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Cancer Survivorship

**Exploring the relationships among Gender,
Religion, Spirituality, Health Behaviours and
the Quality of Life of Cancer Survivors**

A thesis presented in partial fulfilment of the requirements for
the Master of Arts in Psychology at Massey University,
Palmerston North, New Zealand

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ABSTRACT

More people are surviving cancer now than ever before and research with cancer survivors has grown considerably. International research has identified that the cancer experience does not end when treatment ends, but instead is a journey that can continue to weave a complex and multifaceted path that can collide with numerous domains of an individual's life. Many factors have been identified within the cancer experience that can impact on an individual's quality of life for the rest of their life. Factors such as, type and stage at diagnosis of cancer, treatment, social support, ethnicity, socioeconomic status, employment, health behaviours, gender and religious and spiritual beliefs.

The purpose of this study was to investigate the factors that can influence the quality of life of those who have had cancer in the New Zealand population. The particular focus was the differences between males and females and those who identify as Religious or Spiritual, the health behaviours of cancer survivors were also investigated.

The study analysed data from the Health Work and Retirement 2006, 2008 and 2010 surveys, which collected data from over 6000 New Zealanders aged from 55 to 75 years. This group was seen to provide a good representation of those who have had cancer in their lifetime.

Results from this study were varied, supporting as well as contradicting overseas research. No differences in gender and quality of life were identified, however males were found to consume more alcohol and exercise more frequently. Females reported to be more religious and spiritual than males. Religion did not impact on quality of life however spiritual activities impacted negatively on physical health. Over time religion and spirituality contributed to improved mental health. A mediating relationship was identified with those who participate in more spiritual activities consuming less alcohol and in turn have poorer quality of life.

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CHAPTER ONE: THE CANCER SURVIVOR

1.0 Introduction

This chapter looks at cancer and cancer survivorship in New Zealand. Cancer shows no prejudice and can strike anyone at any point in their life. The word itself “cancer” is a word that can often evoke a range of strong emotions, instilling absolute fear not only in those who have received the dreaded diagnosis but also their family and friends. However “survivor” is now another word that has entered the world of cancer, and due to advancements in medicine, more people are now conquering this disease and going on to live for years or even decades after their original diagnosis. This chapter will therefore take a look at cancer, what it is, its effects, and why it is now important for research to start focusing on those who are winning the war against cancer. This will be followed by a discussion on what it is to be a cancer survivor and the emerging field of cancer survivorship.

1.1 Why cancer survivor research?

New Zealand is a country that is very much affected by cancer. In the year 2000, research revealed that New Zealand had the second highest incidence of cancer in the world (Parkin, F.Bray, J.Ferlay, & P.Pisani, 2001) placing cancer as one of the leading causes of death (New Zealand Cancer Society, 2003). Due to improved detection methods and more advanced treatment, a lot of people are now successfully defeating the disease and as a result the population of cancer survivors is potentially increasing. To add to this, it estimated that by 2026, those over 65 will make up approximately 20% of the population of New Zealand, thus potentially further increasing the pool of cancer survivors (Statistics New Zealand, 2006b). In order to ensure a good quality of life (QoL) for all New Zealanders it would be prudent to consider the issues that our aging population may face and in turn that of its cancer survivors.

According to the National Cancer Institute, (2008), (National Cancer Institute, 2008) around 3.5% of the United States population are cancer survivors; approximately 11 million Americans. They project that in the future 75% of American families will have a relative who is or will be diagnosed with cancer and 65% of adults who are diagnosed will be alive after 5 years. In response to the growth of people being affected by cancer, cancer survivorship research in the United States has been steadily growing over the last twenty years (Morgan, 2011). The National Coalition for Cancer Survivorship (NCCS) was established in 1986 specifically for the purpose of serving cancer survivors needs. Following in the coalitions wake, various other organisations in the United States have emerged promoting the needs of cancer survivors such as the Lance Armstrong Foundation, *LiveStrong*, which dedicates research to this special cohort of people. Even though there has been progress in cancer survivorship research in the United States, there has been very little research carried out in New Zealand. New Zealand's aging population combined with high rates of cancer highlights that cancer survivorship is a topic that perhaps needs more attention if we are to ensure that this expanding group of people are to have a good QoL for the rest of their life.

Cancer along with its treatment can impact on an individual's QoL. Treatment for cancer usually involves highly toxic chemicals and radiation to destroy the cancer cells; however these successful cancer eradicating treatments are also destroying healthy non cancer cells leaving a residue of issues for the survivor which can consequently compromise the opportunity of being able to have a good QoL in the long term. For that reason more research looking at the QoL of cancer survivors post treatment could influence professionals and further inform treatment options for the cancer patient, which in turn can have a significant impact on an individual's future QoL. By carrying out research on various factors that impact on cancer survivors QoL, medical professionals, patients and families may be more informed when making decisions regarding treatment, such as including more time to discuss potential risks and complications that can affect an individual prior to selecting for treatment. Issues that have been found to be important are fertility and testing for hereditary cancer (Hoffman & Stovall, 2006). This process of providing more information to the cancer patient could not only prepare the cancer patient more

adequately, but also more information can give back some of the control that has been so abruptly taken away from when an individual has been diagnosed with cancer. Morgan (2011) supports this idea by indicating that survivors who are more informed about their options may believe they have some control over the decisions that are being made and this will in turn provide a sense of control which can contribute to generally having higher QoL.

Research into cancer survivorship can not only assist us dealing with the growing population of survivors and also influencing pre treatment considerations, but also further research in this area can prepare professionals, survivors and their families for the future challenges that they may face. Research has shown that cancer survivors have to contend with many issues that could impact on their QoL. Such issues range from late effects from cancer and or treatment including psychosocial concerns, social problems, employment and insurance issues and discrimination (Herzog & Wright, 2007). The literature has indicated that compared with individuals who have no history of cancer, cancer survivors are more likely to develop progressive, recurrent and secondary cancers, cardiovascular disease and other chronic conditions (Foster, Wright, Hill, Hopkinson, & Roffe, 2009). Additionally older adults are already coping with decreased functional decline and the risk of this being perpetuated is increased with those have had a history of cancer (Mosher et al., 2009).

Cancer survivors have reported to feel like warriors without a war when treatment has ended and they are no longer in regular contact with the health care system (Morgan, 2011). The Institute of Medicine has published various recommendations in the area of cancer survivorship, one recommendation in their 2005 report being the urgent need for more research initiatives focused on cancer survivorship care and ensuring that programmes are created to provide appropriate survivorship care based on evidence based research and practice guidelines. By carrying out research on those who survive we are better positioned to inform the community on how we can best support this group in achieving a good QoL. Reasons that cancer survivors are at an increased risk of developing further health problems may be due to cancer related treatment, genetic predisposition or lifestyle factors (Mosher et al., 2009). Continuing care for this group should be focused on but is still only in the early

stages of refining. Continuing care could include surveillance for reoccurrence, health promotion, disease prevention and monitoring or preventing late treatment related effects and subsequent impacts on QoL (Bloom, 2002). In 2004, the President's Cancer Panel discussed survivorship issues in *Living Beyond Cancer: Finding a New Balance* (Reuben, 2004), which acknowledged that long term and late effects of cancer or it's treatment can occur many years after treatment has ended; meaning that more people could be thrust back into the health system for other medical issues (Reuben, 2004).

As mentioned, due to the advances in drug treatment cancer is now slowly shedding its status as a terminal illness and is becoming more defined as a chronic condition that requires treatment, monitoring and lifestyle adjustments (Pryce, Munir, & Haslam, 2006). Now cancer is becoming more of a chronic condition as opposed to a death sentence, survival is a very real prognosis, but how well can an individual live this survival? More research around survivorship issues could not only influence pre-treatment considerations and aftercare, but research of this nature will also equip New Zealand with more knowledge of its cancer survivors. The knowledge from doing research in this area will assist in policy making and funding that could help to improve the QoL of the growing population in New Zealand of those who have survived cancer. More knowledge, awareness and action will help to give cancer survivors in New Zealand the best possible chance they can have at having a good QoL, for the remainder of their life.

1.2 What is cancer?

"Growth for the sake of growth is the ideology of the cancer cell" Edward Abbey's description of cancer (Abbey, 1988).

Cancer is not one disease but is more of an umbrella term used for many diseases where normal cells become abnormal in the body (New Zealand Cancer Society, 2003). The human body consists of billions of cells which are constantly making new cells to grow and to replace worn out or damaged cells. All cells reproduce by dividing which is a process that is more rapid in childhood when a person experiences more growth. The National Cancer Institute explains how sometimes for

reasons that are still not really understood, a cell can perform an abnormal action. It can start dividing uncontrollably, forming a group of abnormal cells which just keeps spiralling out of control. When cells like this multiply, they form a mass called a tumour which can then go on to invade and destroy normal tissue. In some instances the cancer cells can even break away from the original (primary) cancer and travel to other parts of the body through the blood or the lymph system and may form new colonies of abnormal cells. This new colony formation is referred to as secondary cancer or metastases (The New Zealand Cancer Control Trust, 2005).

The tumour is a lump formed by the cancer cells and there are two kinds; benign tumours which are not cancerous and malignant tumours that are cancerous. As a result there are more than a hundred types of cancers from which a person can suffer which are further grouped into three main categories (The New Zealand Cancer Control Trust, 2005).

1. Carcinomas, which occur in the lining of the body's external and internal surface like the skin and mouth.
2. Sarcomas, which form in the connective tissues like the muscles and bones.
3. Leukaemia's and lymphomas, which occur in the bone marrow and lymph glands.

In addition to the type of cancer, the stage at which the cancer is detected plays a detrimental part in survival (Clark & Stovall, 1996). The National Cancer Institute explains how cancer can be diagnosed in stages which describe the severity of a person's cancer based on the extent of the primary tumour and whether the tumour has spread to other parts of the body. The staging process is important for not only for treatment but also in estimating the person's prognosis. The common elements considered in staging are the site of the original tumour, size and number of tumours, lymph node involvement and cell type, tumour grade and the presence or absence of metastases (Bartels, 2009). There are a few different staging systems which depending on how severe the cancer is when diagnosed, will in turn affect the survival potential of a person. For those cancers that are diagnosed when the cancer is very mature, the chances of survival are harder. Of all the different types of cancer, some present with very few symptoms which don't alert the person to the

problem which in turn leads to a late diagnosis which is common for ovarian, esophageal and pancreatic cancer. Due to health promotion schemes and better research around detection most cancers however can be diagnosed early, therefore making survival more of a reality and a diagnosis of cancer less of a death sentence.

The exact cause of cancer still remains relatively unknown; however there has been evidence to link some factors to cancer. Such risk factors can be behavioural, biological, environmental or genetic (New Zealand Cancer Society, 2003). Specific risk factors that have been identified are; age, tobacco, sunlight, ionizing radiation, certain chemicals, some viruses and bacteria, certain hormones, family history, alcohol, obesity, aging and poor diet (National Cancer Institute, 2008). The New Zealand Cancer Society claims that it is thought that 80% of the cause of all cancers is related to lifestyle and environmental factors with cigarette smoking being responsible for about 25% of all cancer deaths in New Zealand (New Zealand Cancer Society, 2003). There has been a lot of research on this area however there have been no definitive answers yet.

1.2.1 Treatment

“My veins are filled, once a week with a Neapolitan carpet cleaner distilled from the Adriatic and I am as bald as an egg. However I still get around and am mean to cats.”- John Cheever, letter to Philip Roth, 10 May 1982, published in The Letters of John Cheever, 1989, concerning his cancer and its treatment (Cheever, 1989).

Modern treatment has contributed to cancer becoming more of a chronic disease as opposed to a fatal illness. Due to the frequent use of the multidisciplinary approach to cancer treatment, including therapies such as surgery, radiotherapy and chemotherapy, people are winning the war against cancer. However with each treatment there can be associated unwanted late effects which can evolve over time and present even decades later years after treatment (Bartels, 2009). Therefore as the number of survivors increase, so does the number of individuals experiencing the potential late effects of treatment. Like most battles, war wounds last a life time and research has indicated that treatment can have a very profound effect in the long term on a person’s physical and psychological well being, affecting their QoL (Mols et al.,

2007). Julia H. Rowland, Ph.D. the Director of the Cancer Survivorship Office stated, "Unfortunately for many cancer survivors and those around them, the effect of cancer does not end with the last treatment; once a cancer patient always a cancer patient" (Rowland, 2004).

Today most cancers are treated with either, chemotherapy, radiation therapy, surgery or a combination of the three. The various treatments have proved to be very effective and in some cases are able to completely eradicate cancer. As a result the advances in treatments over the years have contributed to the growing survival rate of cancer patients (DeBoer, Taskila, Ojajarvi, Dijk, & Verbeek, 2009). The various types of treatment are described in more detail below.

Radiation therapy/ Haumanu Irauke is where high energy radiation is used to shrink tumours killing cancer cells. About half of all cancer patients receive some type of radiation therapy during their treatment (Aziz, 2009). Radiation is given to the patient to either eliminate the cancer, prevent reoccurrence or as a palliative intent. It is sometimes used in combination with chemotherapy and surgery. The radiation kills cancer cells by damaging their DNA, the radiation can either damage DNA directly or create charged particles, commonly known as free radicals, within the cells which can in turn damage the DNA of the cell (Schulz-Ertner, Jäkel, & Schlegel, 2006). When the cancer cell is damaged through this process it dies and stops dividing and the body's natural processes eliminate it. Unfortunately radiation therapy can also damage normal cells, which is what leads to the side effects. Radiation therapy can cause both early and late effects which can be experienced months or even years later (Bartels, 2009). These effects depend on where on the body the treatment was given and the size of the dose. Early effects are caused by damage to rapidly dividing normal cells that are in the area that is being treated and include things like damage to the targeted region, skin irritation, hair loss, nausea, fatigue and urinary problems. Most of these types of effects disappear after treatment is ceased. However there are some effects that may occur later on long after treatment has finished and can make an appearance from six months after treatment is over. Some of these identified effects are, fibrosis, damage to bowels, memory loss, infertility and a secondary cancer just to mention a few (Ganz, 2001). In

addition to this, the person's lifestyle choices such as smoking or diet can also perpetuate any late effects (Bartels, 2009).

Chemotherapy/ Hahau, can mean the use of any drug to treat any disease; however it is more associated today with drugs used to treat cancer. When you look at the origins of chemotherapy for cancer it is not surprising the word has negative connotations. The first drug used for cancer chemotherapy was not actually used as a medicine but as a weapon in chemical warfare during World War I (Papac, 2001). Mustard gas, which was used in both world wars, was found to destroy white blood cells and therefore doctors reasoned that perhaps this would work for patients with advanced lymphomas. The effect of this treatment was groundbreaking and led researchers down the path to finding other such substances to combat cancer. Today there are more than 100 drugs used in chemotherapy (Morgan, 2011). Unlike surgery and radiation therapy, chemotherapy is not localised but travels through the body in search of its target which can explain the side effects a patient experiences. Chemotherapy works by stopping or slowing the growth of cancer cells (Papac, 2001). However, like radiation therapy, chemotherapy can also harm normal cells and the drugs cannot tell the difference between a reproducing cell or normal tissues and cancer cells. Some common side effects are fatigue, nausea, vomiting, hair loss, mouth sores and decreased blood cell counts. These effects can last whilst on treatment or linger for months or even years (Aziz, 2007). It is therefore a balance for medical professionals to administer chemotherapy that will destroy the cancer cells but at the same time trying to spare as many normal cells as possible to lessen the effects. There have been some studies which are revealing that patients who received chemotherapy experience worse psychological and social well-being and Health Related Quality of Life (HRQL) than patients who had not gone through chemotherapy (Blanchard, Courneya, & Stein, 2008). The long term effects of treatment are not always discussed, and research is trying to ascertain the effects of treatments, however looking at survivors who were treated 20 to 30 years ago may not provide relevant information for those today going through chemotherapy due to the rapid advances in drugs. Work is continuing to improve the type of drugs available and one promising new drug therapy is that of targeted therapy (Ganz, 2001) which is where the chemotherapy directly targets the cancer cells without

damaging the normal health cells which would in turn minimise immediate side effects and possibly late effects.

Surgery is quite common and has many purposes in that it can be used to diagnose, treat, or even help prevent cancer in some cases. Surgery has proved to be a very effective form of treatment, preventing a cancer from spreading at the same time as preserving normal tissue and function (Morgan, 2011). Other types of therapies that are used are, immunotherapy, bone marrow and peripheral blood stem cell transplant, photodynamic therapy, lasers, hormone replacement therapy and hormonal treatment (Morgan, 2011).

1.3 Who is the cancer survivor?

So what does it mean to be a cancer survivor? Over the years there has been some debate as to the definition of a cancer survivor and it appears that the definition is still a work in progress (Feuerstein, 2007). To a layman the term “cancer survivor” may suggest a person who has defeated their cancer. But in reviewing the literature it has become apparent that researchers and organisers have come up with a variety of definitions to suit various purposes such as disease statistics, advocacy and policy making. There is perhaps inconsistency with the term that lacks an evidence base. The term “cancer survivor” was first coined in 1985 in an essay in the *New England Journal of Medicine* by Dr Fitzhugh Mullan. He wrote of his own cancer and what it was like to pass through the “seasons of survival”. Survival for him starts at the point of diagnosis as that is the time when those with cancer are forced to confront their own mortality and will need to make alterations in their present and future (Leigh & Logan, 1991). In 1986 the National Cancer Cervical Coalition (NCCC) came up with the term “survivor” and the word was used in order to empower people to take more control in regards to their care (Twombly, 2006). This term also included families and caregivers of those with cancer since it has such a profound effect on all. The Centre for Disease Control and Prevention, (2008), also includes others affected by the diagnoses such as family members as does the *Livestrong/Lance Armstrong Foundation* (Kelly, Shah, Shedlosky-Shoemaker, Porter, & Agnese, 2011). Family members are not survivors in the same way as those who have had cancer, however this group cannot be totally dismissed as they not only play an important part in a

cancer survivor's journey but they may also undertake a personal journey themselves and therefore have needs. Feurstein (2007) however felt that including families in the definition broadens 'cancer survivor' too much, diverting scientific attention away from the need to better understand the epidemiology of the person with cancer. Other organisations that have come up with definitions are The National Cancer Institute which defines someone as a survivor of cancer from the time of diagnosis throughout the rest of his or her life. Leigh and Logan (1991), and Clark and Stovall (1996), and the National Coalition for Cancer Survivorship also use this definition. In Little, Paul, Jordens and Sayers (2002), they preferred to define a survivor as someone who is living free of cancer after treatment. The American Cancer Society is unique from the definitions above in stating that the definition is up to the individual; each individual has the right to define their own experience with cancer and they consider a cancer survivor to be anyone who defines themselves this way from the time of diagnosis throughout the balance of their life. The American Cancer society offers a further definition of those who have survived Five years from diagnosis as long term survivors (Mols et al., 2007). Also to be considered is that of how other countries and cultures define those who have lived with cancer. Cancer may be viewed differently between cultures and therefore have a whole set of different definitions to describe the experience of the individual.

The terminology to describe those who have beaten their cancers refers not only to the physical but also the social, psychological, spiritual and existential impact of cancer on one's life for the remainder of one's life (Parkin et al., 2001). Looking at all of those people who have cancer, regardless of where they are at in the cancer journey, will provide a better understanding of the natural history of cancer survivorship.

1.4 Cancer survivorship

One of the pioneers of cancer survivorship was Dr Fitzhugh Mullan who described cancer survivorship in relation to seasons of the year. Mullan's view of survivorship is as a "phenomenon" or "experience" with phases. He proposed the need for a new paradigm or way of viewing "surviving with cancer." He argued that "Survivorship" needed to be seen as a notion that can be utilised to help describe, explain, better

manage and prevent the multitude of challenges that those living with a diagnosis of cancer face. Survivorship is a working concept in transition; a way to organize a body of knowledge that will improve over time and ideally impact the health and well being of those diagnosed with and treated for cancer. His three seasons of survival are, acute, extended survival and permanent survival (Aziz, 2007).

Stage One

Acute Survival is diagnosis to the first year. Patients may be facing acute and potential losses as a result of disruptions in family and social roles. They may experience challenges in managing their finances, acute side effects from treatment, and fear of the possibility of death.

Stage Two

Extended Survival stage is the end of first year until three years later. The probability of recurrence is the greatest for most cancers during this stage. Survivors may have periodic examinations or intermittent therapy during this stage, or their condition may be terminal. Cancer survivors may have ambiguous feelings about being alive while dealing with the uncertainty of treatment outcomes, fear of recurrence, or possibly impending death. They may be negotiating physical and psychosocial compromises (Morgan, 2011).

Stage Three

During permanent Survival extends from three years, the probability of recurrence diminishes. General problems are lack of energy, relationship issues, reintegrating into society and late effects of therapy become prominent concerns (Bloom, Peterson, & Kang, 2007) . Diminished probability for recurrence exists, and survivors in this stage may face long-term or late effects of the disease and therapy. Potential challenges they may be confronted with are such issues like workplace discrimination and insurance issues (Morgan, 2011).

Survivorship has been generally under theorized however there is consensus that the long term psychosocial concerns of survivors should be addressed alongside

physiological consequences (Foster et al., 2009) Survivorship is a multidimensional concept involving physical, psychological, social and spiritual aspects of life. The seasons of survival have been referred to in various research and have provided a back bone for cancer survivorship research. Aziz (2007) built on this framework looking at what he terms as late versus long term effects. Long term survivors are defined as those who are five years or more beyond the diagnoses of their cancer and are considered in the permanent season by Mullan. Late effects refer to unrecognised toxicities that are absent or sub clinical at the end of therapy and become manifested later with the unmasking of unseen injury due to either developmental processes, failure of mechanisms with passage of time or organ senescence. Aziz also refers to any side effects or complications of treatment as persistent effects, these are effects that begin during treatment and continue beyond the end of treatment. Late and long term effects can be further broken down and defined. System specific - effects are damage, failure or premature aging of organs or compressed immune systems. Second malignant neoplasms – are increased risk of certain cancers associated with primary cancer or cytotoxic or radiological cancer therapies. Functional changes include pain syndromes, fatigue and lymphedema. Cosmetic changes include amputations, skin or hair alterations and associated comorbidities such as osteoporosis, arthritis and hypertension (Aziz, 2007).

Surviving cancer past five years is now not considered being lucky but more of a reality. Many forms of cancers have become essentially like chronic conditions where survival is not the issue but more so achieving a good QoL with the disease. As acute, extended, and permanent survival blur into a prolonged condition, survivors are left with a QoL indiscriminately signed by an ineradicable disease.

CHAPTER TWO: QUALITY OF LIFE IN CANCER SURVIVORS

2.0 Introduction

Due to research and advances in technology, the prospect of surviving cancer is now a real possibility for a lot of people. However the fight against cancer is perhaps not finished after completing successful treatment and gaining remission status.

Research has found that the Quality of Life (QoL) of those who have been through the cancer journey is complex with multiple factors interacting and impacting on their QoL. Essentially, one's life is turned upside down in many ways when cancer strikes, causing a ripple of effects where the cancer experience can potentially invade all domains within a cancer survivor's world. Areas potentially affected are a person's physical and psychological health, family, social relationships, religious/spiritual beliefs, employment and finances. Every person's experience of cancer is different and these various factors along with a person's age, gender and socio-economic status can further add to and extend the battle with cancer. Issues like these are therefore important to look at in order to get a clearer understanding of what can threaten cancer survivors' QoL. In turn more information can equip cancer survivors, families and professionals with more ammunition to beat this disease once and for all. By looking at QoL in cancer survivors, the multiple aspects of cancer's impact on people's lives are better understood.

2.1 Definition of Quality of Life

QoL is a multi-dimensional concept that over the past 30 years has been researched widely within cancer survivorship literature. Different researchers and organisations within the field of cancer survivorship have formed and used various definitions to suit various research purposes. The World Health Organization (WHO) defines QoL

as “A state of complete physical, mental and social well-being not merely in the absence of disease” (Langfeld, 1998). Their broad definition focuses on the complex effects on an individual’s physical and psychological state as well as their personal beliefs, social relationships and their relationships to relevant features of their environment. Other definitions include Padilla and Grant’s (1995), definition stating that QoL was composed of four dimensions: physical, psychological, social and existential/spiritual well-being where existential/spiritual well-being refers to feelings of hope/despair, personal beliefs, religion and inner peace. Cella (1994), also considered four dimensions at the same time as considering the persons subjective experience. Cella states that QoL can only be understood from an individual’s perspective which justifies including the person’s personal experience in assessing QoL. In Spilker, Molinek, Johnston, Simpson and Tilson (1990), review of QoL, they commented that most authors referred to five main dimensions being; physical status and functional abilities, psychological status and well being, social interactions, economic and or vocational status and religious and or spiritual status.

As a result of these various definitions, there have been multiple measurements created to define QoL. Even though these measurement tools vary in emphasis and length, they all illustrate the multi-dimensionality of QoL. Some measurement tools are even targeted to a QoL after having a specific cancer, for example a self report questionnaire created for gynaecological cancer survivors included questions about bowel, urinary and sexual function (Herzog & Wright, 2007).

A common thread throughout the survivorship literature repeatedly suggests that regardless of what cancer a person has, when they have it in their lifetime and how it is treated, their lives are essentially altered forever (Pedro, 2001). Of the various definitions of QoL, what has been consistently included has been the psychological and physical state of the individual. These two dimensions are the most researched and the most consistently defined that can be easily applied to all cancer survivors irrespective of their type of cancer, providing medical professionals with relevant information that falls within the scope of their expertise. This study will therefore will focus on the psychological and physical dimensions QoL of cancer survivors.

2.2 Dimensions of Quality of Life

2.2.1 *Physical Health Dimension*

The physical dimension refers to the perceived and observed bodily function or disruption (Cella., 1994). Short term physical effects of cancer are well known, however research is starting to suggest that physical disruption does not stop after treatment ends, but possibly carries on for years after (Ganz, 2001). The persistent lasting effects on physical well being can be said to be the most burdensome aspect for a cancer survivor (Ashing-Giwa & Lim, 2010). Research has shown that cancer survivors describe a good general health five years or more after treatment, however there can be specific physical impairments that can impact on the QoL of many survivors (Stein, Syrjala, & Andrykowski, 2008a). Research has identified various common physical ailments such as infertility, impaired cognitive function, chronic fatigue, early menopause, low energy, pain, sexual impairment, cardiac damage secondary to anthracycline treatment, osteoporosis, peripheral neuropathies, lymphedema, secondary cancers and stress incontinence (Stein, Syrjala, & Andrykowski, 2008b). Data from a Nurses' Health Study prospective comparative study which was looking at changes over a four -year period in breast cancer survivors and those who had not been affected by breast cancer, found that those who had cancer did experience a decline in their physical health in comparison with those who had never been diagnosed with breast cancer. Breast cancer survivors had higher rates of decline in physical function, vitality and increases in pain than women not diagnosed with cancer. This was even the case when other factors were controlled for, such as co morbid conditions, age, education, race and lifestyle factors (Michael, Kawachi, & Berkman, 2000). In Stein et al., (2008) review of prostate cancer survivors, general physical function was not found to be in affected except when it came to those who had been treated with androgen deprivation. Androgen deprivation which is used in treating prostate cancer has been proven to result in higher rates of physical and sexual problems (Syrjala, Langer, & Abrams, 2005). This highlights that the type of treatment a cancer survivor has been exposed to may be relevant to long term physical problems. Treatment alone, however, does

not dictate outcomes. Late physical impairments can be influenced by other factors such as lifestyle, socioeconomic status and biological factors (Syrjala et al., 2005).

The physical deficits that cancer survivors may live with could in turn effect their functional well-being. Functional well-being refers to the ability of a person to perform duties that are relevant to everyday living or that are part of the person's social role (Cella., 1994). Daily activities such as bathing and dressing oneself, duties around the house or driving to work could prove to be difficult to carry out for some people due to physical issues that constrain them.

Research on the delayed physical sequelae has not been without its challenges and limitations. Most research has not looked at five years post diagnosis in turn limiting understanding of cancer survivors' challenges with ongoing physical difficulties. A further challenge is being able to successfully distinguish between what are effects of cancer and treatment, other health conditions and common aging ailments (Zebrack, Yi, Petersen, & Ganz, 2008). For example, physical symptoms such as unilateral arm edema after breast surgery can be readily attributed to cancer treatment where as other problems like fatigue, lack of sexual interest or sleep disturbance could be attributed to aging or other co morbid conditions (Zebrack et al., 2008). Therefore there is not enough substantial evidence yet to distinguish between late effects and aging, however it could be the reality for those who have had cancer that there are lingering negative consequences perpetuating or speeding up the aging process which can in turn impinge on lifestyle and in turn impact on QoL.

2.2.2 Mental Health Dimension

Mental health is an integral component of health and the World Health Organisation defines mental health as

“Mental health is a state of well-being in which an individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and is able to make a contribution to his or her community” (World Health Organisation, 2010, pg 1).

Those who have experienced cancer can go through a range of physical, social, psychological and existential stressors and these often multiple stressors can cause survivors to experience considerable distress (Andrykowski, Lykins, & Floyd, 2008). Psychological effects refer to responses that are psychological or emotional in nature, for example anxiety or depression (Stein et al., 2008b). Distress is also a generic term that is considered as a psychological response and can include effects such as fears of reoccurrence, body image disturbances and poor emotional well-being (Pearce, Sanson-Fisher, & Campbell, 2008). Psychological well-being in regards to cancer survivorship is the attempt to maintain a sense of control in the face of a life threatening illness characterised by emotional distress, altered life priorities, and the fear of the unknown as well as positive life changes (S. Levine, 1987). Psychological distress is not uncommon nor unexpected throughout the cancer diagnosis and treatment (Stein et al., 2008b).

How prevalent is distress years after treatment? Research has explored the psychological consequences of cancer and treatments (Ganz, 2001), however less is known about the long term psychological implications. So far the literature has produced somewhat mixed results, with some research finding a higher occurrence of depression and anxiety in cancer survivors than non cancer survivors (Deimling, Kahan, Bowman, & Schaefer, 2002; Maliski, Sarna, Evangelista, & Padilla, 2003). Overall the prevalence of depression in cancer survivors has been estimated to range from 0%-50% and for anxiety disorders 6%-23% (Stein et al., 2008b). These are very wide ranging estimates which suggest no firm answer to the question of prevalence of psychological long term effects in cancer survivors. Also worth considering is that studies where the participants are older adults could skew results as this cohort already has a higher rate of depression and anxiety than the rest of the population.

A lot of this research has not looked at the post five years period. Could it be that psychological concerns are not raised with health professionals as more focus is given to physical concerns? Deimling et al., (2002), points out that physical effects may serve as a reminder of the traumatic events associated with the illness and treatment experience. Furthermore, when considering long term or late psychological

effects, it appears that the focus is more on negative effects and not taking into consideration any positive psychological effects that could transpire as a result of the cancer experience. Such positive responses could include greater life appreciation, improved self esteem and greater feelings of peace and purposefulness (Stein et al., 2008b).

2.3 Aspects that affect QoL Outcomes

Research has looked into multiple factors that can impact on the QoL of cancer survivors. Factors that have been considered are; age, gender, socio economic status, employment, social support, health behaviours, rural/urban accommodation and more recently religion/spirituality.

2.3.1 *Socio demographic factors (Age, Socio-economic Status)*

Age and socio-economic status have been found to impact on QoL of cancer survivors.

There has been ample research carried out looking at cancer survivors across the lifespan with particular attention on child cancer survivors. Research has indicated that age at diagnosis has an impact on QoL for the cancer survivor. Older survivors were significantly more likely than younger survivors to report better mental health status (Zebrack, 2000). Younger women tend to have worse QoL outcomes and more memory problems than older women diagnosed with cancer (Knobf, Musanti, & Dorward, 2007). A reason given for this difference is that older people may have adjusted their perception about their health where as younger people may hold on to higher expectations concerning their physical and functional status. This supports the finding that ratings of QoL tend to be better in older adults compared to younger people (Ganz, Hirji, Shin, Fred, & Polinsky, 1993). Thewes, Burtow & Gigis (2004), also made this discovery finding that younger cancer survivors were more likely to emphasise the impact of cancer on their lifestyle and career. Those who were 65 plus were more likely to ascribe to the “that’s life” attitude to the whole cancer

experience largely due to the many health and personal transitions people in that age group have had to make. Additionally it could be also said that older survivors could find it difficult to differentiate between what are late effects of cancer or simply just aging.

Socio economic status (SES) and QoL has been successfully linked in the literature. There has been a proven correlation between low socio economic status and poor QoL. Within the New Zealand Cancer Control report, the widening inequalities can be seen especially within gender and SES, with those of lower SES having increased mortality rates. Results from a New Zealand study found that SES was a major predictor of QoL in cancer survivors (Haywood, 2010). Other research has found that low SES has continued to exert an impact on cancer survival, stress, more episodes of psychosocial and distress, impaired physical and emotional health and a stronger predictor of mortality among individuals aged over 65 years (Ashing-Giwa & Lim, 2009; Cella et al., 1991). Additionally, SES has also indicated that those with lower incomes were more likely to report worse physical functioning (Zebrack et al., 2008).

2.3.2 Employment

Employment has been found to contribute to QoL in cancer survivors and there are various links. Those that are employed were more likely to report better physical health status which could in turn improve their QoL (Zebrack et al., 2008). Another factor which supports this link is that of what employment provides in terms of social interaction; feeling a sense of worth (DeBoer et al., 2009). The opposite has also been suggested where those who are unemployed have a lower QoL and that cancer survivors may have faced more challenges than those who have not had cancer in terms of finding and maintaining employment. A meta-analysis showed that cancer survivors are 1.37 times more likely to be unemployed than those who have not had cancer (DeBoer et al., 2009). Maintaining an affiliation to working life has been shown to be very relevant to QoL of a cancer survivor. Not being able to be employed or having reduced earnings can be associated with particularly poorer cancer adjustment, a general increase in health related problems as well as reduced

quality of life (Taskia & Lindbohm, 2007). The family as a whole may experience a decline in living standards if the breadwinner is not employed due to their illness. During the cancer experience an individual may have to cease working whilst undergoing treatment, this pause in employment may threaten the economic well-being of the cancer survivor and their families as well as negatively affect their identity, life satisfaction and social relationships.

2.3.3 Ethnicity

Ethnic disparities in cancer have been researched in many populations with research providing evidence that ethnic disparities are indeed a factor not to be dismissed when carrying out research on cancer survivors. Various studies overseas have produced significant results especially in the United States. A study carried out between African American and Caucasian cancer survivors five years post diagnosis found that African American survivors experienced poorer functional health after cancer and higher levels of health related conditions such as co morbidities and decreased physical functioning in turn increasing general health vulnerability (Deimling, Schaefer, Kahana, & Bowman, 2002). A study looked at breast cancer survivors between Hispanic, Caucasian and African American women and Hispanic women reported more concerns related to pain compared to the other two ethnicities (Spencer et al., 1999). Another breast cancer study looking at Asian American women and Caucasian American women found results suggesting a difference in the impact of cancer between the two groups. Results showed that there are differences between the two groups in physical and emotion well-being as well as the overall impact of breast cancer (Kagawa-Singer, Wellisch, & Durvasula, 1997).

New Zealand is a very multicultural country consisting of 69.3% European, 14.6% Māori, 9.2% Asian and 6.9% Pacific Islander (Statistics New Zealand, 2006b). In New Zealand cancer is seen to play a significant part in contributing to the eight-nine year difference in life expectancy between Māori and non-Māori (Blakely, Tobias, & Atkinson, 2007). Survival disparities between Māori and non Māori are significant for most cancers, after adjusting for age, sex, rural-urban status, deprivation and

stage at diagnosis (Blakely et al., 2007). However the causes of ethnic disparities in cancer survival are very complex and integrated. Survival disparities may be affected by stage at diagnosis, co morbid conditions, access to quality healthcare and support services. Fraser, (2006), reported that participants of studies of Māori health care experience reported significant challenges resulting from hidden costs of distance deprivation among rural residents especially for those with low incomes. Research with colon cancer survivors revealed that Māori with colon cancer have poorer survival than patients from other ethnic groups, even after adjustment for stage at diagnosis (Hill et al., 2010). Howard, (2010), found that Māori appeared to be worse off than non Māori however that this was complex and due to multiple variables interacting.

2.3.4 Rural/Urban Accommodation

According to the Ministry of Health (2003), one in four New Zealanders live in rural or small towns and in these areas are a higher percentage of older people and Māori. Cancer services are predominantly in the six main centres of Auckland, Hamilton, Palmerston North, Wellington, Christchurch and Dunedin. Providing comprehensive and quality services for people living in rural areas has become a priority for the Government (Ministry of Health, 2003).

There have been many studies conducted overseas that support the fact that geographic isolation can contribute to poorer outcomes for cancer survivors. DiSipio, Hayes, Newman, and Janda (2010), looked at QoL amongst urban and non urban breast cancer survivors and found that QoL was lower among non urban survivors. One domain that affected the difference between the two groups was physical well-being. DiSipio et al., suggested a few plausible reasons as to how QoL could be affected by living more remotely: access to health services, disruption to family life, work and financial security. Additionally geographic isolation may make it more difficult for survivors to seek support in peer groups or with professionals. There is also the added complication of lack of anonymity in smaller areas potentially

hindering the cancer survivor from seeking help locally (Burriss & Andrykowski, 2009).

Overseas research has provided evidence for a link between urban/rural location and QoL, however can overseas research correspond to New Zealand? Countries like Australia and America perhaps cannot be completely compatible to New Zealand due to the size and vastness of these countries. A New Zealand study done by Gill and Martin (2002) found some strong evidence to suggest that a patient's distance from a cancer centre is not associated with poorer survival in cancer of the oesophagus, stomach, pancreas or liver. Geographical isolation appears to have had no detrimental effect on survival from upper gastrointestinal cancer in patients from remote areas in New Zealand. What was found however was that those who were living in the middle distance range from major centres appeared to have a worse prognosis. Another study looking at prostate cancer survivors (Haynes, Pearce, & Barnett, 2008) found that survival from prostate cancer was worse for men living remotely from primary care. Therefore the evidence is perhaps not yet conclusive as to if living remotely or not does indeed have an impact on the QoL of cancer survivors in New Zealand.

2.3.5 Health Behaviour: Physical Activity

It is common knowledge that physical activity is associated with better health in the general population. There have also been studies conducted to prove that this is also the case for cancer survivors. Physical activity has been proven to be associated with better social functioning, self esteem, body image, mood, stress response and contribute to a decreased risk of heart disease, fatigue, depression, diabetes and cancer (Knobf et al., 2007). Exercise has been shown to enhance QoL in several studies of particular cancer survivor groups. Courney's (2003), study on endometrial cancer survivors found that QoL difficulties may be experienced by those who did not exercise or were carrying excess weight. The National Cancer Institute (2009) lists several studies supporting the positive association between physical activity and survival in cancer survivors. One theory is that by increasing physical activity this may influence insulin and leptin levels which in turn affects breast cancer prognosis

(Holmes, Chen, Feskanich, Kroenke, & Colditz, 2005). Another study of breast cancer survivors found that exercise contributed to improved QoL after diagnosis. Findings revealed that women who exercised moderately had improved their survival rates compared to women who did not exercise (Schmitz, Holtzman, & Courneya, 2005).

2.3.6 Health Behaviour: Smoking

Smoking is risky behavior to health. Research has found a positive link between smoking and decreased QoL. For cancer survivors smoking can be a preventative risk factor for cancer reoccurrence (Blanchard et al., 2008). In general, the QoL of a smoker is worse than the QoL of a non smoker and according to research there is an inverse relationship that exists between increasing tobacco use and QoL. Smoking basically affects nearly every organ in the body and diminishes a person's general health. People who smoke are six times more likely to suffer a heart attack than non smokers (National Cancer Institute, 2011). There has been limited research carried out on the effects of smoking on QoL of those who have had cancer however a study of lung cancer survivors found that persistent smoking after diagnosis impacts negatively on QoL (Garces et al., 2004). In regards to smoking and gender, research has identified that males opposed to females are more likely to smoke. One study found that males are 12 times more likely to smoke than females in India, four times more in Japan and Pakistan. In Germany research found in 2005 that 22% of all females and 32% of all men smoked (Bauer, Gohlmann, & Sinning, 2006). New Zealand has found opposite results with females being more likely to smoke, in particular Māori women. A study revealed Māori women to have one of the highest smoking rates in the world. In 2006 42.9% of Māori females smoked opposed to 35.8% of Māori males (Barnetta, Pearce, Graham, & Moon, 2005).

2.3.7 Health Behaviour: Alcohol Consumption

Health behaviours have proven to influence the incidence and reoccurrence of cancer and in turn can have an impact on QoL (Blanchard, Denniston, & Baker, 2003). Risky health behaviours such as alcohol consumption have not only been shown to affect health in the general population but also in those who have survived cancer (Wilsnack, Wilsnack, Kristjanson, Vogeltanz-Holm, & Gmel, 2010). Alcohol consumption not only puts an individual at increased risk for developing other forms of cancer such as mouth, breast and liver cancer but also risk of other major conditions such as depression, hypertension and stroke (Duffy, Terrell, Valenstein, Ronis, & Copeland, 2002). A number of factors are associated with heavy drinking in the general population such as being male, being young and having lower education, however due to the lack of research into alcohol consumption in cancer survivors it is unclear if these risk factors apply equally to cancer survivors (Lown et al., 2008).

2.3.8 Health Behaviour: Social Support

Researchers regard social support as critical to a cancer survivor's psychosocial well-being (Blanchard et al., 2008). Social relationships and the coping resources that they provide could be essential in managing stress and thereby influencing both psychological and physical health. Reynolds and Kaplan (1990), found evidence linking social relationships to cancer incidence, mortality and prognosis. Socially isolated women were shown to be at a significantly larger risk of dying of cancer. Men with fewer social connections also showed significantly poorer cancer survival rate. Possible explanations include that social support may reduce negative psychological responses, enhance psychological well-being and influence treatment compliance, health behaviours and immune function (Ell, Nishimoto, Mediansky, Mantell, & Hamovitch, 1992). Sammarco and Konecny (2008), found that social support and uncertainty have proven to be pivotal elements that impact on breast cancer survivors QoL. Schrovers Helgeson, Sanderman and Ranchor (2010), study looking at social support in long term cancer survivors found that getting support from friends and family in the period following diagnosis was important in helping cancer survivors to find positive meaning in their cancer experience. Furthermore another study which looked at the relationships between distress and perceived

availability of social support in Hispanic women found that emotional support from friends and instrumental support from a spouse predicted lower distress (Alferi, Carver, Antoni, Weiss, & Duran, 2001).

2.4 Gender and QoL

There has been a lot of research on survivors of particular gender specific cancers like breast and prostate, however very little looking at gender across a broad range of cancers. Looking at gender differences in QoL may contribute to considerations when administering treatment and also help in identifying areas that either sex may benefit from receiving more support in.

In most modern societies, women tend to live longer than men (Goldzweig et al., 2008) which can be attributed to the improvements in health service for women particularly in maternity care. However examination of data in the general population in regards to the status of men's health and well-being suggest that there are potential issues specific to men that should be considered by health planners and policy makers. In looking at comparisons between men and women's QoL in New Zealand, statistics do indicate differences between the sexes in the general population with women living on average 81.0 years to men's 76.2 years (*A Portrait of Health: Key results of the 2006/07 New Zealand Health Survey*, 2008). Women may live longer but how are they faring in terms of QoL? One source of information of QoL in New Zealand is health and disability data. Women represent 54.3 percent of all adults with a disability. A disability is defined as a self-perceived limitation in activity, resulting from a long-term condition or health problem, not completely eliminated by an assistive device (Minister for Disability Issues, 2001). In 1996/97 the New Zealand Health Survey surveyed approximately 9,000 New Zealanders using a health status questionnaire (SF-36) looking at physical and mental health status. Males scored slightly but statistically significantly higher than women on all scales except for general health. Therefore is this the same for those who have survived cancer?

In regards to gender differences in cancer survivorship, there has not been a lot of research comparing QoL of males and females and even more sparse research

conducted looking at those five years post diagnosis. There have been some studies done on cancer patients whilst still undergoing treatment and also gender differences in other chronic conditions (Chin & Goldman, 1998), but so far research has not been very consistent or solid in this area consequently providing very inconclusive findings. Hammerlid and Taft (2001), study looked at gender differences of Health related QoL of neck and head cancer survivors after three years post diagnosis. Their results found that female cancer survivors tended to score better than males in regards to health related QoL. Goldzweig et al., (2008), also reported that women cope better than men 24 months after diagnosis of colorectal cancer. Zebrack and Ganz (2008), study of QoL in long term cancer survivors 5-10 years post diagnosis identified that female survivors report significantly more psychological/emotional distress symptoms than men do. Miakowski's (2004), review of various studies looked at gender differences in pain, fatigue and depression between in cancer patients and found conflicting results across the studies which were not all necessarily post treatment. Schmidt et al., (2005), study confirmed that there were differences in QoL for men and women after treatment. Women appeared to be more affected and impaired in physical functioning and global health and women were associated with significantly higher fatigue levels. However it is not all bad with some research indicating positive outcomes from the cancer experience for women. Bower et al., (2005), found that after 10 years of survivorship many women reported a higher level of positive meaning and healthier lifestyles after cancer. Rowland, Desmon & Meyerwitz (2000), found that some long term cancer survivors emerge from the experience as new women who put their physical changes into perspective and focus more on relationships, existential issues and the pursuit of health. So research carried out to date has provided varied results in terms of comparing how men and women are doing in regards to surviving cancer.

Even though there has been some research looking specifically at gender differences, there has been a lot of research which has focused on various types of cancers that predominantly affect one sex such as prostate, testicular or ovarian and the most common for women being breast cancer. Breast cancer survivors may have more difficulties with physical symptoms and functioning such as lymphedema and menopausal symptoms and perceive themselves to be in worse health (Ashing-Giwa

& Lim, 2010). Demark-Wahnfried et al., (2000) study revealed that women who were breast cancer survivors reported worse physical functioning relative to prostate survivors. There is also the fact that surgery, organ loss and scarring can negatively impact on psychophysical identity and cause or contribute to anxiety and distortions of body image. This type of research has provided some interesting findings in regards to QoL in women and men, however when looking at gender disease specific research only, it can be difficult to draw accurate conclusions and have a clearer understanding as to why there could be gender disparities.

Lepore, Baum and Anderson (2001), proposed the use of a social-cognitive model of emotional adjustment to trauma to explain the processes underlying adjustment to cancer care which could in turn be used to understand gender differences. According to this model, highly stressful experiences such as being diagnosed and treated for cancer presents people with information that may challenge their basic understandings of the world and themselves. Using this model in regards to men and women can highlight why there are potential differences. For example women appear to have access to more source of social support and have more intimate relationships than men and have a wider variety of relationships than men (Vaux, 1985) . It was also suggested that men and women differ in how they use and benefit from their social networks. Men may be less likely to disclose emotion information or express emotion and may receive less emotional support from their friendships than do women (Vaux, 1985).

2.5 Religion/Spirituality and QoL

The factors above have been well researched in the literature with various links being established. A factor that has gained more attention in the last decade is that of considering the impact of religion and spirituality on the QoL of cancer survivors.

Today New Zealand is an increasingly diverse nation both culturally and religiously with two thirds of New Zealanders stating they are religious (Statistics New Zealand, 2006a) and of this two thirds, those over 65 are nine times out of ten recorded as having a religion. Christianity makes up approximately half of the religious

population however New Zealand has become an increasingly diverse community due to immigration which has seen growth in the Hindu, Buddhist and Muslim communities. Other factors such as globalization, indigenous spiritualities and new age movements have also contributed to the growing spiritual arena. A major contributor to spirituality in New Zealand is the Māori perspective and the voice of the Tangata te whenua. Mason Durie (1998), suggested that Te taha wairua is felt by Māori to be the most essential consideration for health. The Māori perceptions of health and well being differ vastly to that of Western thought. Illness includes “Mate tangata” where the causes of illness are visible, and “Mate Atua” (sickness of the Gods) for which there is no visible external cause. Illness is therefore believed to be of spiritual origin from the Gods (Atua) and Tapu violation seen more as the cause. Traditionally a Tohunga (Māori healer) is used and the rehabilitative process includes Karakia (Prayer) and Utu (Act of Restoration), (Sanders, Kydd, Morunga, & Broadbent, 2011). Therefore to ignore the Māori world view on health and well being where spirituality plays a big part is to ignore central concerns for Māori and not meet the commitments of the Treaty of Waitangi. Policies now include Māori health models such as Te Whare Tapa Wha (Durie, 1998), and Te Pae Mahutonga (Durie, 1999), which have contributed to including spiritual discourse in New Zealand. Therefore attending to Religion/Spirituality is imperative when looking at health and in turn QoL in all New Zealanders who have survived cancer.

Research in the area of Religion/Spirituality within cancer survivorship has been growing however there appears to be a lack of consensus in the definition of these terms (Lim & Yi, 2009). Some researchers have referred to Religiosity and Spirituality as very separate entities and other researchers have used them interchangeably. The main difference between the two is that Religiosity which is more prominent in the literature, reflects more of a social institutional concept and is often represented as an institutional structural variable. It can be defined as a person’s adherence to beliefs, values and practices proposed by an organised institution which is devoted to the search for the divine (Thoresen & Harris, 2003). Spirituality is related to more individual and existential experience (Thoresen & Harris, 2003; Vachon, 2008) and is sparser in research. Spirituality can be expressed as a relationship with God but can also be about other things such as nature, art,

music, family or community. There may not be a set definition but the purpose is to find connectedness, direction, transcendence, meaning and purpose (Vachon, 2008). In Māori culture, spirituality is seen as “a *body of practice and belief that gives the spirit (wairua) to all things Māori. It includes prayer and spirit. It pervades all of Māori culture (Tikanga) and ways of life. A word sometimes used to capture this is Māoritanga.*” (Cody, 1944, as cited in McLennen, 2010). What these definitions have in common is that Religiosity and Spirituality may be understood as an active process (Religion and Spirituality), involved in directing a person’s thinking and actions.

Is Religion/Spirituality related to better QoL in cancer survivors? The literature has yielded some varied findings and it is agreed amongst the academic community that there is not enough evidence yet to support this claim highlighting the need to examine factors that may account for the association between religion/spirituality and QoL.

Lazarus and Folkman (1984), model of stress and coping could provide a theoretical framework to understanding the relationship between Religion/Spirituality and QoL in cancer survivors. Through this framework, religion/spirituality could be seen to assist in buffering the adverse impact of having cancer. Studies that have looked into Religious/Spiritual coping in those who are suffering from a chronic health condition found that between 34%-86% of patients reported using Religion/Spirituality cognitions and activities in coping with their illness (Gall & Corblat, 2002), qualitative study of breast cancer survivors found that Religion/Spirituality helped with their response to cancer and how the spiritual resources such as social support, coping activities and relationship with God helped with their experience. Harrison et al’s, (2001), review of Religious coping found that Religious coping strategies such as seeking spiritual support, expressing spiritual contentedness, receiving congregational support and benevolent reframing of stressful events improved psychological outcomes and in turn QoL. Religion/Spirituality practices such as prayer and meditation could be seen to enhance a sense of control over stressful events like cancer by helping the person to achieve a personal relationship with a higher entity that offers strength and support to cope with their illness. Additionally,

Religious/Spiritual coping could be applied to disenfranchised populations such as the elderly, minorities and women who may confront additional challenges in accessing healthcare (Tarakeshwar et al., 2006).

Religion/Spirituality factors have been associated with various aspects of cancer adjustment such as physical health and strengthened social support, general QoL and decreased anxiety (Cotton, Levine, Fitzpatrick, & Dold, 1999). A study exploring the relationships between spiritual well-being, QoL and psychological adjustment in breast cancer patients found a significant positive correlation between spiritual well-being and QoL as well as spiritual well-being and some different adjustment styles (Efficace & Marrone, 2002). These findings could be explained by Brennan's social-cognitive transition model of adjustment. The social cognitive transition model of adjustment deals with both the positive and negative adjustments to cancer. Beliefs about the self, control and self worth, nature of attachment and the spiritual/existential will be affected by the persons experience with cancer (Laubmeier & Bair, 2004). A person who has a helpful frame of mind may possibly re evaluate life's goals, discover more control and better examine their own identity which helps in adapting to the changes cancer brings. Pargament and Park (1995), found that Religious beliefs may help individuals to cognitively reframe or reconstruct the meaning of negative events. Ersk and Ferrell (1994), stated that religion/spirituality can assist the individual with cancer to reframe their experience as having some positive consequences such a being brought closer to others and developing deeper and more meaningful relationships. Religion/Spirituality may assist in positing self efficacy in the cancer survivor which could be essential to the psychological adjustment of those living with illnesses like cancer (Tarakeshwar et al., 2006). For others a relationship with God might be an external framework of control that is more benevolent than fate (Jenkins & Pargament, 1995) which can reduce emotional distress. However God's influence may also be perceived in a negative way such as being the cause of the illness which could contribute to greater distress (Gall & Corblat, 2002).

Few studies have examined gender in the context of religion/spirituality. Although there is some American research suggesting that Religious/Spiritual association and health is not the same across gender (Thoresen & Harris, 2003), the direction and magnitude of the difference in this context is still very unclear. In terms of gender and religiosity/spirituality, it is understood that women are more religious than men (Miller & Thoresen, 2003). In a U.S survey 56% of women versus 53% of men indicated that they were religious (Maselko & Kubzansky, 2006). Ellison and Levin (1998), study suggested that various domains of Religious/Spiritual engagement are related to health and well being as measured by self rated health, psychological distress and happiness and that gender may be an important moderator of these associations. In Krupski et al., (2006), prostate cancer survivor's low spirituality was associated with significantly worse physical and mental health, sexual function and more urinary problems. It was also found that men with low spirituality had worse adjustment than those who were spiritual. Public religious activity was most consistently associated with measures of health and well being among men (Maselko & Kubzansky, 2006). Therefore gender may be a moderating factor and a comparison of gender differences in the association between Religion/Spirituality may provide additional insight into how religion/spirituality is related to QoL.

Research has also identified social support to be a possible mediating factor between Religion/spirituality and QoL (Dunin, 2005). Studies have found that lower levels of Religion/spirituality were associated with higher levels of social isolation (Reynolds, 2006 in Lim et al, 2009). Social networks and access to social support have been shown to promote a variety of health outcomes and therefore participation in Religious/Spiritual groups could be considered the same as participation in other close social groups. It has also been suggested that people who are Religious/Spiritual may have the added benefits of being able to draw on resources provided by religious organisations such as help with getting to know like minded people, being able to develop relationships, informal emotional support, employment guidance and access to counselling (Lim & Yi, 2009).

Research in the general population has found links between Religion and Spirituality and health behaviours (Holt, Haire-Joshu, Lukwago, Lewellyn, & Kreuter, 2005;

Park, Edmondson, Hale-Smith, & Blank, 2009). However the potential for religiousness and spirituality to serve as a resource for facilitating positive lifestyle behaviours in cancer survivors remains virtually unexamined. There has been research conducted indicating possible links between Religion/Spirituality and health behaviours such as substance abuse, diet, exercise and preventative medical screenings (Benjamins, Trinitapoli, & Ellison, 2006). How these links have been explained is through the idea that aspects of Religion/Spirituality may exert effects on health and health behaviours partly through the promotion of positive affect (Oman & Thoresen, 2002; Park et al., 2009). An illustration of this is a study which found that religious people reported their spirituality gave rise to positive emotion which they were able to channel into positive health behaviours (Holt et al., 2005). Other explanations suggested that religious institutions benefit health through advocating healthy lifestyles, having sanctions in place against negative health related behaviours and that the role of social support has a positive affect on behaviour. Additionally, Strawbridge, Shema and Cohen (2001), found that not only was weekly attendance at church associated with improving and maintaining good health and increased social relationships, it was also found that these results were stronger for women in improving poor health behaviours. This could add further credence to the theory that women may utilise social resources more for coping.

Religion/Spirituality is important in New Zealand especially when taking into consideration the Māori approach to health and well-being which includes elements of Wairua (spirituality) therefore further justifying the need for more research in this area. Religion/Spirituality has been shown to influence multiple aspects of well-being (Efficace & Marrone, 2002), so it is also likely that religion/spirituality plays a major role in QoL too. Research in this area may not only inform us if Religion/Spirituality does in fact have an impact on QoL but it will also provide more information on the specific role of religion/spirituality in health and coping and inform us about common psychological, behavioural and biological pathways that may be linked to cancer morbidity and QoL (Stefanek, McDonald, & Hess, 2005).

2.6 Summary and Research Goals

Chapters one and two have discussed the various challenges and concerns that face those who have survived cancer. The QoL of cancer survivors is an important area in terms of being able to help prevent those who have already faced illness in their lives from becoming ill again. Many factors have been identified in the literature that impact on QoL of cancer survivors which also highlights that many survivors' needs may vary due to their own circumstances. Two particular areas of interest that have not been researched in New Zealand are that of gender differences and differences between those who consider themselves Religious/Spiritual or not. By looking more closely at these two factors we will be able to identify what the specific needs are for both men and women and how we can further shape our policies and influence those in the medical profession to tailor cancer survivorship care to suit each sexes needs. By looking at the Religious/Spiritual dimension and its potential impact on QoL of cancer survivors, this may influence whether more after care programmes take a more holistic approach catering for not just the medical challenges but the whole person.

2.6.1 Research Questions

Previous research has found that there are a range of differences between men and women in terms of the factors that affect QoL. Women have been found to be more Religious/Spiritual than men, and this may impact on difference in QoL.

1. Is there a difference in perceived Physical and Mental Health QoL between males and females?
2. Is there a difference in perceived Physical and Mental Health QoL between males and females over time?
3. Is there a difference in health behaviours between males and females?
4. Is there a relationship between Religion/Spirituality and gender?

Based on previous research, it appears that Religion and Spirituality could have a positive impact on QoL of cancer survivors. Most of the research however has been carried out in the United States, so this study will investigate if there is any link in New Zealand. Additionally, Health behaviours have been shown to improve QoL in

the general population and also among those who have had cancer.

Religion/Spirituality may provide incentives and opportunities for improved health behaviours and increased social support. For example, Religious and Spiritual perceptions often include prescriptions for healthy living, and religious practices such as church attendance provide social support. Thus, these factors may help to explain the relationships found between religion/spirituality and QoL

5. Is there a difference in perceived Physical and Mental Health QoL between those who Religious/Spiritual and those who are not?
6. Is there any difference in QoL scores overtime of those that are Religious/Spiritual and those that are not?
7. Do cancer survivors who are Religious/Spiritual also engage in better health behaviours? (less smoking, less alcohol, and more exercise).
8. Is Religion/spirituality related to social support?
9. Does social support mediate the relationship between Religion/Spirituality and QoL?
10. Does this mediating role vary with gender?

CHAPTER THREE: METHODOLOGY

3.0 Introduction

The data for this study was taken from the Health Work Retirement (HWR) surveys which were carried out in three waves in 2006, 2008 and 2010. The research was undertaken in partnership with Massey University, The New Zealand Health Research Council, The New Zealand Institute on Aging, The Centre for Māori Health Research and Development and Te-Putahi- a- toi Massey University. The purpose of the HWR study is to explore what factors contribute to retirees in New Zealand being happy, healthy and independent. The study is an ongoing longitudinal study that was designed to identify and investigate the influences on health and well-being in adults aged 55-70 years when first surveyed. Information was collected to examine multiple areas such as mental and physical health, factors related to work and retirement and to document socioeconomic and demographic status of people as they make the transition from work to retirement. The study used two sub samples, one being the general population and the other being Māori in order to gather more information on Māori New Zealanders as they transition from work into retirement.

3.1 Procedure

3.1.1 The population of interest

The population of interest for this study was New Zealanders aged 55-70 years old which is a group that provides a good representation of those moving into retirement at the same time as still being active members of the community. This group is increasing in the New Zealand population and according to Statistics New Zealand there are approximately 609,000 New Zealanders in this age bracket with this figure looking to increase over the next decade. The HWR study is considered appropriate to this research as the sample is large enough with 6662 participants responding in the 2006 wave, 3116 participants responding in the 2008 wave and 3317 participants

responding in the most recent 2010 wave. The response to the three waves is seen as appropriate to supply a representative sample of the population and to also provide an adequate representation of those who have survived cancer.

3.1.2 Participant selection

For the 2006 and 2008 waves of the HWR study, participants were randomly drawn from the 55-70 year old age group on the New Zealand Electoral Roll. The 2010 wave included an extra group. However for the purpose of this study only the participants who participated in all three waves were investigated. Individuals in institutions such as prisons, nursing homes or dependent care were excluded from the research. The Electoral Roll was seen as an appropriate source for gathering participants as the majority of New Zealanders are registered on the Electoral Roll, providing a substantial database that best reflects New Zealand's population. Equal probability sampling procedures were used to select Māori and general sub samples. Due to the likelihood of a reduced Māori participation rate, Māori were over-sampled to maximise participant recruitment.

3.1.3 Survey participants

Of the three surveys 402 from the 2006 survey indicated that they had cancer, 255 in the 2008 wave and 322 in the 2010 wave. Two samples were used for this research. Participants specifically from the 2008 survey were used to explore Quality of Life (QoL), religion/spirituality and health behaviours. The 2008 survey was selected due to having sufficient questions included in the survey relating to religion and spirituality providing for opportunities for a more in-depth analysis. A sample of 61 participants who responded to the QoL measure across all three waves was utilised for longitudinal analysis.

3.1.4 The questionnaire

The postal questionnaire was designed to collect information on factors relevant to retirement, well being and independence. The questionnaire consists of six sections being: health, physical activity, social support, work status and attitudes, retirement status and attitudes, and socio-demographic information. For Māori participants an

extra section was included to consider for Whakapapa/Whanaungatanga genealogy/relationships.

When the participants received the survey they were allocated a code which allowed for privacy at the same time as enabling the researcher to identify them if needed. The first page of the survey provided instructions for the participants on how to complete the survey, their rights and also contact information. Each survey contained various sections.

Table 1.

Sections of the three HWR surveys.

2006	2008	2010
Health	Health	Health, well-being and quality of life
Physical Activity	Activities	Family and friends
Support	Support	Caring commitments
Work	Work	Work and retirement status
Retirement	Retirement	Financial well-being
Background	Whakapapa	Living in your neighbourhood
Whakapapa/ Whanaungatanga		Personal situation

3.1.5 Survey design

The HWR study used a postal survey which utilised Dillman’s (2010) Tailored Design method. Dillman uses a structured approach to survey design which has proven to increase the success rate of full participation. A feature of his approach is that the researcher is in touch with the participant over various stages of the data collection.

Table 2.

The Dilman structured approach to survey design

Point of Contact	Posting procedure and content	Weeks after initial contact
1	A brief pre-notice letter was sent to potential participants informing them that they had been randomly selected from the electoral roll to participate in the current study, that a questionnaire would be arriving soon and that their participation in the research would be greatly appreciated.	-
2	The questionnaire and a free-post return envelope were sent. This was accompanied by a detailed cover letter explaining the premise of the study, who was involved, participants rights and expectations, and points of contact in case they had queries. Finally, all questionnaires also contained a consent form on which participants could provide their consent to participate in the longitudinal study and be involved in face-to-face interviews.	1
3	A postcard was sent to everyone in the sample, thanking those who had responded and encouraging those who had not responded to do so.	3
4	A replacement questionnaire was sent to all non-respondents to encourage participation.	6
5	A final contact (postcard) was sent to all non-respondents again encouraging non-respondents.	11

3.2 Measures

The HWR study included a wide range of factors that were relevant to health, work and retirement. This study selected from the HWR data specific measures based on their ability to measure the hypotheses being investigated.

3.2.1 *Quality of life*

Quality of life was evaluated using both the SF-36v2 (Ware, Kosinski, & Dewey, 2000) which was used in the 2006 and 2008 waves and the SF-12v2 QualityMetric Health survey which was used in the 2010 wave and is a shortened version of the SF-36v2 Health Survey.

The SF-36v2 is an appropriate and practical survey for this study due to it providing a good overall measure of QoL and its capability to capture both the mental and physical dimensions of QoL at the same time as being brief. The survey is very popular and widely used in health research and has proven to be very reliable in measuring generic health status (Ware et al., 2000).

The SF-36 includes 36 items measuring nine health scales: general health perception, mental health, role emotional, physical functioning, role physical, social functioning, health transition, bodily pain and vitality. The survey uses a five point Likert scale with scores for each of the nine areas being translated to produce scores ranging from 0-100, the higher score indicating more positive perceptions of health.

Summary scores are then produced for both Mental Health QoL and Physical Health QoL consisting of 12 questions measuring overall health status from a participant's perspective.

The SF-12v2 is a 12-item scale which covers the same eight health domains as the SF-36v2 measuring health status across physical and emotional domains to assess mental and physical functioning. For the purposes of the longitudinal analysis, the 2006 and 2008 SF-36 scales were converted into a SF-12 scale. To perform a longitudinal analysis using multiple regression a change variable was created in which the 2010 SF-12 scores were subtracted from the 2006 SF-12 scores, giving a variable of difference in scores over time. The scores ranged from -31.84 to 26.84

and scores with more than a 15 difference increase or decrease indicating a substantial change.

In the longitudinal analysis the two other QoL measures used were World Health Organisation Quality of Life (WHOQoL-8) and the CASP-12.

The WHOQoL-8 measure contains eight items and is an abbreviated version of the WHOQoL-Bref which contained 26 items that were grouped together in four domains, physical, psychological, social and environmental. The WHOQoL-Bref is a sound, cross-culturally valid assessment tool for QoL. The measure uses a 4-point Likert interval scale designed to assess intensity, capacity, frequency and evaluation (The WHOQOL Group Development of the World Health Organization WHOQOL-BREF quality of life assessment, 1998). The scale asks the participants how they felt in the last four weeks with the range 14-40, 14 being the lowest reported score.

The CASP-12 (Wiggins, Netuveli, Hyde, Higgs, & Blane, 2008) is a shortened version of the CASP-19 and has been recently adopted in many national and cross-national studies of aging. The measure consists of 12 Likert scaled agreement items spanning four life domains of control, autonomy, self realisation and pleasure. Each of the four scales evaluates the degree to which these aspects are perceived as being satisfied. A summary score was used to assess the QoL. The range was 11-35 with higher scores indicating better QoL and lower scores indicating poor QoL.

3.2.2 Gender

In each survey there was a question on gender which required a dichotomous response and was scored 1=Male and 2= Female

3.2.3 Religion and Spirituality

Questions were taken from the Enhancing Well-Being in an Ageing Society (EWAS) research programme carried out in New Zealand by The Family Centre Social Policy Research Unit and University of Waikato Population Studies Centre. In addition questions were also taken from the HAPPI project carried out by Ms Annette

Hendricks from the School of Psychology Massey University. Hendrick's conducted a thematic analysis of interview data looking at themes of "other focused" 'personal recreation and interests', 'thoughts and attitudes', 'achievement-related' activities, 'spiritual activities' and 'self-concordant work'.

The questions used in this study were found to be appropriate for measuring both Religion and Spirituality due to the different questions looking at both the importance of Religion and Spirituality as well as Religious and Spiritual activity attendance. The inclusion of both Religious/Spiritual attendance and frequency (meditating, prayer or worshipping) as well as questions requiring the participant to state the level of importance provides more reliability and validity than just looking at attendance alone (Idler et al., 2003).

Questions used within the three waves of surveys were; Religious attendance and importance, Spiritual importance, and frequency of Spiritual activities. The importance of Religion and Spirituality questions were responded to on a five-point Likert scale from 'extremely important' to 'not important'. The two Religious and Spiritual frequency questions were also responded to on a five - point Likert scale ranging from daily, weekly, monthly, yearly or never at all. To capture both Religion and Spirituality together as one construct the two questions ($r=.849$) asking the importance of Religion and Spirituality were combined to compute a measure of religion and spirituality in which 2 = low religion/spirituality and 10= high religion/spirituality.

3.2.4 Alcohol use

Alcohol consumption was measured using the WHO AUDIT- C (Hazardous). The Alcohol Use Disorders Identification Test (AUDIT) was created by the World Health Organisation. The AUDIT-C is a brief version of the AUDIT which was developed for brevity and ease of administration and therefore only uses the first three questions which have shown effectiveness in detecting hazardous drinking in the older population. The 2008 AUDIT-C was used for this research as it provided brief and relevant information in regards to participants drinking behaviour.

The AUDIT-C has shown high levels of sensitivity and specificity in screening for alcohol dependence and alcohol disorders (Gómez et al., 2006). The use of different variable cut points for men and women also increases the measures sensitivity and specificity. It has been shown to perform adequately among all categories of race/ethnicity (Dawson, Grant, & Strison, 2003).

The AUDIT-C consists of three questions looking at quantity and frequency with responses on a five- point Likert scale with 1 = Lifetime abstainer to 5= Heavy drinker.

3.2.5 *Smoking identity*

In the 2006, 2008 and 2010 surveys three questions were asked in regards to smoking. A participant's smoking status whether they are a current or past smoker, the quantity of cigarettes smoked on a given day and if at any stage in their life had they been a smoker. For the purpose of this study the 2008 data wave question was used asking the participant to state if they were 1 = yes a smoker or 2= non smoker.

3.2.6 *Physical activity*

In the 2008 survey The New Zealand Sport and Physical Activity Questionnaire short form (NZPAQ-SF) was used. A short version was created to be incorporated into larger health surveys like the HWR survey therefore making it appropriate for this study. Moderate exercise was selected as an appropriate measure of physical activity for this study as it was assumed that moderate exercise would be a fair representation of participant's regular physical activity behaviours.

The NZPAQ-SF was specifically designed as a self reporting questionnaire used to access the frequency, duration and intensity of an individual's physical activity in a multitude of contexts. These contexts consist of situations such as recreation, sport, work, leisure time, domestic work and transportation. The NZPAQ-SF has been validated by the University of Auckland in conjunction with the Ministry of Health in turn providing a reliable and valid measure for this study (Moy, 2005).

For the purpose of this study and the longitudinal analysis, for the 2006, 2008 and 2010 surveys, the question asking how many hours of moderate exercise does a

participant engage in a week was used with the range of hours being from 0-40 hours per week of moderate exercise.

3.2.7 Social support

Social support was assessed using the Social Provisions Scale by Cutrona and Russell, (1987). The scale was designed to look at the degree to which social relationships provide various dimensions of social support for the individual. This scale was used as it was seen in to provide sufficient and relevant information for the purposes of identifying participant's quantity and quality of social support.

Research has found this scale to have good reliability and validity as well as being adaptable to a variety of populations including older adults, post partum women, spouses of cancer patients, the elderly and individuals working in stressful job situations (Cutrona, Russell, & Rose, 1986). The instrument is broken down in to the following areas: attachment, social integration, reassurance of worth, reliable alliance, guidance, and the opportunity for nurturance. The items either describe the presence or absence of a type of support.

The survey consists of a four-point Likert scale which measures the extent to which each statement describes the individual's current social network. Responses range from 1 (strongly disagree) to 4 (strongly agree).

The present study uses the 2006, 2008 and 2010 overall summary score of the Social Provisions Scale which was summed for each social provision and a total social support score was formed by summing the six individual provision scores. The scores in the present study ($N=253$) $M = 78.69$ ($SD = 9.17$) range from 55.00 to 96.00. A high score indicates a greater degree of perceived support. Cutrona and Russell reported alpha coefficients for the total scale score from .85 to .92 across a variety of populations; the alpha coefficient for this study is .87.

3.2.8 Cancer participants

A cancer survivor is any individual who has had cancer. In the present study all individuals who indicated that they had cancer at some stage throughout their life were included in the analysis.

The 2006 wave contained two questions relating to cancer asking if the participant has had skin cancer or any other form of cancer. The 2008 wave included questions relating to type of cancer, date of diagnosis, treatment status and if the person had secondary cancer. The 2010 survey contained questions investigating the type of cancer and age of diagnosis.

3.2.9 Socioeconomic status (SES)

For SES the Economic Living Standard Index Short Form (ELSI-SF), which is the shortened version of the Economic Living Standard Index (ELSI) developed by the New Zealand Ministry of Social Development, was used to measure participants' economic standard of living (Jenson, Spittal, & Krishnan, 2005). Economic standard refers to the material side of well-being which includes a person's possessions and consumption. The scale assesses restrictions in ownership of assets, restrictions due to cost in social participation, the extent to which participants economize and a self rated indicator of standard of living. Scores are added up for each question and then totals are placed in one of seven categories creating an ordinal value ranging from severe hardship to very good. The range of scores in the present sample ($N=231$) is 0-7, $M = 5.16$ ($SD = 1.42$). The scores are placed into seven categories with the lowest category containing the lowest scores indicating severe hardship to the last category including a range of the highest scores indicating very good SES. Jensen et al., (2005) reported a Cronbach's alpha of .88. The alpha in the present sample is .81. The 2006, 2008, 2010 ELSI scores were used in this research.

3.2.10 Ethnicity

Ethnicity was assessed using the variable primary ethnic group affiliation. This variable was based on the New Zealand Statistics categories of (1) Pakeha/New Zealander of European descent (2) Māori (3) Samoan (4) Cook Island Māori (5) Tongan (6) Niuean (7) Chinese (8) Indian (9) Other. Participants who identified as Māori or part-Māori were categorised as "Māori" (2).

3.2.11 Age

Age is known to influence health and therefore was controlled for in this study. The HWR study utilised the method of measuring age that is used by Statistics New Zealand. The date of birth was obtained and this was subtracted from the year the survey was administered.

At the first step the control variables, age, ethnic identity and socio economic status (SES) were entered. These control variables were selected due to previous research suggesting that they may impact on QoL. These three independent variables together significantly predicted 9.9% of the variance in Physical Health (Adj. R^2 =.099, $F(3,183)=7.81$, $p=.000$).

3.3 Data Analysis

Data was analysed using SPSS software version 18 for windows. To allow for unequal sampling of the populations, a post-stratified weighting variable according to primary ethnicity was applied to all analyses. The weighting variable was based on the population estimates from the 2001 census (Statistics New Zealand, 2002) for the 55 to 70-year-old age group.

To explore the research questions, the analysis used a combination of statistical analysis procedures including: T-Tests, Pearson's correlation and Hierarchical multiple regression whilst controlling for particular factors including age, socio economic status and ethnicity.

The relationships between gender, health behaviours and Religion/Spirituality were analysed using T-tests and bivariate correlations (Pearson's r). An ANOVA analysis was used to investigate gender and QoL over time. A chi square test of association was used to investigate the relationship between gender, alcohol consumption and smoking.

To explore the relationships between Religion/Spirituality and QoL bivariate correlations between the variables were used to examine all associations. A multiple regression equation was then run to test further associations between Mental Health

QoL and Spiritual Activity Frequency. Bivariate correlations were also used in exploring the relationships between QoL and health behaviours.

CHAPTER FOUR: RESULTS

4.0 Introduction

This chapter presents the results of the statistical analysis. All results were produced using version 18.0 of SPSS software. The results are divided into two sets of analyses which investigate the relationships between gender and quality of life (QoL) and the relationship between Religion/Spirituality and QoL. Health behaviours were also investigated.

4.1 Characteristics of the participants

The analysis used data from all three waves of the Health Work Retirement (HWR) survey. In the 2006 wave, of the 13,045 surveys that were posted out, 6662 were returned yielding a 53% response rate. The age range was 50 to 76 years old ($M=60.97$, $SD=4.57$). The sample comprised 2974 (44.6%) males and 3543 (53.2%) females with 145 (2.2%) not stating their gender. Of this group, 402 participants indicated that they have had a diagnosis of cancer.

In the 2008 survey, of the 3,200 surveys that were posted out, 2495 surveys were returned yielding a response rate of 77%. The age range was 57 to 72 ($M=63.27$, $SD=4.59$). The sample comprised 1146 (46%) males and 1207 (52%) females with 42 (2%) participants not stating their gender. This study included all participants who indicated that they had been diagnosed with cancer regardless of age at diagnosis or if they were currently receiving treatment for their cancer. A t-test was carried out between those who were currently in treatment and those who had finished treatment and no difference was found between the two groups in regards to their QoL. The overall sample of those diagnosed with cancer was 255 participants with 110 (43%) males and 145 (57%) females.

In the 2010 wave, of the 4339 surveys that were posted out, 3317 were returned yielding a 76% response rate. The age range was 50 to 90 ($M=64.28$, $SD=8.12$). The sample comprised 1480 (44.6%) males and 1806 (54.4%) females with 31 (.9%) not

stating their gender. In the 2010 wave, 322 participants indicated that they have had a diagnosis of cancer. Initially analyses were going to be performed on the Maori population however due to a small sample ($n=17$) these analyses were not carried out.

For the longitudinal questions in this study, a separate data set was created including cancer participants who had answered all three waves of the SF-36 and SF-12 QoL questions as well as Wiggin's et al, (2008) CASP and World Health Organisation's Quality of Life (WHOQoL) survey questions. This sample included 61 cancer survivor participants of whom 34 were males and 37 were females.

4.1.2 Data management

All results were screened for errors in data entry and missing cases were excluded where necessary. In the longitudinal analyses cases were deleted that did not respond to all three waves of the QoL SF measure. Normality of distribution was checked using normal probability plots and the calculation of skewness and kurtosis statistics on all continuous variables of interest.

4.1.3 Descriptive analysis and frequencies of variables

The mean and standard deviations for each variable used in all analyses were calculated. Refer to Table 3.

Table 3.

Mean and Standard Deviations for all variables.

Variable	Gender	N	Mean	SD
2006 SF Physical	Male	34	48.40	10.41
	Female	27	48.80	9.82
	Total	61	48.58	10.07
2006 SF Mental	Male	34	51.55	11.46
	Female	27	50.95	8.70
	Total	61	51.28	10.25
2008 SF Physical	Male	89	50.68	9.23
	Female	118	48.07	9.72
	Total	207	49.20	9.57
2008 SF Mental	Male	89	54.53	12.00
	Female	118	51.67	8.50
	Total	207	52.90	10.23
2010 SF Physical	Male	34	47.46	9.52
	Female	27	44.69	9.67
	Total	61	46.23	9.61
2010 SF Mental	Male	34	51.61	8.28
	Female	27	46.57	8.17
	Total	61	49.38	8.55
2010 CASP Score	Male	34	27.52	5.75
	Female	26	26.26	5.72
	Total	60	26.98	5.72
2010 WHOQoL Score	Male	34	32.26	5.64
	Female	26	30.19	5.91
	Total	60	31.36	5.80
2006-2010 Change Score Physical QoL	Male	34	0.94	10.62
	Female	27	4.10	9.45
	Total	61	2.34	10.16
2006-2010 Change Score Mental QoL	Male	34	-.06	11.68
	Female	27	4.37	8.52

	Total	61	1.90	10.50
Alcohol consumption	Male	85	3.52	0.94
	Female	103	3.14	0.84
Smoking	Total	188	3.31	0.90
	Male	101	1.90	0.30
	Female	139	1.90	0.29
Physical Activity	Total	202	1.90	0.29
	Male	97	7.19	8.01
	Female	125	4.06	4.01
Social Provisions	Total	225	5.43	6.28
	Male	110	78.80	9.12
	Female	143	78.54	9.24
Religion/Spirituality	Total	202	76.69	9.17
	Male	103	4.51	2.40
	Female	135	5.79	2.63
Importance of Religion	Total	238	5.23	2.61
	Male	110	2.05	1.25
	Female	145	2.84	1.29
Religious Attendance	Total	254	2.69	1.28
	Male	107	2.52	0.80
	Female	139	2.33	0.85
Importance of Spirituality	Total	247	2.41	0.83
	Male	104	2.01	1.24
	Female	135	2.91	1.41
Spiritual Activity Frequency	Total	238	2.52	1.41
	Male	98	3.92	1.45
	Female	133	3.18	1.43
	Total	230	3.50	1.48

4.2 Gender

The first set of analyses investigated gender and QoL of cancer participants in the 2008 study as well as over time from 2006 to 2010. Further analysis was performed looking at gender and various health behaviours; alcohol consumption, smoking use, physical activity and social support.

4.2.1 Research Question One - Is there a difference in perceived Physical and Mental Health QoL between males and females?

To test the hypothesis that QoL may differ between males and females, an independent samples t-test for unequal variances was used to compare the average 2008 SF-36 Physical and Mental Health QoL scores reported by males and females'. The difference between the two groups was not significant on either QoL dependent variable. Therefore no association was found between gender and QoL in cancer survivors in the 2008 survey.

4.2.2 Research Question Two- Is there a difference in perceived Physical and Mental Health QoL between males and females over time?

A change variable was created and used in order to assess the QoL of participants over time In this analysis there was a slightly higher percentage of males to females with males $n=34$ and females $n=27$.

Pearson's r correlations were performed and Table 4 shows that there is a weak but statistically significant relationship between gender and the 2010 SF-12 Mental Health QoL measure $r = -.295$, p (two tailed) $< .05$. However no significant relationship was found between gender and the SF-12 Physical and Mental Health QoL change variables.

The Repeated measures within subjects ANOVA analysis was performed. The observed F value was not statistically significant indicating no difference in QoL between males and females over time.

Pearson's r correlations were also performed on the 2010 QoL measures the CASP and the WHOQoL and no significant relationships were identified between gender and QoL.

Table 4.

Bivariate correlations of relationships with Gender and QoL. N = 61

Variables	(1)	(2)	(3)	(4)	(5)	(6)	(7)	(8)	(9)	(10)	(11)
(1) Gender	1										
(2)2006 SF Physical	.020	1									
(3)2006 SF Mental	-.029	.670**	1								
(4)2008 SF Physical	-.059	.538**	.556**	1							
(5)2008 SF Mental	-.167	.320**	.576**	.591**	1						
(6)2010 Physical	-.144	.534**	.497**	.574**	.421**	1					
(7)2010 Mental	-.295*	.332*	.470**	.426**	.621**	.697**	1				
(8) SF-12 Physical Change Variable	.156	.549**	.196	.072	-.061	-.482**	-.405**	1			
(9) SF-12 Mental Change Variable	.210	.440**	.663**	.254*	.155	-.087	-.440**	.519**	1		
(10) 2010 WHOQoL	-.178	.281*	.368**	.474**	.490**	.778**	.694**	-.448**	-.197	1	
(11) 2010 CASP	-.110	.279*	.403*	.489**	.639**	.558**	.700**	-.269	-.245	.704**	1

**Correlation is significant at the 0.01 level (2-tailed)

*Correlation is significant at the 0.05 level (2-tailed)

4.2.3 Research Question Three – Is there a difference in health behaviours between males and females?

The health behaviours investigated in this study were; alcohol consumption, smoking identity, physical activity and social support.

T-tests were performed on the independent variables of alcohol consumption, smoking identity, physical activity and social support and the dependant variables were males and females. For social support there was no statistically significant difference between males and females. The difference between moderate weekly physical activity for males and females was significant $t(133.0) p > .001$ with males on average doing 3.04 hours more exercise a week than females (See figure 1).

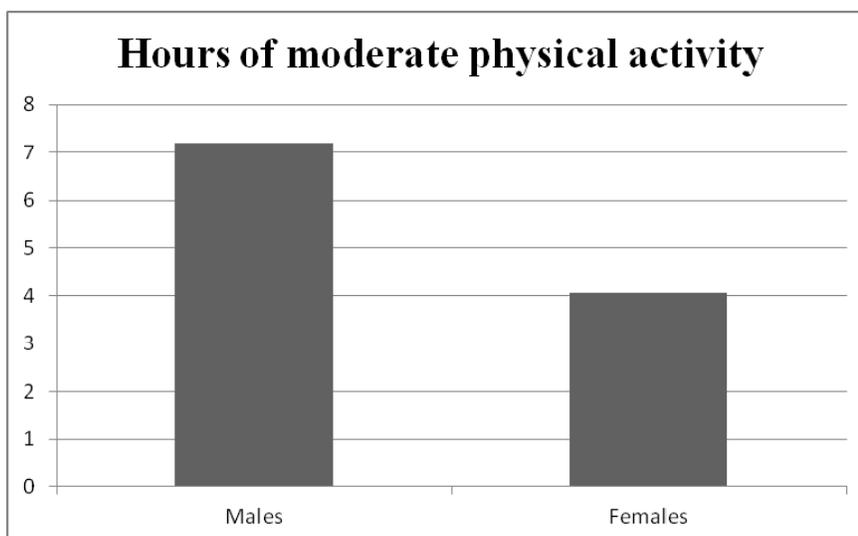


Figure 1- Mean scores of hours of moderate physical activity per week between males and females.

The chi-square test for an association between gender and alcohol consumption in cancer participants (see Table 5) was statistically significant $X^2 (1, N=188) = 15.0, p > .001$.

Table 5.

Levels of Alcohol consumption between males and females.

	Lifetime abstainer		Current non-drinker		Light drinker		Moderate drinker		Heavy drinker	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Males	2	2.4%	8	9.5%	29	34.5%	33	39.3%	12	14.3%
Females	7	6.7%	9	8.7%	53	51.0%	33	31.7%	2	1.90%

A Pearson's chi-square test of contingencies was used to evaluate whether smoking is related to gender and this was not significant (See Table 6).

Table 6.

Number of smokers and non-smokers between males and females.

	Smokers		Non Smokers	
	<i>n</i>	%	<i>n</i>	%
Men	10	9.9%	91	90%
Women	13	8.4%	126	90.6%

4.2.4 Research Question Four – Is there a relationship between Religion/Spirituality and gender?

Pearson's r correlations (see Table 7) showed that there is a significant relationship between gender and Religion/Spirituality combined $r = -.243$, p (two tailed) $< .01$, the importance of Religious faith $r = -.129$, p (two tailed) $< .05$, Spiritual activities importance $r = .318$, p (two tailed) $< .01$ and Spiritual activities frequency $r = .246$, p (two tailed) $< .01$ with males scoring predominantly higher than females.

Table 7.

Correlations between Gender and Religion/Spirituality. N=202

Variables	(1)	(2)	(3)	(4)	(5)	(6)
(1) Gender	1					
(2) Religion/Spirituality	.243**	1				
(3) Attend Religious Meetings	.115	.734**	1			
(4) Importance of Religious Faith	.129*	.958**	.695**	1		
(5) Spiritual Activities Importance	.318**	.695**	.712**	.849**	1	
(6) Spiritual Activities Frequency	.246**	.875**	.786**	.786**	.895**	1

**Correlation is significant at the 0.01 level (2-tailed)

*Correlation is significant at the 0.05 level (2-tailed)

4.3 Religion and Spirituality

The second set of analyses examined Religion/Spirituality and QoL in cancer survivors. Health behaviours (alcohol consumption, smoking identity, physical exercise and social provisions) among cancer participants were also investigated in regards to Religion and Spirituality. Over 76% of cancer survivors stated that Religion has some importance and 88% stated that Spirituality has some importance in their lives. Pearson’s correlations and hierarchical multiple regression were performed for this set of analyses.

4.3.1 Research Question Five– Is there a difference in perceived Physical and Mental Health QoL between those who are Religious and Spiritual and those who are not?

Pearson’s *r* correlations were performed and Table 8 demonstrates Spiritual Activities Frequency and SF-36 Physical Health revealed a slight negative relationship $r = -.145, p$ (two-tailed) $< .05$. No other relationships were identified with the other Religious and Spiritual variables.

Table 8.

2008 Correlations between QoL and Religion/Spirituality. N=202

Variables	(1)	(2)	(3)	(4)	(5)	(6)	(7)
(1)2008 SF Physical	1						
(2)2008 SF Mental	.596**	1					
(3)Religion/Spirituality combined	-.122	-.052	1				
(4)Importance of Religion	-.117	-.154	.700**	1			
(5)Religious attendance	.050	-.023	.734**	.409**	1		
(6)Importance of Spirituality	.004	-.036	.965**	.746**	-	1	

Spiritual activities					.158**		
(7)Spiritual activity frequency	-.145*	.040	-	-.556**	.699**	.715**	1
				.875**			

**Correlation is significant at the 0.01 level (2-tailed)

*Correlation is significant at the 0.05 level (2-tailed)

A hierarchical multiple regression equation was run to test the hypothesis that Spiritual Activity Frequency may contribute to improved Physical QoL in cancer survivors. Before performing the analysis a number of assumptions were tested. The assumptions of normality, linearity and homoscedasticity of the residuals were met. The dependent variable was the 2008 SF-36 Physical Health QoL score. The independent variable at the next step was the Spiritual Activity Frequency variable.

At the first step the control variables, age, ethnic identity and socio economic status (SES) were entered. These three independent variables together significantly predicted 9.9% of the variance in Physical Health (Adj. R^2 =.099, $F(3,183)$ =7.81, p =.000).

At the second step the when Spiritual Activity Frequency was added into the Physical Health regression model, R^2 decreased from .099 to .098 (an R square change of .001). This change was not significant.

4.3.2 Research Question Six- Is there any difference in QoL scores overtime of those that are Religious/Spiritual and those that are not?

The SF-12 scores from 2006 to 2010 indicated a decrease in mean scores over time for both SF-Physical and Mental Health QoL. To analyse the difference in QoL over time, two new variables were created in which the 2010 data for each of the Physical Health SF-12 and Mental Health SF-12 were subtracted from the 2006 data giving a difference score over time from 2006- 2010. The mean scores for both the SF-Physical and Mental Health QoL difference variables are in the table 9.

Pearson's r correlations (see Table 9) showed a significant relationship between the combined Religion/Spirituality variable and the 2010 SF-12 Mental Health QoL measure $r = -.267, p$ (two tailed) $<.01$ and Religion/Spirituality with the Mental Health change variable $r = .288, p$ (two tailed) $<.05$. There was also a significant relationship between Religion/Spirituality and Age $r = .267, p$ (two tailed) $<.05$ (see table 9).

Table 9.

Correlations between QoL, Religion/Spirituality and controlled variables (age, ses, ethnicity), in the 2006,2008 and 2010 surveys. N=61

Variables	(1)	(2)	(3)	(4)	(5)	(6)	(7)	(8)	(9)	(10)	(11)	(12)	(13)
(1)Religion/Spirituality	1												
(2)2006 SF Physical	-.069	1											
(3)2006 SF Mental	.072	.635**	1										
(4)2008 SF Physical	-.162	.597**	.567**	1									
(5)2008 SF Mental	-.158	.371**	.605**	.663**	1								
(6)2010 SF Physical	-.050	.468**	.458**	.550**	.453**	1							
(7)2010 SF Mental	-.267**	.218**	.387**	.366**	.534**	.657**	1						
(8)SF Physical Change	-.021	.549**	.196	.072	-.061	-.482**	-.405**	1					
Variable													
(9)SF Mental Change Variable	.288*	.440**	.663**	.254*	.155	-.087	-.440*	-.519**	1				
(10)Participant Age in 2010	.267*	-.154	-.030	-.116	.130	-.127	.080	-.024	-.095	1			
(11)SES in 2010	-.177	.267*	.146	.211**	.235*	.378**	.477**	-.129	-.205	.159	1		
(12)Primary Ethnicity 2010	-.250	.300*	.167	.355**	.350**	.468**	.488**	-.009	-.281*	.028	.071	1	
(13)Treatment Status	-.252	.154	.135	.345*	.214	.138	.266	.029	-.041	.088	.359*	.108	1

**Correlation is significant at the 0.01 level (2-tailed)

*Correlation is significant at the 0.05 level (2-tailed)

Two hierarchical multiple regression equations were run to determine if Religion and Spirituality contributed to improved QoL over time. The dependant variables were either SF-12 Physical Health 2006-2010 change scores or SF-12 Mental Health 2006-2010 change scores. The independent variable at the next step was the combined Religion and Spirituality variable. Preceding the analysis the variables were screened to ensure that the assumptions were met for the analysis.

At the first step the control variables were used from the 2010 wave including, age, ethnicity, socio economic status (SES) and gender. These independent variables collectively accounted for 5.1% of the variance in Physical Health (Adj. $R^2 = .051$, $F(4,49) = .356$, $p = .838$), however this was not significant. For the Mental Health variable the independent variables collectively accounted for 7.5% of the variance in Mental Health (Adj. $R^2 = .075$, $F(4,49) = .145$, $p = .098$), with Physical Health the independent variables predicted .7.5% of the variance in Physical Health however this was also not significant.

When Religion/Spirituality was entered into the regression model on block 2 of the Physical Health analysis R_2 decreased from .151 to .150 (an R square change of .001). This was not significant. In the Mental Health analysis R_2 decreased from .075 to .088 (an R square change of .003). This was also not significant.

4.3.3 Research Question Seven - Do cancer survivors who are Religious/Spiritual also engage in better health behaviours? (less smoking, less alcohol, and more exercise).

Pearson's r correlations (see Table 10) were carried out on the 2008 data and showed that there was a significant relationship between the Religion and Spirituality variable combined and alcohol use $r = -.291$, p (two-tailed) $< .05$ and the importance of Religion and alcohol use $r = -.278$, p (two-tailed) $< .05$. Religious attendance and alcohol use $r = -.251$, p (two-tailed) $< .05$ and moderate exercise $r = -.153$, p (two-tailed) $< .05$ importance of Spiritual activities and frequency with alcohol use $r =$

.289, p (two-tailed) $<.05$ and $r = -.217$, p (two-tailed) $<.05$. No other correlations were found between Religion/Spirituality and health behaviours.

Table 10.

2008 correlations between Religion/Spirituality and Health Behaviours. N=201.

Variables	(1)	(2)	(3)	(4)	(5)	(6)	(7)	(8)	(9)	(10)	(11)	(12)
(1)Religion/Spirituality combined	1											
(2)Importance of Religion	.968**	1										
(3)Religious Attendance	.717**	.683**	1									
(4)Importance of Spiritual Activities	.968**	.872**	.698**	1								
(5)Spiritual Activity Frequency	.892**	.816**	.737**	.908**	1							
(6)Alcohol Use	-.291*	-.278**	.251**	-.289**	-.217**	1						
(7)Smoking Identity	-.062	-.124	-.036	-.007	.051	-.156*	1					
(8)Hours of moderate Activity	.053	-.025	-.153*	.058	-.058	.119	.010	1				
(9)Social Support	-.052	-.123	.026	-.026	-.053	.179*	.159*	-.065	1			
(10)Age	.190*	.192**	-.236**	.187***	-.201**	-.086	.030	.141*	.002	1		
(11)SES	-.264**	-.192**	.210**	-.289**	.239**	.274**	.077	.072	.410**	.079	1	
(12)Ethnicity	-.091	.128*	-.030	-.080	.099	.062	-.159*	.015	-.044	.020	-.004	1

4.3.4 Post Hoc Analysis. Does alcohol consumption mediate the relationship between QoL and Religion and Spirituality?

A positive correlation was found between alcohol and Physical Health QoL $r = -.217$, p (two-tailed) $< .05$. It was also revealed earlier that there was a slight but positive relationship between Spiritual Activities Frequency and SF-36 Physical Health $r = -.145$, p (two-tailed) $< .05$. Therefore an analysis was run to see if alcohol consumption mediates the role between Religion/Spirituality and QoL.

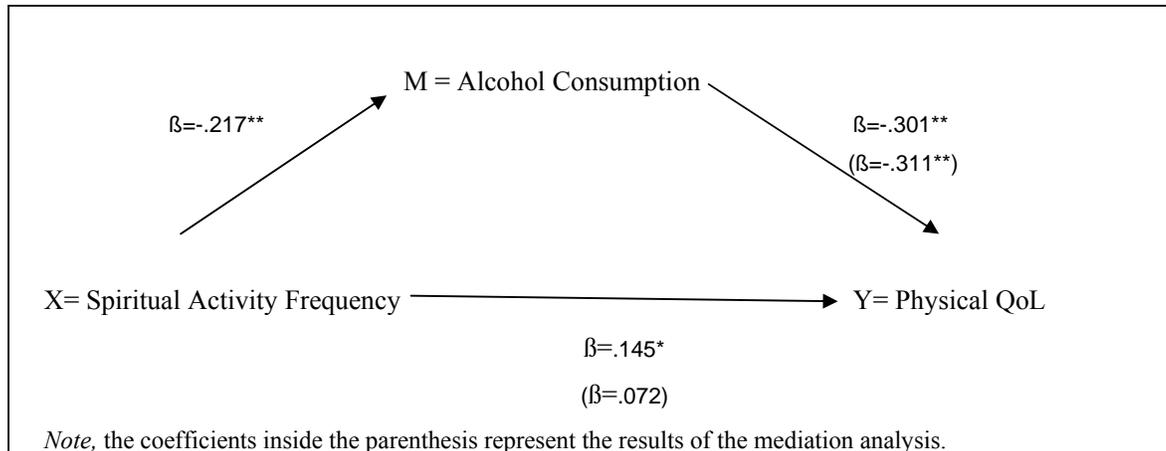
Judd and Kenny (1981) established four criteria that should be met to ascertain if alcohol consumption mediates the relationship between Spirituality and Physical Health QoL. These are:

Step 1: The independent variable of Spiritual Activity Frequency should be associated with the dependent variable of Physical Health QoL. This establishes that there is an effect that may be mediated.

Step 2: The independent variable Spiritual Activity Frequency should be associated with the mediator variable Alcohol Consumption. This step involves treating the mediator as if it were the outcome variable.

Step 3: The mediator variable Alcohol Consumption should be associated with the dependent variable of Physical Health QoL. The independent variable must be controlled in establishing the effect of the mediating variable on the outcome as the mediating variable and the dependent variable may be correlated because they are both caused by the independent variable.

Step 4: The mediator variable Alcohol Consumption completely mediates the independent variable to dependent variable relationship (Spiritual Activity Frequency – Physical Health QoL). The effect of Spiritual Activity Frequency on Physical Health QoL controlling for Alcohol consumption should be zero.



* $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$

Figure 2. Test of Alcohol consumption as a mediator of linkage between Spirituality and Physical QoL.

To determine if Alcohol Consumption mediated the relationship between Spiritual Activity Frequency and Physical Health QoL, four regressions were run. Figure 2 illustrates the results of the mediating relationship.

1. Association between the independent variable and dependent variable. A regression analysis was run between the Spiritual activity frequency and Physical Health QoL. Spiritual Activity Frequency was entered as the independent variable and Physical Health QoL as the dependent variable. The Beta value shows that Spiritual Activity Frequency is significantly associated with Physical Health QoL. Criterion one is satisfied.
2. An association between the independent variable and mediating variable. A regression analysis was run between Spiritual Activity Frequency and Alcohol Consumption. The Beta value shows that Spiritual Activity Frequency is significantly associated with Alcohol Consumption. Criterion two is satisfied.
3. An association between the mediator variable and the dependent variable. A regression analyses was run between Alcohol Consumption and Physical Health QoL. The Beta value shows that Alcohol consumption is significantly associated with Physical Health QoL. Criterion three is satisfied.
4. A fourth regression analysis was run between Spiritual Activity Frequency, Alcohol Consumption and Physical Health QoL. Spiritual Activity Frequency

and Alcohol Consumption were entered as independent variables. The Beta value shows that Alcohol Consumption is significant associated with Physical Health QoL and the Spiritual Activity Frequency Beta is no longer significant. Criterion four is satisfied (See Table 11).

Table 11.

Mediation test using regression on Alcohol Consumption mediating Spiritual Activity Frequency and Physical Health QoL. N=202.

Independent Variables	R ²	β
<u>Equation 1:</u> Spiritual Activity Frequency – Physical QoL	0.16	.145*
<u>Equation 2:</u> Spiritual Activity Frequency – Alcohol Consumption	.041	-.217**
<u>Equation 3:</u> Alcohol Consumption – Physical QoL	.085	-.301**
<u>Equation 4:</u> Spiritual Activity Frequency – Alcohol Consumption – Physical QoL	.098	-.311**

* $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$

CHAPTER FIVE: DISCUSSION

5.0 Introduction

The purpose of this research is to provide more information on how cancer survivors in New Zealand are coping after diagnosis and over time. This study therefore investigated differences between cancer survivors and the effects of those differences on their quality of life (QoL). Literature has identified multiple areas that can influence QoL including gender, Religion/Spirituality and health behaviours. This study investigated differences in, gender, Religion/Spirituality, alcohol consumption, smoking identity, physical activity and social support. These variables were also examined to identify the possible effect on cancer survivor's physical and mental QoL. The results of the analyses performed will be discussed.

5.1 Gender

5.1.1 *Research Question One*

The results of this study indicate that there is no difference between gender and QoL in cancer survivors. This study did not identify any evidence that physical and mental QoL are different between males and females. This was unexpected given that research has indicated that there are differences between males and females and their QoL in the general population. In American literature there are clear differences in health related QoL and these differences are partly explained by socio-demographic and socio economic status (SES) differentials (Cherepanov, Palta, Fryback, & Robert, 2010). Even though The New Zealand Health Status Questionnaire which looked at QoL in New Zealanders was conducted over 10 years ago in 1996/97, the results also found distinct differences in QoL between males and females with males scoring slightly higher than females on all scales except for general health. Although there has not been a wide range of research looking at the differences in QoL between male and female cancer survivors, there has been some research to indicate differences in mental or physical health. Various studies

overseas have reached differing conclusions however the research does point to females experiencing poorer QoL especially in regards to physical functioning and fatigue (Demark-Wahnefried, McBride, Peterson, Lipkus, & Clipp, 2000; Schmidt et al., 2005). One rationale for female cancer survivors reporting poorer QoL in general, is that due to surgery particularly in breast cancer survivors, scarring has been seen to negatively impact on the psychophysical identity of a female, contributing to anxiety and body image distortions (Demark-Wahnefried et al., 2000).

A possible explanation for this study identifying no relationship between gender and QoL may be due to New Zealand having a relatively high standard of living and a public health system that is accessible to all. A lot of the previous research that has been conducted has come from the United States which could be a factor due to the vast differences how the health of the two populations is managed. The World Health Organisation has confirmed through research that the United States does perform poorly in comparison to other industrialised nations (*The World Health Report*, 2000). Reasons for America's substandard performance are complex and multifactorial, however research has continuously pointed out America's historical failure to build a strong primary care infrastructure which has possibly contributed to a high degree of social inequality (Starfield, 2000). Therefore raising the question whether research between countries with such different health systems can be compared?

5.1.2 Research Question Two

Pearson's correlations found no significant associations between the Mental Health QoL and Physical Health QoL difference variables therefore indicating that there is no difference in males and females change in QoL over time. Both males and females reported decreased QoL of life over time however these results show that the decrease is at the same rate.

5.1.3 Research Question Three

T-tests were performed on the independent variables of alcohol use, smoking identity, physical activity and social support and various relationships were found.

An association was found between gender and alcohol consumption. Males were more likely to be heavy drinkers than females, and females were more likely to be moderate drinkers. The results identified that 14.3% of males were heavy drinkers opposed to only 1.9% of women. Research of the general population has identified a higher prevalence of high volume drinking among males than females (Wilsnack, Wilsnack, Kristjanson, Vogelanz-Holm, & Gmel, 2009). Additionally it has been found that females are more likely to stop drinking altogether than males.

Worldwide, literature has revealed that older males are still drinking high quantities of alcohol, where as alcohol consumption within females does in general decrease with age (Wilsnack et al., 2010). The results from this study fall in line with research on the general population suggesting that possibly having had cancer is not sufficient deterrence for males to stop consuming large amounts of alcohol that equate to heavy drinking, and that perhaps there are other factors that need to be explored within this group. Additionally of interest is that the cancer survivors in this research are over the age of 55, indicating that there is a gap in our understanding of why some older people are consuming large amounts of alcohol. What are the factors that could be influencing alcohol consumption in not only males but older male cancer survivors in New Zealand? Factors such as environmental or cultural habits may play a part in older men drinking, are they self medicating to deal with their cancer or other underlying health issues? Is it social isolation? In New Zealand and Australia, a popular place of congregation for elderly males has been establishments like the Returned Services Association (RSA) or sporting events and venues. These places could possibly contribute to creating a culture where drinking is very socially acceptable. The Alcohol Advisory Council (ALAC) of New Zealand offer explanations as to why New Zealanders drink and state that alcohol is intrinsic to cultural significance of socialisation, entertainment and celebration hospitality. That alcohol consumption is definitive of the social characteristics of early settlement by the English (Galloway & Bruce, 2011). Additionally, research has found links between rural pub culture and gender performativity where drinking performance is viewed as essential to masculinity (Campbell, 2000). However, little is really known as to why older New Zealanders and those who have survived an illness like cancer are drinking large quantities of alcohol. Further research is needed to better

understand this and more exploration of the cultural circumstances in which heavy drinking is facilitated by various environments.

In this study there was no association between gender and smoking. Generally overseas it has been found that men are more likely to be smokers especially in countries like Japan, India, Pakistan and Korea. However this does vary from country to country with males only smoking slightly more than females in Europe and the U.S (Chung, Sengji, Lim, & Sunmi, 2009). The New Zealand population is different yet again with females being recorded as more likely to smoke, in particular Māori females (Barnetta et al., 2005). There has been limited research on gender differences in smoking of cancer survivors and this may be due to cancer survivors choosing to quit smoking after falling ill and therefore smoking not being a big enough of a problem to warrant any research. However the insignificant findings in this research are particularly interesting given the high incidence of female smokers reported in New Zealand.

This study found a moderate association between gender and physical activity with males on average exercising 3.04 more hours a week than females. Numerous studies have indicated that physical exercise is associated with better all round QoL (Courney, 2003; Holmes et al., 2005; Knobf et al., 2007; Schmitz et al., 2005). In terms of gender differences in cancer survivors there has been a lot of research carried out on the positive effects of exercise on females however very little investigating if female cancer survivors exercise more than males. Research has resulted in various health promotion schemes being established to support those effected by cancer such as Pink Pilates which was specifically set up to help women diagnosed with cancer, Race for Life conceived for raising awareness of women's cancers: Relay for life, Tri Women's Series for breast cancer survivors and various dragon boating teams racing specifically for breast cancer research. There is however no research that has looked closely at the physical activity patterns of those who have survived cancer and this could be an area of interest in promoting well being amongst cancer survivors.

Results of the research found no association between gender and social support. This result was unexpected given that the literature has been reasonably consistent in

finding that females utilise social support more than males (Goldzweig et al., 2008; Hammerlid & Taft, 2001) . Additionally multiple differences were found in a study done on the same Health Work Retirement (HWR) survey data (Stephens, Alpass, Towers, & Stevenson, 2011) identifying that females were more likely to have more and stronger perceptions of support and social network and more reported loneliness suggesting more need for more social support. However, there were no gender differences found in those with family dependent networks suggesting that at the later stage of life importance of family support are equally important for both males and females. Possible explanations for the lack of differences in this research could be that both males and females increase their level of social support after a diagnosis of cancer therefore balancing out any gender differences that existed before hand. Another consideration is the usefulness of the social support measure used in this research. It may be that the measure was unable to capture a bigger picture of social support in terms of the different types of social support for cancer survivors and the quantity and quality of these types of social support.

5.1.4 Research Question Four

In regards to health it has been proposed that Religion and Spirituality is not the same across gender (Thoresen & Harris, 2003). In this study, associations were found between gender and various Religious and Spiritual variables. Pearson's correlations were performed and there was a significant relationship between gender and the Religion/Spirituality combined variable indicating that female cancer survivors are slightly more Religious and Spiritual overall. When looking at Religion and Spirituality variables separately, females were more Religious and males more Spiritual. This was an interesting finding given that within the literature females are reported as being both more Religious and Spiritual than males (Miller & Thoresen, 2003). There has been little research investigating gender and Religion/Spirituality within the cancer survivor cohort however gender is quite often a control variable in Religious/Spiritual research. There have been few evidential explanations as to why there are differences in gender; however the research that has been undertaken has indicated females to be more Spiritual than males. One study suggested that females who have had breast cancer have turned to Religion and Spirituality for a coping strategy due to the breast being an essential part of a women's femininity and

sexuality (Choumanova, Wanat, Barrett, & Koopman, 2006), this however could be indicative of type of cancer opposed to gender. One more study (Stark, 2002) suggested that females are more likely than males to seek religious consolation, however there was no evidence in this study to support this theory. A different explanation offered in the literature was that females are socialised to be more religious than males, with females being raised to be more nurturing and submissive. However again, this can't be exclusive for cancer survivors. One study found that religiousness was associated with more femininity within each gender (Thompson, 1991) further supporting that Religion/Spirituality is more a of a feminine concept.

Research about Religion/Spirituality and gender is still clearly in its infancy. The literature and the findings from this study has revealed some evidence to suggest that females are more Religious/Spiritual than males. However why this is so is still very unclear. More in-depth research into how Religion/Spirituality impacts on males and females and how this relates to the health and QoL could be useful in further understanding cancer survivor's needs.

5.2 Religion and Spirituality

5.2.1 Research Question Five

Multiple Religious/Spiritual variables were tested against QoL and results revealed one significant relationship. Spiritual Activities Frequency negatively correlated with Physical Health QoL, indicating that the more Spiritual activities one engages in, the worse their Physical Health QoL. The remaining insignificant findings were unexpected given the growing literature in this area which is starting to reveal some strong positive relationships between Religion/Spirituality and QoL in those who have survived cancer.

Spiritual activities in the 2008 HWR questionnaire referred to praying, meditating or worshipping. It has been suggested that Religious/Spiritual practices such as prayer and meditation could be seen to enhance a sense of control over stressful events like cancer by helping the person to achieve a personal relationship with a higher entity

that offers strength and support to cope with their illness (Jenkins & Pargament, 1995). Additionally there has been some research which has taken these findings a step further and identified biological pathways between Religious/Spiritual activities and physical health (Kim & Seidlitz, 2002; E. G. Levine & Targ, 2002) such as Spirituality impacting on the immune system in females with breast cancer. Even though a link has been found in research, this study was not able to establish such links due to the absence of investigation around physiological process of the HWR participants. Literature has also proposed that Religious/Spiritual activities can improve physical health via increased social support and health protective behaviours by reducing the physiological stress response (Idler et al., 2003). This study found no relationship between Religion/Spirituality and social support, which may be a possible rationale why the relationship came back negative. For New Zealand cancer survivors it may be that Spiritual activities are activities practiced in solitude not as part of a group or community thus not providing the social interaction that has been shown to be a possible link to better QoL. Further research on what and how cancer survivors practice spirituality would be valuable in trying to understand why this group have poorer QoL.

There has been some research to which this study can support where Religion/Spirituality has been shown to have a negative effect on QoL. Specifically in cancer survivors, negative religious coping strategies have been found which includes the belief that cancer is a punishment handed down by God (Choumanova et al., 2006). There is also the explanation that those who already feel low in energy and have poor QoL may in turn seek Religious/Spiritual support to help in coping with the negative feelings. Therefore it could be assumed that in this study those who stated that they are Religious/Spiritual could have recently adopted a new faith in order to cope with their poor QoL. However it is hard to identify if this was a probable reason due to no questions asking how long the cancer survivor has considered themselves Religious/Spiritual.

In regards to all other Religious/Spiritual variables tested no significant relationships were found, which was unpredicted given the growing literature revealing

relationships in this area and that this study tested a variety of Religious/Spiritual variables. An explanation could be that the majority of research that has been undertaken on Religion/Spirituality of cancer survivors has been predominantly in the United States, a country that has been found to be the most religious nation in the industrialized world (Martin, 2012). The percentage of New Zealanders identifying with no religion is currently 34.7% - double the United States which is 16.1% (Pew Forum, 2008). Therefore due to New Zealand being perhaps less Religious than the United States this could offer a possible explanation for the lack of positive findings in this study. New Zealand may not be as Religious as the United States however spirituality (wairua) has been acknowledged as an important part of health in particular for Māori and as a result Māori Spirituality has been incorporated into health promotion and treatment. It would have therefore been expected that this may have had some impact on the results of this study, however including Spirituality in health is still relatively a new concept in New Zealand, therefore perhaps not having a strong enough influence yet. Additionally, this study's sample size only contained a small representation of Māori therefore not capturing enough of this cohort.

In conclusion, variables that determine whether Religion/Spirituality plays a positive or negative role are myriad and complicated and context dependent and again the specific pathways unclear.

5.2.2 Research Question Six

When QoL scores were tested over time, Pearsons' r correlations identified that there was a significant negative relationship between Religion/Spirituality and 2010 Mental Health QoL. This suggests that those who responded in the 2010 wave who are more Religious/Spiritual have worse Mental Health QoL. However, a positive relationship was found between Religion/Spirituality and the Mental Health Change variable indicating that those who are more Religious/Spiritual have better Mental Health QoL over time. This is an interesting finding given that there have not been many studies performed looking at these relationships over time. The positive longitudinal results can support existing research that claims that

Religion/Spirituality can contribute to a better state of mind. The literature has provided multiple explanations for this positive relationship including that those who include Religion/Spirituality in their life are more likely to have a better Mental Health QoL. That Religious beliefs can assist cancer survivors to cognitively reframe or reconstruct the meaning of their cancer experience, equipping the cancer survivor with the self efficacy to take control of their cancer journey (Park et al., 2009). Additionally it has been suggested that the relationship that a person has with God may provide an external framework of control that brings with it more sense of security and certainty thus easing anxiety in those who have had to deal with the psychological blow of been diagnosed with cancer (Jenkins & Pargament, 1995). This research could potentially support these ideas, however more investigation would be required into exactly how Religion/Spirituality impacts on Mental Health QoL over time.

Whilst performing the longitudinal analyses, an additional relationship was discovered between Religion/Spirituality and the control variable Age suggesting that those who are older are more Religious/Spiritual. Age was not a focus of this study however this result does support literature which states that older people are more Spiritual/Religious (Yoon, Kyoung, & Lee, 2008). It therefore would be interesting to have looked at the older participants in this study as a separate group to see if there were any more significant relationships between Religion/Spirituality and QoL.

5.2.3 *Research Question Seven*

Various relationships were found between Religion/Spirituality and the health behaviours; alcohol consumption, smoking identity and physical exercise.

The results revealed differing associations between Religion/Spirituality and alcohol consumption with the majority of the Religious/Spiritual variables supporting literature that those who are more Religious/Spiritual drink less. There was however one exception with the Religious attendance variable where those who attended church more frequently reported consuming more alcohol. This finding is in

contradiction to a lot of the research one example being The Gallup survey (Newport, 2010) which looked at drinking patterns in Americans and found that one of the most significant predictors of less alcohol consumption was church attendance. Except for this one negative finding the rest of this study can support existing literature and possibly the explanations given in the literature as to why those who are more Religious/Spiritual consume less alcohol. Rationalisations offered in the literature included Religion being a promoter of social norms against indulging in drinking behaviour and Religion facilitating better coping abilities therefore reducing alcohol consumption as a coping mechanism (Park et al., 2009). However how can this explain the negative association between religious attendance and alcohol consumption in this study? More investigation is required to ascertain why this result was found. If this study revealed a relationship between religious attendance and social support then this could of been a possible avenue to explore in understanding this finding. Due to the nature of this study, the mechanisms by which religious participation influences drinking behaviour cannot be clarified. It could be that religious attendance influences alcohol related cognitions which in turn controls one choice related to alcohol use. Further research in this area would be of interest.

No relationship was identified between Religion/Spirituality and smoking in this study suggesting that for cancer survivors, Religion and Spirituality does not play a part in their choice to smoke or not to smoke. This is the second non significant result related to smoking in this study with the analysis between gender and smoking also revealing no relationships. This could be due to smoking not being a prominent feature in the cancer survivor population and therefore an area that does not need further consideration in cancer survivorship treatment and aftercare.

A significant association was found between religious attendance and moderate exercise revealing that those who attend more religious gatherings exercise less. This was an unexpected and interesting result given the literature claiming a positive link between Religion/Spirituality and health behaviours such as physical exercise. There has however been very little research looking specifically at physical activity with the majority of the literature focusing on alcohol consumption and smoking therefore

making this a relatively new area of investigation. More investigation into this area would be interesting, especially in New Zealand which has strong sporting culture.

5.2.4 Research Question Eight

No relationship was identified in this study between Religion/Spirituality and social support. This was unexpected given the amount of literature finding positive relationships indicating that social support may act as a mechanism through which Religion/Spirituality can improve QoL. Various studies (Dunin, 2005; Lim & Yi, 2009) identified that the social networks that Religious institutions provide may offer extra avenues for social support. There has been an abundance of research on perceived social support and its strong positive effects on mental health. In the elderly population in particular, loneliness, lack of emotional support may leave older cancer survivors vulnerable to physical and psychological problems (Yoon et al., 2008). The link between social support and depression in particular has been found in research (Bosworth et al., 2000). Therefore with all the research pointing in the direction that social support is very much related to Religion/Spirituality and QoL, the fact that this study brought back no significant results was surprising.

Explanations as to why this study failed to identify any relationships could lie in the choice of measurements used in this study not being adequate enough in capturing the appropriate data. As already mentioned, only a few relationships were identified between the Religious/Spirituality variables and QoL, therefore perhaps further reducing the chance of finding any links with social support. This finding also raises the question of is Religion/Spirituality more of an individual than a communal practice amongst cancer survivors in New Zealand? More information around how New Zealanders practice Religion/Spirituality may provide more understanding around how Religion/Spirituality helps those who have survived cancer.

5.2.5 Research Question Nine and Ten:

Due to the lack of identifying any significant relationship between social support, Religion/Spirituality, QoL and gender, no further analysis were performed.

Ad Hoc Hypothesis:

To ascertain if alcohol consumption mediates the relationship between Spirituality and Physical Health QoL regression analyses were performed. Spirituality contributed to 1.6% of the variance in QoL and Alcohol Consumption 8.5% of the variance. Further analysis was then performed and a mediating relationship was identified where those who engaged in more Spiritual activities drunk less alcohol but reported poorer Physical Health QoL. This was an unanticipated finding as recent literature investigating Religion/Spirituality and health has found that those who engage in more Spiritual activities such as prayer and meditation are more likely to have improved QoL compared to those who don't (Jenkins & Pargament, 1995). In addition, research examining alcohol consumption and QoL has found that those who drink more alcohol experience poorer QoL (Hallgren, Högberg, & Andréasson, 2010). Therefore the findings of this study contradict the majority of research conducted on these variables.

There is however some research that this study can support which can in turn provide possible explanations for the results. Some research has identified that in the general population moderate levels of alcohol consumption in older people can have positive effects on health. Studies have found that in middle aged to older males and females, moderate levels of alcohol consumption were associated with better cognitive health, positive effects on cardiovascular morbidity and mortality, and overall improved global health (Allison, 2002; Lang, Guralnik, Wallace, & Melzer, 2007; Stampfer, Kang, Chen, Cherry, & Grodstein, 2005). In regards to cancer survivors there has also been research supporting moderate alcohol consumption and its positive effects on multiple pathophysiological processes such as insulin resistance, inflammation dyslipidemia, endothelial dysfunction and hemostatis. These findings are in complete contradiction to well known literature that claims that alcohol consumption can contribute to worse physiological functioning and play a part in the etiology of some cancers like breast cancer. Due to this research not investigating pathophysiological processes, it is difficult to claim this explanation.

Other possible factors mentioned in the literature to consider when reflecting on the results of this study are that of social support and socio economic status (SES). Recent research has identified that SES may play a role in the amount of alcohol individuals consume. The Gallup survey (Newport, 2010) which looked at drinking among the American population found that the more educated tend to consume alcohol more frequently than other socio economic groups. It has been found that educational qualifications, income and occupation can be related to alcohol consumption in the New Zealand population. That those with higher SES tend to drink more frequently whilst the lower socio economic groups drink larger quantities (Huckle, You, & Casswell, 2010). Possible explanations for why this may be the case is that people who have more wealth are able to afford to consume more alcohol more frequently. Another suggestion being that those who are in a better financial position may have more fun, see more people and are able to do more positive activities. SES was not taken into consideration in this analysis and could of possibly impacted on the findings. Additionally, even though this study was unable to find any relationship between social support and QoL there have been many links found in the literature that social support could also provide a pathway through which alcohol consumption increases levels of socialisation and in turn benefiting QoL. Results from this study and various other studies could possibly challenge the belief that moderate alcohol consumption is detrimental to health and instead may outweigh the risk to specific cancers.

5.3 Strengths and Limitations of the study

The sample size provided by the HWR data combined with the collection of data over the three waves gave good power to this study. Additionally, the age range of 55-75 enabled a solid representation of those that have had cancer in the New Zealand population.

The mixture of Religious and Spiritual variables provided a good quantitative measurement of Religion and Spirituality in New Zealand. The questions included both attendance, frequency and level of importance which is more in depth than existing overseas literature which has predominantly focused on church attendance.

Additionally, this study included both Religion and Spirituality opposed to just one of the constructs making it more pertinent to the New Zealand context. Spirituality may be more prominent in New Zealand than organised Religion due to Spiritual importance in the Māori worldview and also for other newer cultures in New Zealand.

Even though this research accessed a good range of Religious/Spiritual questions other questions would have been of benefit. Looking at different types of Religions may have provided more information and perhaps clarification around some of the findings. A lot of published literature in this area has focused predominantly on Christianity and not other Religions or Spiritual groups. Identification of the main Religion/Spiritual groups in this study may have provided further understanding of the results. Also more information of when and how long the cancer survivors considered themselves Religious/Spiritual would of been useful in ascertaining if the cancer experience played a role in choosing to follow a faith or not. Lastly including questions which could assist in identifying any potential physiological links between Religion/Spirituality and health would of given more strength to the study.

A limitation is that access to all cancer survivors was limited due those who are in nursing homes, dependent care and those incarcerated not being included in the study. These exclusions could of included cancer survivors who were in care for their cancer or in palliative care.

Socio economic status could have been included as a control variable in the mediating analysis as it could of possibly confounded the results.

5.4 Conclusion

The varied results of this study have demonstrated that the issues that cancer survivors face are complex, varied and can depend on different factors. There were multiple unexpected findings given what the literature has offered in terms of cancer survivorship research. It was revealed in this study that there are some differences between gender and those who are Religious/Spiritual and those who are not.

However the results of this study have raised more questions in regards to what impacts on cancer survivors QoL.

The results of this study revealed that gender does not play a role in the QoL of cancer survivors in New Zealand, demonstrating that unlike in the general population both males and females are on equal footing in regards to QoL. Differences were identified in health behaviours with male cancer survivors consuming more alcohol and also engaging in more physical activity than females. Additionally females reported to be more Religious/Spiritual than males. An unforeseen finding in this study was the insignificant findings between social support and QoL. There has been strong research to suggest that social support is a positive indicator for improved QoL in the older population. The literature has also reported various differences between males and females and that social support can play a mediating role between Religion/Spirituality and QoL. The lack of positive findings from this study raises questions around the value of social support for cancer survivors in New Zealand and that for this cohort social support may not be as essential indicating that possibly other factors that were not investigated in this study may be of more significance.

One of the most unanticipated findings of this research was that few relationships were identified between Religion/Spirituality and QoL signifying that for New Zealand cancer survivor's Religion and Spirituality do not greatly impact on QoL unlike what overseas research has shown. One analysis identified that QoL for those who are more Religious/Spiritual did improve over time possibly suggesting that time practicing a faith could play a role in increasing QoL. Those who practiced Spiritual activities reported poorer QoL than those who did not engage in Spiritual activities. The lack of relationships identified in this research suggests that in New Zealand Religion and Spirituality may not play a significant part in cancer survivors QoL. The lack of relationships and the few relationships that were identified have opened up more questions such as how Religion and Spirituality is practiced in New Zealand and if it is indeed useful for an individual's health.

The most interesting finding of the study revealing that those who engage in Spiritual activities consume less alcohol and in turn have a poorer Physical QoL. This finding is very interesting and opens up the road for more research.

5.5 Future Research

This study is only one of few looking at Religion/Spirituality in regards to cancer survivors QoL. The mixed results in this study opens up many questions around the role Religion/Spirituality plays in the future QoL of those who have survived cancer and may be an area that the health sector needs to include in treatment and aftercare. More in-depth research looking at possible physiological processes that link Religion/Spirituality and QoL may be useful. A qualitative study looking at the experiences of those who have survived cancer and who are Religious/Spiritual would be interesting as a quantitative study is unable to capture the cancer survivor's subjective experience. Additionally more longitudinal research would be beneficial to further understand cancer survivor's needs throughout their cancer journey. Age was revealed as a contributing factor and therefore more detailed research into the different age groups may provide more information. As mentioned prior, a lot of the literature on this topic comes from the United States of America. Therefore raising the question of can research between countries with such different health systems be compared? Are cancer survivors better off in New Zealand or America? This would be interesting to investigate.

APPENDIX I: MEASURES USED FOR HWR STUDY

Including 2006, 2008 and 2010

2006

Questionnaire item number	Scales/questions	Origin
1-11	SF36v2	Qualitymetric
1 + 11 3 4 6 + 8	General health Physical functioning Role - physical Bodily pain	Physical health subscale
5 + 9 7 10 (a + e + g + i) 10 (b + c + d + f + h)	Social functioning Role – emotional Vitality Mental Health	
2	Reported health transition	
12	Diagnosed illnesses	<i>Our own</i>
13 – 15	Alcohol consumption	ALAC
13a 13b 14 15	Drinking frequency Drinking past (for non-drinkers) Level of normal consumption Frequency of bingeing	
16 – 21	Healthcare utilisation	'Taking the Pulse' (MOH, 1999)
16 17 18 19 20 21	Doctor visit –category Doctor visit -frequency Healthcare admittance –category Healthcare admittance -frequency Emergency department use Visits to different professionals	
22	Smoking (current/historical)	Adapted from <i>The Quit Group</i>
23 – 26	Physical activity	Compilation (as follows):
23 24	IPAQ sitting questions Total physical activity time	Australian Women's Health Study Australian Women's Health study / SPARC mixed version
25 26	Physical activity level Stages of exercise change	SPARC SPARC/ (Prochaska & Diclemente, 1982)
27	Volunteer frequency	<i>Our own</i>

28 – 30 + 39	Network assessment instrument	(Wenger, 1994; University of Wales, Bangor)
	28 Distance to relatives 29 Frequency of interaction with others 30 Contact with others 39 Attendance at meetings/social events	
31a - x 32 – 36	Social Provision Scale (SPS) Caregiving	(Cutrona, 1984; Russell & Cutrona, 1984) Australian Women's Health Study
	32 Care for grandchildren/other children 33 Regular care for others 34 Number of regular care clients 35 Frequency of regular care 36 Duration of each 'care' occasion	
37 – 38	Connection	(MSD, 2004; 'Quality of life in NZ's largest cities' survey)
	37 Trust in others 38 Feelings of isolation	
39 (see 28) 40	Methods of contact	<i>Our own (Based loosely on MSD questions)</i>
41a	Self-employed/employed by other	<i>Our own</i>
41b	Numbers working for self-employed	<i>Our own</i>
41c	Numbers working for employer	<i>Our own</i>
42a – b + 56d - f	Anticipated finances in retirement	(Adams, 1999)
	42a Can afford to retire 42b Cannot afford to retire 56d Worry over standard of living 56e Worry over income in retirement 56f Satisfaction with income in retirement	
42c + 56g - i	Retirement adjustment	(Taylor & Shore, 1995)
	42c Depressed view of retirement 56g Confidence in retirement adjustment 56h No trouble handling retirement 56i Expectation of enjoying retirement	
42d	Tired of work	<i>Our own</i>
42e - l	Career commitment scale	(Blau, 1985)
42m - q	Career satisfaction scale	(Greenhaus, Parasuaman, & Wormley, 1990)
43a - o	Job satisfaction scale	(Warr, Cook, & Wall, 1979)
44a-f	Work involvement scale	(Kanungo, 1982)
45a-p	Job stress index	<i>Our own</i>
46a-e	Work social support	(Evans & Steptoe, 2001)
47a-d	Current leisure experience	(Gee & Baillie, 1999)
47e-h	Leisure orientation	(Taylor & Shore, 1995)
48a - b	Work status past certain ages	<i>Our own</i>
49	Retirement status	HRS
50	Retirement date	HRS
51	Retirement reason	HRS
52	Previous work satisfaction	HRS

53	Spouse retirement time	HRS
54	Retirement living standards	HRS
55	Retirement work status decision	HRS
56a - c	Retirement context factors	(Naudé, O'Driscoll, & Kalliath, 2003)
56d - f (see 42a)		
56g - i (see 42c)		

2008

PAGE	QUESTION	DESCRIPTION
1 – 4	1 -11	SF-36 v1
4	12	Vision questions x 2 (HWR)
4	13-14	Body Mass Index (HWR)
5	15-16	Diagnosed illnesses and cancer treatment (HWR)
6	17-18	Cigarette and alcohol use. Bush, K., Kivlahan, D. R., McDonell, M. B., Fihn, S. D., & Bradley, K. A. (1998). The AUDIT Alcohol Consumption Questions (AUDIT-C): An Effective Brief Screening Test for Problem Drinking. <i>Archives of Internal Medicine</i> , 15,1789-1795.
7	19-24	Healthcare utilisation
8	25	Prescription drug use (HWR)
8-9	26-28	Quality of life World Health Organisation Quality Of Life - Brief Version
9	29	Locus of control Sapp, S. G. & Harrod, W. J. (1993). Reliability and validity of a brief version of Levenson's locus of control scale. <i>Psychological Reports</i> , 72, 539-550.
10	30-31	Physical activity New Zealand Sport and Physical Activity surveys http://www.sparc.org.nz/research-policy/research-/sparc-facts-97-01
11	32-33	Driving anxiety Dr Joanne Taylor, School of Psychology, Massey University
11-12	34-35	Happiness HAPPI - Ms Annette Hendricks, School of Psychology, MU
13	36	Volunteer activities Dr Patrick Dulin
13-14	37-39, 42	Wenger Wenger, G.C. (1994). Support networks of older people: A guide for practitioners. Bangor: Centre for Social Policy Research and Development, University of Wales.
14	40-41	Trust, isolation,
14-16	43-46	Caregiving Comes from the Women's Health Australia – caring from your health pilot study
17	47	Social provisions Cutrona, C. E. and Russell, D. (1987). The provisions of social relationships and adaptation to stress. In W. H. Jones & D. Perlman (Eds.) <i>Advances in personal</i> (Vol. 1, pp. 37-67). Greenwich, CT: JAI Press.relationships
18	48	Employment status of self and partner (HWR)
18-19	49	Work history (HWR)
19	50	Shift work and Number of work hours
19	51	Work/family conflict Kopelman, R. E., Greenhaus, J. H., & Connolly, T. F. (1983). A model of work, Family, and interrole conflict: A construct validation study. <i>Organizational Behavior and Human Performance</i> , 32, 198-215.
20	52	Job satisfaction Brayfield, A. G. & Rothe, H. F. (1951). An index of job satisfaction. <i>Journal of Applied Psychology</i> , 35 (5), 307 - 311
21	53	Job demands/decision latitude <u>Bernin, 2002</u> P. Bernin, Managers' working conditions -stress and health, Department of Public Health Sciences Division of Psychosocial Factors and Health, Karolinska Institutet, Repro Print AB, Stockholm (2002). Cited in Sundin et al (in press). A scale for measuring specific job demands within

		the health care sector: Development and psychometric assessment. <i>International Journal of Nursing Studies</i> .
21 23	54(a-b) 58 (d-f)	Anticipated retirement finances Adams, G. A., & Beehr, T. A. (1998). Turnover and retirement: A comparison of their similarities and differences. <i>Personnel Psychology</i> , 51, 643-665.
21	55	Age at which R expects self and spouse to retire
22	56	Retirement planning Mr Jack Noone, School of Psychology, Massey University
23	57	Expectations about full-time, part-time-or no work in retirement Health and Retirement Study (USA)
23	58 (a-c)	Retirement context factors
23 21	58 (g-i) 54 (c)	Anticipated retirement adjustment Taylor, M. A., & Shore, L. M. (1995). Predictors of planned retirement age: An application of Beehr's model. <i>Psychology and Aging</i> , 10, 76-83.
23	59	Work involvement Kanungo, R. N. (1982). Measurement of job and work involvement. <i>Journal of Applied Psychology</i> , 67, 341-349.
24	60-61	Positive and negative aspects of retirement Health and Retirement Study (USA)
25	62-63	Reason for stopping work (HWR), satisfaction with previous work (HRS)
26	64-68	DOB, marital status, Ethnicity, tertiary qualifications
27	69	Job title
27	70	Migration questions (HWR)
27	71	Household composition
28	72	Location of residence
28-29	73-76	Economic Living Standards Index (not incl. Q76i) The New Zealand Ministry of Social Development. http://unpan1.un.org/intradoc/groups/public/documents/APCITY/UNPAN028781.pdf
30	77-79	Ways of receiving income, personal and household income New Zealand Treasury – Grant Scobie
31	80-81	Assets and liability ownership New Zealand Treasury – Grant Scobie
31-32	82	Superannuation (HWR)
32	83-87	Financial questions New Zealand Treasury – Grant Scobie
33-34	88-94	Cultural identity Te Hoe Nuku Roa study, Massey University. (Dr Mason Durrie)

2010

YOUR HEALTH, WELL-BEING, & QUALITY OF LIFE		
Q	Content	Origin
1-7	Physical and mental health / well-being	SF12v2: QualityMetric
8	Depression measure	CES-D-10
9	Alcohol use	WHO AUDIT-C (Hazardous)
10	Physical activity levels	ELSA (Wave 4) – also used in HRS 2002
11	Illness checklist	HWR2006/2008 (Health, Work, & Retirement Study)
12	Smoking identity	QUIT group & HWR2006/2008
13	Quality of life	CASP-12: Wiggins et al (2008)
14	Quality of life	WHOQoL-8

FAMILY & FRIENDS		
Q	Content	Origin
15	Social Provisions	Social Provisions Scale (Cutrona & Russell, 1987).
16-18	Social networks	Wenger Network Assessment Instrument
19	Sources and types of social support	Developed by Family Centre on the basis of Agneessens social support typologies (see Agneessens, 2006)
20	Loneliness	De Jong Gierveld Loneliness Scale; de Jong Gierveld et al (2009).
21	Elder Abuse	Vulnerability to Abuse Screening Scale (VASS); Schofield & Mishra (2003)
22-23	Discrimination	Reduced version of the Everyday Discrimination Scale: see Roberts, Vines, Kaufman, & James (2007).
24-26	Religion/faith	EWAS (Enhancing Well-Being in an Ageing Society)
27	Sexual functioning and sexuality	Sexual functioning scale from the LEIPAD questionnaire: De Leo D, Diekstra RFW, Lonnqvist J, et al. (1998)

YOUR CARING COMMITMENTS		
Q	Content	Origin
28	Childcare duties	HWR2008
29	Home-based care/support	NZLSA
30	Care-giving screen	NZLSA (Alpass and Keeling)
31-32	Care recipient information	HWR2008

YOUR WORK OR RETIREMENT STATUS		
Q	Content	Origin
33	Employment status	HWR2006/2008
34	Partner employment status	NZLSA

35	Current & past occupation	NZLSA / HWR2008
36	Hours worked	HWR2006/2008
37	Job satisfaction	Job Satisfaction Scale: Brayfield & Rothe (1951).
38 (a-e)	Anticipated finances in retirement	Adams & Beehr (1998).
38 (f-g)	Retirement context factors	Naudé, O'Driscoll, & Kalliath, (2003)
39	Work stress: Effort-reward imbalance	Siegrist, Wege, Pühlhofer, & Wahrendorf (2008).
40	Anticipated retirement age	HWR2008
41	Spousal retirement	HWR2008
42	Reasons for stopping work	Revised HWR2008 item and EWAS
43	Retirement history	HWR2008

YOUR FINANCIAL WELL-BEING		
Q	Content	Origin
44	Income source - personal	HWR2006/2008 and EWAS
45	Income source - household	EWAS
46	Income level - personal	Family Centre Social Policy Research Unit
47	Income level - household	Family Centre Social Policy Research Unit
48	Housing costs	EWAS
49-52	Living standards	Economic Living Standards Index – Short Form (2008).
53	Asset ownership	HWR2006/2008 and EWAS
54	Government housing valuation	EWAS
55	Asset value	EWAS
56	Student loan (& value)	NZLSA
57	Financial dependents	HWR2006/2008
58	Saving for retirement	EWAS
59	Financial support in retirement (self/partner)	EWAS

LIVING IN YOUR NEIGHBOURHOOD		
Q	Content	Origin
60	Safety	Revised EWAS item
61	Transport difficulty	EWAS
62	Locations difficult to access	EWAS

YOUR PERSONAL SITUATION		
Q	Content	Origin
63	Age	NZLSA
64	Sex	NZLSA
65	Marital status	NZLSA
66	Partners age	NZLSA
67	Educational qualifications	NZLSA
68	Residential description &	NZLSA

	ownership	
69	Internal migration – history & reasons	NZLSA
70	Household composition	NZLSA
71	Recreational activities	EWAS
72	Ethnicity - belonging	NZLSA
73	Ethnicity - identifying	NZLSA
74-75	Ethnic identity	Multigroup Ethnic Identity Measure – Revised (MEIM—R): Phinney & Ong (2007). + Family centre additions
76	Whakapapa/ Whanaungatanga	HWR2006/2008 – from the MSD's <i>Living Standard's of Older Māori</i>
77	Community participation	EWAS
78	General happiness	Fordyce (1988) – Single item happiness measure
79	Life satisfaction	Inglehart, R., Basañez, M., Diez-Medrano, J., Halman, L., & Luijkx, R. (2004). Human beliefs and values: A cross-cultural sourcebook based on the 1999–2002 Values Surveys. Mexico City: Siglo Vientiuno.

APPENDIX II: HWR 2006, 2008 and 2010 Surveys

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