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**SURVIVORS OF CANCER:  
A PHENOMENOLOGICAL STUDY**

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

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2005

## ABSTRACT

This paper explores the experiences of survivors of cancer. Eight participants, who were all diagnosed with cancer and had undergone various treatments, were interviewed. These participants had all survived the prognosis and treatment for cancer and continue to live as survivors. Their stories of survival were transcribed and analysed using a phenomenological approach.

Initially, the research question was aimed at the type of personal qualities these survivors have; for example, a fighting spirit, positive attitude, or internal locus of control, and whether they attributed their survival to a change in life-style or behaviour through, for example, meditation, diet, prayer, or beliefs. However, during the interview and transcribing process it became clear that, while their stories of survival were exceptional, the participants themselves did not attribute their survival to anything outstanding. They did not necessarily have exceptional personal qualities and were not highly motivated at the time of their diagnoses to change their lifestyle or way of being. None of them had remarkable reasons that they could attribute their survival to. Some attributed their survival to luck. This is consistent with the research by Killoran, Schlitz and Lewis (2002) who found that long-term survivors framed their recoveries as "being largely unremarkable".

What was very apparent in all of the survivors stories was that, with survival comes a whole new and different way of being and it poses new psychological issues that have to be faced daily, for the rest of their lives. While each participant's story was one of amazing courage, strength, hope and positiveness, it was also found that surviving cancer can and does have a dark side. Fear of recurrence is always in the forefront of the survivor's mind. Depression and mal-adaptive coping strategies occur in some survivor's lives. Changes in body image, employment, abilities, stress on relationships and ongoing health problems can render a person incapable of coping.

Therefore, the research question changed from one of looking at the personalities and life styles of survivors, to that of "what is it like to live as a survivor of cancer?" As a phenomenological study, this shift in focus was significant and necessary.

The interviews were analysed and data was formulated into four main clusters; "*Why me?*": cause, effect & making meaning & sense out of it all; "*I just want life to be normal again*": the issue of normality, redefining oneself and the physical legacy of surviving treatment; "*I've been told that cancer will eventually get me*": remission or cure? Living with uncertainty, fear of recurrence and "*Keeping busy and my mind off of it helps*": coping styles, control and attitude.

## ACKNOWLEDGEMENTS

I would like to dedicate this research with deep respect to all of those people whom I have cared for with cancer over the years.

Thank you to Massey University for the privilege to study and learn to this level.

I would like to thank Dr. Christine Stephens for her patience, encouragement and supervision during this project.

I am grateful to those people who shared their stories and experiences with me: Zelda, Joan, Jenny, Sally, Marie, Kath, Joyce and May. My life has become so much more enriched by the encounters I have had with you and I am challenged by your courage.

Sally, who has now passed away, gave me insight into survivorship that opened my eyes to a different perspective. One interview with her, lasting less than 2 hours, was incredibly memorable, and has changed my perspective forever.

Jenny has also recently passed away. Her story of survival is one of great courage and strength despite developing another primary cancer 12 years after surviving breast cancer.

Thank you to my parents, Clem and Sheila Schmidtke from South Australia, who have always believed in and encouraged me.

Kyle, thank you so much for your unfailing patience, love and support, and especially for your assistance with word processing, editing and computer technology.

Emily, Jessica and Blake thank you for being in my life and encouraging me to complete this project. You are beautiful.

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## Chapter One INTRODUCTION

*“The diagnosis of cancer, with the fears attached to it and the threat to life itself, result in a complex set of issues that the individual must confront; the physical symptoms (especially pain); psychological reactions of fear and sadness; concern for the family and their endangered future; facing the existential issues of life and death; and seeking a comforting philosophical, spiritual or religious belief system to help give a tolerable meaning to the new world of illness” (Holland, 2003).*

What is it like to be diagnosed with cancer, given a poor prognosis, and from that day on to live with this every day, for the rest of your life? Cancer isn't a particularly popular disease to be diagnosed with. It has attached to its very name a stigma and interpretation that equals a death sentence. It is true, cancer is a most feared disease, imposing an awareness of mortality and threatening life itself. However, with modern technology, early detection and improvement in treatment, the incidence of survival is increasing (Bloom, 2002; Breaden, 1997; Pedro, 2001; Thewes, Butow, Girgis & Pendlebury, 2004).

### **Surviving Cancer: a definition**

Thewes et al. (2004) provide two definitions of survival. The bio-medical definition of cancer survival is that of people with cancer who have lived disease free for at least five years after treatment. A psycho-social definition, in contrast, is given as being a process beginning from diagnosis through treatment and into remission. For this current study, the psycho-social definition is used.

Three stages of survival have been identified for people with cancer. The first stage occurs when the person is first diagnosed with cancer, the acute survival stage. During this stage, the person copes with the diagnosis, aggressive treatment, and faces their mortality. Depression and anxiety are common psychological problems during this stage. The second stage, or extended survival stage, begins at the end of treatment (around the first year following diagnosis to three years after diagnosis). This period is the time when the likelihood of recurrence is highest. The third stage is one of permanent survival, when the chances of recurrence diminish with the passing of time (Bloom, 2002; Mullan, 1985, cited in Thewes et al., 2004). Each stage posed psychological and emotional challenges to the survivor.

### **The Psychological Issues of Surviving Cancer**

Little and Sayers (2004) identify three stages of salience, or awareness that occur in the cancer survivor which interestingly correlate to the above stages. The first stage, mortality salience, occurs at the time of diagnosis through to around the two-year mark. The second stage, death salience, begins at around two

years of survival and can last for many years beyond. Dying salience, the last stage, occurs as the person becomes terminally ill and faces imminent death. These stages are very significant psychologically, because each stage has implications as to the way in which the survivor copes with their illness and life, and also for those caring for them and close family members.

During the mortality salience stage, the survivor and their family rally to “fight” this disease. Closer bonds occur between family members and the affected person, and often the survivor is very determined to help others through similar experiences. During this time, these survivors may join the local cancer support groups and offer their time to helping others. They turn outwards for solidarity and support. Family members and partners will also experience this stage along with the survivor. However, unlike their afflicted loved one, family members very often do not go beyond this stage, and find it very difficult to understand their loved one once they have gone into the second stage. Death salience is a much more introspective stage for the survivor, and they find themselves often in a place that is very isolated and lonely. During this stage they turn inward, searching for deeper meaning and purpose for their lives and suffering. Death has been faced and the reality of dying is prominent in their lives. These survivors often feel they cannot talk to their close family and partners of what they are going through and feeling. Partners and family also cannot understand the survivor, as think that they should be able to get on with life and be happy and thankful that they have survived. Paradoxically, when help and support are still very much needed, it is during this stage that relationships can break down. When a survivor is in this stage, it is less likely that they will be active in support groups, as they no longer identify with those in the mortality salient stage. It is during the death salient stage that the person tries to reconstruct their identity and meaning around the experience of surviving cancer. For many this is a very difficult process. Those who are finally overcome by their cancer enter the dying salience, which can be a time of great loneliness. Communication can be very difficult for those involved during this stage (Little & Sayers, 2004). These findings have huge implications for those who care for the survivor and for support groups who often use survivors to counsel others. Little and Sayers suggest that using survivors as providers of support for the dying may be inappropriate. *“The discomfort that both parties may experience can impose unreasonable burdens on those who need support and those who volunteer to provide it.”* (Little & Sayers, 2004)

It is estimated that one in four people with cancer experience impairment of social function and distressing psychological disorders (Greer, 1995). These psychosocial disorders can persist for years, even if the disease itself is in remission, or no longer active. The treatment for cancer can create disorders that contribute to the psychological distress of a person. Fatigue, infertility, impotence, chronic pain, mood changes and cognitive impairment are all residual symptoms from chemotherapy. Some survivors may experience post traumatic stress disorder from the diagnosis and treatment, and some have developed conditioned responses to certain triggers from their treatment (Holland, 2003).

Grief and anxiety are high on the list of psychological issues that are experienced. Grief is defined as keen mental suffering or distress over affliction or loss (Macquarie Dictionary, 1982). Grief may be experienced over real or imagined loss (Nelson, 1996). Real or actual loss experienced by a survivor is related to the disease progression and treatment. For those who have undergone mutilating surgery, the losses are great. There are cosmetic changes, such as loss of hair, loss of body parts with loss or changes of certain bodily functions. Depending on the type of cancer, some people are rendered sterile, which has psychological implications in that they cannot have children. This brings about redefining one's sexuality and spirituality (Greer, 1995) causing significant changes to body image and self-perception. If this process of grief is not worked through, self-esteem and self worth may suffer. Many people experience incredible fatigue and cannot continue in their current employment bringing about loss of income and changes in lifestyle (Bloom, 2002; Greer, 1995; Taylor, 1995). Permanent changes to the body may challenge the sense of personal identity. In fact, a diagnosis such as cancer can profoundly affect one's sense of personal identity, and those who survive find that they need to redefine their identity in terms of life after cancer (Little, Paul, Jordens, and Sayers, 2002). Imagined loss is defined by Nelson as loss that focuses on the inability to plan or control one's future life. Grief is experienced by the survivor in an imagined form as the survivor thinks of the inability to see their children marry, see their grand-children born or see any future for their lives (Nelson, 1996). Kubler-Ross used the term 'anticipatory grief' to describe the mourning of the prospect of one's own death (Kubler-Ross, 1969).

Anxiety, depression, and apprehension are possibly highest after the initial diagnosis occurs, however many survivors experience anxiety whenever they are due for a follow-up scan or consultation (Nelson, 1996). Depression is an ongoing psychological issue for many survivors (Holland, 2003). As the years pass, the psychological issues of survivorship continue. These are experienced as continued reported loss of energy, relationship issues, re-integration back into society and issues in resuming employment. Adaptation to these psychological aspects is necessary in order for the survivor to cope and live with their legacy. Holland identifies three factors that contribute to the psychological adaptation of a person to cancer. The first set of factors relate to the disease itself: site, type and stage of the cancer and the availability of treatment, medical support and rehabilitation issues. The second set of factors concern the person: their personality characteristics, coping skills, level of maturity, and social surroundings. The third set of factors are societal issues, which not only affect the person with the cancer, but their family, friends and community (Holland, 2003).

Both positive and negative coping skills may be activated in intense times of stress and grief. It has been documented that people with a fighting spirit and positive attitude will be pro-active in their treatment and have a higher chance of coping and surviving (Levenson & McDonald, 2002).

The psychological issues surrounding surviving cancer form the basis of the research question: What is life *like* for those who live beyond a diagnosis of cancer, with the threat of recurrence? Love, when writing about breast cancer, states that the public wants to see the stories of survival as courageous stories with a happy ending rather than the reality of living with a chronic and life threatening disease.

*“Almost all of the books, television shows, and magazine stories about breast cancer depict the woman who is newly diagnosed. She faces breast cancer squarely, and after undergoing surgery, radiation and chemotherapy she wins her battle. Society’s message is relentlessly up-beat. Early detection saves lives. Aggressive treatment is the best hope. There is almost nothing said about the woman in whom breast cancer comes back”* (Love, 1999, cited in Sigler, 1999).

Most research has been focused on those in the acute stage of cancer, from diagnosis through to the end of the treatment stage (Gil, Mishel, Belyea, Germino, Porter, LaNey, and Stewart, 2004; Mahon & Casperson, 1997). Less research has focused on the long-term survivor, or those in the extended survival stage (Bloom, 2002). The most common areas of research have been on depression, anxiety, self image and fear of recurrence, and these are mostly studied on those who have been recently diagnosed and treated (Bloom, 2002). It has also been found that research surrounding the psychological and psychosocial needs of cancer survivors, in particular longer-term survivors, has often been neglected (Lee-Jones, Humphris, Dixon, & Hatcher, 1997). Previous research has been focused on quantitative factors such as the likelihood of survival when given x or y treatment and relationships between variables for example: self esteem, learned resourcefulness and social support (Pedro, 2001); the measurement of psychological distress by the use of models and scales (Lee-Jones, Humphris, Dixon and Hatcher, 1997); and the extent that survivors search for meaning (Dirksen, 1995), however these approaches do not address the *experience* of surviving cancer. Qualitative research can provide insight into the importance of aspects of survival. A phenomenological approach, in particular, focuses on the experience and is interested in understanding *what it is like* to live as a survivor of cancer. Further questions arising from this research area are numerous. For example; What is it like to live beyond an expected time? What does it feel like waiting for follow up appointments? How is it to live with the uncertainty of being a survivor? How does being a survivor affect the way in which one relates to their loved ones? How easy is it to get back to “normal” after treatment? Does the threat of recurrence ever leave one’s mind? How does this affect the way in which these people live their lives?

From the perspective of a health professional, it is important to realise that for survivors these psychological issues are real. There is a tendency for health professionals from a bio-medical model of training to treat the physical symptoms, rejoice at the success of the treatment, but fail to recognise that life goes on for these people well beyond the medical/physical treatment phase. This, then becomes a large motive for such a research topic: to find out, and understand, what it is like to survive, and to learn from those who have had first hand experience, how to provide better support for the journey of survival.

From the researcher's perspective, I have a great interest in this topic. I have worked as a nurse providing health care for many people who have been diagnosed with cancer over the years. I have worked in all areas of cancer nursing: paediatrics, surgical, oncology, supporting those in the community on chemotherapy and having radiotherapy, through to palliative care, both in the community and within an institutionalised setting. I have often felt that the psychological care for many people was minimal, if not non-existent. The way in which many people courageously coped with their life-changing situation was incredibly brave and remarkable. It is from this background that I have been motivated to learn and discover more of what it is like to be in the situation of survivorship. As a nurse, I was witness to many situations that have had a profound affect on me. Many nights after an evening shift I left work with the face of a patient and their suffering in my mind. Theoretically, health care establishments talk about providing opportunities for debriefing for staff, however, in the real world, very often nurses sign off, and drive home with incredible sadness and grief of an immeasurable intensity. Many nights I have cried myself to sleep as a result of viewing horrific sights. On many nights, sleep has totally eluded me.

A phenomenological approach is appealing therefore, from both the participants' view- point, and also that of the researcher. Emotions, feelings, spirituality and essence of being cannot be measured or quantified. Phenomenological research gives the participants the opportunity to tell their stories of experience exactly as it was for them. In a sense it asks the participants "what would you like us to learn from your experience?" For this reason, this type of research is invaluable, because it is not the researcher suggesting solutions, but rather a more "bottom up" approach, where learning is generated from the participant's experiences.

### **Research Aims**

The aim of this research is very much defined by the phenomenological method; that is, to better understand the experience of survival of cancer from the perspective of those who have had the experience of the phenomena. The qualitative nature of this research explores what it is like to survive cancer and is deeply personal. There are no absolutes or quantitative conclusions, however, it is hoped that through this study there will be a greater insight into these people's lives and experiences.

Little et al. (2002) discuss survivorship from the perspective of discourse and social constructs, and believe that while these are well established for the illness phase, they are lacking for the survivor. Survivors have no defined status, or modes of performance and therefore have to try and either fit into pre-existing paradigms of 'normal' or chronically ill, or into those of hero or victim (Little et al., 2002). From this and other recent research, and with the increase in the numbers of people who are now survivors, it is clear that more research on survivorship is necessary to further understand what life is like for them. Certain areas of

inadequacies within the health system are identified which may assist in raising the awareness for the need for specialised care and considerations when dealing with survivors. It is hoped that, after reading this thesis, the reader will have a richer and deeper understanding of what it is like to be a survivor.

## Chapter Two INTERPRETIVE PHENOMENOLOGY

*"...transforming the lived experience into textural expression of it's essence"*

(Van Manen, 1990).

The purpose of this chapter is to give a comprehensive review of interpretive phenomenology as an approach to research, and a reason as to why this approach was taken in the present study.

### Qualitative Research

When deciding whether to use a quantitative or qualitative approach to this study, both approaches were looked at in terms of their technique, methods, analysis, and the paradigms from which they are derived.

A paradigm is a certain world-view or basic set of beliefs or assumptions that guide research. The assumptions relate to: ontological (the nature of reality); epistemological (the relationship of the researcher to that being researched; Axiological (the roles of values in a study); and methodological (the process of research) (Cresswell, 1998; Denzin & Lincoln, 1998).

Qualitative research differs from quantitative in that the fundamental research question is "how" or "what" (exploring and aiming to understand a given experience) rather than "why" (comparing groups of people or variables) (Cresswell, 1998; Marecek, 2004). Qualitative research is chosen over quantitative for several reasons. The nature of the research topic and the primary research question determines the choice very often. Topics where the variables are not easily identified, or the theories have not been developed are more suited to a qualitative approach. It is more appropriate for research where a detailed view of the whole topic is required, and where the topic is to be explored, rather than one aspect of a topic. Qualitative research enables the researcher to study the participants in their natural setting, and enables the researcher to write in a literary style. This type of research also enables the researcher to be an active learner in the dynamic process of the research process (Cresswell, 1998). Rather than studying one construct of a particular phenomenon, qualitative research encompasses the context of history, society and culture and considers the social and reflective natures of the people who are being studied. Qualitative research is concerned with the human experience (Marecek, 2004).

Theoretically, the current study is based on an existential paradigm and phenomenology. Existentialism, as defined by Tillich (1952) is "*participating with the whole of one's existence, including temporal, spatial, historical, psychological, sociological, biological conditions*". As a philosophy, existentialism focuses on

people's attempt to make sense of their existence by giving meaning to it and taking appropriate responsibility for it (Reker, 2000). Further, it is also approached from an ontological perspective. Benner states that interpretive phenomenology is more easily undertaken once the researcher has shifted from an epistemological perspective (what it is to know) to that of an ontological one (the questions as to why and how we know things and what constitutes our knowing) (Benner, 1994). Existentialism, with an ontological theoretical base, enhances and compliments the phenomenological philosophy and method of research. Each of these theoretical perspectives aims to better understand what a given experience is like, from the perspective of the individual who has experienced the phenomenon.

This type of research enables the use of reflexivity. Reflexivity is defined as a process undertaken by the researcher to reflect critically on the self as researcher. It is a dynamic action that brings the researcher into the process of research itself. The whole process of the research is one of discovery: of the topic itself, and discovery of the self (Lincoln & Guba, 1989).

The complexities of surviving cancer cannot be easily or effectively examined by quantitative means. The individual experience and perception are unique and to examine them in a linear way of cause and effect is limiting. *"Both cancer and the immune systems are highly complex and non-linear (chaotic) systems whose interactions cannot be predicted from linear analysis"* (Szlosarek & Dalglish, 2002).

Cresswell uses the metaphor for qualitative research as *"an intricate fabric composed of minute threads, many colours, different textures and various blends of material"* (Cresswell 1998). Many experiences in life share this intricacy and cannot be quantified or measured. The complexities that life brings makes study of certain phenomenon quite challenging, and while some generalisations can be made, most often the individual experiences life in a totally unique way.

The narrative nature of phenomenological research is also worth noting. The participants are invited to tell their stories of survival. They do this with the use of language, describing the events and their feelings in ways in which convey best their experience. The concept of reality, from a post-modern perspective is such that realities are socially constructed; they are constituted through language; they are organised and maintained through narratives and there are no essential truths (Freeman & Combs, 1996). Thus, the stories that are told are unique and individualised. What is a real concern for some may not be for another, yet does not make it less real for the one who expresses it as a concern. Further, the actual telling of one's story may in itself be therapeutic. People make sense of their experience through the telling of their stories. *"It is in the performance of an expression that we re-experience, re-live, re-create, re-tell, re-construct and re-fashion our culture. The performance does not release a pre-existing meaning that lies dormant in the text. Rather, the performance itself is constitutive"* (Bruner, 1986, cited in Freeman & Combs, 1996).

Qualitative research is usually undertaken in a natural setting. The researcher collects information and data from the participant, analyses it, focuses on the meaning that the participants give their experience, and describes the process in an expressive way (Cresswell, 1998). Research in a natural setting allows the participants to feel comfortable and free to express themselves without constraint. The use of everyday language is encouraged, as this also promotes openness. (Benner, 1994).

There is a certain ambiguity arising from this type of research due to the way in which the process is often evolving and changing, with often a lack of specific procedures and guidelines. This is quite different to that of quantitative research, where the variables are constant, the conditions are controlled, and there is a specific procedure and process to adhere to. In the present study, an interpretive phenomenological approach was used. Denzin & Lincoln (1994) summarise qualitative research as an attempt to make sense or interpret phenomena in terms of the meanings people bring to them.

### **Interpretive Phenomenology**

*“Human being is a unique way of being in that human experience and actions follow from their self interpretation”* (Benner, 1994).

Phenomenology’s background is in philosophy. The German philosopher, Husserl focussed on lived experience and the concept of experience being *“one’s perceptions of his/her presence in the world at the moment when things, truths or values are constitute”* (Morse, 1994). While it considers the subjective experience, and is very interested in the way in which the world is perceived, phenomenology does not exclude the objective. Husserl questioned “absolute truths” even mathematical “realities” such as geometrical magnitudes, and stated that these, along with colour and smell, were dependent on human interpretation. Following on from Husserl’s philosophy, Heidegger pursued the questions of life from an epistemological approach, to that of an ontological one; that is, what it means to be a person, and how the world is intelligible to us all (Leonard, 1994). Heidegger defines world as the *“meaningful set of relationships, practices and language that we have by virtue of being born into a culture”*, with culture, linguistics and history being at the core. From this core comes the view of oneself within this world, and that people are beings for whom specific things have significance and value. This Heideggerian phenomenological view point also sees the person as self interpreting (we are engaged in, and constituted by, our interpretive understanding), the person as embodied (rather than having a body, we are embodied) and the person “in time”, or temporality (being-in-time rather than the linear view of time) (Fjelland & Gjengedal, 1994; Leonard, 1994). Another philosopher, Merleau-Ponty, has stated that it is impossible to separate the body from the mind (Fjelland & Gjengedal, 1994). According to Van Manen (1990), phenomenology is guided by four existentials: lived space (spatiality), lived body (corporeality), lived time (temporality) and lived human relation (relationality, or communality).

As a philosophical approach, there is an assumption that human existence is meaningful and of interest in the sense that we are always conscious of something. Existence is defined as “being in the world” and the phenomenological perspective believes that human behaviour occurs in the context of relationships to people, objects, situations, and events. It attempts to discover and understand how people attend the world (Morse, 1994). Fjelland and Gjengedal (1994) assert that the fundamental aim of studying human beings must be “understanding” rather than “explaining”. This implies taking the spiritual part of human beings into consideration rather than just the physical, and that it is the presence of this spiritual aspect that distinguishes the human experience from that of the animals.

Language takes a very important role in the experience and definition of the human experience. Humans are linguistic, and from the personal experience, to the family, to the larger community, language is the way in which we express the essence of our experience. Tracing the etymological sources of words can be helpful in understanding their meaning. Analysis of words that are used to describe a phenomenon helps also to give a rich complex picture of the experience; the language and words used by the researcher, in interpretation of the experience, are important (Marecek, 2004; Van Manen, 1990).

As well as being a philosophy, phenomenology is also an approach, and a research method, with the researcher seeking a deeper and fuller meaning of participants experience of a phenomena (Cohen, 1987; Morse, 1994). Phenomenology, as a method of inquiry, asks the participants to express their experiences, transcribes these and interprets them, aiming to understand the meaning of the experience and finally using literary methods to formulate a documentary that is in itself meaningful to those who read it. According to Leonard, it involves a shift in orientation away from the traditional concepts of objectivity, generalisations, and judgements, with the goal of prediction and control, to that of interpretation, reflection, and understanding the human experience (Leonard (1994) cited in Benner, 1994). Van Manen (1990) defines the task of phenomenological research as “*a construction of a possible interpretation of the nature of a certain human experience*” and phenomenological reflection as trying to grasp the essential meaning of something. Meaning is multi-layered and multi-dimensional and is a desire to make sense of an experience.

As a research method, phenomenology is a reflective, interpretive, and descriptive way of research where the researcher searches for a fuller, deeper meaning of the participant’s life. It endeavours to promote human understanding. Van Manen states that the interpretive process occurs through writing and rewriting the text and the researcher must always be open and receptive to new interpretations. The process of rewriting, rethinking, reflecting and recognising is a complex process, but adds to the fullness and ambiguity of the experience being described. He suggests that the purpose of the phenomenological text is to describe and interpret a particular phenomenon and enrich those lives who read it (Van Manen, 1990).

Phenomenology is an appropriate research method for studying people who have experienced a particular phenomenon. This is, quite obviously, a criterion for participation in the study. It is rich, complex and contextual, and does not have pre-existing theories, but rather evolves throughout the procedure. Benner (1994) identifies 5 commonalities explored in phenomenological research: Situation (historical and contextual understanding of the person's situation and their perception of this); embodiment (the understanding of embodied knowing involved in perceptual and emotional response); temporality (how one experiences time in the way in which one understands oneself in the context of past, present and future); concerns (how one applies meaning to ones experiences and defines what matters to them) and common meanings (linguistic and cultural meanings that identify possible issues, agreements, and disagreements between people).

Cresswell recommends that for this type of research 3 to 10 participants are involved. The data collection is usually done by interviews within the participants' environment, which are very often taped. Multiple interviews are recommended so that clarification can be made and the interpretive process and reflection is optimal. The researcher needs to use active and open listening skills, and allow the participant to tell his/her story with out suggestion from the researcher (Benner, 1994). The process begins with interviews with people who have experienced the phenomenon. Rather than being structured, the interview is dynamic and evolves through the process and it is important that the researcher puts aside all pre conceived ideas and pre-suppositions before the interviews begin (Benner, 1994; Moustakas, 1994). After the collection of data, the researcher then orders and groups themes according to meaning. The researcher then reflects on the data and interprets the themes. This information is then written in an expressive way, describing the individual's experience, to discover the essence and meaning of a phenomenon (Morse & Field, 1994). Writing and re-writing is a huge component of an interpretive phenomenological approach. The process of writing encourages reflection, externalises thoughts and gives further insight into a given experience.

Through out the present study the predominant question was "what is it like to live through a diagnosis of cancer, have treatment, and continue to survive"? The participants' interviews were consulted regularly. In order to attempt to describe the participants' experiences as fully and truthfully as possible, experiences were written and re-written.

There are limitations with phenomenological research. There are no absolutes, and problems are not solved, nor does it aid in prediction. It does need to be undertaken by researchers who fit well with the philosophy and methods of phenomenology, and it also requires participants who have experienced the particular phenomena that it being studied. The researcher's preconceptions and biases must be acknowledged and placed aside and they must be open to understand the perspective of the participants.

**Summary**

Surviving cancer is an experience that is highly complex, and will be experienced and perceived differently by each individual. The aim of this present study is to understand what is it like to survive; to hear the stories of survivors, and give the reader insight into how this has been for them. The aspects of survivorship cannot be quantified, but are more suitable for deep descriptions, insight and capturing the essence of the experience. Phenomenology, with its background in philosophy, is a research method that is very appropriate to use in this topic of survival of cancer.

## Chapter Three METHOD

### Recruitment

Ethics approval was obtained from the Massey University Human Ethics Committee. The criteria for participating in this research was to have been diagnosed with cancer, have been treated, and ideally to be free from active disease for at least 5 years. The participants for the present study were recruited by placing an advertisement in local newspapers (Appendix C). A poster was also placed in the Cancer Society office, however, all of the participants responded to the newspaper advertising. The participants responded by calling a phone number at Massey University. A telephone message system was set up, asking them to leave their contact details, and the respondents were individually contacted by the researcher. At the initial contact by phone an information sheet and consent form was sent out, along with a self addressed envelope (Appendices A and B). Once these were received, an appointment was arranged to visit each person who agreed to participate.

### Participants

Ten people responded to the invitation to participate, all of which were women. No conclusions can be drawn from this fact, however it is worth reflecting on. It may suggest that women are more willing to share their experiences, or perhaps they have more time to read the paper, and to volunteer their time for such research. From these ten respondents, only eight went on to actually participate. One respondent decided not to participate because she was quite angry. She was unfortunately involved in a medical misdiagnosis several years ago, and her cancer of the cervix went undiagnosed for some time. Eventually it was discovered and she had treatment, however, she was extremely angry and hurt over the situation. The other respondent did not return her consent form.

Survival years ranged from 5 years to 40 years. Despite clearly stating the criteria, two of the eight participants had more recent recurrence of cancer. However, they did fit the psycho-social definition of a survivor as defined by Thewes et al. (2004) and so were still interviewed and their very courageous stories have been used. One of these participants did fit the criteria in that she had breast cancer twelve years ago, and was treated for that, and survived it without developing metastasis. However, 2 years ago she developed cancer of the lung, which was another primary cancer, not related at all to the breast cancer. She has been receiving treatment periodically for this since her diagnosis. The other participant is elderly, and her primary cancer was breast cancer 22 years ago, but she had just had a relapse two years ago, and was not expected to survive. She had metastases in her spine, ribs, neck, under her arm and was told she would only

survive for approximately a month. At the time I interviewed her, she was very well, all evidence of active disease was gone and she had survived for two years, having a relatively good quality of life at 86 years of age.

The youngest participant was 36 years, and the oldest was 86 years. The types of cancer were malignant melanoma, with the development of secondaries (1), bowel cancer, with several re-occurrences and surgery (1), lung cancer (1), cervical cancer (1), and breast cancer (4). Of those with breast cancer, one participant has not had metastases, and one has had metastases, but has been treated and has remained well for over 5 years. One participant has developed another primary cancer in the lung and has unfortunately passed away in the latter stages of this project. Another participant has had a recurrence, but had survived it for two years. Yet another participant, with cancer of the cervix 22 years ago, has passed away since being interviewed, however, I understand her death was unrelated to her previous cancer. All participants had undergone treatment involving surgery, radiotherapy or chemotherapy or a combination of these.

All participants were married and had children. Two were widows. Four of the participants were diagnosed when their children were young, which impacted very much on the children and families, and their will and desire to live. The other participants were diagnosed around the time of their menopause, after most of their children had left home or become more independent.

### **Overview of Participants**

The names of the participants have been changed for the publication of this study, and ages are given as they were at the time of the interviews.

Zelda (79 years) was first diagnosed with bowel cancer 40 years ago, and has had several operations for this over the years. Her last operation means that she now has a colostomy. She is very thin and sprightly. Zelda is an extremely resourceful person and still expresses her excitement and zest for living. She is a widow but her grandson lives with her currently.

Joan (75 years) is a survivor of lung cancer for over five years now. She was previously a heavy smoker, but gave this up 20 years ago. She nursed both her parents dying of cancer, and also her husband. She has a very sober view of cancer and how it affects those around her. She is thankful to her General Practitioner (GP) for taking her seriously and picking up the lesion early. Joan lives alone and is a widow.

Twelve years ago Jenny (62 years) was diagnosed and treated for breast cancer. She has had a mastectomy. She no longer has this type of cancer, however, two years ago she developed another primary site in her lung. She is an incredibly positive person. At the time of the interview she was still actively having

chemotherapy, yet her strength and positive spirit shone. She is married with a very supportive husband. Her three children have left home and have families of their own. Her greatest pleasure is being with her grandchildren. Jenny passed away on August 19<sup>th</sup>, 2005.

Sally (56 years at the time of interview, now deceased) survived cancer of the cervix for 22 years. Sally struggled with all aspects of her life, and, although was happy on the day of the interview, expressed her unhappiness and sadness at how her life was. She was incredibly brave and honest, and shared her story with courage. Sally passed away on September 18<sup>th</sup> 2004.

Marie (58 years) is a survivor of breast cancer for eight years. Of all of the participants, Marie was the only one who talked about the use of imagery, affirmations, music and relaxation to aid in her recovery. She is a retired school teacher and strongly believes that control is very important to her, and to her survival. She has three grown children who no longer live at home, and a very supportive husband.

Kath (36 years) is a survivor of malignant melanoma diagnosed eight years ago, with secondaries discovered two years after the initial diagnosis. She is very involved in the Sun Smart Cancer organisation, Cancer Support groups and Relay for Life. She also supports others with malignant melanoma. Kath was the most introspective of all of the participants. She shared not just the facts of her experience but the deeper thoughts, feelings, and emotions behind the experience. She is an amazing lady, with outstanding courage, even though she is very quiet and gentle. Kath has four teenage children, three are still living at home. Her children were all quite young when she was first diagnosed, and this has had a huge impact on them as individuals even now. Her husband has been a major support through the years.

Joyce (55 years) survives breast cancer. She was first diagnosed nine years ago, had reconstructive surgery, and was then diagnosed with secondary breast cancer two years after. Joyce, like Kath, talked more in depth about her experience of survival. She is involved with the Breast Cancer support group and Relay for Life. Her four children were all teenagers at the time of her diagnosis, but have all since left home. She lives with her husband, who is very supportive.

May (86 years) is the oldest participant, yet mentally is extremely youthful. When talking about her life she described herself as being very "ahead of her time". She is an educated woman with a Masters degree in mathematics. She is a vegan, did not believe in childhood immunisation and hardly ever went to a GP, even for her children. She does not believe in orthodox treatment. At the time of her diagnosis, she did have a lumpectomy, but refused further treatment with radiotherapy or chemotherapy. Two years ago, May developed secondaries, however she has refused further orthodox treatment. She does not have a very high opinion of the medical profession, yet, ironically, she really wanted to be a doctor when she was young, but her family could not afford to send her to study this. Her four children were all adults at the time of her first

diagnosis. Her husband suffered brain damage as a result of an accident many years ago, and so May has been his life coach for all of these years. He was incapable of being supportive to her throughout her traumatic times. They both now live in a nursing home. Her fighting spirit and sharp mind are inspirational. Her secondary cancer, which recurred 2 years ago, is currently in remission, and she was symptomless at the time of the interview.

### **Data collection and interviews**

Each participant was visited in their homes and interviewed. Two women declined to be audio-taped, so these interviews were transcribed at the time of interview. The other six women were taped as they told their stories, and these were transcribed later. Each interview was conducted in a dynamic way, without structure or many questions. This unstructured approach was to encourage the participants to talk about the issues that were important to them. Each participant was invited to share their experience of diagnosis, treatment, hospitalisation, family issues, coping mechanisms, and their beliefs as to why they feel they have survived. Most of the participants began their stories at the time of their diagnosis, and discussed their survival in terms of where they had been and come from to where they are now. The participants were told that if at any time during the interview they felt uncomfortable, they could stop talking and/or the tape could be turned off. This did not happen, as all of the participants were more than happy to tell their unique stories of survival. Each participant was reassured that further counselling could be arranged for them should they feel concerned about any unresolved issues that may arise from the interviews. Each interview was transcribed verbatim. These interviews were printed and placed in a folder for the process of analysis. They were read and re-read through out the process of analysis. After the process of transcription was completed, a further letter was sent to each participant, just giving a very general summary of the types of things that were found. This highlighted common themes from each experience, and was also a further opportunity to thank them for participating.

### **Data Analysis**

Analysis of the data followed the technique taken from Cresswell (1998) who gives a template for phenomenological analysis (see Appendix D). Cresswell's model has been adapted from previous research by Moustakas (1994). The transcripts from each interview were read over several times to gain a sense of the over-all stories of survival. Significant statements and phrases relating particularly to the topic were extracted and these were highlighted and coded for easy future reference. Meanings and themes were collated, and re-checked against the original data. The statements were grouped into "meaning units". A textual and structural description was developed asking "what" happened, "how" the experience was, and what the "essence" of the experience was. The final essence of the experience was presented in current form. In typical phenomenological form, these steps were loosely followed. Some overlapping and

revisiting certain steps, writing and re-writing occurred, however this is part of the reflective nature of the mode of method.

### **Prior Assumptions**

Phenomenological research method is reflective and dynamic with the researcher becoming involved in the process by reflection, re-writing and shifting perceptions as the process evolves. One requirement of phenomenological research is that the researcher should try to have freedom from suppositions (Benner, 1994; Moustakas, 1994). Van Manen (1990) uses the term “bracketing”, which he defines as “*putting aside one's own assumptions*”.

Prior to interviewing my participants my research question was “what psychological attributes do survivors of cancer possess?” I wanted to find answers as to why some people, when given a poor prognosis, die, while others defy all odds, and survive. Coming from a nurse's perspective, I believe I had a rather fatalistic, pessimistic view of any diagnosis of cancer. My experience of nursing people through all stages of treatments, and nursing them palliatively through the dying process has given me this pessimistic view. I was interested to find people who have come through the treatment, and who have survived, because that in itself challenges my paradigm that cancer equals eventual death; treatment equals torture. I had some preconceived ideas about what I might find. I was supposing I might find highly motivated individuals who changed their life-style, took control, and conquered cancer. I thought that these individuals would have definite beliefs as to their survival and attribute it to life-style, diet, faith, meditation or alternative treatments. I also supposed that to survive cancer was “good”; something to wish for all people with the disease.

I found my eight participants to be tremendously courageous people, however, I did not find that they were the super, motivated human beings that I had expected to find, but rather “normal” individuals, who mostly didn't have a strong idea as to why they survived. One participant stated that her survival was just luck. Most of the others could not give any predominant explanation as to their survival. While most of them were grateful that they had survived beyond their expected time, they continue to struggle with many issues. Most of them have ongoing physical problems as a legacy from their disease and treatment. Every time they go for follow-ups, they psychologically revisit the trauma of the first diagnosis. They live with the knowledge that perhaps one day this will overcome them, and they are constantly reminded of their mortality. Surviving may not always be experienced as “good”. One of the participants found life as a survivor, with all of its uncertainties, very difficult, and not necessarily good at all. Therefore, from the beginning, I had preconceived ideas. After I completed the interviews, I found that my fundamental research question had changed to “what is it like to survive a poor prognosis of cancer, and live beyond an expected time?” This shift in my own perception of survival has enabled me to be much more open to the

experience of surviving cancer, and while personal and psychological attributes do come into the thesis, it has become much more a true reflection of the participants' experiences, and therefore more phenomenological.

The research process has challenged me in several other ways. Coming from a predominantly bio-medical paradigm of cause and effect, I was constantly challenged with the fact that often a cause cannot be found; reasons and the understanding of certain situations can be sought, but may not become apparent, and often go beyond our understanding. Personally, I am someone who likes to be in control of my health and life. Over the years in community nursing I was employed to educate people in the ways of making healthy choices, taking control over their health and lives. If I were to become hypertensive, for example, I would read up all about it and find ways of lowering my blood pressure so that I didn't have to take medication: loose weight, exercise, reduce salt and coffee in the diet, or meditate. To a certain degree we do have some control over our health. The question for me, when I read from The Cancer Society of NZ web site that 80% of all cancers are thought to be related to environmental or lifestyle factors, is "why aren't we as a society doing more in the way of prevention rather than cure?" This question suited my cause and effect paradigm, and also my need for a certain amount of control. I now realise that not everyone places such importance of control over his/her lives, and indeed, sometimes the issue of control can be obstructive to healing. I discovered also that to try and change the fundamental beliefs and paradigm that someone has established for themselves is very difficult, perhaps even an unrealistic expectation.

Throughout the project I discovered many challenging things that totally threw my theories into question. I found very healthy, in control, strong people who for no apparent reason, developed cancer. Others developed cancer and survived, however did not feel particularly in control, or particularly fortunate people. They often could not understand why they were still here. There was often no rhyme or reason as to why these people got the disease or why they survived, while others with the same type of cancer have passed on. The chaotic, non-linear experience of cancer challenged me to expand my mind from thinking in the linear way of past, present and future. Perhaps my ability to accept that which cannot always be explained has grown. The process of this thesis has certainly encouraged my personal growth and openness. Theoretically, I believe that in the early stages of my research, I was still asking and looking for the "whys" rather than the "hows". I think that even though I had an intellectual knowledge of phenomenology, I had not made the shift that Benner describes: the shift from a more quantitative paradigm to that of a qualitative one; changing my question from "why" (and looking for a reason) to that of "how".

### **Overview of findings**

From the interviews with the participants four themes emerged as being significant for survivors of cancer. These themes were:

“Why Me?” Cause and effect and making meaning and sense of it all;

“I just want my life to be normal again” Issues of normality, redefining one’s self and the physical legacy of survivorship;

“I’ve been told this will eventually get me” Remission or cure? Living with uncertainty and fear of recurrence; and

“Keeping busy and my mind off of it helps”: Coping styles, control and attitudes.

From the sample of eight participants some generalised observations were made. All participants were women who were more than willing to tell their stories of survival.

The older women (over 60 years) tended to talk in more concrete terms of their diagnosis, treatment and continuing survival. They were less introspective than the younger women, who were often reflective about their experiences. In general, the older women often expressed full trust and faith in their General Practitioners (GP’s) and health professionals, and, when asked about their choice of treatment, did not question the treatment offered. However, some of those older participants did not share this ‘faith’ in medical health professionals, and actively took part in decision making in relation to their health and treatment. The older women also had extremely good diets prior to their diagnoses, and were quite independent people, coming from rural/farming backgrounds, and an era when doctors were only consulted in cases of severe illness.

The younger women (36 years to 60 years) tended to go deeper into their experiences, seeking fuller understanding and meaning to it. They were more aware of having choices, even though they often were guided by the advice of their health professional. Perhaps with more assertion, they were more likely to question or refuse treatment, and ask more about treatment, its side effects and consequences. These women were more likely to eat take-away and refined foods, and did not change these patterns in the long term, after being diagnosed.

While four stated they were of the Christian faith, and believed that their faith in God had helped them through the difficult times, they were not by their own standards excessively spiritual people. They stated that they went to church, but not on a regular basis. One woman said she used prayer as a meditative process to aid in relaxation and visualisation. The other three expressed that they did not actively participate in prayer, but had a deep faith in God and his love for them.

The presentation of findings is structured into four chapters each covering the themes identified above.

## Chapter Four "WHY ME?" CAUSE AND EFFECT: SEARCHING FOR MEANING AND MAKING SENSE OF IT ALL

Common to all participants in this present study was the question "Why me?" Very closely linked to this question are aspects of searching for a meaning to the experience, finding a cause or something to blame, and looking for ways in which to prevent it from happening again. Learning and growing from the experience aids in finding meaning and purpose from the experience, and assisting others on the same or similar journey is often therapeutic. It has been found in previous research that searching for meaning aids in understanding unexpected and traumatic experiences. Finding meaning to a certain traumatic event can powerfully motivate people to make sense of their lives and their experiences (Frankyl, 1959; Turnquist et al., 1988, & Witenburg et al. 1983, cited in Dirksen, 1995). Searching for a cause and a search for meaning are closely related and are initiated by the individual in order to understand why they had experienced an event, and its significance to their lives (Taylor, 1983; cited in Dirksen, 1995). On discovering they had cancer each participant searched their lives and pasts to try and understand why they "got it".

*"I have lived a very careful and healthy lifestyle. I don't drink, don't smoke, have a good diet. I grew all our own veges, so they were organic. I steam my food. I don't eat pastries."* (Zelda)

This retrospective examination of lifestyle was common with the survivors of breast cancer and bowel cancer, however, with the lung cancer and malignant melanoma survivors, a more definite reason was found. The lung cancer survivor had previously been a heavy smoker, and the malignant melanoma survivor had very fair skin, and had, as a young child and teenager, been exposed to unprotected sunlight. However, it is fair to say that seven of the eight participants had felt they had lived a relatively healthy lifestyle, and could not understand purely from that point of view, why they had become afflicted with cancer.

Joyce, at the time of her diagnosis with breast cancer could not believe the diagnosis and states:

*"It couldn't possibly, you know, I'm not a smoker; don't take drugs. I'm a mother who breast fed her children, you know. I sort of feel I had done all the right things, apart from being over-weight, which may have been a problem. It took a long time to sink in because I just couldn't believe that somebody as healthy as me, this could really happen to"*.

Joyce further explored the cause by looking at her family history, but could not understand it from that perspective either.

*"We were a family who had never been involved with cancer and at that stage I still had my parents alive. We were not a cancer family, by any means".*

Jenny, on the other hand, felt her situation was clearly one of genetics, although there was not a strong family history of cancer.

*"I firmly believe that diet does play a big part. I haven't really changed my diet hugely but, we've always watched what we eat. We don't tend to go overboard with fried foods and fatty things. Yes, I have my beliefs about food and vegetables, grains and I think a lot of what we put into our bodies determines, I don't say everything, because I think, when you really get down to it it's probably a genetic thing. So I firmly believe it's a genetic situation, not that we have a big genetic cancer situation in our family, but for some unknown reason our body wants to do this, and it does."*  
(Jenny)

From this dialogue it became quite clear that Jenny searched for a reason at the time of diagnosis twelve years ago, and continued to struggle with "why". Having looked at her lifestyle and diet, she resolved the mystery by assuming that her situation was genetic.

Joan, the survivor of lung cancer had been a heavy smoker for 10 years previously but had given up in 1971. She believed that her cancer was a direct result from smoking, but she also stated that there was a very strong family history of cancer.

*"My father died of cancer; my mother died of breast cancer. There is a strong family trait for cancer. My husband died of cancer. I always thought that I might get it at some stage and have always been aware of the possibility"* (Joan)

Marie, a breast cancer survivor didn't notice the lump in her breast as she said her breasts were often lumpy. The lump was found by her nurse when she went to her GP for another, unrelated problem.

*"This was out of the blue. No-one in my family has ever had it. My sisters are now a bit more astute in the area of mammograms and things. I was jolly annoyed, because I've never been on HRT's [Hormone Replacement Therapy used to treat menopause]. I don't drink much, I've never been on the pill, you know. Perfectly healthy, athletic, so it was nothing to do with lifestyle. Brought up on the farm, fresh air, so there's, I don't know."*

Later in the interview Marie stated that the doctors believed her breast cancer to be related to the onset of menopause, however, the internal search for a reason was very apparent, and she continued to grapple with the cognitive processes of understanding why this had occurred.

Kath, survivor of malignant melanoma, saw her cancer as a direct cause from sun exposure as a younger child. However, during the interview, she discussed other people's experiences of searching for a cause and the anger and frustration that can result if they cannot understand the experience or find a cause.

*"There have been too many people that I know who have died angry because they did everything right. They didn't smoke. They were really healthy. Why did they get it? There is a lot of anger there, and they can't let it go, and some die really horrible deaths. My friend died like this. She died very angry, she fought right to the end. It's such a waste of energy, because she had so much anger in her, that she actually stopped being aware of what was still good in life, and her little girl was one who suffered as a result. Living in the moment rather than being angry is something everyone should learn more of."* (Kath)

Failure to find meaning and understanding to a traumatic experience may cause more stress and discomfort. Sally, a survivor of cervical cancer, was one participant who was plagued with psychological discomfort. She did not give any explanation as to why she acquired cancer, but had some general views on why cancer is so prevalent in our society.

*"It's more chemicals. For instance, working out at spotless. They have this spray for cleaning, and my throat was sore for weeks, and even though they water it down, and I blame the chemicals".*

Learning to prioritise was a common theme among the survivors interviewed. Deciding what is worth holding on to and what is better to let go of seemed to be an important lesson in making sense of a traumatic situation, a lesson that not only survivors can benefit from.

*"You learn to drop those silly little issues, and you drop those shields, and you become aware that everyone is wearing those shields, and you learn that some things just aren't worth one ounce of worry over, they now don't even come on the list. Dropping of facade and pretence, is very important. The actual having cancer made me re-evaluate priorities and I did re-discover spirituality"* (Marie)

Kath stated that being diagnosed with malignant melanoma, having treatment and surviving had completely changed her life.

*"I couldn't go back into who I was before. The experience had changed me, because I had looked death in the face". (Kath)*

She found that integrating her cancer experience with who she is has been helpful.

*"I've actually got to find a way to integrate that my experience with cancer is a part of who I am, and have integrity about having cancer, and accepting that it is a part of who I am. That it changed me. That good things have come out of the experience, but that I also have to live with the uncertainty."*

From my interview with Kath it was very apparent that she was introspective and thoughtful, and finding meaning and sense of her experience was very important to her. She felt that to be able to have something good come from her experience was not only important to her, but other survivors whom she had met on the same journey. The other survivors interviewed shared her beliefs in this respect as well.

*"So for me, the impact of cancer has been far more a psychological experience than anything else, because it's been about me looking for meaning in it and wanting to find something good to come out of it as well, this has been a huge thing. That I can use it to help others and that I also help myself as well. And I still want to live life hopefully, live life simply and the best that I can, and learn how to be gentle with myself, when I muck it up". (Kath)*

Several participants discussed the importance of learning from the experience; that somehow, through their own suffering and difficulties, their experiences could assist them in their own personal understanding of life, and also assist others. Several survivors discussed the common but difficult concept of living in the present as a very important thing to learn and practice. Kath summarised it well:

*"One of the things I've learnt about life is to live more in the moment, live more in the present, and to take time to sit and enjoy a cup of coffee. Look at the daffodils. Being a bit more present focused than I used to be means that I have the ability to learn from what is right there in front of me, rather than, I used to be so idealistic, that my head was always about tomorrow, and I would always be looking at tomorrow, into the future. I found it very hard to stay in the present, to stay connected to what is going on around me" (Kath)*

She also felt she needed to change her expectations she placed on herself and on others.

*"I had to let go of my expectations, not only of myself but of other people. And now I think "I'm doing the best that I can, with what I have". And I have that about other people as well. And now I think "they're doing the best that they know how to."*

Surviving a diagnosis of cancer gives an opportunity for re-evaluation of one's life and changes to one's priorities. All of the survivors interviewed discussed this opportunity for re-evaluation.

*"I had to re-evaluate my life and get rid of the junk. I've got my funeral planned. Anything that I do, like photos, I had such a clean out and I've got, I've got my life sorted out. But I didn't do it really for death, if you know what I mean. I went through a lot of things. And my belongings are sorted out, things marked out for my children. And yeah, I didn't do it because I was dying, it was because I wanted to get my life sorted out. And that's the shock of cancer, hell, I might not live. I've got to do this and that, and that changed my life." (Joyce)*

The concept of life as a journey came through from the interviews, which gives a sense of continuity, acceptance, and even at times enjoyment. All survivors interviewed had a sense of undefined incompleteness: that cancer was and is a continual part of their journey, but is by no means all there is to it, and that their journey is one of becoming.

*"It's all been part of a huge journey. It's even recognising that it is a journey, is a big thing. That where I am now is very different to where I was 5 years ago. And hopefully, 5 years time I'll have a whole different understanding of it" (Kath)*

Throughout Kath's survival journey her beliefs have changed. She expressed that everything about her has changed, even her beliefs about God.

*"I think the journey that I've been on certainly meant that I have developed my beliefs. They have changed. Even my spiritual beliefs. My relationship with God has really changed. It's not so much a religious thing now, it's more about that I needed to find out who God was for me".*

For these participants, finding meaning and making sense of their experience was important for them they share this with others who survive cancer as previous research has found.

### **The importance of finding meaning in the lives of survivors: previous research and discussion**

Many people who face a life threatening illness experience inner turmoil and searching for the meaning and purpose of their lives and their disease (Coward, 2000; Mahon, 1997). Constructing meaning from their

experience is of utmost importance as they work through the process of diagnosis, treatment, life after treatment, and then, possibly facing the return of the disease (Coward, 2000; Taylor, 1986). In one study with survivors it was found that some people with advanced cancer who found and gave meaning from their illness experience had a more positive self image and were less anxious than survivors who did not find meaning (Lewis, 1989; Post-White, 1998; both cited in Gotay, Isaacs, & Pagano, 2004).

Folkman suggests that meaning is an important aspect of coping with illness and loss, stating that individuals have a “global meaning” which lasts a life-time and which is composed of values, goals, beliefs and self-image. A diagnosis such as cancer challenges this global meaning, and so new meaning is sought, incorporating the illness, enabling the person to cope with the new situation (Folkman, 1997, cited in Holland, 2003). In a quantitative study with cancer survivors, Dirksen found that 52% of those studied searched for meaning in their experience, while 48% did not. He also found that younger survivors were more likely to seek meaning to their experience than older survivors (Dirksen, 1995). Little and Sayers found similar results in their qualitative study on cancer survivors, with 30% of their participants searching for meaning of their lives, achievements and identities (Little & Sayers, 2004).

It is theorised that this search for meaning is an attempt to understand stressful and unexpected events, and it assists people in finding meaning in their lives. It is also thought that searching for meaning may have an adaptive purpose because it helps one to regain a sense of control and well being (Dirksen, 1995). Frankyl believes that suffering provides a strong motivation to make sense of a situation (Frankyl, 1959).

Reker and Chamberlain (2000) divide the construct of meaning into two aspects: implicit or definitional meaning (the personal significance given to objects or events in life) and existential meaning (how events in life fit into a bigger context). The process of searching for existential meaning asks the questions: “What is the meaning and purpose of life?” (Reker & Chamberlain, 2000). Coward (2000) defines the search for meaning as a process of making sense of something. The effects of stress on the physical and psychological health and well being are modified by exploring and discovering existential meaning. The quest to find existential meaning is an ongoing process, which changes over time and differing experiences. Despite changing themes and sources of meaning, the central purpose of finding meaning is to preserve personal identity and one’s sense of coherence (Reker & Chamberlain, 2000). Constructing a positive meaning to the experience of surviving cancer can assist the survivor in reconstructing their values and priorities, assist them in learning to live more in the present and live life in a more meaningful way. Better adjustment is predicted for those who do construct positive meaning to their survival (Taylor, 1983, cited in Dirksen, 1995). For the purpose of this study, the focus was to be on existential meaning; that is, how do survivors perceive the meaning and purpose to suffering from cancer and its treatment, and continuing on to survive.

Closely linked to the search for meaning is the attribution theory. According to the attribution theory individuals seek a reason or cause for sudden or stressful life events in an effort to understand the situation better and gain a sense of control over their lives (Kelley, 1967; Heider, 1958, cited in Dirksen, 1995). Understanding why the cancer occurred may help by alleviating anxiety for some survivors by giving them a sense of decreased susceptibility for recurrence of the disease. Certain habits may change, certain foods may be avoided, and practices adopted in an attempt to prevent recurrence. This change in behaviour may give a sense of control over maintaining health and preventing the recurrence of the cancer (Nelson, 1996). Attributions of blame are significant to the fundamental questions as to why cancer occurred. For those with cancers that are directly related to lifestyle, such as smoking and lung cancer, the blame is focused on the contributing cause. These survivors may also blame themselves, and take on the responsibility to change these habits and therefore feel they have a certain degree of control over their disease progression or recurrence. However, for some survivors of cancer with no known aetiology, the cause is unknown and self-blame is less likely to occur. These survivors have nothing significant to focus their blame. Dirksen found a positive significant relationship between the search for meaning and self blame among survivors. He deduced that attributing responsibility to one's self for the cause of one's cancer is strongly associated with a search for meaning (Dirksen, 1995). Individuals often develop their own attributions for illness which are highly personalised and externalised. Stewart, Cheung, Duff, Wong, McQuestion, Cheng, Purdy, and Bunston (2001) found that many long term breast cancer survivors attributed the cause of their cancer to stress, even though scientific evidence does not support this. Further, it was also found in this study that many of these survivors believed that their positive attitude prevented further recurrence of the disease. Attributing their survival to staying positive possibly gives a sense of control over an uncertain and uncontrollable disease, and often personal attributions affect the health and choices that are made by individuals (Stewart, et al., 2001).

Searching for a reason why and finding meaning to their experience assisted the survivors in the present study in coming to terms with their experience of having had cancer and surviving. One survivor, Sally, struggled with meaning and making sense of her situation. On the day that she was interviewed, she was relatively happy, however she referred many times to her unhappiness. She suffered from guilt of surviving, knowing of others who were diagnosed with the same cancer, who had passed away. She survived 22 years past initial diagnosis, but still could not come to terms with the "whys".

All of the survivors interviewed had ongoing physical issues, and continuing psychological challenges due to their survival. Seven of these saw these aspects of survival as providing more texture to the puzzle; more enrichment of the journey. Sally, on the other hand, struggled with these issues, and suffered depression, insomnia, social constraints and adopted maladaptive coping styles as a result. Sally's failure to find meaning and purpose to her suffering stands out as a very obvious case to argue the importance of finding

meaning to life's experiences. The other seven survivors had a way of taking the difficulties in life and using them to further enhance and deepen the quality of their lives.

## **Chapter Five “*I JUST WANT LIFE TO BE NORMAL AGAIN*” ISSUES OF NORMALITY, REDEFINING ONESELF AND THE PHYSICAL LEGACY OF SURVIVORSHIP.**

What is normal anyway? It is a good question. For most of us life goes on day by day, and without a life changing experience to shock us, perhaps we don't even think about what is normal for us, and what is not. After a life changing experience, which is usually acute and sudden, life is turned upside down and the life that was known before is no longer, change has occurred and a quest for some return to the status quo is sought. In the case of surviving cancer there are many changes that happen as a direct result from the diagnosis and treatment. Obviously, there are physical changes; surgical removal of body parts, loss of hair, chronic tiredness from chemotherapy or radiotherapy, loss of libido, and ongoing physical issues, such as limb oedema. Limb oedema is chronic swelling of an arm or leg, due to the pooling of lymphatic fluid in the limb. It is a very common side effect from surgery where the lymph glands have been removed either under the arms or in the groin. It is common practice with cancers of the breast, for example, to take the breast off, and examine all of the lymph nodes under the arm of the same side, to see if the cancer has infiltrated into the lymph nodes. If it has, or if the cancer is seen to be invasive, often these lymph nodes are removed. This removes the ability for the lymphatic fluid to be circulated from the arm back into the general blood system. As a result, the arm becomes very swollen, sore and often the range of movement of the limb is inhibited. In the case of melanoma of the leg, the surgeon will also often analyse the lymph nodes in the groin of the affected leg, and remove them according to the severity of the cancer, and the chances of infiltration to other parts of the body via the lymphatic system. Compression arm sleeves or stockings for the legs do help in minimising this problem, as do specific exercises. Wearing them and doing the exercises depends very much on the individual motivation and strength of the person who has just had major, radical surgery that has removed important structures of their lymphatic system. Increased oedema in a limb also increases susceptibility to infection in that limb because, overall, the lymphatic system in that limb has been severely compromised. Care needs to be given to the affected limb to protect it from trauma, and if it does become scratched, hurt or traumatised, early treatment with antibiotics is necessary to prevent serious infection and cellulitis. Closely linked to the physical changes are emotional and psychological changes. Also related are socioeconomic changes, especially if the survivor can no longer work in the job that they previously were employed in.

Each survivor interviewed identified the search for return to normality as being very significant. They also came to a point where they found that this search was almost impossible: that life as they previously knew it was no longer, and they therefore had to redefine their lives around their cancer experience and survival.

Ongoing physical problems were a constant reminder of the futile effort to return to “normal”, and often hindered their progress back into “normality”.

Zelda, the survivor of bowel cancer, was sent home after her last surgery with a colostomy bag. It's hard to imagine life after having been given one of those. They attach to the side of the abdomen, collecting the faecal waste, right under the nose; it has to be emptied frequently, and changed often. Diet becomes an issue as some foods may cause problems with a colostomy and this needs to be taken into consideration for all aspects of one's life-style. The psychological effects of a colostomy are great, and the implications for the partner are huge also. So, for Zelda, returning to “normal” is almost impossible. Yet, during the interview she was bright and chirpy and extremely positive about living a full and happy life with a colostomy. For her, returning to normal was getting back home after her surgery, and re-gaining her independence, and learning how to incorporate her colostomy into her life-style. She has done this well.

For others, the search for returning to normal did not come so easy. For some, the return to work helped them feel as though life had some sense of normality again. This was very much the case for Jenny, who worked right thorough out her treatments and continued to see work as a means to gain a sense of normality, and a way of coping. After her mastectomy she states:

*“...and after that it was getting over it, and I had about 4 weeks off of work and then I went back to work, and there were no problems. That was 12 years ago.”*

Unfortunately, Jenny developed another primary cancer in her lung 2 years ago, but she continued to work through her treatment in an effort to retain some sense of normality. Returning to work featured in several survivors' stories and their desire to return to a normal life. Kath, with a physical legacy of an oedematous leg had to seek employment which meant that she could sit down mostly, however is currently in a job which requires a lot of standing. Her frustration is expressed:

*“I stand a lot in my job, and I don't want to be going to my boss and saying “I'm sorry, I can't do my job, because I can't stand up”. Because I want to have a normal life, so that means I can't get treated differently from other people”.*

Once, she developed cellulitis in this leg because she was not looking after herself as well as she should have:

*“I was in hospital for about a week. Part of it was, here was me trying to live a normal life, and then being told, well, you've got to be really careful. If you get scratched you need to go to the doctor. If your leg starts to get inflamed, you've got to go to the doctor. How can you live a normal life?”*

For many survivors, suitable prostheses and/or reconstructive surgery is immensely important to their return to normality. Joyce, following a mastectomy, felt that reconstructive surgery was very important to her life. She did not cope at all well with her prosthesis.

*"I couldn't handle the prosthesis...I'd gone on to have my reconstruction surgery when they found the second lump". (Joyce)*

There has been quite a lot of research done on the role of support groups with cancer patients and survivors. Research suggests that belonging to a support group can be beneficial and therapeutic (Taylor, 1986). However, in this present study only two of the eight interviewed were active with cancer support groups. The other six found that belonging to a cancer support group meant that they identified with others with cancer, and they did not find this helpful in their integration back into "normality".

*"I know it sounds awful to say that you don't want to get involved, with people in that situation. And I don't mean it like that. But I just find it better to, just be living as if, you know, you're normal. I've never got into the cancer society groups or things like that. I just find that I'm better off in just a normal situation, rather than being surrounded by people in the cancer situation, and I don't mean that in a horrible way" (Jenny)*

The quest for a return to normal was strong. Marie gives insight into this desire:

*"All you wanted to do was to feel normal, be a normal person. I remember saying to my husband "I just want to be normal. To be treated as a normal person as well"*

For Marie, it was important for the district nurses who came to dress her wounds to treat her as a normal person. She described her frustration when some of them seemed extra sympathetic, or focused on her as being a person with cancer, rather than being just a person who was experiencing the effects of cancer on her life. There was one nurse who did treat her "normally":

*"The male nurse came one day and asked would I mind having a male nurse? And I said I didn't mind. And he was brilliant, he was just so positive. He talked about everything. He didn't just talk about cancer, where the others were very much focused on the symptoms and the cancer, too sad and dramatic about the whole thing, but with him, we'd talk about the library closing down, about the weather. I always felt quite elated when he came."*

Marie also had problems within herself when she lost her hair due to chemotherapy. She had lost her breast to surgery, however, the more obvious loss of hair caused her more stress, due to the public and social reactions and expectations to “normality”. She explains:

*“One of my biggest traumas was losing my hair. I didn’t worry so much about the breast, but losing my hair. I did get a good prosthesis for my breast and you really can’t tell. But the hair: No-one said to me how it would affect me, to see it falling out piece by piece. It was horrible. Much later on I thought it would have been far better to have had it all shaven off in the beginning, because it was just real horrible. And so I had a lot of trauma about losing my hair. Extraordinary really, because I used to wear those turban things, but everyone stops and looks at you in town. So my advice would be to get your hair shaved off and get a wig, right from the start, then no one would even know. You feel you stand out, but if you blend in, then no-one knows”.*

For some, getting on with life as though nothing is wrong, is a way of coping and feeling normal:

*“...To take it as it comes. I read at one stage that 90% of what we worry about is not going to happen anyhow, so why are we going to worry about it? Why are we worrying about it before it happens? Get on with just living at the moment. So I find just doing every day things, and act as if nothing’s wrong. I can’t say it doesn’t leave your mind because it’s with you when you wake up in the morning and when you go to sleep at night, but generally, to try and put it out of your mind is the thing to do” (Jenny)*

For some of these women, normality, or life as they once knew it, was not possible, and so they felt they needed to re-define themselves and their lives, around their new identity as a survivor. Kath, in particular, expressed her struggle with this redefinition of her identity:

*“I couldn’t go back to who I was before, the experience had changed me. In the first year I had a lot of struggle with trying to work out who I was as a person, my identity. I found who I was as a mother had changed, as a wife, as a friend. I wasn’t working, I had to stop work. All of that had changed. I really struggled with trying to work out who I was meant to be as a person”*

Later, Kath felt that she needed to integrate her experience of having cancer into who she is.

*“I thought “I’ve actually got to find a way to integrate the experience with cancer as being a part of who I am, and having integrity about having cancer. And accepting that it was a part of who I am, that it had changed me, that good things had come out of the experience, but that I also had to live*

*with the uncertainty. That is still ongoing, because I think that has probably been the hardest lesson”.*

Self-acceptance was hugely important for Kath. She felt she needed to become more accepting of herself as a quiet and introverted person, and accept the way in which she coped with her cancer experience and her survival.

### **Physical legacy of survivorship**

All of the participants had on going physical problems that inhibited their lives and integration back into “normality”. Zelda has now a colostomy bag to contend with for the rest of her life. Certain foods upset her digestion. The survivors of breast cancer have their prostheses or reconstructive surgery to cover their loss of a breast, however all suffer a certain degree of lymph oedema in the affected arm. Some of these women who had radiotherapy in the course of their treatment now also have thyroid problems. One woman felt that this was directly due to the radiotherapy treatment, and the close proximity of other vital organs, such as the thyroid gland. She was also concerned at the time of treatment about her lungs and her heart and oesophagus.

*“They’d call you in. Nothing is said, just bundled up onto the table. Then you’d wait for the machine, and you’d think ‘ Oh God, I hope they hit the right spot’, because there was a suggestion that they might get the oesophagus. And I was also worried about my heart. They did not reassure me that they wouldn’t be damaging other parts. So, I don’t know, I was never very happy about that”.*

*“...after all of this, I was feeling very tired and the doctor found that my thyroid was not working, and they wondered if it was zapped by the radiotherapy, but we don’t know. So I’m taking thyroxine now. Because it was so close, I suspect that they might have got the thyroid gland with the radiotherapy.” (Marie)*

Joyce, too, has had problems with her thyroid and attributes it to her treatment for breast cancer. She also believes that her treatment from chemotherapy and radiotherapy has caused her to have an irritable bowel.

Sally, the survivor of cervical cancer, had chronic bowel problems, due to the cobalt therapy she had been given 22 years prior. She also has ongoing bladder problems, and the surgical removal of her uterus and ovaries brought on a premature menopause.

*"I have ongoing problems with a weak bladder. If I cough, I've got to go. I have a lot of problems with my bowel. I've got to watch what I eat, like fatty food or a lot of fruit, and alcohol. The treatment put me into premature menopause, that's when I had to go on to hormone pills, when I was 34 years old"* (Sally)

Kath, survivor of malignant melanoma, had severe lymph oedema in her leg, due to the radical surgical removal of her lymph glands in her groin. Her leg has a tendency to swell, particularly if she stands for long periods of time, and she is also susceptible to getting infections in her leg. Considering the physical, psychological and social changes that occur as a direct result of treatment for cancer it is very understandable why returning to normal is extremely difficult, if not impossible. Previous research has found this to be true also.

#### **Maintaining normality and the re defining of oneself as a survivor: previous research and discussion**

*"When one has a disease like cancer, you can never get away from it. It will never go away. Wherever I go, the cancer comes with me. It is as if I had acquired a new nationality. I am now a citizen of Cancer Country, and only other people with cancer know its language"* (Sigler, 1999).

Maintaining or regaining a sense of 'normality' has been identified by some survivors as being important to their survival (Thewes et al., 2004). For this reason, many survivors do not go to cancer support groups, because they feel it prevents them from moving on. It has also been found that when survivors attended support groups with in the hospital, associations were made of illness, treatment, and unpleasant memories from the past. Many survivors wanted to forget their cancer treatment phase, and get on with the normality of life (Nelson, 1996; Thewes et al., 2004). Support groups can be beneficial, however they also place the survivor in a community of people who constantly remind each other of their mortality, as they share their stories and experiences of life with cancer. Some have identified that watching one's friends die, while they struggle with the disease themselves, is a very difficult thing to do (Little & Sayers, 2004).

'Normal' is very difficult to define, and for survivors who realised that to return to 'normal' is impossible, a 'new normal' needed to be found, incorporating a new way of being (Nelson, 1996). After a diagnosis of cancer an individual's life may be changed forever, and survivors do not return to the state of normal health that they experienced before. The process of normalising their life after a diagnosis and treatment of cancer is life-long for the survivor, and the quality of their life can be severely affected (Pedro, 2001).

A diagnosis of cancer for some may cause an intense attempt at reconstructing ones personal identity. Personal identity is defined by Locke (1992) as embodiment, continuity and memory. (Locke, 1992, cited in Little et al., 2002). Being diagnosed with cancer may cause discontinuity and therefore become very

threatening to one's personal identity. The reconstruction of identity involves drawing on past memory and preserving continuity between past and present memories. Little et al. also identify the construct of "future memory": "*Future memory is not the same as 'plans' or 'expectations'. It involves an act of imagination whereby we envisage looking back at identity-defining events which have yet to occur*" (Little et al., 2002). Future memory assures continuity of our lived lives into the future. Disruption of future memory can have a profound affect to one's personal identity, threatening hope for the future and good things to look forward to. Survivors of cancer may often struggle with this loss of continuity, and restoration of continuity and the reconstruction of an adapted future memory are important issues for these people to strive for. This may be very difficult for the survivor to accomplish and cause ongoing psychological distress through out their years of survival (Little et al., 2002; Little & Sayers, 2004). Little et al. (2002) also identify several disruptions to one's sense of personal identity when a diagnosis of cancer is made: discontinuity of memory; discontinuity of embodiment; existential disruption and the disruption of the memory of others. With these disruptions, normality is very difficult to re-capture.

Alienation, a feeling of being different, is a psychological issue that some survivors experience. Their lives are now different to their previous state, and also perceived as being different from those around them (Thewes et al., 2004). The psychological issues surrounding cancer survival are less recognised than the understanding and sympathy that goes with the illness phase. The role of being a survivor and the discourse for survival is less defined than the discourse of illness (Little et al., 2002). The feelings of alienation may also occur within support groups if the survivor perceives that they are different, or their circumstances are different (Thewes et al., 2004).

Regaining a sense of normality is recognised as important to survivors of cancer. It is seen as a coping mechanism as an attempt to construct order in a crisis or disruptive situation (Tishelman & Sachs, 1998, cited in Killoran, Schlitz, & Lewis, 2002). Killoran et al. found that many of their participants not only normalised their diagnosis of cancer, but also their survival. Normalcy for these survivors was more important to them than issues of uncertainty related to their diagnosis of cancer (Killoran et al., 2002).

## Chapter Six REMISSION OR CURE? LIVING WITH UNCERTAINTY AND FEAR OF RECURRENCE

*"In losing a breast, there is a sense of loss. It is a feeling I own only to myself. But the fear of recurrence took a hold of my life. The illusion of fear has been lost when I encountered my cancer for a third time. There is nothing to lose now." (Sigler, 1999)*

What makes a cancer survivor any different to any one else? In the end we all die, whether from cancer, trauma, accident or another disease process. In many ways we all live with uncertainty. There must be something unnerving, however, about living with the knowledge that cancer has invaded one's body, and it's cells may still be present to grow and multiply else where with in the body. This must create uncertainty as to when the end will come and what it will be like. One can only imagine the horror of living with the threat of recurrence, waiting for the time, but never quite sure when. If all sources of hope are perceived as lost, then the circumstances become indeed bleak. In the present study, several of the participants discussed the concept of remission as opposed to cure, and the difficulty in accepting the uncertainty of the future mixed with the fear of recurrence. An increase in fear and anxiety often occurred just prior to follow-up visits for check ups.

### Remission or cure

*"After my five year check-up, I was given the clear. I was very elated. Occasionally you hear someone say "oh, but you are never really cured of cancer", and that really annoys me. And then another thing that annoys me is the remission they talk about. I hate that word! Because it suggests that it could come back, and I hate that. I was thrilled when the doctor said that I was right back on the level that anyone on the street was, and they all have a chance of it, so I thought "yep! Cured!" I will keep looking after my immune system. I still make sure I get my rest, and keep positive and don't really dwell on it." (Marie)*

Marie was not the only one who expressed the problem of remission or cure. May also spoke of her inability to understand the concept of remission:

*"I had a relapse 2 years ago. Yes, I don't know what caused that, but all of a sudden things sort of caved in. I really don't know what is meant when they talk about remission. Do I say that I have had cancer and then had a long period of remission, do I say that?"*

### Uncertainty about the future

*"I've been told that cancer will eventually get me. Apart from any accident, I won't die of old age"*  
(Joyce)

Uncertainty, is something that all humans have to live with, because we do not know what lies ahead of us except that we are mortal, and will die. The survivors interviewed all gave indication throughout their interviews that this uncertainty was often on their minds.

*"I feel nobody really cares, you know, once you're sick, they don't really want to know. Because cancer, it runs in my family, my real mum died of it, and two of my aunts, and my real mum died at the age of 56 years. Well, I'm now 56, and you think, well, it goes on in my head, "How many years have I got left?" you know? It's awful. And that's why I've got to get out of the house and get my mind onto something else"* (Sally)

She further discussed her drinking:

*"...to be honest with you, I was just drinking so much just to deaden everything, just the thoughts 'am I going to die? When am I going to die?'"*

Later on in the interview this came up again. Sally stated she was constantly thinking about her death, when it would be and at what age she would be.

*I was frightened of dying, as a 30 year old. My real mother died at 56, my stepmother at 62, and I think " how long will it be before I die? Always thinking about it"*

Malignant melanoma is very invasive and does not respond to radiotherapy or chemotherapy like other forms of cancer. These treatments were not offered to Kath. As a result Kath felt that the uncertainty of her future was exacerbated.

*"I have only had surgery. In some ways I think that people that have, like, chemotherapy or radiotherapy, it's almost like their insurance, "well this is what you can do to make it strengthen your chances of not getting cancer again". And, well, melanoma is not like that. I was quite horrified at just how brutal surgery was. If there was some kind of insurance that taking some type of drug meant that I could not have this again, it would be great".* (Kath)

Kath's uncertainty and fear of recurrence was planted in her mind by medical professionals just after she had recovered from the surgical removal of all of the lymph nodes in her groin (secondary site).

*"I asked the surgeon, "I mean, what sort of survival chances have I got?" and because it involved about five out of seven lymph nodes, he said, "well I'm sorry, but your chances of survival beyond five years aren't great, but, you know, you might be one of the lucky 20%." Well, I've never thought of myself as being a particularly lucky person, so for me to be told that, it was almost like saying, 'well, you're going to die, you know. Get used to it'".*

Later in the interview, Kath expressed her uncertainty about her life in this way:

*"I want to have the best life I can, but maybe I won't have a very long life. Maybe I will. You know? And I look at hope, and I hope that I am old. It's also knowing that if I can live the best life that I can, in whatever time I have, then it doesn't have the power to undo me quite as much as what it used to. You know, that I am not living as if I'm dying already".*

Jenny shared her feelings about changing priorities and the uncertainty of life:

*"Yes, your priorities do change. You take a more relaxed attitude to life. You have thought out your priorities in relation to your family and grandchildren. Yes, what you do with your life and how you live your life. These things also come with age. I think when you are younger, and first married with a family, you're striving to get your life and home running, so it's basically a progression thing that does come with age. You just sort of think, "well, I really want to spend more time with my grandchildren, because I really don't know how much time I've got, although none of us know how much time we have, but you are just faced with it a little bit more".*

### **Fear of recurrence**

*"Anxiety runs wild... there is nothing that is insignificant... there are no simply little pains...it doesn't really terrify me... it angers me... I want to live a full life" (Sigler,1999)*

All of the participants expressed concern, and increasing anxiety just prior to their scheduled follow-up medical examinations. Medical follow-up for cancer survivors may be in the form of a physical examination, blood tests, x-rays and scans. These are done routinely, often to pick up early development of metastases, or as a precautionary practice, to re-assure the survivor that they are one hundred percent well, and there are no signs of secondary infiltration. For these people, who had worked so hard at integrating their cancer history into their present lives, fear of recurrence was often suppressed for the long periods of

time between follow-up checks, but as the time drew closer to the check-up date, their anxiety grew in intensity. Some stated that as time neared, they almost fully re-lived the horror of the first time they were diagnosed. They would recall all of the unpleasant memories associated with their diagnosis and treatment. This is understandable, considering that for many of them, their follow-up included re-visiting the hospital, x ray or scan department where they spent unpleasant times, waiting in anticipation for treatment or news.

*“I do get apprehensive just before my check-ups. I am due to have another one next week. I will be having a scan, chest x ray and other tests” (Joan)*

For Jenny, who is still currently being treated for another primary site in her lung, recurrence is a reality:

*“When it comes back, it’s pretty daunting. I have a couple of bad days, and every time it comes back I say to myself “Why am I feeling like this? I should be used to it by now”, but after two or three days I just think to myself ‘just get on with it and do what you have to, and hopefully it will work’” (Jenny)*

Sally talked about some women that she came to know, who had been diagnosed with the same type of cancer as her, yet had since passed away. This seemed to have a negative impact on her, and increased her fear of recurrence:

*“A lady who had the same kind of cancer as me, she had chemotherapy, and she died 8 years ago, and there’s a lady down the road, she had the same treatment as me, and she died a couple of months ago. And I talked to my nurse about it, and she said ‘but, Sally, she didn’t keep coming back for her smears’, and I know that one day it’s going to come back to me”*

Sally also talks about the relationship between feeling good about herself and hope:

*“When I’m feeling good and think more of myself, then I feel hopeful that it won’t come back, but when I’m down, that’s when I think it will, because it definitely runs in the family, but it’s truly more in the mind. As they say, ‘it’s mind over matter’”*

Kath discussed her thoughts about how she felt just prior to her regular check-ups:

*“I was still going to the hospital every six months for check-ups, scans, and I found what I was starting to do was, I’d almost separated out the cancer from the rest of my life, and so what I’d started to do when I had an appointment was, I’d just fall apart, because it was almost like revisiting, every time, about being in hospital, about dying...and then I’d fall a part when I knew I*

*had an appointment. Almost three weeks before the appointment, the letter would arrive, my appointment card, and then I would start going in this downward spiral."*

Most of the participants, in the early survival years, found it difficult to discern common aches and pains from the recurrence of their cancer. They felt it was difficult to know what to be alarmed about and what not to be. The treatments often caused increased tiredness, malaise and lack of motivation. The physical legacy of altered body chemistry was also confused with recurrence. As the years of survival increased, each woman began to re-learn their body's symptoms of distress, and began to feel less paranoia concerning the recurrence of cancer. Indeed, after each survivor reached the five-year milestone, they became more and more positive that the cancer would not recur. However, most will admit to their greatest fear of recurrence of cancer, and eventually dying from it. These findings are consistent with the findings of previous research.

#### **Living with uncertainty and fear of recurrence: previous research and discussion**

Cancer has the dangerous ability to metastasise to other areas of the body. The possibility of recurrence is a very real threat to survivors and is something that is frequently on their minds, and fear of recurrence persists long after the diagnosis has been made and the treatment has been given (Breaden, 1997; Gil, et al., 2004). Fear of cancer recurrence is very prevalent among survivors and is most common in the second extended stage of survivorship (the death salient stage as identified by Little & Sayers, 2004) (Aufdenkamp, 1997). Often, during this stage, every ache or pain is perceived as being a recurrence of the cancer. Survivors express concern at not being able to distinguish between normal bodily changes arising from aging from symptoms of disease progression (Gil et al., 2004; Thewes et al., 2004). As well as fear of secondary sites developing, there are also fears of new primary sites, some of which are a direct result from treatment such as chemotherapy and radiotherapy (Aufdenkamp, 1997; Gil et al., 2004). Some women with certain types of breast cancer are put onto Tamoxifen, which alters their body's hormonal levels, making a more hostile environment for the oestrogen reliant cancer to reproduce or metastasise. Tamoxifen, however also has side effects, one being an increase in the possibility of getting endometrial cancer (Aufdenkamp, 1997). For women who have had their ovaries removed, hormone replacement therapy may be advised. This prevents younger women from going through a premature menopause, however, these too have side affects. Being female hormones, there is a possibility of these precipitating a recurrence (Aufdenkamp, 1997).

Even after five years without recurrence, many survivors still experience uncertainty related to the threat of recurrence and the physical symptoms of residual effects of treatment (Gil et al., 2004). Uncertainty may be triggered off by general medical visits to the doctor, or by the development of aches and pains that may be perceived as a recurrence of the disease. This uncertainty precipitates persistent anxiety (Gil et al., 2004). It is well documented that follow-up visits to the doctor are anxiety provoking for the survivor (Mahon,

1997). Other triggers came from hearing about another person's disease progression, environmental triggers, and information from the radio, TV, and printed media controversy.

Fear of recurrence and uncertainty about the future are very significant to those who survive and to health professionals who work with survivors. It has been identified that interventions designed to help manage fears and openly discuss issues of uncertainty may be helpful, therapeutic and necessary for cancer survivors (Lee-Jones et al., 1997).

There are also often feelings of guilt upon recurrence. Again, a common reaction is to look for a cause; a reason as to why the cancer has recurred. Survivors will feel responsible for their health, and blame themselves that they did not find the lump soon enough, did not eat the right things, did not meditate, or change their lives in ways as to prevent a recurrence (Lee-Jones et al., 1997; Mahon, 1997; Sigler, 1999).

Thewes et al., in their research with breast cancer survivors, found that many women felt their needs were not met in relation to receiving reassurance concerning general aches and pains that are normal as opposed to recurrence. They also found that many women had ways of coping with living with uncertainty, however some found dealing with uncertainty disabled them to make plans for the future. Research has found that while the initial depth of uncertainty experienced at the time of diagnosis and active treatment fades somewhat over time, it could also recur at any time and with the same intensity as initially experienced. Uncertainty often led to feelings of hopelessness, which also brought about depression. Distraction, keeping busy, and techniques to suppress emotions were all adopted as means to deal with uncertainty (Nelson, 1996). A positive side to uncertainty is that it is facilitative in learning how to live more in the present and valuing the positive aspects of life. Uncertainty enabled many women in Nelson's research to discover how precious life is, and how meaningful it can be, if one learns to live more in the present. Some also found that uncertainty gave them a new passion for their lives (Nelson, 1996).

To summarise, uncertainty for the future, and fear of recurrence are well recognised as being significant issues to cope with during the years of survival.

## Chapter Seven “KEEPING BUSY AND MY MIND OFF OF IT HELPS”: COPING STYLES, CONTROL AND ATTITUDES.

Keeping busy does indeed give us all less time to ponder about our lives; our past successes and struggles and our future concerns. Our western style of living is very much one of keeping busy. How often do we ask ourselves “Is this really what I want to be doing with my life?”, “If this was my last year of life, what would I be doing with the time?”, or “what things are really important to me, and what is just a superficial filling up of time and keeping busy?”. A diagnosis of cancer, and subsequent years of survival, gives survivors some insight into these questions, because they have had to face them. However, keeping busy is also a very effective way of coping.

Each participant has their own individual way of coping with their experience of having survived cancer. For some, getting back to work was important to them in terms of coping, while others felt that a positive attitude was most important. Other ways of coping were expressed in terms of regaining a sense of control over their lives. Beliefs as to why they felt they have survived, or beliefs as to what helped them through the process were also identified by some as being valuable coping strategies.

### Coping styles

During the process of interviewing the participants, it became obvious that there were two main coping styles that were adopted by the participants during their survival time. The first type could be considered a positive coping style, in which the person engages in ways or strategies which are helpful throughout the difficult times in life, and do not harm them in any way, physically, psychologically or spiritually. Examples of this type of coping style are exercise (going for a walk) and meditation/relaxation. The second type of coping style that was apparent was a negative coping style, or mal-adaptive. In many ways this form of coping was quite effective in the short term, because it took Sally’s mind off of her struggles with life and survival, however, it was damaging to her physically, emotionally and spiritually. Her method of coping was drinking excess alcohol, taking prescribed tranquillisers and antidepressants, smoking heavily, and relying on these to dull the intense psychological pain that she was experiencing. Sally realised that smoking was not good for her, but she felt that it was a comfort to her, and helped her cope.

*“The doctor asked me ‘how many smokes do you smoke?’, and of course I didn’t want to say, you always tell lies, I said ‘about 10’, and he said ‘I think you should give it up’, but I thought, ‘what the hell would you know? You aren’t sick. I’m the one who is sick, if I get sick of smoking I’ll stop’, but I wasn’t getting sick of smoking because it kept me calm, you know, and that’s how I try and*

*look at things, you have to do what you think. If I didn't have my smokes, you know, I wouldn't have known what to do, and drink, you know, of course it was not just the amount."* (Sally)

She struggled with excessive drinking as well:

*"Sitting around and I think 'have a drink'. Drink would be my biggest downfall. Because of nerves, it always made me feel good, at the time, not the next day. I was just drinking so much just to deaden everything."*

Along with excessive alcohol drinking and smoking, Sally also relied on prescribed medication.

*"I'm on hormone pills and my body is riddled with arthritis. And I take amitryptiline. Every bone in my body aches. And I take sleeping pills, because my brain just doesn't stop.... I was living off of sleeping pills and amitryptiline. I couldn't wait until I was home and I could dive into them and just sit there. I'd be vacuuming and thinking 'Sally, when you get home, take your pills, sit down and relax' ...I was driving myself mad".*

It's quite sad for me to read her interview over and over. I feel that perhaps throughout her 22 years of survival, she did attempt at reaching out for help. One needs to ask "what could have been done to change her situation from one in which she perceived herself as hopeless and out of control?" Somehow her situation makes me uncomfortable. I am much more at ease with those participants who adopted more positive ways of coping. In fact, these more positive coping styles fit in more with the preconceived expectation that I had held prior to the research process.

The positive coping styles undertaken by the other seven participants vary from keeping busy, to relaxation, meditation and other activities such as listening to music and walking. Keeping busy and active was very common with the older participants, who were retired (not in paid employment), but kept busy by being involved in community organisations, voluntary work for churches, gardening, baking and craft activities. Zelda, in her 79<sup>th</sup> year, was still very active, and did not let her colostomy cramp her lifestyle.

*"I do voluntary work at the Methodist Social Services, and I'm on the board for the Methodist Social Services. I go to Church on Sundays and I attend the gardens at the Aokautere community Church. As hobbies I like gardening, crochet, braid rugs, reading and baking. I don't believe in feeling sorry for myself. I have helped to set up Neighbourhood watch in this area, and am still active in that now. I sometimes talk to others who are facing surgery/colostomy and have been able to help them"*

Joan, too, is active in her later years. She is the treasurer of Probus, a member of the Palmerston North Coffee Club, and she enjoys playing cards with friends.

For some of the women, staying in their employment during their acute stages of cancer, and through the years of survival, has been a way of coping and keeping busy. It also assisted in regaining a sense of normality, which has been identified as being an important aspect of being a cancer survivor. Employment was also expressed as an important aspect in personal identity, giving a sense of “who I am” and a sense of belonging. Interestingly, it also ties in very closely with the initial topic of meaning and purpose.

*“I’ve worked right through it, before I had the lung cancer I worked full time... now I just work as I want it, like with the chemo, if I was feeling sick, I just didn’t go to work, but as soon as I was feeling up and onto it again, I thought “ right, you’re up today and going to go back to work. So work is important to motivate me. It’s too easy to sit home and sit on your couch and think about it all day” (Jenny)*

Marie also found that her employment as a teacher helped her to keep busy, and cope through some difficult times. Apart from her work, however, Marie also felt that relaxation and visualisation helped her to cope, and survive.

*“I also did a lot of relaxation. I had a really lovely fellow come over from Marton to help me with relaxation, and that was good. And I practiced that, and visualisation. I think that was a big help. Memories of our bach by the sea. So I did a lot of that... and to visualise the chemo, not as a toxin, but as a ray of gold, and something positive and helpful. You imagine it helping you. That was good because you could visualise it as you went”.*

Walking was an important activity when defining coping strategies. Marie went for long walks in the fresh air every day. Long walks on the beach were also part of Joyce’s way of coping with survival. Joyce made a complete life style change as a direct result of having cancer. Her and her husband sold their town house, which was large, labour intensive, conventional and financially draining, and moved into a small bach by the beach. When she talks of the decision to move to the beach, she identifies the change as being hugely significant. She no longer is a slave to house work and maintain the gardens as an attempt to keep up the image of respectability. Now, living in a small, warm and comfortable bach by the beach means that she has left her previous life behind. Mortgage free with a simplified life, there are no expectations placed upon herself by herself or others, she feels free to just be herself.

*“We were lucky. We were able to sell the house and come here. We had no children now at home, in town. We had a 2 story, 4 bedroom house, and I was walking past the bedrooms thinking, “what the*

*hell do I want this great big house for?" to be worrying about looking after it, cleaning it. You know? I had a vege and flower garden in town. That's all changed now. Out here I'm not interested in the garden and the house keeping...that was the shift. It made me positive in surviving. It was a big change."*

Joyce perceives her own attitude as much healthier now. As the interview progressed, she brought my attention to the lovely fresh, seaside air, the relaxed feeling of the seaside village, and the sense of being on holiday. It certainly did feel very therapeutic. Her and her husband go for frequent walks along the beach. Joyce also walks alone. It gives her time to think, to breathe in the good air, and discover and enjoy the simple pleasures of life.

*"I have Tuesday and Thursday where I stay at home. I've been lucky that I am able to be on my own at times. Me being down at the beach on my own is my way of coping, my way of surviving".*

Helping others through similar circumstances was identified as being an important coping strategy for some. This enabled survivors to see a greater meaning to their own suffering, as they helped others. Helping others ranged from simply looking out for the elderly neighbour in Joan's case, to being heavily involved in the Cancer Society as in Kath and Joyce's situations. Becoming involved in helping others gave meaning and purpose to their own suffering, and also kept them to be busy and occupied. Zelda occasionally speaks to people who were about to have surgery for a colostomy. For those facing such surgery, having a visit by someone so full of life and cheer would be most beneficial.

Kath and Joyce were the two survivors who were very involved in cancer support groups. Their involvement in these groups was initially as cancer sufferers, but as they are both now considered survivors, they have taken on a more of a mentor role for others. Kath is involved with the Cancer Society, the Sun Smart programs, the Relay For Life and mentors several people with malignant melanoma here in New Zealand, and also by phone with several in Australia. For her, it is important to educate young children to protect themselves from the harmful sun's rays. She has also taken a training course in grief counselling for children, because she feels that her own children had a lot of grief to cope with during their young lives, with her illness and the uncertainty that came with her illness. Kath believes that there is still a lot of education about cancer and survival to be done in the community.

*"I actually need to learn to be ok about speaking in public about what I have learnt about having cancer. About being a voice for survivors. Often the stories that I hear over and over again in the cancer support groups is that people would often go back into their lives knowing they were changed, but they knew they wanted to make a difference. Or they wanted other people to know what they'd been through, and sometimes they wouldn't know how to say that. Because cancer still*

*has amazing power. Just the word. There's a lot of education that has to be done about it. That it doesn't have to be a death sentence, it's about all of us living the best lives that we can"*

Kath did a cancer connect course. After talking to other survivors she says:

*"For a lot of people that were there (all cancer survivors), we were all there because we wanted to do something to help other people with cancer. We wanted something good to come out of it. When we looked at survivorship, one of the issues was the feeling of just being totally abandoned. Once you leave the hospital system it's "off you go", but I'm not ready to go."*

The need for good to come from suffering was high amongst these survivors, but they all continued to need each other's support, as they felt that the health system as such, had abandoned them. How can one fully understand what these people have gone through, unless one has been through a similar circumstance? It reminded me of the Vietnam War veterans, who returned to their respective countries, but not being able to relate to any one, for those who had not been there could not understand. This is the feeling I had as Kath spoke.

Joyce is also involved in the Breast Cancer Support Group, and the Cancer Society. Again, it is through her own experience that she is able to see where others need help. At the time of her treatment, she could not get home help, because she had a husband living there and it was assumed that he would care for her. This he did, but he also had a full time job, young teenagers to deal with. Joyce feels very strongly that young mothers need help and assistance with housework. The Breast Cancer Support group tries to provide this assistance to women who are newly diagnosed.

### **Beliefs**

Marie felt that her faith in God and prayer helped her through the difficult times of diagnosis, treatment, and the years that have passed since.

*"We are told if we ask it will be given to us, but we still have to ask. God has a plan, it may not be for us to be healed, but you still have to ask, and then believing is the tricky thing.. I was involved in our church and they all prayed for me. Someone prayed for me every day. I thought that was beautiful" (Marie)*

Her Christian faith was very important during her experience with cancer, and continues to be an important aspect to her life as a survivor.

*"Faith really helped me get through all of this. Friends, family and support. Visualisations of old testament passages. You can get that strength. I believe it does wonders. And who knows? It could be that that I am still here. You can't put it onto anything specific. My Christian faith gave me inner strength to cope, and prayer, I certainly believe in prayer". (Marie)*

Sally also stated that she prayed:

*"I don't go to church, but I do whisper prayers to God, and I do believe. I loved Sunday School. I had peace of mind as a child, and I wish I could go back to that time when I didn't have so many worries".*

May believed that it was not so much her prayers, but the prayers of her family, which had enabled her health to stay intact for so many years. Further, during her more recent relapse, she believed that it was the prayers of her family that had caused her to regain a further remission, and be pain and symptom free for the time.

*"They didn't really hold much hope for my survival, but my way of dealing with things, lots of people prayed for me, and I have a strong belief in natural therapies. My daughters prayed for me. For my arm to be comfortable and soft, under my arm it was like a rock. It is now very good, not perfect, but quite good...Well, I'm guilty of not being as ardent of prayer as my family are. Catherine is very sincere (daughter). I believe in it, but I'm lazy. My children all pray for me all the time. I can't say prayer didn't help me, because I'm still here. My daughters felt that prayer was the only alternative. They prayed that I didn't suffer. If I have any fears, it's about a long drawn out suffering". (May)*

May stated that her family and the medical staff felt that her more recent recovery was miraculous.

*"My wounds heal quite well. I had secondaries all over my chest and back, and they all healed. I had a lumpectomy, not the breast removed. The secondaries were all over me. The nurses made all of these pads to cover my wounds. They consider it a miracle that these scabs healed. My family were praying for me to feel comfortable. The nurses feel it is a miracle, even the doctor, because they told me I wouldn't get better".*

Other participants did not place such a high importance on their faith in God or prayer, but they did feel that surviving was significant to their spirituality.

[on spiritual beliefs] *“no, not really, um, I don't have anything against it, but I can remember, 12 months after cancer I did feel I needed a bit of guidance. I was still going through the “why me”, and I had a sit down and a talk with a minister. We talked through it. That was a help, for sure. But it didn't make me feel as though I had to hop off to church on Sunday, but I was pleased that I had that talk with him. It wasn't “please god help me” or anything like that, it was just being told that what ever my beliefs are, you stick to them. It was about the blessings of life, like the birth of your children's children. And that's when I learnt that life was a blessing and a very special gift to me. I don't have any assets; my children and husband are my blessings. I don't have any value on anything else. Being alive is a very special blessing”* (Joyce)

### **Other beliefs identified**

When asked why they believe they survived cancer some gave definite answers, while others were less sure. Joan put her survival down to “just luck.” Zelda believed her survival is due to:

*“Good country living, being involved in the church, being active and not sitting idle, and having a grandson living with me to help to motivate me. I don't believe in feeling sorry for myself”.*

Some simple things that we all tend to take so much for granted were identified as being important and therapeutic to their health and well being, like fresh air, sunshine and good healthy food.

### **Alternative remedies**

Some women used alternative or herbal remedies throughout their illness and into the following years of survival. Sally used cod liver oil and spirulina and believed these helped her physically. May stated that during her recent recurrence of metastases she applied a herbal ointment to the wounds which have miraculously healed. She did not know the name of it, but a friend, who is very strongly involved with homoeopathy, gave it to her. The nurses used it on her wounds, and also massaged it into her oedematous arm. She also believes in Aloe Vera and prune juice, and tends to prefer organic, homoeopathic remedies to conventional medicine. Marie increased her water intake to 2 litres a day, believing that this would be beneficial to her in many ways. As she drank it throughout the day, she would visualise it washing out the toxins and the disease. She does believe this was helpful in her survival. She also practiced meditation, visualisation and relaxation during her acute illness phase, and throughout her surviving years. For some women, belief in their GP, specialist or the treatments given was important to them. These women believed in modern technology and the modern, orthodox medical approach to their illness. Some were very relieved that their GP took them seriously, found their tumour and acted quickly in treating it.

*“I attribute my survival to good luck. I am thankful to my GP for picking it up early. I went to my GP who, thankfully, took me seriously and sent me for a chest x-ray. Many other doctors might have said “you’re old and it’s just aches and pains, just go home and take some pain killers”, but he was good and sent me for the x-ray. I did not feel I had a choice, but I felt I needed to listen and follow the advice of the surgeon. He said I needed surgery ASAP and I listened to that advice. I trusted my surgeon and specialists”.* (Joan)

Others realise that without surgery and the other treatments that were given, they might not be here now. Out of all of the participants, May was the only one who shared her lack of trust and faith in modern medicine, and health professionals.

### **The issue of control and motivation**

*“I think the feeling of having some sort of control is in itself a healing thing. I do think that most people like to feel they have some control, and you need to have some understanding of what they have done to your body. I always wanted to know exactly what they were going to do, and the side effects”* (Marie)

The issue of control was identified by all participants as being very important to their experience of life as survivors. All expressed that at the time of diagnosis and through out their treatment phase, they often felt out of control. Regaining a sense of being in control was important in getting them through the hard times, and continued to be important in their survival years. Some identified that a sense of control over their lives was important to their personality type.

*“For my personality type, control is very important. I think school teachers are. Some people are, some people aren’t”* (Marie)

The older women all expressed that they were brought up in circumstances that enabled them to be very independent and self-sufficient. These women, in their earlier years, lived in rural areas, often on farms, and were miles away from doctors or other professionals, and learnt to cope with circumstances on their own. They rarely visited doctors but drew on their internal resources when it came to their own health and that of their children.

*“I was always in charge. I was the eldest of a large family. I think country people are more in charge than town people.”* (Zelda)

*"I was always a very independent person in a way. Country life, you know. You are not next to the doctor. I hardly ever went to the doctor before 1988. I hardly took the children to the doctor. We didn't rely on doctors or medicine." (May)*

Being able to make decisions in regard to their health and the choice in treatment was also important in assisting them to have a sense of control over their circumstances. Some felt that the doctors and health professionals did not give them any choice in treatment, while others felt that they were included in the decisions concerning their care. For some, the lack in choice and personal decision as to their care did not concern them too much. These people were more likely to accept the guidance of their doctor or specialist. For others, the lack of involvement in decision making just added to their feelings of loss of control.

*"I don't think they [the health professionals] give you a choice if you're easily led." (Zelda)*

Refusing treatment was also a way in which participants could regain a sense of control, but often refusing treatment was seen by health professionals as unhelpful and unwise.

*"I went to see an oncologist after my recent surgery. The appointment was made for me, I suppose by the hospital. He wanted to put this thing [she pointed to her chest and described a Portocath, or Hickman's catheter] into my chest, so they could give me this treatment in there, but I flatly refused. No. If I'm going to die, I'm going to die. I don't want any of that stuff to deal with. It would have killed me if they had given it to me then. I was so weak after the operation and wasn't eating much. It would have killed me. All of the people that I knew that had bowel cancer around the same time as me have died. Those that had chemotherapy included. I think the oncologist thought I was making a big mistake" (Zelda)*

*"Some of the specialists were angry because I didn't want the treatment they were offering. I refused some treatment and the surgeon wasn't very happy. Well it's very annoying because they feel a personal grudge against you in a way. It's not the way it should be". (May)*

Relinquishing choice of treatment to health professionals was acceptable by some. These people had full faith in their specialists, and their advice. There were some who relinquished their freedom of choice to the health professionals, however looking back on this saw this as an act of handing over their control to someone else.

*"They [the health professionals] just told me what I needed. To be honest, I was weak, you know. They said "you have this", and you have it. I was weak. I did what I was told. If they said "you're*

*having a hysterectomy”, I would have had it. If they said “you’re going to have chemotherapy”, I would have done what ever they said”. (Sally)*

In this situation, where the person felt that all sense of control and decision-making was given over to someone else, it was expressed that another person could act as a support or advocate on behalf of them. Some husbands took on the role of advocating on behalf of their unwell wives, who could not assert their rights to decide at this point of their care.

*“ My husband found hospital a place where, he’s very matter of fact about life, so he dealt with things as they came up. He was my real advocate and my rock when I went in for the secondary cancer. He’d go in and he’d be saying “right, OK, what were the results of this test.” So he was prepared to take on arguing with the doctor. I wasn’t. I wasn’t strong enough to do it.” (Kath)*

Some of the participants clearly admitted that they lacked assertion. As well as this, they perceived themselves as being extremely vulnerable and weak. Others, like Joyce, felt their assertive natures actually helped them through the whole process of surviving treatments.

*“...I am a very forwardy type person as well. I, um, you know, if I was not happy with something, I would find out, you know. My specialists and the radiology department would see, “Oh it’s Joyce coming, we’d better do everything right today because she will question us more”. So I’m a bit of a forwardy person... to me, if you just sit and say yes and no and don’t ask, well they will be inclined to brush you off.”*

Joyce also believes very strongly in taking a support person with her. She feels fortunate that her husband was always able to go with her for her consultations and treatments. At times, especially when the situation seemed most uncertain, the feeling of being out of control were expressed.

*“I am a person who likes to feel I have some control over my life. For several days just after the diagnosis, I felt very much out of control. Not so much with the breast cancer, but with this one. I thought “Oh my God, lung cancer, people die.” I think I really did feel that this was it. Then there are times when I decide to take control, yes, with the chemo, when I was at my sickest, I just thought “ I can’t do this any longer.” You know?” I just can’t feel like this any longer”, but the next day you feel a bit better, then the next day. And you think to yourself “Come on! Get on with it again”, because basically there was no alternative”. (Jenny)*

*"... you do feel helpless. You feel like you have no control, and it was awful, because I'm a person who has always been in control, like organising things at school. I like to feel in charge, as a mum, and a teacher. Suddenly you feel you can't do anything."* (Marie)

Talking with each of the survivors, it became clear that each of them experienced their hospitalisation as dis-empowering. Hospital stays were remembered as being times when they felt mostly out of control.

*"Taking control was definitely important to my survival. Up until then, I had been feeling really powerless, and I didn't like feeling like that, and I didn't like the space I was in either. I think too, being in hospital, I definitely felt totally at the whim of, even just relying on whether a nurse would bring your medication to you. Whether they'd remember to bring my antibiotics when my leg was infected. I was always dependent on someone who remembered to do that. For me, taking control was really important. Also since then it's been a thing of me making decisions of how I deal with things. I've had a lot of stuff like that I've had to work through, to need to know that, yes, I'm back in control."* (Kath)

Regaining control, for some, happened immediately after they went home. For others, the regaining of control has been an ongoing process, through the disease and treatment phase, into the years of survival. Zelda felt the loss of control while she was in hospital, but always, once home again, felt she was again in control of her life.

*"Once I got home, I felt like I was once again in control"* (Zelda)

Being informed, continually researching treatments and issues relating to treatment and side effects was important to some in regaining a sense of control. While some things were out of their control, there were other things that these women could have control over. Things like being disciplined with exercise, diet, and making healthy choices about the way in which they coped with certain aspects of their lives.

*"... but I did do the water thing. I drank 2 litres a day. That was a good feeling. It's the control thing again. I think my control was the water, exercise, walks, carrot juice, diet, relaxation and visualisation. I felt I had a bit of control."* (Marie)

For some, like Sally, control was something she struggled with, in all aspects of her life. She felt that the cancer would one day return, and she perceived she had no sense of control over that. Her drinking and life style seemed out of control as well, and she stated that she often felt that she allowed her family and others to control her, rather than her taking control of her own life.

## Attitude

All of the women interviewed felt that having a positive attitude was helpful in their experience of having cancer, being treated and surviving. Some did struggle with being positive all of the time, in fact, at times some felt far from being positive. However, through out the interviews, the prevailing feeling was one of incredible positiveness. Some of the women have a strong belief that they have a positive attitude.

*"I do believe I have a positive attitude". (Zelda)*

*"I have a positive attitude. I believe it helps" (Joan)*

For others, being positive was a definite decision that was made:

*"I just decided to be positive. I did first think, "why me?", but then I felt, I'm not just going to sit and take this. I am very positive" (Joyce)*

Sometimes the positive attitude was more covert; that is, the person did not openly admit to being positive, yet, despite some very difficult times, the positive strength was very apparent. Kath does not see herself as being particularly positive, yet over the years of survival has developed ways of looking at life more positively and learning more about the importance of self-acceptance.

*"Most of the time I am a fairly positive person, but I am more realistic now than I used to be. I was so idealistic before. Reality never measured up. And I'd be always consumed with self-doubt and worrying about things. Winter times are not good for me. I had post natal depression when I had the girls, but now I actually think that's OK "well this is just how I am at the moment, you know? It's not a good day, but that's OK; that's just how I am today". I am a lot gentler with myself, and because of that I've become more positive, accepting myself of where I am, and this is what I am dealing with right now"*

In Jenny's case, as a survivor of breast cancer, but still being actively treated for lung cancer, extreme strength of character and positive attitude exuded from her.

*"When it comes back, it's pretty daunting. I have a couple of bad days, and every time it comes back I say to myself " why am I feeling like this? I should be used to it now", but after 2 or 3 days I just think to myself " just get on with it and do what you have to do, and hopefully it will work... my family say I am very positive..."*

She discussed her experience of having chemotherapy, which gives a further idea of just how tenacious and positive she is:

*“The first chemo I had, that was the hardest one. I believe it is a very strong one. I found it made me sick for about four days, actually physically sick. A week of practically nothing to eat. Your bowels go absolutely bezerk, and then it's trying to keep positive and on track again. Then you come right for two weeks, and then you'd be back again. So that was, yep, I must admit, quite hard...during the third lot of chemo, on the fifth cycle, I felt it (the cancer) had come back, so I had six weeks off, then back onto the pills. It was seven days on and ten days off type thing. I had two days where I did actually feel quite sick, physically sick, but after two or three days had gone, then I got back into it again, grit my teeth, and got over it, and, at the moment, touch wood, I'm fine.... I've heard of people, and I know some, who have actually stopped it because they felt they couldn't go on, and said “ I can't do this any longer”, but I just keep on saying to myself “ Tomorrow is going to be better. Tomorrow will be better than today”. (Jenny)*

When asked if she has always been a positive person, Jenny believes that she has been,

*“I have always been a positive person. I don't feel as if I am a depressive type person. I can get down for a day, but then I think “no, just get on with it again”. Being positive does help. I think you have to do that for yourself. If I'm sitting at home feeling entirely miserable, I just think, “I've got to get myself out of here”. I just go up town or visit a friend. I do something like that for a couple of hours, just to get myself out of this, to take your mind off of it, so you're not thinking about it”*

Marie identified her belief in the relationship between being positive and her immune system:

*“Being positive, and being aware of the immune system, because I think at the time I was run down with my job and menopause. I was absolutely galloping...”*

She discusses how she maintained her positive attitude over the years:

*“I do think you have to make an effort in being positive. I do think you have to sometimes be taken through the process. If you tell someone to be positive, then where do you start? My husband taped a lot of positive affirmations for me, and I used to keep them by my bed. They were positive reinforcement tapes. And when you're lying in bed and hearing all of these things. I was told to look in the mirror each day and say “I'm beautiful”, but that was jolly hard when your hair is falling out.” (Marie)*

Joyce agrees that being positive is something that has to be worked at.

*"Being in control is one of the things that has made me positive. I strongly believe that having a positive attitude does help. Determination. But there are real times when it really gets you down. "I can't be bothered with this any more", but then, the next day, something good happens, and I always look for the good. It's hard to be positive all of the time. You have to work at it".*

The connection between having a positive attitude and survival is summed up by these words from Jenny:

*"...Yes, and I think I read at one stage that doctors didn't attribute just being positive to getting yourself back on track. Whether that's true or not, I don't know, but I think that it would be very easy, that if you just sat here and wallowed in it you'd go down hill. I surely believe that being positive does help" (Jenny)*

Each individual survivor has ways of coping with their unique experiences. Previous research gives further insight into how others cope with living as a survivor of cancer, with all of the challenges and uncertainty that this entails.

#### **Coping styles, issues of control and attitude: previous research and discussion.**

*"Coping consists of efforts, both action orientated and intra-psychic, to manage (master, tolerate, reduce, minimise) environmental and internal demands and conflicts among them" (Lazarus & Launier, 1978; cited in Taylor, 1995).*

A diagnosis of cancer is quite devastating and may be perceived by the person as being tragic. Taylor has defined three cognitive responses to tragedy: the search for meaning in the experience, gaining a sense of control over the situation, and cognitive efforts to enhance the self and restore self esteem (Taylor, 1983).

Greer and Morris have identified five categories of coping styles in cancer patients. The first is the coping style of having a fighting spirit where the patient accepts the diagnosis, is optimistic, determined to fight the illness and wants to participate in decisions relating to their treatment. The second coping style is defined as one of avoidance/denial where the patient either rejects the diagnosis or minimises the seriousness of it and avoids thinking about it. Fatalistic/stoical acceptance is the third coping style where the patient accepts the diagnosis and has resigned themselves to a fatalistic attitude. Anxious preoccupation is the fourth coping style where the patient is pre occupied with the cancer and seeks reassurance and fears that any aches or pains are indicative of disease progression. The last coping style is the helplessness/hopelessness

style, where the patient feels overwhelmed, is pessimistic, and feels like giving up (Greer and Morris, 2002, cited in Anderson & Walker, 2002).

The way in which one copes with a diagnosis of cancer may not act directly on the disease, but may influence other behaviours which may affect survival (Watson & Ramirez, 1991). Anderson and Walker (2002) have proposed a model of coping with cancer, based on previous work by Lazarus, Folkman and Bandura. The model consists of the ongoing appraisal of the situation (what is the demand and what are the consequences?); the physiological aspects (the stress response); affective responses (depression, anxiety, happiness); coping styles (for example, fighting spirit, hopelessness); perceived self efficacy (the extent to which the individual believes that he/she can control the outcome); and behavioural aspects (compliance with treatment, lifestyle changes: diet, sleeping habits, exercise, healthy living). These factors are further influenced by personality variables for example: extraversion, neuroticism, emotional suppression, and social conformity.

It has been theorised that a lack of fighting spirit, external locus of control, hopelessness and helplessness are associated with an inability to cope with cancer and the progression of the disease (Levenson & McDonald, 2002). Research has found that women with breast cancer who had a fighting spirit or denial survived longer than those who coped in a stoic or helpless way (Greer, Morris & Pettingale, 1979, cited in Levenson & McDonald, 2002). Previous research has also found that educating survivors on coping skills and stress management skills enhances the survivor's prospects of recovery, helps them to tolerate and adjust to treatment and enables them to maintain satisfying relationships with others. It also reduces fear, anxiety and helplessness and increases the feeling of being in control (Calde, Classon, & Spiegel, 2002).

Some people turn to religion or faith as a way of coping with an illness such as cancer. These people often give meaning and value to their experiences and consider the spiritual realm with questions about the nature of our existence and the reasons for certain experiences (Booth, 2002). Psycho-spiritual therapies promote healing in cancer patients by diminishing fear and anxiety, increasing peace of mind, engendering hope, purpose and meaning and are therefore beneficial (Booth, 2002). Faith in western medicine, or God, or their own ability to remain positive have been identified as beliefs which provide inner strength to cope (Killoran et al., 2002).

Joining a support group can be beneficial to some survivors. In a group where all of the members share similar experiences therapeutic and beneficial relationships are built between members. The survivor may then feel less isolated and less alone in their experience. In a supportive environment, they can learn from the other members, receive support from the other members, and also offer support to others. In such a group coping skills and stress management can be taught to reduce feelings of fear and anxiety and to increase feelings of control (Calde, Classen, and Spiegel, 2002).

Control has been identified as being very important to the survivor. The opposite of control is helplessness and hopelessness. Seligman's theory of learned helplessness states that people can learn to be helpless by repeated experiences of lack of control. This creates deficits in motivation, cognition, and emotions (Seligman, 1975, cited in Taylor, 1995). In the case of the journey with cancer, treatment, hospitalisation, recurrence, uncertainty and anxiety, learned helplessness is very possible. The person with cancer can very often fit into the role of "victim", and become helpless, which then leads to hopelessness and depression. With the increase of stress within the person, the immune response may be affected by alterations to the endocrine system, thus rendering them more susceptible to physical illness, recurrence and disease progression (Marzio & Sabbioni, 1991). Sigler describes the loss of control she felt from having chemotherapy and radiotherapy:

*"The operation was followed by chemotherapy. I detested the weapons she (oncologist) used: surgery and chemical "bombs". I felt I had lost control of my body, first to the cancer (images of rampant armies of cells), and then to the doctors with their vicious counter-attack. Metaphors of war are sadly apt". (Sigler, 1999)*

However, the issue of control does have a paradoxical side as well. From her personal experience with breast cancer and further metastasis to her bones, Sigler describes that her need for control did not allow her to be happy in her younger, healthy years. The experience of getting and living with cancer has enabled her to let go of the need to control.

*"Today I can say that I am really quite happy, even living with the diagnosis of cancer. The main reason for this happiness is my letting go of the need for control, which the experience of cancer actually facilitated. Also I feel a satisfaction with my life. I take advantage of opportunities in the present. In the past I would put off chances for play in order to get some work done. Now, I choose enjoyment, especially of the simple things, and without guilt. This is the good news, or one of the blessings, of my situation. I have no choice but to live as I can in the present." (Sigler, 1999)*

So, the issue of control has two sides. It is important for survivors to feel they have some control over their lives and decisions, yet it is also part of a learning experience, to recognise when to let go of this need, and become accepting. Sigler has described this as a very freeing experience. Closely linked to the way in which people cope with a life threatening illness are the personal attributes of self-esteem and learned resourcefulness. Social support is also identified as being significant in the lives of survivors and the way in which they cope. These all work to buffer the negative effects that cancer brings (Pedro, 2001). Many survivors attribute their survival to having a positive attitude despite the fact that research does not support this. It is theorised that this aids in personal control and feelings of personal efficacy (Stewart et al., 2001).

In conclusion, the way in which one copes with a life threatening illness such as cancer, and lives through the years of survival vary greatly from person to person. Those interviewed in the present study coped in ways that are common to many survivors.

## Chapter Eight DISCUSSION AND CONCLUSION

### Discussion

From this research, all eight of the survivors who participated had some degree of ongoing psychological issues that they had to cope with. These issues were specific to each individual, with some experiencing them very intensely and others recognising them as issues that were always there, even if somewhat in the background. Some searched for meaning more than others, a finding that is supported by previous research. Some of the participants talked more in terms of their chronological experience: diagnosis, treatment, its effect on their family at the time, and through the years, how they came to be where they are now. These participants focused on the time that the cancer was diagnosed, and tended to see it as something that they went through in the past, but were now past it. They saw their survival as almost separate from the initial cancer experience. Others, however, were much more reflective in their narrations, giving insight into their own introspections and thoughts and how they felt and feel now. Their way of talking about the experience of having cancer and surviving it were much less chronological in nature, and the experience of survival was an integrated part of their lives. They talked less about the experience of diagnosis and treatment, and more about the journey since; where they are today and what surviving means for them now. For all of the participants it was observed that their stories about the time from diagnosis through the treatment phase were very important for them. This was apparent in the way in which they spoke very accurately and in fine detail, the accounts of the time from diagnosis through treatment, to the present time. For some of the participants, their diagnosis was quite a long time ago, yet they recalled names of surgeons, dates, and episodes in much detail. All of the participants recalled their stories with appreciation, which gave a sense that even in their recollections and narrations, they were hoping to further understand their experiences and hoping that their stories might be listened to and understood by someone else.

The way in which people speak about their illness has been identified as facilitating their further understanding and gaining meaning from their illness (Linde, 1993, & Robinson, 1990, cited in Killoran, Schlitz and Lewis, 2002). With the exception of May, the older women were less introspective, more likely to accept advice from health professionals without question, and framed their experiences in more matter of fact ways. This finding is supported by Thewes et al., (2004) who found that cancer is experienced and expressed differently by different age groups. In an anthropological study by Killoran (2002) et al., it was found that older survivors often framed their survivorship as unremarkable. It was observed that often, at the time of diagnosis, they were unaware of just how serious their illness was, and they just got on with their lives never fully understanding the full implications as to their diagnosis. The role of denial is an interesting one. Killoran et al. found the following: of the long term survivors researched, there was a tendency to "(a) view the diagnosis as insignificant, (b1) question the severity of the illness, disbeliever the diagnosis, and

*(b2) not worry; (c1) not question the cause but explain the "cure" in terms of faith in medicine, spirituality and personal volition, or (c2) explain both cause and cure in terms of bio-medical and personal volition*" (Killoran et al., 2002). Perhaps denial actually protects one from the full realisation of the gravity of the diagnosis, enabling one to resume life and cope without delving too deeply into the "why's and wherefore's". These findings were apparent in May's story and also, to a certain degree, in Zelda and Joan's as well.

The previous research done by Little and Sayers (2004) was very interesting and made it clearer as to why some of the participants in the present study were reluctant to belong to support groups. It also helped me understand Sally's depression more. I do feel that she was very much affected by 'death salience', and found herself in a place where she felt no-one would understand her.

### **Limitations of study**

*... "A phenomenological description is always one interpretation and no single interpretation of human experience will ever exhaust the possibility of yet another complementary, or even potentially richer or deeper description" (van Manen, 1990, cited in Bredan, 1997).*

Paradoxically, this quote by van Manen gives both the limitations and the potential of phenomenological research, which is why it is such a fascinating and dynamic method of research. From a quantitative standpoint there are many limitations. The sample size is far too small. What are the results? There are no hard and fast conclusions to be made. From a qualitative perspective, there is always a certain degree of ambiguity, however, that is the nature of this type of study.

I found the data collected from the interviews to be rich, deep, and complex. This study itself could have taken many different perspectives. At times it was difficult to keep focused on the experience of the person surviving cancer, rather than the issues identified by the participants concerning cancer survival. For example, for Kath, a huge issue for her was how her children coped with her initial diagnosis, and how this has affected them even up to this day. A whole thesis could be written on this topic: how cancer survivorship affects the children and family members. The complexity of survivorship made it impossible to do justice to every issue and aspect that were identified by the participants, and simplification of these issues were placed into the four broad psychological issues in the present form. Phenomenological research is open to other interpretation, and the present study is a single interpretation by myself. Others may have interpreted the data differently. On a positive note, and using van Manen's above quote, there is always "another complimentary, or even potentially richer or deeper description" to be found. Thus, ongoing research possibilities are infinite.

### **Future research and education**

Throughout the interviews, the participants raised other issues that were beyond the topic of this thesis, yet were very relevant to their experience and which are also relevant to health professionals and future research and education. There are many ways in which future research could be directed, especially from a phenomenological perspective, for who can fully understand another person's experience? It has been identified that more research is needed and more psychological care necessary in the area of preparing cancer survivors for possible recurrence. This also needs to facilitate survivors in helping them identify their existential meanings to their experiences, allowing them to adjust better to their disease, and life after treatment (Mahon, 1997). It has also been found that although physical concerns may persist for years, psychological, social and spiritual concerns are much more relevant to address for the longer term survivor (Pedro, 2001). It has also been recognised that coaching survivors through their experiences is extremely important (Benner, 1985, & Dow, 1991, cited in Aufdenkamp, 1997). The fear of recurrence is very valid and real for these people. It is therefore important for health professionals to recognise these fears and support these people through them (Aufdenkamp, 1997). Thewes et al. identified the importance of providing adequate reassurance to survivors during their follow-up visits, and allowing them the opportunity to talk about their emotional, psychological and existential issues (Thewes et al., 2004). Some participants in this research by Thewes et al. perceived that their doctors were only interested in their physical care, and were therefore reluctant to discuss emotional, psychological or existential issues with them.

Several participants expressed the importance of health professionals instilling hope when they care for people. From doctors who give the first bad news of the diagnosis, to nurses who give continuing physical care, it is important for health professionals to know that their demise and attitude carry extreme importance to the way in which the person with cancer perceives themselves. Hope is an extremely important aspect for all of humanity. If we remove all hope from someone, what do they have left? Some participants stated that often they were treated as a "number" or a "case" rather than a person, and were often not given choices or involved in decisions relating to their treatment. Somehow our health system does well in depersonalising people. Some of the participants felt that their intelligence was in question; that somehow the diagnosis of life threatening cancer rendered them as unintelligent. One woman said that as she entered the radiology room she left her self behind. To the staff at the radiology department, she felt as though she had no history, no past, no name. They were not interested in her as a person, but just as a piece of meat presented on a slab, with a tattooed 'X' marking the spot where the radiation had to be directed. I do know that these departments are extremely busy, and that the individual health professionals are most often very caring people, however this impression is not one that conveys a caring and nurturing attitude. This reveals areas of future work and education for health professionals. Training and ongoing education for health professionals dealing with survivors is essential to improvement of delivery of care.

Another area that arises from this current study is the role of beliefs in survivorship. From a cognitive-behavioural perspective, our beliefs determine our cognitions or thoughts, which determine our behaviour. Future research directed at identifying beliefs and how they affect one's way of thinking and behaving is an extensive area to be investigated. Changing behaviour has been identified as being important to maintaining healthy lifestyles; making healthy choices; being pro-active in decision making in terms of treatments, and learning and adopting new skills to cope with treatments and side effects and ongoing physical, emotional and psychological challenges. There is a growing awareness that psychological support is necessary for those who survive cancer and its treatment.

*“Psychological intervention to help cancer patients cope with the emotional stress of their disease may improve their long term survival. In a recent study, the 5 year survival rate of 38 malignant melanoma patients who received psychiatric support was significantly higher than that of 28 control patients who received routine care. Intervention consisted of health education, stress management and problem solving techniques designed to prevent patients from becoming helpless victims of their disease. It is suggested that psycho-social intervention become a part of the routine care of cancer patients to help reduce emotional stress and enhance coping mechanisms in a effort to positively impact on the immune system”* (Information Age Resources, Research and Information Consulting Services, Chicago, cited in Sigler, 1999).

Training and education about coping styles and issues of control might be valuable to survivors. Helping them to understand the choices; empowering them to become pro-active in their treatment, and talking with them about what they might expect in their years of survival may be of benefit to them.

Another area which is interesting and challenging is that of psychoneuroimmunology: how our thoughts and beliefs can affect our neurological system, which in turn affects our immunity. Marie gave some insight into her beliefs about how she felt she activated her immune system by rest, meditation, imagery, positive affirmations and drinking lots of water. A quantitative component within a qualitative approach may suit this type of research. Future studies with cancer and survivors could reveal very interesting things from research in this area.

Learning from Sally's experience is important for health professionals. For 22 years she lived as a survivor, yet was “living” on prescription medication: antidepressants, sedatives, pain killers, sleeping pills and consuming large amounts of alcohol. She was miserable. How could her situation have been made less tragic? How many doctors' visits did she make and give indication that all was not well? How many prescriptions were written out for her without question as to how she really was? It is possible that health professionals need to be more aware that surviving cancer is not all just a good story with a happy ending. Survivors still have life to live, with all of the challenges that life brings, with extra uncertainties and

psychological pressures, social adaptations and relational issues. Possibly it is important to identify these people and expect some issues to become apparent, and deal with them appropriately. At present, I feel our health system addresses the physical manifestation of illness quite well. After that is done, however, the person is very much left alone to deal with the psychological issues, which can last for a very long time after the physical issues have gone.

### **Conclusive thoughts**

*"If we are made aware of our own mortality by such things as the illness of a friend, terrorist attack near home or even by a proximity to a funeral parlour, we are made 'mortality salient'. Because of the depth of the innate fear of death, mortality salience provokes a deep sense of anxiety. We become aware that we too are finite beings, whose lives and deaths may seem to have no meaning"* (Little & Sayer, 2004).

Thursday night (7 July 2005) I worked a late shift and a patient who was watching the late news on TV told me about the London bombings. As I attended to her care, I watched the images on TV, of confusion, chaos and tragedy. We live in very uncertain times. How does an event like this affect the "future memory" of individuals that Little et al. speak of? Can any of us imagine our future lives knowing that our global existence is under such threat? What does this mean for our children? How does this influence our sense of hope? We all do not live with cancer or the fear of recurrence, however we all do live with uncertainty, every day. Death is inevitable for us all. In my current employment I am daily made aware of my own mortality, that one day I will die. Kubler-Ross, in her famous work on death, dying and grief, believes that our western way of being is to spend most of our lives in fear and denial of the fact that we will die. The medical profession models itself on this absolute denial of death and works to save lives at all cost. When someone does die, it is perceived as a failure rather than a natural progression (Kubler-Ross, 1969). Somehow, we have forgotten what life is; that it is extremely uncertain for us all, that one day we will die; if we are "lucky" we will have a long, pain free life which is happy and comfortable; if we are "unlucky", we will die young.

As I sit in my study writing this thesis, I think of my own mortality. I might expect that I will be alive in six months to finish this project, but I really cannot be sure. And if I were living in the last six months of my life, would I choose to spend my time in this way? In the end, is the completion of an academic exercise so important in the whole scheme of things? Reading the interviews of my participants, I want to learn from them. Why do we have to wait for a diagnosis of cancer to fully grasp the intensity of our limited time here on earth? What can I take from these unique people as a lesson in my path on the road of humanity? I believe that I have learnt to take my health and life less for granted. I am so thankful that I am healthy. I do

not have to think about my next follow up visit to the specialist, or that I have developed a new, mysterious symptom that could mark the recurrence of my dreaded disease.

Each participant expressed their love and the gratitude to their families and partners for their support. How often do I take my husband and family for granted? How often do totally healthy people become hindered by things that clutter their lives? Live life to its fullest; seize the day. Joyce gave a good description of uncluttering her life, especially after she developed secondaries. Sorting it all out, throwing out all of the rubbish, discovering what is important and what is not; these are the challenges to me, as I begin to discover what is like to fully live. I have this thesis and my participants to thank for this discovery and my new way of learning to be.

Sigler (1999), when reflecting on her experience of surviving breast cancer, talks about the importance of hope and distinguishes between healing and curing. She defines a cure as being free from the disease and healing as becoming reconciled to the situation and the restoration of mind, body and spirit to each other. She also speaks about how her experience with cancer has been much more than physical.

*“As I live my life with this disease, it becomes more abstract. I do not live with physical pain. I do not have to cope with the loss of physical abilities. I feel physically the same as I always have. Cancer has been an emotional trial, mostly. But the emotional impact has changed my life forever. That is why I have found my experience more of an exploration into the realms of spirit, heart and mind”.*

Recognising that surviving cancer is much more than a physical issue is immensely important.

In conclusion, the personal journey of cancer survival is much more than a physical life without symptoms of a disease. It is the passing of time in which emotional, spiritual and psychological issues all become an integral part of the journey. Kath gave insight into this when she said that for her, the journey of survival was very much more psychological, emotional and spiritual than purely a physical manifestation of a disease and the treatment for it. After her treatment she describes the psychological void:

*“There was no recognition that this would change your life completely. I was being sent home with a discharge summary, and, yes, I had district nurses, and home help, but no follow-up as to someone to talk to. So I think that would be some thing that health professionals might need to take on. A huge part of it. They need to realise that dealing with cancer and the impact it has is.. recognising what it is doing to someone psychologically, spiritually and emotionally, not just the physical impact”*

Phenomenological research comes to its fore in a research such as this. These rich, complex lessons would not have been discovered if research was purely quantitative in nature. It was the aim to impart a deeper understanding of what it is like to survive cancer. I hope that from reading this, the reader has achieved this aim. Surviving cancer is much more than physical.

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## APPENDIX A

# SURVIVING CANCER

### Information sheet

My name is Janet Miller. I am a registered nurse, and I work at Aorangi Private Hospital, Palmerston North. I am currently completing a Masters degree in Psychology at Massey University. My supervisor is Dr. Christine Stephens, a senior lecturer in psychology at Massey.

The research that I am about to commence has been approved by the Massey Human Ethics Committee.

Over 25 + years of nursing, I have cared for many people with cancer; young and old; in hospital care, home care, palliative care; for those having just been diagnosed to those having treatment, and palliative care for those who have tried all treatment and are dying.

I have a huge personal interest in those who survive having cancer. The central question to this research is: "from the perspective of a person who has survived cancer against all odds, what do they believe to be the reason/cause for their return to health?"

The purpose of this research is to gain insight into those who have survived, and to discover what it is they believe to have caused their recovery. I believe that much can be learnt from their experiences, both for those who have cancer, and for those who don't, from a primary health /prevention perspective.

I would like to interview people who have been through the diagnosis, treatment of cancer, and who have lived beyond the expected time. I will ask some questions, however I hope that the interview will evolve from the experiences of the participants. Some aspects that I am hoping to cover are the beliefs in certain treatments, changes in life style, changes in psychological approach to life, changes in attitude to life, shifts in perceptions.

The interviews will take about 40-60 minutes, and may be done over one to three sessions. These interviews will be taped and transcribed by myself for further analysis. The location as to where these interviews will

take place will be determined to suit you, either in your home, or at a place convenient to you. This can be further discussed to suit your situation.

Myself and my supervisor, Chris Stephens, will be the only people who have access to these tapes, and after the research is completed, they will be either given back to you, or destroyed. There will not be individual names on these tapes, nor in the final document so as to ensure confidentiality.

The participation in this research is entirely voluntary. You will have the right to decline to answer any question. At any time you may request to have the tape turned off during an interview, and can withdraw from the study at any time. A summary of the interviews will be provided to ensure that your experience has been interpreted correctly.

If the recalling of past events should cause you any concern or trauma, I will ensure that you receive adequate care and counselling, with the guidance of Christine Stephens, and the Psychology Department at Massey University.

If you agree to become involved in this research it will be under the conditions set out on this information sheet.

Please contact myself or my supervisor if you have any questions.

Thankyou,

Janet Miller.

Contact: Janet Miller

Ph: (number to be arranged by Psychology Dept. Massey)

Email: ...

Dr.Christine Stephens

Ph:

Email:

*This project has been reviewed and approved by the Massey University Human Ethics Committee, PN Protocol NO/NO.....*

*If you have any concerns about the conduct of this research, please contact Professor Sylvia V Rumball, Chair, Massey University Campus Human Ethics Committee: Palmerston North, telephone 06 350 5249, email [S.V.Rumball@massey.ac.nz](mailto:S.V.Rumball@massey.ac.nz).*

**APPENDIX B****SURVIVING CANCER****CONSENT FORM**

This consent form will be destroyed at the completion of the research

I have read the Information Sheet relating to this research, and have had the details of it explained to me. I have had the opportunity to ask questions about this research and these have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I understand that the information that I provide will be used only for the purpose of this research and publications arising from this research project. I understand that my name will not be used, to ensure confidentiality.

I understand that my interview with the researcher will be taped and I have the right to ask for this to be turned off at any time during the interview.

I agree/do not agree the interview to be audio taped.

I wish to be given the audiotape / I am happy for the audiotape to be destroyed at the completion of the study

Should I agree to participate in this research, I have the right to withdraw from the study at any time. I am able to decline to answer any particular questions.

I agree to participate in this research under the conditions set out in the information sheet.

Signed: ..... (participant)

Name: .....

Date: .....

## APPENDIX C

Advertisement for recruitment of participants to be placed in The Evening Standard, The Tribune and the Guardian, and possibly the Cancer Association and some GP Surgeries around Palmerston North.

### **Survivors of cancer**

Massey student undergoing a Thesis to complete a Masters degree in Psychology requires 3-10 people who have survived a poor prognosis of cancer, and who have survived despite their prognosis, to participate in her research.

Participants must be willing to share their experiences and have their stories transcribed for the purpose of this research. Confidentiality will be respected.

This research has been approved by the Massey University Human Ethics Committee.

For more information please contact: J Miller ph: (number to be designated)

Email: ...

## APPENDIX D

Table of Data Analysis and Representation for phenomenology outlined by Cresswell 1998, pg 148-149.

Data Managing	Create and organise files for data
Reading, memoing	Read through texts, make margin notes, form initial codes
Describing	Describe the meaning of the experience for the researcher.
Classifying	Find and list statements of meaning for individuals. Group statements into meaning units.
Interpreting	Develop a textural description, "what happened?" Develop a structural description, "how" the phenomenon was experienced. Develop an overall description of the experience, the "essence"
Representing, visualising	Present narration of the "essence" of the experience; use tables or figures of statement and meaning units