and toward the possibility of a greater connection with God.

Transformation occurs when the system is unable to accommodate to outside influences. "By spiritual transformation, we mean profound, qualitative or *second-order* changes in the ways in which a person relates to the sacred" (Sandage and Shults, 2007, p. 264). Second-order change is demonstrated through significant change in spiritual practice, including such things as asking new questions and praying in new ways.

Exploring new spiritual practice. In accordance with the outcomes associated with spiritual transformation, couples in this study reported that they had new spiritual practices after the cancer experience. Michael and Julie expressed increased openness to exploring spiritual and religious influences in the lives of their children and the family as a whole. Even during the interview Michael demonstrated his openness to explore new spiritual questions regarding his children's relationship to religion and the experience he had while going through the cancer treatment with his child. Angela and Kevin continue to explore relating to spirituality in new ways, including praying to spirit guide, angels and spirits of deceased ancestors, as well as exploring spirituality through nature,

meditation and books. This couple also spoke about having a new openness to the beliefs of other people from different religious backgrounds.

Shults and Sandage (2006) defined this openness as “relational alterity” and presented it as a result of spiritual maturity: “Perhaps the core challenge of spiritual maturity is one of integrity and differentiation, which involves holding on to one’s own spirituality while also relating respectively to others and their spiritualities” (Shults & Sandage 2006, p. 166).

Relational alterity was displayed in the couples as they described experiences of growing in spirituality and embracing new practices and traditions. Both Kevin and Angela described a new interest in discussing different ways of relating to the Divine in an attempt to learn more about their spirituality. They illustrated a broader understanding of how to relate to God in the belief that God is everywhere and in everything. For Harriet and Bob the result of dealing with cancer did not mean that their belief system was torn down and rebuilt again as new, but they felt as though it was more real. Harriet described two possible results of going through crisis: that one either gets “bitter or better”. She said that her family strengthened as opposed to hardened. This is a possible result of having gone through more than one transformation. “One of the powerful benefits of surviving an intense spiritual transformation (or two) is that a person can develop a stronger sense of spiritual efficacy or agency for engaging the risk of further cycles of transformation” (Shults and Sandage, 2006, p. 35).

The results of this study show some evidence for the occurrence of alternating cycles of spiritual dwelling and spiritual seeking resulting in transformation. This

evidence should be considered preliminary due to the limitations necessarily found in a master's level thesis. Further studies are required to determine conclusive evidence for the theoretical framework.

Limitations of the Study

Absent from this study were couples who started out at different places in their spirituality, which may be reflective of the small sample or it could also be indicative of the inclusion criteria of selecting participants who were still together as a couple and willing to interview together as a couple. Further research should sample a whole population of all parents of children treated for cancer within a specified period of time, in order to reduce the possibility of participants excluding due to the topic of spirituality, and measure the different periods of time following completion of treatment to measure changes and possible stages in the spiritual development.

Results from this study indicate that emotional processing continues after the treatment period is completed. Further research is required to investigate the timelines associated with this emotional and spiritual processing in order to identify the supports required for these families. This qualitative study was not able to measure the attachment styles of participants and their attachment to God. In order to facilitate increased understanding of attachment styles and the relationship to childhood cancer, future studies are needed. All participants in this study reported having significant support from family, communities, churches and schools. Possibly due to a small sample size or the method of recruitment, the study did not reflect the experience of families who did not have such support systems. Further research is required for further understanding of how

spiritual development is experienced by families who do not have strong support systems. The issues of grief and loss were not directly addressed by participants in this study, this may also be considered as areas for further investigation. In addition, future studies should examine couples who did not stay together during or following treatment in order to further understand the aspects that maintain the couple relationship as well as factors which may impede upon it.

Another drawback of the obtained sample is the lack of cultural and religious diversity among the participants. All participants had a background in Christianity and diversity of other non-Christian faiths should be considered for future research in this area.

Implications for Clinical Practice

Understanding the commonalities and uniqueness in response to childhood cancer is important for practitioners to help couples who may have different understanding and meaning between the partners. Knowing that individuals have different definitions of spirituality and move towards spiritual seeking at different periods can help practitioners to understand the interaction that is functioning between the partners. Greater understanding about the couple crucible as a holding environment for spiritual transformation, and the dwelling and seeking cycles, will enable practitioners to educate couples and assist the partners in supporting each another at various stages in the cycle. Knowing that anxiety can increase during periods of seeking, pastoral counsellors may assist clients to self-soothe and to soothe one another during initial periods of seeking. These suggestions for clinical practice are consistent with those recommended by

Shermon and Simonton (2001), which include enhancing family cohesion, differentiation and assisting families to find meaning.

In addition, this research informs practitioners about the importance of being authentic in their own spirituality as they can also function as attachment figures to clients and thus create a holding environment for spiritual transformation leading to growth and maturity. “The problem of pastoral ministry to persons in crisis in our time is one of facilitating trust in the person who has experienced something which, in its impact on the person’s structuring of his or her life, has undermined the very basis of trust” (Gerkin 1979, p.34). Despite this challenge posed by Gerkin, the results of this research show that the presence of authentic, genuine people makes a significant impact on a client’s coping. Pastoral counsellors who have the courage to go through their own periods of seeking may be more effective in walking with others, more likely to hold on and let go at appropriate moments in the cycle and less likely to try to “save” clients who are straying away from their dwelling place. “Secure attachments with caring but non-rescuing relational figures can offer a secure base for tolerating the anxiety of seeking, and this highlights the need for differentiated leaders who have been through their own crucibles of intensification” (Sandage & Shults, 2007, p. 266).

Personal Reflection on Spiritual Transformation.

The process of researching, analyzing and writing a thesis about couples and their spirituality has led to my own personal experience of transformation. Throughout my journey as a researcher, I encountered periods of challenge and crisis which forced me to deeply reflect upon my own personal process and spirituality. This thesis is a culmination

of personal exploration and academic learning in the areas of family counselling and spirituality. Throughout the process I was consciously aware of how my development was impacted as I challenged myself to be aware of my family history, my romantic relationships, my spiritual beliefs and the interrelatedness between them all.

Becoming a student at St. Stephen's College and taking on this thesis research was an unplanned event which represented homecoming in a number of different ways for me. I began my Master's degree at another university which focussed on family therapy and due to unforeseen circumstance I could not continue in that program and was forced to find another. During my time in the first university I confronted some of the emotional residue from my family of origin and my parents' divorce which occurred when I was a teen. Pastoral counselling contained associations with my parents' divorce that I might not have been able to embrace without the previous experience studying family of origin, family systems and couples counselling. Perhaps it was due to my resolution of these issues that I felt a need to return to my home town of Edmonton and open my heart to the influence of God. Thus it was both physical and psychological homecoming.

During the process of completing this research there were moments of complete frustration and feelings of being out of control. Some of the most difficult moments came for me during the beginning stages of putting together a proposal and recruiting participants. I discovered strength in my faith as a result of my growing personal relationship with God. One of the most powerful moments for me came when I released my sense of control and prayed for help from God:

This morning I was feeling discouraged by the barriers and obstacles that I have

encountered with recruiting people, with my thesis/Masters program in general and in the breakdown of my own couple relationship. I have been praying and asking for His help in all of these... I remembered that I have been wanting to read the book of Job...what I read soothed my soul and gave me faith that God will reward those who have integrity- He will restore you. And so I prayed. Today I have seen such a quick and direct answer to prayer as I have recruited not one, but TWO new couples!

I have learned so much about spirituality through my experience of working with the data provided in the interviews and compiling research on spirituality. During this process I have seen my prayer completely transformed. It was virtually non-existent prior to enrolling at St. Stephen's, then it became petitionary prayer where I asked God to give me the things that I wanted or needed and now I find myself having more in depth conversations with God about my inner most thoughts. I know that God is with me and surrounds me, I know that He always has been but I was choosing to block Him out. Never before have I felt peace and comfort the way I feel it now because of my new found strength in the belief that God has a plan for me. Now instead of feeling anxiety about my future, I find myself in excited anticipation to see what God has in store.

I have always been conscious that my interest in couples was a way to resolve my feelings about divorce and my own singleness. Writing in a reflective journal provided a way to keep my issues and beliefs separate in order to remain objective about my research, but it also provided another function. The reflective journal enabled me to combine my personal exploration with the learning I was gaining through classes, reading

and research. One such example is the following entry about my spiritual growth:

Is it possible that God created this period of time for me of being single...in order to create the liminal space where I would have my spiritual transformation? Last night I was bemoaning and grieving the fact that I grew up as the only girl in my family and now I feel excluded once again as an adult because I am the only single one. Just now for the first time, the thought comes to me that my personal experience of being single not only informs why I have chosen this topic but it may have spiritual implications, indeed, it already has. It is my “dark night”, it is my test of faith.

Throughout the process of this thesis, I have been careful that my personal bias does not affect the outcome of my research. Little did I know how much the research was going to affect me. I have come to realize that this is an important aspect of studying to become a pastoral counsellor; one must have the courage to confront their own beliefs and emotions, and the courage to risk spiritual seeking in order to obtain transformation.

Chapter Six: Conclusion

Clearly, the couple relationship provides stability and support for the entire family while going through the difficult experience of a cancer diagnosis in their child.

Overcoming such a challenge can be analogous to climbing a mountain, where couples require faith and trust in each other’s ability to ease the journey. The evidence found in this study supports previous studies who found that spirituality is a part of the process and it also supports the conceptual framework presented by Shults and Sandage (2006).

Future research can broaden this initial understanding by including a variety of faiths and

studying a larger sample. Further research may also focus on exploring the possibilities that crisis of faith, and grief and loss have upon the experience. These issues were not illuminated in this current study. At this point, we can not be definitive in saying that every person or every couple will have aspects of spirituality in their process; however, further research may provide more clarity. Ultimately, spirituality is an area which can be illuminated with the support of pastoral counsellors, or other clinical professionals, in order to provide a smoother and easier process for parents and families who are going through such an experience.

Bibliography

Anderson & Fite (1993). *Becoming married*. Louisville, KY: Westminster/John Knox Press.

Barbarin, O.A, Hughes, D. & Chestler, M.A. (1985). Stress, coping and marital functioning among parents of children with cancer. *Journal of Marriage and the Family*, 473- 480.

Bowen, M.D. (1966). The use of family theory in clinical practice. *Comprehensive Psychiatry*, 7(5), 345-374.

Bowlby, J. (1969). *Attachment and loss: Vol.1 Attachment*. New York: Basic.

Bowlby, J. (1973). *Attachment and loss: Vol.2 Separation anxiety and anger*. New York: Basic.

Bowlby, J. (1979). *The making and breaking of affectional bonds*. London: Tavistock.

Bucci, W. (1997). *Psychoanalysis and cognitive science: A multiple code theory*. New York: Guilford Press.

Burnard, P. (1991). A method of analysing interview transcripts in qualitative research. *Nurse Education Today*, 11, 461- 466.

Canadian Cancer Society. (2009). *Childhood cancer: A guide for families*. Retrieved September 23, 2009 from <http://www.cancer.ca/canada-wide/publications/alphabetical>

Canadian Cancer Society's Steering Committee. (2009). *Canadian Cancer Statistics 2009*. Toronto: Canadian Cancer Society. Retrieved September 23, 2009 from <http://www.cancer.ca/Canada-wide/About%20cancer/Cancer%20statistics>

- Cardella, L.A. & Friedlander, M.L. (2004). The relationship between religious coping and psychological distress in parents of children with cancer. *Journal of Psychosocial Oncology*, 22(1), 19- 37.
- Clarke-Steffen, L. (1997). Reconstructing reality: Family strategies for managing childhood cancer. *Journal of Pediatric Nursing*, 12 (5), 278-287.
- Cummings, E.M. (1994). Marital conflict and children's functioning. *Social Development*, 3(1), 16-36.
- Efficace, F. & Marrone, R. (2002). Spiritual issues and quality of life assessment In cancer care. *Death Studies*. 26, 743- 756.
- Gerkin, C. (1979). *Crisis experience in modern life: Theory and theology for pastoral care*. Nashville: Abingdon.
- Glaser, B.G., & Strauss, A.L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Chicago, IL: Aldine.
- Glesne, C. (2006). *Becoming qualitative researchers, 3rd Edition*. Boston, MA: Pearson Education, Inc.
- Goldbeck, L. (2001). Parental coping with the diagnosis of childhood cancer: Gender effects, dissimilarity within couples, and quality of life. *Psycho-Oncology*, 325–335.
- Grant, B.W. (2001). *A theology for pastoral psychology: God's play in sacred Spaces*. New York: Haworth Press.
- Groeschel, B. J. (1989). *Spiritual passages: The psychology of spiritual development for those who seek*. New York, NY: Crossroad Publishing.

- Guba, E. & Lincoln, Y. (1982). Epistemological and methodological bases for naturalistic inquiry. *Educational Communication and Technology Journal*, 30 (4), 233-252.
- Hall, T.W., Brokaw, B.F., Edwards, K.J. & Pike, P.L. (1998). An empirical exploration of psychoanalysis and religion: Spiritual maturity and object relations development. *Journal for the Scientific Study of Religion*, 37(2), 303-313.
- Hall, T.W. (2004). Christian spirituality and mental health: A relational Spirituality paradigm for empirical research. *Journal of Psychology and Christianity*, 23 (1), 66-81.
- Hall, T.W., Fujikawa, A., Halcrow, S.R., Hill, P.C., Delaney, H. (2009). Attachment to God and implicit spirituality: Clarifying correspondence and Compensation models. *Journal of Psychology and Theology*, 37(4), 227-242.
- Hart, J.T., Limke, A. & Budd, P.R. (2010). Attachment and faith development. *Journal of Psychology and Theology*, 38 (2), 122- 128.
- Howes, P. & Markham, H.J. (1989). Marital quality and child functioning: A longitudinal investigation. *Child Development*, 60, 1044- 1051.
- Hunt, M.R. (2009). Strengths and challenges in the use of interpretive description: Reflections arising from a study of the moral experience of health professionals in humanitarian work. *Qualitative Health Research*, 19, 1284- 1292.

- Kegan, R. (1982). *The evolving self: Problem and process in human development*.
Cambridge: Harvard University Press.
- Kirkpatrick, L.A. & Shaver, P.R. (1990). Attachment theory and religion:
Childhood attachments, religious beliefs, and conversion. *Journal for the
Scientific Study of Religion*, 29, 315-334.
- Kirkpatrick, L.A. (1992). An attachment-theory approach to the psychology of
Religion. *The International Journal for the Psychology of Religion*, 2(1),
3-28.
- Kirkpatrick, L.A. (1999). Attachment and religious representations and behaviour.
In *Handbook of Attachment: Theory, Research, and Clinical Applications*.
Eds. P.R. Shaver and J. Cassidy. New York, NY: Guilford Press. pp.803-
822.
- Lavee, Y. & Mey-Dan, M. (2003). Patterns of change in marital relationships among
parents of children with cancer. *Health and Social Work*, 28 (4), 255-263.
- Lindahl Norberg, A. & Bowman, K.K. (2008). Parent distress in childhood
cancer: A comparative evaluation of posttraumatic stress symptoms,
depression and anxiety. *Acta Oncologica*, 47, 267- 274.
- Mahoney, A., Pargament, K.I., Jewell, T., Swank, A.B., Scott, E., Emery, E. & Rye, M.
(1999). Marriage and the spiritual realm: The role of proximal and distal religious
constructs in marital functioning. *Journal of Family Psychology*, 13 (3), 321-338.
- Mansager, E. & Eckstein, D. (2002). The transformative experience questionnaire
(TEQ): Spirituality in a couples context. *The Family Journal*, 10 (2), 227-233.

- Morse, J.M, Barrett, M., Mayan, M., Olson, K. & Spiers, J. (2002). Verification strategies for establishing reliability and validity in qualitative research. *International Journal of Qualitative Methods* 1 (2).
- Murray, J.S. (2000). Attachment theory and adjustment difficulties in siblings of children with cancer. *Issues in Mental Health Nursing*, 21, 149-169.
- Nicholas, D. B., Gearing, R.E., McNeil, T., Fung, K., Lucchetta, S., & Selkirk, E.K. (2009). Experiences and resistance strategies utilized by fathers of children with cancer. *Social Work in Health Care*, 48: 260-275.
- Noffke, J.L. & Hall, T.W. (2007). Attachment Psychotherapy and God Image. *Journal of Spirituality in Mental Health*, 9(3/4), 57- 78.
- Pargament, K.I. (1997). *The psychology of religion and coping*. New York, NY: Gilford Press.
- Patterson, J.; Holm, K. & Gurney, J. (2004). The impact of childhood cancer on the family: A qualitative analysis of strains, resources, and coping behaviours. *Psycho-Oncology*, 390-407.
- Plouffe, R. (2005). Belief Transitions. *ARCAPPE Newsletter*, Summer 2005, 6 (2), 2-4.
- Rizzuto, A.M. (1979). *The birth of a living God*. Chicago, IL: The University of Chicago Press
- Rowatt, W.C. & Kirkpatrick, L.A. (2002). Two dimensions of attachment to God and their relation to affect, religiosity and personality constructs. *Journal for the Scientific Study of Religion*, 41 (4), 637-651.
- Sandage, S.J. & Shults, F.L. (2007). Relational spirituality and transformation: A

- relational integration model. *Journal of Psychology and Christianity*, 26 (3), 261-269.
- Schnarch, D. (1997). *Passionate Marriage*. Owl Books: New York, NY.
- Schneider, M.A., & Mannell, R.C. (2006). Beacon in the storm: An exploration of spirituality and faith of parents whose children have cancer. *Issues in Comprehensive Pediatric Nursing*, 29, 3-24.
- Sherman, A.C. & Simonton, S. (2001). Coping with cancer in the family. *The Family Journal: Counseling and Therapy for Couples and Families*, 9 (2), 193-200.
- Shults, F.L. & Sandage, S.J. (2006). *Transforming spirituality: Integrating theology and Psychology*. Grand Rapids, MI: Baker Academic.
- Spilka, B., Zwartjes, W.J & Zwartjes, G.M. (1991). The role of religion in coping with childhood cancer. *Pastoral Psychology*, 39 (5).
- Stern, D.N., Sander, L.W., Nahum, J.P., Harrison, A.M., Lyons-Ruth, K., Morgan, A.C., Bruschiweiler-Stern, N., Tronick, E.Z. (1998). Non-interpretive mechanisms in psychoanalytic therapy: The 'something more' than interpretation.
- Strang, S., Strang, P. & Ternstedt, B.-M. (2001). Existential support in brain tumour patients and their spouses. *Support Cancer Care*, 9, 625-633.
- Swinton, J. & Mowat, H. (2006). *Practical Theology and Qualitative Research*. London: SCM press. Grand Rapids, MI: Baker Academic.
- Tillich, P. (1963). *The Eternal Now*. New York, NY: Charles Scribner's Sons.
- Thorne, S., Reimer Kirkham, S., MacDonald-Emes, J. (1997). Interpretive Description: A noncategorical qualitative alternative for developing nursing knowledge.

Research In Nursing and Health, 20, 169- 177.

Thorne, S., Reimer Kirkham, S., O'Flynn-Magee, K. (2004). The analytic challenge in Interpretive Description. *International Journal of Qualitative Methods, 3 (1), 1-21.*

Thorne, S. (2008). *Interpretive Description*. Walnut Creek, CA: Left Coast Press.

Ulanov, A.B.(2001). *Finding Space.: Winnicott, God and psychic reality*. Louisville: KY. Westminster John Knox Press.

VanKatwyk, P.L. (2003). *Spiritual Care and Therapy: Integrative Perspectives*. Waterloo, ON: Wilfred Laurier University Press.

Varni, J.W., Katz, E.R., Colegrove, R. & Dolgin, M. (1996). Family functioning predictors in adjustment of children with newly diagnosed cancer: A prospective analysis. *Journal of Child Psychology and Psychiatry, 37 (3), 321- 328.*

Watzlawick, P., Weakland, J.H., & Fisch, R. (1974). *Change: Principles of Problem Formation and Problem Resolution*. Oxford, England: W.W. Norton.

Winnicott, D.W. (1971). *Playing and Reality*. London and New York: Routledge.

Woodgate, R.L. & Degner, L. F. (2003). A substantive theory of keeping the spirit alive: The spirit within children with cancer and their families. *Journal of Pediatric Oncology Nursing, 20, 103- 119.*

Appendix 1

Demographic Information

Name (Partner 1): _____

Age: _____

Member of Faith Community? No _____ Yes (please specify) _____

Member of Faith in Childhood? No _____ Yes (please specify) _____

Name (partner 2): _____

Age: _____

Member of Faith Community? No _____ Yes (please specify) _____

Member of Faith in Childhood? No _____ yes (please specify) _____

Date of beginning of Relationship: _____

Date of marriage (if applicable): _____

Children's Names and Date of Birth:

1. _____ Age: _____

2. _____ Age: _____

3. _____ Age: _____

4. _____ Age: _____

5. _____ Age: _____

*please place star beside child who was diagnosed with cancer.

Child's Diagnosis: _____

Date of Diagnosis: _____ Age of Child at Diagnosis: _____

Describe any other cancer diagnosis in the family, the person diagnosed, relation to the child, year of diagnosis, type of cancer (continue on back of page if necessary)

Appendix 2

Newsletter Article**Research Participants Wanted****This question of relational spirituality will be explored in an upcoming study of couples with a child diagnosed with cancer.**

Having a child with cancer is perhaps one of the most difficult burdens that can be imposed on a family. It may be hard for families in the midst such a frightening experience to see the grace of God. The goal of this study is to explore how professionals can provide clinical support to the couple to enhance their spirituality and help the whole family to cope better. Couples are being recruited to participate in 90 minute interviews.

Some research has shown that spirituality increases parental coping and decreases the amount of distress experienced by parents during childhood cancer, however, to date there is no research that explores how spirituality works in the couple relationships. This study focuses on the parents' because the strength of the couple relationship provides a foundation for the whole family. The parent's marital relationship can affect how the child with cancer adjusts, how the whole family functions, and how they cope emotionally.

Although most people fear the thought of dealing with a cancer diagnosis, surprisingly many families who have experienced it will say that there are positive aspects mixed in with the negative. Some of the positive effects of experiencing a journey with cancer are the increased meaning of life, deepened religious faith and increased closeness in relationships. Through this study we hope to help more people experience such positive effects.

Leigh Teghtmeyer is a Master's degree candidate in the Master of Arts, Pastoral Psychology and Counselling program at St. Stephen's College in Edmonton. If you are a parent of a child who has had cancer and would like more information about this study and how to participate, please call Leigh at _____ or email.

Appendix 3

Email to Personal Contacts

Hello.

I am writing again because I am struggling to recruit people for my master's thesis and I would like to enlist your help. Even if you do not know of anyone personally who fits the description of who I am looking for, it is possible that within your network of contacts there is someone who knows someone who might be interested. I am asking you to forward this message to people who might work with children or families, people in your churches or who are active in church, and in general people who are connected and active in the community. I have attached the information below which you can forward on to your contacts. Please also ask them to pass the information on to others in their network.

I am recruiting couples who have had a child with cancer. The child should have been younger than 18 when diagnosed. The purpose of the study is to learn about how couples experience spirituality and get through the experience of having a child with cancer. The commitment is minimal, there is a one time interview and a slight possibility that they may be contacted again to answer a few questions. Both partners will be interviewed together for approximately 90 minutes.

Thank you so much for your help! With any luck you will be hearing from me soon to say that I have recruited and interviewed my participants and I am well on the way to writing!

Leigh

Appendix 4

Leigh Teghtmeyer
St. Stephen's College
Edmonton, AB

September 2, 2010

Dear Parents:

This letter is being sent to you, as parents of a child with cancer, to inform you about a research study that you might want to participate in. The purpose of this study is to describe the spiritual experience of couples who have a child with a cancer diagnosis. I intend that this information will be used to inform clinical practice and support other families who have a child with cancer. The research will be carried out just as it is stated in this letter. I will not deceive or lie to you about the description of the research. This study is being conducted as a thesis project for the Master's of Pastoral Psychology and Counselling program at St. Stephen's College in Edmonton, Alberta. Successful completion of this thesis will result in a Master's degree.

I will ask you to meet with me to talk about your experiences with cancer. Some things to know about the interview are:

- You will also be asked to complete a form with information about your family.
- I will ask you about all the members of your family at the beginning of the interview. At this time I will draw a diagram of all the people in your family called a genogram. The genogram will help me to remember who is in your family and how everyone is related.
- In the interview, I will speak with both you and your partner together. I will ask questions about how the cancer has affected you. There is a possibility that you may learn new information about your partner that she or he has not revealed before. If needed, resources for counselling support are available.
- I will ask questions about how this has affected your spirituality as an individual and as a couple.
- The interview will be audio taped.
- The interview will be about 90 minutes long.

After we finish, I will listen to the interview recordings and type everything that was said onto a word processor. When I type the interview, your name will be replaced by a fake name. All the names in your family will be changed and I will be the only one who knows which fake name is used for which person. I may ask to talk with you a second time to follow up on some interesting ideas from your previous interview and to make sure I got your story right.

If you choose to take part in this research study, you have the right to stop at any point. You do not have to finish the interview. Even after the interview is done, you can ask me not to include your information. All of the information from your interview will be destroyed and will not be included in the study. Due to the nature of this study, the information is combined with other information so it is not possible to extract it after this is done. Thus, if a participant decides to opt out, they must notify within two weeks from when the interview was completed.

Some possible benefits of participating in this research are:

5. You may feel better from sharing your story.
6. You may understand yourself, your partner and your family better regarding the experience with cancer.
7. You may experience a new closeness with your partner and/or a change in family relationships
8. You may have a new experience of spirituality.

Some possible risks of participating in this research are:

4. You may learn new information about your partner that you didn't know before. This information could create discussion or disagreement in your relationship.
5. You may feel confused or overwhelmed with some of the feelings that you experience as a result of sharing your story.
6. You may not feel comfortable that you shared your story or have other feelings about telling someone about this personal event in your family's lives.

If you want a copy of the final report, I will send one to you in the mail when the project is complete. What is learned in these interviews will be presented on the graduation day at St. Stephen's College. If it is used for another purpose, the same guidelines as above will be followed. If the data is going to be used for additional research, another ethical review will be done.

The researcher can be contacted at any time if you have any questions. You may also contact either the thesis supervisor or Coordinator, Master of Arts in Pastoral Psychology and Counselling (St. Stephen's College).

Sincerely,

Leigh Teghtmeyer

Appendix 5

CONSENT FORM

Title of Project:

Climbing the Mountain Together: Describing the Spiritual Experience of Couples who
have a Child with Cancer.

Investigator:

Leigh Tegtmeyer

Consent: Please circle your answers:

Have you received and read the attached Consent Letter?	Yes	No
Do you understand the benefits and risks involved in taking part in this research study?	Yes	No
Do you understand that you can quit taking part in this study at any time? You do not have to say why and it will not affect the services you are receiving.	Yes	No
Has confidentiality been explained to you?	Yes	No
Do you consent to being Audio-taped?	Yes	No
Do you understand who will be able to see or hear what you said?	Yes	No
Do you understand that people at St. Stephen's college may know that you participated in this study, but they will not know what you said?	Yes	No
Do you know what your information will be used for?	Yes	No
Do you give us permission to use your data for the purposes specified?	Yes	No

Date _____

Participant's signature _____

Researcher's signature _____

Appendix 6

Interview Guide

Title of Project:

Climbing the Mountain Together: Describing the Spiritual Experience of Couples who have a Child with Cancer.

Investigator:

Leigh Teghtmeyer

Master of Arts in Pastoral Psychology and Counselling Program

St. Stephen's College

Thesis Question: How do couples' describe their spiritual experience when their child is diagnosed and treated for cancer?

Interview Guide

1. Ask each person: Could you tell me about your spiritual beliefs growing up?
2. As you came together as a couple, what were the important aspects of your spirituality?
3. How did you, as a couple, bring your individual perspectives of spirituality together?
 - Probe for shared elements and differing elements
4. Ask each person: Can you tell me about your spiritual beliefs now?
 - Probes: What does hope mean to you? What is faith? Do you believe in a higher power?
5. Can you tell me about how your spirituality affects your beliefs about death and the meaning of life?
 - Probe for most important spiritual elements
6. When *child's name* was diagnosed and going through treatment, what did you notice about your spirituality?
7. How do you think you have influenced each other through your spiritual journey?
8. Has witnessing your partner's experience impacted your understanding of the process that you are going through? If so, how?