Including Spirituality: A Means to Cope with Cancer and Recommendations for Health Care Professionals

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Canada
Including Spirituality: A Means to Cope with Cancer and Recommendations for Health Care Professionals

by

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THESIS

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ABSTRACT

Although psychosocial oncology is gaining in popularity as more research is conducted to support its inclusion in health care, there is still a lack of incorporation of spirituality in health care. The purpose of this study is to answer the following research questions: 1) How do participants use spirituality to aid in their healing? 2) How would participants like their health care professionals, specifically social workers, to incorporate spirituality into their formal care?

A qualitative, phenomenological methodology was selected for this investigation in an effort to gain an understanding of the lived experiences of people with cancer. Semi-structured interviews were conducted. The data was manually analyzed using color coding, first to identify the major categories and then to identify themes within each category.

The findings of this investigation were contained in five major categories: healing, spirituality, feeling supported and connected, role of health care professionals and recommendations for health care providers.

The processes of healing described by the participants in this study were compared to Kubler-Ross's stages of grief and Goldsworthy's grief and loss theory and intervention. This study provides an alternative theory of healing that suggests four possible emotions people may experience when diagnosed with cancer: questioning, denial, fear and acceptance. These emotions are not experienced in a linear and they may not be experienced by everyone, however they were common emotions experienced by the participants in this study.

Recommendations for practice were provided by the participants. They suggested that by exploring spirituality, engaging in a holistic approach and by providing tools such as peer support and meditation programs, social workers can better meet people’s spiritual and emotional needs during their cancer experience.
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CHAPTER ONE: INTRODUCTION

General Overview of the Phenomenon of Interest

Currently there is little incorporation of spirituality in cancer treatment by health care professionals despite studies that have shown that spirituality has a positive effect on disease treatment planning, including cancer treatment planning (Sulmsay, 2006; Powell, Shahabi & Thoresen, 2003; George, Ellison & Larson, 2002; Thoreson & Harris, 2002). Additional research indicates that cancer patients view their spirituality as an important aspect of their illness and healing process, and that they would like more inclusion of spirituality in their medical treatment (Whitman, 2007). The purpose of my study is to determine how people with cancer use spirituality in their healing and how they would like their health care professionals to integrate spirituality into their formal treatment plan. By asking participants about their spirituality in relation to their cancer treatment, I will be able to provide information to health care professionals, specifically social workers, so that they may better meet the needs of the people they work with and ultimately improve client care.

This topic is especially relevant to the field of social work, as social workers will play a vital role in bringing these changes to fruition. Social work’s roots lie in religion and spirituality (Hicks, 2006). Therefore it fits that social workers continue to include these aspects in their work. Carr & Morris (1996) claim it is easier for social workers to identify clients’ spiritual coping needs as they are well versed in active listening and the use of self to help people explore these needs. Social workers are in an ideal position to work with individuals to negotiate their spiritual beliefs and the inclusion of them in their cancer care. They can then use this acquired rapport to advocate for clients’ spiritual
needs to be incorporated into their cancer treatment planning. This enhanced awareness of clients’ spiritual needs will in turn improve the ability for health care professionals’, specifically social workers’, to more fully address people’s needs thus improving overall care.

Defining Spirituality

The word spirit is derived from the Latin word “spiritus” meaning breath, spirit or soul (Wheelock, 2000). Spirituality therefore refers to one’s connection to his or her breath of life, spirit or soul. Today the term spirituality is sometimes confused with the term religion. Baskin (2002) argues that spirituality and religion are not equivalent. She states that religion is usually structured and group oriented while spirituality “can include individual experiences with or without a structured belief system” (p.2).

Coates (2007) also discusses the differences between religion and spirituality. He speaks of Robert Forman’s four common elements of spirituality. These include: a sense of connectedness and being in relationship with something greater than the self, acting as a source of comfort and guidance, dealing with the inner experience, being inclusive and holistic, and being subjective, non-rational, and non linear, appealing to our intuitive, meditative side (p.9). Coates notes that people who identify themselves as being spiritual may or may not identify themselves as being religious. He (2007) quotes Furman’s definitions of religion as a “framework for beliefs, values, traditions, doctrine, conduct, and rituals … whereas spirituality is a much more encompassing term” (2007).

A common definition of spirituality which can be found on many websites including the Ontario Consultants on Religious Tolerance (1996) is “activities which renew, lift up, comfort, heal, and inspire both ourselves and those with whom we
interact.” This definition does not prescribe certain activities or practices that define spirituality but instead allows for individual interpretation of activities that result in spirituality as it is defined.

Wright (2004) defines spirituality as “whatever or whoever gives ultimate meaning and purpose in one’s life that invites particular ways of being in the world in relation to others, oneself and the universe.” This definition also allows for individual interpretation of what spirituality entails. Unlike the previous definition this one does not prescribe the ways of being in the world in relation to others and the self. This too is left to the interpretation of the individual.

LaPierre (in the Catholic Health Association of Canada, 1996) describes six factors of spirituality: journey, transcendence, community, religion, mystery of creation and transformation. Journey involves the quest for meaning and purpose. Transcendence is a belief that there is more to us than the limits of human existence. Lapierre suggests that the transcendent can be most powerfully encountered in nature for many people. Community refers to the idea that our spiritual life occurs by knowing, loving and being with others. Religion he acknowledges may or may not be a part of an individual’s spirituality. If it is involved, it provides traditions and rituals that connect us to the spiritual journeys of those who have come before us. The Mystery of Creation refers primarily to nature and the wonderful creations within it. Finally Transformation involves the ongoing growth from a place of fixation on ourselves toward a relationship with the other.

I found Lapierre’s six factors to resonate with me. I believe that spirituality is an ongoing journey that is facilitated by the people we are surrounded by. My spirituality
involves a belief that there is something greater than simply human existence and a feeling of connectedness to that something more. Similar to what was suggested by Lapierre, I have had my most spiritual moments, feeling the most connected, when I am in the wonder of nature. While I believe religion can be useful in some people’s spiritual journey, I do not believe it is a necessary component. I believe it is more important to embark on the journey of being transformed from a self-fixated being to a loving, compassionate being toward others, one’s self, and the something greater.

McCarroll, O’Connor, and Meakes (2005) conducted a literature review regarding the definitions of spirituality used in health care literature. While they identified common themes within the definitions, they also note that it is something that can be described but not “univocally contained and defined by human language.” There are as many definitions of spirituality as there are people. In order to be respectful of this I chose not to provide a definition of spirituality to the participants in order to allow them to interpret spirituality in their own way.

Experiential Context for the Investigation

My interest in this topic stems from my personal experiences and beliefs. In the past ten years I have watched family members battle with breast cancer, endometrial cancer and most recently, esophageal cancer. All three of these women found not only strength and guidance from their spirituality, but also peace in the face of their disease.

My Great Aunt is a breast cancer survivor and attributes at least part of her ability to overcome cancer to her spirituality. She found great comfort in her faith in God. She prayed a lot, read her bible and relied on both her family and her church community for
support. I recall her talking about God and the comfort she felt because He was with her and therefore she was not alone.

Her sister, my fraternal grandmother, used spirituality to help her accept the less optimistic diagnosis of her endometrial cancer and eventually her death. While she had always been spiritual and faithfully attended church each week, she relied on her faith most during the time of her diagnosis and the duration of her disease. Immediately after her diagnosis I recall her feeling similar to my great aunt in that she too felt that God was with her. As the cancer progressed, she became closer to God as her death drew near. I remember hearing her talk about conversations she had with God that helped her make decisions about her treatment options. She was comforted not only by God’s help in these decisions, but also by the feeling that no matter the outcome, this world was not the end. If she were to die, she would be with God. That provided her, my family and me with great comfort in the days before and after her death.

My maternal grandmother is currently using her spirituality to find strength to fight esophageal cancer, and the grace to accept this challenge. While her diagnosis is terminal and the treatment options are palliative, she too finds not only comfort in God but also strength. Her appreciation of God for her 86 previous years of good health is expressed, as is her appreciation for His support during this time. She not only finds comfort in knowing that she will be with God when she dies but also that she will be reunited with loved ones in Heaven.

As a daughter, I have used my spirituality to better cope with my father’s struggle with chronic pain. For over 20 years I have watched my father suffer from chronic pain. I had to develop effective coping strategies to endure witnessing such intense pain and
suffering. One coping strategy I found was my spirituality. I used it in two ways. First, I have used it to make meaning of my father’s suffering. I have found meaning not only in how it has affected the lives of my mother and brother, but also in the ways in which it has affected me. Part of my own spirituality involves a belief that every experience prepares us for something else we must face in the future. My father’s pain and suffering has become a defining part of who I am and has forced me to become not only accustomed to, but comfortable with, being constantly involved with the health care system. This experience has not only affected my personal life, but also my professional life. This experience played a substantial role in my choice to enter social work as a career. My interest in medical social work and my desire to help others who are suffering due to medical conditions has stemmed from this experience. I have also used my spirituality and faith in God to gain strength to cope with his suffering. When he is in great pain and I cannot bear to watch I find myself asking God for the strength to witness this and to deal with the pain of watching someone I love suffer. I also ask that God be with him and give him the capacity to endure this suffering. In addition to witnessing his suffering I have also witnessed how he has dealt with this challenge. While I myself initially relied on finding meaning and comfort through my spirituality, my father has only recently included spirituality as a coping mechanism. He has struggled to find meaning in his experience of pain.

Coming from a white middle class background I have learned to think of healing in the western medical sense. That is, doctors, nurses and other health care professionals heal people with new advances in medical technology and techniques. As I have grown and gained more life experience I have come to see that healing is not necessarily limited
to being physically healed. I now consider that healing includes mental, emotional, spiritual and physical health. My bias is that I believe in western medicine, and that while other interventions, such as spirituality, can assist western medicine, they cannot entirely replace it.

Watching the people in my life use spirituality in the face of illness has led me to consider and solidify my beliefs about the role of spirituality. I believe that spirituality can play a role in healing. I believe it helps people accept and face their circumstances, in addition to giving meaning to situations. Spirituality also can have positive effects on physical health. It is important to note that while spirituality can, it does not necessarily have to, involve organized religion. Although I grew up in a middle class, white, Christian culture, I believe that the benefits of spirituality are not limited to this culture and privilege. The benefits of spirituality apply equally to all social classes, races, and faiths, both organized and individual.

Cancer Support Centres

In preparation for this investigation and as part of my recruitment (which will be further expanded in a later chapter), I spoke with staff at three cancer support centres, Wellspring, Halton-Peel, Wellspring Chinguacousy and Hopespring Waterloo to learn more about these centres and what services they offer.

Wellspring is a network of cancer support centres located across Canada. It was founded in Toronto by Anne Armstrong Gibson in 1992 who had been diagnosed with non-Hodgkins lymphoma. With the help of oncology experts, family and friends, she established the non-profit organization to provide psychological, emotional, social, spiritual and informational support to individuals and families experiencing cancer. She
wanted to create community-based centres that provide people with the tools to cope with cancer. Since then they have opened centres across the country and initiated partnership programming in other communities in Ontario. This follows Armstrong-Gibson’s vision of a Canada-wide network of centres.

All programs offered at Wellspring are free of charge for both people with cancer and their families. Some of the programs offered are: informational library, wig boutique, support groups, peer support, financial concerns program, coping skills programs, yoga, Tai Chi, massage, Reiki, returning to work, transportation and child care, and short-term individual counselling.

Hopespring Cancer Support Centre in Waterloo was founded in 1995 as a place where people with cancer and their families can receive support, information about their illness, and other life-affirming therapies to support their existing medical treatments. In 2006 they opened a second location in Cambridge. Volunteers are available to offer hope and inspiration to members. Similar to Wellspring, all the programs and services offered at Hopespring are free of charge and do not require a referral. Some of the programs offered at Hopespring include: relaxation therapies, information sessions, wig boutique, courses, workshops, and seminars.

There are aspects of Wellspring and Hopespring that make them unique cancer support centres. First the setting, the centres are located in a house where they provide a more home-based environment for the services. The centres combine both eastern and western ways of healing, and provide a wide variety of tools and programs available to members. Finally, the centres focus around living and finding new ways to live the best life one can.
Statement of Purpose and Research Questions

While exploring my interest in the connection between spirituality and cancer, I spoke with Pat Carty, Acting Director of Hopespring Cancer Support centre in Waterloo (personal communication, February 27, 2008). From her experiences working with the members of Hopespring, she identified the lack of incorporation of spirituality by health care professionals as a common issue of concern for people with cancer. During our conversation we determined that neither of us knew how members would like to see spirituality incorporated into their care, and the research question for this study was born.

The benefits of spirituality are evident in the research and it is beginning to be integrated into palliative care (Kaut, 2002; Sulmsay, 2006; Baumann & Englert, 2003; Gordon & Mitchell, 2004). Some palliative care has begun to expand to include the spiritual needs of patients and their families. However, there is still a gap in its application into pre-palliative cancer treatment. The purpose of this study is to investigate the spiritual needs of people with cancer and how they would like those needs to be met by their health care professionals, specifically social workers. For example, Gurm, Stephen, MacKenzie, Doll, Barroetavena & Cadell (2008) encourage practitioners not to assume that all people have the same spiritual beliefs and needs. They encourage practitioners to conduct spiritual assessments on a case-by-case basis in order to develop an individual plan to incorporate spirituality and ensure its effectiveness. My hope is that the participants of this study will be able to provide some suggestions about how they would like social workers to conduct a spiritual assessment and assist them in meeting their spiritual and emotional needs.
My specific research questions are:

1) How do participants use spirituality to aid in their healing?

2) How would participants like their health care professionals, specifically social workers, to incorporate spirituality into their formal care?

It should be noted that the term healing, when used in this paper, does not necessarily mean being cured of cancer. Instead I am defining healing to encompass the emotional, mental and spiritual healing of a person. The physical healing may be involved (that is the cancer may be cured), but is not necessary for healing. Healing is possible for all people regardless of their prognosis. Healing can occur even in the face of death.

Organization of the Thesis

The first chapter provides a general overview of the phenomenon of interest and my experiential context for this research. The research question, purpose, importance and approach of the investigation will be outlined. Chapter two is a review of the relevant literature pertinent to this topic of inquiry. The third chapter outlines the methodological framework for the investigation and provides a detailed description of the process of data collection and analysis. Chapter four presents the findings of the study including emerging themes supported by excerpts from the interviews with the participants. Finally, the fifth chapter is a discussion of the themes identified in chapter four in the context of the pertinent literature and concludes with an overview of the limitations of this investigation and recommendations for future research.
CHAPTER TWO: LITERATURE REVIEW

Spirituality has become a topic of much research in recent years. In 1997, Grant found that 93% of North Americans believe that a spiritual life is important (as cited in Coates, Graham, Swartzentruber & Oullette, 2007, p.8). Therefore it can be presumed that a spiritual life is also important to people with a diagnosis of cancer. As such it needs to be considered as part of the healing. I will review the current literature in terms of: health outcomes and the importance of spirituality, the lack of incorporation of spirituality in health care, theories of healing and spirituality, psychosocial oncology, social work and spirituality, social work in health care and the limitations of the research.

I have chosen to use the terms client or participant instead of patient in this paper in an attempt to minimize the power imbalance between the health care professionals providing service and those receiving the services. However, the literature review section will reflect the terminology used in the literature. Much of the literature is written for an audience of medical practitioners. The common term used by this group of people is patient, therefore, this is the terminology used in the literature.

Health Outcomes and the Importance of Spirituality

Many studies have shown that there is a positive correlation between religion or spirituality and health outcomes. Powell, Shahabi, and Thoresen (2003) found that church service attendance protects healthy individuals from death. Wachholtz & Pargament (2005) found that spiritual meditation helped decrease anxiety, and elevate mood, spiritual health and spiritual experiences. The participants tolerated pain almost twice as long as participants who used non-spiritual meditation. That is, people who incorporate spirituality into their healing process, either formally, or informally, have been shown to
have a higher quality of life (Breitbart, 2005) and a better emotional acceptance of their diagnosis (Kaut, 2002). Breitbart (2005) states that "being able to sustain a continuing sense of meaning during cancer illness and treatment contributes to improved quality of life and reduced psychological distress".

Additional studies have found similar results related to health outcomes in cancer patients. They have shown that spirituality influences people’s ability to cope with cancer, pain control, other symptom control and the onset of clinical depression (Baider, Russak & Perry, 1999; Brady, Peterman & Fitchett, 1999; Koenig, Cohen & Blazer 1992; Koenig, George & Peterson, 1998; Nelson, Rosenfeld, Breitbart & Galietta, 2002). Bussing, Ostermann, and Koenig (2007) found that cancer patients often utilize a belief in a higher power and use conventional religious activities to help them cope with their illness. Rippentrope, Altmaier and Burns (2006) conducted a quality of life assessment with 61 cancer patients and found that spirituality is more strongly related to the quality of life of cancer patients than is religiosity. In this study spirituality was defined as the search for what is sacred in life. This may or may not include being a member of an organized religion. Religiosity on the other hand was defined as including an organized system of beliefs to facilitate a relationship with and understanding of a deity (Rippentrope et al., 2006). Finally, Denz-Penhey and Murdoch (2008) conducted a grounded theory study to identify the common factors in people with a serious diagnosis. These people had less than 10% chance of survival and had a good quality of life at the time of the interviews. They found that spirituality was one of five dimensions of resiliency. It is evident that the integration of spirituality, not just religiosity, into cancer treatment planning is important to patients’ health.
Additionally there has been research conducted in the field of spirituality and health care that demonstrates the value cancer patients place on the inclusion of spirituality in their treatment. In 1997 Gallup conducted a study of several thousand individuals and found that people identified medical expertise as less important to cancer treatment than a doctor who was “spiritually attuned” to their needs and who showed that he or she genuinely cared for them and their well-being. Moadel, Morgan & Fatone (1999) conducted a survey with over 300 cancer patients asking them to rate the importance of issues and with which issues they most needed assistance. Over 75% of patients identified at least one need for spiritual support. Frick, Riedner, Fegg, Hauf & Borasio (2006) evaluated the usefulness and distressfulness of a short clinical interview to assess cancer patients’ spiritual needs and preferences. Both physicians and patients found the interviews helpful and non-distressing. Such studies reinforce the importance of this research topic and the need for action on the inclusion of spirituality in cancer treatment planning. So much so, the World Health Organization has changed the palliative care guidelines to include spirituality in the care of end of life cancer patients (Gordon & Mitchell, 2004).

Lack of Incorporation of Spirituality into Health Care

Despite the evidence of the importance of spirituality in health care, there is currently a lack of inclusion of spirituality into health care practice (Kaut, 2002). Sulmsay (2006) found that health care professionals often do not recognize the spiritual issues of their patients, and therefore do not address these needs. This is due in part to the education of physicians and other health care professionals regarding spirituality. Barnett and Fortin (2001) conducted a needs assessment of Yale medical school’s preclinical and
residential program curriculums and discovered that there was no content surrounding spirituality and medicine. Quattlebaum and Cascio (1999) reported that few Social Work programs provide training in addressing spiritual issues (as cited in Reese, 2001). As a result, health care professionals are often uncomfortable discussing spiritual issues with clients, thus making it even more difficult for patients to address their spirituality. Kristeller, Zumbrun & Schilling (1999) interviewed oncology nurses and physicians and discovered that spirituality is not addressed as often as it could be due to constraints in time, uncertainty of roles, and a lack of confidence in one’s effectiveness in addressing these concerns.

In the past 15 years the United States of America (USA) has increased the number of physician schools with courses or topics in spirituality from 3 schools to over 70% of schools (Puchalski, 2006). There has been an increase in conferences, debates, and scholarship surrounding spirituality. Despite this, Puchalski (2006) still recommends that more needs to be done to ensure this continues. Marr, Billings, and Weissman (2007) say that in the USA there is not enough evaluation of the training to ensure that fellows obtain the knowledge and skills needed. They recommend enhancing spiritual education in these programs.

Theories of Healing and Spirituality

There are a variety of ideas and beliefs about healing and spirituality that are important to consider when looking at spirituality and cancer. Barford (2005) describes the Buddhist ideology of healing that first involves a will to be healed. This mental turn allows one to work upon the mind with confidence that the body will unconsciously
adjust itself to the new mental state. One does not go to work on the physical body to work on the mental and spiritual levels (Barford, 2006).

Baumann and Englert (2003) suggest theological, psychological and human becoming as being three possible views of spirituality in oncology. The theological view involves institutional and/or personal beliefs, rituals and practices and the experience of living faith or wonder. The psychological view involves relaxation or meditation, self-examination and reflection and the experience of human connectedness through supportive relationships and stories. The human becoming view involves moving beyond the immediate, quieting, and the experience of the paradoxical nature of the human-universe process.

Thorpe and Barsky (2001) discuss healing through self-reflection in women. They identified three themes that signify women’s ability to heal themselves: spirituality, being versus do-ing and eustress versus distress. Finding a balance between do-ing, caring for others, and be-ing, caring for one's self signifies that one is able to heal oneself (Thorpe & Barsky, 2001). Eustress is a positive response to stress that can stimulate action. Distress is a negative response to stress that impedes action. Finding a balance between the two types of stress is important to facilitate healing (Thorpe & Barsky, 2001).

Despite a lack of incorporation of spirituality in cancer treatment planning, there has been a recent shift towards more acceptance of spirituality playing a key role in health care (Breitbart, 2005, Whitman, 2007). This study is based on the theory that spirituality has a positive effect on health outcomes. Numerous studies provide empirical
evidence to support this theory (some are: Powell et al., 2003; George et al., 2002; Thoreson & Harris, 2002).

Holland and Lewis (2000) discuss the “human effects” of cancer including psychological, social, and spiritual effects. They note that these human effects are part of every encounter with health care staff and even though it is central to their care, it is often not recognized by health care staff. Individuals with cancer and their families deal with these issues daily and want these issues to be addressed by health care staff (pp. 9-10).

Milstein (2008) presents a new model of health care that introduces spirituality into medicine. He argues that forging a spiritual connection between patients and the significant people in their lives can restore a sense of control, meaning, and the ability to manage. This allows patients who are experiencing a catastrophic event, such as cancer, to shift from a state of hopelessness to one of wholeness. He suggests that this is done by creating a “healing space” in addition to the curing space currently created by the medical model. Milstein describes the healing space to be one which permits and encourages “being with” family and close loved ones in order to better connect with them. The curing space is a place of “doing to” where the medical procedures and care are provided. He suggests that these two spaces be physically separate. He recommends that the healing space be facilitated by at least one member of a team of facilitators. Possible team members include physicians, nurses, social workers, and chaplains. In the “healing space” the team can facilitate a spiritual intervention, which can restore a sense of order and meaning, thus improving the patient’s ability to cope and attain a sense of wholeness (Milstein, 2008). The intervention may occur by addressing the patient or family’s cognitive and emotional needs first, and then moving toward their spiritual needs. The
spiritual paths taken by patients and their families are honored and encouraged. This model also fits for those who do not identify with being spiritual. If a patient or family identified with a background of non-belief the facilitators would focus on enhancing the one-on-one connection with family rather than a higher power (Milstein, 2008). Milstein suggests this model involves the facilitators encouraging both patients and families to explore their narratives, as this can be a valuable exercise in constructing meaning for both parties.

Psychosocial Oncology

The Canadian Association of Psychosocial Oncology (CAPO) defines psychosocial oncology as “the specialty in cancer care concerned with understanding and treating the social, psychological, emotional, spiritual, quality-of-life and functional aspects of cancer, from prevention through bereavement. It is a whole-person approach to cancer care that addresses a range of very human needs that can improve quality of life for people affected by cancer (What is Psychosocial Oncology?: CAPO, n.d.). That is, it deals with the whole person, not only the cancer. It can include support interventions both individually and in groups, education, stress management, coping strategy training, and behavioural interventions (Mustian et al., 2007).

Psychosocial oncology is a relatively new field. From 1920 to 1950 surgery was the only treatment option and survival rates were low (Kash, Mago & Kunkel, 2005). Just 50 years ago cancer was know as the big “C” with a major stigma attached to it. Minimal care was given to patient’s emotional and psychological needs, and a stigma was also associated with seeking assistance for these needs. (Kash, Mago & Kunkel, 2005). For years patients were not told of their cancer diagnosis because it would take away all hope,
although the family was informed. Initially, psychiatrists and psychologists were told not to discuss cancer with patients because it would upset them. It was not until the increase in survival rates in the 1950’s, with the advent of chemotherapy, that people with cancer could have hope for long term survival (Kash, Mago & Kunkel, 2005). In 1977 psychiatrist Dr. Jimmie Holland began the first psychiatric service in New York City at Memorial Sloan-Kettering Cancer Centre to address the psychosocial needs of patients. (Holland & Lewis, 2000).

By 1981 there was a limited psychosocial program in most Canadian Cancer Centres (History: CAPO, n.d.). In 1982, Dr. Margaret Hovanee of Toronto visited Dr. Rona Jevne of Edmonton and Dr. Barry Bultz of Calgary and they discussed psychosocial aspects of working with people with cancer. In May 1985, a conference regarding psychosocial oncology was held in Calgary, Alberta. One hundred and ninety professionals registered for the conference from all across Canada, and even some registrants from the United States of America. The last session of the conference was a “Workgroup Formation Meeting” where colleagues from the major Canadian regions heard the “will of the audience.” Over the next year and a half they met and worked on a constitution and created the Canadian Association of Psychosocial Oncology, a non-profit organization, in 1987. Since then the CAPO has grown into an internationally recognized organization actively pursuing its goals of promoting excellence in both clinical and research areas (History: CAPO, n.d.) As the survival rates of cancer continue to increase, being distress-free and improving quality of life becomes a more necessary aspect of cancer care (Kash, Mago & Kunkel, 2005).
Wilson et al. (2000) found that depression is the most frequent mental health issue among terminally ill patients. A study conducted by Carlson et al. in 2004 (as quoted in Bultz and Carlson, 2006) found that 46% of all patients among a representative cross-section experienced fatigue, 26% pain, 24% depression and 24% anxiety. Anticancer drugs have been shown to be associated with significant depressive symptoms. One study found that 30-50% of patients experience such symptoms (Capuron, L., Ravaud, A, Miller, A et al., 2004). Sharpe et al. (2004) conducted a study including over 5600 cancer patients. They found that 8% had major depressive disorder (MDD) but that of this less than half had spoken about the low mood with their general practitioner and that less than a third had been prescribed any type of anti-depressant medication.

Although some psychological distress is considered to be common, Zabora et al. (1997) found that approximately 30% of cancer patients experienced elevated psychological distress levels. A study by Potash and Breibart (2002) found that up to 58% of palliative care patients experience significant levels of emotional distress. That number was 70% in a study done with a sample from Jordan (Khatib, Salhi & Awad, 2004 in Bultz & Carlson, 2006). With the negative effects of psychosocial distress discussed above, this level of elevated distress should be of concern to the medical profession. However, there has been little funding devoted to psychosocial oncology. In fact, less than two percent of direct operating dollars for cancer care in Canada are spent on psychosocial care. Five percent of the money is spent on cleaning staff and supplies. Bultz and Carlson (2006) argue that it is the responsibility of psychosocial professionals to communicate the evidence of the benefits of psychosocial work and attempt to
influence the care provided to people with cancer to include a greater psychosocial component.

Newell, Sanson-Fisher, and Savolainen (2002) conducted a review of psychological therapies for cancer patients and found that studies have repeatedly shown that psychosocial care benefits patients. A study regarding the reduction of anxiety found that a cognitive behaviour stress management group reduced the anxiety and emotional distress of women with breast cancer both during treatment and for one year following treatment (Antoni et al., 2006). According to the Institute of Medicine (2004), unmet psychosocial needs are specifically associated with coping response and quality of life (in Knobf, 2007). These examples combined with the finding that when the emotional needs of cancer patients are left unresolved they are more likely to use health services and emergency facilities (Carlson & Bultz, 2004) support the need for psychosocial care to become a more important aspect of cancer care.

Many studies have found that women with a social support system from family, friends, and the health care system cope and psychologically adjust better after a breast cancer diagnosis (Helgeson, Snyder & Seltman, 2004; Boyle, 2006; Jones, 2001; Ballenger et al., 2001; Friedman, 2006; Lewis, 2001). Additionally, a lack of social support has been found to be a risk factor for depression, anxiety, post traumatic stress disorder (PTSD) and increased mortality (Kroenke, 2006; Amir & Ramati, 2002).

Miller and Massie (2006) report that the characteristic response to a cancer diagnosis is a period of shock followed by a period of turmoil including anxiety, depression, irritability and the disruption of appetite and sleep. The psychosocial oncology approach to people with cancer allows the holistic nature of people to be
addressed. This includes the mental, physical, emotional and spiritual aspects of people. Therefore psychosocial oncology is a crucial component in the holistic healing of people with cancer.

Social Work and Spirituality

Spirituality has been an integral part of social work from the beginning. Social work began with foundations in the Jewish and Christian faiths (Hick, 2006). Hick divides the history of social work into three era’s: the era of moral reform prior to 1890, the era of social reform 1891-1940 and the era of applied social science 1940 to the present (2006). During the era of moral reform, private charities which were often associated with a religious organization provided assistance to those in need. During the era of social reform the assistance of those in need shifted from the private charities and volunteers to publicly funded programs run by paid workers. In the era of applied social science, social work continued to grow into a respected profession, for the most part staying away from the area of religion and spirituality. In the late part of the twentieth century there has been a re-emergence of interest in the area of spirituality.

McKernan (2007) identifies three factors that allow spirituality to become a greater part of social work today: our connection to spirituality is changing, we are living in a time of pervasive anxiety that is calling for a new vision of life and finally the fact that spirituality is found in the origins of social work. McKernan says that not only is information about spirituality and its practice available in different forms, new words and metaphors for discussing these issues are being discovered. He also discusses the desire of people for a new vision of life to replace the current dominant myth of “scientific progress”. This current vision no longer meets the challenges of this world such as
terrorism, environmental crises and global poverty. Finally McKernan says that the history of spirituality/religion in social work allows it to become a greater part of social work in the future. He predicts that greater involvement of spirituality will be the result of the progressive consensus of social workers invested in including the spiritual aspect in their work, not from the colleges of social work or the universities (2007).

Coates (2007) discusses spirituality as a response to the anxiety of modernity leading to three views of spirituality in search of direction through uncertainties and perplexities in today’s world (as cited in Coates et al., 2007). First is a subjective, personal and experiential perspective of spirituality. Second is a self-transcendence and the third leans toward more traditional, religious, or indigenous perspectives.

Butot (2007) believes that the current times require the blending of critically informed spirituality into social work practice and the consideration of the possibilities that spirituality might offer to social work. He invites social workers to begin a dialogue about how spirituality could inform their work.

Social Work and Health Care

In the early 1950’s social work’s role in health care was dealing with discharge planning and financial concerns (Hicks, 2006). Since then its role has broadened to assist in the identification of distress and effective ways of treatment. As well the majority of group psychosocial support is currently being provided by Social Workers (Kash, Mago & Kunkel, 2005).

As people begin to use complementary and alternative modalities (CAM) more frequently, the need for credible information is crucial to helping people make informed decisions. Runfola, Levine and Sherman (2006) discuss the important role Social
Workers play in assisting patients to make decisions about complementary and alternative treatments in their cancer care. They talk about the unique role Social Workers have on the health care team and the skill set that makes Social Workers ideal to promote discussions between patients and their health care providers. Social Workers are well versed in how to help create an atmosphere conducive to open dialogues, education, and clear decisions regarding treatment. Social Workers provide a safe and accepting place for clients to explore their feelings, concerns, and preferences about their treatment options. Social workers can also advocate to the rest of the health care team on behalf of the client if the client does not feel able to do so him or herself (Runfola et al., 2006).

Carr and Morris (1996) argue that the social work perspective encourages a holistic approach to working with people in a health care setting, making social workers the ideal people to support and encourage coping through the use of spirituality. They specifically discuss the times in which Social Workers are better able to deal with spiritual issues than other members of the health care team. They also note the importance of referring to a Chaplain for religious rituals or questions about theology.

Limitations of Research

While there has been research conducted surrounding spirituality and health care, there are limitations. Recently there has been a trend in investigations into how spirituality impacts health care (Baider et al., 1999, Koenig et al., 1992, 1998; Brady et al., 1999; Nelson et al., 2002). As a result of this research there has been increased interest into the inclusion of spirituality into cancer treatment. This increased interest in psychosocial oncology is a good step forward. However, much of this research is focused on the benefits of including spirituality in palliative care (Kaut, 2002; Sulmsay, 2006;
Baumann & Englert, 2003; Gordon & Mitchell, 2004). What is not receiving much research attention is the incorporation of spirituality into cancer care throughout the entire disease experience, from diagnosis to death. As the prognosis for cancer improves, the place of spirituality must expand to include all phases of the cancer experience. There has also been very little input from clients about how spirituality could best be incorporated. The voice of clients is vital to the successful integration of spirituality into treatment plans by health care workers. This study will help add this crucial component to the discussion in hopes of better integrating spirituality into the care of people with cancer. Specifically, my research questions are:

1) How do participants use spirituality to aid in their healing?

2) How would participants like their health care professionals to incorporate spirituality into their formal care?
CHAPTER THREE: METHODOLOGY

This chapter discusses the procedure of data collection and data analysis in two sections: research design and research procedure. In the research design section I have discussed the rational for using phenomenology and a brief description of the phenomenological approach to data analysis. This topic is then expanded in the research procedures section focusing on the implementation of the phenomenological approach in this specific study. Within the research procedures section I have included information regarding the participants, site selection, data collection, my own biases and assumptions, and ethical considerations.

Research Design

Rational for a Phenomenological Approach

The topic of spirituality is both sensitive and individualized. After reviewing the literature and considering my own beliefs and experiences, many questions came to mind. In the process of conceptualizing this research investigation some of the questions that stood out for me and helped guide me to my identified research questions for this study were: When diagnosed with cancer, are people’s emotional and spiritual needs met in ways that are unique for each individual or are there common themes regarding how these needs are met? How do people use spirituality to cope with a diagnosis of cancer? What supports are available to people with cancer in terms of their emotional and spiritual needs? What would people with cancer like in terms of emotional and spiritual support from health care professionals? The methodology used to address these questions, as well as my specific research questions, needs to facilitate a deep
understanding of the experiences of the participants. This suggests the use of a qualitative approach.

Punch says “the point of qualitative study is to look at something holistically and comprehensively, to study it in its complexity, and to understand it in its context” (2005, p.186). This approach fits with my desire to fully understand each participant’s unique spiritual views, the role spirituality played in the participants’ healing processes, and the suggestions for the inclusion of spirituality into cancer treatments. A qualitative approach was necessary.

Creswell, Hanson, Plano Clark, and Morales (2007) describe the purpose of phenomenology to be to reduce the experiences of people with a specific occurrence to a universal description of the fundamental nature of the phenomena. Despite a range of philosophical foundations, there exists the common desire to study people’s experiences, which are viewed to be conscious, as they are lived every day (Creswell et al., 2007). Transcendental phenomenology is based on Husserl’s idea that the researcher must set aside his or her experiences as much as possible in order to view the phenomena through a clean perspective (Creswell et al., 2007; Patton, 2002). While it is acknowledged that this will never be perfectly accomplished, the researcher “brackets” out his or her own experience, by describing it before going on to the experiences of the participants (Creswell et al., 2007).

Groenewald (2004) states that the aim of the researcher, in phenomenology, is to describe the phenomenon experienced by participants as accurately as possible. Following this approach, my aim was to describe the experiences of the participants’ use of spirituality to aid in their emotional healing, as well as their recommendations to
health care providers to better meet the emotional and spiritual needs of people with cancer.

**Phenomenological Data Analysis**

Tutty, Rothery and Grinnell (1996) say the main purpose of qualitative data analysis is to sort and organize the information from data collection into themes and interpretations that have emerged through the analysis process, and address the research question (p.90). They describe five steps that are important to the analysis of phenomenological data. The first step is to transcribe the data. There are many decisions to be made surrounding the transcription of data, including who will transcribe it and how it will be formatted for analysis. The next step is to establish a plan for analysis. The third step involves the first level coding. This entails identifying meaning units and categories. The data is then reconfigured into the categories until “category saturation” is achieved. This ensures that the meaning units fit easily into your current categories and that no new categories are emerging (Tutty, Rothery & Grinnell, 1996, p. 103-106). The fourth step includes completing the second level of coding. This involves creating themes and sub-themes within the categories and looking at the relationships between the categories (Tutty, Rothery & Grinnell, 1996, p.106-108). The final step is interpreting the data and theory building. This involves developing a conceptual classification system and presenting the themes or theories that have emerged from the data (Tutty, Rothery & Grinnell, 1996, p. 109-11).
Research Procedures

Researcher Assumptions and Biases

In accordance with the above method of phenomenology, my first step was to use self-reflection to contain or ‘bracket’ my own preconceptions.

As I mentioned in Chapter One, my experience watching both my grandmothers and my great aunt battle cancer, and use their own spirituality to aid in their emotional healing, provides me with a personal interest in this topic. These experiences, combined with my own experience of using spirituality to cope with my father’s chronic pain and researching this topic have resulted in my developing certain beliefs and assumptions about the use of spirituality to cope with cancer. These beliefs and assumptions are:

- Spirituality is not limited to religion
- Spirituality will positively affect people facing cancer
- A cancer diagnosis creates stress for individuals and their families and can result in individuals needing more mental, emotional, and spiritual support
- People want emotional and spiritual support when faced with cancer
- Emotional and spiritual support is not offered to the same degree as medical support is offered through the health care system in Ontario
- Spirituality is important but cannot replace western medicine

I feel my secondary experience with cancer and my own use of spirituality as a coping strategy enhanced my ability to empathize and build a positive rapport with the participants in this study.
Participants and Site Selection

This investigation took place in southwestern Ontario including Kitchener – Waterloo, Brampton, Oakville and Tillsonburg. The interviews were conducted in a setting that was comfortable for the participants and which provided adequate privacy and safety for both the participants and myself. Nine participants, five women and four men, were interviewed and met the following criteria:

- They were at least 18 years of age
- They had been diagnosed with cancer more than six months ago
- They had either completed/ended treatment or are at least halfway through treatment

These criteria were selected both to protect the participants as well as to ensure that the data collected would be useful in answering my research queries. By requiring that participants be at least 18 years of age, I ensured that they were old enough to competently judge the ethical considerations presented in the informed consent form. By requiring that participants had been diagnosed for at least six months I was trying to ensure that I did not place additional stress or anxiety on participants. I wanted participants to have had the time and space to work through the initial emotions that followed their cancer diagnosis. The requirement of being at least half way through treatments was chosen in an effort to ensure that participants would have had enough experience with health care professionals to provide recommendations regarding how they would like their emotional and spiritual needs met.

A variety of recruiting methods were used to secure the nine participants. These included posters placed at holistic cancer support centres in the communities mentioned
above (Appendix A), flyers handed out at support group meetings at the cancer support centres (Appendix B), an email sent to the Faculty of Social Work students at Wilfrid Laurier University, and word of mouth from other participants. The information provided in these recruiting methods included the purpose and aims of the study and my contact information. Initially ten to twelve participants were anticipated, however this researcher had difficulty recruiting participants and only nine were found and interviewed.

Data Collection

All interviews were conducted by me. Prior to beginning the interview, I reviewed the Informed Consent Form (Appendix C) with each participant. An overview of the process was given to the participants and any questions they had about the process or procedures were answered. Participants who still wished to be involved in the study then signed two copies of the Informed Consent Form, one for my file and one for their own records. Additionally, my contact information was pointed out on the Informed Consent Form and the freedom to withdraw from the study without penalty at any time was reiterated. I emphasized to participants that all names and identifying information would be either eliminated or changed in this paper in order to maintain the participants’ anonymity. At the end of each interview the participant completed a short demographic questionnaire (Appendix D). Time was spent at the beginning of each interview building a rapport with the participant before the interview began. This enabled me to create a space in which participants could feel safe to describe their experience.

The semi-structured interviews with participants were led by my interview guide (Appendix E). The guide was designed by me, based on my research questions. Open-ended questions were chosen to encourage and enable participants to tell their story in
their own way. This allowed participants to share as much or as little as they felt comfortable with. It ensured that participants were able to tell the parts of their story that were of most importance to them. Participants were free to discuss or not discuss any experiences they felt were relevant. A question was included at the end of the interview to ensure that each participant had the opportunity to describe all of the important aspects of their experience with cancer. Each participant was also informed that they would be contacted with an opportunity to approve any quotations used by me in this paper in order to ensure that I accurately understood and represented the participant’s story.

Throughout the interviewing process I reviewed and critiqued the questions and how I asked them. After reviewing the first and second interview, I determined that the questions in the interview guide were not addressing the healing process of the participants. As a result I added a question asking participants to tell me about their healing and the process they went through.

The interviews ranged from 30 to 60 minutes. Each interview was recorded on a digital recorder and then transferred to an audio file on my personal computer. This computer required a password, known only to me, to access. After the interview I answered any questions the participants had regarding the investigation.

Data Analysis

Data analysis was completed according to the steps outlined by Tutty, Rothery and Grinnell (1996). All the interviews were transcribed by me. This not only maintained confidentiality but also enabled me to become immersed in the data prior to the analysis. First level coding was completed and the data was reorganized into the categories determined by this coding. This was done by identifying meaning units. These are the
building blocks of the classification scheme (p. 101). I manually completed this part of the analysis using a system of colour coding to identify the various meaning units throughout all the interview transcriptions. From here the meaning units were examined to determine patterns, and placed into categories. After reorganizing, combining, adding and eliminating meaning units, five main categories were identified. The data was then reorganized into these five categories. Following the second level coding, fifteen themes emerged. This excerpt from my interview with Samantha demonstrates how the meaning units were identified and placed into categories.

**Interviewer** — So I guess, maybe, can you just tell me a little bit about your kind of experience with cancer.

**Samantha** — Sure, I was diagnosed in April of last year with Hodgkin’s lymphoma, I’d had some symptoms for about a year but I’d just had a baby so it was kind of disregarded and then eventually I was diagnosed and so I’ve been doing chemo. And then in August they told me I would need a stem cell transplant which I just had in December. So I was at Princess Margaret for a couple of weeks. And my mom was diagnosed with breast cancer three years ago so I have some family history. And I actually have a sister who had Hodgkin’s lymphoma 15 years ago. Both of them are in remission and healthy now but I guess I’ve sort of had a lot of experience with family members and then now of course myself.

**Interviewer** — yeah. And so you just had, you did the chemo last year

**Samantha** — yeah. Last year and then I had a stem cell transplant in December so that involved some chemo as well, so I probably finished treatment about a month ago.

**Interviewer** — oh okay. And so can you tell me a little bit about how you kind of, the emotional healing process that you went through?

**Samantha** — Sure. Well I was introduced to Wellspring through my Mom. And I took, it’s called Healing Journey part 1 and then after I completed that I did Healing Journey part 2. And now I’m doing, we just started today, Healing Journey part 3. Just sort of as an emotional, to help me emotionally because obviously having cancer can be pretty traumatic and I guess I just saw family members have it and I never really thought it could happen to me, you know, I’m only 30. So I kind of thought that was something that would maybe happen later on in life. I’m married and I have 2 small kids, a 4 year old and a 1 and a half year old so I guess I just thought it was something that wouldn’t happen to me so I was pretty traumatized when I was diagnosed. I just, you know, was in shock, so emotionally it actually really affected me because I’m so young and you know, I had to tell all my friends and it was just, you know, why me? Out of all my group of friends, out of all my colleagues that I teach with, you know, why did it have to be me? So ah, Healing Journey really helped me a lot. Wellspring has been a wonderful place to be and just to help guide me through and even some of the psychological side effects that you
can have from the chemo is something that’s not always talked about. You know the doctors give you a big list of, you know, physical side effects that you can have, like hair loss and nausea, but no one really talks about what can happen emotionally when you do, even just side effects from the drugs. You know even just like anxiety and depression and stuff, which I had a bit of experience with. I don’t know if it was just from the whole event or, you know, side effects from the drugs. But um, definitely Wellspring has helped a lot. I have a strong faith, I’m Catholic and you know we attend church every Sunday. So that sort of has helped me. Prayer is important to me and it definitely has been through this whole ordeal.

Within this excerpt I first identified meaning units, and then identified that the meaning units fell primarily into the categories of healing and feeling supported with some units near the end of the quote falling into spirituality.

Second level coding was then completed to develop themes within the categories. Again a manual colour coding system was used to identify themes. Fifteen themes were eventually chosen within the five larger categories. Finally, the themes and categories were interpreted by me and compared to relevant theories of grief and loss. These interpretations and comparisons are presented in subsequent sections of this paper.

In the example provided above, the meaning units within the category of healing were then divided into the themes. The themes within the category of healing present in this excerpt are questioning and denial.

Throughout this process I continued to reflect upon my experience during the analysis and monitor my subjectivity. Journaling my thoughts assisted me in maintaining an awareness of and containment of my biases.

Because everyone’s definition of words can be unique, it is important to define some of the terms used in this paper. The theme questioning refers to asking “why me?” There are variations in the meaning behind this question and these will be discussed in the subsequent chapters of this paper, but the “why me” question is what is being alluded
to by the term questioning. Denial refers to the disbelief of participants in response to cancer or not thinking about the possibilities. Again, there is variation in the ways denial was present in the experiences of the participants and this will be discussed later.

Trustworthiness of the Study

Jackson, Drummond and Camara (2007) discuss the criteria for evaluating qualitative research. They state that instead of measures of trustworthiness like reliability, objectivity and internal/external validity that are common in quantitative research, qualitative research uses “credibility, transferability, dependability, and confirmability respectively.” One way in which this is accomplished is through member-checking (Jackson, Drummond & Camara, 2007). That is, the themes and descriptions are taken back to the participants in order to ensure that the participants feel they are an accurate representation of their experience. This was accomplished in this investigation by reviewing the quotes and themes with each participant after the initial data analysis. The five main categories and the fifteen themes within these categories were made available to the participants. As well, the participants were given the opportunity to view their quotations within each theme. This was done either through email or the phone, with an invitation from me to meet to further discuss my interpretations or for the participants to clarify the meaning of the quotation. Seven of the participants responded, and none chose to have a further conversation regarding the study or the preliminary results I presented. Tutty, Rothery and Grinnell (1996) also discuss the importance of documenting one’s work in order to ensure consistency, control bias, and establish one’s credibility.
Ethical Considerations

The ethical considerations of this investigation were reviewed by, and received the approval of, the Wilfrid Laurier University Ethical Review Board in June 2008.

Informed Consent

Participation in this study was voluntary. Before each interview I provided an opportunity for the participants to read through the Informed Consent Form (Appendix C) and also reviewed it with them. I ensured that participants were aware that they could choose not to participate at any time throughout the process without penalty. It was also established that they would be provided the opportunity to approve any quotations used in this paper. Each participant signed two copies of the form, one for my records, and one for their own. All participants signed both the consent to participate and the consent for the use of quotations in this paper.

Confidentiality

The limits of confidentiality were explained to each participant and were included on the Informed Consent Form. The confidentiality of participants was maintained by refraining from the use of the participants’ names in addition to removing or changing any identifying information in participants’ quotations.

The digital audio files were transferred to the researcher’s personal computer. To access this requires a password known only to the researcher. The interviews were transcribed by the researcher and the transcriptions were locked in a filing cabinet at the researcher’s home. A copy of the digital audio files were put onto a USB storage drive and placed in the locked filing cabinet as well. Only the researcher had a key for the filing cabinet. After the requisite period determined by the Wilfrid Laurier University
Ethical Review Board the transcribed interviews will be shredded and all audio files will be destroyed.
CHAPTER FOUR: RESULTS

Introduction of Participants

The following description represents the accounts of the participants' experiences of cancer and their use of spirituality. There were nine participants in total, five women and four men. All the participants in this study were Caucasian and at least 18 years of age. Three participants identified themselves to be in the 18-44 year age range, while the other six participants identified themselves in the 45-65 year age range. Six participants reported they were married and three reported they were single. The participants were diagnosed with a variety of cancers. Three were diagnosed with breast cancer, two with prostate cancer, two with lymphoma, one with bone cancer, and one had two diagnoses, colon and skin cancer. The length of time since their cancer diagnosis ranged from ten months to 18 years. Seven of the participants identified themselves either as Christian or as a member of a Christian church. Two participants did not identify any religious affiliations. Two participants had a high school education, three had college or university level education. Three have completed graduate studies and one has a college or university education with a professional designation. Two participants reported an income of less than $60,000 per year. Three reported earning between $60,000 to $100,000 per year and two more than $100,000 per year. I assigned each participant a pseudonym in order to maintain confidentiality. Additionally, pseudonyms were used for any names that were used during the interviews. The participants lived in Kitchener/Waterloo and nearby Southwestern Ontario cities. They were treated in and around these areas as well. All participants expressed an interest in discussing their experience of cancer and spirituality.
Thematic Analysis and Presentation

After examining the experiences of the participants as described in the previous chapter, five major themes or categories emerged. The categories are identified as Spirituality, Healing, Feeling Connected and Supported, Role of Health Care Professionals, and Recommendations for Health Care Professionals. These categories reflect the overall portrayal of the participant’s description of their experiences. The categories were then divided into fifteen themes: questioning, denial, fear, acceptance, meditation and stillness, prayer, changes in spirituality, family and friends, other people with cancer, cancer support centres, medical support, emotional and spiritual support, exploring spirituality, holistic approach, and providing tools. These categories as well as the themes within them can be seen in Table 1 on the next page. These themes are then explored further and the meanings of the categories are supported by content from the participants. The order in which the themes appear in this paper is not intended to represent their importance, rather the order was chosen by me to be in logical sequence. Given that the intent of phenomenological research is to discover commonalities across participants, each of the themes presented was discussed by at least four of the participants. It is important to note that while the themes presented here were common to several participants, there was variation within the themes among participants.

Category: Healing

This first category characterizes the experiences of emotional healing as a result of the responses to the question “Tell me about your emotional healing and the process you experienced”. These responses provide insight into the participants’ emotional journey as a result of their diagnosis of cancer. Christine said, “I would say that the battle
Table 1: Categories and Themes Emerging from Participants Interviews

<table>
<thead>
<tr>
<th>CATEGORY</th>
<th>THEMES</th>
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<tbody>
<tr>
<td>Healing</td>
<td>Questioning</td>
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<td></td>
<td>Denial</td>
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<td></td>
<td>Fear</td>
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<td></td>
<td>Acceptance</td>
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<td>Spirituality</td>
<td>Meditation and Stillness</td>
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<td></td>
<td>Prayer</td>
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<td></td>
<td>Changes in Spirituality</td>
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<tr>
<td>Feeling Connected and Supported</td>
<td>Family and Friends</td>
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<td></td>
<td>Other People with Cancer Experience</td>
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<td></td>
<td>Cancer Support Centres</td>
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<td>Role of Health Care Professionals</td>
<td>Medical Support</td>
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<td></td>
<td>Emotional and Spiritual Support</td>
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<tr>
<td>Recommendations for Health Care</td>
<td>Exploring Spirituality</td>
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<tr>
<td>Providers</td>
<td>Holistic Approach</td>
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<td></td>
<td>Providing Tools</td>
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for me wasn’t so much a physical battle, it was an emotional battle. The whole thing has been an emotional battle.” This section includes a description of the emotions participants experienced as well as those coping strategies that they identified as helpful in surviving this emotional journey.

The presenting order of the themes in this category is not representative of the order in which the participants experienced them. Not all the participants reported experiencing all of the themes. Some of the themes, for example questioning, denial, and fear, occurred for different participants at the same time, or by the same participant simultaneously. The presenting order was chosen based on the combined narratives of the participants. It is somewhat chronological, in that the first three themes were experienced initially, with the fourth theme following. It should be noted that the process is not a linear one and participants reported moving back and forth among some or all of these themes.
Theme: Questioning

This element refers to the participants’ initial reaction upon hearing their diagnosis. Five participants mentioned questioning “why me?”, though the meaning behind the question varied. Samantha described her initial reaction to her diagnosis.

I just, you know, was in shock so emotionally it actually really affected me because I’m so young and, you know, I had to tell all my friends and it was just, you know, why did it have to be me? -Samantha

She goes on to discuss how she eventually accepted that it was her, and she didn’t know why. She also stated “like I said I do have days when I’m not as accepting and I’m a little angry.” While most days she has reached acceptance, she admits that this is sometimes still a struggle and the anger returns.

Jake also described wondering “why me?” but never really finding an answer to that question.

I guess the best I can say is that it was that kind of why me? But I don’t think I came up with an answer really... I don’t think I came up with any particular answer. Because I think every time I did it was just sort of intrinsically rejected. It’s like, well, I mean, like, some supernatural force didn’t give me cancer. –Jake

As Jake moved towards acceptance, he became more comfortable with not knowing the answer to his question of “why me?”.

A third participant also discussed questioning. Christine mentions the expectation that all people with cancer would question “why me?”, but unlike the previous participants she describes asking a different “why me?” question.

It wasn’t a “why me?” Like it wasn’t like everybody would do. I mean it has to be somebody right? [...] So it wasn’t… But I do look at it like what am I supposed to learn from this? How can I benefit other people? Or how can other people benefit from my experience? ‘Cause I always thought I was an empathetic person and a compassionate person before and I’m thinking like, what now, you know? What
am I supposed to do with this? Like I do ask myself that a lot, what is my job, you know, because of this? That I do want to help other people, but I don’t know how. I don’t know what I’m supposed to do with it so I have asked why in that sense. Not the why me? Sort of what do you want me to do with this now? What am I supposed to do with this? -Christine

For Christine the question was not why did it have to be me instead of someone else, but rather, why did she experience this? What was she to do now with this experience and knowledge? How could her experience benefit others?

Two participants identified that they did not feel angry or wonder “why me?”. This in itself appeared to defy their own or others’ expectations. Lindsay identified that fear was the emotion she experienced, not anger.

Someone recently asked me “aren’t you angry?” And I have never gotten angry. With having cancer. I’ve never said “why me?”. I’ve never... I just haven’t. And that thought hasn’t entered my mind [...] But even from the beginning I wasn’t angry about it. Scared though. –Lindsay

She describes the expectation that anger and questioning “why me?” always comes with a cancer diagnosis as well as her deviant response to her diagnosis. However, she does not know why she didn’t get angry or question “why me?”. Scott expresses this same expectation.

I did not freak out, a lot of people would have freaked out. Especially at 55 as opposed to 75 or 80 where cancer is a lot more common then. This diagnosis. Right? So a lot of 55 year olds would have freaked out. “What do you mean I’ve got cancer already? I’m only 55.” But I did not freak out. I was calm and patient. –Scott

He had the expectation that many people would get angry or “freak out” with such a diagnosis and felt that his reaction was unique.
Interestingly, while both Lindsay and Scott identified not feeling angry or questioning “why me?” they did identify fear as an emotion that they did feel on some level. Perhaps this can account for the difference between these participants and those who did get angry and question “why me?”.

Theme: Denial

This theme describes another emotional response to participants’ experiences. Five participants described feelings of denial at some point through their journey. Denial is defined in this context to be a sense of unbelievability about what is happening to them and not the literal denial of the diagnosis of cancer. The first common reaction of denial came with the diagnosis. John described the denial he felt around being diagnosed and wanting it to be something else and the eventual acceptance that it was cancer.

I’d pray actually for, that it wouldn’t be cancer. I mean that’s the funny stages of denial right. It can’t be, you know, “you’re wrong, right God?” You know, those kinds of prayers. And the realization would come, John, they’re not thinking. They’ve tested. It’s positive. And I would find myself crying and praying and asking for, just asking for strength to get through. —John

His denial about his cancer was eventually faced and he began to find ways to accept this new reality. Christine expressed the denial she experienced because of her lack of risk factors and the type of life and the care she had given to her body.

I discovered the lump myself, so I had discovered it prior to my diagnosis and I thought I had led an exemplary life. I’m a runner, vegetarian, never smoked or drank, had none of the risk factors, none in my family. So I was ah, in denial and I was also under the care of a naturopath who I’d been with for 9 years so I was getting no guidance to seek medical attention from him. So um, I really, I just thought it couldn’t have been cancer. —Christine
Her denial was not only because of how she had cared for her body, but was encouraged by her alternative medicine practitioner. She went on to describe that by the time she did seek medical attention, she had already moved past denial.

Samantha described her denial because of her age, despite a family history of cancer.

I guess I just saw family members have it and I never really thought it could happen to me, you know, I’m only 30. So I kind of thought that was something that would maybe happen later on in life. I’m married and I have 2 small kids, and 4 year old and a 1 and a half year old so I guess I just thought it was something that wouldn’t happen to me so I was pretty traumatized when I was diagnosed.

–Samantha

While she had experienced family members with cancer, she had not really considered the possibility that she may be faced with cancer. Perhaps it was something she would have to deal with down the road, but certainly not in the near future. As a result of her denial she was shocked and disturbed by the diagnosis.

Two participants described experiencing denial not in terms of the diagnosis itself, but instead in terms of the possible severity of the diagnosis. Melanie spoke of her denial about the possibility of death as a result of her cancer as well as the moments that made her realize otherwise.

And I don’t know if... I think when I was going through it I don’t really think that I ever thought that I was going to die or that I was threatened or anything. I don’t know. I just didn’t ever think that way. So then I never really thought of myself as a survivor... until this spring, I had, you go back every 6 months for my mammograms and checks and there was a little issue came up and that ah, made me realize you know what I am a survivor [...] I never was mopey and thinking oh I’m not going to make this or this is going to get me or anything like that. But it was hard when my hair fell out. I think that was the first that I actually thought oh, I’m sick. –Melanie
It wasn’t until she lost her hair that she realized she was sick, and not until she had a check up and an issue came up that she began to see herself as a survivor and consider the possibility that the cancer could have been fatal. Jake experienced the same sense of denial about the possibility of death.

I guess I retreat into this little shell. And um, and I mean, you just sort of distract yourself and, like, I get the feeling it was a lot of denial. But um, I mean I was fully aware of what was going on. But like the prospect that I could die or something never really consciously entered my head. And so, one good thing, it was just like distracting myself and the fact that they had a schedule for me and this is it and when June hits this is done and I get on with my life kind of thing. So I guess it was very forward looking, but very like, I didn’t really acknowledge a lot, a whole lot, of the situation I don’t think. —Jake

Perhaps the differences regarding what was being denied relate to what people are capable of considering at any given time. For example, one may be capable of considering that they have cancer but not that it may be life threatening. This denial is different from fear because it is not acknowledged as fear. There is a denial of the emotion as well as the situation.

Theme: Fear

This theme reflects the fear that was experienced by the participants during their experience with cancer. As John said “There’s nothing minor about it. Whether it’s on the tip of your finger or full-blown lung cancer, it’s still cancer. And it still has the same fear factor as far as I’m concerned.” Five of the participants reported fear to be a noteworthy part of their experience and four participants identified fear as an initial reaction to their diagnosis. Lindsay said “I wasn’t angry. Scared though. […] Just the fear, it was fear definitely. Yeah, fear.” This experience of fear initially was similarly expressed by Greg.

So I wasn’t prepared for that news, of course I don’t think anybody ever is. […] it’s really horrible to be diagnosed with cancer because the majority of the people
that I know, particularly in my family that have been diagnosed with cancer didn’t live. And so it was, like there’s sort of this terror. And I think because cancer is somewhat a word that does or it presents terror to many people, of course myself included, it really and truly does. And so for me it was tremendous fear, very deep-rooted fear. —Greg

John also reported experiencing fear as his initial reaction to his diagnosis. He had been expecting something much less scary and had known people to die from similar cancers in the past. This only increased his fear.

It was scary, it was a scary time cause I thought it was just, you know something else going on. He suggested um, breaking hemorrhoids or something and that would cause bleeding but... So when I went to uh check it out and they found more than that. [...] the colon cancer that was there, that was pretty serious ‘cause I mean I’ve known people who have died, um, from bowel cancer, stomach cancer. [...] And when they told me that, I mean that scared me. I was younger, you know, [...] I was probably 28ish. [...] but I felt, I felt, wow, I’m too young to have cancer. That was my first reaction. I can’t...I’m too young to die and I can’t have cancer. Now I guess it’s the C-word that scares me the most. And, yeah. So there was a lot of fear. —John

Christine discussed not only the initial fear she felt but also the ongoing fear she experiences.

I guess it was fear was my reaction. Fear of the unknown I guess and what my chances were, what the outcome would be from the diagnosis. [...] I would say fear is a big one, fear is still with me. You know fear is. You know every little ache and pain, then you get, like you might have had them before, but when they show up now, I mean you have an automatic, your mind goes somewhere, you know it automatically thinks it’s cancer. So I would say that that would be what all of your experience would be. I would think that fear. Yeah. I think the fear thing sort of is always kind of there. —Christine

Scott described the fear as subconscious, because consciously he had put his trust in God. However once he learned that the cancer is low grade and contained both he and his spouse experienced a sense of relief.
I think subconsciously there’s still a human element and a human concern there. But consciously, the trust in God the faith in God is what sustains you. [...] Because when we finally did get the news in January, that everything was contained and everything was low grade and the prognosis was very good, there was a huge emotional release at that point. So subconsciously it was obviously bothering, but consciously...not. —Scott

This theme of fear was also discussed in relation to the possible reoccurrence of the cancer. Two participants spoke of this type of fear in addition to Christine who mentioned it above.

You go back every 6 months for my mammograms and checks and there was a little issue came up and that made me realize you know what I am a survivor. Because it gave me a little scare, like, oh, you know this could reoccur or something. [...] And I remember saying to somebody too, that I don’t think this is any real problem but it’s kind of scary to think, will it reoccur, you know, will it come back again. —Melanie

This ongoing fear was also expressed by John.

But at first I still wasn’t sure. I kept wondering. You know there were nights I’d think about it a lot or go for walks and be concerned that, you know I wonder if they got it all. They always think they got it all and then it finally shows up somewhere else and then you die. So there was always that fear. —John

The variation among participants is again seen as some referred to the fear of the unknown, some to fear the course of the disease, others to the fear of the possible return of the disease in the future, and some to a combination of these. Additionally the association people have with cancer prior to their diagnosis can affect the emotional reaction people have to the diagnosis. For example, if cancer is associated with death, pain or suffering, fear may be an immediate response to a diagnosis of cancer.
Theme: Acceptance

This dimension refers to the feeling of acceptance and overcoming the fear, questioning or denial. Six participants identified acceptance as a part of their emotional healing. Jake said “I think there came a point where I just accepted that it did happen to me and that was that and I mean why it happened I think I just accepted that I wouldn’t really know.”

Two participants identified acceptance and healing as an ongoing process that they continue to work at each day. “So then I guess once you realize that this is the hand that you’ve been dealt, so then ah, you start looking for ways to cope with it ‘cause your life has changed. [...] It’s ongoing; it’s an ongoing process” is how Christine described it. Samantha also discussed the ongoing struggle to be accepting and not angry.

I guess I sort of went from shock to a little more acceptance. You know, this is what I’ve been given and this is what I have. [...] And you know this is what I have and this is what I have to deal with, so I might as well just do what I can to get through it. Like coming to Wellspring and do what makes me relaxed and feeling good. I think time kind of just did that on it’s own. Just sitting with the diagnosis and definitely the support of family and friends definitely helped me too to be more accepting. Like I said I do have days when I’m not as accepting and I’m a little angry, but yeah, I think support, time, Wellspring was wonderful. Just peer support, people that I’ve met through Wellspring, and I guess all those things together sort of helped me get to that point of acceptance.

–Samantha

She described a few of the things she found helpful in reaching acceptance, such as support of family and friends, time, peer support, and Wellspring. Greg also described some of the same things that helped him achieve acceptance and move forward with his healing.

Actually I became more accepting of it when I knew that perhaps there was an end to this or there’s going to be some treatment to it. So when I started visiting London and getting some perspective as to what could be done for myself and
what treatments could be done. I was actually starting to feel better about it. I actually felt this was a, this isn’t hopeless, this is not sort of the end of the world, I’m going to live, and whatever so. It is not you know sort of devastating. So I went through a sort of devastation and then moved into something that is more hopeful. And also coming here to Hopespring actually was very hopeful also because I was no longer just a man who had prostate cancer, there were other people here who were, in my opinion, far worse than I was. So it was like I thought, oh right, okay so I was then moving then into acceptance and just like okay, this is what I’ve been dealt with as far as life is concerned and here I am now, and everything is going to be fine or I am going to go through this so.

-Greg

For Greg the acceptance came in conjunction with treatment options, and witnessing others who in his mind were in worse situations. After this, he began to accept that this is what he had to deal with and everything would be fine.

A similar feeling of acceptance is evident when Melanie said “I think I just knew I had to do it so that’s what I did you know?” Accepting that this treatment is what one must do in order to deal with the cancer allowed this participant to move forward and heal emotionally as well as physically throughout the treatment.

Scott reported feeling accepting of his situation right away. He attributed his acceptance and lack of fear or anger to his faith. His belief that God was in control allowed him to accept his diagnosis and have faith that everything would work out, so there was no need to be worried or angry.

We have confidence that God is in control of things. [...] So when my daughter in law first found out I had cancer she looked at me and said “so did you freak out when the doctor told you that? And I said “No. Why should I freak out? God’s got everything under control” [...] I’m not worried about the outcome of anything. You know, ‘cause I know God has everything under control. –Scott
The confidence that God was in control allowed Scott to reach acceptance early on in his experience with cancer. As he described, even initially he didn’t freak out because of this faith in God’s control.

*Category: Spirituality*

In the first category, healing, participants identified that spirituality played a large role in their emotional healing process. In this section this idea is further developed as participants talked about their spirituality; how they practice it, what it means to them and how they utilized it throughout their healing. As mentioned in chapter one, my definition of spirituality involves the belief that it is unique to each individual, therefore a definition of spirituality was not provided to the participants. Instead the participants were simply asked what role, if any, spirituality played in their healing process?

*Theme: Meditation and Stillness*

Participants described how they used meditation, yoga, quietness, stillness and awareness as part of their spiritual practices. They discussed how this helped them cope with the cancer experience. While being still, emotions such as anxiety, worry, depression and anger occurred, but the participants were able to use meditation and stillness to reduce these feelings.

Participants described the use of meditation and stillness to help them cope with the day-to-day experience of cancer. “A lot of relaxation techniques like meditation helped as well. [...] You know just quiet time for myself, relaxation. Even if it’s not necessarily prayer or dialogue, it’s just time for myself and just quietness, stillness that kind of thing. Yeah, just, it’s not necessarily prayer but just doing things for myself.”

(Samantha)
Melanie described spending hours just thinking and meditating. “I spent a lot of time, like I remember I would spend hours sitting in doctors’ offices and so I spent a lot of time thinking. [...] So I think I did spend a lot of time thinking and meditating, maybe that would be a word.” She used meditation to release her anxieties and relax. This was a significant step for her as she described herself as a worrier before her cancer diagnosis.

Similarly Christine also identified herself as a worrier before being diagnosed with cancer. She too found meditation to be a helpful tool in lessening her anxiety and relaxing.

Meditation sort of goes along with that, and calming and lessening your anxiety. And that’s what I wanted to do, remove the fear and anxiety that I experienced. And I was a worrier before I got cancer so, I had to let it all, I had to force myself and had to let it go because I didn’t want to worry and weaken my immune system either. Like it was, like I’m a health nut right? So I just I wanted to release all my anxieties and my fears and my stress. And coming here to Hopespring has helped that. Meditation class, and I also purchased meditation tapes at home that I now incorporate meditation into my life. I force myself to take the time to be more relaxed and aware and sort of introspective rather than be on autopilot and just go go go from 5 in the morning. —Christine

Through her cancer experience she has the come to appreciate the skill of meditation and recognized the importance of meditation in lessening her anxiety.

Two other participants also identified learning to be still and listen to the quiet or meditation as something they did through the experience of having cancer. Lindsay said “I think learning to slow down. Listen to the quiet. That is one of my biggest things that I never do.” John also described incorporating more meditation and quiet into his life after his cancer diagnosis. “Just quiet, quiet meditation and the contemplative type meditation. And connecting. That’s how I connect. And that would have been probably where I started connecting like that...” Both of these participants not only learned the skill of
being still and listening to the quiet but continue to take time to do so and have
incorporated this into their everyday life.

Greg discussed the close connection between his spirituality and awareness. He
describes the use of various spiritual practices, but especially meditation, to become
aware of what is going on both inside himself and around him.

Be aware actually is the big thing in my opinion. [...] By being aware what I mean
is being aware of what’s going on with me at any given time. [...] So it’s an
internal awareness and also an external awareness as to what is really and truly
going on [...] Yoga is one, meditation is another. Prayer could be you know, I
would have to say prayer is although they are very similar, but yet I don’t believe
they are the same, prayer and meditation. So I participated in both prayer and
meditation, yoga. [...] Like for myself meditation is one. I participate in the
meditation group here and also I meditated, you know, on my own as well or
whatever. So there is that. That definitely, I’d have to say mediation more than
anything. [...] I believe that our spirituality has a great deal to do with our
emotions and again, back to awareness I think that being aware of just who I
am... -Greg

Although these six participants have all discussed the use of meditation or
stillness, the ways in which they use it or find it beneficial vary. Some use it to lessen
their anxiety and cope with the day to day experience of living with cancer. Others used it
to bring them closer to their own spirituality.

Theme: Prayer

The idea of prayer and the connection to God was spoken of by seven of the
participants as an important part of their journey. The individual prayers and relationship
to God were discussed. Sarah spoke of the comfort and peace she received from praying
herself. “Well I think through the whole process, like, I prayed, you know for healing, for
strength throughout and I continue to do that for guidance. [...] it’s just comforting to
know that he’s there and he’s listening. Yeah and I would feel a sense of peace then.”
Samantha discussed the various methods of prayer that she engaged in. She explained the feeling of hope and reassurance and of not feeling alone she experienced as a result of her prayers.

Prayer is a big one. You know my mom gave me books on prayer and reflection and that kind of thing, which was helpful. [...] I guess prayer’s just, just a dialogue with God. Just asking for, you know, help through, you know, some of the treatment and that kind of thing. But it was definitely helpful for me. Whatever way it was, whether it was reading a prayer or just, like I said, a dialogue. [...] I guess just knowing that I wasn’t alone. Knowing that maybe God was taking care of me in some way sort of gave me some reassurance. Rather than just, you know, being on my own and having this illness. You know, not having any hope. You know, so I think that prayer sort of gave me that hope, that things might work out or just the reassurance that I was okay and, you know, not necessarily that I was going to get better but just that it, gave me some hope of being able to cope with what was going on. –Samantha

John also described feeling comforted through his prayers and his relationship with God.

And that reassurance was there and I think my faith was developed. I developed a really strong faith at that point. I found myself praying more. Leaning into that comfort that’s in prayer and God. I mean I was a Christian before but, just a happy go lucky kind of Christian. Now there’s a reason to be, you know, praying. –John

Melanie felt the benefits of her own prayers, like the participants above, but also when others were praying for her. She also describes the prayers as not just being for her physical healing, but for her emotional state as well.

I believe in prayer so I believe that people praying for me, not even necessarily just for my healing, but for my, you know for my morale, and so I wouldn’t be discouraged and things like that, was a major part. And I mean just, you know, myself and my prayer life. You know I feel like I got great strength from that. [...] I know there was different times that I would email the kids or even times since it’s been past, you know times that I go for my check ups, you know some little thing might come up and it’s a little upsetting and I, you know, well just actually last week said to one of the kids you must be praying for me ‘cause I feel
better today. So I mean, it’s hard to describe but I do believe we get some kind of inner peace, like that the worry or the stress is lifted or taken away. —Melanie

Lindsay spoke twice of the comfort she felt as a result others praying for her. First she described an experience in which her friends prayed for her in the quiet of the empty church speaking from their hearts.

They prayed over me which I had never had done before [...] we just went into the church and it was very quiet. [...]. It was the most beautiful thing I’d ever, because they each spoke from the heart. And all they were doing was, um, just saying what they felt in their heart. And were asking God for healing for myself and that kind of thing. And it was the most beautiful experience. —Lindsay

Lindsay also spoke of the comfort she felt receiving the sacrament of healing that is part of the Catholic faith.

Before I went for surgery, in the Catholic faith one of the sacraments is the sacrament of healing. [...] And the words the priest uses, and it’s private, you’re just in his office and my friend was with me and it was, they’re just such beautiful, calming, comforting words. [...] It’s just warm and loving and they’re beautiful words. And I found that a comfort and I felt very blessed that we have that belief in our church for healing. —Lindsay

Like Melanie, Lindsay also experienced benefits as a result of others praying for her.

Sarah discussed her need to know that someone was praying for her. Although she engaged in her own prayers, as mentioned above, she also felt the need for someone else to be talking to God on her behalf.

I really felt that I needed someone that I knew was praying for me. And so I went to a, I guess you would call him a spiritual guru, that from my past and I said you know I need to you pray, and he came over that night and ah, I always knew that he, and he would check in with me and, ah, do those things and I felt really comforted knowing that. ‘Cause he’s the type of guy, a lot of people will say they’ll pray for you, but I know this guy will. —Sarah
Although prayer was mentioned by the majority of the participants, there was variation in how that prayer was beneficial. For some it was personal prayer and a personal connection or relationship with God. Those who spoke of the benefits of prayers from other people also spoke of praying themselves. They found comfort in knowing that others were talking to God for them, as well as praying themselves. This variation among participants cannot be explained by any obvious factors. It may have had to do with the needs of the participants at any given time. When they needed more support the benefits of the additional prayers of others was important. When they were able to handle the situation with only their own relationship with God, that is where they found comfort. Regardless of the variation in the type of prayer, the participants were all comforted.

Theme: Changes in Spirituality

This theme looks at the changes participants experienced in their spirituality before and after cancer. Five participants identified that some part of their spirituality had changed after their cancer diagnosis. Some spoke of questioning it initially and then it having more meaning and becoming stronger, while others described being more appreciative and finding more comfort in their spirituality.

Samantha described the questioning of her faith that she experienced as well as how it was changed and strengthened through her cancer experience.

I think at the beginning it was sort of questioned. Like my faith was kind of questioned, like, oh you know, why would God have this happen to me or why does this have to be me? And then as I said, I think when I sort of started to accept it a little more then I started to think, well okay, maybe I can use my spirituality and my faith to help me cope with this, rather than blaming or you know feeling sorry for myself. So yeah, I think there definitely was a change with acceptance of the illness, which I still deal with, some days it’s easier to accept than others. But it definitely changed from, you know, being angry and questioning my faith to sort of accepting and realizing that my faith could help me through this. Generally I have a pretty strong faith. You know we attend church every Sunday; faith is
important to me. […] But you know I guess I just went along with, you know my faith was pretty strong but I think you know in difficult times like illness you know, faced with certain things like this, you do sort of question it. But I think before, you know things were pretty good and I didn’t question it so much. Yeah, you know what, I would say it is stronger. You know I had a strong faith, I went to church, I said my prayers casually and that kind of thing. But I think being diagnosed, after accepting what I had, I think I was more, it was stronger. Because I would sit in a room on my own and have quiet time or, you know, read a prayer to myself which I didn’t always make time for. So you know I had a strong faith before but it probably wasn’t as strong as it is now. Where I wouldn’t sit quietly in a room and pray. Whereas after my diagnosis, I did. So yeah, I guess it is stronger now. –Samantha

She was not the only participant who questioned her faith, and God, before finding strength and comfort in her beliefs. John went through a similar process.

I mean I was Christian, I was active, but again, it’s that happy go lucky. Where this caused me to actually stop and think and really ask some questions you know. Is there a God? Is this real? Am I okay, if…no matter what? Because I think prior to this incident, prior to this cancer diagnosis, um, my life was fairly happy go lucky. […] But then when this happened it was a reason. It was, there was a definite switch from this being casual to this being more serious. And um, especially when I couldn’t talk to people. You know about my feelings, what I was truly feeling. Instead when I was getting, you know, you’ll be fine, everything’s going to be good. I needed more, I needed to talk more about it. And I think that’s when I found myself searching for answers, you know, through God, through meditation, through…So there was a shift there. And that shift has stayed with me. […] it was such a profound shift and I, uh, I would think a transition in my faith, that it stayed with me all my life. […] I mean I can be in church or not. I can be in fellowship or not. I still have the same strength in my faith. And it says to me it’s something that comes from inside, it’s not something that I get from connecting with people or even a church. –John

The change expressed by these participants reflects one way in which participants challenged, and then embraced, their spirituality as a coping strategy to deal with cancer. Christine discussed how cancer made her question her spirituality, although in a different way. Instead of questioning if there was a God, she began to do more reading about other types of spirituality and really embraced the idea of energy, vibrations and connection.
I am a Christian person and I believed in God or a higher power but, I’ve been reading other books now and I sort of always believed, like, in parallel universes or um, energy... I don’t know. It’s just a strange thing but I pursued it a little further here or it sort of came up more with books that I had read on, like, vibrations and energy and, you know, how... how it is possible to sort of change the chemistry in your body. And I sort of mentally sort of change how you saw things. Like when I used to worry, and now I’m in control of my thoughts and focus on breathing and... Well I believe in, like, that there’s another vibration out there that I can sort of connect with and I want to incorporate that into my daily life. [...] And now, having this, its taken me further into a deeper self. More introspective and thinking that... [...] Like looking at everything differently, like the trees and just everything I guess, living and non living. Just I look at things differently and sort of see the life in everything. I don’t know how to explain it, it’s... And thinking that there’s another. I don’t know, I just think there’s some vibration, some other parallel existence that we don’t see. –Christine

She embarked on a journey of discovery of the existence of a higher power and how it affects the physical world.

The final two participants who described a shift in their spirituality talked about finding comfort in their spirituality after their diagnosis as well as their greater appreciation for the time they do have.

I just find more comfort. The one thing that I, that’s changed is that every morning when I wake up I do say thank you for the gift of another day. I’m very grateful for that ‘cause I’m still here. And I try it at night time, I don’t always remember to say it, but, to say thank you again for another day, but I don’t... I guess maybe I’m more aware now. Like it’s always been there and I’ve always found it a comfort but, I guess I think about it more now or I, ah, I feel it more now. Like I really sense and feel things more now. Just in faith, like I, if I’m having a really bad day or I’m you know, it’s just this warm, like a calming presence or feeling inside that I’m just like, you know what, you’re not alone. [...]Or like when you are a child and you’re held, you feel safe, like you feel (hugs herself). –Lindsay

Similar to Lindsay, Melanie also felt more appreciative of life and for the time she does have.

I think after, you’re just more appreciative because you realize that life is fleeting and it can be gone and I think it makes you, I think it made me more appreciative and more you know, trying to, aware of what really is important. But um, so, I
would think although going through it and different things since there, I know there’s a lot of times that, when I’m worried or concerned about something, I spend a lot more time praying about it, but I think in the long run, it just makes you realize that life can be gone so you focus more on what is of value. [...] For me that would be my family and friends, but also my spiritual life and my relationship with God. And that would be the most important and yet, my relationship with God flows into my relationship with those that are closest to me, so to me that all intertwines, and to me a big part of spirituality is how you treat other people and how you show your love to others. So I think that made me, it makes me more aware of, to not miss those opportunities to show other people your love and appreciation for them. –Melanie

For these participants, the shift in their spirituality involved not only finding greater comfort in their spirituality but also a greater appreciation for life and identifying what is most important to them. This variation from the other participants may be due in part to their age and previous relationship with God. These women were both in the 45-64 year age range, older than some of the other participants and had both described themselves as having a very strong faith prior to their cancer. They then were able to use their faith to find greater comfort since their diagnosis. They did not describe questioning the existence of God but rather emphasized gaining more comfort now from their spirituality.

*Category: Feeling Connected and Supported*

All nine of the participants discussed the fact that feeling connected and supported by others played an important part in their emotional healing journey. These discussions of support and connectedness were further broken down into Family and Friends, Other People with Cancer Experience, and Cancer Support Centres themes.

*Theme: Family and Friends*

Participants discussed the support they received from family and friends throughout their cancer experience. Four participants specifically discussed the support
from their immediate family and friends. The manner or mode in which the support was
given including being present, prayer, cards and emails, and intuitive phone calls.

Melanie described the support she received from her family by having them
present for her surgery and accompanying her to her treatments. She also described the
support of friends through cards and letters and them accompanying her to her treatments.

And my husband and my kids were there for me all the time. You know wanting
to be with me when I was having my surgery or taking, going with me up to my
cancer treatments, you know things like that. [...] And then I had different friends
in town that would ask if they could drive me up there so I could, you know so I
wasn’t driving by my- well I couldn’t drive by myself when I was having chemo,
but when I was having radiation I had to go up everyday. And then again, just
different, the encouragement from other people, when I would get cards and
letters and you know just knowing other people were thinking about me that was
an encouragement and uplifting you know too. [...] That you know I had lots of
people thinking of me and there to support. —Melanie

Christine also experienced the support of family and friends through a constant
stream of phone calls, emails and cards. This was a vitally important part of getting her
through her treatments and through the winter months.

I had the support of my husband, who was with me for the diagnosis and ah, you
know him and I, I guess, dealt with it initially. [...] Actually through the whole
thing, but initially it was him, and then family members and friends. Just through
constant, their barrage of cards and emails and phone calls and just hearing from
them, getting calls from them. The well wishes, or the concern, being there for
me. That’s how I coped initially was with them. [...] Yeah it really touched my
heart and made things easier to know that people cared about me and that were
concerned about my well being and that made things easier. And just people
bringing the support that way. I guess for me it was just, because I didn’t go out,
the contact, either by phone or email or a card in the mail. [...] ’Cause without
those, and people maybe don’t know how, I mean I keep telling people how
important that was for me, that it really did matter and that really got me through
the winter. It really got me through. —Christine
Sarah described the intuitive sense of one of her supportive people and how helpful that was to receive the support when she needed it most. She also discussed the support of both her immediate and extended family.

My immediate family, my husband George, and the kids. They’re 12 and 14, so they would have been 11 and 13 last year when I was going through this whole thing. [...] Extended family you know, my mom, my dad, my dad’s friend, George’s mom. Probably more, George’s side for brother and sister in laws. [...] Yeah so I had support there. And I have a couple good friends, too, from work, and so one from work and one from social as well, so they all kind of supported. [...] Actually a former student, and I would check in with her and she was almost, intuitively she knew, and she’d say, I need to talk to you, how are you doing? And I’d get an email when I was like, you know, when I was at chemo or something and I was at a low point. She would always send me an email just, or call me just at that time. And that was really great, like, feeling supported.

–Sarah

Scott discussed the support received from the church his family was involved in. Additionally he discussed the proactive nature of the support that was offered which allowed him to simply receive it as he needed.

And I’ve had a lot of prayer support and support from all of our friends at the church and so on over the period and that, so it’s been really good that way. [...] Very strong family support as well. [...] There was, there’s lots of people at the church that were concerned and they’d be asking how we’re doing and what’s up, and they’d be checking in with us as soon as they found out. I mean they didn’t ask me all along “did you have cancer? Did you have cancer?” But once they found out they were very supportive and following up on how things were going and everything else. [...]Which was really good. They were proactive, we didn’t just have to go to them all the time for spiritual support they were there. [...] And it’s, more than just our own local church congregation. It’s through other contact and people we’ve known through other churches and friends and stuff that we’ve had as well. –Scott

All of these participants discussed not only the support but also the large network that it came from. These networks included family, friends, co-workers, church members, and even former students. The feeling of being supported, not only by a couple of people, but
by a large network of people was experienced by all these participants and was an integral part of their healing.

**Theme: Other People with Cancer Experience**

This theme examines the other type of support that participants identified as important and helpful in their experience. The support of people who either have cancer, or who have survived cancer, provided understanding and hope to the participants.

Christine discussed the peer support program that was run by the Cancer Society. She describes the experience of being partnered up with someone who has been through a similar experience as being life saving.

The cancer society has a number that you can call to connect with people that have gone through. They try to hook you up with a similar, a person that’s had a similar situation to yours. So pretty much, ah, I would say almost right away, I connected with someone that had had similar circumstances to me and I found that to be life saving for me. Because then you could talk to a person who knows exactly how you’re feeling. You could talk to a person who’s a survivor which gives you hope. And you can talk to that person about your fears and your side effects, and everything that you’ve been through. So you can talk to someone who’s experienced the same thing you’ve experienced. –Christine

She described the ways in which speaking with someone who was in a similar situation to you and has made it through was helpful in helping her to find hope. She found reassurance by connecting with a cancer survivor who had undergone similar challenges.

Lindsay described the comfort she received by attending a support group with other people with the same type of cancer.

So I started going right away to the lymphoma support group, and I still go, and I find a lot of comfort. Knowledge is power and to hear people who have walked or are still walking this walk, ‘cause I mean it’s a whole new ball game. [...] Through Wellspring, and talking to other cancer patients that helped to alleviate some of the fear. –Lindsay
She found that talking to others who are in a similar situation helped alleviate some of the fear she felt surrounding her diagnosis.

Samantha talked about the differences between talking to people who have had personal experience with cancer compared to talking to those who have not.

I think it’s just an understanding that they have. You know, talking to a Social Worker or a Psychologist is helpful up to a point, but I think talking to people that have experienced the same thing as you, people who have had cancer and are familiar with it. It’s just reassuring, I think, to hear their stories and to, you know, they may be experiencing feelings that you have and there’s just an understanding there. Not that people who haven’t experienced cancer can’t be good listeners, or good advisors, and give you good advice, but I think talking to people who are experiencing it, or have experienced it, just gives you that reassurance, and there is that understanding there that they know what you are going through.

–Samantha

She described a more complete understanding that someone who has had a similar experience with cancer has compared to those who have not dealt with cancer. She spoke of the reassurance that comes with knowing that there is another person whom she can connect with that truly understands what she is experiencing. She found it comforting to hear stories from others that resonated with her. Melanie also talked about the experience of being able to talk to someone and hear about their experiences. She spoke of the mutual support she was able to offer and receive from her friend as they both embarked on this journey together.

Our daughter Jane, her mother in law, wasn’t her mother in law at the time, and I knew her, then we, I was diagnosed and going through treatments and she was diagnosed you know. And so we called each other a lot and just, you know, tried to be there to talk and things like that. And another lady I know through our church that had gone through it maybe two years prior to me. She was a major support to me. Constantly sending me cards, constantly calling me and saying, you know, and asking different things and she’d say, oh yeah, that happened to me too or just, you know things like that were a help. –Melanie
She described the support she received from a woman who had experienced cancer a couple of years earlier and how helpful it was to hear that she had similar experiences. Sarah spoke of conversations that can be more easily had with people who have cancer, either because they better understand what you are going through or because they were conversations she didn’t want to have with her family.

Well I think because you can talk to people like that, you can talk about your fears ’cause they can relate to that as well. And you’re not afraid of talking about really anything with them. Some things you’re not as apt to talk to your family about because you don’t want to scare them either. You know, when you get into mortality conversations and things like that and next steps. –Sarah

Jake discussed the importance of having the support of someone who is also experiencing cancer when in the hospital. This was especially important for him as his other friends were not in the same city as the hospital he was being treated at.

I had one friend in (the hospital) […] but we were in and out a different times […] but having a friend there to talk to really did help you cope a lot, me cope a lot more. Because my friends were removed […] so I think that I derived a lot more support out of that. […] I think I just wanted to talk to someone. –Jake

He talked about the importance of having someone to talk to, especially when in a hospital setting.

Theme: Cancer Support Centres

This theme reflects the importance of the cancer support centres that were used by some of the participants, specifically Hopespring in Waterloo and Wellspring in both Oakville and Brampton. These support centres were discussed in detail in chapter one. Programs offered at these centres include meditation, yoga, the Healing Journey program, support groups, and resource libraries. Most of the participants who used the
cancer support centres reported using not only one service, but a variety of the services 
provided, to assist in their emotional healing.

And then Hopespring has been amazing too. The courses that they offer here I 
find really good. The meditation, I’m in mediation, *Tools for Healing*, the Chi 
Gung, and the *Laugh and Lymphersize* program. And coming here you’re with 
people that are in similar situations that you are as well and the programs are 
really just amazing. —Christine

Samantha heard about Wellspring and the programs and support it offered through a past 
member of Wellspring.

Well I was introduced to Wellspring through my mom. [...] She attended here 
while she had breast cancer and she said it was very helpful emotionally and 
spiritually so it was definitely something that I wanted. Just to have to support of 
people who are going through, you know the illness, or who have had the illness. 
You know it’s a wonderful support so it’s been really helpful. —Samantha

Like Samantha, Lindsay also attended Wellspring on the advice of others and found it to 
provide very helpful tools in reducing the fear she had experienced.

I was lucky enough that I had two very good friends, one who has since passed 
away with cancer, who introduced me to Wellspring in Halton-Peel. So I started 
going right away to the lymphoma support group, and I still go, and I find a lot of 
comfort. Knowledge is power and to hear people who have walked or are still 
walking this walk, ‘cause I mean it’s a whole new ball game. You don’t know the 
terminology, you don’t know the lingo, but you don’t know anything. [...] So 
um... I don’t know. Through Wellspring, and talking to other cancer patients ,that 
helped to alleviate some of the fear. —Lindsay

The participants found the cancer support centres provide spiritual support, peer support, 
information and programming to facilitate their healing.

*Category: Role of Health Care Professionals*

In this category participants discussed their experience with the health care 
professionals and the role that they played throughout the participants’ cancer experience.
There were commonalities and differences among the experiences of the participants. The two themes that were evident in the participants’ discussions were Medical Support and Emotional and Spiritual Support. This dichotomy stood out because the participant’s views on the two areas of support were very different. While they felt the medical support was good, they felt the emotional and spiritual support was lacking.

**Theme: Medical Support**

This theme refers to the participants’ experiences with health care professionals in regards to their medical support. This includes the support provided by physicians, nurses, surgeons, radiologists and other medical staff. While four participants mentioned the support of the health care professionals, there were differences in their experiences.

Jake referred to the support and care provided by the nurses at the hospital.

> I mean like, the nurses were very good in that, like, there was one there all the time and you could just chat with one if you wanted, during the night especially. When you are just sort of awake because you have to pee every friggin’ five seconds. [...] I don’t know, they were just very down to earth people. Like doctors, I always feel like, a little bit, I mean they’re treating you, you’re done. But the nurses, I feel like, they’re the work horses of the entire hospital and they have that sort of, you know, easy going light attitude that goes with you know, that sort of practicality. And so I think that they were very good that way. —Jake

He had a positive experience with the nurses and found not only the medical care from them, but their general attitude to be helpful. Christine also had a positive experience and described the medical care she received by the staff at the hospital as amazing.

> They made the whole, from start to finish, from my diagnosis to my radiation, the staff has been amazing. Like I couldn’t have asked for a better, I don’t have anything to complain about in the whole situation. [...] But the staff was just amazing, the nurses, the technicians at the lab, the secretaries, the volunteers, everybody else, you know, the doctors. Everything was amazing. —Christine
Similar to Christine, Melanie found the medical care to be wonderful. She described how the care provided made her feel like she was a personal patient, not just another body they were working with.

I think that everybody up there, they never ever made you feel like, you know, they didn’t have time for you. [...] But they’re just always just, take the time and just want to make sure how you’re doing, and not just the physical part of it, you know do you, or even, you know, with the surgeon, you know, are you comfortable with what we decided to do? You know just, and at the cancer clinic I think I mentioned I always had this questionnaire to fill out, and then the nurse would come in and you know, go through a bunch of things to find out how I was doing. Things like that, but I think just the fact that they took time and didn’t rush you and didn’t, you know, make you feel like you’re just another body going through their system, kind of thing. They made you feel like you were a personal patient or case of theirs and they were interested. –Melanie

Greg felt differently. He described his feelings of being a number during his cancer experience. “It was almost as if I was a car being worked on. I didn’t get it. I really didn’t get anything like that so it was...I was just, I think it was just sort of like a number, like, next, so to speak. So, it sounds very shallow but that’s sort of been my experience.”

Because all people are unique they create unique relationships with each person they interact with. As a result the varying experiences of the participant may be due to the relationships formed between the individual health care providers and themselves.

Theme: Emotional and Spiritual Support

This theme refers to the emotional and spiritual support participants received from the allied health care professionals. These professionals primarily include psychologists, and social workers. John spoke of the lack of spiritual support he received from anyone involved in his care. He found his spiritual support outside the hospital and was grateful that he did.
It was just the medical, all, mostly the medical model that was involved. There was no pastors, no, I mean I was connected with my own church and they were involved in my life. Had it not been for them there would have been no spiritual remedy involved at all. It would not have even, no one came to me while I was there. –John

Scott too talked about the medical model that was primarily used in his experience. He also touches on possible reasons why spirituality was not addressed.

In terms of spiritual support… I would say no. They were on a strictly business medical level. […] And then the doctor was very clinical, very methodical about, you know, this is what the result say and so on. […] And the people at the clinic were very supportive but again, in a medical perspective not in a spiritual perspective. […] the medical profession has to be very careful and the Social Workers have to be very careful what they do on a spiritual side, so they normally steer clear of that and there really wasn’t an mention of that at all with any of the professionals that I was involved with. –Scott

Greg too spoke of the clinical way in which his encounters with health care professionals were conducted. He talked about the topic of spirituality being mentioned on a questionnaire he was required to fill out, but that the question was never followed up

I really can’t say that any health care providers really did. At least it wasn’t, that hasn’t been my experience. […] As far as anything spiritual, no, it really wasn’t. I can’t sort of see that it was. It was sort of clinical and sort of matter of fact or whatever. […]there was a questionnaire I had to fill out in London, every time I go to London I have to fill out this questionnaire, and it does touch on spirituality but it’s only on paper ‘cause during the interview or whatever that I’m having for the checkup or whatever, about how I’m doing, my monitoring, whatever, they’ve never mentioned spirituality even though it’s on this form. It’s like I thought, well why bother? If you’re not going to read it or you’re not going to ask the questions then what’s the point. To me it doesn’t make any sense.

–Greg

Greg’s frustration with the lack of follow up regarding the spirituality question is evident and valid. Christine also appeared agitated, as she discussed how her emotional support did not come from the social worker available in the cancer clinic.
But as far as the emotional I don’t think they’re, for me, it didn’t work emotionally. I didn’t find any support from them emotionally. None of my emotional improvement or care came from them. [...] I mean I could call them at anytime, and my family members would be, you know, would have access to them at any time, but I didn’t get my emotional support from them at all. And that might just be my personality. [...] But for the cancer I didn’t find it beneficial for me. Outside the hospital is where I found things that were beneficial. —Christine

Sarah on the other hand, had a positive experience with the social worker at the cancer clinic. “It was good. It was good. There were a couple of issues. One was around my daughter, behaviour issues, and I think the other as I was getting anxious about returning to work. And she was good, just kind of talked me through the issues.”

The differences between participants may be due to the issues assistance was sought for. For example, Sarah had specific issues with which she received support from the social worker. Perhaps, with a more specific need, positive assistance and support is more easily provided. It is important to note that in any relationship of emotional support, there are two aspects to be considered: that which is being offered, and that which can be received. Differences in either of these two aspects may be responsible for the differences among the experiences of people in terms of emotional or spiritual support.

Category: Recommendations for Health Care Providers

In this category participants discussed their recommendations to health care professionals regarding how to better meet the spiritual and emotional needs of people with cancer. There was great feedback from participants in regards to this, so much so that I could not discuss all of the suggestions from all of the participants. Three themes that are explored in this study are Exploring Spirituality, Holistic Approach and Providing Tools. A complete record of the recommendations of the participants can be found in Appendix F.
Theme: Exploring Spirituality

In this theme the recommendation to health care professionals, specifically social workers, around exploring the topic of spirituality with people was addressed. Lindsay noted the sensitive nature of this topic and the potential for people to be unwilling to discuss it. She also suggests possible ways to broach the topic.

I think asking the question. [...] So, but I think asking. (pause) And I think you’d have to be delicate with it because I think some people would... But I think asking the question would, and if they’re not faithful, then asking the question “would it be alright if I prayed for you?” Or is there anything I could, I don’t know. But I think asking would be.... I think. Or, I mean the listening skills that we’re all told to have. If someone just mentions, like I wear a cross. Make a comment on the cross and work it out that way. [...]Cause some, I mean, like if there’s a sudden death, I mean, people turn to faith, to fall back on faith. Being told you have cancer, would that be the time, I don’t know. (pause) I think if it was explored very gently. Then if there was something, and you could channel or put them in touch with whoever. Like I know there’s a non-denominational chapel at the hospital. I don’t know that anybody after having chemo, they wouldn’t be well enough to go upstairs. I don’t know if they would. (pause) I would explore it, but that’s me. —Lindsay

John spoke at length about the role spirituality played in his own healing. He expressed his own desire to have had someone ask about that aspect of his life in addition to the physical medical aspects.

okay. I think it’s important that social workers or, or anyone who’s involved in the person’s life that way, supportively, are open, are aware of that, of the spiritual connection. And that it could, could, um, assist in the healing. Because it is a very deep piece right? I mean, medical model is great, they can give you all kinds of support there, but if you can get to a person on the inside and get them, like for me, connecting on the inside and connecting on a spiritual level, really, really, I believe was my strength. Um, but had somebody you know, been there and encouraged me along, say at the hospital level, and it, it would have been, probably more helpful than doing it alone at the hospital. [...] I think if a social worker were to come in, or someone, and ask, you know, do you have any spiritual connection? Do you, is there a side of you that’s... Then they can find out right? If a patient is actually open to that or not. You can’t impose it on people, but you can explore it, see where it... what kind of spiritual side they have. And then if they have one, then you can help them lean into that for
For John, the inclusion of spirituality in his healing was vitally important. He felt that having someone there to encourage him in exploring this aspect of himself would have been beneficial in his healing process. Similarly to Lindsay, John spoke of being respectful of people, noting that social workers cannot impose beliefs or spirituality on others, but that exploring the topic with those who are willing in an open way could be beneficial. Greg also recommended that questions around spirituality or religion be asked to people experiencing cancer.

And also, like in other words, it used to be asked, like in other words, you know do you have a church; are you not in a church, do you feel the need for that? I think that needs to be asked. Like for myself, yes I work for a church, I’m not necessarily, say I’m a Christian, I’m not sure what I am. But I think that should, those are questions that need to be asked also. ~Greg

Again, it is about asking the question and exploring the topic with people.

Theme: Holistic Approach

In this theme participants expressed their recommendations that the cancer care provided by health care professionals become more holistic. That is they would like to see more than simply the physical, medical aspects of cancer being addressed.

I think they have to at least acknowledge that there are emotional stressors that go along with the diagnosis of cancer and, and spiritually too, like, I guess emotional and spiritual kind of relate together, but that there is that sort of questioning of your faith and your spirituality when you are diagnosed and I don’t think that health care providers necessarily recognize that. Like I said before, they give you a list of your physical side effects that you’ll have from your chemo and your diagnosis but they don’t necessarily tell you that, you know, you may experience anxiety, you may experience depression, you may experience um, you know questioning your faith, and anger and resentment and all those kinds of things. They kind of just mention it so vaguely that when it actually happens you don’t
necessarily know where to turn, you know, where to go. I think that’s why Wellspring is so good because it is a place where you can talk about those things and nobody questions why. So I think for health care providers and oncologists, for them to at least mention it (laughs) that you may experience these things. Even if it’s just a little bit, and kind of give you resources. And they were good about giving pamphlets on Wellspring and community support, and I mean that was okay. But them recognizing that its things that will happen when you are diagnosed and just giving awareness to the patient and where they can find help. Just a little more detailed than what they did. –Samantha

Samantha spoke of the importance of the medical team not only acknowledging the emotional and spiritual side of cancer, but also doing something to assist people in coping with this aspect. The emotional and spiritual needs of people begin almost immediately and people often do not know where to turn for this kind of support. Even a referral to a place such Wellspring, where the support can be found, can be vital. Christine also talks about the importance of expanding the medical profession to include a spiritual and emotional aspect.

I think there needs to be a more spiritual aspect to it. There is a huge disconnect between the medical profession and sort of, I don’t know if you would call it a holistic or a complementary medicine. Now I’m a big believer in complementary medicine, but I do think services like what we get here (Hopespring) could be used at the hospital. […] Because I don’t, there are no programs set up, well I don’t feel there are any programs set up in the hospital to deal with emotional. Because your emotions run the gamut right, during this whole thing. So one minute you’re up, the next minute you’re down. Your doctor is doing everything they can medically to sort of deal with your fears, but um, I even find that they don’t deal with depression. I don’t know if I had depression but your down days, they don’t really deal with your depression. […] But the emotional needs aren’t met. I had to look elsewhere, outside of the hospital for the emotional needs. So that being your peer support. So um, and then, the programs that are offered here, like the meditation and, the relaxation techniques that are offered here at Hopespring really benefited me. –Christine

She felt that more programs and services available at the hospital, like those offered at Hopespring, would have been incredibly beneficial not only to herself but to others as
well. Greg discussed the importance of having someone on the medical team whose role is specifically to address the emotional and spiritual aspects of people, especially those with major medical diseases.

I think what I would suggest is I would have a person that that is what they do, that that is part of, like, whether it be a psychologist or a social worker, someone dealing in, I’m going to say theology, they’d have to be very broad minded in that. But definitely you know, social workers, psychotherapists, whatever, I think they actually need to be part of the team. Particularly with something as, ah, with the diagnosis of cancer but not just cancer but heart disease, some of the very major medical diseases that we have. I think that there should be the social worker element there, I think that really needs to be there. [...] I think there needs to be this far more broad opportunity for people to access the social worker. [...] I think health care, I think it’s on the right track, I just don’t think it’s anywhere near where I think it needs to go. And that is the entire package. You know the health, the emotional body, spirit, emotions. That, I believe, is where we need, the total holistic view. –Greg

While he later admitted that the hospital may have had someone whose role is to deal with the emotional or spiritual side, he noted that he did not see this person, and was not offered any support in these areas. The participants were overall very happy with the medical care provided by health care professionals. However when it came to the emotional and spiritual care provided by health care professionals, the participants said it was significantly lacking, if present at all. They encourage the incorporation of these aspects of human existence in to the treatment of people with cancer.

*Theme: Providing Tools*

The final theme in this category refers to the recommendations of participants for health care professionals to provide or refer people with cancer to various programs and resources. While a variety of programs were mentioned, the overwhelming response was that these programs were incredibly helpful to the participants in providing them with
tools to use throughout their journey, and that these programs should be employed more
directly by health care professionals.

Samantha spoke of the benefits of the programs at Wellspring and how she found them to be more effective than similar care offered individually through the hospital. These differences could be partly due to the environment.

So I think Wellspring definitely gave me that which I didn’t get at the hospital. And there’s more choice of programs to take like Yoga, meditation, that kind of thing. Tai Chi, you know there’s choice. And at Wellspring, you feel more of a participant, like you’re participating more and you’re choosing what you want to do to better yourself. And you don’t get that just meeting the psychologist in her office. [...] Well, the programs they provide, like the Healing Journey has been wonderful, and the part 3 is on spirituality so it just, it gives you more practical sort of things to use and things like CD’s to help you, you know, meditate or relax or reflect. And you can take that home with you so it doesn’t just stop here in the building, it’s something that you can take home with you, and it’s just, they give it to you in your hand, like you go and get the CD, where as at the hospital with the psychologist we would just go through some visualization techniques but it wasn’t as practical and the atmosphere wasn’t as good. It just wasn’t as helpful as it is here (Wellspring). –Samantha

Even though some of the same tools were provided by a psychologist she found they were more effective at Wellspring. She went on to discuss how being told of Wellspring and all that it offers by a social worker at the hospital would have been helpful. Christine spoke not only of the importance of having the tools, in this case meditation, but also the importance of having these tools prior to treatment if at all possible. She discusses the benefit being that one could better prepare oneself for treatment in advance.

Where if they could maybe incorporate it either sooner, or talk to you about maybe wanting to bring meditation into your treatment regimen, but not when you’re sitting in the chair. Like those are things that if you knew, I don’t know, I just think that you could prepare yourself better ahead of time, before the treatment, and maybe if you had the knowledge of what she was trying to offer a week before. –Christine
When asked about recommendations for health care professionals, Sarah spoke of a variety of programs which she found to be very helpful and that she would have liked to see implemented at all cancer centres.

Well I would say the healing Journey, even the one program at Hopespring. That gives you a little bit of meditation, little bit of mindfulness, I can’t remember what else was in there, visualization you know, like bad, getting rid of the stuff. That’s good. I would suggest the Wellfit program, I don’t know if you would call that spiritual needs, but I just found that was a really positive thing to go through. And especially when you’re knocked down far, they built up your self-esteem I think that was really helpful. [...] The one thing though is that, I didn’t talk about this, the Juravinsk Cancer Centre in Hamilton has a fabulous, it’s called Out of the Shadows program and it’s for specifically people with breast cancer. And they do seminars once a month on all sorts of different topics and they were fabulous.

-Sarah

These suggestions of providing tools and coping strategies to people experiencing cancer could be easily implemented more fully by social workers in the cancer centres. While some referrals occur, partnerships between the cancer clinics and the cancer support centres would make the programs and tools more accessible to all people.
CHAPTER FIVE: DISCUSSION AND CONCLUSION

This chapter is presented in four sections. It begins with a summary of the findings of this investigation. The second section discusses the research findings in reference to the relevant literature. The third section reviews the recommendations of the participants and the implications for practice. The final section concludes this thesis with a discussion of the limitations of this study and my own personal reflections and final thoughts.

Summary of Findings

The data of this investigation is presented through the narratives of nine people who have experienced cancer in southwestern Ontario. This research project focused on understanding people’s experience of cancer and what they think health care professionals, and specifically social workers, could do to better meet their emotional and spiritual needs.

Although each participant shared their unique story, there were common themes that emerged throughout the narratives. These reflected five main categories: Healing, Spirituality, Feeling Connected and Supported, Role of Health Care Professionals, and Recommendations for Health Care Providers. These categories were then divided into fifteen themes: questioning, denial, fear, acceptance, meditation and stillness, prayer, changes in spirituality, family and friends, other people with cancer experience, cancer support centres, medical support, emotional and spiritual support, exploring spirituality, holistic approach, providing tools.

The data showed that there were commonalities among people’s individual processes of healing. Participants felt some, or all of, questioning, denial and fear in
response to their diagnosis of cancer. They spoke of the strategies they used to cope with these emotions and to move towards acceptance. Spirituality, the support of family and friends as well as others with cancer experience, and cancer support centres were the main coping strategies employed by the participants.

In regards to spirituality, the participants spoke of their use of meditation and stillness to overcome anger, questioning, fear and denial. They also spoke of their use of prayer, and the benefits of the prayers of others for them. Finally, the participants spoke of the change in their spirituality that they experienced as a result of their cancer experience. They reported their spirituality being strengthened and their connection to God becoming greater after their cancer experience.

The support of others was also identified as an important coping strategy for participants. They spoke of support from family and friends, other people with cancer experience, and from cancer support centres. With respect to the support from family and friends, participants spoke of how this was helpful in easing the burden of cancer and how important it was to stay connected to the important people in their lives. Support from others with cancer experience was also essential. This allowed participants to have conversations with people who more fully understood what they were experiencing. Most importantly, speaking to survivors of cancer gave them hope. Both these types of support from others were identified as being necessary in their healing process.

Participants spoke of the role of health care professionals in their healing journey. In terms of the medical support, participants were overall happy with the service they received. However the emotional and spiritual support participants received from the health care professionals in the medical system did not meet their needs. They were able
to provided suggestions about how health care professionals, and specifically social workers, could better meet the needs of people with cancer. They suggest exploring the topic of spirituality with people. They were also aware of the sensitive nature of this topic and recommend being sensitive to the individuality of spirituality. They suggest a holistic approach in the health care system that would encompass the emotional, spiritual, and mental aspects of the illness. Finally, they suggest that health care professionals can better provide people with tools to assist in their coping with cancer. These tools include programs, information, and support groups.

Theoretical Implications

The diagnosis of cancer can involve a variety of emotions, only one of which may be grief or loss. There are a number of theories surrounding grief and loss. Often these theories involve a consideration and discussion of whether grief can be best understood in terms of stages or phases, or alternately in regards to tasks that need to be accomplished (Noppe, 2000). These theories have primarily come out of work and research around death and dying. Although the loss associated with one’s imminent death or the death of a loved one is not exactly the same as the loss associated with the diagnosis of cancer, both invoke a grief response. Because of this commonality, the results of this study will be compared to the current literature on grief. A full description of all of the theories surrounding grief is beyond the scope of this discussion. Instead, only a few of the theories of grief will be reviewed and compared to the current investigations findings. The theories discussed in this paper were chosen because they best fit with the findings of this study.
Kubler-Ross and Kessler’s Stages of Grief

Elisabeth Kubler-Ross first described the five stages of grief in 1969 in her book *On Death and Dying* as pertaining to the person who is facing their own death. More recently she worked with David Kessler to expand her stages of grief to be relevant to those who are grieving the death or loss of a loved one. In 2005 they published the book *On Grief and Grieving*, which describes their stages of grief in regards to those who are grieving the death or loss of a loved one. This book was the source of information for the stages of grief by Kubler-Ross and Kessler. Kubler-Ross and Kessler’s stages of grief are denial, anger, bargaining, depression, and acceptance. These stages are the same as the stages as those described in *On Death and Dying*.

The first stage Kubler-Ross and Kessler describe is denial. They discuss the symbolic as opposed to the literal nature of denial. This can include feelings of shock and numbness. They also refer to the protective nature of denial in pacing the grief, allowing people to let in only what they can handle.

The second stage they describe is anger. Here they discuss the variety of ways anger can be expressed as well as the importance of feeling anger. They say that anger does not have to be valid or logical, but that it occurs when a person is feeling safe enough to know that they can survive the loss. Kubler-Ross and Kessler compare grief to being lost at sea. Anger can provide an anchor for people and give a sense of structure to their grief.

Kubler-Ross and Kessler’s third stage is bargaining. This stage involves the “what if” questions as well as a variety of forms bargaining takes. As with the rest of the stages, Kubler-Ross and Kessler describe the stages of grief in reference to the death of a
loved one. They discuss how in the beginning, bargaining can occur for their loved one to be saved, but can then move to trying for the return of a loved one or for a reprieve from the pain. Once a person has accepted their loved one’s death the bargaining can move to future events, such as being able to see them again in Heaven, or the care of others that they love.

The fourth stage of grief presented is depression. They describe depression as a natural response to a great loss. It is a way for nature to protect us by shutting down the nervous system to allow us to adapt to a situation that we do not feel we can handle (p.21). They encourage people to embrace depression saying that often we do not allow depression its place in dealing with grief. It is a balancing act between embracing depression and knowing when it becomes a long-term issue requiring professional assistance. Like the other stages, depression plays a role in facilitating the process of healing. It slows a person down and allows them to really acknowledge the loss (p. 24).

The final stage is acceptance. They note that it is a process, not an end point (p. 27). It can take years and the process may need to be started again and again. Acceptance is not the same as being all right or okay with the loss. Instead it is accepting and recognizing the new, permanent reality of a loved one being lost. It involves the acknowledgement that the past has been forever changed and that we must reorganize roles, reintegrate, and learn to live again without our loved one physically present (p. 25).

Kubler-Ross’s stages of grief as discussed in her book *On Death and Dying* have been criticized by many (eg. Feignberg, 1980; Pattison, 1977; Shneidman, 1980, Weisman, 1977; Kastenbaum, 1986). These critics have called the model inadequate, superficial and misleading. Corr (1993) suggests that people cope with dying do so in
unique and individual ways that cannot be described in only five stages. He also
discusses the idea that even if there was evidence to support coping with death in five
phases as suggested by Kubler-Ross, there is no reason they should then be linked in
stages that imply a linear, fluid movement through them. Lastly, he suggests that the
stages presented by Kubler-Ross should not be prescriptive of how a person should cope
with death. That is, there is no “right” way to grieve dying, and to insist that people do so
by following the stages only imposes guidelines on people’s grieving.

In response to some of the critiques on Kubler-Ross’s stages of grief in her book
On Death or Dying (1969), some changes and acknowledgements were made in the book
On Grief and Grieving (2005). They acknowledge the individuality of people’s grief. Not
everyone will experience each stage, nor in the prescribed order (2005, p. 7). They note
that the stages can last for weeks or months, or simply minutes or hours. As well, they are
not always moved through in a linear order. A person can return to a stage after leaving it
for another (2005, p. 18).

The results of the current investigation also involved commonalities among
people’s emotional processes of healing and the strategies that moved them towards
acceptance. Both fear and denial were found to be common among the participants’
processes of healing. As well, acceptance was talked about as an important part of
healing. The participants described moving back and forth through questioning, denial,
fear and acceptance and describe their healing as an ongoing process. This is similar to
the acknowledgements of Kubler-Ross and Kessler who said that the movement through
their stages of grief is not linear.
The commonalities among the participants’ processes of healing are depicted in Figure 1: Emotional Healing After a Cancer Diagnosis found on the next page. Participants described the outlying emotions of fear, denial, questioning and acceptance as part of their experience. They discussed the non-linear movement through and among these emotions throughout the journey. The participants also spoke of the importance of spirituality, support, and cancer support centres in facilitating their movement through these experiences toward healing. Health care professionals can help facilitate people’s healing by ensuring that people have social support, connecting them with cancer support centres, and exploring spirituality with people if it is their desire. This can be done by providing or referring people to programs, support groups and other professionals when appropriate. The broken line surrounding healing in Figure 1: Emotional Healing After a Cancer Diagnosis (found on the following page) allows and represents the movement back and forth among fear, denial, questioning, acceptance and healing.

The participants described feelings of questioning, denial and fear as their initial reaction. In reference to the stages of Kubler-Ross and Kessler, some of the participants described experiencing more than one of the stages initially. For example, Samantha experienced both shock (a part of denial) and anger.

“I just you know was in shock, so emotionally it actually really affected me because I’m so young and you know, I had to tell all my friends and it was just, you know, why me? Out of all my group of friends, out of all my colleagues that I teach with, you know, why did it have to be me? –Samantha

Samantha demonstrated the rapid movement between stages Kuber-Ross and Kessler suggested was possible. They recognized that not everyone would feel all of these stages, and that the length of time in the stages could vary significantly among people.
Figure 1: Emotional Healing After a Cancer Diagnosis
For Samantha the denial stage was quickly followed by the questioning and anger stage. Additionally Samantha spoke of the struggle she had to be accepting. She reported that some days the anger returned and she was not as accepting. This demonstrates the non-linear flow through the stages people experience.

Participants in the current investigation described denial both as an initial reaction to their diagnosis and in regard to the potential severity of the disease. Kubler-Ross and Kessler (2005) discuss the protective way in which denial works. These findings of denial can be explained using the protective benefits of denial. For example John said “I mean that’s the funny stages of denial right. It can’t be, you know, “you’re wrong, right God.?” You know, those kinds of prayers. And the realization would come, John, they’re not thinking. They’ve tested. It’s positive.” When denial was experienced as an initial response to the cancer diagnosis, it worked to pace the grief the participant felt. This allowed John to slow down and only process as much information as he could handle at the time. As John was able to handle more information, the denial lifted and he was able to move forward toward accepting his diagnosis.

This same theory can be applied to the participants who experienced denial regarding the possible outcome of the cancer.

And I don’t know if... I think when I was going through it I don’t really think that I ever thought that I was going to die or that I was threatened or anything. I don’t know. I just didn’t ever think that way. So then I never really thought of myself as a survivor... until this spring. I had, you go back every 6 months for my mammograms and checks and there was a little issue came up and that ah, made me realize, you know what, I am a survivor [...]. I never was mopey and thinking oh I’m not going to make this or this is going to get me or anything like that. But it was hard when my hair fell out. I think that was the first that I actually thought, oh, I’m sick. —Melanie
By denying the possibility of death, denial serves to protect Melanie from more grief than she can handle. When she was capable of handling more grief the denial ended and she was able to face that she was sick, and that she was indeed a survivor.

Fear was the third emotion that was described by participants as an initial reaction to their diagnosis. Fear is not a part of Kubler-Ross and Kessler's grief stages. When considering why this emotion was present for the participants but not a part of the grief stages, I considered the assumptions of the grief stages. Kubler-Ross and Kessler (2005) discuss these stages as a response to the death of a loved one. While grief still occurs in response one's diagnosis of a serious illness such as cancer, the response is understandably different. It is not a matter of how do I go on without this person? but instead, a question of will I survive? How will my life change because of this? Fear is a very real part of a diagnosis of cancer. A cancer diagnosis can also involve the loss of dreams, loss of possibilities, a loss or change of daily routine, loss of ability, and the loss of innocence. These losses may be temporary or permanent, but either way, they invoke a grief response. Sarah describes this loss of innocence.

> I read somewhere that we’ve really lost our innocence, like we know that we’re going to die, and we’ve faced that we’re going to die. We’re hoping that it’s going to be way down the road, but we have a loss of innocence around that and that’s a good thing. ‘Cause we can change that way that we’re living and what’s important. -Sarah

Facing our own mortality can be a fearful event, especially when it involves an illness in which the outcome may not be known immediately.

Neither bargaining nor depression was identified as a theme of this research. While none of the participants spoke at length about depression, a couple of participants mentioned it in passing. Christine spoke of experiencing some depression or low days. As
well, Sarah spoke of a program she attended where an oncologist normalized her feelings of depression or sadness. Samantha also spoke of feelings of sadness during her cancer experience and speaking to her doctor about it. She then found out this was a common side effect of the medication she was taking and she began to see a psychologist regarding the depression. Therefore, although depression was not identified as a major theme within this investigation, it can be noted that some of the participants did mention depression as a part of their cancer experience.

The final stage in Kubler-Ross and Kessler’s (2005) stages of grief is acceptance. The participants in this study discussed acceptance as another emotion they experienced along with questioning, denial, and fear in their healing journey. As well, participants described acceptance, not as a final point, but as a process. Christine said, “it’s ongoing. It’s an ongoing process.” She also spoke of the fear that was still with her. Since her diagnosis, she worried that every ache and pain was cancer. This fear was something she was still working through. Samantha also spoke of acceptance as a process, “like I said I do have days when I’m not as accepting and I’m a little angry.” Both of these women’s experiences fit with the Kubler-Ross and Kessler (2005) model of grief. They spoke of the way people can move back and forth between the stages in a non-linear fashion. Samantha and Christine are examples of that.

Overall there is a similarity between the processes of healing that were described by the participants in this investigation and the stages of grief presented by Kubler-Ross and Kessler (2005). Both involve denial and acceptance. The differences have been discussed above and can be explained when the context is considered. Kubler-Ross and Kessler based their stages of grief on the death of a loved one, while the participants’
processes of healing were a result of their own diagnosis of cancer. Although these two life events both invoke a grief response, they are still quite different and therefore the response to them and the process through them is different as well.

Goldsworthy's Grief and Loss Theory and Intervention

Goldsworthy describes recognizing and working with grief and loss issues as one of the core skills of social work practice (2005). She noted that while there is plenty of literature regarding grief and loss from a death and dying perspective, there is little literature from other perspectives. In an effort to begin to remedy this, she provides a review of existing theories of grief and loss including: psychodynamic theory, attachment theory, task theory, social learning theory, cognitive behavioural theory, constructivist theory, and the Kubler-Ross stages. Goldsworthy concludes her paper with a development of a theoretically expansive approach, which emphasizes the individual uniqueness of grief. Here she describes the task of grieving to be integrating reconstructed meanings in relation to the loss into life. A meaning-making approach to grief and loss not only allows respect for the individual grieving process but also enables social workers to serve as a catalyst and collaborator in the process of meaning reconstruction (Saleebey cited in Goldsworthy, 2005). This theory of grief and loss does not limit loss to death or dying, but accepts the different ways loss can enter an individual’s life, including the diagnosis of cancer.

The findings of this research study fit well with this theory by meeting the client where they are at and allowing for the unique and individual grief. This theory allows the individual’s unique emotions of grief to be worked through as they arise. There are no prescribed stages or timeline. It is not linear and therefore allows and acknowledges the
non-linear way in which people work through their grief. Goldsworthy’s theory supports the ongoing process of acceptance and the movement back and forth that this involves that was described by the participants of this investigation.

*The Impact of Coping Mechanisms*

The current investigation found that the participants used a variety of coping mechanisms to aid in their emotional healing. Spirituality, feeling supported, and the use of cancer support centres were highlighted. The impact of these coping mechanisms is visually depicted above in Figure 1: Emotional Healing After a Cancer Diagnosis. The use of these coping strategies can assist people in moving towards healing.

*Spirituality*

Spirituality was identified as a coping mechanism. It was then divided into three themes or practices of spirituality: stillness and meditation, prayer, and changes in spirituality. All three of these themes assisted participants in their emotional healing. Stillness and meditation were discussed as ways to calm the mind and lessen the anxiety, worry, fear and questioning. It allowed people to become more connected to God or to a higher power. Participants described prayer to benefit them, both by allowing them to feel that God was with them and they were not alone, but also by easing their emotional and mental burden when others prayed for them. The participants noticed that their faith was stronger as a result of the experience.

Stillness and meditation assisted participants to lessen their worry, anxiety, fear and anger. Christine said “Meditation sort of goes along with that, and calming and lessening your anxiety.” She described learning how to meditate and the benefits that she felt by lessening her anxiety. It also allowed participants to relax and slow down, taking
more time for themselves throughout this process and afterwards. This time spent in
meditation or stillness helped participants to feel connected to God or a higher power and
helped facilitate a change in spirituality.

Prayer was used by the majority of participants to cope with their cancer. It was
an important aspect of maintaining and growing their relationship with God or a higher
power. This reduced the isolation and feelings of being alone. They reported feeling
comfort knowing that God was there and listening, and that they were not facing this
battle alone. For example, Sarah spoke of the comfort and peace she received from
praying by herself. “Well I think through the whole process, like, I prayed, you know, for
healing, for strength throughout and I continue to do that for guidance. [...] it’s just
comforting to know that He’s there and He’s listening. Yeah and I would feel a sense of
peace then.” Participants also discussed the ways having other people pray for them
comforted or benefited them. Melanie, for example, said “well just actually last week I
said to one of the kids “you must be praying for me ‘cause I feel better today”. So I mean,
it’s hard to describe, but I do believe we get some kind of inner peace, like that the worry
or the stress is lifted or taken away.” This comfort or emotional improvement aided the
participants in overcoming their fear, denial, and anger.

The changes in spirituality that were described by participants involved both
strengthening their belief or relationship, as well as finding more comfort in their
spirituality. For example, some participants noticed that their belief in God or a higher
power was stronger after they questioned their faith and/or God. John talked about how
he no longer needed to be in church or bible study or anything church related in order to
feel a deep connection to God. It now comes from within and is unrelated to his
surroundings. Lindsay spoke of the comfort she now feels when she said “if I’m having a really bad day or I’m, you know, it’s just this warm, like a calming presence or feeling inside that I’m just like, you know what, you’re not alone.” This comfort and feeling of having someone with them ties in with the next coping strategy of feeling supported and connected.

**Feeling Supported and Connected**

Participants discussed the importance of feeling supported and connected to people throughout their experience with cancer. They discussed the support of family and friends and the support of others who have had or are experiencing cancer.

The support of family and friends was important to participants through their experiences. The participants described large support networks made up of people from various aspects of their lives: family, friends, co-workers, church members, and even former students. Christine described how the support of family and friends made it easier to handle her situation. “Yeah it really touched my heart and made things easier to know that people cared about me and they were concerned about my well being and that made things easier.” The support of family and friends helps people to not feel so alone, and can make the challenges associated with cancer easier to bear. This can help people move towards acceptance, by reminding them that they are not alone, and by providing a place for people to talk about their experience and process their feelings including denial, fear, anger and questioning.

Maly, Umezawa, Leake and Silliman (2005) conducted a study on the mental health outcomes in 222 women over age 55 newly diagnosed with breast cancer, in relation to the impact of the perceived family support and adjustment. They found that
the support and positive adjustment of the women’s spouse and adult children predicted less anxiety and depression in the women.

The support of people who had had or were currently experiencing cancer was also identified to be important. The participants spoke of the comfort they felt speaking to people who had experienced similar situations. Christine described this support as life saving, “I would say almost right away I connected with someone that had had similar circumstances to me and I found that to be life saving for me. Because then you could talk to a person who knows exactly how you’re feeling.” She went on to describe not only the feeling of hope when talking to someone with similar experiences, but also the comfort of knowing they understood her struggles. Samantha also spoke of the reassurance that came from being able to relate to a person who truly understood what she was going through in a way that people who have not had personal experience with cancer cannot.

Lindsay also found comfort in speaking with people who have cancer experience.

So I started going right away to the lymphoma support group, and I still go, and I find a lot of comfort. Knowledge is power and to hear people who have walked or are still walking this walk, ‘cause I mean it’s a whole new ball game. [...] Through Wellspring, and talking to other cancer patients that helped to alleviate some of the fear. –Lindsay

She speaks of the way in which the support of people with similar experience helped her move past her fear. As was discussed previously, overcoming fear is a step towards acceptance. The support of people who have achieved acceptance, and who can truly understand the way a person with cancer feels, plays a major role in helping people move toward their own acceptance.

Studies have shown that social support plays an important role in assisting people
to cope with distressing situations, such as cancer. After conducting a study with 81 women, Friedman, Kalidas, Elledge, Chang, Romero and Husain (2006) suggest that facilitating social support for women experiencing breast cancer may help women cope with the stress of their diagnosis. Shelby, Crespin, Wells-Di Gregorio, Lamdan, Siegel and Taylor (2008) also found that social support can help women better adjust to breast cancer diagnosis.

*Cancer Support Centres*

The cancer support centres Hopespring and Wellspring provided great support to participants. I believe these centres are so beneficial because they provide the emotional and spiritual support that the participants described previously as being crucial in their healing. Those who used the centres reported finding a variety of helpful tools. Christine described her experience at Hopespring.

And then Hopespring has been amazing too. The courses that they offer here I find really good. The meditation, I’m in mediation, *Tools for Healing*, the Chi Gung, and the *Laugh and Lymphersize* program. And coming here you’re with people that are in similar situations that you are as well and the programs are really just amazing. *—Christine*

The peer support at both Hopespring and Wellspring centres allowed participants to feel less alone, as well as provided an opportunity to speak with others in similar circumstances. Meeting those who were further along in their journey often provided hope to the participants that they too would get through this experience. The programs and services available were beneficial in participants’ healing process. For example, Samantha said that the support she received at Wellspring aided her in achieving acceptance. In addition to the peer and individual support provided at these cancer
support centres, they also offer complementary medicine such as massage, Reiki, meditation, Tai Chi and Yoga.

**Role of Social Workers**

Based on the theory presented in Figure 1: Emotional Healing After a Cancer Diagnosis, the role of social workers may be providing people with emotional and spiritual support by focusing on increasing their access to coping strategies. This involves ensuring that people have supports, both family and friends and peer supports, and encouraging them to embrace and use these supports to aid in their healing. If this is not available, a substitute support system should be created. This could include both professionals and peer support. It also involves exploring spirituality with people and supporting them in their spiritual journey, while connecting them to additional resources in this area if necessary. Social workers need to be able to provide or refer people to places such as Hopespring and Wellspring that can provide an environment where people can explore their spirituality. Cancer centers are vital in providing tools in which participants can use this to overcome feelings of anger, denial, and fear. As a result, people will be more supported as they move among fear, denial, questioning and acceptance towards healing. My theory is supported by the recommendations provided by the participants for health care professionals, which are discussed in the next section.

**Recommendations and Implications for Practice**

In this study participants were asked for their recommendations to health care professionals and more specifically social workers, about how to better meet people’s spiritual and emotional needs while they are dealing with cancer. The three main recommendations that were identified were: explore spirituality, provide a holistic
approach, and provide tools. A complete list of the recommendations provided by the
participants can be found in Appendix F.

*Exploring Spirituality*

The participants of this study provided recommendations for health care
professionals in regards to better meeting people’s emotional and spiritual needs when
they are dealing with cancer. While participants noted the importance of spirituality in
their emotional healing, they reported that they received little or no emotional or spiritual
support from health care professionals and were forced to take the initiative to meet their
needs. They recommend that health care professionals, and specifically social workers,
take the initiative to explore the subject of spirituality with people. For example Greg
said “I think that needs to be asked. Like for myself, yes I work for a church, I’m not
necessarily, say I’m a Christian, I’m not sure what I am. But I think that should, those are
questions that need to be asked also.” Lindsay and John also suggested that the topic of
spirituality be explored, although they also discuss the sensitive nature of the topic and
the possible unwillingness of people to talk about it. This being the case, they also feel it
can be a valuable coping strategy for people and an aspect of care that is often missed or
ignored by health care professionals.

practitioners not to assume that all people have the same spiritual beliefs and needs. They
encourage practitioners to conduct spiritual assessments on a case-by-case basis, in order
to develop an individual plan to incorporate spirituality and ensure its effectiveness. The
Canadian Association of Social Workers identifies the first core value of social workers
to be respect for the inherent dignity and worth of persons in their Code of Ethics (2005).
This involves upholding each client's right to self-determination. Congruent with this guiding principle, it is our goal as social workers to explore spirituality with clients while not forcing any belief or practice upon them. Whitman (2007) also discusses the importance of practitioners being sensitive to the unique religious or spiritual beliefs of patient. He suggests having a grounding of knowledge with which one can begin to discuss these issues with patients. By adhering to these values, it becomes possible for social workers to explore the sensitive topic of spirituality with people of all faiths and beliefs. This would then result in people feeling more supported emotionally and, especially spiritually throughout their healing. It can also allow people to incorporate spirituality into their healing.

Holistic Approach

The second major theme of recommendations that was identified from the participants' stories is having a more holistic medical system. The participants were generally very happy with the medical care they received from their health care professionals. However, when asked about the emotional and spiritual care they received from the health care professionals, the answer was very different. There were glimmers of hope and positive feedback, such as from Sarah who received support from a social worker at the hospital. However, the overall sense was that the emotional and spiritual support was lacking. Christine said, "there is a huge disconnect between the medical profession and sort of, I don’t know if you would call it a holistic or a complementary medicine."

Participants spoke of having to seek their emotional and spiritual support independently and outside the medical system. Christine reported that she received no
emotional support from her health care professionals at the hospital and had to look to Hopespring to meet those needs. She said, “I had to look elsewhere, outside of the hospital for the emotional needs. So that being your peer support. So um, and then, the programs that are offered here, like the meditation and, the relaxation techniques that are offered here at Hopespring really benefited me.”

Samantha spoke of hearing a great deal about the physical aspect of her disease and what to expect but was not told about the emotional and spiritual aspect, leaving her unsure of where to turn for support.

They give you a list of your physical side effects that you’ll have from your chemo and your diagnosis but they don’t necessarily tell you that, you know, you may experience anxiety, you may experience depression, you may experience um, you know, questioning your faith and anger and resentment and all those kinds of things. They kind of just mention it so vaguely that when it actually happens you don’t necessarily know where to turn, you know, where to go. -Samantha

She too would have liked to have had a more holistic approach used with her, one that included a more in depth discussion about possible emotional and spiritual challenges throughout her cancer experience. This would have not only allowed her to possibly prepare herself for these emotions, but also normalize them when they did occur. A more detailed discussion that included resources or support would have enable her to find support more quickly and with less stress as she would have known exactly where to go to access these resources.

A holistic approach involves not only addressing the emotional, spiritual, mental, and physical, but also the merging of these issues with the medical issues. As Greg said, “I think health care, I think it’s on the right track, I just don’t think it’s anywhere near where I think it needs to go. And that is the entire package. You know the health,
emotional body, spirit, emotions. That, I believe, is where we need the total holistic view.”

In order for spirituality to be explored with people diagnosed with cancer, and a more holistic approach utilized in the medical system, there needs to be a shift towards a more psychosocial oncology framework. That is, the emotional, mental, and spiritual needs of people need to be acknowledged and addressed as equally important to the person’s physical needs and treatment. This will involve training of health care professionals working within cancer care settings about the importance of the emotional, mental, and spiritual aspects in the care of people, as well as regarding specifically how to address these issues with people. This can begin in the training programs for all health care professionals. Educating people about the impact of cancer on the whole person, not just the physical impact, will assist people in understanding the importance of addressing the other aspects of people. Also, giving examples of how to address these aspects of people will be important in training health care professionals and increasing their use of these skills. Continuing education workshops and seminars on this topic will also be important to educate the people already working in cancer care.

Providing Tools

The third theme of recommendations is providing tools to aid people in coping with cancer. This includes programs, workshops, individual work with people, or a combination of the above. The participants in this study had experiences with a wide variety of programs and tools.

Christine discussed some of the programs she was a part of at Hopespring.

The courses that they offer here I find really good. The meditation, I’m in meditation, Tools for Healing, the Chi Gung, and the Laugh and Lymphersize
program. And coming here you’re with people that are in similar situations that you are as well, and the programs are really just amazing. –Christine

While no one program stood out as the most useful, all the programs were described to be helpful to participants. These programs provided tools that not only helped them cope with the day-to-day experience of living with cancer, but also facilitated their movement towards acceptance as discussed in previous sections. The environment in which the tools were provided had an effect for one participant. Samantha discussed the differences she noticed between resources provided to her at the hospital to those she received from Wellspring.

So I think Wellspring definitely gave me that which I didn’t get at the hospital. And there’s more choice of programs to take like Yoga, meditation, that kind of thing, Tai Chi, you know there’s choice. And at Wellspring, you feel more of a participant, like you’re participating more and you’re choosing what you want to do to better yourself. –Samantha

While receiving the tools at the cancer support centre was more beneficial for Samantha, Christine noted the importance of when the tools are gained. She would have preferred to know more about meditation as a method of controlling her anxiety before she was anxiously sitting in her treatment chair.

Where if they could maybe incorporate it either sooner, or talk to you about maybe wanting to bring meditation in to your treatment regimen, but not when you’re sitting in the chair. Like those are things that if you knew, I don’t know I just think that you could prepare yourself better ahead of time, before the treatment, and maybe if you had the knowledge of what she was trying to offer a week before. –Christine

There are many aspects to be considered when providing people with tools to cope with cancer, including the environment and timing. There are a variety of ways in which tools and resources can be provided. Groups, workshops, seminars, individual work, and
partnerships with other organizations are all possibilities. It is most important that people with cancer know about, and have access to, the tools and supports to help them best cope with this experience.

Because funding is always an issue in the medical system, partnerships with other agencies and organizations, such as cancer support centres and the local Canadian Cancer Society chapter, may be an effective way to provide tools to people at a lower cost. Knowledge of the resources available outside the hospital setting and referring people to these resources is important. Partnering with these organizations to provide seminars for people with cancer in a hospital setting may be a good way to introduce people to other supportive organizations and agencies.

Limitations and Conclusion

Limitations of the Investigation

I have taken steps to enhance the credibility of the findings in the current study. These include making my orientation toward this phenomenon overt, checking the interpretations with the participants, and ensuring that the themes are present in several of the narratives before being included in the final analysis. There are, however, potential limitations to this investigation that need to be considered in order to better interpret the findings. These limitations also highlight room for improvement in future research.

My own personal experiences of spirituality with respect to my family members, combined with the knowledge of previous literature on this topic prior to conducting the investigation, had the potential to create pre-conceived expectations regarding the results. Additionally, my previous experiences and values may have caused me to overlook other angles from which the issues may have been examined. Alternatively, having previous
experience using spirituality may have increased the trust and empathy during the data collection, resulting in richer narratives from the participants.

Qualitative research does not seek to generalize results (Patton, 2002). The results of this investigation are bound by context. That is, the findings are only true for these nine participants with me as the author. Therefore the implications for practice presented below should be interpreted as suggestions, not directions. I acknowledge that with different participants, a different researcher, and under different circumstances, the results could differ. The reader needs to decide for him or her self if the findings of this investigation apply to others.

The participants in this investigation all lived and were treated in an urban location in southwestern Ontario. They were all Caucasian, highly educated and were from middle class socioeconomic backgrounds. It should not be assumed that people with cancer from other locations in Canada, those with less or more education, or those from minority groups, have experiences with spirituality that are similar to those described in this investigation.

This investigation used posters and flyers at Holistic cancer support centres as the primary method of recruitment. This reflects the view of the participants that spiritual and emotional healing is an important part of their cancer experience. A similar study conducted with participants recruited from a centre with a different focus may have resulted in different findings.

An interview guide was used to conduct the interviews. This ensured that the same set of general questions was asked to all participants. However it had the potential to limit participants' narratives. In order to try to address this limitation, the interview
ended with an open-ended question allowing participants to discuss any issues they felt was important to their experience that was not previously addressed.

However, this research will add to the knowledge base of how people use spirituality to aid in their healing and the recommendations to health care professionals, specifically social workers regarding how to better meet people's emotional and spiritual needs. It also contributes to the knowledge about what services people with cancer are looking for to aid in their healing. This study will hopefully spark additional research in this area to provide suggestions for the better implementation of emotional and spiritual support to people experiencing cancer.

**Recommendations for Future Research**

The current investigation has contributed to the limited knowledge of how people use spirituality to aid in their healing process while managing their cancer, and their recommendations to health care professionals in this regard. In this type of exploratory research, the results often raise more questions than they answer.

Because of the limited literature regarding how people with cancer use spirituality to aid in their healing, more research is needed to better understand the lived experience of these people.

Further investigation could confirm and validate the themes and issues raised in this study. This could provide an even deeper reflection on the needs of people with cancer and how health care professionals can better meet these needs. A reproduction of the methodology used in this study with different participants and researcher could enhance the findings.
Further research is needed to consider how to best provide effective emotional and spiritual support for people with cancer. There are several possibilities including creating independent support centres, partnering with existing cancer support centres, and implementing more services in the cancer clinics. This research could involve people with cancer, health care professionals and staff at cancer support centres.

This investigation’s recruitment took place primarily through holistic cancer support centres. It would be important to repeat this research with individuals recruited in other locations in order to broaden the knowledge base of people’s emotional and spiritual needs. It would also be valuable to study how people who do not identify as spiritual recommend if and how health care professionals should broach the subject of spirituality. This would demonstrate whether the themes identified in this investigation are applicable to people with cancer in general.

While the idea of hope was sensed in this investigation, further questioning and discussion would have been necessary to accurately represent the participant’s views on this idea. Future research could look at the role hope plays, and its influence on the healing of people with cancer.

Conclusion

Conducting this investigation has been an incredibly rewarding process for me. Because of my own experiences and those of my family members, I have an obvious connection to this phenomenon. I have greatly enjoyed the opportunity to learn more about the experiences of the participants who volunteered both their time and their intimate personal stories to me. These people allowed me to see a glimpse of their world from their perspective. In providing a means for these people’s voice to be heard, I hope
that others will gain a deeper awareness of people's need for emotional and spiritual support to be a part of their medical treatment.

Throughout the process of this investigation the narratives of the participants have challenged me personally as well as professionally. My own definition of spirituality has been challenged and expanded to include not only God or a higher power but also a feeling of connectedness. While I was aware of the various methods of practicing spirituality prior to embarking on this research project, I did not utilize anything except my own individual prayer. As a result of hearing these participants' stories and the ways in which they benefited from the various methods of practicing, I have begun to consider using other methods such as meditation and asking others to pray for me as well. The stories of these participants have inspired me to take advantage of the benefits of the coping strategies used by these people when faced with challenging situations and experiences in my own life.

In preparation for my future role as a social worker, I have gained valuable knowledge about the commonalities in the holistic nature of people and their need to have all aspects of their healing addressed when facing an illness. The recommendations of the participants gave me direction about how I can better meet people's needs in my future work. I can also see implications for the use of this knowledge not only when working with people experiencing illness but with all people. Similar coping strategies may be employed and found beneficial by people facing a variety of issues including medical illnesses, mental health concerns, catastrophic life events and everyday challenges. This has been excellent training for my future endeavors as a social worker.
Overall, the findings of this study reveal the varying needs of people with cancer in regard to their emotional and spiritual healing. It is obvious to me that emotional and spiritual support is a vital component to overall holistic healing, and yet participants were left to meet these needs on their own, outside of their formal medical care. My ultimate hope is that this research has contributed to the understanding of the emotional and spiritual needs of people with cancer and will serve as momentum for further exploration in an effort to increase the incorporation of these issues into the formal medical care of people.
APPENDIX A: RECRUITING POSTER

Discuss the experience
of cancer and spirituality

Principal Investigator: Lisa Green, Master of Social Work student
Wilfrid Laurier University (Supervised by Dr. Peter Dunn)

Have you been diagnosed with
cancer more than 6 months ago?

I am looking for people with a cancer diagnosis to participate in a study about the experiences of people with cancer and spirituality.

In this study you will be asked to have a discussion about your experience with cancer and spirituality. Discussions will take about 1-2 hours.

For more information or to participate contact Lisa Green at 519-954-0726 or gree2020@wlu.ca
APPENDIX B: RECRUITING FLYER

Discuss your experience
of cancer and your emotional healing

Have you been diagnosed with
cancer more than 6 months ago?

I am looking for people with a cancer diagnosis who
are willing to participate in a study about the
experiences of people with cancer and their emotional
healing process.

The study involves a discussion with the researcher
about the process of emotional healing and what role
spirituality played in this. Discussions will take about 1
hour. A small monetary incentive will be provided.

For more information or to participate contact
Lisa Green at 519-954-0726 or
gree2020@wlu.ca

Principal Investigator: Lisa Green, Master of Social Work student
Wilfrid Laurier University (Supervised by Dr. Peter Dunn)
APPENDIX C: INFORMED CONSENT FORM

WILFRID LAURIER UNIVERSITY
INFORMED CONSENT STATEMENT
Understanding and Incorporating Spirituality into Cancer Treatment
Lisa Green MSW Student (Peter Dunn PhD)

You are invited to participate in a research study. The purpose of this study is to explore and understand participants' experiences incorporating spirituality into their healing. As well I want to gain an understanding of what participants would like to see from health care professionals in terms of including spirituality into their formal treatment plan. I am a Master of Social Work student at Wilfrid Laurier University.

INFORMATION

Participants will meet individually with the investigator for an interview of approximately 1-2 hours. The interviews will be recorded using a digital recording device and the investigator will complete a reflective journal after each interview. The recorded data will be transcribed by the investigator. The journals and the transcribed data of all the interviews will be combined and coded to determine the major themes. The initial data analysis will be presented at optional presentations of 1-2 hours at each agency to which participants will be invited. 10-12 participants will be included in this study.

RISKS

The risks of the interview include discussing the sensitive and private nature of spirituality. Confidentiality will be maintained, and the investigator will be open and respectful of people's beliefs and opinions. The risks associated with the optional presentations of the analyzed data include identifying oneself as a participant in the study by attending. To try to minimize this risk, the presentations will be open to all members and staff of the agencies.

BENEFITS

This research will add to the knowledge base about how spirituality is used by people with cancer and the knowledge base of how to incorporate spirituality into health care by health care professionals.

CONFIDENTIALITY

Interviews will be conducted in a private room at the cancer support centers. The investigator will be the only person with access to the digital recordings. The recordings will be kept on the investigator's personal computer which requires a password to access. After one year the digital recordings will be deleted from the investigator's computer. Any documents with identifying participant information will be kept in a locked filing cabinet to which only the investigator has access. When presenting the analyzed data, care will be taken to remove any identifying information. Quotes may be used in both the presentation and paper, however identifying information will be removed. Participants will have the opportunity to verify and approve the use of all quotes.

CONTACT

If you have questions at any time about the study or the procedures, (or you experience adverse
effects as a result of participating in this study.*) you may contact the researcher, Lisa Green, at gree2020@wlu.ca and 519-954-0726. This project has been reviewed and approved by the University Research Ethics Board. If you feel you have not been treated according to the descriptions in this form, or your rights as a participant in research have been violated during the course of this project, you may contact Dr. Bill Marr, Chair, University Research Ethics Board, Wilfrid Laurier University, (519) 884-0710, extension 2468.

Participant’s Initials

PARTICIPATION

Your participation in this study is voluntary; you may decline to participate without penalty. If you decide to participate, you may withdraw from the study at any time without penalty and without loss of benefits to which you are otherwise entitled. If you withdraw from the study before data collection is completed your data will be returned to you or destroyed. You have the right to omit any question(s)/procedure(s) you choose.

FEEDBACK AND PUBLICATION

The initial data analysis will be presented to all of the agencies and participants if they chose to attend the presentation in the fall 2008. A final paper will also be written for the purpose of the author's thesis. Participants may receive a copy from the investigator if they wish. This paper will be available in spring 2009.

CONSENT

I have read and understand the above information. I have received a copy of this form. I agree to participate in this study.

Participant's signature ___________________________ Date _____________

Investigator's signature ___________________________ Date _____________

I agree to the use of non-identifying quotes in the presentations and the final paper, with my verification.

Participant's signature ___________________________ Date _____________

Investigator's signature ___________________________ Date _____________
APPENDIX D: PARTICIPANT QUESTIONNAIRE

Interview # _____

Gender: ____________

Ethnicity: _________

Education:  ____ Partial High school
            ____ High school
            ____ College/University
            ____ Graduate studies
            ____ Professional Designation

Age:  ____ 18-44
     ____ 45-65
     ____ 65+

Income:  ____ $0-60,000
         ____ $ 60,000-100,000
         ____ $100,000+

Religious affiliations:

Relationship Status:  ____ single
                     ____ common law
                     ____ married
                     ____ separated/Divorced
                     ____ widowed

Length of cancer diagnosis:
APPENDIX E: INTERVIEW GUIDE

1. Could you tell me about your experience with Cancer?
   - Age of diagnosis
   - Disease site
   - Status of cancer (remission, palliative, treatment)
   - Type of treatment (chemo, radiation, surgery etc.)

2. Tell me about spirituality in relation to your cancer.
   - Changes in spirituality before and after diagnosis
   - How have you used spirituality to aid your healing?

3. Tell me about the role of health care professionals in relation to your spirituality.
   - What did health care professionals do to meet your spiritual needs?
   - Which health care workers worked with you in relation to your spiritual needs (physicians, nurses, social workers, chaplains)?
   - What role, if any, did social workers play in your spiritual care?
   - How could they be more attuned to your spiritual needs?
   - What recommendations would you make to health care professionals (specifically social workers) to better meet your spiritual needs?

4. Is there anything I haven’t covered?
Samantha – I think they have to at least acknowledge that there are emotional stressors that go along with the diagnosis of cancer and, and spiritually too, like, I guess emotional and spiritual kind of relate together, but that there is that sort of questioning of your faith and your spirituality when you are diagnosed, and I don’t think that health care providers necessarily recognize that. Like I said before, they give you a list of your physical side effects that you’ll have from your chemo and your diagnosis but they don’t necessarily tell you that, you know, you may experience anxiety, you may experience depression, you may experience um, you know, questioning your faith and anger and resentment and all those kinds of things. They kind of just mention it so vaguely that when it actually happens you don’t necessarily know where to turn, you know, where to go. I think that’s why Wellspring is so good because it is a place where you can talk about those things and nobody questions why. So I think for health care providers and oncologists for them to at least mention it (laughs) that you may experience these things. Even if it’s just a little bit and kind of give you resources. And they were good about giving pamphlets on Wellspring and community support, and I mean that was okay. But them recognizing that it’s things that will happen when you are diagnosed and just giving awareness to the patient and where they can find help. Just a little more detailed than what they did.

Samantha – They did it, but it was very vague, very, you know, oh yeah, you may, this might happen and it wasn’t enough.

Samantha - yeah, well they give you a whole binder when you’re diagnosed of your physical symptoms that you’ll have. And you know that’s where you can buy your wig and where you can, you know, get make-up for cancer patients and that kind of thing. It’s all like, physical things and there’s not a whole lot about, you know, what to do if you experience anxiety or depression or um, questioning your faith, where to go for that, or where to go for help. Definitely it was much more of a physical, you know here’s all the physical things that you can experience, that you will experience, not so much on the emotional and spiritual part.

Interviewer – And so that would have been helpful if you would have known a little more about what to expect in terms of that stuff?

Samantha – Definitely. Especially for me where my physical symptoms weren’t that bad, as compared to anxiety and things like that, that I had never experienced before. And you know, just came with yeah, the medication or whatever reason.

Samantha – I think it’s (Wellspring) more personal. You know even the atmosphere of the house and that kind of thing as opposed to an office in the hospital. You know it’s just, and Wellspring gives you contacts of people who have been through the same thing as you, like the lymphoma support group where you’re talking to people who have experienced it. So I think there’s more or, there’s definitely more of that than in the hospital where, you know, you just meet with the psychologist in her office or in your room, you know, when you’re an inpatient.

Samantha – So I think Wellspring definitely gave me that which I didn’t get at the hospital. And there’s more choice of programs to take like Yoga, meditation, that kind of thing, Tai Chi, you know there’s choice. And at Wellspring, you feel more of a participant, like you’re participating more and you’re choosing what you want to do to better yourself. And you don’t get that just meeting the psychologist in her office.
Samantha – And Wellspring just, Wellspring gave that emotional support and even spiritual support, a lot more than, you know, the social worker or the psychologist at the hospital.

Samantha – Well, the programs they provide like the Healing Journey has been wonderful and the part 3 is on spirituality so it just, it gives you more practical sort of things to use and things like CD’s to help you, you know, meditate or relax or reflect. And you can take that home with you so it doesn’t just stop here in the building, it’s something that you can take home with you and it’s just, they give it to you in your hand, like you go and get the CD, whereas at the hospital with the psychologist we would just go through some visualization techniques but it wasn’t as practical and the atmosphere wasn’t as good. It just wasn’t as helpful as it is here.

Samantha – Um, I guess with what they have there, they’re sort of limited as to, I guess at Wellspring you can talk to people who have experienced it. Which maybe the psychologist or social worker could have arranged, but I guess, they are limited at the hospital with what they have. But I guess maybe they could consider contacting someone who’s experienced the same thing to meet as a peer support or something, you know. Maybe that’s something they could have done differently. Or things to take home. Like I was saying, here you can take home CD’s or books or that sort of thing, whereas at the hospital it’s hard for them to provide that, which is understandable, I mean they’re quite limited but that’s something they probably could have done differently.

Interviewer – Do you think it would have been helpful for them to kind of referred you or told you about Wellspring, or kind of in terms of, or did they ask at all about what other emotional supports and stuff you had in place?

Samantha – yeah. Um, they asked like pretty vaguely. You know, do you have a good support system with your family? Do you have help at home? Do you have friends’ support? If anything I think I brought up Wellspring because they were talking about like, techniques to help you relax and that kind of thing and I think I was the one that said oh yeah, well I kind of do that at Wellspring. And they were like oh yeah, Wellspring’s a great place, so they know about it but they weren’t really, you know, stressing it or encouraging it. You know, if anything, I was the one that kind of brought it up and they said oh yeah, that’s a good place, but they didn’t initiate a discussion about it.

Interviewer – yeah, or kind of say here’s where you can find some of these resources or anything.

Samantha – yeah, yeah and I think there was a pamphlet inside the binder that they had given me initially,

Samantha – yeah, for Wellspring, yeah actually there was, but that was kind of it, like it was just a pamphlet in there. It wasn’t really encouraged that much, it was just kind of sitting there

Lindsay - I think asking the question […] So, but I think asking. (pause) And I think you’d have to be delicate with it because I think some people would… But I think asking the question would, and if they’re not faithful then asking the question, “would it be alright if I prayed for you?” Or is there anything I could, I don’t know. But I think asking would be… I think. Or, I mean the listening skills that we’re all told to have. If someone just mentions, like I wear a cross. Make a comment on the cross and work it out that way.
Lindsay – ‘Cause some, I mean, like if there’s a sudden death, I mean people turn to faith, to fall back on faith. Being told you have cancer, would that be the time, I don’t know. (pause) I think if it was explored very gently. Then if there was something, and you could channel or put them in touch with whoever. Like I know there’s a non-denominational chapel at the hospital. I don’t know that anybody after having chemo, they wouldn’t be well enough to go upstairs. I don’t know if they would. (pause) I would explore it, but that’s me.

Scott – Um, well I’m going to be biased in that because Christ says “I am the way, the truth and the light” so I’m going to say Christ is the answer, not Islam or something else. And if I say that in a social work context I’m going to be offending someone.

Scott – Certainly the advice I would give is that’s the answer spiritually. That assurance, that knowledge of Christ and his saving grace and, and all that. And there’s a lot of, that spiritual dimension is really supportive, for us anyway. No sure that other faiths can say the same thing, they probably believe the same thing, that theirs is the right answer. But my advice of course would be to have the Christian element throughout the social system. You know and that would really make a difference. But like I say, that’s going to be a biased opinion, but...

John – okay. I think it’s important that social workers or, or anyone who’s involved in the person’s life that way, supportively, are open, are aware of that, of the spiritual connection. And that it could, could, um, assist in the healing. Because it is a very deep piece right. I mean, medical model is great, they can give you all kinds of support there but, if you can get to a person on the inside and get them, like for me, connecting on the inside (cough) and connecting on a spiritual level, really really I believe was my strength. Um, but had somebody you know, been there and encouraged me along, say at the hospital level, and it, it would have been, probably more helpful than doing it alone at the hospital. Um…I mean they were good, um, naturally good just being supportive and “you’ll be fine,” things like that. “you’re okay, you don’t have to worry. There was no, it was very general support. So I think if a social worker were to come in, or someone, and ask, you know, do you have any spiritual connection? Do you, is there a side of you that’s… Then they can find out right? If a patient is actually open to that or not. You can’t impose it on people, but you can explore it, see where it... what kind of spiritual side they have. And then if they have one, then you can help them lean into that for strength. ‘Cause certainly that’s where I went. I mean, there was no talk probably that would have helped, it was the spiritual connection that got me through it.

John – That would have been hard, I mean, what I would have probably, if I hadn’t been involved in a church and I was just an inpatient and getting support around that, you know cancer. I would have liked to have had someone come to me and explore my own spirituality. Very openly make it a point of interest. ‘Cause you know they do cover all the other aspects of your life you know family, next of kin, all that kind of fun stuff. But yet they don’t touch on the spiritual side and it’s an important piece of your personhood. I mean we’re holistic people, to touch on all aspects of a person’s life would probably be a very helpful model to follow in a hospital setting. Yeah. I think it’s something to, I mean that piece around, I mentioned checking the box. I think it’s standard in most hospitals. Especially in hospitals that are not any particular denomination, like Catholic
hospitals naturally they will come visit you. But if you’re in a, in a generic hospital like KW, Grand River, it’s open to everyone. And I think there you have to actually sign on the dotted line if you want a visit. Cambridge Memorial is similar to that. My friend is a chaplin there. People get visits because they check the box. and um, then you know, the chaplin will come and visit. So having that kind of clarity on an application, or on the intake form. More questions about that would probably be helpful.

**Interviewer** – what do you mean by more questions?

**John** – Well, questions, rather than just would you like a visit from the Chaplin? Um you know, questions around do you, are you connected with a church or a faith organization? And do you , um, is your faith important in your life? More along those lines. And then in that questionnaire, a person could look at it and see, maybe this person might benefit from a visit, rather than just a yes no question. Even if the yes, no question wasn’t so clear, so strong. ‘Cause if it’s strong and no, you can’t go in. You’re imposing. But if it’s more general, and maybe four or five questions, to try to feel out where the person is. And so you can, in their crisis, know that they might actually benefit from a conversation. I mean even as you go in to visit, if you’ve got a questionnaire that’s got five questions that covers the person’s spiritual side. And if in those five questions you get a sense that wow, this person has a real spiritual connection or has had one, I wonder where it is today? And are they even thinking to lean into that? And that could be, you know, a direction that could help you for exploring, ways to go in and meet with the person. Whether or not... you’re not going to expose them to a religion or spirituality or even impose it on them but just in a general kind of way. Bring it up in conversation. You’d be surprised how many people might want to talk about God or spirituality in crisis times. And if they said no in that box, they may have said no because they don’t want to be you know, proselytized in the church or in the hospital, right. “I don’t want anybody preaching at me while I’m sick in bed,” could be what they are thinking. “I don’t want to be bothered by you know religion. I’ve got more than enough to deal with right now.” They’re not thinking along the lines of your, it, being a positive thing.

**John** - Maybe the physicians could be a little more sensitive around the smaller pieces of, around the smaller diagnoses. ‘Cause you know they say skin cancer, it’s supposed to be minor in terms of the bigger cancers, you know.. But the person receiving the news, it’s major. There’s nothing minor about it. Whether it’s on the tip of your finger or full blown lung cancer, it’s still cancer. And it still has the same fear factor. As far as I’m concerned so...

**Christine** - Where if they could maybe incorporate it either sooner, or talk to you about maybe wanting to bring meditation in to your treatment regimen, but not when you’re sitting in the chair. Like those are things that if you knew, I don’t know, I just think that you could prepare yourself better ahead of time before the treatment and maybe if you had the knowledge of what she was trying to offer a week before

**Interviewer** – so you’re saying that should have been more ...

**Christine** – preliminary

**Interviewer** – ... programming or whatever around how to deal with what might come so that when you were actually in the situation?

**Christine** – right
Christine – What can I, what recommendations can I make that would improve the care? And I would say other than the component where you’re just, you know, you go for your last radiation treatment and you don’t know anything, um, beyond that, like, other than having to accidentally run into one of my former supportive care nurses, that’s the only reason I know what to expect on my next appointment or in the mail.

Christine – okay. Right, like I kinda think you need to move this house, (Hopespring) into the hospital. That’s what I think.

Christine - The whole, I think there needs to be a more spiritual aspect to it. There is a huge disconnect between the medical profession and sort of, I don’t know if you would call it a holistic or a complementary medicine. Now I’m a big believer in complementary medicine, but I do think services like what we get here could be used at the hospital. I think you would reach a lot more people ‘cause I don’t think there’s that many people that come here. When I go to my laugh and lymphersize for women that have had lymph nodes removed, there’s like 4 people, and one time it was my mom and me and another lady. Like, and how many women have breast cancer?

Christine– And I feel that way about emotional looking, or servicing the patients emotionally. Because I don’t, there are no programs set up, well I don’t feel there are any programs set up in the hospital to deal with emotional. Because your emotions run the gamut, right, during this whole thing. So one minute you’re up, the next minute you’re down. Your doctor is doing everything they can medically to sort of deal with your fears, but um, I even find that they don’t deal with depression. I don’t know if I had depression, but your down days, they don’t really deal with your depression. And if you, I was told if I wanted, you know ‘cause your sleep is disrupted you know and everything is. Your hormones are all out of whack and to go to my GP. So um, like I just think that you sort of need to simplify things ‘cause when you’re going through like a health care, like when you’re sick, you don’t want to be going everywhere right?.

Christine - But the emotional needs aren’t met. I had to look elsewhere, outside of the hospital for the emotional needs. So that being your peer support,

Christine - So um, and then, the programs that are offered here, like the meditation and, the relaxation techniques that are offered here at Hopespring really benefited me.

Interviewer – mmhmm. And you think they would probably benefit others if they were provided in a bigger...

Christine – Right, like I think that would help if they were offered at the hospital. I also think they could have, I think they could change the environment a little more as well, I think they could have, like, more plants and maybe have relaxing music playing in the hospital. More sort of tactile or visual things. I know they’ve got quilts from the quilters guild. Like I know they have those things, but sometimes, like even in the treatment rooms, well they did have music in the chemo suite and I know they’ve really tried to set that up well. They listen to patients, and it is set up fairly well, but um, I think if they could have more visual things, like in the radiation room when you’re lying flat on your back and maybe have something on the ceiling or you know, just a lot more visual things would help as well as, actual people in there for emotional support to maybe help you with meditation or visualization right?. When you are getting your treatments, if you can visualize being in a meadow or a lake or whatever’s calming for you. Like I think if people could learn those things, then I think that would help as well. I’m trying to think of what else I thought of. Definitely I think that’s an aspect that’s missing. In as much as
they’ve tried to make it patient friendly, I think there are other things um, such as music and visualization techniques, meditation techniques and....

**Sarah** – mmmhm. Well I would say the Healing Journey, even the one program at Hopespring. That gives you a little bit of meditation, little bit of mindfulness, I can’t remember what else was in there, visualization you know, like bad, getting rid of the stuff. That’s good. I would suggest the Wellfit program, I don’t know if you would call that spiritual needs, but I just found that was a really positive thing to go through. And especially when you’re knocked down far, they built up your self-esteem. I think that was really helpful.

**Sarah** – Well I tell people Wellfit and like the Healing Journey was really really good. And connecting with other people and maybe that’s just the way I am is that I need to connect and walk with other people along the journey.

**Sarah** – And it was a book, a booklet and I gave it to the Social Worker and I said we need to do this here. Because what it is, is what to expect afterwards.

**Sarah** – But I went once, the oncologist talked about, you know, what it means, because you don’t find out, and I never got told what my follow up would be. I got a letter that told me what it was about. And you know, my radiation, I was discouraged by my radiation oncologist because, he had a tough year, he’s the one that lost his daughter so he was all messed up for a while. Like sometimes I’d go down and he was like Jekyll and Hyde, he’d be really nice one minute, and the next he’d be like (rrrr!) and I’d be like whoooo, buddy, you know. He was going through some pretty significant personal stuff. And no, but those were really good. One time an oncologist spoke, one time a social worker talked about depression and feelings and so it normalized you. It’s not like I’m some, you think you’re some freak that’s going through this, but everybody has these same type of different emotions, so...

**Sarah** – They were really really well done. Actually, we drove to Hamilton and I drive all over the place to get, but when I’ve heard, and if it’s helpful then I like to go and see what it’s about. So I would recommend those types of programs would be good. Feelings and emotions and I think the title was “Adjusting to the New Normal” was one. There was one we didn’t get to go to but it was on sexuality. And it was, he’s actually a, he’s the only OHIP sexual therapist in Ontario, he’s at the Juravinski Cancer Centre. There was one on hot flashes, but I don’t have menopausal symptoms so I’m not doing Tamoxifen so I didn’t go to that one. We went down to about 4 of them But I can’t remember what the other ones were. The oncologist was...

**Sarah** – And I can’t remember what the other ones were. Yeah, I can’t remember but they were all really well done and you know it was only an hour and they did it, you know, like in the lobby of the cancer centre. Just in the waiting area, but it was at night, like maybe 6:30 or 7 for an hour, hour and a half. And it was good because then you’re covering all those things too. The other thing that was comforting about that was he did talk about chemotherapy. In Hamilton they’re treating women the same way they are treated in Kitchener and to me that was comforting, to know that they aren’t doing something differently or better you know like... you’re getting the same treatment...right. So in knowing that. And the other thing was the oncologist talked about the numbers ‘cause you know they give you all these, well if you do this type of
chemotherapy then here's your number, blah blah blah, but he explained where the numbers come from.

**Greg** – I think what I would suggest is I would have a person that that is what they do, that that is part of, like whether it be a psychologist or a social worker, someone dealing in, I'm going to say theology, they'd have to be very broad minded in that. But definitely you know, social workers, psychotherapists, whatever, I think they actually need to be part of the team. Particularly with something as ah, with the diagnosis of cancer but not just cancer but heart disease, some of the very major medical diseases that we have. I think that there should be the social worker element there, I think that really needs to be there. No one could sort of say, well it is there, the trouble is though, I never saw one. It never happened for me. I was the one that had to go out and access that. Like in other words I, you know, I went to see a psychotherapist, actually a social worker now and I'm still working with her and on a one to one basis. So that is what I would like to see as part of the treatment is where I think that in my opinion, social workers, anything to do with emotions regardless of whatever that is, there should be that person there. Like in other words, we send, you know, my medical doctor sent me to a urologist. Okay that's fine. But because of cancer is being diagnosed, I think there needs to be this far more broad opportunity for people to access the social worker. It needs to happen, that's what I would like to see. And also, like in other words, it used to be asked, like in other words, you know do you have a church; are you not in a church, do you feel the need for that? I think that needs to be asked. Like for myself, yes I work for a church, I'm not necessarily, say I'm a Christian, I'm not sure what I am. But I think that should, those are questions that need to be asked also. Like in other words, and it also needs to start at the very grass roots. Like in other words when a person comes in for an examination, let's look at the physical, the emotional aspect of the individual, even their beliefs because that is part of the human package.

**Greg** – That is where I think it really needs, and then branch out from there. And when a serious illness does occur for an individual whatever that may be. I believe the social worker then, that's when I believe they need to be part of all this team. I think health care, I think it's on the right track, I just don't think it's anywhere near where I think it needs to go. And that is the entire package. You know the health, the emotional body, spirit, emotions. That, I believe, is where we need the total holistic view. So...

**Greg** - And there's also all of that, I think we're on the right route, but we just haven't gotten there yet, and we still have a long, long way to go. With that because we need to get out of that, what I call that clinical factories of health care. Where its, where it's the entire being that's looked at.

**Greg** – And therefore then, spirituality becomes all part and parcel of that. Yeah.

**Greg** – I think they would have to be part of the whole system, the team. I guess I sort of look at it as the team. They'd have to be in the very early stages of it. Like in other words when I was first diagnosed with the prostate cancer, I think that at that point, yes let's look at the treatment here, but let's also you know, let's look at, let's deal with the emotional aspects of that. Because the two are totally tied in together in that. In fact it's the emotional aspects that really make it far worse than what the physical aspect because it's the terror. And so how does one deal with the terror, how am I coping with this? Do I have coping skills? If I don't then where can I get them? Like Hopespring here has a
tremendous, um, what can I say, support system here because the tools for the healing journey so that is all there. Now, I have to say I’m going to be somewhat arrogant here, well I knew most of this stuff before, I just hadn’t tapped into it. But I think I’m somewhat the exception, particularly in a man, it’s an exception that I’m the actual, the reality of most men, and that is the fact that many men I don’t think have great coping skills. Or if they do they’re not sure how to tap into this, so I think that the team, the social worker would be part of the team. And then you deal then with the emotional aspects of this because when you deal with the emotional aspects of it then it’s far easier then to be um, look at choices and options as far as what treatment am I going to go? If I have that option, like there are some that don’t have an option, you know they really and truly don’t.

**Greg** - So it’s sort of where there needs to be, as I say, this goes back to the team making, so in other words, are you okay? Is someone checking up on you or, and whatever. Because I think that when we’re given this sort of life crisis, whatever that may be and however severe it is, where do you turn to? Like we’re not, because we’re a society that’s shifted community and whatever it is, because there’s many, you know, we’re strangers to everybody in most cases. And we’re so fragmented as far as, you know, connecting with people. I think that that’s absolutely crucial. I think that we need to bring that into for the individual and have that there with the team and that. And it needs to start right at the beginning.

**Greg** – that’s right. connected with, yes yes. And also, as I say, and also you know when you go for your physical examination you know like, how are you emotionally? Do you see a psychologist do you see a social worker? How do you deal with this? I think that’s absolutely crucial. Ah, your spiritual well being. Do you, how do you participate in your spirituality? You know like if you just go for a walk and you’re with nature, that’s one way of doing it, you know. Oh like I go to a church. That’s fine too. So I think it really needs to be right from the beginning and as I say then it’s already in place for the individual when the crisis happens.
REFERENCES


