

Facing up to Cancer

The lived experience of being diagnosed
with a life threatening form of cancer

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Attestation of Authorship

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person nor material which to a substantial extent has been accepted for the qualification of any other degree or diploma of a university or other institution of higher learning, except where due acknowledgment is made in the acknowledgments.

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Abstract

This Heideggerian phenomenological hermeneutic study explores the lived experience of those coming to terms with the diagnosis of a life-threatening form of cancer. It offers an interpretation of the narratives of eight adult New Zealanders, three men and five women, aged between 25 and 60 years of age who had been recently diagnosed. The study, based upon van Manen's (1990) six-step method, uncovers the experience of the person facing up to being told they have a life-threatening form of cancer within New Zealand society. It is informed by the writing of Heidegger.

The study explores the meaning of cancer to the person involved and how this meaning affects them and their world. The study explores the changes within the person and how this change in the person subsequently changes the understanding they have of themselves and the world.

The narratives of participants reveal a journey that is undertaken, a journey they thought they would never undertake and were not prepared to take. The cancer journey begins suddenly, is frightening in its intensity, towards a perceived destination of probable death. The real journey for many takes an unforeseen detour along the way, a detour of hope and eventual enlightenment. The final journey for all human beings will always end in death. The realisation that all human journeys must and do end in death and learning to live with the reality of this one fact in life is the major lesson learnt by those who experience the cancer journey.

The journey is made more difficult and lonely by a society that wishes to fool itself that this journey does not happen or wishes to believe that one day this journey may be totally avoided. Society and the people that make up society need to face the reality of the cancer journey for many of its members in order to better prepare the person for the journey and to support the person while on this journey.

Key to Narrative

The following abbreviations and conventions have been used in the presentation of these research findings.

- Italics: Represent quotations from the interview data of participants.
- Names: Pseudonyms are used for participants, family members, health professionals and towns.
- [] Denotes the researcher's alterations for clarity within quotes.
- ... Indicates material deleted from the interview excerpts.

Jack and Jill learnt the lie
Jack and Jill thought they would never die

Along came the cancer
Which made them see the answer

The real reason for life
Is to live with, amongst, and for others, without strife

Achieved through 'simply' being true to one's own most self
Avoiding the pull to climb the socially constructed shelf

One can avoid the illusion of having to be a star
By simply facing up to the reality of who and what we are

(Lothian, N. 2002)

Chapter One

Introduction

The social hero-system into which we are born marks out for our heroism, paths to which we conform, to which we shape ourselves so that we can please others, become what they expect us to be. And instead of working our inner secret we gradually cover it over and forget it. (Becker, 1973, p. 83)

The study

This Heideggerian hermeneutic phenomenological study will explore the adult patients' perspective of their experience of being diagnosed with a life-threatening form of cancer. The study is not set around the giving and receiving of the cancer diagnosis itself. Instead this study explores what the diagnosis means to the person and the effect of this meaning upon the person, for the initial period of approximately two or three months following.

The study was conducted retrospectively through the interviewing of eight participants, voluntarily sourced from one New Zealand public hospital. The participants, with ages ranging from 25 to 60 were asked to tell about their experience of cancer, for the initial period following their diagnosis. These eight stories were analyzed individually for the themes within. These themes are revealed in the participant statements that best express the human meaning and structures that tend to lie hidden within the experience.

Background

For many the diagnosis of cancer is a frightening event of nightmarish proportions. It has even been described by Hall (1997, p. 173) as “ the standardized nightmare of our society”. As well as their own previous experiences with relatives and friends, many people envisage cancer as being a horrible death, based also on film and television portrayals (Hall, 1997; Burton & Watson, 1998). Hall (1997), after reviewing

population surveys carried out in the past 25 years, proclaimed that cancer is perceived as the most frightening and serious of all diseases. This was despite cancer having better 5-year non-recurrence rate statistics than many other seriously fatal illnesses.

The point being expressed here is that the diagnosis of cancer alarmingly frightens many people. To many, it is like a death sentence, conjuring up images of torturous illness and pain that must be endured prior to death. It is often the unknown mysticism that cancer conjures up in people's minds, that contributes to this image (Hall, 1997; Burton & Watson, 1998). What cancer is and what contributes to the cause of cancer is not widely known in the general population. From my own experience the actual subject of cancer is not discussed in public. It only appears to be mentioned when someone says, "Did you know old Tom's in hospital. They say it's 'cancer' ", or, "I went to old Tom's funeral the other day. He died of 'cancer' you know".

In New Zealand cancer is responsible for 41% of all deaths, and the incidence of cancer continues to increase at an alarmingly rapid rate. Cancer prevention and support services have remained limited. Much of this work is being carried out by a non-profit organization called 'The Cancer Society of New Zealand Incorporated'. The government-funded public health services usually run an 'ambulance at the bottom of the hill' service in trying to cure the person who has contracted cancer with some encouraging successes in some areas, but with poor results in many other areas.

Cancer is usually diagnosed within the person when they approach a general practitioner with feelings of unwell-ness. The cancer diagnosis is often made following a series of tests. At times the cancer is found through various national screening programmes or through health awareness programmes directed at the general public informing them to be aware of certain symptoms and if they think they may have any of these symptoms to seek professional help. The three main treatment options provided through the New Zealand health service are surgery, chemotherapy and radiotherapy. Funding in public health, budget decisions and constraints have led to staffing shortages, with waiting time for many surgical and radiotherapy treatments. Those whose need is most urgent are still managing to obtain treatment fairly promptly.

The purpose of this study

The helper's first task is to climb into the patient's shoes for long enough to sense from the inside a bit of what it is like to be this person at a particular moment. (Burton & Watson, 1998, p. 4)

In order to help the person through the experience of being diagnosed with cancer, one needs to have a good idea of what their actual needs might be. In order to ascertain what their needs might be one must at first have some understanding of what it is like for a person to experience the cancer diagnosis and the effect that this has on them for the following period. Not understanding fully the problems and meanings cancer holds for people can impede the effective care of that person (Houldin, 2000).

Most of the literature I have reviewed on this topic is not from the patient's perspective. Those that I have found from the perspective of the patient are focused on a specific type of cancer or on a narrow predefined segment of the experience. Many of the studies in this area that are from the patient's perspective are studies of the person's experience of the various treatments, and not of cancer itself. Very few studies have been found based on the patient's perspective of the effect that the cancer diagnosis had on their lives in the period immediately following diagnosis. Ashbury, Lockyer, Mckerracher and Findlay (1997) from their study on the experience of cancer concluded that there is a need to develop a more comprehensive understanding of the cancer experience.

The literature I have read points to the need for health providers to know the person they are caring for who is involved in the experience of having cancer. Patients in their own writings, and studies from their perspective, have indicated the desire to be understood and treated as individuals, with individual needs. The literature also indicates a need for more-in depth studies, with the focus being on the patient's perception of the cancer experience, in order that health providers can better understand what it is they may need.

What drew me towards this study

When I first began my nursing training in 1991, the ideological approach then being taught was a move away from medical and institutional dominance to a more patient-focused perspective of care. The health professional was no longer going to be the one to decide what was best for the patient. The professional was now going to work in partnership with the patient by asking the patient as an individual what it was they needed from those providing health services. What was being taught then was that the nurse as a health professional was to act on behalf of the patient, assisting, facilitating and supporting them in their decision-making. A very important part of the nurse's role being taught at this time was to ensure that the patients retained freewill in decisions and were not dominated by 'other' or institutions.

Now more than ten years on I wonder how much I do understand about the people I care for and how well I meet their actual needs. When I began working in hematology I found I had an awkward gap in my understanding of the person who I was trying to care for. They were there and I was being paid to perform these tasks around them, but I felt there should be more to this. My relationship with them was awkward. I did not possess the insight to understand what this awkwardness was and how to address it. When I did attempt to breach the gap I felt unconfident and clumsy. I did not know what these people were feeling or thinking and I could only come from my own perspective, which was how frightening all this must be to them.

Some patients appeared to be particular in who looked after them. They seemed comforted to have around them people they knew and trusted. I had been qualified and working for four years at this time and had not experienced this need for stable attachment to this extent before. I still had questions I could not find the answers to, such as: what is the experience for the person like when confronted with both a serious illness and the health system? What effect does the health system have on them as a person? Does the service provided really meet their needs at this time in a manner that is supportive and caring; or, is the service still dominant and presumptive in what it believes their needs are? How is it one might know and check at varying intervals what these needs might be? Is the health service meeting these needs as best as practicable in an ever-changing society? But most of all I simply wondered what

people thought and felt when diagnosed with cancer and why so many did not appear to remain very long in a state of shock and disbelief. They seemed to just accept their situation, still being able to smile. The situation was just not making total sense to me.

Satisfaction surveys are one means of answering such questions as listed above, but this form of questionnaire is limited in its focus and the type of response it draws from people. It does not open people to a full expression of their inner feelings. People find it very difficult to express deep feelings and emotions in the comments section of a survey form. Understanding of the patient's experience from these surveys remains only surface level at best. A surface-level understanding does not prepare health professionals to assist people through one of the most emotionally difficult periods of their life, a time when support of the highest quality is vital to their sense of well being.

Currently I remain unaware of any training or guidance being offered that gives insight into the patient's inner personal experience of cancer. One is only provided with the broad concepts of shock and denial, and one somehow has the impression that these are negative behaviours to be found in some patients at times.

Although research into all areas of the patient's perspective when faced with illness is important, it is my nursing involvement for the past four years in the area of hematology, and dealing with many patients with blood cancer disorders, that has drawn me to this study. It is also society's silence on cancer and the care of those afflicted, as opposed to much greater attention being given to the cure of cancer that provides further impetus to this study.

I would like to contribute to some attention being given to the focus of care of the person with cancer. I want to know that I am being as effective as possible in my work and to seek to offer recommendations to other health professionals involved in caring for patients with cancer. I wish to ensure that the service that I am involved with is providing the best patient care that is possible.

Why hermeneutic phenomenology

Van Manen (1990) states that phenomenology should be chosen when the question under study requires a phenomenological sensitivity to lived experience. He also advises that the appropriate studies for phenomenological research are those that look to the essential nature of lived experience. This is a study of what it means to be a human being involved in an everyday part of the human life world. It is an in-depth investigation looking to describe and interpret what the experience of receiving a life-threatening cancer diagnosis is like for people and how this diagnosis affects them in that initial period (as they come to terms with the diagnosis). The study strongly fits with Heideggerian hermeneutic phenomenology for a number of reasons.

Heidegger (1926/1996) argued that people act purposefully in taking care of their world and give meaning to the events and things of their world. The world has been given the term 'their world' to indicate that individuals perceive and construct a world from within their own experience and understanding. They construct a world in which they can make sense of what's happening, a world in which they can find purpose and meaning for themselves. People see and interpret the events and things of the world from their own perspective. They have no other way of viewing the world. The so-called 'truth' is always distorted through the interpretation in which it must be made. In order to obtain an understanding of any human experience, one needs to somehow get inside the person in their 'being there'.

The aim of phenomenology is to replicate lived experience in a communicable, usually textual expression of the essence of the experience, in which the reader can share (van Manen, 1990). The term essence is a linguistic construction of the thing or structure within a certain phenomenon which enables one to grasp from description the nature and significance of the experience in a unique, yet universal way that was previously unseen. Through reflective reliving, gained from insight in the experience being captured in words, the reader can grasp the meaning of the experience from those who have lived it.

In this study I am looking at the meaning of the cancer diagnosis for people who have

experienced this diagnosis. This search for the meaning within the experience of being diagnosed with a life-threatening form of cancer requires a hermeneutic ability to make interpretive sense of the phenomena. This is more than just a description of an individual's experience. Through asking the participants for their stories, I'm also wishing to gain an insight about how the experience has affected their sense of structure and meaning within their world and what new meanings they may have constructed out of this experience. Hermeneutic interpretation is a method of seeing the significance and the meaning within the participants' experiences, based on the view of the person as described in Heideggerian phenomenology. This view of the person derives fundamentally from Heidegger's shift back from epistemological thinking about the knower's relation to what it is we know, to a more basic ontological stance of what it means to be human and how that human comes to understand their world (Leonard, 1994). By asking what it means to be a person, we come to understand more clearly how it is we know the world (Leonard, 1994).

This study does not search for factual truths that are present in the experience of being diagnosed with cancer, nor to build a model or theory of the processes involved within the experience. The study, rather, searches to uncover hidden or veiled elements that were unknown to us, or were forgotten, that could help to open new ways of seeing and understanding patients more fully both as uniquely individual beings, and as those who share in the universal phenomena of living with a recent diagnosis of cancer.

My own pre-understandings and influences

Although the goal of phenomenology is to study the phenomenon in its own terms, as it is within itself, Husserl (1964, in Benner, 1994) and Heidegger (1926/1996) thought one could only get close to the thing itself and never fully understand all there is to know of a phenomenon. In hermeneutical phenomenological research understanding is looked upon as a fusion of two perspectives, that of the participant's involvement with the phenomenon and that of the interpreting researcher (Bentz & Shapiro, 1998). It is assumed that the researcher is part of a culture of understanding within which the phenomena is to be understood. Both participant and researcher are embedded in

historical contexts through which all interpretations are made (Bentz & Shapiro, 1998).

Keeping this in mind the researcher attempts to approach the study without any fixed sense of the direction it will take. Van Manen (1990) terms this approach “presuppositionless”. When one takes a “presuppositionless” approach there is no prefixed hypothesis, or theory on which to base the study. The researcher attempts to approach the data with an open mind and to see the data for what it is. One of the methods employed to assist the researcher approach the study with an open mind is for the researcher to note his preconceptions, influences and biases. The researcher is required to disclose early on in the research project his influences, preconceptions, and biases in order for both the reader and the researcher to be aware of these and how they may possibly affect the research process. This, according to Benner (1994), requires the researcher to be critically aware and reflective of how the methods used within the research process, personal knowledge and the context within which the study falls can influence one’s understanding. Heidegger (1926/1996) believed that although we need to be mindful of our traditions, we cannot ‘remove them’ from our mind. Therefore, he argues that a pre-suppositionalist approach is not possible. I agree. I will now disclose what I can of my relevant preconceptions so that the reader of this thesis can have some insight into where it is I stood as I set out upon the journey of interpreting the experience of the person who receives a life-threatening cancer diagnosis.

Disclosure of own pre-understandings

In disclosing my own influences and preconceptions of what I think it would be like for an adult person to receive the diagnosis of a life-threatening form of cancer, I am aware that I’m very much influenced by my own place in time, and by the various experiences that I have encountered in my life. I am now a 43-year-old male registered nurse. Prior to my nursing training, I worked in the commercial finance and banking sector here in New Zealand, for twelve years. Up until then I had a brief layman’s knowledge of cancer. That knowledge being that science did not know what cancer was, or what caused it, except for smoking. If you were unlucky enough to get cancer it would probably kill you, as it was usually not curable. The films and

television played out the death sentence role for cancer as follows: “ Mr. Jones, you have cancer and have six months to live”.

I had an uncle who died of bowel cancer when I was 21. He would go to hospital now and then, have bits removed, and appendages added on to him. He slowly got smaller and quieter each time I saw him, up until the time I was told he had died. This was what cancer was to me and perhaps what it means to most people in our society today.

I left my work in the commercial sector for many reasons. One of the reasons was because of a strong underlying feeling that people, including myself, were not in touch with the reality of life. I felt I was being suffocated by this unreal world. I left to find the real world, a world that was not about profit, or position within the social fabrication of human society. These things seemed so empty, false and unsatisfying to me. I spent some two years ‘walking about’ Asia and Europe, thinking about life and about what to do next. Towards the end of my two-year adventure I had the opportunity to experience some voluntary respite care work, looking after physically handicapped people in Britain. I discovered that I enjoyed the realness of these people after I had overcome my own initial fear and standoffishness. Through the basis of my relationship experiences with these people I decided to train as a nurse.

During my nursing training I learnt what cancer was, the body’s own cells continuing to divide and replicate endlessly until they were somehow stopped. Cancer is often only stopped when it overruns the capabilities of the body’s system to function and sustain life. Most people today still do not seem to know what cancer is, and the subject does not appear to be discussed openly within current society, despite its prevalence. The literature would appear to support this view.

So I have the preconception that for most people the diagnosis of cancer remains a frightening event that is perceived by many as a probable death sentence. It comes as a shock for most, of mind-numbing proportions. People need time and support to adjust and come to terms with their diagnosis before they can begin to understand about the disease and the treatment options. Meanwhile they may feel anxious, isolated, afraid, vulnerable and lonely. During this stressful period of adjustment, they may become depressed, listless, have no appetite, feel nauseous, have poor

concentration, and have difficulty sleeping.

Most people in my recent experience within an acute hospital environment appear to make the adjustment in coming to terms with their having the disease in a matter of days. I don't understand or have any great insight into the mental adjustment that the person goes through in accepting and living with cancer. I do believe there is a gap in the understanding of what it is actually like for people at this adjustment stage of the diagnosis process and in the support services we offer.

Most patients I see in hospital have gone through this adjustment phase, and appear calm and able to sleep. They appear to have a huge trust in the health system, accepting without question the accuracy of the information they are given about the disease and the treatments being offered. Conventional treatments of cancer appear to be accepted readily, despite their inability to actually cure cancer and often having a poor short-term prognosis. These are often long and difficult treatments for people to endure. Only a few seek alternative treatments and then usually in concurrence with the conventional treatment, or when conventional treatment has failed.

Those people who are religious appear to maintain their faith, often praying with friends and family members. I have not experienced anyone newly turning to religion for support. Patients don't appear to discuss death, even when it becomes imminent. Most appear to have accepted death when it comes. Some family members find coming to terms with the death of a loved one difficult and often become very upset when you remind them or express that death is a possibility.

In my own experience, dead bodies until recently were never shown in the media. The human dead body is generally still hidden from the general public. There still appears to remain in the practices of our society, a strong underlying assumption that the death of the human person must be hidden from people. In the hospital environment when a patient dies, their body is kept behind a shut door in a room to itself. Living patients often can't get their own room, but a corpse soon can. In working in this area there appears to be an underlying rule that death will be hidden, even from the person who is dying. Other patients are never told what happened to a dying patient, once the dying patient has been removed from amongst them. When the

orderlies come to take the body away all hospital doors are closed to other patients' rooms so they and their visitors cannot see the body leaving. Even sick patients must not be transported around the hospital within the publicly used lifts; perhaps in order to not remind and upset the general public that people do get sick and can die. The dying patient themselves are always given some other excuse for hiding him or her away. They are never told the reality of the situation, "We think you are dying and we think this will be upsetting for others". Illness and death still remain hidden.

How in control a patient feels during and after receiving the diagnosis of cancer is dependent on the individuals and where they stand. Their culture, knowledge, beliefs, prior experiences, communication skills, and personal support systems seem to greatly impact on their ability to cope with the cancer diagnosis. For many patients the sense of control over their lives is lost. Their life is placed on hold while they undergo treatments for which the final outcome remains unknown. A sense of limbo, of wait and see, must prevail.

Most leukemia, lymphoma, and multiple myeloma patients that I have discussed the matter of causative factors with appear to have some idea of what it is that has contributed to their cancer. The link they make is often to a product of our industrial modern age. I also strongly believe that the major causatives of cancer are linked to the natural human body being in contact with a modern unnatural world that consists of all its various products, labour saving devices, and wastes. I also don't fully understand why mainstream society is unable to recognize this, acknowledge it, and begin to do something about it.

I have attempted to capture my influences, preconceptions and biases, prior to data collection. These influences are continually being added to through experience and are forever changing. Also it is impossible for me to put these influences entirely aside while conducting this research. The best I can do is to be aware of them and through reflection try to limit their influence on my interpretation of the experience under study.

Throughout this work I have used quotations from distinguished authors that capture some of the meaning that I'm trying to express in my writing. I believe this method

adds a further dimension to the overall presentation and leaves a haunting impression of humanity's echoing denial of its reality. This also gives an overall sense of connection to the denial of reality theme, which appears to rise up from within the narrative.

The exploration of what it is like to be diagnosed with a life-threatening form of cancer might sound 'soft' to the scientific-minded reader, but I assure you it is not. The journey reaches deep into the human soul and echoes down the ages, while also transcending up the years and into the very future of humankind. It is a journey that faces and questions the very meaning of what it is to be human. It is the journey many are afraid to face. It is the journey many may find themselves involved in. Before the data is presented in chapters four, five and six, and then followed by a discussion of the findings within chapter seven, I wish to provide further explanation of the Heideggerian person, on which the study and method has been based. But first, in chapter two I wish to discuss what it is I have managed to find revealed within the literature.

Chapter Two

Understandings of the person coming to terms with cancer

The irony of man's condition is that the deepest need is to be free of the anxiety of death and annihilation; but it is life itself which awakens it, and so we must shrink from being fully alive. (Becker, 1973, p. 68)

Introduction

I had originally drafted a literature review prior to commencing the data collection. As I analysed the data collected from participants, I found layers and elements I had not expected. As I drew these elements from the data I went about searching the literature to see what it was that might have been written around them. Much of what I found within the literature had not been written specifically about the cancer experience, but had been written about the phenomenon of trauma, which receiving the diagnosis of cancer causes for many people. I also searched the literature for insight into the person facing their own possible death. Approaching the data analysis in this way assisted me in reaching a level of analysis that was much deeper than I had earlier envisaged. The literature that has been presented in this chapter has been chosen for how well it can give some explanation or insight to the reader into the data that has come out of this research project. I hope by presenting the data in this way the reader will be better prepared to follow how I came to my own understandings as revealed in the data chapters four, five and six.

There has been much literature written on cancer, the treatments of cancer and people's experiences with the various treatments. This research project is not about the current medicalisation of cancer. This project looks to the effect that the diagnosis of a serious form of cancer has on the person; what the diagnosis may mean to the receiver and why; and the effect upon them. This review also investigates why the person is so shocked to be told that they have cancer, what they think and feel and what changes occur in them over the initial two or three-month period. I have also attempted to give the reader some insight in why these changes may occur within the person.

What it is the person goes through

We can say that the essence of normality is the refusal of reality.
(Becker, 1973, p. 178)

We are all human beings and in order to care for ourselves we must first understand who and what we are. When caring for the cancer patient we need to know just what it is they may be going through and why. It may prove helpful to both the patient and the carer to have some understanding of this and where the overall journey within the experience leads. It might be comforting for those forced on this journey to have some understanding of just what it is that is occurring within them and why.

Loge, Kaasa, and Hytten (1997) state that we know little about how the information we provide is perceived by the patient, and that there are serious gaps between the patient's preference in the area of how information and services are delivered, and the practice of many doctors. This statement indicates the need to check patients' experiences and see if his or her needs and preferences are being accommodated by today's health services. Sardell and Trierweiler (1993), in a study that looked at the best ways to give the diagnosis of cancer in order to encourage hopefulness, concluded that there is a need for health professionals to have a more in-depth understanding of the person they are attempting to care for from the patient's perspective. Patients have indicated within their own writing of their experiences, the need for health providers to have a greater understanding of their experience, in order that a more holistic service of care and treatment may be provided.

Joel Nathan, an Australian leukemia patient, after initially recovering from his cancer, decided to write a book that he wished had been available to him at the time when he was first diagnosed with cancer (Nathan, 1998). It would be a guide that would tell people all the things that doctors did not mention, things that nobody took responsibility for, which he had to find out for himself the hard way. Joel in his book listed the areas where he had support needs that were not met by his health service, for example:

- How does one break the bad news to one's family and friends?

- How does one build the confidence to make one's own decisions?
- How can one and one's family best handle the practical and psychological stresses of one's changed life?
- How does one maintain optimism and hold despair at bay?
- How does one find meaning in life while facing one's own death?
- How can one conquer one's fear of dying?

The above unanswered questions were important to Joel in the initial stage following his diagnosis. I imagine the answers to these questions would also be helpful to a number of people newly diagnosed with a life-threatening form of cancer.

As no foreseeable cure for cancer is evident, Burton and Watson (1998) advise that it is important to support a more holistic model of patient care that encompasses psychological support. Burton and Watson (1998) point to the importance of taking account of the psychological needs of patients at all points in the cancer experience. They state that the response of the health-care providers in their attitudes and behaviours towards patients and diagnosis, and the patient's emotional responses to the disease and its treatments, need to be viewed and focused upon as part of the problem (Burton & Watson, 1998).

In this particular study the focus is on the patient's response to the meaning that the word cancer has to them, and why this may be so. The purpose of this study is to uncover any hidden or forgotten elements within the person's experience and bring it into focus in order for society and its health providers to gain some understanding and to take into consideration when providing services. Highly costly medical support is often visible but the literature raises the question of how good and effective is such support to the actual person within the experience itself?

Why people are unprepared for cancer

We protect ourselves and our ideal image of ourselves by repression and similar defences, which are essentially techniques by which we avoid becoming conscious of unpleasant or dangerous truths. (Maslow, in Becker, 1973, p. 52)

The shock people have when being told they have cancer is well known. What is not so well known is why they experience such shock and how it is they overcome this shock. Research into the topic of psychological adjustment to being diagnosed as having a life-threatening form of cancer is still in its infancy with most of the research coming from the positive paradigm using quantitative methods with preconceived hypotheses, frameworks and models. Often the focus has been on the method of coping (Tedeschi, Park & Calhoun, 1998). These methods of research do not begin from the perspective of at first openly looking at what the experience itself is and consists of, for the person involved. Instead these research methods arise from the angle of pre-thought-out hypotheses often looking for the pre-expectations of the researchers. These quantitative methods often do not see other matters within the experience, as the design is not able to obtain a measure of what it is not designed for. Therefore quantitative methods are only able to test some measure on some matter that had been thought of prior to undertaking the research project itself. These methods are unable to uncover what is not already known in some way.

One study that was undertaken from within the scientific paradigm of psychiatry looked at the first 100 days immediately after the cancer diagnosis. This study was conducted by Weisman and Worden (1976), who gave the initial 100-day period of the diagnosis the term 'the existential plight'. Weisman and Worden (1976) suggest that the concept of existential plight is a distinct phase of cancer to which almost every patient is subject. The existential plight begins with a definite diagnosis and continues for a period of two or three months, being a period of approximately 100 days. Weisman and Worden (1976) state that at the time of their writing the existential plight in cancer had been poorly recognized and understood, but they believed this period to be a significant part of the cancer experience. They argue that during this period the person is primarily concerned with thoughts of life and death caused by an image of a relentless and deadly disease. As well as thinking about one's possible death, the person thinks about a variety of significant concerns that affect

many different aspects of their life. These thoughts bring about measurable changes in emotional responses and in the person's interpretations of how they relate to the network of people and the things of their immediate world.

Weisman and Worden (1976) in their study interviewed and followed for a period of three to four months 120 newly diagnosed cancer patients. Being psychiatrists, they approached this study looking for a cause and cure to emotional dysfunction or deviation from the norm. They were not seeking to understand the individual person within, and showed no great interest or insight into the journey/processes the person may go through and why. Weisman and Worden came from the perspective that the way in which science and mainstream society viewed themselves and their world was the only correct perspective and that deviation from this perspective was measurable. The assumed correct perspective was termed normal. Any deviation from the normal was considered abnormal and thus was seen as something negative that needed fixing in order to gain the desired state of normality.

Weisman and Worden (1976) sought to build a model that enabled prediction of deviation from the normal behaviour that is brought about through the knowledge of knowing one has cancer. They used a number of preset multi-questions based on behavioural models circulating during this period. The study tried to gain understanding of the ways in which physical and psychosocial dimensions contributed to emotional distress during the existential plight. The distress caused was measured with the aim to better be able to predict the patients who would be able to cope effectively and those who would not. Those who could not cope effectively were recognised as having subsequent associated problems. From the findings within the study a model of behaviour had planned to be built. In their study, Weisman and Worden found that most people usually came to terms with their cancer after some drastic reappraisal of the self, work, family and life plans.

Weisman and Worden (1976) made no account of why many patients may feel better, stronger and freer within themselves after the journey of existential plight, as they and their methods did not look beyond what was then considered normal. According to Berger and Luckmann (1971) the knowledge of an institution/society is what constitutes that society's motivation dynamics in its conduct in gaining knowledge.

This knowledge is socially accepted as knowledge and any radical deviance from the socially accepted order appears as a departure from reality. This deviance from the accepted norm of the day can be designated immoral, labelled as a mental illness, or be considered quackery. This provides the framework into which new knowledge must fit and controls and predicts all conduct in obtaining knowledge. Knowledge is then learnt as truth in the course of socialisation and is internalised by the person as a subjective reality. Weisman and Worden's study had been hamstrung by the unquestionable truth that what was considered to be the normal perspective was believed to be the only true and correct perspective.

Other authors have explored and articulated what it is the person goes through and why, in coming to terms with their cancer diagnosis. These authors recognise that the person understands their world and themselves from the subjective perspective of being there and involved with the phenomena. They recognise that the person devises their own meaning of the experience not only from the experience itself, but also from their prior perspective and understandings.

Caplan (1961) saw the shock of crises as situational. The situation the person finds themselves in at the time of the diagnosis causes psychological disequilibrium for a period of four to six weeks. He goes on to say there is often significant learning and psychological growth during this period and the changes that occur within the person's understanding during this time remain stable within their lives for years. These changes can be adaptive or maladaptive (Tedeschi et al., 1998).

Parks (1975) and Janoff-Bulman (1992) outline how people have a strongly held set of assumptions about the world and the self, which is maintained and used by the person as a means of navigating through their world. Through the assumptions they have about themselves and the world they are able to recognize, plan and take action. The assumptions people have about themselves and their world are learned and confirmed by their experiences over the many years of their life. One is not consciously aware of the assumptions he/she holds. Assumptions are a preconscious conceptual system that automatically structures a person's experiences and directs his or her behaviour (Epstein, 1984); (Janoff-Bulman, 1992).

Such literature is describing a conceptual system, which is developed over time that provides us with expectations about the world and ourselves. This conceptual system is made up of a set of assumptions about ourselves and the world that gives us meaning and order, and overall enables us to function effectively. We hold fundamental assumptions that are the foundation stones of our conceptual system (how we understand our world). These are the assumptions we are least aware of and least likely to question, they are just taken for granted in their permanence and being, they are without question, as we assume them to just be.

At the core of our assumptions are abstract beliefs about ourselves, the external world, and the relationship between the two (Janoff-Bulman, 1992). According to Janoff-Bulman (1992) people also have three fundamental assumptions: (1) The world is benevolent (2) The world is meaningful (3) The self is worthy. People in general hold a belief about goodness and badness and that the world is usually safe and benevolent to those who are good and that things happen for a reason. These three basic assumptions/beliefs do not exist independently of one's emotions. The positive feelings that people hold are connected to these positive assumptions.

People tend to be over-optimistic about their own lives (Janoff-Bulman, 1992; Becker, 1973). People feel invulnerable to misfortune. Tolstoy's fictional character Ivan Ilyich (Tolstoy, 1886) was told at school, 'all men are mortal' but did not think this would apply to himself. Only at his own death did he realise the significance of this statement. Janoff-Bulman (1992) states that in spite of people's statements sometimes to the contrary, people do not really believe that serious negative events or even death will occur to them. They hold a universal fundamental belief that they are safe which becomes apparent by people's reactions of disbelief to their own negative life events such as when they are told that they have cancer. People know disasters and horrors can occur all around them but they hold an underlying assumption that they themselves are indestructible. Janoff-Bulman (1992) goes on to suggest that although inaccurate, our positively biased core assumptions provide a means in which one can trust one's self and the world.

So in brief, people hold assumptions about the world and these assumptions give the events of their world meaning. People like to believe in justice and fairness so they have an underlying belief that things do happen to people for a reason.

Many people feel deeply threatened by the possibility that negative events such as cancer can just randomly occur in their lives. People like to feel that if they live right and do the so-called right thing, they can ward off bad the things occurring to them. This gives them a sense of not only justice and benevolence, but also of security and of control (Janoff-Bulman, 1992).

Philip Mairet in his introduction to Sartre's 'Existentialism & humanism' (1946) discusses the Heideggerian view that the only hope for the human being lies in his full realisation and acceptance of the truth and that although one's personal fate is simply to perish, he can triumph over it by inventing purposes and projects, which in themselves give meaning both to oneself and to one's world. Mairet suggests that not many show the capacity to live while facing death and instead will try to reassure themselves by thinking as little as possible of their approaching death. Reassurance is sought through worshipping idols such as humanity's superiority over other life forms and its great progressive march to prosperity and all this entails, including a strong belief in science or some form of objective divinity. The cancer diagnosis can force one to look and face truth for what it is.

Western society reflects the notion of thinking as little as possible of death and instead in its turning away from death will worship humankind and science. Particularly in the United States according to Janoff-Bulman (1992) success leading to happiness is emphasized and failure and suffering is ignored. There is no cultural role for trauma victims who are seen as losers and are hidden from the mainstream. This cultural avoidance of negative life events and death is echoed in the interpersonal avoidance of the victims of life's negative events. Victims are avoided because they threaten the many non-victims' underlying positive assumptions and can make them feel awkward as it brings into question their own feelings of invulnerability. People try to maintain their positive illusions and spend their lives in a way that helps to preserve the illusion that their positive assumptions have created for them (Janoff-Bulman, 1992). The potential significance of death anxiety, although great, remains largely uninvestigated.

Perhaps this is because the modern scientist is afraid to breach his own denial defences (Levitt, 1968)?

In summary, people are unprepared for themselves having cancer because they assume that they are not vulnerable to cancer. The society they live in encourages them to focus inwardly on the living within the bounds of that society only and not outwardly towards death and other possibilities. In this way society through its many members can reassure each other of their safety. The person, to feel safe, needs only to be what is considered a good member of society and not deviate from within the set directions and boundaries of what society sets. If a person was to think about having cancer or about death, this would be considered as a deviation from the normal and society has many in-built methods to try and encourage that person back within the set margins of what is considered proper. In this way, the person who is told they have cancer is left unprepared for an event that was not ever supposed to happen to them. In order to understand the shock caused by having cancer, one needs to ascertain what it is that cancer means to the ill-prepared person.

What cancer means to the recipient of the diagnosis

To someone who has to face it, it is powerful, terrifying and mind-numbing. It takes time and courage to be able to acknowledge cancer is within you, to find the power within you. (Farr, 1997, p. 4)

Historically cancer has been considered more frightening than other lethal illnesses (Burton & Watson, 1998). Cancer in Australia is associated as a common symbol of death (Kelleher, 2000) and in Western society is associated with death (McNamara, 2000). Cancer is so feared because it appears often unexpectedly. It is often thought to have a fair degree of certainty concerning the terminal prognosis and the nature of the dying is thought to be prolonged and painful (Field, 1996). It appears that today cancer is death and if you have a malignant cancer then both popular and professional views often define you as dying (Kelleher, 1990, 2000).

Cancer has been poorly understood by the public and is largely associated with long-term suffering, mutilation, often frightening treatments, long-term wasting away and

lingering death. The fear of cancer may rise from the perception that cancer is uncontrollable and little can be done to control it (Burton & Watson, 1998). Patients who have had relatives or friends die from cancer are likely to respond rather differently from one who has observed other people make a good response to treatment. Some people have been deeply influenced by portrayals of the illness in novels, plays, films or television (Barracough, 1999).

The individual gut-wrenching fear associated with cancer is rooted within a cultural terror. Not only is it death we fear, but pain, dependency, loneliness, the abandonment of family and unfinished life goals. In most Western countries cancer epitomises death. Newly diagnosed cancer patients will begin to live with the possibility, if not the probability of death following a diagnosis of cancer. Death for them becomes life's only certainty and one can no longer pretend immortality through health and fitness and workaholism (Stacey, 1997).

Beliefs about how people of different ages may react to cancer are not always backed by factual data. One cannot make generalised assumptions to the reaction of the diagnosis based on age (Barracough, 1999). Barracough (1999) states there is some evidence showing younger people suffer greater emotional distress. Generalisations based on sex cannot be made although there is some evidence that men make greater use of denial, while women take a more realistic view. For some, having some form of religious belief tends to assist in their adaptation to illness (Barracough, 1999).

To summarise, what cancer means to the person, is affected by how cancer is presented or not presented to them. The literature would appear to confirm that cancer means death, or the strong possibility that death may occur, for most people in modern Western society. People gain this perception of cancer through their own experiences with cancer, through people they have known, by word of mouth in conversation with others or through the portrayal of cancer via the media. Earlier the unpreparedness of people for cancer was discussed and attributed to people in general being encouraged to turn away from negative life events such as cancer and the possibility of death. This desire to turn away leads to a possible explanation as to why cancer and death are so poorly understood and feared. What are the factors contributing to our fear and poor understanding of this common human disease?

The fear of death: A good reason for the silence

...that of all things that move man, one of the principal ones is his terror of death. (Becker, 1973, p. 11)

According to Griffin (2000) in the 1920s the Western world entered into a long period in which death and all that was associated with it became taboo. During the period of taboo, death and the funeral moved out of the family home and into institutions such as hospitals, and funeral parlours. Death in this way became banished and the avoidance of death became internalised within each one of us. Death largely remains locked away, guarded by denial, taboo and euphemism (Griffin, 2000).

Through having death institutionalised and thus hidden from mainstream society, death has been removed from everyday life. Death is something we no longer usually see and only hear of when some acquaintance dies. Death no longer disrupts mainstream life (Stevens, McFarlane & Stirling, 2000). The belief in the medical profession, and that treatment is always possible, mirrors society's denial of death. The medical profession perpetuates this denial of death and the myth of its own ability to beat death by insisting on treating people right up to death itself. This modern medical approach reduces people's preparedness for death and reinforces the culture of denial, impacting on people's ability to cope with death (Stevens et al., 2000). The medicalisation of death makes death an unnatural and alien experience, as death is no longer part of life (Seale, 1998).

Adams (2000) states how one lives life is defined by the way one views death or how one chooses to ignore it. He goes on to imply our avoidance of death over the centuries has contributed largely to our problems in life.

What is often socially constructed can appear to be a natural law of nature. What today appears as universal human qualities about ourselves are often constructed through societies leading powerful discourses. Language and conversation have a role in society of maintaining an inter-subjective version of reality (Berger & Luckmann, 1971); (Seale, 1998). Discourse constructs a sense of order and meaning within what

otherwise appears as chaos. Normality is constructed in this way. The desire to be normal and to fit in with others ensures allegiances to these constructed ways of thinking, ensuring allegiance to the current scientific denial of death and of this denial appearing to be something that is natural (Seale, 1998). In illness and death, the body acts as a reminder of humanity's position within nature (Seale, 1998).

Because of the veil that is drawn over death, this being part of the 'civilising process' over the more animal and natural aspects of human existence, people no longer know how to be emotionally close to people who are dying (Seale, 1998). Modern society's glorification of the famous, rich and powerful helps the worshipper to deny their own natural being as a creature of nature (Seale, 1998).

Seale (1998) in an argument about why modern Western society and the people within it avoid death puts forward the possibility that the reason we instinctively appear to fear death and to turn away in denial is that in order to continue to struggle to live we must generate within us the will to live. Humanity lives in such away as always to be in avoidance of death because our psyche is directed towards life. If we are attuned to living in this way human social life can be viewed as a constructed refuge that provides meaning and purpose to our lives, within what appears to us as the meaningless natural world. Without this attunement in living, participation in society and culture probably would lose its meaning for the person.

Our current society's fear of death is so implicit and therefore hidden from the person that Seale (1998) writes that he finds remarkable the general absence of the concept and consideration of death in published discussions of old age. A further example of just how unacceptable the thought of death is within modern Western society is when this research study was proposed to the ethics committee here in New Zealand, they requested that the words, 'life-threatening' be removed and replaced with the words serious, in case prospective participants were alarmed by this thought of death.

Therefore there can be no doubt that the fear of death remains strong within Western society. The fear may be natural in its basis as proposed by Searle (1998), or be socially constructed, or both to some degree. The background to the fear within cancer has been focused upon here to enable the reader to have some insight into the

subject I now proceed to the person's experience of being diagnosed with cancer. Fear has been shown to contribute largely to societies and thus the person's approach to cancer. The effect of fear and its impact on the overall general approach to cancer has tremendous consequences for the person at the time of diagnosis and their following adjustment to their diagnosis. Let us now look at what it is people have to go through in being diagnosed with a life-threatening form of cancer.

The impact of the diagnosis upon the person

Mr. Average Man, just daily trying to negotiate a semblance of tranquil heroism by embedding himself in the powers of others. When these tactics fail and he is threatened with the exposure of his life-lie, how logical it is that he give way to his own version of fainting by bogging down in a depressive withdrawal. (Becker, 1973, p. 211)

Although the diagnosis of cancer does not come as a shock to everyone (Krause, 1991), most when suddenly confronted with a diagnosis of cancer are forced to come face to face with their vulnerability within life. They become abruptly aware that their future continuation is not something to assume and take for granted. Intense shock, disbelief and confusion are how most people are at first affected when forced to see the reality of their mortality in this confronting and sudden way (Becker, 1973). They also experience feelings of horror, anger, surprise, of time standing still, emptiness, absence of reality and guilt (Krause, 1991). This is because the event of having cancer was not included as a possibility in the script of one's life (Becker, 1973).

The cancer diagnosis can overwhelm the person's ordinary coping mechanisms, leaving them in a state of helplessness and terror (Herman, 1992). The essence of this trauma is the abrupt disintegration of one's inner world caused by the sudden awareness of one's fragility as a physical creature. This sudden awareness of one's fragility is what threatens one's psychological integrity (Janoff-Bulman, 1992). One finds one does not have ready answers, or is equipped with ready-made responses for the situation (Kfir & Slevin, 1991; Janoff-Bulman, 1992). One's most fundamental assumptions have been shattered and one finds oneself face to face with a deadly world that one can no longer make sense of.

The most immediate response to the cancer diagnosis is probably the fear associated with the possibility of one's own death (Janoff-Bulman, 1992). While the idea of treatment can give the person hope, they also know from previous life experiences that cancer is death and that the treatments can be painful, sickening, slow and ugly, which can leave the person feeling helpless and undignified (Kfir & Slevin, 1991). These are factors that can make cancer appear so fearful to people. According to Benner (1994) making what the person is fearful of more familiar will reduce their fear. One of the problems with trying to reduce the person's fear at, or immediately after their diagnosis, is that the information required by people is totally new to them. They find new information difficult to absorb at this time (Kfir & Slevin, 1991).

After hearing of their diagnosis most people are too shocked, or upset to request, understand or remember anything else (Barraclough, 1999). The person is now trying to cope with fear, anxiety and the feeling of helplessness as well as the cancer itself (Hagopian, 1993). They are so overcome and involved in their thoughts of life and death that a complete lack of information can often be easier for them to deal with than partial information (Kfir & Slevin, 1991). Barraclough (1999) states that many of the psychological effects of cancer can be understood in terms of reaction to loss, or to the threat of loss in the near future. The loss of independence, vocation, roles, interpersonal relationships, health, physical integrity, and the loss of life expectancy all impact upon the person.

The cancer diagnosis can also be profoundly distressing because people anticipate the grief reaction of their loved ones. People often worry about their spouse, and children and the effect upon them of their diagnosis and possible death. Many often worry about how these others will manage without them (Brennan, 2001).

Kfir and Slevin (1991) state the suddenness of the realisation and shock of having cancer is often surprising even to those who suspected cancer. The diagnosis usually finds one without any previous experience or personal solutions. One needs time to readjust to cancer and the effect that this word has on them. One's life goals of family, welfare, success, fun, love, ambition, social involvement, changing the world, relaxation, art, power and money, are now viewed from a different perspective. When one is faced with the diagnosis of a life-threatening form of cancer these things seem

to lose their meaning because one can no longer relate these things to their new-found situation. A person does need goals and meaning in order to live a purposeful life and in order to survive, so new meanings within life need to be found in order for the person to live (Kfir & Slevin, 1991).

To summarise, the diagnosis sends the person into a state of shock and disbelief. They must face the possibility of their death. The whole purpose and meaning of their life seems to immediately evaporate. They are unable to take in new information at this time, as their senses are so overwhelmed with the news that they themselves have cancer. They must find new meanings and goals for themselves in life in order to survive. The next question is, 'how might the person go about finding new meaning and a sense of purpose on which to base the continuation of their lives?'

Finding new meaning

The arrival at new possibility, at new reality, by the destruction of the self through facing up to the anxiety of the terror of existence. The self must be destroyed, brought down to nothing, in order for self-transcendence to begin. (Becker, 1973, p. 89 in discussing the writings of S.A. Kierkegaard)

A number of authors have written about how it is a person finds meaning in life after the diagnosis of cancer. Calhoun and Tedeschi (1998) discuss a process termed rumination, where the person who has been recently diagnosed, in their daily thoughts frequently return to the cancer and how it affects their life. These thoughts can be positive, like finding new meaning to life from within the event and noticing positive changes in one's self, in which to continue to function with a positive outlook. Or these thoughts can be negative, looking towards the past and wishing it did not happen, with the person being regretful of their situation. The process of rumination appears to be involved in readjusting one's goals, beliefs in how the world functions, and the meaning of life for oneself, under the changes caused by knowing one has cancer and subsequently knowing that one is not immortal (Calhoun & Tedeschi, 1998). The person needs to disengage, or let go beliefs, activities, and goals they held prior to the trauma of knowing he or she has cancer. It is often a very difficult struggle

for people to let go of the beliefs they had held and on which they had constructed their reason for being (Calhoun & Tedeschi, 1998).

People may have to let go assumptions they held in such things as their personal safety within a benevolent world, in order to find beliefs that can better accommodate the existential changes brought about by the diagnosis (Calhoun & Tedeschi, 1998; Janoff-Bulman, 1992). The person experiences the feeling of loss and disintegration as the assumptions of the known comforting old world are shattered. In order for the person to have a sense of balance and purpose new assumptions need to be constructed (Janoff-Bulman, 1992).

Immediately after their diagnosis, the person can find themselves trapped between two untenable cognitive worlds: the pre-diagnosis assumed world that no longer makes sense in light of the diagnosis, or, the new unknown world that appears extremely negative and frightening (Janoff-Bulman, 1992). Only those that already hold realistic assumptions about their world will be less shocked by this experience (Janoff-Bulman, 1992).

Holland and Lewis (2000) suggest that a pervasive sense of uncertainty probably characterizes the cancer journey and that it is learning to live with uncertainty that people need to adjust to. The bubble, which people held of the certainty that they will be living a healthy life in the coming future, has now burst. This period is often made more uncertain as the person spends time waiting for information of various medical concerns. The medical concerns for the patient are: the accuracy of the diagnosis, the treatment and its side-effects, and their overall prognosis (Burton & Watson, 1998). Often patients will need to wait for accurate answers to these questions.

Holland and Lewis (2000) talk of a three-stage adjustment process that the person appears to go through in coming to terms with having cancer. The first stage is of denial and disbelief, followed by a second stage of turmoil, when the person begins to confront the reality of having cancer. This creates a period of restlessness, fearfulness, and a preoccupation with the diagnosis and its implications. At this stage the person develops a sense of helplessness and hopelessness, feeling that there is nothing they can do. These negative feelings alternate with a sense of vague calm, a sort of

thinking it will be all right. The person becomes dependent on others, but loses a sense of being accepted by family and friends, which can lead to further insecurity and a terror of being finally abandoned. The second stage can often last for a week or two, which often ends when the treatment begins. Treatment can give the person a sense of hope. Holland and Lewis (2000) speak of the third stage of when adjustment and acceptance to having cancer takes place partially to the relief that action is being taken against cancer. This leads to renewed hope and a feeling of getting back some control over one's life.

In their writing Holland and Lewis (2000) attribute a lot of the person's acceptance of their situation in the faith that the treatment is going to work. Although they talk of the adjustment of living with uncertainty, Holland and Lewis do not mention the sense of positive growth many patients appear to attribute to the experience. Holland & Lewis seem to have the perspective that the fear of death cannot be adjusted to in some way by the person and that they need to be given hope in the form of some sort of saviour from death.

Elisabeth Kubler-Ross's study of terminal cancer patients (although based on the acceptance of death) according to Barraclough (1999) offers a useful framework for understanding adjustment to the early-stage of having cancer. Kubler-Ross's (1969) model has the following four stages:

- (1) Shock, numbness or disbelief on learning the truth, the bad news would appear too much to be taken in. This stage of denial usually lasts no more than a few days, and may not occur at all.
- (2) Acute distress as the full reality dawns: anxiety, anger, bargaining and protest, often lasting several weeks.
- (3) Sadness and despair, which may also last several weeks.
- (4) Gradual adjustment and acceptance, often taking several months.

Like Holland and Lewis's explanation of the stages people go through, Kubler-Ross's model (despite Kubler-Ross herself having good insight and a deep understanding of

the human journey) offers only a partial insight into the personal journey the person goes through and why. Although helpful as an explanation giving insight into the experience of having cancer, both Holland and Lewis's and Kubler-Ross's models give little hint that the person may undergo this journey in the first place in order to come to an entirely different destination on how they view themselves and their world. These models give little insight to the idea that the person's understanding of themselves and the world has changed and it is this changed world that they are adjusting to and not just to the idea of their possible death. These models do not provide specific insight into what changes occur in the person and why these changes should and need to take place. The positive changes within the perspective of the person are not recognised in these models. Holland and Lewis, and Kubler-Ross, like many other medical writers, approach their understanding of the person from the perspective that the sanctioned normality of the day is the only true, correct, and healthy understanding. They view the person who is adjusting to having cancer in terms of deviating from the path of normality. But what if the path of normality is poorly built and full of pitfalls? What if the person through their cancer experience has found a straighter, stronger and more practical path? What if the person after learning to accept and live with death has a greater sense of fulfilment in life by doing so? Kubler-Ross (1978, p. 12) herself wrote,

It is fear and guilt that are the only enemies of man, and if we have the courage to face our own fears and guilts and unfinished business, we will emerge more self-respecting and self-loving and more courageous to face whatever windstorms come in our direction.

Soren Kierkegaard (1813-55), a Danish writer and social critic, according to Becker (1973) knew health was not the adjustment to normality. Kierkegaard believed that to be normal was to be sick. So with this thought in mind he posed the idea that the healthy man must then in turn need to transcend beyond the cultural normality of his day.

Current theories of adaptation to traumatic life events describe both automatic processes and deliberate efforts by the person to adjust (Tennen & Affleck, 1998). There is also a powerful interplay of both cognitive and emotional factors within the adjustment process (Janoff-Bulman, 1992). Horowitz (1986) talks of 'dosing', when

the person is able to control the timing, frequency, and duration of trauma-related thoughts and images. The person thus deals with the trauma, as they feel able to manage. Denial and numbing are examples of automatic processes that enable the person to pace the integration of the meaning of the traumatic event in a manner that they can tolerate into their overall cognitive scheme of things (Greenberg, 1995; Janoff-Bulman, 1992). The initial onslaught of the trauma can be massive, causing dramatic cognitive upheaval and emotional responses. Fear and anxiety can become so intense that the cognitive-emotional system largely shuts down and denial processes are brought into play where the person is able only to acknowledge and feel little (Janoff-Bulman, 1992). Horowitz (1986) says that avoidance and denial are normal adaptive temporary defences brought into play by overwhelming trauma that gives the individual time to integrate the event into their cognitive world view. The trauma and its meaning are integrated at a pace with which the person can cope. The interaction with others can assist or impede this process (Janoff-Bulman, 1992).

Brennan (2001), a psycho-oncologist, looked for a model of adjustment that recognised the personal growth reported by many people. But the models up until that time had all been based on deviation theories from normality. The term adjustment had meant returning to a state where psychological morbidity was absent. The term adjustment, in psycho-oncology, gave the impression of reaching some measurable end point rather than being based on an ongoing process of interpretation at a certain stage in time within a person's present ongoing and ever-changing understanding of themselves and their world.

In his paper Brennan (2001) attempts to ask the questions: What are the components of a normal adjustment to cancer; what exactly is being adjusted; and what are the processes involved. He proposes that the concept of adjustment is a psychosocial developmental process. The processes of adaptation occur over time, as the person learns from the experience and accommodates the multitude of changes which have been brought about by the cancer diagnosis. He argues that people are not only responding and having to cope with the crises, they are also drawing conclusions from their cancer experience. Some of these conclusions drawn may be the cause of psychological distress and subsequent disorders for some. For many others these

conclusions will be the basis of what has been termed 'post-traumatic growth' (Brennan, 2001).

The person in their healing needs to reconstruct a new self, in order to face what is now for them a vulnerable life. The cancer diagnosis can create uncertainty and cause regression, mental illness and negative coping behaviour in some (Tedeschi et al., 1998). Other negative changes can include increased negative moods, disruption in relationships, and physical symptoms (Calhoun & Tedeschi, 1998). Others can grow through re-examining and facing up to the reality of the experience of the cancer diagnosis (Tedeschi et al., 1998).

The assumptions the person holds about the world are useful to predict, appraise and interpret various experiences. They enable the person to have a manageable coherent understanding of their world by which the person is able to navigate and live in that world. Strange events or the unexpected will require changes be made in order to accommodate and give a sense of order and meaning within the person's assumptive world. Events such as the diagnosis of cancer can temporally overwhelm (shock) the ability and capacity for previously held assumptions to predict or react quickly in their adaptation to these new unforeseen circumstances (Brennan, 2001). The person does recover from their shock of having cancer, and through doing so their perspective of life has changed. They have adapted and accommodated their experience into their schema¹ (Janoff-Bulman, 1992).

The person, after adjusting their cognitive assumptions to having cancer, realises that their prior assumptions were naïve and that tragedy can strike anyone at anytime. Although being aware of tragedy, they do not allow it to pervade their self and worldviews. Over the course of time the person re-establishes positive, yet not as unrealistically positive, core assumptions with which to navigate life (Janoff-Bulman, 1992). Not everyone will triumph over trauma, but for the many who do, the positive changes result from the person's active attempts to cope with the situation (O'Leary, Alday & Ickovics, 1998).

¹ A schema is a mental structure that represents organised knowledge about a given concept or type of stimulus. The use of schema implies an active mental construction of reality (Goleman, 1985)

In brief, the person constructs their own understanding of themselves and their world. They have come to assume through previous experiences, and through the experiences of others, that life is fairly certain in its predictability and that life is a fairly stable platform to be upon. The cancer diagnosis shatters these held assumptions of life, and the person then needs to reconstruct new understandings of their world and their place in it for themselves. Let us now look at how it is the person learns to adapt to having cancer and how they can hold a positive outlook on life.

Learning to cope

...our neurotic shield that protects us from our dread of truth gives us insight just how painful psychological rebirth is. The worst is not death, but this rebirth. (Becker, 1973, p. 68)

Once a person is diagnosed with cancer they will live with the cancer identity and the uncertainty of cancer. A person can recover from cancer, but they live always with the possibility of cancer returning. The cancer patient is forced to deal with a new identity that is constructed around cancer (Field, 1996). When the work of denial is completed, hope takes its place (Breznitz, 1983). Hope is important for cancer sufferers. It is vital in their adaptation to their illness and will have an effect on their quality of life, coping skills and adherence to treatment regimes (Downing, 2000).

According to Lowden (1998) the positive mental attitude of a person appears to contribute to a positive outcome in terms of survival. A positive attitude can help to alleviate the stress of having cancer. How the person perceives cancer is dependent on cancer's image within the broad concepts of society, how the health professionals approach the disclosure of this information, and the support the individual feels they have. According to Kumasaka and Dungan (1993) information about cancer and its treatment can help individuals gain control in an otherwise chaotic environment.

People, after receiving the diagnosis of cancer, are in a state of disequilibrium. Their understanding of the world has been shattered and things look unpredictably bleak and frightening. They must search for new meaning, which is coherent with their newfound situation. The perception the person holds about their diagnosis must be

faced and processed before any positive meaning can be attributed to the situation (Taylor, 2000). Janoff-Bulman (1992) talks of three strategies people use to cope:

1. Comparing yourself with others, especially others in a similar situation to yourself.
2. Interpreting one's own role in causing the trauma (was I to blame).
3. Looking at the diagnosis in terms of what are the benefits from this (what purpose does this have in my life?)

In this way people begin to reevaluate the event in terms of themselves and their world. They attempt to find and create evidence of benevolence, meaning, and self-worth in the cancer experience itself that had shattered their prior understandings (Janoff-Bulman, 1992). Many people use the strategy of positive appraisal to give themselves a sense of control over the illness. This also helps them to highlight and concentrate on the brighter aspects of the experience (Barraclough, 1999).

An individual's belief that life is purposeful and meaningful assists the person in coping with trauma, but how people experience meaning is not that well understood by health professionals. It is difficult to understand people's illness and suffering without being able to understand the personal meaning involved within the experience (O'Connor, Wicker & Germino, 1990).

One study by Halstead and Hull (2001) investigating the personal meaning for people within the cancer experience looked at the experience of the diagnosis of cancer from a spiritual perspective. They defined spirituality as a life-long developmental process, which has unique individual connotations but does not develop in isolation. For its development spirituality was dependent upon relationships and community support. Spirituality requires a sense of connectedness, direction, transcendence, meaning and purpose. Religion may be a part of someone's spirituality but is not the whole of spirituality. Halstead and Hull proposed that strength, stamina, courage, hope and support were the necessary ingredients for a successful adaptation.

Halstead and Hull (2001), in their grounded theory study of ten U.S. women aged 45-70 diagnosed with cancer, found that the women were struggling with opposing

concepts like; life or death, or were focussing on a cure while dreading relapse. Halstead and Hull proposed that this struggle with these opposing concepts (for which they termed as paradoxes) was a three-phased process consisting of: (1) deciphering the meaning of cancer for the person themselves; (2) realizing human limitations; and (3) learning to live with uncertainty.

In deciphering the meaning of the cancer phase, the person attempted to maintain understanding by using old and new methods. Most felt the need to stay connected to their usual support systems and although their own lives no longer felt normal, they did not wish to interfere or change the lives of those others close to them. They wished for the lives of others to go on as normal. When old methods of coping did not seem to provide the stability needed, the women tried new strategies such as meeting with support groups. All the women in this study expressed a religious belief in 'God' (I envisage they meant the Christian form of God due to the U.S. culture), so many tried religious healing services.

In the second phase of realising human limitations after having been frightened and having to relinquish control over many aspects of their life including life and death, the connection with other people provided much-needed support in relinquishing some previous roles or continuing in others. Assistance from others was sourced through family, social groups, other cancer patients, healthcare providers, and God. These others assisted in meeting their physical, emotional, and spiritual needs, while they searched for reason and some form of control. One woman spent a lot of her time alone in reflection about her connection with others. Humour with others helped to release some emotional tension and give connection with others, putting the illness into some form of perspective for them. With time as they passed into the third phase, learning to live with uncertainty, the physical, emotional and spiritual distress diminished. Their perspective had changed. They now lived with cancer and death. Through a process of evaluation and revaluation meaning had formed. They talked of making the most of their days and living life more fully, enjoying an improved quality of life, not taking things for granted, and having a greater sense of peace. They had an overall sense of growing through the experience. This growth was in areas of greater spiritual awareness of, and feeling closer in connection with, nature, others, God, in themselves in the form of confidence and strength (which they could not explain).

They also found more time for reflection. Not all things to do with the changes brought by cancer were resolved in their minds but became less important over time.

These women came to accept their limits in controlling their lives; they learnt to live with an uncertain future. Halstead and Hull's (2001) paper makes no comment or comparison about just how sustaining these women's faiths were during and after the crisis stage. They did not go on to find out if participants still strongly believed in a certain future life after death, which means that these women may have maintained a certain element of stability in their lives by having a vision or belief of themselves as an ongoing everlasting entity and thus not having the same fear of the possibility of total annihilation, which others not holding strong religious faiths might have.

In short, in order to cope with their cancer the person would appear to develop goals of some form of obtainable future given through hope. In order to increase a sense of hope the person searches for positive aspects within the cancer experience. The information they receive from others adds to their overall perspective either positively or negatively. The provision of information also adds to a person's sense of being in control and making sense of the situation for themselves. The person begins to reevaluate their situation, looking for meaning, and the positive aspects within the experience itself. The person's sense of spirituality can grow and comes from having received support and connection from others. The support of others would appear to be a very important element in the person's search for meaning, as they learn to cope and live with having cancer. Let us now investigate the importance of other within the cancer experience of the person.

How important is the support of other

The most terrifying burden of the creature is to be isolated. (Jung in Becker, 1973, p. 171)

The human person is a social animal whose interpersonal experiences have a major impact throughout ones entire life. Our interpersonal connection with others is how we initially develop and grow as human beings (Janoff-Bulman, 1992). The people in the social world of the trauma victim have the power to influence the eventual

outcome of the psychological trauma caused by the diagnosis (Herman, 1992). Social support facilitates psychological wellbeing (Janoff-Bulman, 1992) as others maintain the subjective reality for the person and is crucial to the element of the person's reality called identity (Berger & Luckmann, 1971).

The belief in a meaningful world is formed in relation to others, and begins at birth through the establishment of trust (Herman, 1992). Our interpersonal connections are what maintain us through our lives and, when it is necessary, help us to rebuild our world and self-views after trauma (Janoff-Bulman, 1992). Herman (1992) says that recovery can only take place within the context of relationships and that recovery cannot take place in isolation. O'Leary et al. (1998) suggest that a variety of personal and environmental resources may enhance the likelihood of positive outcomes following life-changing or traumatic events. The most frequently appreciated social resource is the social support of others. This social support gives a sense of coherence, motivation, optimism and hardiness (O'Leary et al., 1998).

The support of close caring others is crucial during the recovery to a traumatic event such as the diagnosis of cancer. Core experiences of psychological trauma are disempowerment and the feeling of being disconnected from others. Therefore recovery is based largely on the empowerment of the person and reconnecting or creating new connections with others. Assurance of safety and protection are of the greatest importance in the early stage of trauma. The person is often terrified of being left alone and will crave sympathetic company. The person through their diagnosis of cancer has become intensely aware of the fragility of all human connection and they then need clear and explicit assurance that they will not be abandoned (Herman, 1992). This social support provides direct evidence that the world is not cruel and meaningless. It also makes the person feel safe and secure and that they are personally worthy of support (Janoff-Bulman, 1992).

Once a sense of basic safety has been established for the person, they need the help of others in rebuilding a positive view of themselves (Herman, 1992). In this environment of feeling cared for the person can feel encouraged to openly explore the experience, gaining acknowledgment and feedback from supportive others (Janoff-Bulman, 1992). To be empowered, the patient must feel in control of their own

recovery. Others can help to provide a healing environment through advice, moral support, assisting as required by the person, show of affection and care, but they can't mend what is hurting. Only the person can do this within themselves over time. No intervention that removes power from the person can aid in their psychological recovery (Herman, 1992).

In his book 'Cancer Ward', Solzhenitsyn (1968) warns of how medicalisation and the bureaucracy of institutions can dehumanise and disempower a person:

No sooner does a patient come to you than you begin to do all his thinking for him. After that, the thinking's done by your standing orders, your five-minute conferences, your programme, your plan and the honour of your medical department... I become a grain of sand... nothing depends on me.

Institutional dehumanisation and disempowerment can be minimized through the person receiving intense social support during the period of adjustment to the diagnosis of cancer. The person can be helped in this way to facilitating positive personal and social changes (Scafer & Moos, 1998). Psychological faculties such as trust, autonomy, initiative, competence, identity, and intimacy can be damaged within the traumatic experience of the diagnosis. Through their connection with supportive and caring others the person can repair and reform these damaged psychological faculties (Herman, 1992). The necessary transformation of the person's subjective reality cannot take place without the interrelated contact and communication with significant others. This contact is required by the person to re-identify themselves with the world that has now changed for them. The cancer diagnosis can cause for the person a replication of the childhood experience of being emotionally dependent on significant others. These significant others act as a guide into the new reality and help to mediate this new world (Berger & Luckmann, 1971).

Talking, discussing, venting and the sharing of trauma-related thoughts and feelings provide the environment for the person to approach, reappraise, and to work through their cancer experience (Janoff-Bulman, 1992). When there is someone with whom the person can share their burden of cancer, it becomes less threatening to them. They feel more in control and confident than if they were alone (Holland & Lewis, 2000;

Brennan, 2001). Conversation with others maintains the person's sense of reality by being able to talk through the various elements of the experience and allocating them a definite place in what is being recognised as the real world for that person (Berger & Luckmann, 1971). The person is more able to handle their distressing emotions and are more adventurous in openly exploring their feelings and their meaning when in a supportive environment. In this way, a recovery can be facilitated that enables the person to live in their cognitively now-changed world (Janoff-Bulman, 1992). Those who are isolated, with little connection to others, have higher mortality rates from all diseases (Holland & Lewis, 2000).

At times survivors attribute their survival to an image of a connection to someone, which they hold onto and preserve through their trauma (Herman, 1992). Burton and Watson (1998) point out the importance of empathy, and that the helpers need to be empathic listeners and learn about patient's experiences from the inside. They have suggest that empathy can make a huge difference to the patient's feeling of well-being, hope and self-esteem.

Bloom (1998) argues that the natural human response to danger is to gather together with other human beings and to seek the safety of human companionship, to seek the safety of the crowd. Berger and Luckmann (1971) state that the real world is an illusion constructed within the group; each member through language maintains their group illusion of what is for them reality. There is an intimate and interactive relationship between the person and the group. The person's identity as an individual is closely connected to one's position or image within the group, "group self". Our group self may be the core component of our sense of personal identity. 'Group mind' is a word used by Cohen, Fidler and Etting (1995) to describe a concept of the super collective mind of a social group that all individuals are deemed to hold and be a part of. The group mind can exist as a meaningful concept for people. The individual is seen as a living vessel who represents aspects of the group's unconscious mind, in which the group mind can be expressed, acted upon and understood (Hewstone, Stroebe, Codol, & Stephenson 1989). People conform to the group because of the desire to be liked. To not conform would cause possible conflict and bring upon one resistance through dislike and non-acceptance by the members of the group (Van

Avermaet, 1996). Tedeschi et al. (1998) suggest that being diagnosed with cancer can reveal the uselessness of attempting to create security.

All in all, the support of others would appear to be the crucial component necessary for the person to make the adjustment to their personal meaning of self, life, and the world, in order to cope and to live well with having cancer. The person grows through childhood and slowly learns about the world surrounded and supported by others. They come to an understanding about themselves and a sense of purpose and belonging within the world. Their life holds meaning for them. The diagnosis of cancer can destroy the sense of connection the person has to the world. The person needs to rebuild new connections and find a sense of belonging. Only through their connection and communication with others are they themselves able to slowly realign their understanding which must now include the cancer experience and its meaning. The cancer experience may cause the person to redefine their connections. These connections will not be exactly as before and the person may no longer seek the security in others in the same way they had before having cancer. An understanding of the changes the person obtains from within the journey of their cancer experience will now be explored.

A new understanding

To realise one's mortality is like being born again but without the neurotic shield that hides the full ambiguity of one's life (Becker, 1973, p. 57).

Much of the person's sense of who they are, or their identity, comes from their personal pathways in life which offers goals and rewards in the future (Tennen & Affleck, 1998). Cancer and its threat to life lead people to re-examine their implicit life priorities and assumptions (Aldwin & Sutton, 1998; Brennan, 2001). Often, through having experienced and through coming to terms with having cancer, people develop enhanced coping skills with increased abilities to regulate the effect of problems and to think through these problems. They also learn to seek help when required (Schaefer & Moos, 1998).

After going through a period of painful emotional reaction and heightened distress, most people adapt successfully to their cancer diagnosis. More than 50% of people who experience a life crisis report some benefit from the experience (Schaefer & Moos, 1998). According to Barraclough (1999) many patients have experienced positive aspects within their cancer experiences, as well as negative ones. Many people can experience both positive and negative changes (Calhoun & Tedeschi, 1998). Many often reflect upon their having cancer as a learning experience. The person can feel a sense of triumph, of mastering something that in the beginning appeared so terrifyingly difficult, leaving them feeling stronger and not weakened by the experience (Janoff-Bulman, 1992). Some people discover a new sense of personal control (Brennan, 2001) and a confidence and reassertion of themselves through re-examining who they are in all things (Brennan, 2001). This reflective re-examining can cause alterations in attachments within social and personal areas of life, often leading to more creative, valued and engaged relationships (Aldwin & Sutton, 1998; Brennan, 2001). The cancer experience can often bring about emotional honesty, which may also lead to the termination of some relationships (Brennan, 2001). People can find they have a new sense of wisdom coming from within the experience as they now interpret reality differently, through their now knowing life to be so fragile and temporary (Janoff-Bulman, 1992).

After the period of adjustment some previously held goals may be looked upon as trivial, while some often latent unspoken, but long-standing life goals may suddenly become clear and distinct. Some people have reported that they had developed many new motivational priorities since the experience (Schaefer & Moos, 1998). People often talk of feeling that they are now more patient and caring (Janoff-Bulman, 1992).

In Barraclough (1999, p. 5), Margaret a 51-year-old woman diagnosed with breast cancer wrote:

There have been some positive changes. I am learning to tell people what I want to, and not what they want to hear. Increased self-confidence...More time to enjoy simple things like taking a walk when I want to. And I have completely lost the rushed feeling I used to have of never being enough hours in the day - this is wonderful.

Margaret here shows a confidence in who she now is by feeling she is more able to speak her own mind. She also talks of more time. She has lost a feeling of having to rush through her life. What exactly this rushed feeling is the literature does not say, but one person having been diagnosed with AIDS stated that human beings do not realize how driven they are by their fear of death, and without being so afraid there is an immediate shift in priorities (Janoff-Bulman, 1992).

The diagnosis frees one from seeking security by revealing the uselessness of this to the person, instead the person can concentrate on living to the full (Tedeschi et al., 1998). The mental confrontation with one's own death essentially strips life to its essentials, and can be a turning-point away from a more superficial form of living. People often talk of enjoying life a whole lot more, of no longer taking it for granted. They are more inclined to live each day as it comes (not so much future focused as before) spending far less time on insignificant tasks, such as household chores, and spending time on redirected priorities such as spending time with the people they feel close to (Janoff-Bulman, 1992).

In brief these statements reveal why people may feel less rushed and have a sense of more time after they come to terms themselves with having to die. Having come to terms with cancer and one's own death appears to give people a sense of mastery over an adversary. They feel confident about who they are and become more patient as time is no longer rushing by for them. Perhaps this confidence and feeling that time is not against them is that they, unlike mainstream society, no longer feel the encroachment of death upon them as they age. Death has been accepted as a part of their life. Some of the personal reports found within the literature about the cancer experience and what it is people have come to understand from their experience is now offered.

What some of those having been through the experience express

Would it not be better to give death the place in actuality and in our thoughts which properly belongs to it, and to yield a little more prominence to that unconscious attitude towards death which we have hitherto so carefully suppressed? (Freud in Becker, 1973, p. 53)

In the reading of some of the many accounts of people's own experiences with their cancer, there appears to be an underlying theme of a journey within their stories. A journey where a sense of control over one's self is at first lost and then further into the journey there is a sense of finding a truer, more self-oriented control over one's self, which is alive in the now of life. But at the same time the person remains very aware of the vulnerability of life. Dennison (1996, p. 5-10) captures this change in perspective towards life well in the following piece of Anne's writing:

I can't really describe the devastation I felt; it was mostly a blank nothingness. I remember too a strong sense of unreality. All these years spent studying and establishing a career, why had I bothered... In retrospect it is difficult to describe the luminous intensity of the first few days at home. I was blissfully conscious of beauty, warmth, the sheer sensuous pleasure of convalescence. Lying in the sun in my garden for days on end was not something I had had time to do before... closeness between Paul and me was much heightened and very tender... I wondered whether the shock had made me mad, I felt so alive, so happy and so self-conscious. Sometimes it was intoxicating like being reborn with a new awareness. Everyday sensations, the sun on my arms, listening to a favourite piece of music, were more intense than they had ever been before. I just wanted to keep the moment. The future was irrelevant... I was aware for the first time how fragile life was, I might lose all this.

Anne describes a shift here through her knowing how vulnerable life is, from living towards the future, to living in the present 'now', and only having concern for the 'now'.

Swan (1996) also writes about her experience:

Was like reconnecting with an old life of mine, when I was free and creative and happy. I felt a resurgence of confidence and ability and insight about where this long hard journey is leading me. Closer to truth and freedom within myself.

Swan describes of a feeling of finding herself which would imply that she had lost touch with her own self prior to her diagnosis. What is the freedom Rebecca is describing? Is it the freedom from living without the fear of death? Is death, although hidden, always underlying our thoughts and ever-present in one's life anyway? Is this fear of death the motivational force in how one conducts one's life, or, is it simply the

no longer taking life for granted?

Contrary to the idea of passing through one's fear of death and thus growing, Calhoun and Tedeschi (1998) state that associations between perceived benefits (Post Traumatic Growth) and adjustment could be because of enhanced functioning, meaning-making, or people re-evaluating the experience through altering their perceived value and meaningfulness of the event itself over time. Growth may have also occurred in people's resources, which allow the person to remain relatively stable when facing future difficulties (Calhoun & Tedeschi, 1998).

What we have then is that many people after adjusting to their cancer, report feeling more confident, freer within themselves, more patient and caring as they no longer have a sense of time rushing by. The answer to why this is could be because they have overcome their fear of death, or, because of improved coping mechanisms, personal resources, and enhanced functioning and meaning making processes.

In favour of facing death Adams (2000) writes, death gives our lives the urgency and motivation to act. He states: "Without death we'd all be slob." He goes on to say that instead of being afraid of death we should use death as a means of intensifying our lives. Our society conceals death and cancer from people, hoping not to upset and disturb them with their situational reality. Let us turn to the literature that discusses the effects of disclosing and shedding light upon what it is we fear in cancer.

Decreasing the fear of the unknown

The person faces life now without the neurotic shield that hides away the truth. This takes extreme courage to stand tall as oneself, defenceless in nature. (Becker, 1973, p. 56)

Educating and having people understand the disease mechanisms can help to demystify cancer (Burton & Watson, 1998). It has been shown that the concealment and control of information has not maintained a hopeful attitude for patients and has lead to increased anxiety due probably to a decreased feeling of control and an increased feeling of helplessness (Sardell & Trierweiler, 1993). Good and full

information may help to provide the person with emotional support and help to provide a sound basis to their psychological adjustment to having cancer, thus reducing psychological morbidity, enhancing hopefulness and improving treatment compliance. Good and full information may also help the patient feel supported and able to take control of their care. They are more likely to feel they are working together in partnership with their health-care providers. Trust is more easily obtained when they feel that health professionals are working with them and not following their own agendas (Loge, Kaasa & Hytten, 1997).

People who feel well informed about their diagnosis and treatment have been shown to experience less anxiety and depression than those who felt poorly informed (Brennan, 2001). The literature gives some foundation that people within society should be more informed about cancer in general, then perhaps they might be better prepared for when they are told they have cancer.

Conclusion

Literature seeking to understand the personal journey involved with having a life-threatening form of cancer has only been undertaken in fairly recent times. Authors working in the field of psychology have only begun looking to understand the person's psychological journey in the last 20 years. In brief what they appear to have uncovered about the journey to date is that the person is led to believe through natural instincts, or through society's construction of reality, that they are immune from cancer and death. Either way the person is ill prepared for cancer, due mainly to the illusion created within them and within society as a whole. The diagnosis of cancer soon destroys this illusion for them and for a time they are in a state of shock when they must face their fear of death in order to go on and grow through this journey. The person, with the help of others, finds hope within their situation. They look for positive aspects within their experience in order to find meaning. Over time and in mental communication with others, the person comes to a new understanding of themselves and of their world. Their new understanding is not always positive, as they must learn to live with uncertainty, but for many the destination of this journey is seen

as a positive one. In what at first appeared as total despair, they find a new strength in who they are. They no longer live so much directed toward a future time, but live in the 'now' of life. Because of this they feel less rushed and have a sense of more time. They find they are more patient in matters, and more caring in attitude to other beings. This shift can be attributed to overcoming the fear of death or to a cognitive development through the journey of overcoming the cancer, or both.

The evidence is strongly presented in the literature that most people do find a sense of growth within the experience and do feel better within themselves because of the experience. It is not well understood if this growth is due to overcoming one's fear of death, or due to some form of cognitive growth within the person that comes from having gone through this form of experience. The person's perspective of time has changed from something that is always illusive to something that is present in the 'now'. The person would appear to learn from the experience as revealed in the literature, that he/she lives now and not in a future time.

The growth that people report and the feeling of greater confidence and security within one's own being must bring into question society's turning away from all things leading to death including its current practice of ageism. The largest and most glaring gap in the literature is the lack of investigation into explaining why people feel better about who they themselves are once they adjust to having cancer and why it is they feel they have more time in their daily lives. People interviewed within the literature have been rarely asked why it is they may have reached this positive perspective on life, more so than before having cancer. Also the idea of educating the general public to a greater degree about cancer in order to overcome their fear of cancer and perhaps death has not been mentioned in the literature. Let us now move on from the literature and firstly examine what Heidegger has to say about this topic, before looking to the data coming from participants within this study.

Chapter Three

Part One: Methodology Heideggerian Hermeneutic Phenomenology

The evasion of death which covers over, dominates “everydayness”... ‘They’ makes sure of a constant tranquillization about death. But basically this tranquillisation is not only for the “dying person”, but just as much for those who are comforting him. (Heidegger, 1926/1996, p. 234)

The philosophy underpinning this research project will be Heideggerian hermeneutic phenomenology. The study asks what it is like to be the person involved in the experience of receiving the cancer diagnosis. Hermeneutics according to Leonard (1989) is the method for studying human beings that stems from the Heideggerian view of the person. Hermeneutics stems from the Greek word *hermeneuin*, meaning to interpret (Grondin, 1995) and flows out and is consistent with the Heideggerian view of person (Leonard, 1994).

In using Heideggerian hermeneutics, one attempts to identify and remove dominating traditions within cultures that cover over and hide one’s self-awareness of one’s own being within a phenomenon (Grondin, 1995). In this study I have looked to remove from the experience of being diagnosed with cancer those things which hide from us the real human being within. The things like our own defence mechanisms, such as fear, learnt behaviour and pre-assumed opinions; the cultural and institutional accepted ways of processing and dealing with matters and the taboos and prejudices that are in-built within these human structures that hide our own being-in-existence from us. I have attempted to see past all these layers of taken-for-granted human traditions in order to understand the person within. In looking for what lies covered over, I am looking for more than just a phenomenological description of the experience, I’m also trying to interpret human meaning and significance within the person’s experience.

According to (Heidegger, 1926/1996) we can be so embedded within the social and cultural

practices, which we do not see in our taken-for-granted acceptance of these constructed human structures, that we lose sight of who and what we are as a being that lives and dies. That is as a being that is not permanent within what appears to us as a permanent society in which we hold some sort of permanence ourselves.

I myself am embedded in the same cultural world. In the process of 'peeling back the layers' during the research process I also went through a process of learning, in the seeing of these layers of human structure, before I was able to look beyond them with some clarity to the next layer that was hidden beneath. I will discuss my own realizations later in the discussion chapter.

Moving on, Heidegger looked to the ontological (what is our perception of reality based upon) question of what it means to be a human being and to what being means to that person while being (Leonard, 1989). Heidegger used the word 'Dasein' to symbolise the understanding of what it is to be there in the activity of being (Leonard, 1989). Dasein is not a person, but the being-there in the situation knowing of the person.

The Heideggerian person

When something at hand is missing or threatens in our minds to be missing, whose everyday presence was so much a matter of course [our lives] that we never paid attention to it. Circumspection notes the emptiness and now sees for the first time what the missing thing was at hand for and was with. (Heidegger, 1926/1996, p. 70)

Martin Heidegger (1889-1976) was a German philosopher who trained under Edmund Husserl (1859-1935) the so-called founder of modern phenomenology. Heidegger's view of the person differed from that of Husserl's, mainly in that Heidegger saw the person not as a separate subject apart from the other things that make up the world. He saw the person as an integral part of that world that could not be separated and taken out of the context of their world.

Human beings are thrown into the world. This means the world exists before the person is placed into it. This world is not just the person's physical environment that they find

themselves in. The world also consists of human structures and human given meanings. When we are born we are placed into a world of other people, who teach us their language, laws, morals, social structure, and our possibilities for being within human society. The person is taught and learns the practices and skills that are necessary for life within a human society and that society's culture. Because the world to the person's experience has always been, the person takes the world for granted and is unable to see how it influences their understanding. For the person the world just is.

Unlike Kant, whose Cartesian philosophy saw the person as originating first as the central unit having a consciousness (subject), then coming into contact with external separate objects and reflecting upon them in order to make sense of them, Heideggerian philosophy sees the person as a self-interpreting being who interprets their world as it appears and has meaning for them. Heideggerian philosophy sees both the world and the person as constructing and constituting each other. The world and person are interrelated and cannot be separated without causing change in the other. The person is shaped and formed by their world. The world is what gives the person significance and meaning in their life. If this world changes in some way to the understanding of the person then that person must change. The person in turn after changing to their now-changed world will reconstruct their world through realigning and readjusting the meaning and significance of that world to them. In this way the person reshapes their world in order to find purpose and further understanding for themselves. The person must always be studied in context with their world. Heidegger saw the person as a self-interpreting being involved and connected in the world by simply being. The person is involved in their world through intentional activities. Heidegger saw a person not as a Cartesian subject that passively processes sense impressions, but as an agent dealing with equipment in a skilful way (Guignon, 1993). The person learns how to navigate and get on in their world from within the perspective of their situation, and the needs this generates for them.

Other

Dasein is a with world - Being-in is being - with others.
(Heidegger, 1926/1996, p. 112)

The person is not an isolated subject in this world. The person carries out their activities

with and among others. People live in social systems that intersect with others. This social contact with others gives the person their possibilities (Gugnon, 1983). A person alone is incomplete. “ Being is only in the understanding of those entities to whose Being something like an understanding of Being belongs” (Heidegger, 1926/1996, p. 116). Heidegger means in this statement that it is important for a human being to be understood by one’s fellow beings because only in their own ‘being’ can they gain some understanding of the other. It is the interconnection with others that gives meaning and purpose to the person’s being. The human being is a social animal and part of the person’s being is the others in their life. It is this cultural and linguistic sharing with others that makes up a background of significance from which the person forms their own interpretation of the world (Leonard, 1989).

What is meaningful to the person is constituted and made possible by a shared language and history with others. The person’s shared language and history (culture) enables expression of communal ideas and interests. This forms a common ground that enables the person to communicate with others. This shared transpersonal meaning is the background the person is thrown into when they first become a human being (Guignon, 1993). It is what constitutes the human being as a person and that person’s understanding of their world.

How the person knows

If knowing “is” at all, it belongs solely to those beings which know... In that knowing belongs to these beings and not an external characteristic, it must be “inside” the being.
(Heidegger, 1926/1996, p. 56)

Benner and Wrubel (1989) describe several dimensions of human knowing. As well as conscious reflective knowing the person has an embodied intelligence. Embodied intelligence is what makes it possible for people to carry out their activities within the world. It is not the person’s theories and beliefs on how the world operates, but their ability to carry within their bodies a pre-reflective pre-learnt knowledge that helps them to navigate the world as they carry out their activities in the world. As babies people explore their world. They learn how to operate various parts of their body and to gain understandings through the activity of trial and error. As the person progresses in their

learning, the various skills and understandings they obtain become automatically held within by their bodies and are taken for granted in their availability in the everyday activities the person carries out. This leaves the person free to think and concentrate on other aspects of daily life with which they are not so familiar. Examples of the person forming automatically taken-for-granted understandings are our eventual automatic abilities to walk, eat and talk. The body itself eventually comes to know how to do these things in a world it has come to understand. If the person tries to consciously be aware of how they perform these skills as and when they carry them out, the body then becomes confused and awkward. It is this bodily retained knowledge and understanding that requires when functioning smoothly no further effort from the conscious self to carry out daily practices and skills that allows the person to function actively in their world. Over time the person acquires a culturally skilled habitual body (Benner & Wrubel, 1989).

Benner and Wrubel (1989) point out that in the world the person lives amongst many pre-established background meanings. The human person gives meaning to things based on what they are taught by others and their previous experience. Through their learning, the person arrives at various assumptions about themselves and their world. They give meaning to certain signs and symbols like the ones on this page. Certain faces and expressions portray meaning to the person. Certain events, like blue sky or dark cloud, give meaning to the person. Certain words such as cancer or pregnant have various background meanings for the person. These background meanings can differ from person to person dependent on their historical viewpoint, including past experiences. The understanding a person holds is constructed in this way and is deconstructed and reconstructed through these same influences.

The person also learns to care about the various things that make up their world, and through caring the person becomes engaged or emotionally attuned to that world (Benner & Wrubel, 1989). The person's attunement causes the person to find purpose, to make goals and enter commitments that shape their activities in the world. In caring the person is

motivated to carry out various actions within their world. Benner and Wrubel (1989) explain that the three dimensions of embodied knowing: embodied intelligence, background meaning, and caring, allow the person to act rapidly in a non-conscious way. Through embodied intelligence the person comes to know the familiar, the person recognizes it as their world. The world has meaning and significance for them. This allows the person to immediately grasp a situation, which in turn enables them to interact as beings in the world.

But the person's world can change. It is only in the changed context that the normally smoothly functioning unnoticed background meanings, habitual bodily understandings, and personal concerns are then noticed by the person, as they are no longer functional in coping with their changed world. The person must then take some time to reflect upon these changes, readjust to the changes, give new meaning and significance and acquire new skills in order to continue to navigate in their world (Benner & Wrubel, 1989).

Because all that the person interprets is dependent upon their personal historical perspective, all human knowledge is a matter of historical interpretation. Truth is unobtainable. There is no Archimedean point. Truth is a matter of perspective. All human knowledge about humanity emanates from persons having been or being already in the world, who seek to understand other persons who are already in the world (Leonard, 1989). The hermeneutic circle of knowledge is ongoing, always adding to existing knowledge in order to form the person's whole knowledge at that time. The process is never complete. As human beings are temporal, all human knowledge is temporal. Nothing can be encountered without being interpreted from the person's own temporal and historical background understanding. The mode of being of understanding, is itself temporary and ever-changing (Gadamer, 1960/1995).

Temporality in phenomenology means that the person is their past, present and future. Their past goes with them influencing their present and future. The future is what the person projects themselves towards in their activities. So the future influences our present. The

person's being in their world can only be of a temporary nature in time.

Time itself is what it is to the person involved in the being. Time is an activity of being. Without being there is no time. Time is not a sequence of measurable units waiting to be filled up. The being in time is constituted by temporality and must be studied in context of its past and expectant future (Leonard, 1989).

As the human being itself is temporal, the person in being is projected towards death. One day he or she will die and be no more. So time is finite. Thus the person, in their being, only has so many possibilities. The person's awareness that they will die, possibly at any moment, enables the person to realize that they need to get on and do the things that they want to do (Inwood, 1997).

The possibilities for the person in life depend on their situated freedom. The person is only as free as their situation in the world allows them to be. The person may constitute their world. But the world by its language, culture, history, purposes and values limits the person's freedom in being (Leonard, 1989). The person's situational freedom is not only limited by age, sex, class, financial resources, knowledge and skills, but also by a sense of belonging and being regulated by a concept for which Heidegger termed the 'they'.

The great "they"

It can only have lost itself and it can only have not yet gained itself because it is essentially possible as authentic, that is, it belongs to itself... Awareness of one's own death snatches one from the clutches of the 'they' as one must die on their own... This confers on Dasein a peculiar sort of freedom, freedom towards death.
(Heidegger, 1926/1996, p. 263-266)

Dasein loses touch with its true being by getting caught up in the everyday things of the world, such as work, careers, relationships and its social demands and expectations. This lostness to one's own being is termed inauthentic. The inauthentic being can easily fall prey

to the influence of 'they'. Heidegger (1926/1996) talks of the concept of 'they', which comes into play through cultural influences playing on a human instinct of feeling or desiring belonging to and being a part of others (a greater group). As the person is thrown into a culture of human structure and has always been in that culture to some degree, they form a sense of belonging through that culture. In this way the person assumes a feeling of not being alone and a sense of protection by being part of a larger entity. For the sake of this sense of belonging and safety the person gives up much of their own free will, in order to conform and be accepted into the greater 'they' group. The greater 'they' constructs its own limited and restricted reality and in order to protect this world limits the thoughts and actions of individuals. The 'they' can feel threatened by original thought, or thoughts outside their limited established parameters. So members of the greater 'they' group are limited in how they can conduct themselves. The person takes on the mantle of the 'they' world, losing sight of their own being, losing the courage and confidence to be themselves.

The 'they' shield the person from their fear of death by pretending that it will never happen to 'myself'. One learns to believe that death only occurs to others, but will never occur to oneself. For the opium effect of this lie the 'they' gains the person's allegiance.

In facing death the person sees his or her own being for what it is. Heidegger (1926/1996) explains that when something is always to hand, it is only when missing, or threatens to be missing, that we see it for itself. The person through the possibility of his or her own death sees their own being, and is immediately freed from the culturally enforced 'they' world (Inwood, 1997). Heidegger (1926/1996, p.243) states that the knowing of the fact that one will die and thus eventually coming to terms with this fact "shatters all one's clinging to whatever existence one has reached". The person's 'they' humanly constructed world disintegrates, as they realize they too will die. The person in facing their fear of death is freed from the tyranny of the 'they'. The person in facing up to the reality of their death has an authentic shift. An authentic being is one's own being, who is their own master in control of one's own destiny within the limits of being a human being. The authentic being

is aware of why they behave in a certain way and of their own inner thoughts, as they are aware of being. The beings within an inauthentic state of being are not aware of why they behave and think in certain ways, as they are unaware of their being because they gave their awareness and decision-making options up for the numbing effect of the 'they' (Inwood, 1997). The inauthentic being now can reassure himself/herself that he/she is not responsible and there is nothing they can do anyway. In this way they can turn away from being. The person turns away from their own being through fear.

Fear and the unknown

But along with this tranquillization, which keeps Dasein away from its death, the 'they' at the same time justifies itself and makes itself respectable by silently ordering the way in which one is supposed to behave toward death in general. Even 'thinking about death' is regarded publicly as cowardly fear, a sign of insecurity on the part of Dasein and a dark flight from the world. (Heidegger, 1926/1996, p. 254-255)

Heidegger (1926/1996) explains it is not so much the thing itself we fear, but the unknown quantity of what it is we fear. Using this Heideggerian notion, it is not so much the cancer people fear but the unknown qualities perceived within having cancer. Have I, or have I not got cancer? Will I, or won't I get away with it? Will I be cured, or will it kill me? It is the unknown that is most fearful. It is our fear and the anxiety this creates that attunes us to this cancer. What we perceive as being harmful to us is what we attune to in its approaching near us. Through anxiety the thing we fear is revealed to us in the possibility of it not happening and passing us by. This does not lessen or extinguish our fear, but enhances it (Heidegger, 1926/1996). This means that by ignoring death/cancer and pretending and hoping it will not happen to one, only increase one's overall fear.

The Heideggerian hermeneutic phenomenology research method

The person involved with the being in the situation of having received the diagnosis of cancer is the focus of this study. The person in being is aware of being in the situation through thought. The being is aware of its being, but the human being can only gain an understanding of another person's being through communication and observation. One is unable to quantify this being-there through another's thoughts. A method that leads to insight and understanding to what it is that occurs in that person, while being situated in the experience under study, needs to be found.

In this study, I am looking for what lies covered over and hidden within the experience of being diagnosed with a life-threatening form of cancer, from the practice of nursing in New Zealand. I am looking for more than just a description of individual experience. I'm trying to interpret human meaning and significance within the participants' experiences in order to reproduce a written analysis of what the experience may involve and mean to the many people having to face the cancer diagnosis.

Not only does Heideggerian philosophy give structure to the concepts of the person and their world that allows the researcher an understanding of how the person and their world interrelate, but it also leads to a particular method of inquiry which enables greater understanding. Van Manen (1990) advises that the preferred methods of inquiry of human science involve description, interpretation, and self-reflection or critical analysis.

Some things to be mindful of in conducting Heideggerian hermeneutical research

Both Heidegger and Gadamer [1900-2002], a French hermeneutical philosopher who did much of his work based around language, gave emphasis to the idea that language (including signs and symbols) embodies the only medium from which we can use to communicate our thoughts within ourselves and to others (Heidegger, 1926/1996; Grondin, 1995). Language particularly sets up a pre-structured world for us that explains and forms a way of seeing and understanding (Leonard, 1994). Our personal and shared understandings are linguistically formed and ontologically come from our language (Grondin, 1995). But

much of what is human feeling and lived significance can not be fully captured in the words of language (van Manen, 1990). Our use of words and our understanding of these words and of our world come about from living within a shared world of language and culture. This shared understanding is created by and understood within the context of various social groups, practices, skills, histories and situated events (Benner, 1994).

Our shared world only forms part of our total world. We often lack the means as individuals to express much of our meaning. It is only in these shared parts, that are described as clearings by Benner (1994), that our shared meanings overlap, and become clear to another. The actual understanding of our meaning of what we are trying to express is less in the words that we manage to use than in our stumbling search for the right words that will capture and express fully what it is in our very souls (Grondin, 1995). The point of Heideggerian phenomenological research is to reach for a deeper, more accurate understanding of the meaning of what it is participants are trying to express.

Heidegger (1926/1996) warns that although things will show themselves in some way, the researcher will need to look deeper than mere semblance or appearance of the phenomena. He says: “They can show themselves as they are not in themselves” (Heidegger, 1926/1996, p. 25). A person can appear to be one thing when they are not that at all. An example of this would be a patient in hospital, although frightened and worried, appearing when people are present to be smiling and happy. They do this in order to give the impression that all is well so that they will not be abandoned, which might be the case if the people around them were made to feel uncomfortable through their own discomfort.

Heidegger (1996/1926, p. 25) also discusses appearance and talks of how things can appear in the body, “Symptoms are occurrences in the body that show themselves and in the self-showing as such ‘indicate’ something that does not show itself”. Shock is largely seen as a symptom reaction to the news of cancer and our general understanding ends there, as we believe people just get over their shock and return to a general state of normality. In general one does not look into the shock reaction and beyond it to see what is really behind this shock.

Keeping in mind these particular elements within Heideggerian philosophy, I set out to mine the human meaning within the experience of facing up to ‘myself’ having cancer. In part two I explain the process I went through in producing data chapters four, five and six.

Part two: Method

Introduction

As stated earlier in the introductory chapter, I needed to make explicit my own understandings, beliefs, biases, assumptions, presuppositions, and theories (van Manen, 1990). Through such awareness I can recognize to some degree and remove much of my own prejudices from within my analysis and reporting (van Manen, 1990). If I am as aware as possible and mindful of my own prejudices as I process the data, the data is then more likely to emerge in its own form and ‘speak for itself’ (Crotty, 1998). In the introductory chapter I attempted to disclose not only to the reader but also to my self my own biases and influences, in order for both parties to be aware of these and how they might influence the research process. Benner (1994) advises that the guiding ethos in this form of research is to be true to the text.

When disclosing the experience to the reader, it is appropriate according to van Manen (1990) to use the language of the inner world of being when attempting to convey the meaning of Dasein. The language of prose and music can often capture human meaning in a soulful way. The narrative form of story-telling can also disclose meaning in a way that can move our inner being. Narrative writing manages to capture and express this, but not so much in the stated words, as building a picture that can get to the point of what it is to be human in a way that a precise statement constructed from words is unable to convey. According to van Manen (1990) the aim of phenomenology is to replicate lived experience in an understandable, usually textual expression, capturing the essence within the experience. The reader can then grasp an understanding in a way that they had not previously thought of about the experience.

It is the purpose of hermeneutic phenomenology to describe and interpret the meaning and structures within a given phenomenon, to lay open the phenomenon for what it is. The researcher does not go on to attempt to explain or to theorize on what is uncovered within the research. Other methodologies would need to be employed for this purpose. The knowledge that comes from hermeneutic phenomenological research allows the practitioner to become more experienced with those involved in a certain phenomenon. One is then able to act more tactfully in practice (van Manen, 1990). This is my purpose in undertaking this research project, so that we the health professionals may act more tactfully and effectively in practice.

The process

As stated earlier, the question I am asking is, what is it the person being diagnosed as having cancer goes through in the initial period after being told that they have a life-threatening form of cancer? I have explained the Heideggerian view of the person and the philosophical underpinnings of Heideggerian hermeneutic phenomenology. I feel strongly that these Heideggerian notions give a very sound basis of understanding from which to explore the topic under study. I needed a research method that stayed true to the Heideggerian notions of the person on which to base my own method of inquiry and analysis. I chose van Manen's (1990) six-step method as it was designed to reach deeply into the inner person involved within a particular human experience, to bring out and describe the meanings and structures within that lived experience; to find out what it is to be human in the situation of being diagnosed with cancer.

In conducting phenomenological research, according to van Manen (1990), one does not rigidly follow a predetermined set of fixed procedures and techniques, because one must employ whatever methods that allow one to get as close to "the thing itself" as possible, one still needs a framework through which to approach the study. Van Manen (1990) also explains that in doing phenomenological research one borrows the experience of others through their reflection of that experience when they convey that experience to the researcher. Although human life is complex and often unique to the individual, one can

make one's own sense, upon reflection of the conveyed experience of another, about what it means to be there.

van Manen's six-step method

Step1. Turning to the phenomenon which seriously interests us and commits us to the world

I gave my reasons for choosing this topic earlier in chapter one. In order to begin my investigation into the being-there and receiving a life-threatening cancer diagnosis, I needed to come up with a design for the study and gain the necessary ethical approvals and permission to access the people that would provide me with the type of data I was looking for.

Ethical approval

Ethical applications were concurrently sought from Auckland Healthcare and the Auckland Ethics Committees of the Ministry of Health in New Zealand. Also subject to these two bodies' approvals, ethical approval was sought from the Auckland University of Technology Ethics committee. The application was approved in September 2001 after having gained an additional approval from the Maori Research Review Committee for the Auckland District Health Board. The basis of the ethical approval was to ensure that participants and their interests were totally protected in the course of the research process. In order to protect the participants within the research project all names mentioned within this study are not the real names of those involved.

Selection of participants

In discussion with my two supervisors it was decided that the stories of six-to-eight participants should provide a good coverage of the main elements involved in the initial period of the experience of being diagnosed with cancer without swamping the researcher with too much data to have to analyse. Ethical approval was gained for eight participants to take part in this study. The eight participants were sought from within the haematology department in which I worked. Staff recommendations of patients from that hospital's

oncology department were also sought, but no recommendations were forthcoming. Staff within the haematology department were informed of my proposed study and asked to nominate any patients they thought might be suitable and interested in being involved in the study. The staff did not know who had been finally approached or selected. The participants' identities are only known to myself.

Invitations were sent out at various intervals over a four-month period, in a letter-form, explaining who I was, the purpose of the study, and the expected participant involvement of one tape-recorded interview with myself of approximately one to one and a half hours in duration. Participants were chosen on the criteria that they had been diagnosed with a life-threatening form of cancer, were over the age of 20 and under the age of 70 years, and were able to and interested in articulating their experience. The age criteria was set because I thought that a person younger than 20 would have possibly a different perspective on the experience to that of an adult and also that an elderly person may be more accepting of the diagnosis, having possibly accomplished much of what they had hoped in life.

Invitations concluded for persons interested in participating in the study to phone me to answer any questions that they might have. The response to the invitations was positive, with ten out of the fifteen participants sort, contacting me and showing an interest. From within these ten people, eight returned written consents to participate within the study.

These eight participants within this study comprise three men, named for the study as, John, Joe and Jack, and five women called, Jill, Jenny, Jane, Trudy and June. Participants had received their diagnosis of cancer within the time frame of six months to two years at the time of their interviews. All are from an urban area with their ages ranging from 25 to 60 years of age. Seven are of mainly European descent and one is of mainly Maori descent. I have turned to these eight participants in order to seek the knowledge and understanding they hold regarding being diagnosed with cancer and the effect this had on them.

The participants told me many things within the stories of their individual experiences. At first the focus of this study was not as clear to me as it has now been presented. I needed to focus on the human being 'being' within the experience of realising that I 'myself' have cancer. I wished to extend my understanding of the person 'within' having to face up to having cancer. I wished to understand what it was they went through in facing up to this

element of human life. I did not wish to know about medical treatments and the effects of these treatments. I wanted to understand and reveal the effect upon the person of knowing that oneself has cancer and how this may change the person's world.

Step 2. Investigating experience as we live it rather than as we conceptualise it

According to van Manen (1990) in step two, the researcher investigates what it is to actually be in and live the experience, looking for the various elements involved with being in the experience. One explores the experience in its fullness and attempts to uncover all aspects, especially those that are hidden from us so that new understandings might be generated.

Prior to beginning my interviews and while waiting for the necessary ethical approvals I had undertaken a preliminary literature review. I had formed an idea from the literature I had read what it was that might come out from within my own data collection.

I began by conducting, firstly, four tape-recorded interviews, with four of the participants, John, Joe, Jack, and then Jill. All participants were asked how the diagnosis of cancer had affected them in that initial period, specifically their thoughts and feelings they had experienced at the time. These interviews were spaced approximately two weeks apart in order for me to gain some understanding from the data before undertaking the next interview. This enabled me to obtain a grasp of each individual story before they became infolded and fused with the stories of others. The tape recordings were then given to an experienced research typist (after having signed a confidentiality document) I had sourced through my supervisor. On the return of the tapes, together with the full transcripts, I began to read fully several times what had been said. I would then edit out what did not specifically pertain to the focus of this study. The tape recordings captured the interviews well and only on two occasions have I used notes I had made of matters that were mentioned before or after taping. These two occasions have been mentioned in the data analysis chapters (4 & 5). I found the initial transcripts difficult and time consuming to analyze because initially I did not know what I was looking for. Eventually certain elements began to come out from within each person's story. Each interview transcript became easier to analyze than those preceding as I now began to understand the story of being diagnosed with cancer for myself.

Step3. Reflecting on the essential themes which characterize the phenomenon

At this stage according to van Manen (1990), the researcher looks to find distinctions between what appears to be involved within the phenomena and the actual essential primordial essence of the phenomena. I needed to make a distinction between what is influenced by popular culture, by tradition, by our attitude to everyday life, and what is essential to the experience regardless of these influences. One peels back these layers of overlying traditions and preconceptions to find the naked experience for what it is itself.

Certain elements would begin to show themselves, and any new elements quickly stood out. Each story was crafted to describe the essential elements pertaining to the focus of the study. I organized each edited transcript into themes, placing what the participants had stated under these various themes. I also separately added my own thoughts under theme headings as I gained an understanding of what was being said. After various discussions with my supervisors it was decided to complete eight transcribed interviews in order to gain a good grasp of the diagnosis experience and its effect on the person.

Step 4. Describing the phenomenon through the art of writing and rewriting

Van Manen (1990) writes that in step 4 the researcher is trying to clarify the essence within the phenomena, so one must be in a state of thoughtfulness towards the phenomena when writing. One writes down what it is one understands, and in this process one generates further thoughts, when focusing on explanations of the phenomena under study, prompting one to rewrite the new and more precise understanding.

Once all eight transcripts had been completed and I had completed the process of placing significant statements under the various themes that arose from the data itself, I began to write what it was I thought each person was saying. Often I would look beyond the words said, examining the persons meaning in context. Comparing this to my understanding of the Heideggerian person and to what the others had been saying on the same topic. I had also been reading around the various themes coming from the data at this time.

Often, after revisiting what it was I had attempted to write about the meaning within participants' statements, I would see what was being expressed in a new light and need to rewrite their meaning afresh. In time the meaning within the selected statements of participants felt clear and I no longer felt it necessary to make any further alterations. In 'deriving narrative from transcripts,' I followed Caelli's (2001) advice in using the participant's own words as far as possible. The statements that have been presented within the data are quotes using the participants' own words.

Step 5. Maintaining a strong and oriented pedagogical relation to the phenomenon

Van Manen (1990) advises that the researcher must keep to the question they are searching to answer and not get side-tracked. The phenomenon is to speak for itself and not to be covered over with my own ideas, or the ideas of others.

In consultation with my supervisors I found that I sometimes read too much into what a participant had said. The interpretation was influenced by my own theories or prejudices and thus I would need to go back and reappraise what it was the person was trying to convey in their statement. At other times I had not explored what was being stated fully enough. Eventually my supervisors and I felt that the meaning behind the data had been revealed, while recognizing that the quest never comes to an end.

Step 6. Balancing the research context by considering parts and whole

Van Manen (1990) advises the researcher to compare the various parts to the whole in order to gauge their overall significance to the final work. Then the researcher can allocate the writing space given to the parts in relationship to their significance to the overall study.

All the separate participant stories at this stage had been edited down to their significant statements that gave me some insight into their experience. When all eight transcripts had been edited and grouped into various themes I began the process of putting together all these eight stories into one story that I hoped would reveal the being of receiving the cancer diagnosis for the reader.

At this stage I placed the most significant, or the statements that appeared to capture what was being said, under the various themes, but this time within one story. In looking at the one whole story I was able to recognize the significance of each part in the overall experience. I could also see from having a picture of the whole, parts that could then be further edited, as they did not give any further insight into the experience than what had already been said. A journey began to appear beginning from the moment that the participant had been told they had cancer, to a time when the participants felt comfortable with their understanding of themselves having cancer. I then looked through the individual transcripts of each participant, to see if I could find showings of the emerging themes within their stories to clarify this journey for me.

Eventually I felt I had captured a deep sense of what appeared to be of significance to the person involved within the experience. I then began the process of giving the writing shape, maintaining a balanced structure within the overall presentation.

Much of what was revealed within my data I had not found in my initial search of the literature. So, as various elements showed themselves to me, I would look to the literature to see what had been written around this topic. Some of my reading around these topics would have influenced my understanding and interpretations. My approach has been first to find the element within the data, then go and try to find what had been written about it, rather than reading about it and then trying to find it within the data. I tried to allow the data to at first speak for itself and to then try and uncover the elements within the data. Turning to the literature was helpful in giving me understanding and confidence in looking even further into the experience. As I delved between my own data and that of the literature I felt I was peeling back the various layers that had covered much of the person's experience. This uncovering enabled me to form a clearer picture of the phenomenon. Often the various insights gained of the various parts would lead to a deeper and greater understanding of the overall experience.

Security of data and further safeguards to participant identity

Except for my first interview with John, participants' own names were not used during the taped interviews. All participants were given their pseudonyms to be used within the interview itself. After John's interview, I had edited John's real name from the tape, by

overdubbing the tape with his pseudonym 'John' prior to handing the tapes on for typing. The identities of the participants within this research project are known only to myself. The original tape recordings of participant interviews have been kept in a locked cabinet and will be destroyed upon the final marking of this thesis. The transcripts will be stored securely for 10 years as required by the Ethics Committees.

Rigour

Koch and Harrington (1998) argue that trying to apply the evaluation criteria from one paradigm of inquiry to another is inappropriate. In doing phenomenological research, one has the understanding that we all are the makers of our own interpretations based on our personal standing in the world (Walters, 1994). It is impossible to be totally objective or to generalise findings as the interpretation of data is always dependent upon the perspective of the interpreter of that data. I, the researcher, can only try through my best mindful endeavours to present data in an open presentation form where the reader can look to the data themselves and to my background and interpretation so that they can form for themselves their own interpretations of what it is that is being expressed.

The analysis should be presented in a way that the reader is able to evaluate the quality of the analysis, to see if the data could perhaps have other interpretations to those that I have presented. Koch and Harrington (1998) suggest that evaluation criteria can be generated and shown within the research product itself, by way of detailed and contextual writing and a reflexive account of the actual research process.

In the research process I used tape-recorded interviews that were directly transcribed, then checked myself to ensure the verbal accuracy of the data. The data is presented in the form of a selection of participants' own words (which was dependent on which participant I thought was saying it best) followed by my own interpretation of these words. This method provides the reader with a visible trail, by which they can follow my thoughts and my interpretations throughout their reading of the final thesis product.

Hermeneutic interpretation presupposes that as the researcher I hold prior understanding of the phenomena under study, because it is only possible to interpret something according to the interpreter's own lived experience of being in the world (Walters, 1994). The

participants are interpreting their own stories in their telling of them. I in turn have interpreted their individual stories, in order to create this representation of the inner person's diagnosis experience. Readers in turn will make their own interpretations from their perspectives. Guignon (1993) states that bringing crucial features of my own or participants' self-understanding to light can make my interpretations more insightful. I have included these crucial features of participants' or my own understandings within the data chapters. In order that the reader has some understanding of my own perspective, I have attempted to disclose my viewpoint in chapter one, when I was first setting out on this project and in chapter six when I discuss crucial features of participants' self-understanding and my own insights that came from within this project.

Kirk and Miller (1986, p. 20) define reliability as "the degree to which the finding is independent of accidental circumstances of the research." In order to minimize myself and my research process having any influence over the participants, or of my findings, I tried to follow Polkinghorne's (1989) advice of being mindful when carrying out ones interviews and of not influencing the participants in any way. To ensure this the participants were voluntarily selected, with the understanding that their decision to participate would have no consequences upon them. I wanted to hear their story about their cancer experience at a time and place of their choosing and from their own point of view. It was their point of view of the experience I wanted in order that I might gain further insight from listening to their perspective. What they told me remained confidential and an edited version of the material which I intended to use in the study was first sent out to them for confirmation of its accuracy and to allow any parts to be removed. Themes and conclusions arising from transcripts have been discussed with supervisors with alternative possibilities being recognized and explored in order to ensure congruence. The overall structural description of the experience of being diagnosed with cancer, as presented in chapters four, five and six, I believe will hold in general for most people experiencing this phenomenon. I also found that many of the findings within my own data fitted with other findings or thoughts given in the literature.

Summary

Through using a method based on Heideggerian hermeneutic phenomenology, I hope that I have achieved an accurate re-representation of the effect upon the person having to face up to the diagnosis of a life-threatening form of cancer. This methodology has enabled me to look deeply into my own being, so that I could more fully understand the being within the experience of being diagnosed with cancer. In approaching the data from a Heideggerian perspective of the person, I was able to understand what elements constitute the person and how the cancer diagnosis can immediately separate the person from their world. The data presented in chapters four, five and six enables the reader to follow the effect that this diagnosis has upon the person from the perspective of being there.

Chapter Four

Meaning and its relation to the person

For life is at the start chaos in which one is lost. The individual suspects this, but he is frightened at finding himself face to face with this terrible reality, and tries to cover it over with a curtain of fantasy, where everything is clear. It does not worry him that his “ideas” are not true; he uses them as trenches for the defense of his existence, as scarecrows to frighten away reality. (Jose Ortega Y Gasset in Becker, 1973, p.47)

Introduction

When a person thinks to themselves, ‘I am really going to die’, a lot of things change in them and in their world. As this research project follows the journey of being diagnosed with cancer from the moment of receiving the diagnosis up until a period of approximately three months later, it tries to give light to what it is cancer means to the person and to focus on participants’ experiences when told that they have cancer. Many participants within the project talk of going into a state of shock. The project tries to understand not only why participants are shocked, but also how they overcome their shock. The data reveals the journey they go through in order to find a way out of their shocked state and what the overall effect of having cancer has had on their perspective of themselves and their life.

In this chapter the participants’ data is first presented and then followed by my interpretation, exploring within the early period of the cancer journey the following parts: the meaning of cancer to the person; the realisation that one has cancer; the shock of understanding that one is not immortal; the uncertainty created in realising one’s own mortality; the initial effect of understanding that one is not immortal; the contribution of fear within the experience; the silence placed upon cancer; and initially facing up to the new reality. Chapter five will cover the adjustment phase, and chapter six the new found freedom and understandings reached by participants after a period of time.

The cancer meaning

I suppose it was just the shock of waking up to the fact that no matter what sort of life you have, there's always the catch at the end of it. (Sargeson, 1964, p. 118)

To begin this journey I will first look at what the diagnosis of cancer means to the participants in this story. Joe explains: *“I think people are in the dark a lot about cancer. They just see it as basically the passage to death... I felt that way myself.”* Joe in this statement reveals that he originally felt his cancer diagnosis to be a form of death sentence. He also reveals he has learnt within his own experience that cancer for him does not necessarily mean death. What has occurred in Joe's experience since he was at first diagnosed to cause this change within his perspective about the meaning of cancer?

Prior to being diagnosed, most participants had little experience with cancer. They thought very little, if anything, about cancer. When the participants were told they had cancer, the effect upon them was overwhelming and powerful. The participants have their own understanding of themselves and their world. They bring into the diagnosis experience their previous knowledge, coping methods, cultural background and social networks. Not only do they bring their past experiences, but also their future vision of themselves. According to Heidegger (1926/1996) the human being in their approach to day-to-day living projects himself/herself towards future life. The human being in their present time of being looks from his/her past and on into his/her future. Present, past and future are not separate time periods but flow through the person and are connected in the present that the person is then living. Joe in his statement about perceiving cancer as ‘the passage to death’ had established the overall picture of what he understood cancer to be and how he believed most people saw cancer. His own diagnosis has reshaped his understanding.

Jack describes what was in his mind on receiving the diagnosis of cancer: *“Cancer portrayed a horrible lingering death...He said you have got cancer, you have got two years to live.”* For Jack cancer was not only a death sentence, but also a sentence of a slow, tortuous, debilitating, undignified ending to his life. The news that he had

cancer was shockingly bad and totally black.

The meaning of cancer for Jill was based strongly on the experience she had with her father:

I saw my father really badly off from cancer, and going from a big healthy man to skin and bones and dying a very painful death after weeks in hospital... obviously I thought I was going to die, between life and death you know, as I said my only experience had been seeing my father go... In a way I think the scary part is thinking that you are going to die... I think that is what puts you into shock, because I think everyone at that stage thinks they are going to die, or they feel strongly if they don't admit it, that they could die, underneath...

Her father's illness and death had been a nightmare situation for her. Cancer had also meant to her not only death, but also similar to Jack, a slow painful and debilitating death. Jill had been very ill when she received her diagnosis. She felt at the time as if she was already dying. Cancer for her was confirmation that she was dying. She found the concept of her own death to be frightening in its possibility, which scared her into a state of mind-numbing shock. The shock was caused by the realisation that one can and does die. As Jill realised the full extent of what her own death would mean to her she went into shock.

The above statements reveal cancer to have a strong association with death. For some participants cancer was more than death because it brought to mind images of a tortuous undignified journey ending eventually in death. This association with death had been established through participants' previous associations with the word cancer. All participants, except for John, had previous experiences where they had known people close to them who had died of cancer. These previous negative experiences of cancer would have reinforced for them cancer's strong association with death. We all learn through our experiences (Heidegger, 1926/1996).

John was the one participant who had experienced positive outcomes from his past experiences with cancer:

My previous experience with cancer had been with two people who had been closest to me. My Dad had a scare of colon cancer with polyps, and they took them out and everything is okay. So it was a bit of a scare.

My father-in-law had bowel cancer and he apparently had symptoms of bleeding in his stools and stuff for months prior. He was just so lucky it was all contained, and they surgically removed it. He had a bit of a thing, they took something out and reconnected for a while, while he healed, and connected back. But he doesn't have to have a permanent colostomy and he is fine and everything is working well.

John's father and uncle both had brushes with cancer and had the cancers successfully surgically removed without any life-altering complications following their initial recovery. When John had been initially diagnosed he had not been overly anxious as he had an underlying faith that the cancer would be just surgically removed and that would be the end of that. Unfortunately this is not the way things proceeded in John's case:

The CAT scan showed that I had several small tumors. That had more of an effect on me psychologically and was more stressful than the original diagnosis. I guess because I knew it had spread... It knocked me for a bit of a six... My mortality was just something I just really did not think about before. I thought if I lived right I would make eighty years of life minimum. But all of a sudden I found I could go at any time... It puts things like your mortality into perspective, and in some ways I would rather have this happen to me and have some lead-in time and some time to have that light bulb go on in terms of your mortality. So you can do something about it.

The realisation that the cancer had spread within his body to a point where it could not be surgically removed had meant that John could die. He was immediately pulled up by this disclosure. John was made to face the possibility of his own demise in the

immediate future. He suddenly realised he could die at any moment in life. Not just in some far-off distant time that did not need to concern him in his present life, but soon.

John's metaphor of 'the light bulb going on' in terms of one's mortality reveals that not only that John appear to realise that he would actually die at some time in his life, but that the possibility of death was an ever-present part of life which had become overlooked (covered over) in his everyday understanding of himself and the way in which he approached life. John had what Heidegger (1926/1996) termed 'a shift towards authentic living'. That is, living life in the face of death and the realization that one's own self is a temporary being within life. John was appreciative of this shift in his perspective after he came to terms with the initial shock. He had appreciated being reminded that his life was not something that was to be taken for granted as just being always there, that his life and the things of his life were fragile and precious. It was a reminder for him to spend the time he had available on the things that were important to him. He now knows, by having a more personal understanding through his cancer that life is not for ever. Through having this new knowledge, he does not wish to be distracted from his own self in life.

In short, how the participants have actually viewed the meaning of cancer has been largely influenced by their previous experiences of cancer. For all those discussed in this section, except for John, the diagnosis immediately meant death. John was the only participant whose previous contacts with cancer had not terminated in the death of the person who had the cancer. When John heard that his form of cancer could not be fixed quickly by surgery he also realised he was mortal and could die. The perceived meaning that the word cancer held for participants within this story was either the immediate realisation of the possibility of their own death, or, as in John's case, it eventually led on to the realisation of the possibility of his eventual death. This chapter will now discuss five elements that impact on the experience of realising that one's own self will die. The five elements are: the realising that one will die; living with uncertainty; entering a state of shock; fearing the unknown and finding a silence.

Realising one will die

The usual thought came to his aid that death had visited not him, but Ivan Ilyich, and that such a thing could not and should not happen to him. (Tolstoy, 1886, p. 228)

This research project has revealed that being diagnosed with cancer appears to bring home to participants the realisation of their own mortality. Through realising their mortality they also realise just how temporary life is. The realisation of one's own temporality (as defined in Chapter 3) in the world appears to come as a shock. The realisation that one will die and can die at any time would appear to require a great deal of adjustment. The diagnosis appears to consist of more information in its meaning than many of the participants could take in and fully comprehend in any one moment. Each participant expressed this in his or her own way.

Jill explains just how unprepared in her thinking she was for the possibility of having cancer:

I really went into shock, like this cannot be happening to me, this happens to other people... you never prepare yourself for you might get cancer. There is just no way. You know there is cancer in the world, and people have a great chance of getting it, but it is just one of those things that will never happen to you, and I think in a way I just cut off from it because I just went into total shock, and I was really scared. I was really scared.

Jill lived her life aware of the existence of tragedies in the world such as cancer. Cancer was something she heard about in her day-to-day life. Cancer was something she heard other people having, she never considered it possible for her to have cancer. It was not something she lived with as being a possibility for her own self. Jill for some reason felt safe from cancer. She just took it for granted that she was immune to cancer and would never have cancer. The realisation that she had cancer broke her 'bubble of invincibility'. The thought that she could die at any time came as a mind-

numbing shock to her. The sudden realisation of her vulnerability in life was frightening.

Why are participants shocked and why don't they expect to receive the diagnosis of cancer themselves when in New Zealand at the time of writing the annual death rate from cancer is 41% of all deaths and rising? It appears to be the realisation that one may actually die. But do not we live always with death as a real possibility for us all? When we are going along in the car, death is a real possibility. When sleeping in our home, death is a real possibility: fire, earthquake, bodily system failure, being murdered are always possibilities in our every-day lives. So why is the sudden realisation that one has cancer and that one might die such a shock to those who receive the diagnosis of cancer?

Jane gave me some insight into why she was so shocked when she received her diagnosis:

I thought I was invincible, so immediately I had a bombshell to realise that I was not invincible, and that I was mortal like everybody else, so the first few months were probably, actually completely traumatic, to the point that I cannot even remember them.

Jane in this statement reveals that she had an underlying assumption that she was immune to cancer/death, and that her life would proceed on in its course uninterrupted. As long as she lived to the rules and did not actively seek death, her life was lived without death being present as a possibility for her. She lived her life immune from death itself. She never, until the moment of her diagnosis, felt the threat of death upon her in life. Her diagnosis of cancer, with its implied meaning of death, had been a sudden awakening for Jane to the real possibility of death being able to occur at any time in her life. The diagnosis made her realise that she was the same type of being as the other beings of this world and that she too could die, just as they could and would eventually. The realisation that she can in fact die shattered her perspective of the world and herself in the world. The coming to terms with the possibility that she could and would eventually die captivated almost all of her attention to the extent that paradoxically she was unaware of blocking off the

realisation. Jane found the realisation that she can and will die so devastating to her person that she was hardly conscious of her life at that time. The reality of her own normality was difficult for her to come to terms with. It took Jane a few months to adjust to a new perspective on things.

Jenny also reveals just how covered over the possibility of her having cancer was for her. *“But no-one prepares you for it, I think that is probably biggest. I mean the biggest shock was that you just do not expect it to happen to you.”* Jenny, like all the participants in this study, was fully aware of cancer happening to others in her world, as she had had two cousins die from it. But despite vicariously experiencing this through her cousins she also found the news that she had cancer to be earth-shattering news.

What does Jenny mean by no one prepares you for it? She appears in her statement to mean that possibly our lives are constructed in such away that we live in a mode that shuts out the possibility of ourselves having cancer. Jill states this idea quite clearly when she says: *“This cannot be happening to me, this happens to other people.”* Jill also says how poorly we prepare ourselves for such possibilities in life. Does one live in denial of the possibility of cancer, or, death happening to one’s self or is there some other explanation for this? Jill does go on to say about cancer that: *“It is just one of those things that will never happen to you.”* Jill is shocked because she thought cancer would never happen to her. The reality of finding that she has cancer is a shock, as it was to all participants.

Jane sums up the assumption she held that her life was free from the threat of death as follows:

We all have parents who might pass away, we have grandparents who have probably died, we all know someone who has died of cancer, we all know people who have been really ill or specifically disabled for some reason, so it is not that far removed from us but again unless someone tells you, ‘you are threatened’, you take things for granted.

Jane explains that although death is all around us in life, we take the fact that we have a life and that our lives will continue on for granted. We live without realising that we ourselves can get cancer and die at any time. Jane's statement here about her perception of how people view the possibility of themselves contracting cancer is similar to that of Jill's. That is, until she was told she had cancer, cancer was not a perceived possibility for her or Jill in their lives. They approached their lives in a way that seemed to presume they were in some form of a special protective bubble of their own. They assumed that these things could not happen to them.

Joe reveals how he assumed that he was free of the threat of serious illness like cancer through being young and healthy. *"I did not think in my wildest dreams, being a fairly fit, healthy person of 35, that I would ever come down with something like this."*

Joe thought that by being young and living a healthy life style he would be protected from serious illness, including cancer. This was so far removed from his thinking it was not even something he could imagine happening to him. Youth and health had been assumed to be safeguards.

Heidegger (1926/1996) says that the human being has an attitude and a way of living with dying/cancer as something that happens to other people, but not to themselves, not until some far distant future time that does not concern them in their present. This expression of Heidegger's philosophy about our attitude in living towards death can be applied to the participants' attitude to their own possibility of contracting cancer.

Jenny stated: *"I know cancer is out there but I did not think I could get cancer... I used to think that cancer was something that happens to people who are horrible or real bad or something, but it doesn't, it happens to everybody."* It was only when Jenny was faced with the reality of herself having cancer that she really captured the essence of the possibility that we can all (meaning myself as well) get cancer. Until she was faced with the reality of having to face up to herself really having cancer, Jenny like other participants did not live with the possibility of having cancer. That cancer was something that happened to others appears to be an underlying construct that the participants held prior to their diagnosis. They believed themselves immune to the death and carnage that went on around them. It's like the attitude of people that overtake on the open road without the visibility of sufficient road to complete the

manoeuvre. They overtake with the attitude that a head-on collision won't happen to them. They feel protected somehow. They may possibly reason that a head-on collision at high speed would not happen to them because it has never happened to them. It is outside their personal experience just as cancer and death was outside the participants' personal experience prior to their being diagnosed.

The participants seemed to have had a similar attitude towards cancer/death. An attitude something like, I won't die or get cancer; it's never happened to me before, I'm bullet proof. They live with an underlying attitude that death might pass them by. 'They' may find a cure; perhaps 'they' will bring us back to life, as it is only a matter of time until 'they' find out how to. 'They' say 'they' can reconstruct the entire human being from just a genetic map from one body cell ('they' being Heidegger's concept of 'they' as discussed in Chapter 3). In our fear of death we seem to shut out the possibility of its being. Heidegger expresses this point as follows: "For the most part, everyday Da-sein covers over its own-most non relational possibility of being not-to-be-bypassed" (Heidegger, 1926/1996, p. 256-237) by death.

Jenny, who thought she could not get cancer prior to receiving her diagnosis, expresses the change in how she now lives with the concept of death. *"Death is part of your life because you know it is going to happen."* Death from the moment she was diagnosed became part of Jenny's everyday life. This is the real change that has occurred for Jenny and the other participants. The participants now live with death as an every-day-possibility. This realisation that death can happen at any time and will happen does not appear to come easy. It comes as a shock realisation that takes time for people to get used to.

In summarising the journey so far it seems to be the realisation that they could die that has shocked participants. Apparently they believed themselves protected from death and cancer somehow. The diagnosis burst this bubble for them. The bursting of this bubble came as a shocking realisation that they too were mortal. They were not prepared for being mortal. They needed time to adjust to the thought of living with the possibility of death in their lives. The realisation that one is mortal and can and will die also brings to light other matters that many of the participants previously took for

granted. One further thing the participants come to realise is that their future is not guaranteed.

Living with uncertainty

...what comes to mind immediately is how fast cancer alienates one from the usual routines and behavior... there is no pain, no dramatic change caused by this malignancy except in my mind. (Cornelius Ryan, in Holland & Lewis, 2000, p. 37)

A person is characterized by their past, present and future. Who the person is and how they live their lives now is strongly influenced by their past (including their past cultural history and the pasts of those who have had an effect on their understanding). Human beings come from out of their past through to the present and live into a future that they are always anticipating. When the person anticipates their future one always anticipates one's own possibilities within the context of the events in which one can and may be involved (Heidegger, 1926/1996). In other words human beings have a sort of map or idea of what their future might involve (Kohl, 1965). The person also holds an image of who they are in that future. The diagnosis of cancer threatens the person's anticipated future. Jane explains:

...and all of a sudden I couldn't look too far ahead, and I had to get well... my whole identity was threatened... but the first four weeks, even eight weeks... just in shock... just coming out of the numbness... and after that I could go beyond my family affairs, and do the celebrity walk around my work and catch up with people and start making decisions about the future.

The diagnosis of cancer not only threatened Jane's life, it also took away her vision of her future. Not only the potential time factor of her future, but who she saw herself being. She immediately went from Jane the confident person in her life role to Jane the person with cancer and all that entailed for her. It was a role that was unfamiliar and unpredictable for her. The shock of the effect of the diagnosis made Jane take refuge within the bounds of her immediate family. She took some eight weeks to

come to terms with this before she could begin thinking about her future in the wider world; re-meeting up with the people she worked with who now knew she had cancer.

Not only was the long-term future of participants threatened, their immediate future was abruptly changed from that which they had planned. June brings to light the abrupt change that occurred:

My daughter and I had planned a trip to Australia at Christmas time, and I said to my haematologist I have got a trip planned, I am going to Australia, and he said I was to cancel it. That was scary. He said you can take that trip in April or May after you have had all the treatment. Then six months seemed like an eternity... because I had six months of my life mapped out for me.

The feeling of control over and the ability to plan events in her own life were suddenly wrenched from June. Being informed that she had to cancel any plans she had made for herself over the next six months brought home to June just how serious her illness was. It brought home the effect it was going to have on her life. She was immediately thrown into a strange and scary world of the hospital and cancer treatment. The six months of proposed cancer treatment loomed up like a journey down a long, endlessly dark and gloomy tunnel, which she had already begun to enter. She seemed to feel kidnapped. She had no say in the direction of her life at that time.

Jenny talks of her uncertain future since her diagnosis:

I probably don't really talk about the future much. If somebody said to me about their retirement, and I probably wouldn't talk about that because I guess if I face reality I probably would not think I would be here.

It made me realise I have things to do... I realise how short life is... Everybody lives their life, you don't expect to know what you will die from, you just think you will die at eighty-five from old age if you are really good, whereas it puts a time limit on your life... you think there are still a lot of things I want to do in this life before I go anywhere

and that is the shock, because you want to think that you have quite a few years to do the things that you need to do, or things you want to do in life. And to be told there is a time limit.

Having received the diagnosis of cancer has caused Jenny to see the time frame of her life differently from how she had perceived it prior to her diagnosis. Before cancer, life was an almost endless time one had up until some mythical age of eighty-five. This age would have been difficult for Jenny to conceptualise and actually perceive for her own self to be. She has seen others as being old but has had no experience of being old herself. She has always been young in her experience. Suddenly it is not that strange old person that remains unknown to Jenny that is faced with death through cancer, but the Jenny she knows in the here and now. This comes with a shock as she wishes to think there is always time available to her to do the things she wishes to do. The realisation that time ahead of oneself is not guaranteed shatters Jenny's understanding of her world. Jenny is unsettled by this realisation that the time one has available can expire without warning. She did not receive the preparation she expected to have for that old stranger that she 'might' become in the far-off distant future, a future that might never come.

Jenny and Jill say that they were not prepared for anything like this to happen to them. Their lives were supposed to run their course into the realms of an expected ancient old age. Instead Jill and Jenny face their own mortality in the here and now. They find themselves experiencing what Heidegger (1926/1996) would describe as being exposed to the reality of their 'own most' being. That is, being a human being that is temporary in its being and not a constant thing in the sense of always being. The cancer diagnosis in itself does not place a time limit on Jenny and Jill's lives. It just brings home to them that their time in the world is limited. The participants all had a limit on their lives before because like for most of us they live in the hands of what Heidegger termed the 'they' and think 'they' thoughts. The participants appear to have forgotten the real possibility of dying in the living of their normal everyday lives. They were now denied the comfort of forgetting.

Jenny also found there were some positive aspects within the experience: *“That is probably when it hits home. You have got time to plan your funeral... a lot of people*

don't get to do that, whereas I have time to plan things. So it puts life in a bit more perspective." Jenny has no more time to plan her funeral than anyone else. We will all die one day just as Jenny will. The only difference is that the cancer diagnosis made her face up to the reality of her own mortality. She now lives with death as an ever-present possibility for herself in her life. All human beings are faced with death as an ever-present and eventually definite possibility. The time to plan our funerals is something that most of us have. The difference is that many people in New Zealand society live lives where death is either hidden or veiled from their everyday reality. This form of living without death being seen as a possibility within the living is what Heidegger (1926/1996) terms inauthentic. We live life fleeing from the possibility of death. We live life fleeing from our real 'own-most' understanding of our being in this world. We flee from the fact that we are beings that will die.

In realising that there is a good possibility that they could die from cancer the participants came to realise the future that they envisaged for themselves was threatened. Having one's future possibilities threatened seems to also threaten the participants' identity and bring them to wonder who they are. They realise that life is only for a limited period of time and that one day their life must come to its end. These are the factors that seem to add content and weight to the punch within the shock experienced by the participants. Let us now examine in more details the effect of the shock upon the person who has just received the diagnosis of cancer.

Being in shock

Pain can make a whole winter bright,
 Like fever, Force us to live deep and hard,
 Betrayal focus in peculiar light
 All we have ever dreamed or known or heard,
 And from great shocks we do recover.

May Sarton's poem, "Humpty Dumpty."(In Holland & Lewis, 2000, p. 42)

The intelligence within the human body still remains a mystery to science. It would appear that the body always has a purpose for its response to events of concern to it. Shock also would appear to have a specific functional purpose within the workings of

the human body. Participants hearing they have cancer and realising that they could die mention the shock of this revelation. Jane describes:

I was not flipping or freaking out but I had some sort of healthy veil over the time... I was just incredibly exhausted, not sleeping well, not eating well, not tasting things, being quite detached from the world. Not really understanding what was going on, or believing it but knowing it as well.

Here Jane is describing what the actual shock feeling and the effect of shock upon her person was like following her diagnosis of cancer. She held herself together and did not scream or go mad. But her thinking processes, her awareness had been dulled to some sort of trance-like state. Although she knew she had cancer, she felt she was not really all that involved with what was occurring in and around her life at that time. In this way Jane managed to cope with those initial days following the diagnosis.

Jill had been so ill when the doctors told her she had leukaemia:

I was sort of half-prepared when the doctor did come and say I have got some bad news, and I think because I was so sick... I found that incredibly hard to cope with in that first hour. All I wanted was someone then to make me feel a little bit better. I didn't think I could cope with all that information, and I just basically knew I was sick and that I could not cope with all that information. I think I asked the doctor to put me down... You are pleased to become aware that you need help because you have felt so ill for the two days before I went in. So number one you had that feeling that thank god you are getting some help, but it is almost like on the other hand that I really went into shock, like this cannot be happening to me, this happens to other people... in a way I just cut off from it because I just went into total shock.

Jill knew that something was seriously wrong, as she had been feeling so ill. The diagnosis of cancer was just all too difficult to cope with when feeling so ill. She looked for ways out of the situation. She needed someone to tell her it was going to be all right, to hold her and steady her from the effects of this news. She was just not ready for the information and was unable to adjust to the situation. She was pleased to know that they had found what it was that was wrong with her, but not cancer, anything but cancer. She just could not cope at this moment and needed to escape this situation somehow. Shock stepped in and rescued Jill from the full impact of the situation that she had not been prepared for. Through shock she managed to keep her distance from the full impact of the event.

Jill describes her emotions at this time as firstly being pleased that she was going to get help, as she had been so ill. She had found trying to cope with the illness over the previous few days very difficult. Now others knew of her difficulty and were going to help. Secondly, Jill went into what she describes as shock. She was extremely frightened by the news. So frightened that she felt this was not happening to her but to another person. She felt her body was cutting her off from the full impact of the news in this way. It was just too shocking for her to face it all in just one moment. So it was happening to this other person and Jill just happened to be there in that place passively observing the events around her.

That first hour was horrific for Jill as she describes:

It is like you are not living in a real world, it is like being transported almost out of your own life... You are taking in everything, listening and crying, but it is almost like it is not you, it is not your life, it is almost surreal in a way... I think at the time it is almost like you go into another plane because it is such a big thing and because you do not have the knowledge about it.

Jill found herself, as her self, to be only partially present in that diagnosis space at the time. The rest of her self-awareness had gone to someplace else. Where the rest of her inner self had gone for refuge Jill did not know. Jill did express the feeling that she could not be fully present at this time. She had gone into shock because she realised she

could die. Jill needed time to adjust to this new possibility in her life, the possibility of her own death. She herself explained it as: “*I think that is probably the body’s way of dealing with it.*” She saw the shock as her body’s way of protecting her from the full emotional impact of this news. She describes her experience of shock further:

But I felt those first two days it was not really me. I had heard all the information; I didn’t want to know about it really. I knew I did, I knew I had to deal with it, but I could not deal with it, I didn’t even want to know what they were going to do, just do it.

For the first two days Jill remained in a state of detachment from the world of the hospital that was going on around her. Jill was not ready to handle having cancer. At this point Jill remained in a state feeling outside of the situation going on around her and was not as yet prepared to fully participate. She was still assimilating the effect of being diagnosed with cancer. Jill still remained in shock. In this initial period Jill could not bring herself to fully face the situation and its implications upon her. She knew she needed help there and then and just wanted the health professionals to get on with it. Apparently she trusted them and had faith that they knew what to do. Just leave me to grieve and make some sense for myself is how she felt.

Jill tries to explain what it’s like being in that shocked time and space immediately following the diagnosis. She begins by describing the concept of time within the situation:

Oh it almost stopped, it was very weird. It was so strange. It is like you are not living in a real world, it is like being transported almost out of your own life. It is like, I don’t know how to explain it, it is not like being told something little, it is almost like it is another life; this is not happening to you, it is almost like a dream. I wonder if that is the body’s way, when you cannot understand something, or when it is such a big thing dealing with it, and it is almost like it is removed, like it is somebody else, it is strange, it is really really strange. There is horror, scare, relief, and it is just so much rolled into one that it is almost like it is not you. I cannot really explain it.

Jill described time at this period as if it was almost standing still. As if her body put time on hold so that it could put its damaged house back into some form of order. Jill feels she was placed partially in some other dimension while her body underwent its repair work. Her body needed its own time to adjust and come to terms with what was happening to her. Jill simply found all that was the cancer diagnosis to be so beyond her current understanding of herself, so beyond her control. It was all just too much to deal with.

Jill tries to explain further her thoughts and feelings during and immediately following the diagnosis.

It was very strange, a very strange feeling. Nothing like that I had experienced before. I am pretty good at dealing with things, but this was so beyond my control... it was almost like your body going into shock, and no it is not happening to me, it is someone else... I think it was probably the first two days, from the night you went in there, initially, you knew you were being, and it is just your mind swirling with all of this, and I said it doesn't matter Ronnie is writing it down. Ronnie my brother was asking the questions, and my mind was going tick, tick, tick. Is this me he is talking about, or not... I think about the second day, when I had been through just so many emotions that I just really felt that I was totally removed from it, it was not really me, and I didn't know if that was because I was so sick or because of what they had told me, I didn't know. So I think about the second day you realise, or when you are getting wheeled down to have your groshong² put in, it is me, and it is almost like you come back to within yourself then.

Jill's mind was racing with the effect of the cancer diagnosis. Things had gone so far beyond any possible concept of control that she had held previously. Her previous understandings did not reach this far. The understandings for which she had held up

² A groshong is a type of vascular access line used for administering chemotherapy.

until this time no longer fitted her situation. She needed to come to new understandings. She was so busy assimilating and trying to piece together what having cancer meant to her. Jill's mind had no spare capacity for anything else at this stage. She was relieved to have her brother with her at this time. She could rely on him to ensure that she would be looked after. This was such a relief. The support of her brother helped Jill to feel free to deal with her own emotional turmoil. The emotions that having cancer brought out from within her would not stop. Her emotions were pulling her this way and that. It was impossible for her to focus at this time. So strange was the effect that she wondered if it was real. It didn't seem to be real. She does not know if the feeling of being removed was because of the effect of the news or if she was just too sick to cope, or both. She thinks it was somewhere towards the second day when she had come sufficiently to terms with having cancer that she was able to face the full reality of it. Not only the reality of having cancer, but also of the things that went with having cancer. The situation of tubing being placed inside her chest and reaching into the vein that is just above her heart brought Jill back to the reality of cancer.

Cancer is a common occurrence for New Zealanders in today's society. Nevertheless, the participants in this story point out just how unprepared they were to have cancer. They were totally shocked by the news. It would appear to be this unpreparedness of the participants that contributes to the shock factor they experience. This research project will now turn to two possibilities that appear to be contributing factors to the shock of being told you have cancer. Firstly, I will discuss the participants' fear of the unknown qualities within cancer and, secondly, look to gain some understanding of the silence concerning cancer that the participants themselves have had to face.

Fearing the unknown

Such thoughts (about death) would only lead him into a state of depression, a thing that was to be avoided. (Tolstoy, 1886, p. 228)

Anxiety and fear go hand in hand and when you have one, the other is always present (Heidegger 1926/1996). Fear is intensified by anxiety. The unknown intensifies anxiety. Both fear and anxiety are something that no one enjoys and everyone tries to

avoid. It is not so much that humans fear the harm, it is what they do not know or understand that they find the most fearsome (Heidegger, 1926/1996). The exploration of the participants' fear of the unknown will commence with Jill's disclosure: *"I just cut off from it because I just went into total shock, and I was really scared. I was really scared. But I was scared of the treatment."* Not only had the realisation of her own mortality shocked Jill, but the little she knew about the treatment involved (chemotherapy) was enough to frighten her. The treatment was unknown to her; her life had suddenly changed. She now had cancer and was about to undergo chemotherapy. The effect of the proposed treatments upon her person was frightening in its unknown qualities. The final outcome of the treatment upon her, and on her cancer, remained unknown.

Jack describes: ... *"I felt after the diagnosis, I was losing control simply because I did not know what was going to happen."* Jack felt that he had control of himself and his day-to-day life as he lived into the future he perceived for himself. "You have cancer," he was told. This diagnosis shattered many of Jack's concepts and the assumptions he had about himself and his world. He was in a situation he had not prepared for. The world of having cancer was new to him. He did not know where to begin. He was no longer in control. Jack had been up to this time a person who had felt that he was always in control. *"I always had my days planned to what I was going to do."* Jack thought the cancer would take away his independence:

... I got some information from the hospital... it does affect your bones, your spine and with most people it is quite a debilitating disease... you will be bedridden quite quickly... When I read things like that it really did depress me... Every time I went to bed I just pictured myself lying in bed totally unable to feed, or get up, or go to the toilet, or do anything myself.

Jack had always been an independent person. He prided himself on his independence and his ability to get things done. Now he was faced with the vision of himself being bedridden and totally dependent on others. Jack found this vision too much to bear and was not going to allow himself to get into such a state. One way Jack could maintain control over his life would be to take that life when the time came. *"I was*

going to either buy a shotgun or... I would gas myself in the van". This was the only way that Jack could see to avoid the horrible life he had before him. This appeared to be his only option for controlling his situation.

Joe sums up the effect of having to face the unknown at the time of his diagnosis: *"At the time it was very scary because we did not know quite what was going on."* Joe is expressing his feeling of the fear attributed to what he did not know at the time. Joe had just been told he had cancer but he had not experienced cancer and the subsequent treatment of cancer before. Most of what this implied for him was unknown to him. It was the unknown factors that were so frightening. "What did this having cancer exactly involve? What am I in for? What are my chances?" These are likely to have been some of the many questions going on inside Joe's head.

Upon receiving the diagnosis of cancer the participants were brought face to face with the possibility of their death. But this possibility could not be pinned to a definite moment. It became unknown how long they would exactly live for. Exactly how they would live and cope with cancer was unknown. The treatment and its effect were also unknown. So much had suddenly changed, so much remained unknown. After being told of their cancer they were left in the dark with their personal thoughts regarding their own being. No preparation had been provided for this moment, no map or guide had been made available. The unknown was frightening and added to the shock of having cancer in its very unknowingness. The silence of cancer/death contributed to the extent of the unknowingness.

Being hidden within silence

He was tortured by this lie, tortured by no one's wanting to acknowledge the lie, by his knowing the truth and everyone else's knowing the truth, and yet pressing this lie upon him because of the horror of his position, forcing him to become a party to the lie. This lie, the lie forced upon him on the eve of his death, the lie degrading the solemn, awesome act of his dying to the level of their social calls. (Tolstoy, 1886, p. 264)

Cancer and especially death are a big part of life within New Zealand, the part that remains largely hidden. Joe gives some insight into the lack of information and

general discussion about cancer that still goes on in New Zealand today: *“I don’t know why it has to be kept like secret squirrel from people, a lot of the information about cancer. Not enough knowledge or whatever to the general public.”* Joe is expressing here the hiding over of cancer by New Zealand society in general. Cancer like death (with which it is strongly associated) is not widely put out there for discussion in the general public arena.

Jenny also reveals the silence of cancer:

Just knowing there is support would be really good, and that people talk about it. Whereas probably people don’t talk about it, and having somewhere to go where you can maybe talk to people about it. That would be really good... It is not just something to sweep under the carpet, it is there, and if you need to talk about it you talk about it.

Jenny thinks that knowing there is somewhere to speak freely about cancer would be helpful. Just to know you can openly talk about cancer without feeling uncomfortable about the subject. She has an underlying feeling that cancer is something most people don’t wish to talk about. They avoid the subject, hoping it will go away. Jenny believes cancer needs to be brought out into the open and be focused on and faced. She knows that it is real, can happen to anyone and that it will not go away. She knows that pretending cancer is not a real threat will not protect people from it.

Jill talked of her experience of finding it difficult for herself to bring the topic of death into conversation with people, although she felt the need to talk on the matter with someone.

I really felt that I was going to die at that stage, and I think I had private moments when I could not express it to my family or to any nurses or anything, that was how I felt... But I do not think I could express it to my family because they would think that I was dying... I did not feel I could talk to the nurses about it because I thought that they might think I was being negative.

Jill suddenly finds herself having to face the real possibility of her own death in the immediate future. In this situation of hers, family, friends and professional health workers surround her. She finds the topic, which disturbingly consumes her, is not a topic she is able to discuss with others. She feels she would not be approved of if she were to bring this topic into her discussions. She feels the other people around her would be upset by the topic of death. Jill finds herself to be isolated in her fear of death. During my interview with Jill, I asked her if she felt the need to talk about death with someone. Jill replied: *“Yes I did. I felt I would have liked to talk to somebody, but it was too big, and how do you approach it, oh can I talk to you about dying? ...It is a huge thing!”* Jill did not feel that it was publicly acceptable to discuss the topic of death. She was facing the possibility of her death on her own because of some underlying unspoken rule that this topic cannot be openly discussed as it would upset people. Death is such an implied tabooed topic that Jill felt that she was totally hamstrung. Discussion of death is unthinkable, how does one approach the unthinkable?

June who arrived home with her immediate family who had been present with her in the doctor’s office when the diagnosis was disclosed, mentions a silence they all felt:

So he went home with our daughter, because he had his car and I had our car, and there we are, came back in and did not really know what to say... we were not prepared for this? Definitely not! It was just the last thing I would have thought of.

June is describing the feeling of ‘being lost for words’ between her and her husband. Certain normal expressions would probably have seemed to trivialise or deny the situation they found themselves to be in. While the real issues they were feeling and probably deep down wished to discuss would have begun an avalanche of revealed emotions and fears that they were holding within each of them. The fear and emotion was already within them. By keeping silent June and her husband were unable to address these fears, talk about the emotions they were feeling and generally share in openly supporting each other during this crisis. They did not know where to begin a conversation on the topic of cancer. They had not been prepared for this. The silence of cancer made the impossibly tough to bear even tougher.

Trudy discusses how she felt in the first few days after her diagnosis in hospital regarding the atmosphere which she tried to maintain for herself and her visitors.

...and if I was outwardly positive... but my being positive outwardly then everyone else would think I was going to be okay as well, and therefore them coming in and treating me like I was normal, even if that was possible for a short period of time, it will speed my recovery and them being happy and normal would make me feel normal.

Trudy may have also been attempting at this stage of her illness not only to avoid the subject of death, but not having to think about it, or show that she was worried about the possibility of dying. She used the expression: “*and if I was outwardly positive*”, meaning she was possibly trying to hide outwardly what she was feeling inwardly.

During the interview I inquired further about what Trudy meant by being normal. I asked her: “If you weren’t positive, what do you think their reaction might have been? You are talking normal, what would have been abnormal?” Trudy replied:

People coming in and crying around my bed like I was dying. I didn’t think that when I was first told, I didn’t think right I don’t want people coming in and crying at my bedside because I had so many visitors that I just took them as they came, but obviously a subconscious part of me kept me bright and happy and bubbly despite I was in quite a bit of pain and quite a lot of discomfort, so that they would be happy, which makes me happy. I don’t know if I am explaining myself right.

Trudy gives an insight in her statement here that she and others would have felt awkward if she or they had the impression she was dying. She makes an effort to ensure that others feel comfortable in her presence and does not reveal her fear of dying. She behaves this way in order to keep everyone happy. Yet although they appear comfortable, it is likely that everyone was thinking about cancer. Trudy tries to hide her illness and pain from her visitors so they would not be disturbed by her discomfort.

Jenny wished that she could have been more supportive towards people whom she had met prior to herself being diagnosed:

You look back and think you wish that you had, if you had met people who had it, you wish you could have been more supportive, but because you didn't know anything about it, or you were scared to talk to them about it, because you did not know anything about what they had, whereas now I am probably more able to talk to people.

Jenny through making this reflective statement has indicated that she wishes other people talked more openly about cancer. She indicates that she feels a more open discussion by people rather than avoidance would be more supportive to those who have cancer. She also indicates that prior to having cancer, the knowledge about the topic she was provided with in the public arena was practically negligible. She only knew sufficient information about cancer to make her feel scared of the topic.

Jenny through experiencing cancer has come to know and understand the real meaning of having cancer. She now feels comfortable openly discussing this topic with people. But when Jenny was first diagnosed she found it very difficult to tell the people in her life that she had cancer.

Telling people was probably one of the hardest things... I think perhaps saying the word, for me saying the word, the "C" word, and to say it without crying, because you know if you cry it gets awkward for people, so yes I guess you are trying not to make them feel uncomfortable, because for me it is a serious disease, and it is not like saying I have something that can be cured.

Jenny demonstrates here that cancer, by being termed the "C" word by society, demonstrates the euphemistic hidden over, or desire to hide the meaning implied within the word itself by New Zealand society. It demonstrates in its design and usage that the word cancer itself is too emotionally powerful to be used openly in a public

context. Jenny found it difficult to tell people of her cancer because people did not like to hear this sort of thing. To say you have cancer is to say you are going to die.

Jane found telling people that she had cancer extremely difficult. She explains:

I was incredibly exhausted physically, probably from the illness, and then incredibly, emotionally exhausted because it seemed to me it was my role to tell everybody... and I got a bit stroppy with my parents because I thought that maybe they could have taken some of that burden off me.

Jane was surprised just how difficult it was to tell someone you know that you have cancer. It drained her energy to do this as she dug deep into her reserves in order to gather the resolve and courage to tell others. Jane looked for help and a possible way out of trying to tell others of her cancer by trying to hand this role on to her parents, a role they might have undertaken for her if she had still been a child and not an adult.

Jane further explains her experience of having to tell people she had cancer:

I found it hard telling people, not because it was bad news but because it was how they would feel. I was worried about them... It was how they would take it, if they would be upset that would be hurtful... I think it was just sharing grief.

Jane had been rocked and upset with the news that she had cancer. She had no choice but to try to cope with her own grief, but she did have a choice in how much grief she shared with others. She found herself in a situation where she had to tell others the news that she had cancer, to put someone else on the receiving end of this bad news. She found telling other people of her cancer to be difficult for she knew they would find her news very upsetting. It was also hard not to tell them because she probably knew that they would want to know and would want to share her grief. They would feel left out and hurt if they were not told.

June talks of the reaction of people close to her when they were told of her cancer:

I rang my Mum. She lives in another town, and [I] told her and she was just blown away, she was most upset and I had to calm her down... I didn't know how to tell her, but I just told her, and she had to gather my brother and my sisters and told them, and from what she has told me that was not a very pleasant thing either.

June, herself in shock and disbelief, needed to tell those close to her of her cancer. This was very difficult for June who had no training or prior experience in breaking bad news. June had had to summon courage and told her mum the bad news. This was not a pleasant experience for those involved and was very emotionally upsetting for them. It would appear that people do share in the grief of those they know who have cancer, but perhaps within a socially defined 'time and place'.

June told me that she found it difficult to say the word 'cancer'. I asked her why this was so for her. She replied:

Just because of what that word means, you know. For a lot of people it means death. I never told people I had cancer. I used to tell them I had leukemia and what type of leukemia I had, and give them the brochures, the pamphlets that were given to me, and that explained it. And I used to say, but it is treated like a cancer. The treatment. Oh, you have got cancer? No, I have got leukemia. And it is still true today. Some of my friends they had problems and stuff health wise, and she said the same thing too, and I said I can't stand that word, cancer. She said why? I never ever refer to myself as having cancer. But I guess if you have got breast cancer or you have got bowel cancer, but because it was leukemia there is no leukemia cancer... And I could just say leukemia, and then people would say what is that, and I would try and explain it as best I can. I know that sounds pretty weird but even today I do not use that word.

That word 'cancer' that sends people into shock if they are told they have it. Cancer is a powerful word in what it implies. It implies death. June avoids the word and all it

means. New Zealand society as a whole, appears to avoid the word 'cancer'. According to Seale (1998) a person reflects the norms and cultures of their society, the same as society mirrors the norms and cultures of the people living within it. June finds it easier to tell people she has leukemia, rather than the broader concept of cancer. June does not wish to be associated with cancer and the implications of death. In this way June is also not telling people she may die. Death is again avoided from being seen as a possibility within life. June avoids becoming a cancer patient in the eyes of others with the implications of death hanging over her head.

These expressions from participants of just how difficult it is to openly discuss the topic of cancer in New Zealand give us some insight into one reason why cancer is such a shock for the participants to accept. The topics of cancer and death appear to be avoided. It is as if there is some unwritten law stating that one must not mention these two topics. When the participants were faced with having cancer (a topic that they themselves have avoided in life) it is no surprise that this diagnosis generates such a large shock for them. Because of this taboo, people's understandings and knowledge of cancer is limited. The Western world's tendency of trying to hide the existence of cancer only increases society's fear of cancer and death. Cancer is something many within the Western world will have to face up to. Death is something all humans will face. As Jenny implies, hiding will not protect people. Only through facing our fears do we learn to overcome them.

At this point of the journey, I now wish to focus upon how it is the participants overcome their own fear of cancer and the possibility of death. It appears that at first they must face and come to terms with the reality of the situation.

Working through the shock to a new understanding

[Ivan Ilyich] once more found himself alone with it. Face to face with it, and there was nothing he could do about it. Nothing but contemplate it and feel his blood running cold. (Tolstoy, 1886, p. 261)

The news of having cancer disrupts participants' understandings of themselves and their world. They are gripped by the thought of their own death. The participants are

now forced to face their greatest fears, the fear of cancer and of death. How is it the person overcomes their shock and fear of cancer?

Trudy describes that point after the diagnosis has set in: *“So that was the lowest, lowest, lowest point and then I started to climb up, and I felt like my whole purpose and my whole sight on life changed.”* Trudy found the time of the diagnosis to be the lowest she has ever felt. She could not remain there. She started to find a way back up, but not to where she had been before. She found things had changed, things looked different. She needed to reach for new understandings about her life.

Jane also gives some insight into the period when the cancer diagnosis takes root and begins to settle into her perception of herself and her life. *“I think it took a while to sink in. It was quite unbelievable to start with, so I don’t think it actually hit, I think that was gradual over the next six weeks. But it is quite a surreal experience”*. Jane’s body needs time to assimilate the full meaning of this diagnosis. Jane’s body allows her only to take in the extent of the news in bits that it can manage. She needed some six weeks to work through the effect of what it meant to have cancer. The time during this process felt strange and surreal to Jane as her unconscious automatic self mixed its processes with her conscious aware self. That mixing and reforming of her understanding of herself was a surreal experience. An experience that was occurring to someone other than herself.

Jill found in this initial period that her concentration wasn’t the same: *“You can get told something and ten minutes later you cannot remember it, or you have forgotten it.”* June found her concentration and memory similarly affected. *“Then she came back and she told me and tried to explain it to me, but I did not absorb that.”*

Both Jill and June state that their concentration and their ability to retain new information had been heavily reduced during the initial period following diagnosis. Are parts of the participant’s bodies busy with something else as indicated in Jane’s ‘surreal’ experience? Are their bodies unbeknown to Jill and June busy in forming new understandings of whom they are and of the world they now live in? All that has outwardly changed is that June and Jill now know they have cancer. This news sent them into shock. How is it they manage to find their way out of shock? Do their

bodies reformulate their previous understandings, which had been changed by their cancer diagnosis in order to reach new understandings?

Jane explains this time when she finds that she can suddenly no longer function as fully as she had prior to knowing about her cancer:

I took three weeks out and just rested, but it was still incredibly full on, just telling people. Everyone wanted to come and visit, the phone was hot all the time, I ended up putting a message on the phone saying I just need time out, leave me your name and I will call you back, but I need this time to myself. And that was the first step to taking some control that was significant. But just physical and mental exhaustion.

Jane needed time out in order to assimilate the meaning of the cancer as it pertained to her. She found the assimilation process to be both mentally and physically exhausting. She found she needed time to herself and had to make time for herself. Jane felt that by managing her contact with other people in order to give herself time out was the first step in gaining some control over what was happening to her. She needed time to process her thoughts, to find out where she was and where she was going.

Jane explains further the feeling of lost control, lost direction in her own life. “Generally there was a huge sense of no control, but there was little things like organising my support network, that I could do to get some feeling of control back and to participate.” Jane lost the sense of being in control of her life through the effect of the diagnosis upon her and the unfamiliar world this had thrown her into. The diagnosis of cancer not only changed her understanding of her life, but altered its direction. The first thing she did to gain some stable ground was to gather her friends and family around her for a sense of security, familiarity, and connection. This gave Jane some feeling of stability enabling her to set herself upon some form of a structure in order to take stock of her situation. She did this to begin to participate in her own life again, to set herself goals and to gain new understandings and some sense of direction.

Jane explains further what she did and what others did to help her find her feet again:

So it is like who am I is shaken... I think what I did was, and it was something I had to learn, and part of it was trial and error and also advice, was just keeping things very simple for a while. But achievements were big achievements and slowly. But you are maintaining a bit of all of those facets of me, with my... work still doing ... but in a reduced role, and then just with time and with the trauma kind of easing, the confidence comes back and I could resume where I was before the diagnosis. So it was probably strategies and necessity created that situation.

Jane was emotionally overrun by the diagnosis and its effect on her understanding of herself and her world. Her confidence had been shattered and she felt uncertain about herself and the world in which she lives. She needed to relearn. So much of herself was involved with coming to terms with her newfound situation and finding new understandings that Jane had little energy for the everyday tasks of her life. She had people who helped her to find ways she could manage to function in her roles. They helped her to lessen the demands that would normally be placed upon her. While only having to function at a reduced capacity, Jane slowly came to terms with the realisation that she had cancer and that she could die. She could only manage to function in part, but over time she began to become more and more confident within herself, and soon resumed her life roles in full. Jane thinks that taking some time out was a necessary means of addressing the situation she found herself in. Having the time out enabled Jane to process the new meaning that the diagnosis, acting as the catalyst, had brought upon herself and her life.

For Jill, the diagnosis of cancer had suddenly disconnected her from what until then she had perceived as her roles within her life. She had suddenly become a cancer patient and had not been prepared for this role. She had no prior training for this role. Suddenly she was expected to function as the cancer patient. At the same time she needed to come to an understanding of her own self in all this.

I know that I was really, really sick, but I still had to just lie there and be sick, that was my job, I did not have to get up and do anything else, I had people to look after me... I don't have to get up and go to work; I don't have to do anything. I just have to try and deal with it, and that is my job.

During her early days in hospital Jill searched for a role within her sickness; a function for herself to perform, some sort of foothold in which to gain control. What was her job in all this she had asked herself? What should she be doing? She realised her function was to deal with the cancer, to cope with the situation and to get herself back up on her feet.

Summary

News of having cancer comes as a huge shock. The shocks related mainly to the thought that they could die. There is a realisation that one is mortal, that one day they will die and until that day the possibility of death will be ever present. The participants are shocked by the thought that the future they perceived for themselves is not guaranteed and they have little control over their fate. The unknown factors within the cancer experience adds to their anxieties and feeling of loss of control.

The participants described this shocked state as surreal, or not feeling all there, as if part of them was off doing something else. They felt as if they were only a 'bit player', a partial observer in what was being played out around them. Their concentration was poor and they often forgot what they had been told. They knew what was occurring to be real, but it did not feel real. Some mentioned not feeling prepared to have cancer. Although they had an understanding of cancer and knew it was prevalent, they did not ever think that they could get cancer. After they had been diagnosed with cancer most participants found the subjects of cancer and death very difficult to approach in discussion with others, leaving them with a sense of being isolated.

The news of having cancer and the subsequent shock caused the participants to feel emotionally low. They felt a loss of control within their own life situations. Energy levels and their ability to carry out life as normal appeared to have been diminished. The participants talked of feeling lost, not knowing what to do. They appeared to need time out of their normal daily lives in order to regroup to face the world again. The participants needed time out to make sense of their situation and to recover from the shock.

They needed to tell people in order for them to rally in support. They needed to feel understood but remain connected to the world of others. This made it awkward for them to bring up the topics of cancer and death. There remained the need to fit in with others and appear 'normal'. Their futures had changed and they needed to give themselves new futures in which to aim their lives. They needed to find a sense of control over themselves and their own lives. They needed to find out who they were in all this.

The participants used various strategies to protect themselves from emotional fallout in the early period of coping with the meaning of their diagnoses. The coping strategies included automatic unintentional responses of the body, and purposeful intentional actions carried out by the participant in order to achieve a desired outcome. Shock was the first protective mechanism brought in automatically by the body. Shock appeared to numb the awareness of those traumatised by the news of having cancer. Shock appears to stop people in their tracks and forces them to rethink what it was they had previously taken for granted. The shock made participants take stock of the situation in which they were placed. Participants asked themselves if this was really happening, how, why. Shock made the participants rethink what had just occurred in order for them to readjust to living with this new knowledge about themselves and about the world they live in. The effect of shock caused participants to step back and become more dependent on others. Jill became reliant on her brother and just wanted the health team to get on with it as she felt she didn't need to know. Jane wanted her parents to step in and take over some of the responsibility of telling others about her having cancer. Jane also rallied together her support network. Jane talked of the need to find time out, of letting people know she required time to herself.

The participants in time get over their shock of having cancer. I have briefly touched on some of the early strategies that participants may instigate in order to reevaluate their situations and begin their journeys of coming to terms with cancer. I will now venture deeper into the journey, looking at what it is that helps participants not only come through the shock, but eventually to come to new understandings of themselves, their life and their world.

Chapter Five

Coming to terms with one's own most reality

Obviously we shall put it off as long as we can. But it makes very little difference. So long as human beings stay human, death and life are the same thing. (Orwell, 1949, p. 844)

Introduction

In the cancer journey so far, the participants have received the news that they have cancer. This news struck many like a lightning bolt. To use their own words, they were 'knocked for six', 'blown over'. Their world and what it meant to them had suddenly, with one word, changed. Their life was suddenly threatened, their sense of future was disrupted and their very identity under threat. The participants found their understanding of things to be confused and muddled. It was a frightening place to be. They had lost control over themselves and their situation in the world. Their old understanding was now smashed by the diagnosis of cancer. They found themselves in a state of shock and bewilderment. They could not remain in shock. In order to come out of the veil within the shock it appears that they need to formulate a new understanding of what cancer means to them, a new understanding of life and a new understanding of who it is they are in life. This section of the thesis will describe what the person goes through in their journey towards a new understanding.

The participants are immediately thrown into the strange world of the cancer patient; they spend a lot of time in suspension awaiting results, and treatment outcomes. They need to learn how to cope with these additional burdens as well as with the cancer. Many look towards positive indications that things are going well for them, which enhances their overall sense of hope. The participants discuss the importance of support of others in this early period of coming to terms with their cancer. Many talk of a sense of new-found freedom and finding time for themselves in their lives. Most came to new understandings about their own being in this world, through learning to cope, looking for positive signs, finding hope and having support from others.

Being in a strange world

Poor little old human beings - they're jerked into this world without having any idea where they came from or what it is they are supposed to do, or how long they have to do it in. Or where they are gonna wind up after that. But bless their hearts, most of them wake up every morning and keep on trying to make some sense out of it. (Flagg in Holland & Lewis, 2000, p. 79)

The person lives in a world that has become familiar to them. Much of the everyday things of that world are taken for granted and lie hidden in their very familiarity. The diagnosis of cancer threatens that familiar world and throws the person into the unfamiliar world of the cancer patient.

Jane is not only hit with the 'bombshell' that she is mortal, she must now face up to the present-day world of cancer treatment and what this implies for her. Jane explains in the following statement her feeling of losing the world she knew and having to suddenly step into the unknown world of the cancer patient.

It is just that it was like a new culture to step into, and it is quite interesting to participate in. I don't have any problems with it. I had really good experience with it... Yes, and that rocks you as well, that is not what you are used to... I don't think it is about stepping into the other one, I think it is more about stepping away from what you know. Because you are stepping into the unknown and that is uncharted territory. And in this cancer case, the scenario is a scary place, but even just normally that is a tentative place.

Jane describes what it's like to become the cancer patient. Not only is she faced with having cancer, but also she must now assume the role of the cancer patient. She finds that she has to let go of the world she knows so well, and move into a world that is totally unfamiliar to her. She had to move into the world of the hospital which, on its own within its own space, was a scary place to her. She now finds she is a 'cancer

patient'. The hospital has now become her world. She is inside the scary space of the hospital. Waiting is one of the scary elements that the person must now endure.

Waiting

The silence had to be broken, but nobody dared to break it. They all began to fear that something might expose the lie that was being supported for decency's sake, and things would suddenly be seen in their true light. (Tolstoy, 1886, p. 272)

A large part of the initial period of being a cancer patient is spent in waiting. Waiting for biopsies, scans and waiting to see how effective the chemotherapy was. This waiting is a large and emotional part of what goes on in the world of the person diagnosed with cancer in that first couple of months. Joe expresses his feelings about the times that he had to wait during that initial period.

Waiting for tests and various treatments was a very frustrating and very tensioning sort of time because it is always the unknown in life that is the scary part of things... was the most humiliating and frustrating and stressful part... You just want answers and to know what is going on.

Waiting might not look very taxing on the human being but many find it one of the most difficult, anxious and stressful events to be involved with in their ordinary daily lives. Waiting in the queue, hoping to get a ticket to that show before they are sold out, waiting to see if he or she will call you for that date, waiting for that exam result, can all be stressful in one's life. Just think about what it must be like waiting to know whether the cancer has responded to the chemotherapy, how deadly the cancer might be, or, what type of cancer it is.

The results Joe is waiting for will indicate to him if he lives or dies in the immediate future. Waiting to know this sort of information is extremely stressful. Joe's life is not only on hold while he waits, his life exists upon the 'knife edge' of the answer for which he waits. All he can do is wait. He feels totally helpless while he waits to find

out if he lives or dies. He hopes he will be all right, but the results could be deadly in their consequence. The unknown results are frightening in their very unknown quantity. There are no progress reports or indications of how events are shaping up. All he receives is the final result when it is all concluded. One can only feel trapped and wait in a state of hope and dread mixed into one. Joe finds he is humiliated in the powerlessness of waiting.

June also mentions this tension within the waiting time that must be endured by the cancer patient.

...Then we went up to hospital and had that bone marrow done, and it was agonising waiting for the results from that. And then it was like people forgot that I was in that room, on the side there, and popping out and saying yes, I am here. Then the results came back in.

June had a bone marrow investigation carried out on her to confirm her cancer. As she sat and waited for the result she found it difficult to sit still. Will it be all right, or won't it? Time seemed to drag. To speed up the time it was taking, to feel she was doing something, she needed to jump up and remind the hospital team she was still waiting. The jumping up helped to release some of her nervous energy. It gave her something to do to help take her mind off it. Then the moment of the result suddenly arrived and the adrenaline kicked in. Did she really want to know the result? She could still run. The absolute power of the result over her life was frightening.

Waiting was not a time enjoyed by participants. Waiting is torturous in its design. Waiting further drains the energies of the participants by placing additional stress upon them, additional stress at a time when they searched for methods of alleviating the overburdening stress they already were dealing with in coming to terms with cancer. How is it the person learns to cope in this new world?

Learning to cope

[death]... came and stood facing him, staring him straight in the eyes... and once more he asked himself, "Is it the only truth?" (Tolstoy, 1886, p. 260)

Participants have been told they have cancer, they have become patients within the hospital system and they are often waiting for indications from various tests about the form their cancer has taken and how well they are responding to treatments. Jill talked of some of her thoughts in those first few days as she learnt to deal with being a cancer patient and how she tried to manage her thoughts in a manner that she could cope with:

I think also while you are having chemo, and while you are going through all that, I wound my mind around coping with the illness, coping with getting better and that I was going to beat it... you shut off what is happening to you because you are fighting it, and then you are so busy getting well, and then it is like, this has happened to me and I could have died... and I think that is the emotional thing that comes to me.

Not only does Jill have to come to terms with having cancer and the possibility of her own death, she must also endure illness and chemotherapy. Jill found not thinking about the big picture helped her cope at the time. She tried to lock her mind onto the idea of getting better and of overcoming the cancer. When she felt stronger she reflected upon what might have been and that she could have died. She finds that she gets emotional when she realises this and that she has survived so far. Jill has put so much effort into getting this far. The realisation that she has come so far and against such odds is a very emotional realisation for Jill. She has got this far; she has made it this far!

Jill reveals here that she has a strong emotional feeling of triumphing over the adversity of her cancer and of her treatment and perhaps her own self as well. Let us

now look at what it is the participants had to come through and what might have aided them in their struggle against adversity within their journey.

The effect of the cancer diagnosis immediately removed the sense of control Jill thought that she had over her life. *“It is too overwhelming that you have absolutely no control over what is happening to you”*. The diagnosis of cancer and the complete change this and the subsequent treatments mean to the unprepared cancer patient’s life is more than they can deal with in one moment. They feel helpless in their lostness with it all.

Jill talks further about what it was like for her during those early days of her chemotherapy treatment and what steps she found she could take to help her to cope.

I cannot vomit and drink water. So this was my way of coping with it, mentally you just cannot make yourself feed, I cannot do this, but you have to have some positive little thing that you can do that you think is helping to make yourself better, and mine was sleep. It was the only thing that I could do to help myself.

When the effects of the chemotherapy became intolerable Jill needed to have a way out for herself from that sick space. Jill found her only refuge in sleep. Sleep allowed Jill to escape to a different space for a while. Sleep was her only possible escape. She desired sleep to escape the nausea.

Jill has given an example of when someone is feeling very ill and very much beaten down by his or her situation often it is the little things that can help. To be able to sleep might seem such a little thing but for Jill it was a great achievement. It was her way of coping and getting through the bad moments.

Joe talks of his awareness of his helplessness after being diagnosed and how he rallied himself to take back some control in matters that pertained to his life.

I was determined to beat this thing, this cancer. I was not going to let it get on top of me and basically take my life if I could help it, or if I

could have anything to do with it anyway. I was going to fight it all the way... It was just a matter of coming to grips with the situation and dealing with it the best possible way you could. I just knew I was not going to let this get on top of me and beat me if I had anything to do with it. I was determined to get through the treatment and get back to a normal healthy lifestyle again.

In order to combat the feeling of having no or little control over himself and his life, Joe rallied himself through willing himself to fight. He realised he needed to come to terms with his new-found situation. In order to achieve this he set his targets and visualised his goal of returning to a normal functioning lifestyle free of illness.

The participants develop ways of coping, gaining a sense of control after being diagnosed. Some rallied themselves and set themselves the goal of getting better. When things got too much to bear some found the means to escape the situation for a while like Jill's refuge in sleep.

One of the methods many participants utilised in 'beating' or overcoming their cancer ordeal was to look for positive indicators that matters were in hand and proceeding in a direction that would enable them to get back into a healthy normal lifestyle and once more free from the hospital system.

Looking for positive signs

And presently it became clear to him that all he had been tortured by and been unable to throw off, was now falling away of itself. (Tolstoy, 1886, p. 283)

In order to cope and begin to gain an element of control many participants looked for positive signs that things were going well for them. Maintaining an overall positive perspective that things are going to work out all right was important for Jill in coping with her illness during treatment. *"Remaining positive really helps you mentally get through the bad physical days"*. Jill believed that mental attitude affects the physical

state. Despite the nagging doubt, she felt that she needed to believe that she would get better in order to actually get better. To have a positive goal and to look forward to something helped Jill endure the bad moments of her illness and treatment.

At first, Trudy felt her world to be totally destroyed by her diagnosis. She explains how she looked for things that were positive within her experience in order to climb from the abyss that she felt herself to be in. *“So every day that I was told your hemoglobin has come up, or little things, it was a huge boost for me because I put my mind into such a mindset that any positive little thing was a huge step forward for me because I had gone as low as I could possibly go.”* Trudy found that any positive news helped her to feel hopeful about her situation. Trudy’s increased hope in turn helped her outlook not only to be more positive but also aided her in maintaining a positive attitude. She looked for things that would help her to feel positive. She was feeling bad and wanted to feel better about things. Little things helped her immensely.

John talks of this early low period also and the need he had to focus on the positive.

At the time of diagnosis I knew the setback was only temporary because I knew there was a fairly high rate of cure and that was the key word for me ‘cure’. I wanted a cure... I always tried to be a positive thinker. I tried to think positive things. I knew if I took things one day at a time eventually it was going to be over and I would be back on track... I knew that throughout the treatment, I was going to have to alter my fact process on how I approached life because this timeframe in my life is like a speed bump. It is there and there is nothing I can do about it. I am just going to have to ride it out; change my way of thinking while this is going on, and when it is over I can get back to things.

John focused on the chance he had that his cancer would be cured. This means he tried not to think of the negative possibilities. John changed his approach and took the necessary time out mentally while undergoing treatment. During his initial treatment phase John tried not to concern himself with the future. He tried not to think about if the treatment would work or not. He knew he could do nothing about the outcome of

the treatment that he was receiving. Although he could only wait during this time he looked no further ahead than the day he found himself involved in at any one time. One day was a time period with which he could cope. One day made the treatment process bearable as he took it on in bite-size chunks. John felt all he could do to help himself was to take the time out that was required and to be as positive as he could in his outlook.

Many found that to focus on what they considered to be the positive signs was helpful in getting through the day and coping overall with their treatment. The positive signs gave them hope in that things were going well and that they were going to be okay in the end. Hope is another theme that was continually present for many of the participants.

Finding hope

The very fact of the death of the one they had known so well made each of them rejoice that it was his friend rather than himself who had died. “Fancy that: he is dead, but I am not,” was the thought or feeling of each one of them. (Tolstoy, 1886, p. 225)

Participants found themselves thrown into the situation of having cancer. Hope gives them the possibility of escape to a more desired future situation. Hope provides comfort, and hope does not always require probability. But we must believe that what we hope for is at least possible. To think a desired outcome may be possible is comforting through hope (Perry, 1978). Hope differs from optimism in that it gives the person the ability to imagine avenues for attaining goals (Snyder, Irving, & Anderson, 1991).

Jenny gives us a look into the importance of hope to her as she tried to come to terms with herself having cancer.

You tend to look for positive stories, you tend to want to hear about people, whereas I at the time had two negative stories so that was hard... You hear of people who have been cured, and I guess you tend to want to hear that. So that helps you and makes you realise, and in years from now they have got a new drug out, or hopefully, and it

might be available, but you tend to want to hear positive stories. Even five years down the road, hopefully there will be more breakthroughs to find a cure for it. That is what you cling for. And talking to people, I have spoken to someone who actually had bowel cancer, and she is fine now and you sort of think great... You hear the stories that they have got, and they might have good stories, so that gives you hope, so I think you try to look to that, hey here is someone who has had thirty years, and that to me at 33 years of age is great you know. That gives you hope.

Jenny is looking for stories that will give her hope about her life and chances of beating the cancer. She is well aware that her two negative experiences of cancer affect her overall perception of cancer and she is trying to find positive experiences for herself in order to give herself a more optimistic outlook on her cancer. An optimistic outlook helps Jenny to feel better within herself and about her situation. She not only hopes to live, she hopes to have a good quality of life.

Jenny's form of cancer is Chronic Myeloid Leukaemia (CML). I interviewed Jenny when a new drug Glivac was being hailed as the wonder drug in curing CML. The drug had just had a lot of extremely positive press and during the week to two weeks prior to my interview with Jenny, a national documentary had just screened on television, which had been very pro Glivac. The media had painted the picture that this drug cured CML without a doubt and it was just a matter of swallowing a few pills for two or three months. So Jenny was feeling very optimistic. Jenny also likes to hear of others in her situation doing well. This gives her hope for her own future with cancer.

Through finding other people in her same position with cancer, Jenny found a reconnection with others. The sharing with others in her situation gave her the hope and means that enabled her to find ways of reconnecting her self with her world in terms that she found acceptable. Hope helped participants to cope with having cancer and the treatment of cancer. Another major means of coping participants found during the early period when they tried to come to terms with having cancer was the support of others.

Needing other

He wanted to be petted, kissed, cried over, as sick children are kissed and comforted. (Tolstoy, 1886, p. 265)

When born, human beings are born into a world consisting of others; they learn to live with others, communicate with others, learn what it is others expect of them, and what they should expect from others. The human being lives amongst, with, and for others. Human beings do not live in isolation, even when alone they compare themselves with others, try to live as others would expect them to live, and even communicate internally within themselves with beings, such as God(s) and ancestors. The human being cannot and does not live alone. The human being is always living with others in some form, be it in the flesh, or in thought. There is always someone else involved with us all.

It is well known that the person who has received the diagnosis of cancer needs good support from others during their illness. How effective the support is and in what form the support should be provided is less known or perhaps unrecognised. It was something Jenny said, *“I needed to be around people”*, that signified what the company of other people had meant to her immediately after she had received her diagnosis. The participants described the support they received and appreciated from others while they themselves struggled to come to terms with their cancer. Jenny also went on to say:

When you have been told something like this you tend to not want to be alone in the first few months. I needed to be around people... I think just the support of your family and your friends that is really important and I think that having that support is really what helps you through.

Jenny found the support of the people to whom she felt close, to be very important to her during the time immediately after her diagnosis. This was the time when she was

trying to come to terms with herself having cancer. She did not want to be alone during this period. Jenny felt vulnerable and needed reassurance. She felt the need to feel connected with other people. To know someone is there is reassuring. To be just able to talk to someone about things as the need arises. Jenny feels strongly that the support of other people helped her to cope and come to terms with her cancer and the implications it held for her.

Joe has a similar appreciation and understanding that it was the support of the people in his life that helped him to mentally cope with cancer. *“It was probably through getting a lot of support, moral support, through family and friends that helped me come to grips with the situation.”* Joe confirms the idea that it is the support of those we can identify with and are familiar with that can aid the person come to terms with their traumatic new-found situation.

Jill tells of the strong need she felt upon receiving her diagnosis to have someone at hand for reassurance and psychological comfort. *“I found that incredibly hard to cope with in that first hour. All I wanted was someone then to make me feel a little bit better. I didn’t think I could cope with all that information.”* After the shock of the diagnosis Jill felt the need to be comforted by someone. She could not cope with what having cancer meant to her on her own. She needed to be reassured that she was still a part of the world which she had known up until that moment and that all was not lost.

Jack gives an example of how others can lift our spirits and reconnect us to life. *“Some people had the right knack of saying the right things to you. One of my nurses just happened to say the right things to me a couple of days, which sort of makes you perk up.”* Other people helped Jack to feel all was not black, that he was still in life and that life goes on. That life can still be good and worthwhile in the living despite his having cancer.

The fact that the participants highlighted just how important other people were and are to them in facing cancer argues questions about the form of these connections with others?

Experiencing connection to other

Jill explained one experience she had early on one night just after she had received her diagnosis of leukaemia, as she lay there in bed feeling closer to death than life. The bed represented the boundary of the life world. The area above the mattress was life and the area within the mattress was death.

I really felt like there was only my head sticking out of the mattress. I felt I had sunk right into it... I saw my mum who had died years ago and I can picture what she had on, absolutely everything. Running across the room, almost grinning like what are you doing Jill. What are you doing this for, you know you have got too much to live for... It was almost like she gave me the will to fight it. From that moment on I knew I really wanted to live and that I could fight it no matter how ill I was. I felt almost from that instant... like it was a turning-point for me.

Although Jill's mum was dead, Jill still felt the connection with her. Jill's mum was a close loving person in her life. It is possible that somewhere deep in Jill's subconscious while she was feeling so terribly ill and unable to cope, a rallying point was mustered deep within herself through this connection with her mother. This connection with her mother was something that provided her with the meaning and the will to live. The image of her mother talking to her gave Jill a sense of familiarity, of something solid to cling to. Her mother would have guided her and helped Jill deal with the problems in her life from birth. The image of her mother guiding her back to thinking about living is associated with not only Jill's past relationship and connection with her mother but also her present relationship with her. The connection we have with people we carry with us and we remain connected to them even when they are no longer physically present. Jill remains connected to her mother, who is still a large influence in her life.

Building on from this Jill wanted to live for her family, *"I really wanted to be there for them, and I wanted to be part of their lives, and I think that is what gave me the strength when I was really ill to keep fighting it"*. Jill's connection with her family

also gives her meaning in her life and a reason to live. This helped Jill to pull herself around from her illness and the shock that having cancer had caused her.

When someone is diagnosed with cancer their crisis touches the hearts of others. Others close to them feel their pain in some way and are drawn to try and help in some way. Jane explains how family and friends rallied around her:

Well my family and friendships are incredibly important, so it was really important and I knew I would need support (Jane was near tears at this stage as she told her story) and I was not afraid to ask for that and I knew that I would get it, no questions... I also learned quite quickly that other people wanted to participate as well, and that was good for them and it was good for me.

People are important to Jane, and she needed the support of the people in her life while she came to terms with having cancer. She trusted her family and friends. Jane found that it also helped her friends with their concern for her to participate in assisting her at this time.

I asked Jane during the latter stage of our interview if she felt she had come through something or that she felt she had achieved something. Jane replied: “*Yes I am very proud of myself, but I am not alone. I have had lots of help too, they have come with me.*” Jane confirms in her statement that she has a sense of overcoming adversity, but also strongly implies it was the support of others that helped her to achieve this. Jane and her supporters all came through the trauma and adversity of cancer together. Not only this but Jane implies that she has a continual sense of these others as being always with her as she goes about her life.

So other can be the others in our past, present, or future life. They can be physically present, or be family, friends, and various acquaintances, that may not be present but that can live within us in thought. What is it that professional people can provide that our own support network cannot?

Experiencing professional support

In a world of limited resources, health services should avoid duplicating (or taking from) the support and functions that families and friends can already provide. Health services should be asking what is the best possible support to provide those recently diagnosed with cancer that cannot be taken care of by the patient's own support network (providing the patient has their own support network)? What else do these people need to help to get them through their journey as quickly and with as much comfort as can be managed?

Jane tells of one area she found very difficult to negotiate. *“Getting information is not easy... and if you don't know the questions... I found that I needed to have the right questions to have the answers.”* Jane was thrown into a foreign strange world, a world she was not prepared for at all. She needed to learn new information in order to find a means of navigating this new world, but she did not know where to begin. Jane was without the basic tools. No one handed her a map she could interpret for herself or gave her the necessary directions to find her own way in the world. The health service providers need to have knowledge of their patient's perspective in order to anticipate what it is their patient may wish to know. The patients themselves are often so completely lost they don't even know how to begin asking directions for that initial period after their diagnosis.

Jill talks about the support she received from experienced nurses. This support was a form of moral support she could not receive from her inexperienced family at this time of proceedings:

To have the reassurance that you have of the nursing staff is really important because in a way they are like your lifeline. You know your family is very comforting, but they do not know what is happening to you, and the nursing staff have experienced it, and I think more than anyone else there, even if they have not been through it, they

understand in a lot of ways what you are going through, and I found that really comforting to the point that when the first time I went home I was scared to go home, I was so scared that something might happen and I did not have the help right at hand.

Jill had learnt to trust and have faith in the knowledge and judgement of the nurses around her when she was at first ill. Her family gave her life meaning and connected her being with her life outside of this illness, but the nursing staff had experienced her situation through caring for others. Jill felt safe in the company of the nursing staff. When the time came to leave the hospital with her cancer Jill felt unsure. She had never been home with cancer. This was again unfamiliar territory for her. She would also be leaving the people who had and could guide her through any problems she might incur at home.

Jill discusses further the guidance she received while in hospital, giving some insight into what professional support meant for her during her first month of treatment.

...Over the month, as you deal with chemo, the best help you can get is just people being there and telling you all the time exactly what is happening as the treatment is coming. It is just so important for me to know that and all the time to be told this is what is happening, and I know you are basically told that all the time, but even the next day, that is just so important because you forget things.

To know what is going on helps the unfamiliar to become familiar to Jill. The unfamiliar is strange and frightening. To be kept informed builds up Jill's feeling of being connected with the others working around her. Through this connection her trust and feelings of security returned to her. She is ill and still affected by the trauma of knowing she has cancer so her concentration is not at its best which causes her to forget things. But she is not worried about forgetting she knows that she is in caring hands that will remind her of the important matters and re-explain things to her.

A further example of what this professional support meant to Jill is disclosed in the following:

...A big help was a very caring nursing staff, well I think the first day I cried a lot, or was it the second day, you know it was just this is happening to me, but that was fine, and the nurses were there that understand, and it is okay to do that, all those kinds of things, and that is really super important because it is just such a huge thing to deal with.

To feel cared for during the early stages of shock was important for Jill. She felt free to grieve while still feeling cared for. Jill felt that she was understood in her grieving. She felt she had been allowed the time and space to meet her own needs. This form of professional support and guidance Jill found helped in supporting her as she came to terms with her situation.

Professional support can aid the newly diagnosed person to navigate their changed world, help them to feel secure and reassured in their journey. Professional health workers can give acceptance to emotions and provide a forum for discussion. The person while coming to terms with cancer should not feel isolated or removed from their everyday world. The health professional can help in facilitating continued connections to this world.

Others in maintaining a sense of connection

People who have cancer still wish to remain and be treated as the everyday person they are. They wish to remain involved in life. Being treated as an everyday normal person and hearing about the lives of others was important for Jill to feel she was a part of life herself still.

Just that help of being there and I think nurses bringing their everyday life into work too, you can ask them what have you been doing and they have been tramping or doing things like that, and it is really important. It is like when you are at work in an office, or you are at home, you talk about everyday things, and just having that

communication with patients is so important, because it does become your second home.

To remain human, amongst her fellow humans, while being a patient in hospital with cancer, was important to Jill's feeling of wellbeing. She did not feel normal within herself. Her body was not functioning, as it should. To feel inclusively part of the humanity that makes up a hospital, and to hear about the lives of those around her was important to Jill's sense of wellbeing in belonging. To be included in normal conversation and not excluded as the patient was reassuring and comforting. It not only reassured Jill that normal life continued, but helped her to not feel isolated from normal life. She felt that she still belonged and was accepted. To be able to have a laugh with the staff and others about everyday things lightened her load.

To have some semblance of normality and celebration brought into the hospital environment lends to it that human element. Jill gave the example of one Christmas morning when her grandchildren came to the hospital: *"They came in their jarmies, like they would have at home you know to open presents, and they had glowing antlers on, and jumped up on the bed."* Jill was in hospital but she felt as if she was part of normal life. This connection with normality was important for her. She was not isolated. She was still alive.

Sharing a similar experience

The participants often found themselves in situations for which they were not prepared. Their family and friends didn't have any real experience or insight into the situation that they then found themselves to be in. Health professionals, although they can provide lots of information and guidance, can't answer those emotional questions that only someone who is there or who has been there can provide. Jenny explains:

It is only speaking with someone who has actually gone through it that you can start to understand, and I think in a way people don't. Actually somebody sent me a card and it was really lovely, and they said things like, they can't understand what it is like, they are not in my shoes.

And that is one of the things, they are really supportive, but they do not understand what it is like.

Jenny's familiar world had been shattered and with it her established understanding of that world. As a human being, she needed to make sense of her world, to find new understandings of her world that would work for her. She found that in discussing with others, who had gone through what she was going through, helped her to form an understanding for herself, which she could use to make sense of things. I asked Jenny if it was important to be understood in terms of what one is going through. Jenny replied:

Yes, I think because you do not want to feel alone. I think initially I wanted to know there were other people out there that had what I had, and you wanted to talk to them because you wanted to know, I guess, that you are not alone in it. And I don't feel alone now because I know there are other people.

When Jenny first received her diagnosis of cancer, she was not only traumatised into shock by the diagnosis; she also felt suddenly alone with her cancer. She felt pulled out of society somehow, disconnected in so many ways and all through just one little word, 'cancer'. Jenny wanted to find a connection; she wanted to find others in her situation, others with her type of cancer who were faced with the same type of problems she was now faced with. She needed this connection, to talk in order to redefine meaning and understanding, to feel part of a group, to belong.

Jane also talks of the importance of making connections with others in a similar situation to her own.

I have actually made friendships with others, particularly one female patient, and that was actually the best thing that ever happened to me. And that happened within those first two months of diagnosis, and I think that actually might have been, or that definitely was a pivotal point. To meet someone else who had been there and was getting on with it and living life really well. It made me think well okay, there is

good stories as well. And when we hear about cancer we hear about dying, and you don't often hear about people living well.

Jane's meeting and talking with someone else in her position that she could relate to helped enormously in coming to terms with her own situation with cancer. Not only did Jane not feel so alone with her cancer but it helped her to see that life with cancer can be worthwhile and enjoyable. This meeting helped Jane to realise that cancer did not necessarily mean that her life was over.

Summary

In their cancer journey so far the participants have revealed just how vital they believe the support of other people to be. Many believe that they would not have made it this far without this support. They talk firstly of the vital support of family and friends in helping them come to terms and make sense of their cancer. These others also gave their life meaning, which enabled them to motivate and rally themselves into wanting to beat their cancer. Others can help them to see the funnier and brighter side of life; help them to feel safe in a world that appears to have so completely turned on them. Some others can help them to find hope and a reconnection to life itself. Other people have the ability to help direct participants in a way that helps them to find the means to navigate again their own world for themselves with confidence and hope. In talking with others in a similar situation participants managed to dispel the feeling of loneliness and found understanding and solace within their journey. The support of other people would appear to be the major force in the participants, ability to adapt and come to terms with having cancer.

The participants within this research project are expressing their need for support from people who are real to them, people they know and have built up some form of relationship with. In the next chapter I will describe how participants seem to become more their own persons, secure within their own beings. They also discuss the sense of being freed from the feeling that they have to conform and fit in, in order to be accepted by others. These 'others' they talk about are a concept only. A concept of a large group of others that are of the same thought and will, who are forever in a state

of unison with one another ('A force of will'). Through their new-found sense of freedom the participants find they have more time to be their 'own-most-selves'.

Chapter Six

Something has changed

And that lifeless profession of his, and the worry over money - year after year, one year, two, ten, twenty, without any change. And the longer it lasted, the more lifeless everything became. As if I had been going steadily downhill, while I fancied I was going uphill. (Tolstoy, 1886, p. 275)

Freeing oneself

Only by smashing this layer do we get to the layer of our 'authentic self,' what we really are without sham, without disguise, without defences against fear. (F. Peals, in Becker, 1973, p. 55)

When the participants were told that they had cancer the shock of this disclosure appeared to stop them in their tracks. The news would appear to deconstruct much of the fabrication and understandings they held of their world. It seems that they needed to reevaluate themselves and the world in which they found themselves living.

Jane gives us her thoughts of the effect that the news that she had cancer had upon her. *"Because of being freaked out you appreciate the situation in a different way... I can't imagine anyone could go through this experience and not be affected somehow in their perspective on life, and it has affected everything that I do."* 'Being freaked out', is the word used by Jane to sum up the overall effect of the shock value of this news upon her. She was pulled from the perspective she had held on life. She was made to look at the things she previously had taken for granted, contemplate and reform new understandings.

Trudy talks about this concept of being awakened and of reevaluating one's life, one's purpose, one's being. *"To me it was a wake-up call to start living life properly, because I knew I had been denying myself the life I am supposed to live... and I knew*

the deep-rooted health problem that would not go away was to do with that, I was not living my life properly.” Trudy had felt she had been compromising herself in life prior to the cancer diagnosis. She was not being true to herself in who she was and in the way she conducted her life. She felt that her cancer could possibly be attributed to the stress and unhappiness that this compromised life style was causing her. The diagnosis was the signal to live her own life in the way she wanted.

Jenny talks of a similar feeling about how she conducted her life prior to the cancer.

Your whole life flashes before you, and so many things do not become so important any more, and that could be anything. When I say they do not become important, things that probably had stressed you before, you start to say well that does not matter any more, because I have always been a person who probably didn't put myself first, whereas now I do put myself first and I don't do anything that I don't want to do, and it has probably given me that strength to say if I don't want to do something, then I am not going to do it.

Jenny has had to face her worst fears and reveals in so doing that she has grown and come to have a fuller understanding of herself and her life. Her perspectives have changed. Many things which might have seemed important before, no longer appear so. The pressures of living up to the expectations that she felt that others had put upon her were diminished in her eyes. No longer did she feel the need to try and be that desired ideal perfect person. Trying to always please others and doing and saying what she felt was expected of her in order to be accepted. Cancer helped her to see that these others and the things which she had previously thought were important, really no longer mattered. Jenny is no longer stressed in trying to meet the perceived needs of others. ‘They’ and what ‘they’ think are no longer important to her. ‘They’ no longer hold influence over her. She has become her own person. She now knows what she wants. She is no longer afraid of not being accepted by these others. She is no longer afraid to express her real inner self.

Jenny goes on to say. *“Now I look after me. It really puts your life into perspective to say hey, this is my life, and I want people around me who are good to me, who*

support me, and who will be there for me... It has made me stand up for myself a lot better." Jenny has come to understand that she is the person who has the control of her own destiny within her own life. She has come to realise that her life is her own and that it does not belong to others. Her life is her gift. Jenny through this experience is now more authentically aware of herself and her temporal life. She is guarded about being manipulated and pulled astray in her life by the will of others. She now holds this force and its demands at bay. She enjoys the company of others, the company of real people who allow her to be Jenny, and accept her as Jenny's Jenny. She ignores the will of 'they'- others who don't know her, who try to make her conform to their will.

What did Trudy and Jenny mean when they decided that they were not living their own lives in the way in which they had wanted? Earlier in Chapter Three the concept of Heidegger's 'they' was explained. The concept of the 'they' gives some insight or explanation at this point of what and who did have some form of power over the lives of Jenny, Trudy and other participants. According to Heidegger (1926/1996), when one realises that one is actually going to die within a limited time span, the actual authentic knowing of one's imminent end as one currently understands oneself frees the person from previous ties. This Heideggerian concept provides an understanding of how it is that Jenny has become aware of her own self, through knowing that her time is limited in life, she has pulled herself away from the world of the 'they'. She is aware of the pull and avoids this, as best she can, by surrounding herself with people she feels will genuinely respect her individuality and accept her for herself.

Trudy also has the feeling of being freed to be herself by the shock factor of having been told she has cancer and through realising that she could die. She tells her story as follows.

So it was a wake-up call in the sense that I needed to start taking my own advice and look more into who I was and what I needed to do to make my life (a) to be fulfilled and (b) to start taking better care of myself. And to do whatever I really wanted to do, because as everybody says, life is so short.

Trudy thinks of her cancer diagnosis (through its making her aware of her mortality) as a wake-up call, a call to be more her own person and to do the things she really wants to do in life. Being diagnosed with cancer has helped Trudy to realise she had not been leading her own life, had not been the one giving her life its direction. She had not even had her hand on the steering wheel. Some other force had been doing that for her, some force so hidden from her that she did not realize it.

Trudy's above statement led me to ask her if "she found one, was maybe freed by realising your own mortality?" She replied, "*Very much so. I suddenly felt, if I can explain it, like harnesses snapping open, and it was like what have I been doing, why have I been holding myself back, and realising I was the only person who could change anything in my life, no-one else can.*" Trudy felt that a force which had previously bonded her in place was now gone. She felt freed from something. She now feels that she is the master of her own destiny. This means she did not feel she had full control over herself prior to the diagnosis. The harness Trudy describes as snapping open, what actually was the thing that was harnessing her? Trudy tries to explain further how she lived prior to being diagnosed:

I tend to stop now and actually think a lot more about things, whereas before it would have just passed me by because all I was thinking about doing was having my diary and all the different things I had to go to, or to work, or to the gym, and just to cram so much into my day to be everything that I felt I should be... But I am now filling my time with things I really want to do.

Trudy now takes the time to think about things for herself, making her own judgments and conclusions about the things of her world. Before she spent her energies on trying to fit, to be accepted by others. She no longer just follows in trying to do what she believes is expected of her. She now has the time and energy to think for herself and to live her own life free of these social influences that had covertly conducted her life for her previously.

Trudy tries to give further insight into the very subjective feeling of being now freer in one's life and the concepts of what she may have been freed from.

... you think you/I must get that vacuuming done, but that vacuuming can wait. ... I am learning to accept that I cannot be perfect.

Realising that I often strive to be the best, not that I always succeed and not that I get totally disheartened by that, but the fact that there will always be people who are better at something than me, and accept it.

Trudy is no longer rushing about trying to be that image of the perfect person. Nor does she feel she has to do what's expected of her to fit that perfect person image. Trudy uses the example of vacuuming here. One vacuums to show one is clean and tidy. One feels that if someone comes one must vacuum. Before Trudy couldn't have them thinking she had flaws. She couldn't show herself as being different. 'They' might tell others. 'They' might have seen her impurities. She feared being outcast from the security of belonging to the group. Although Trudy never realised it prior to her diagnosis, she had led a very stressful life in trying to live up to the perceived expectation of the others. She now is more relaxed in her approach to her life.

Jack implied something similar by his statement; *"and now I find that the lawns can wait"*. The feeling one must do these household chores before one really believes it to be necessary depicts the hidden pressure one feels in one's day-to-day life. The pressure that one must keep one's house in order otherwise what will others think. These things must always look in place. This is not really one's own perception of how things should be, but the order one feels that others expect. One must be seen as conforming in order to belong. One is allowed to belong by showing one's acceptance of the order of other, by being part of the order of other. This is how the order of other is established and sustained within society. One in turn feels a sense of belonging to the march of humanity, on towards greatness and prosperity. One feels one won't be left out when the earth ends and those star ships go off to new lands. In this way one can escape the reality that one is just one of the many creatures of this planet that live and die. Trudy used to so badly want to have a share in the 'they'.

Trudy's cancer freed her from the insecurity of fearing being outcast by the group, of not belonging; of not sharing in the sense of immortality and safety that the sense of

belonging to the ‘they’ had appeared to covertly offer her. She no longer minds so much any more if others see her house as not being spotless. Small inconsequential tasks such as vacuuming can wait, if she wants to do something else. Trudy can do the vacuuming in her own time when it suits her. Jack will do the lawns when it suits him. Trudy no longer feels the need to be seen as the immortal star in her and everyone’s eyes (as she is no longer living in avoidance from the fear of death) and is happy to be herself, a mere mortal. Trudy knows the group can offer her no additional safety or fulfilment that she cannot offer herself. She is now more willing to follow her own judgment on things: *“...learning to turn away from opinion and not really listen. That has been a huge thing”*.

Trudy tries to give further expression and insight into the hidden power and actions of the ‘they’-crowd: *“People quote that and say that all the time, everything in moderation, but people don’t do it. People are huge ravers and talkers; just say what you mean, don’t say what you want other people to hear... What is expected to be heard, yes.”* Trudy is describing how people bind each other to each other in a falsely constructed world of pretence, pretending to know what they hear as real and regurgitating it as if they have figured it out for themselves and know that it is true. The pretence is carried on to appease all the fellow pretenders. One fits in so that one can belong with all the fellow pretenders, who want to hear this sort of talk, talk that only repeats what is already known as acceptable; that does not challenge or question but reinforces the comfortable lies they wish to live with. This makes them feel safe in their falsely constructed reality. Trudy and other participants had not been as free or as happy as they had thought they were prior to the diagnosis of cancer. They have since felt a sense of freedom once they had come to terms with the thought of their own mortality.

Trudy explains further the sense of freedom she now has:

And it is really people are quite dispensable and it is important for you to take that time off, and to hell with it, they will cope, the whole world is not going to come tumbling down because I am not there. That is a huge thing. Now when everyone is out, and I am not out, I

love it, I don't really care what they're doing. I am at home, I am in my own world, and it is a safe world. I find myself now very protective of myself and who I am.

Through the diagnosis experience Trudy has since learnt that the world goes on without her. She feels more secure in her world now than she did before. She now knows that she can take whatever time out she needs to in order to do the things she wants to do without feeling she is letting the side down. She no longer feels harnessed to the crowd. Trudy feels she is a free but insignificant individual living within a very big world. She no longer feels the pull of the crowd. She no longer feels that she might be missing out on something. She enjoys the simple things in life, like her own company and space. She very much enjoys and appreciates the time she has with herself. She is happy and secure in this knowledge. Trudy wishes to maintain this state of being. In order to do this she points out: “... *So I am very protective of myself. It is just learning to listen, and I cannot stress that enough*”. Trudy thinks it's important to listen to yourself more and not so much the voice of the crowd, when it comes to the matter of your own needs in order to lead a healthy fulfilled life.

I asked Trudy the question if the cancer diagnosis had helped her to find herself? To this she replied: “*Absolutely, I have never felt more secure, more strong, and more capable of dealing with things in life*”. Trudy now feels she is a whole person. She is no longer feeling as vulnerable as she did prior to her diagnosis. She believes that she is more equipped to meet life and all the things it might throw at her with confidence and without too much fear or anxiety. She adds: “*But now I have learned that no, you have to make things happen for yourself because you are in charge of your own destiny at the end of the day.*” Trudy has found the steering wheel for her life and will not be letting go. She enjoys being the driving force in her own life's journey.

What this means then, is that the shock revelation that one has cancer and that one is mortal changes the perspectives that many of the participants held on life. Many imply they have a new sense of freedom. Priorities have changed. They no longer spend their lives in trying to live up to the expectation of others, although they have not become more selfish since being diagnosed. They now know that life is short and is finite. They have come to an understanding that their lives are their own to live out

as individuals. They have a greater sense of themselves. The participants talk of being happier in who they are, having a greater self-confidence in their own judgments. They have become more assertive people, who no longer feel they are missing out on something by doing their own thing. The participants now take the time they need for themselves, to be in contact with their own bodies, their own thoughts, and their own world. They have found the time for their own needs by freeing themselves from following the perceived unnecessary wishes of others. They no longer care what these others think of them, as they now know who they are and their place in the world. Also from knowing who they are they find they are better able to understand the motivation of others. They have become assertive in protecting themselves from any future domination by others. The participants feel they are more attuned to life and to their own selves. They feel more in control of their own destinies. So why is it that knowing one has cancer and that one could die at any time gives the person a greater sense of personal assurance and freedom?

The pull of other (they power)

In them he saw himself, saw all that had formed his life, and saw clearly that all of this was aside from the real thing, that it was all a dreadful and enormous deception hiding the truths of life and death. (Tolstoy, 1886, p. 280)

Trudy in the previous section talked of the feeling that the ‘harness had snapped’. She had felt freed from something. Previously she had been rushing about in her life trying to please others at her own expense. She was sure that the diagnosis of cancer had freed her from this. She felt happier and more secure in herself since having had come to terms with her diagnosis of cancer. Why has this occurred and what has changed in order for Trudy, Jane and Jenny to feel this way? This section will explore further the notion of not being in control of one’s own self and one’s own life.

Prior to her diagnosis Trudy felt she had been drifting along in life without any set purpose of her own. She had always spent her time in earning the money she thought would give her the necessary security in life; a life of earn and consume. There had been so many things one just had to do. The days, weeks, months and years rolled by

in this fashion. I asked Trudy why she thought her diagnosis had given her the strength to take control over her life? She replied: “*Because I did not believe in the power of who I was, really, I don’t think.*” Prior to being diagnosed Trudy felt vulnerable as herself. She was unsure and insecure. She lacked confidence in herself and who she was in the world.

Apparently it was the diagnosis of cancer that aided Trudy to find the confidence and security in being her own person. Trudy explains further:

I had been living my life. And I thought, how could I ever have let myself, how did I have so little respect not only for my physical self, but my emotional self, and it is a shame that it takes something like cancer to make you wake up and realise... It made me realise that you only have one life; you don’t get a second chance at all. So if you believe something in your heart that you should be doing, or if you do not want to do something, then jolly well do not do it. It is a matter of believing in yourself, which I think in society we live to do things to make other people happy. You are not doing things that fulfil yourself.

In understanding that she will actually die, Trudy realised that much of what she thought was important actually was not. It had appeared to be important to the wishes of other people. Through her coming to terms with having cancer, Trudy came to see through the constructed world of the ‘they’. Trudy had been freed to see and do as she now wished.

I asked Trudy at this stage of the conversation if she had been talking about trying to please real people, or a concept of a force of people out there somewhere. I had asked her this question because I had thought it was important to distinguish any possible misconception that she was trying to please real other people who were in her life. She replied: “*A concept, it is an absolute concept!*” Trudy is confirming here that Heidegger’s concept of the ‘tyranny of the they’ was real for her in her life up until the time of her diagnosis. To ensure I was understanding Trudy correctly I further

asked, if she was not talking about making her mother happy, or someone like this? She replied: “*No, no, not at all.*”

I further inquired if it is the concept, the peer pressure that this is what you should be doing, sort of thing? “*Yes!*” was her reply. Trudy tries to give further explanation to the feeling that one should comply with the wishes of the other (‘they’).

But you don't realise that you do, but you do, because you don't want to miss out. So you are not going there for you, you are going to be part of the group, against your own free will... but it has taken me until now, and particularly since I was diagnosed with cancer, to be able to know who I actually was, and what do I really want. And now, if I don't want to go there because they are not my favourite people, I would rather spend time with people I genuinely love, all the time, I am not just going to go to make acquaintances, it is all about quality not quantity.

Trudy had no idea of the covert ‘they’ power over her life prior to her diagnosis. She had just complied in things as she had felt was expected of her. She complied even when she did not wish to do so. It had been an underlying feeling of some other force or will, that was not her own, a force of will that remained hidden from Trudy until she had faced up to her own mortality. Having to face the thought of her own death appeared to have wrenched Trudy from the power that the ‘will of others’ had held over her. She has since found her own will power. She seems to have found a confidence within herself which she did not possess prior to her diagnosis. Before she felt she had to comply and fill her time with lots of things. Now she realises life is about quality time, time spent doing the things that she wants to do and not the many things ‘they’ would have her doing.

Jane talks of finding strength in her own independence through having an overall sense of greater security in belonging with and being accepted by others.

I think perhaps you could say one is more independent, because you really are part of a community, you are more part of a community, or I

am more part of a community than I ever was in lots of ways, whether that be my family or my friends, or patients, or whatever and that is quite good.

Jane now feels even more secure and accepted as herself within the community of humankind. Jane feels this way probably by firstly being freed by her cancer diagnosis and then through finding the support during the time she was trying to make sense of her subsequently altered world. Jane learnt from her experience that she belongs in life with others. She is here in her life with others. She feels more a part of the greater community of mankind. Jane feels less under threat of being left alone in her life. She does not feel the pull upon her to be always having to please others in order to be accepted. She no longer fears being outcast and being left alone. In the section headed 'A need for other' Jane had expressed how she felt that her family, friends, fellow patients, and health workers had shared her journey with her. She has grown closer to people and accepts them warmly for who they are as she now knows they accept her.

Trudy also reflects her new found confidence and the independence she now feels she has in her following statement. *"I find now I can read people's emotions a lot more clearly, and I can understand what is going on before people will pass comment. I find it easier to say no and walk away."* Not only does Trudy feel confident in her new-found freedom. She feels she is better able to read and understand what is really going on with people. She is more able to trust her own judgement and resist the forces of the 'will of other'. She is no longer drawn in by the 'will of other'. If things don't feel right for her she finds it easier for her to disconnect herself from people and situations with which she does not wish to be involved.

Jenny now finds it much easier to tell people she has cancer. *"But you get used to it"* she says. Why is this? What has changed for her to be able to say 'cancer', to people without feeling awkward about it? Jenny gives some insight into this question:

It has probably given me that strength to say if I don't want to do something, then I am not going to do it... I have probably learned to stand up for myself a lot more than I did... and also in the ways that

people treat you, I have had people in my life who I have thought were my friends but they have not been very nice to me... I think it has made me say well you know what, I don't need people like that in my life, and I won't have them... So I guess you start to see the way people treat you and say that is it, no more, and I won't have anyone in my life treat me badly, and that is probably one of the biggest things... It has made me stand up for myself a lot better... It's my life, it is my choice... it does change your perspective on life in a lot of ways... I just don't worry about things so much any more. It is like who cares. But you worry about yourself.

Jenny has been made to face her fear of cancer, of death. She has had to stand alone to face her fear of these things. Heidegger (1926/1996) expresses that in death the person is made to stand alone in their own individuality. In standing alone in facing her fear, Jenny has found a sense of strength within herself, a new-found confidence and trust in herself and in her judgement. She also expresses the idea that she is now better able to understand the motivation in others. Jenny will no longer tolerate being manipulated by insincere others. She no longer cares what they think. Through her diagnosis of cancer Jenny has become her own person. Therefore she is now able to stand up to the 'will of others' and talk openly about cancer.

Through being diagnosed with cancer Trudy expresses strongly the feeling of being freed from something. She goes on to explain how although she thought she was a strong person she often found herself doing and saying things she really did not want to be involved with. She even went on to say she found herself doing things against her own will. Up until the cancer diagnosis she was not aware of this power that a concept of the 'will of others' had held over her. The cancer diagnosis somehow caused the 'will of other' to dissipate. It no longer holds any power over her. Since her diagnosis Trudy is able to see it as some sort of illusion that prior to being diagnosed had huge power over how she conducted her life. Jane talks of feeling a greater sense of security in knowing that she belongs. She has gained a wide sense of community from her experience. Both Trudy and Jenny believe in themselves more and have found a confidence in who they are. They no longer care so much about

what others may think of them. They do however feel very close to and care about the real people in their lives.

The connection with other

I am taking leave of life with the realization that I have squandered all that was given to me, and that it is too late to do anything about it - what then?
(Tolstoy, 1886, p. 280)

Real other people are not only important in our lives when we are coming to terms with an illness such as cancer, they are an important part of who we are in our everyday lives. Many of the participants have lost the sense of being willed by some unknown force of other, and have replaced this with an enhanced appreciation of who they are and for the real relationships they have with the people in their lives. Let us now explore further the idea of a greater appreciation of the others that participants have in their lives.

Jenny articulates just how important and taken for granted others can be in our lives. When she realised she could die Jenny had this to say about what worried her most: *“I would be leaving behind people that loved me.”* Jenny has realised that upon her death the connections she has with the others of this world would be broken. Jenny’s perception of this facet of death is similar to that of Heidegger’s.

Heidegger (1926/1996) suggests that in death, or when one is faced with the actuality of one’s own death, the person realises their own singular beingness in their existence. It is in this existence that we have our connection with all the others we have come to know. All these connections the participants have with other beings are to be broken when they die. John reveals his awareness of his inevitable future disconnection with the others in his life in the following statement: *“When you go through something like this you start to value friendships and family, and the time you spend together a whole lot more because you realise that you are vulnerable to these things. You are not superman.”* John now realises he won’t be around always, he also now realises his connections with his friends and family are also vulnerable through life being

vulnerable. He no longer takes family and friends for granted as he now appreciates his time with them is limited.

So, faced with one's own death, one sees one's relationships with the others of one's world to be broken. One suddenly sees oneself in isolation, and at the same time sees ahead to the breaking of relationships with those one loves. One is alone but not alone in life and death. The real others who one loves within one's life live within one and go along with one as explained earlier by Jane and Jill.

Therefore the participants through their cancer experience have come to realise for themselves the importance of their relationships with others. The real others in their lives give to them, a reason for living. The participants realise the importance of the support of others in coming to terms with the adversities of life. Through being diagnosed with cancer participants have been made to realise their vulnerability in life and that they are mere mortals. The realisation that life can end at any time has enhanced their appreciation of their relationships. They have come to realise that it is these relationships that are the cherished wealth within the gift of life. Has anything else changed in how the participants view the world since they have come to terms with themselves having cancer? I wish to now examine what it is that participants think has changed the most in them since coming to an acceptance of cancer within their lives.

New understandings

The philosophy which is so important in each of us is not a technical matter; it is our more or less dumb sense of what life honestly and deeply means... it is our individual way of just seeing and feeling the total push and pull of the cosmos. (W. James, 1907, in Holland & Lewis, 2000, p. 7)

The participants at the beginning of the journey when told they had cancer went into a state of shock caused by fear of death and the unknown. It appears they also went into shock because the understandings they then held for themselves of invincibility and of a presumed and taken-for-granted future had disintegrated in the moment of the diagnosis. They found themselves to be not only frightened but also lost and

vulnerable. After a period of a few months, a change had occurred in how they viewed themselves and their lives.

When the participants were diagnosed with cancer many found themselves freed from the influence of 'the will of others' ('they'). Participants talk of feeling a greater sense of security within their own being and feeling more confident and able to make their own decisions about what it is that they want in life. Through having a greater sense of freedom and self-assurance participants find they have increased their time for living now and for appreciating the moment.

More time

Because the participants spend less time in doing things in order to please the perception of others, they talk of having more time to themselves. John, Jack, Jenny and Jill have all described this feeling of having more time and not being so caught up in the day-to-day taking care of the 'they' things which can imply the material and social niceties of this world.

John explains this affect of the cancer diagnosis upon his concept of time as follows:

I realised that it is time for me that I have at my disposal ... you can do something about it! You can make the changes and get closer to your family and buy that kayak, and make that extra trip home. Rather than not having the time to take care of those things. That was huge for me. As opposed to dying suddenly without any warning.

John by knowing that he has cancer gained the knowledge that his time is limited. He has readjusted his priorities within his life and has found the time to do those things that are important to him personally. He also implies here that most people die without having this warning that he has been thankful to receive. The warning that one is certain to die and this could happen at any time. He also implies that by not realising that death is always an everyday possibility, people spend much, if not all, of their time not doing those things that they would really want to do. People are too busy doing those things they feel they should be doing such as lawns, the vacuuming,

and being with the crowd. People are busy doing what they feel is expected of them. John realises that the time he has in his life is his time and nobody else's. Being diagnosed of cancer freed John from the overall feeling that he had to please others, the feeling that to be considered a good person he had to fit in with their wishes.

Jack explains a similar change in his perception of what it is that time is there to be used for:

I used to be an impatient sort of person. I always had my days planned, I did not like them to be interrupted by visitors. Now I am much more relaxed and accept these things much more readily. It is nice to see people... Time does not mean quite the same to me; it's probably more limited now, I am happy to spend more time with my family. The tasks can wait; they do not matter as much... I noticed there were all sorts of things, little things like, I told my oldest son that I was proud of him. I now talk to my older daughter who is a thirty-year-old woman, as an adult and not as a child. I think of them as nice kids now. So relationships have changed.

Time prior to Jack's diagnosis of cancer was time to fit things in to do the tasks he had set for himself. He had various projects on the go, with more to follow when they were done, both at work and at home. These tasks had been given priority by Jack and had filled up his day. Time was time available for jobs and there was not enough of it. Time was not something to be wasted with idle banter. Since being diagnosed, time has a different meaning for Jack. Time is now the time for being connected with people. Tasks are things that might need to be done eventually; but usually are not as critical for him to do as he once thought. Cancer has brought Jack to an understanding of this, an understanding that tasks are not the reason for living. Jack realises his time with his family is limited but also very special to him. This understanding has caused Jack to feel relaxed about time and within himself. Time is no longer something that races by. Jack chooses to spend time in relation to the real people of his life. He no longer feels the pull of having to please others.

Learning that living is now

Trudy sums up her experience by talking of the very valuable lesson she has learnt through receiving the diagnosis of cancer:

I really like who I am, now. I know people love me, and I always tell people now, I am not ashamed to tell people I love them because as much as I might die of cancer tomorrow, they might get hit by a car tomorrow... That is what people forget, and that is why I am happy in a way, not happy that I have had cancer, I am happy that I have been given this lesson, I don't have any regrets about having it, I don't say why me, why me.

Trudy's lesson is that she has been reminded of her mortality and that it is pointless trying to avoid the reality of this. She, like John, is thankful of this lesson. The lesson of one's mortality appears to be the most important positive factor that many of the participants are thankful for from their cancer experience. Trudy also likes herself more since her diagnosis. She feels loved through the experience and is more willing to openly reveal to people the return of their love. She knows they are in the same boat as her and that they could just as easily die tomorrow. Trudy understands that her relation with the people in her life can be severed through her death or their death at any time. She is thankful that she now understands this and lives with this knowledge. Trudy now appreciates her life and the lives of others. She no longer takes life for granted.

Jack now thinks about his future and while accepting the cancer he looks to his future with warmth and an attitude of 'what will be will be'. *"I think about my future, you could not say it was bright because sooner or later this disease is probably going to get me, but it is nice, you know. I don't feel too bad."* Jack remains aware of his cancer and that it will probably shorten his life. He is philosophical about the time he has and enjoys life. Since being diagnosed Jack has noticed a change within himself.

Now I am much more relaxed and accept these things much more readily. It is nice to see people... I am quite happy to spend much more time with my grandsons for example, whereas before I would say well I have got the lawns to mow and something else to do. Now I don't care. I do it when I have got the time to do it...

Despite cancer and the possibility of death, Jack is content and happy in his life. Not only this, but he finds he is a more relaxed and accepting person. What has changed for Jack? What has changed is that Jack (like other participants) now lives knowing of his mortality. Jack implies this in his statement above when he says: “*It's probably more limited now*” referring to his measurable time in life. Jack also says: “... *you could not say it was bright because sooner or later this disease is probably going to get me, but it is nice, you know...*” Jack now knows he is not here indefinitely, that his grandchildren and the people of his life will not always be there. This is what is important in life for Jack; quality time with the people he loves. The lawns can wait!

John similarly values his time with others more than he did previously.

You start to value friendships and family and the time that you spend together a whole lot more because you realise that you are vulnerable to these things... You try not to take things for granted, and it is not just the other things that happen in your life, but the people and relationships that matter the most... you do not worry about things, that maybe you would have worried about before. They become less significant... I hope this is something that stays with me... I hope I do not fall back into that... rather than not having the time to take care of those things. That was huge for me.

John feels that his life has now been placed into a more real perspective for him through his cancer experience. He is appreciative of this, appreciative that he has been made more aware of the fact that he will die. He now lives with the awareness of the reality of imminent death being a real possibility in life. Knowing that he could die at any time in his life, John feels a happier more fulfilled human being. He feels more

fulfilled through knowing his time is limited and by being able to act on this knowledge and do the things he feels is important to him. He hopes not to fall back into the perspective he held of life prior to his diagnosis, a perspective in which his life was being used up worrying about the insignificant. When one lives a form of life where no matter what it is one does one feels that time is being wasted.

Living in and for the moment

Jane talks about a shift in her perspective where she feels she is more alive in her moment of living:

I want to really make the most of everything I can do. Relationships, and day-to-day relationships and anything like that, I just want to make the most of it. Whereas I think I am actually more in the moment now than I ever was, and that is actually a nice thing, it is wonderful... I just think it is a healthy perspective now.

Jane's perspective of life has been changed by the cancer diagnosis. She now understands and accepts that her time in life is finite and she wishes to make the most of the time she has available to her. Relationships matter to her. They are important in her newly formed perspective of life. Jane lives for the present and is not so much striving for that better time in the future, a future that she is well aware may never come. Jane is aware that because her life is now, her time for living is also now. She finds living, while knowing she is in her moment of life, to be a joyous way of being in life. She does not worry so much about the future. Jane feels her perspective now to be a healthier perspective than before.

Jill implies in the following statement that she is not so much made afraid by the things of her life when she says: *"In some ways I don't find it so scary. I think I have learned so much more about myself."* Jill is no longer so afraid. She also has faced cancer and through it death. She has come to know herself better through this experience. Jill goes on to explain some of what she found about herself.

Before [the diagnosis] we were thinking about renovating the house,

and I was thinking about doing this and doing that, and all of a sudden when you get some illness like that, it just changes your whole perspective on life, on how material things are so unimportant, I mean, we have really close extended family and immediate family, and it just made me realise how lucky I was to have that.

Jill, like many of the other participants, prior to receiving their cancer diagnosis was running around being very busy doing the things she was expected to do. The diagnosis forced her to face her mortality also. Through facing the real possibility of her own death and coming to the realisation that she will die and can die at any time caused the significance of the material things of this world to disintegrate in their importance to her. Instead she came to realise how wealthy she really was in the things that mattered most to her, 'family'.

Jill gives us an insight into her realisation of the importance of family in the following statement:

... We were all lying there on the bean bags and I was lying there with my grand-daughters and my son and my daughter, and my daughter-in-law, and I just burst into tears, and [they asked] what's wrong, and I said, nothing is wrong everything is perfect. You know, just to be able to have that relaxed relationship with people close to you, and things that you just take for granted every day, I do not take for granted ever now.

Jill found this moment she was having with her family to be an absolute joy for her. At the same time Jill also realises that the time she has with the people that make up her family is not always going to be there. She no longer takes these moments for granted and recognises the wealth in these moments for her.

Jill has also found a heightened appreciation for life itself. She demonstrates this in her following explanation of the difference between living in the now and in living towards the future:

So yes I think your whole perspective [changes], and I think you become very close to nature in a way, like trees, and just everything I really enjoy, and I always have been close to nature but I really enjoy now getting out on a windy day and walking along the beach... sometimes I will walk and I will just - cry. It is just because I am thankful I am here to enjoy what I can, I guess. And you can get so wound up in life that you look at the negative things, you are a bit tired from work, and you get to work so much that you forget that it is a beautiful world and there are a lot of neat people in it, and you just look past it, and it is almost like how can I have ignored this for so long, how can I have got so caught up in work and the day-to-day bustle that I have let this all go, and I think that has become overwhelming, and I found that, and I make a lot of time for all those things now.

Jill states that previously she got caught up in something that caused her to look past life itself. She became so wound up in just living that she took the things of everyday life for granted. She did not think she had the time to appreciate life itself. Jill's daily time remains the same on the clock. The things of everyday life had always been there. So how is it that Jill notices the good things of a natural life now?

Through being diagnosed of cancer, Jill now knows the fragility and temporary nature of life and normal everyday things. She now sees the things of everyday life in her knowing that they will not always be present for her. Chasing the things of immortality such as golden wealth, fame and stardom no longer seems real. She now looks past these things for they are only an illusion for those frightened by death. Jill is no longer as frightened as she was prior to her diagnosis. She knows that she has come a long way. Jill now lives in the moment, with and amongst the everyday things of life. She now knows their true value.

In short, when the participants come to terms with their diagnosis and what it means to them, it would appear by having a changed perspective on life that they do not only feel a greater reassurance in their own individuality, they also come into a position of having more time available for themselves. This is time to spend with family and

friends, enjoying the simple pleasures of life. They become appreciative of time in the present. They are no longer focused on the future. The participants have learnt through their experience to live in the now and through doing so enjoy every moment they can get.

Conclusion

The assertions of the consumer world on which Western society is founded upon, just disintegrate into the illusion it is, when the human being is faced with his/her death. Humankind is part of the natural world and no matter what a human thinks, does, or consumes, he, or, she, will never escape this reality. This is just an illusion of the 'they'. The illusion that one can live forever also disintegrates. As John realised: *"What is the point in being the richest man in the graveyard?"*

It would appear that it is not cancer itself which causes the shock within the experience, but people's perception of what it is that having cancer means to them. At the time of diagnosis they were not prepared to face cancer and its meaning of death. Their previous approach to life had not included an understanding of cancer/death. When faced with cancer and their own mortality the participants come to the realisation that they are no more special than anyone else. They come to accept their own mortality and that they are just one of the 'everyone' of humanity, involved in their own journey of life. All journeys of life will include death no matter what individuals do or think. No one is more special than anyone else. Human beings are all special. Upon realising this, participants stop striving to be that special person they feel they have to be in order to find acceptance. They suddenly find that the people who matter to them accept them anyway. They also find acceptance of themselves, the acceptance of a way of being in life which Heidegger termed "authentic being", which is a life many find to be more fulfilling than before they had cancer. They are happier people who accept life as it is. They are no longer rushing about, not seeing life for what it is. They see life as their own special gift. They see life as something to be savoured in its every possible moment. The participants in this story love life. It is true that they would all love to not have cancer. But most of the participants in this story cherish the one major lesson they received from within the experience. That lesson is knowing that they will die and that their lives are now their own to live. The

findings within the data will be summarised as a whole and discussed in terms of how this relates to current health provision services.

Chapter Seven

Discussion

It seems plain and self-evident, yet it needs to be said: the isolated knowledge obtained by a group of specialists in a narrow field has in itself no value whatsoever, but only in its synthesis with all the rest of knowledge and only in as much as it really contributes in this synthesis toward answering the demand, “who are we?” (Erwin Schrodinger, in Goleman, 1985, p. 7)

Introduction

In the ‘real world’, which humans to some degree have created for themselves, rapid and abrupt change does not usually occur. Change normally occurs gradually at a pace that can be managed. People within society are usually advised that a planned and controlled change is going to occur. They are introduced to the change in bite-size chunks. They are even given training in how to navigate within this changing world.

The person who has cancer is faced with sudden and abrupt change. A change that they thought would never happen to them. This is a change considered so unthinkable that no one talks about it until it actually happens. A change, that once it occurs, evokes a silence from those closest about the topics of cancer and death. The person so much wants the comfort and understanding of others, but these others appear to be uncomfortable being with the person and facing the situation with them.

In the following summary of findings, I have fused the interpretations of the data presented in chapters four, five and six, together with philosophy as presented in chapter three, and the ideas relating to the fear of death and the assumptive world of the person, presented in chapter two. As I was interpreting the participants’ experiences, I was reading the literature around the various elements as they came to light, while trying to think from a Heideggerian perspective. While the literature review was placed before the data analysis to prepare the thinking-ground of the reader, it grew out of the understandings that came from the data. The reader is therefore encouraged to engage in a circular process of reading, and return to Chapter Two to confirm the support offered by the literature for the findings. This fusion of

understanding guides my discussion of these findings and explanation of how they relate to oncology services, nursing practice, and policy makers, health delivery services and consumer groups.

Revealing the experience

For most the diagnosis of cancer is met with a shock reaction - they never thought they personally could have cancer. The possibility of their dying before old age never occurred to them as being real. The person's understanding of themselves and their world is immediately thrown into confusion. They had somehow believed that they were immune. Yet they soon realise they are not immortal. Shock appears to act as a defence mechanism against the full emotional impact of the chaos that having cancer inflicts upon them. The numbing effect of shock removes them from the situation in a partial state of unawareness. They make adjustments in their understandings and learn to face having cancer, being mortal and being temporary in within their world. They face a new world where nothing is certain, nothing can be taken for granted in its being always there. Death is now part of life. People do not talk of cancer and death. There is an underlying force, or rule, that implies these topics are improper and people do not want you to talk of such things. Most human beings feel isolated and unable to express their feelings and thoughts in relation to cancer and death. They find a wall of silence around these topics. They feel isolated, alone, and frightened. They lose control in a world that has become strange and confusing. They do not understand what is happening or going to happen to them. They do not even know if there is going to be a future and what this future will bring. The unknown-ness is frightening. They need to learn to live with uncertainty.

In time, through connection and in their discussions with mainly family and friends, they find purpose and meaning for themselves, they begin to look for positive things in order to gain hope (also described by Berger and Luckmann 1971; Janoff-Bulman 1992). Eventually they gain a sense of control, which helps reduce fear and their feelings of isolation. Yet they also find that somewhere within the journey they have become more self-assured and accepting of others. They live lives that are less fearful, and so have a greater sense of freedom. They have an increased awareness in their

own being, being alive and what this means to them personally. They enjoy being themselves, having connections with others in their life, and they come to appreciate their own time within life. Their sense of time as something that is always present, but illusive, has gone and instead, time is seen as something on hand and to be enjoyed in its presence. Time is a gift in life. It can leave the person at any time, but while it is there, it is the person's own to make of it what they will. Paradoxically then, within the cancer experience they experience being happier and more contented.

Discussion of implications

Revealing the experience

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Discussion of implications

The purpose of this thesis is to make the experience more visible to all those involved, be they the person having to face up to the new reality of cancer in life, the people who are there as significant others and the health workers involved in provision of care. By making the experience more visible and understood, I hope to alleviate some of the person's anguish, emotional pain and suffering. This journey can be made to be less daunting in its current apparent loneliness and in its frightening intensity, if its unknown quantities are revealed. This change will come through all parties having greater understanding of themselves within the cancer experience and finding the courage to stand and face the reality of cancer with open concern and fellowship.

I have been working with people diagnosed with cancer within the hospital environment for some four years. Until I had began the process of reflecting upon the interviews of which I conducted during the course of this study with participants, I did not understand the experience of people for whom I cared. I knew about shock and the fear of death, but I had no real understanding of the journey these people were forced

to undertake. I know that others working with cancer patients will lack in-depth knowledge of this journey. The plight of people's experience may have been unrecognised because of the approach created by the positivist paradigm informing modern science, and through society's own fear of death. Those who think in terms of there only being one possible reality are unable to recognise the person as a being that is thrown into a world, making understandings based upon the situation and personal experiences. In the Western world, the positivist paradigm assumes that there is only the one reality. The diagnosis of cancer, which has caused the person's shock, is seen to cause a deviation from the normal state, in which members should live. Western health systems seem to assume the person who has managed to pass through the shock stage returns to a perspective of normality. The assumption that shock is a negative symptom caused by traumatic news, that people will get over or not, reflects Western societies' unwillingness to understand such experiences. Western culture and thus Western health systems until recently have concentrated on avoiding exposing people to the possible thought of cancer and death, even when the person themselves is aware they are at the moment of their death (Kubler-Ross, 1969). In so doing, studies into their effects on people have been few. Also, by trying to avoid exposing people to the thought of cancer and death, the person facing cancer has often unknowingly been isolated emotionally from the mainstream of society. The person facing cancer is often forced to enter this frighteningly uncharted territory alone.

A number of important elements have been brought to light in the course of my research. These elements are: The need to belong, to be accepted, and to have a purpose; the need of the person to understand what is happening to them; and the need for human connection, support and understanding. The literature (Berger & Luckmann 1971; Herman, 1992; Janoff-Bulman, 1992) and the participants within this study have made it clear that their recovery from their trauma of knowing they had cancer comes from a base of self-empowerment which can be found in one's connection with others. Those supporting and caring for the person need to understand this. I also believe it would be comforting to those commencing this frightening journey to know that their shock has a purpose, that their fear can be overcome with understanding and through openly communicating these fears, thoughts and emotions with others. I believe that they would be comforted to know

that the many people like them that have been through the cancer journey have had positive things to say about the outcome of this journey.

I believe additional understanding of the initial period of the cancer journey from my study will help offer insights that are currently missing. These insights guide and provide insight and understanding to the person and their supporters, so that the many facing this journey no longer feel so lost, so alone, and so frightened, as they set out upon the cancer journey.

Erwin Schrodinger (1985) in the introductory quote to this chapter points out that knowledge that remains isolated and not put into practice is worthless. I found, as I ventured into the various elements of the initial cancer journey, that I was unaware of many of the elements, such as: the sense of freedom, the need to adjust to a new reality, the reasons for others in coming to terms with the changes. Some authors, as described in chapter two, had previously written or touched upon these elements, but in my search of the literature I found only partial explanations of various parts of the cancer journey. I found no in-depth representation or explanation for the journey as a whole that could be used to convey the journey to those working with and in support of the person recently diagnosed, or to person beginning the journey themselves.

The real significance of this research is the ascertainment of a greater understanding of the person involved in coming to terms with the cancer diagnosis and their subsequent journey. Up till now, the understanding of the person having to face the trauma of cancer has been largely ignored and, in my experience, has not been encapsulated enough within our practice. Through having an understanding of the cancer journey, health professionals, family members and other support people, should be better equipped to make those vital connections with the person.

In order to convey the cancer journey clearly and in an easily understandable manner to others, I needed to firstly obtain a good clarity of understanding for myself. I then had to ensure that the clarity I obtained was passed through my writing on to potential readers. I hope that I have achieved that clarity so that the following recommendations I wish to make to oncology services, nursing practice and to policy makers, health

providers and consumer groups, are easily understood in terms of the reason for their need.

Recommendations for oncology services

Oncology services focus on the care of the whole person from the time they are diagnosed with cancer. In order to care for the person, oncology services and those working within oncology need to be always seeking to understand those to whom they provide their services. The service should be designed around the needs of the person diagnosed with cancer. Matters coming to light through this research project that can be utilised to guide oncology services in improving their service to the patient fall into two distinct areas. These are, firstly, in providing a resource on which patient, family and staff education material can be based, and, secondly, providing a greater understanding of the person to which oncology services are directed.

Resource on which to base education and understanding

The understanding of the person's experience of being recently diagnosed with cancer can be used as a base resource from which to provide patient, family and staff education resource material. Oncology health workers who have a good in-depth understanding of the needs of the person at this time would be better equipped to help the person through their trauma caused by the news of having cancer.

The participants in this study have expressed that in talking with others who have been through a similar experience to their own, they achieved a sense of connection with these others, and found that they became much comforted through finding insight into their own journey from these talks. This revelation not only reconfirms the importance for the person to meet with others in, or having been in, a similar situation to their own, it also reveals the strong need that they have to find understanding within their situation. Guidance in understanding from support people

with insight and an understanding of this experience may also prove to be extremely beneficial and comforting to the person. The more others can understand and openly communicate with the person, the less isolation, loneliness, fear and loss of control the person should experience. The more understanding that can be given to the person and is provided around that person, the less the burden and the sense of lost-ness they should experience. Understanding by all parties concerned may also help to shorten the person's adjustment period, as they should be more able to openly discuss what it is that frightens and confuses them. Through improved understanding leading to open communication, the person possibly may be able to move more quickly in finding new meanings and reconnect with the world around them.

How this understanding may affect oncology services

Those working in oncology areas should be openly encouraged to address their own fears of cancer and death, so they themselves will be better positioned to support the person who is adjusting to cancer. Kubler-Ross (1969) pointed out that until a person can face the reality of their own death, they are in no position to support someone facing theirs.

Oncology services need to understand that the person they are caring for has been thrown into a chaotic world and while they undergo the adjustments that are necessary to make sense of things again, they need a stable environment (Herman, 1992; Janoff-Bulman, 1992). A vital part of the stable environment that is important in aiding the person to make a positive adjustment to having cancer consists of supportive and caring others (Herman, 1992; Janoff-Bulman, 1992). The environment established for the person should be inclusive and not exclusive of the others within that person's life. All possible connections to their normal lives should be maintained in order to maintain some form of environment that they can understand and make sense connections with. This should help to decrease the overall sense of chaos, confusion, isolation and lost control that many participants experienced. This could mean that delivery services should be provided as much as possible in the home and in the community of the person. Health service environments need to be designed and delivered in ways that encourage inclusion of the person's others, not exclusion.

Perhaps oncology services can encourage and allow friends and families to deliver much of the care? They could provide services that support the supporter better in education, counselling, and respite cares. In the health service delivery environments, services could provide the supporter with a bed, tea-making and food-preparation facilities and areas in which all parties can relax and unwind.

The person's own support team should be included as part of that person's care team. Oncology services need to maintain the attitude that all those around the person are equal members of that person's team. Health workers should never exclude other members of the support team thinking their intervention is more important than, say, the family member who is present with them. The care of the person should be shared, with no party other than the patient having the ultimate control.

In the initial period, the person's world has become turned upside down. They need stability, regular people on which to build relationships with, not just a nurse or a doctor but the doctor/nurse they know and have come to trust. They need a sense of safety and security during their period of adjustment. Seeing different faces each time they come into hospital, or seek advice on some information or care, will not help them feel supported and safe. This will only inhibit the adjustment process rather than assist it. Support and care is about the relationship and understandings between people, not the tasks and no, not just anyone will do. It needs to be people they know and have learnt to trust and open up to, as much as is practicable.

Recommendations for nursing practice

Many of the recommendations I have made for oncology services also apply to nurses working in the oncology area. Nevertheless, in order to achieve effective and total patient care, nursing itself needs to include the journey of the person within its own educational delivery to its membership. If nursing as a whole has greater understanding of the journey, there may be a greater shift within nursing practice towards 'being there' with the person. Many nurses still see the person as the patient, and as something separate from themselves. Nurses need to fully understand the

importance of human connection and why this is so important. Through understanding the importance of other, nursing practice will ensure the inclusion of other within the services in which they are involved.

Through the understanding of the person within the cancer journey, nurses are reminded that it is not just the tasks they perform around the patient that are important, it is how they relate to, and empathise with the person, that will facilitate healing for that person. It is also their total connection with that person as another human being who has similar fears, emotions and needs to that of their own. Nurses will obtain a greater therapeutic relationship with the person when they understand their own being, and the potential of their own being, as a therapeutic agent in context with the relationship they form with the person they are caring for. It is the relationship itself that the person finds comfort in through trust, respect, friendship and empathy.

By understanding that the person is trying to re-establish their own personal identity in the chaos of things, nursing may be better situated in preparing the path for that person. In order to better prepare the journey's course for the person, nursing needs to encourage a break-down in the wall of silence surrounding cancer and death in all areas of the community in which they are involved. In order to achieve this, nurses at first need to recognise and overcome their own fears and biases. Education surrounding the taboos of death and cancer should be included and open discussion of these topics should always be encouraged within the nursing profession. In this way nursing can help to reduce the fear surrounding these topics and also reduce the isolation for the person having to face cancer. Nurses should then themselves be better prepared to discuss the topics of cancer and death openly with their patients when the patient has a need to talk of these matters.

Nurses, through having some understanding of the person who is coming to terms with cancer, are best situated in facilitating and meeting that person's needs. They can help provide an environment that sustains, comforts and assists the person through their shock. Nurses can facilitate understanding in the person, and in the person's support network. They can reduce the normal everyday burdens of the person, while maintaining the person in an environment as normal as possible. The nurse can

reassure the person of their safety and that they will not be abandoned, while also addressing other fears expressed by the person. Nurses should realise that the person will need to find positive meaning within events occurring in their life, as a way for them to gain a sense of control and hope (Barraclough, 1999; Janoff-Bulman, 1992). At the same time the nurse needs to understand the positive things the person is searching for are based upon their own level of reality, and cannot be falsely constructed by others, as this can only serve to jeopardise the empathy and trust that is so badly needed by the person at this time. Open honesty and courage in others is likely to serve the person best at this time.

Recommendations for policy makers, health providers and consumer groups

The public perception of the cancer diagnosis is still seen as a death sentence despite some forms of cancer now being treated fairly successfully, especially when detected early. Cancer education programmes directed at the general public may help to distance the meaning of cancer away from death, thus reducing the fear of cancer within the general public. This may also increase awareness of cancer prevention and increase people's willingness to seek advice early.

This study reveals that most people believe cancer won't happen to them. This gives an insight into why people and society continue to take risks around cancer, and possibly why it is that more resources are not put into the prevention of cancer. Society denies the reality of cancer and death as a personal possibility. As Jenny pointed out, pretending it's not there is no protection. Policy makers and health providers need to face up to cancer's prevalence in modern society, and bring about the awareness that the threat is real. They need to influence and provide the impetus in making provision for and resourcing greater preventative measures. The current trend of placing most resources into curative measures for something that might prove impossible to cure is a further reflection of society's denial of its creaturely existence

and the denial of death. The most effective approach toward controlling cancer is to prevent occurrence in the first place.

Through turning toward and facing the reality of cancer, the current silence that tries to hide cancer can be removed. The health providers can provide services around cancer that no longer isolate the person who has cancer. Services can be provided at a more humanistic level that no longer deny the possibility of death, but includes the possibility in its approach to service delivery around cancer. In New Zealand there is an increasingly growing aging population and the goal of our health services is still aimed at keeping people alive for longer. Money is poured into new technologies that keep people alive long after the quality of life has gone for them. New Zealand is facing huge cost blowouts in health and it is the preventative end that is missing out. Only the preventative end will reduce the overall drain on the health resource and deliver the best overall quality of life to the people of New Zealand. I believe the Western health service is aimed and directed at unobtainable goals based on the unreality that a person can escape death. Policy makers and health delivery services need to look at what it is they wish to achieve and what it is they actually do and find some sort of parity between the two.

Health providers need to include the voice of the patient when planning service delivery. They need to liaise closely with the various cancer support groups that are forums for patient needs and concerns. Cancer services need to be delivered in ways that include the whole person, in environments that include all the others in a person's life. Family and friends need to be catered for and considered when delivering cancer services, especially in the initial period when the person is trying to come to terms with having cancer.

Bridging the gap between practice and research

In order to have the findings from this research project communicated to oncology services, the nursing profession, and to policy makers, health providers and consumer groups, it is my intention firstly to disseminate the findings of this thesis to the health organization in which the research was carried out; the university under whose guidance the study was undertaken, and to the New Zealand Cancer Society. In this

way I hope that that interested parties will have the access to read the insights that have been revealed. I hope those within these organisations, through their reading, gain a deeper understanding, which they can apply to their own practices, services, and education programmes. I hope people reading this thesis in turn can give influence and insight to further research programmes.

It is also my intention to condense the story into its essential parts, sending it to publications such as ‘Oncology nursing forum’; ‘Cancer’, ‘Cancer Nurse’, and ‘Psycho –Oncology’, in order to reach the greater audience involved with supporting the person who is afflicted by cancer. The condensed version of this cancer story can also be used as a basis for presentation to various forums, be they small professional groups, large conference meetings or in talking with patients and their support networks.

Limitations

This study provides insight into the phenomenon of coming to terms with having cancer and why it is they need to make this journey. Although having uncovered many universal elements within the journey, the findings cannot be used to make the statement ‘this is the way it will always be,’ or as a base on which to build behavioural models. Precise and factual explanations about the inner being are impossible to obtain. The purpose of the study was to uncover a more in-depth understanding of the person being involved in the experience of being diagnosed with a life-threatening form of cancer. I believe this study has achieved just that. Although every person having to undergo the cancer experience will have his or her own unique journey, the level of insight reached and conveyed here should help the many undertaking this journey to relate with and to find some solace in the connections they will make from the understandings that have been reached.

Although, eight participants is sufficient for a study of this nature, this number does not ensure the study is extensive in covering all possibilities related to the phenomena of being diagnosed with a life-threatening form of cancer. Also participants were sourced through only one area of a public health service within one urban area of New Zealand. All participants had a blood form of cancer being leukaemia, lymphoma, or, myeloma. People with other forms of cancer and coming through other institutions

within New Zealand or others parts of the world could have different experiences from those interpreted here. The variability of the reported experiences may have been affected by these factors, although I believe the study has aspects that transfer throughout New Zealand at least, because individual treatment and service elements had been put aside in the process of analysis. In interpreting the data, I tried to reach deep within, going past and beyond the effects of individual health service experiences. I did this in order to search for the primordial being (the person stripped back to the inner most being) faced with the news of having a life-threatening form of cancer, and what it was that having cancer meant to them and their inner experience from that point, up until a period where they could concentrate on other things besides cancer. It was only the effect of the cancer diagnosis I was investigating and not the affect of treatments, individual doctors, nurses or institutions.

All participants at the time of their interviews had had positive responses to their treatment. If they had not responded well to their treatment their journey would have taken a different path and their responses would have been different. That path is outside the scope of this study, which is focussed only on understanding the effects of the initial diagnosis and not the terminal phase of cancer.

As stated in chapter three, this study only relates to adults that do not as yet view themselves as elderly. A person who has come to view their life at or near its end may have already passed through an adjustment process in accepting death or cancer. Those under the age of 20 years would also have possibly a different journey to make, as their perspective of themselves, life, cancer and death again would possibly be different to that of an adult. The findings within this study may also be affected by belief systems and the cultural backgrounds of various people.

The study is my interpretation of eight people's retrospective interpretations of their own experiences. A number of biases or misunderstandings could have occurred and have remained hidden within my interpreting, although I have tried to present the data and my interpretations in a way that may reveal possible misinterpretations to the reader.

Recommendations for further studies

Further similar studies, looking at the phenomenon of the effect of the cancer diagnosis upon the person within different cultures will possibly reveal further insights into the person having to face up to having cancer. Also similar studies of people faced with various forms of cancer may reveal further insights that have not been revealed here. For example, how does the impact of surgery and removal of body parts impact on the experience? Studies with children and the elderly would prove interesting and extend the findings of this study.

Participants believe their new-found perspective post the adjustment period to cancer to be a healthier perspective than before. In this study I have only provided limited understandings of why this may be so. The literature also would appear to have only limited insight into this important phenomenon. This phenomenon of feeling self-assured, more content, less rushed, more alive and healthier needs to be further investigated. The sense of freedom so many mention needs further investigation. Freedom from fear and anxieties, or what exactly is it that people are feeling freed from? These findings possibly mean that many people in mainstream society don't actually feel free in living their lives. It appears that only when the shackles are broken that people seem to realise that they were not previously free and wasted much of their own time. Further insights into this phenomenon may prove beneficial to humanity in understanding themselves. It may possibly prove to be the answer of many of our physical, mental and social problems. This also leads on to the idea that perhaps if people were to face their fear of death earlier in life they might lead happier more purposeful lives. This phenomenon is worthy of further investigation.

Death appears to be denied pre-old age and is associated with getting old. Is this possibly the reason for Western societies ageism? There appears to be a turning away from growing old. Is this the reason underlying society's apparent focus on youth and the growing market in all things youthful? Awbrey (1999, p. 43) seems to think this is so when he advises us to "listen to the wisdom of our aging bodies telling us to move beyond youth" and not try and deceive nature in trying to remain youthful! This also gives some insight into possibly why those working with the dying and the elderly are

not empowered, or not highly funded and are generally not given much attention at all. It also gives a possible insight into why much of nursing is so disempowered despite people always repeating what every one else is saying, 'that they admire those working with the elderly, sick and the infirm,' but venture no closer than this in deed or thought. Is it because the mainstream is just so frightened in facing these realities in life? This area also needs further investigation.

The recommendations I have made need to be piloted or studied to see how well they help comfort the person, reduce their sense of isolation, fear and anxiety and aid their overall adjustment to having cancer. The findings and recommendations within this study are not the final answer. They are merely a step forward.

Conclusion

All our progress is but improved means to unimproved ends.
(Bertrand Russell, in Awbrey, 1999, p. 145)

During my interviews with many of the participants I got the feeling that the one message they wished to convey to people was, enjoy your lives now while you can and stop concentrating on the things that do not matter. The exuberance that many of the participants had found in their lives led me to include in my data analysis the sections on 'freeing one's self' and 'the pull of other'. I wished to explore within the data why it was that participants were more accepting of themselves and were feeling so much better because of this. I explored these notions so that some understanding into the reasons for positive growth could be grasped and possibly understood.

Western society clings to the myth that time is progressively marching on towards a brighter and better future, where we all will live free and happy harmonious lives for ever after. A sort of heavenly complex of promised immortality here on earth, if only one can hang on. This thesis leads to the notion that if people face their fears, the fear of cancer and death, people can live happily in the 'now' of their lives. They can live appreciating the time they have and the many taken for granted elements of life. This

appreciation is currently lost to many in the mainstream, who seem to live with an underlying sense that time is running out for them as they clamour to avoid the one thing they can't avoid, 'death'.

This thesis leads to the notion that instead of turning away from the possibility of death, people need to turn towards this possibility, in order to improve their overall quality of life and health. This may bring about an awakening to a freer, accepting and more content perspective for people. Society needs a turn in its perspective, a turning towards who and what we are, a turning towards a more practical reality, a turning towards each other in support and understanding. A turning away from the hopeless pursuit of immortality.

References

- Adams, P. (2000). Death and contemporary popular culture. In A. Kelleher (Ed.), *Death & dying in Australia* (pp.105-115). Melbourne: Oxford University Press.
- Aldwin, C.M., & Sutton, K. J. (1998) A developmental perspective on posttraumatic growth. In R. G. Tedeschi, C. L. Park, & L.G. Calhoun (Eds.), *Posttraumatic Growth: Positive changes in the aftermath of crises.* (pp. 43-64). Mahwah, New Jersey: Lawrence Erlbaum Associates, Publishers.
- Ashbury, F. D., Lockyer, L., McKerracher, K., & Findlay, H. (1997). Focus groups with cancer patients: towards a more comprehensive understanding of the cancer experience. *Prevention & control en cancerologie, 1*(3), 222-227.
- Awbrey, D. S. (1999). *Finding hope in the age of melancholy.* Boston: Little, Brown and Company.
- Barracough, J. (1999). *Cancer and emotion: A practical guide to Psycho-Oncology.* Chichester: John Wiley and Sons Limited.
- Becker, E. (1973). *The denial of death.* N.Y.: Free Press.
- Benner, P. (Ed.). (1994). *The tradition and skill of interpretative phenomenology in studying health, illness and caring practices.* Thousand Oaks: Sage Publications.
- Benner, P., & Wrubel, J. (1989). *The primacy of caring: Stress and coping in Health and Illness.* California: Addison- Wesley Publishing Co.
- Bentz, V., & Shapiro, J. (1998). *Mindful inquiry in social research.* Thousand Oaks: Sage Publications.
- Berger P.L., & Luckmann, T. (1971). *The social construction of reality.* Harmondsworth: Penguin.
- Bloom, S. L. (1998). By the crowd they have been broken, by the crowd they shall be healed: The social transformation of trauma. In R. G.Tedeschi, C. L. Park, & L. G. Calhoun (Eds.), *Post-traumatic growth: Positive changes in the aftermath of crises* (pp. 179-213). Mahwah, New Jersey: Lawrence Erlbaum Associates Publishers.

- Brennan, J. (2001). Adjustment to cancer - coping or personal transition? *Psycho-oncology*, 10, 1-18.
- Brenitz, S. (1983). Denial versus hope: Concluding remarks. In S. Breznitz (Ed.), *The denial of stress*. N.Y: International Universities Press.
- Burton, M., & Watson, M. (1998). *Counselling people with cancer*. Chichester: John Wiley & Sons.
- Caelli, K. (2001). Engaging with phenomenology: Is it more of a challenge than it needs to be? *Qualitative Health Research*, 11(2), 273-281.
- Calhoun, L. G., & Tedeschi, R. G. (1998). Post-traumatic Growth: Future Directions. In R. G. Tedeschi, C. L. Park, & L.G. Calhoun (Eds.), *Post-traumatic Growth: Positive changes in the aftermath of crises*. (pp. 215-238). Mahwah, New Jersey: Lawrence Erlbaum Associates, Publishers.
- Caplan, G. (1961). *An approach to community mental health*. N.Y: Grune & Stratton Inc
- Cohen, B. D., Fidler, J. W., & Etting, M. F. (1995). Introduction: From group process to political dynamics. In J. W. Fidler, & B. D. Cohen (Eds.), *Group process and political dynamics* (pp. 1-22). Madison, CT: International Universities Press.
- Crotty, M. (1998). *The foundations of social research: Meaning and perspective in the research process*. Sydney: Allen & Unwin.
- Dennison, A. (1996). *Uncertain Journey: A woman's experience of living with cancer*. Newmill: The Patten Press.
- Downing, J. (2000). *Nursing in Haematological Oncology*. London: Harcourt Publishers Ltd.
- Epstein, S. (1984). Controversial issues in emotion theory. In P. Shaver (Ed.), *Review of personality and social psychology: Emotions, relationships, and health*. Beverly Hills, California: Sage.
- Farr, D. (1997). *My cancer journey*. Mt Maunganui. N.Z.: Ramose Enterprise.
- Field, D. (1996). Awareness and Modern Dying. *Mortality*, 1(3), 255-265.
- Gadamer, H. (1960/1995). *Truth and Method*. N.Y: Continuum.
- Goleman, D. (1985). *Vital lies, simple truths: the psychology of self-deception*. N.Y: Simon and Schuster.

- Greenberg, M.A.(1995). Cognitive processing of traumas: The role of intrusive thoughts and reappraisals. *Journal of Applied Social Psychology*, 25, 1262-1296.
- Griffin, G. M. (2000). Defining Australian death: Religion and the state. In A. Kelleher (Ed.), *Death & Dying in Australia* (pp. 40-51). Melbourne: Oxford University Press.
- Grondin, J. (1995). *Sources of Hermeneutics*. Albany: State University of New York Press.
- Guignon, C. B. (1993). Heidegger and the problem of knowledge. In C. B. Guignon (Ed.), *The Cambridge companion to Heidegger*. Cambridge: Cambridge Press.
- Hagopian, G. (1993). Cognitive strategies used in adapting to a cancer diagnosis. *Oncology Nursing Forum*, 20(5), 759-763.
- Hall, A. (1997). Psychological support for cancer patients and their medical carers. In J. W. W. Sweetenham, C. J. (Ed.), *Supportive care of the cancer patient* (p. 173-184). London: Arnold.
- Halstead, M. T., & Hull, M. (2001). Struggling with paradoxes: The process of spiritual development in women with cancer. *Oncology Nursing Forum*, 28(10), 1534-1544.
- Heidegger, M. (1926/1996). *Being and Time: A Translation of Sein und Zeit* (J. Stambaugh, Trans.). Albany: State University of New York Press.
- Herman. (1992). *Trauma and Recovery: From domestic abuse to political terror*. London: Harper Collins Publishers.
- Hewstone, M., Stroebe, W., Codol, J., & Stephenson, G. (1989). *Introduction to social psychology*. Oxford: Basil Blackwell Ltd.
- Holland, J. C., & Lewis, S. (2000). *The human side of cancer: living with hope, coping with uncertainty*. New York: Harper Collins Publishers Inc.
- Horowitz, M. J. (1986). *Stress response syndromes*. Northvale: NJ. Aronson.
- Houldin, A. D. (2000). *Patients with cancer: Understanding the psychological pain*. Philadelphia: Lippincott.
- Inwood, M. (1997). *Heidegger*. Oxford: Oxford University Press.
- Janoff-Bulman. (1992). *Shattered assumptions: Towards a new psychology of trauma*. New York: The Free Press.
- Kelleher, A. (1990). *Dying of Cancer: The final year of life*. London.

- Kelleher, A. (Ed.). (2000). *Death & Dying in Australia*. Melbourne: Oxford University Press.
- Kfir, N., & Slevin, M. (1991). *Challenging Cancer: From chaos to control*. London: Tavistock/Routledge.
- Kirk, J., & Miller, M. L. (1986). *Reliability and Validity in Qualitative Research*. London: Sage.
- Koch, T., & Harrington, A. (1998). Reconceptualizing rigour: the case for reflexivity. *Journal of Advanced Nursing*, 28(4), 882-890.
- Kohl, H. (1965). *The age of complexity*. N.Y: New American Library.
- Krause, K. (1991). Contracting cancer and coping with it: patients' experiences. *Cancer Nursing*, 14(5), 240-245.
- Kubler-Ross, E. (1969). *On death and dying*. New York: Macmillan Publishing Company.
- Kubler-Ross, E., & Warshaw, M. (1978). *To live until we say good-bye*. Englewood Cliffs, N. J:Prentice-Hall, Inc.
- Kumasaka, L., & Dungan, J. (1993). Nursing strategy for initial emotional response to cancer diagnosis. *Cancer Nursing*, 16(4), 296-303.
- Leonard, V. W. (1989). A Heideggerian phenomenologic perspective on the concept of the person. *Advanced Nursing Science*, 11(4), 40-55.
- Leonard, V. W. (1994). In P. Benner (Ed.), *The tradition and skill of interpretive phenomenology in studying health, illness and caring practices (pp.43-63)*. Thousand Oaks: Sage Publications.
- Levitt, E. E. (1968). *The psychology of anxiety*. London: Staples Press Ltd.
- Loge, J., H., Kaasa, S., & Hytten, K. (1997). Disclosing the cancer diagnosis: the patients' experiences. *European Journal of Cancer*, 33(6), 878-882.
- Lowden, B. (1998). The health consequences of disclosing bad news. *European Journal of Oncology Nursing*, 2(4), 225-230.
- McNamara, B. (2000). Dying of Cancer. In A. Kelleher (Ed.), *Death & Dying in Australia* (pp. 133-144).Melbourne: Oxford University Press.
- Nathan, J. (1998). *What to do when they say "it's cancer": A survivors' guide*. St. Leonard's, Australia: Allen & Unwin.
- O'Connor, A. P., Wicker, C. A., & Germino, B. B. (1990). Understanding the cancer patient's search for meaning. *Cancer Nurse*, 13, 167-175.

- O'Leary, V. E., Alday, C. S., & Ickovics, J. R. (1998). Models of life change and post-traumatic growth. In R. G. Tedeschi, C. L. Park, & L. G. Calhoun (Eds.), *Post-traumatic growth: Positive changes in the aftermath of crises* (pp. 127-152). Mahwah, New Jersey: Lawrence Erlbaum Associates, Publishers.
- Orwell, G. (1949). 1984. London: Jarrold & Sons Ltd.
- Parks, C., M. (1975). What becomes of redundant world models? A contribution to the study of adaption to change. *British Journal of Medical Psychology*, 48, 131-137.
- Perry, J. (1978). *A dialogue on personal identity and immortality*. Indianapolis: Hackett publishing company.
- Polkinghorne, D, E. (1989). Phenomenological research methods. In Valle, R, S., & Halling, S. (Eds.), *Existential-Phenomenological perspectives in psychology* (p.41-60). N.Y: Plenum Press.
- Sardell, A., N., & Trierweiler, S, J. (1993). Disclosing the Cancer Diagnosis: Procedures that influence patient hopefulness. *Cancer Nursing*, 7(11), 3355-3365.
- Sargeson, F. (1964). *The Stories of Frank Sargeson*. Auckland: Penguin Books.
- Sartre, J. P. (1946). *Existentialism & Humanism* (P. Mairet, Trans.). London: Eyre Methuen Ltd.
- Schaefer, J. A., & Moos, R. H. (1998). The context for post-traumatic growth: Life Crises, Individual and social resources, and coping. In R. G. Tedeschi, C. L. Park, & L. G. Calhoun (Eds.), *Post-traumatic Growth: Positive changes in the aftermath of crisis* (pp. 99-126). Mahwah, New Jersey: Lawrence Erlbaum Associates, Publishers.
- Seale, C. (1998). *Constructing Death: The sociology of dying and bereavement*. Cambridge: Cambridge University Press.
- Snyder, C., Irving, L., & Anderson, J. (1991). Hope and health. In C.R. Snyder & D.R. Forsyth (Eds.), *Handbook of social and clinical psychology: The health perspective* (pp. 285-305). New York: Pergamon Press.
- Solzhenitsyn, A. (1968). *Cancer Ward*. London: The Bodley Head Ltd.
- Stacey, J. (1997). *Teratologies: A cultural study of cancer*. London: Routledge.

- Stevens, J., McFarlane, J., & Stirling (2000). Ageing and dying. In A. Kelleher (Ed.), *Death & Dying in Australia* (pp. 173-189). Melbourne: Oxford University Press.
- Swan, R. (1996). *The Big C*. Auckland: Hodder Moa Beckett Publishers Limited.
- Taylor, E. J. (2000). Transformation of tragedy among women surviving breast cancer. *Oncology Nursing Forum*, 27, 781-788.
- Tedeschi, R. G., Park, C. L., & Calhoun L.G. (1998). Posttraumatic Growth: Conceptual issues. In R.G. Tedeschi, C. L. Park, & L. G. Calhoun (Eds.), *Post-traumatic growth: Positive changes in the aftermath of crises* (pp.1-22). Mahwah, New Jersey: Lawrence Erlbaum Associates, Publishers.
- Tennen, H., & Affleck, G. (1998). Personality and Transformation in the face of Adversity. In R. G. Tedeschi, C. L. Park, & L. G. Calhoun (Eds.), *Post-traumatic Growth: Positive changes in the aftermath of crises* (pp.65-98). Mahwah, New Jersey: Lawrence Erlbaum Associates, Publishers.
- Tolstoy, L. (1886). The Death of Ivan Ilyich, *Six short masterpieces by Tolstoy* (pp. 221-283). New York: Dell Publishing Co. Inc.
- Van Avermaet, E. (1996). Social Influence in Small Groups. In M. S. Hewstone, W. & Stephenson, G.M. (Ed.), *Introduction to social psychology: A European perspective* (pp. 487-526). Oxford: Backwell Publishers Ltd.
- van Manen, M., V. (1990). *Researching lived experience: human science for an action sensitive pedagogy*. Ontario: The state University of New York.
- Walters, A., J. (1994). Phenomenology as a way of understanding in nursing. *Contemporary Nurse*, 3(3), 134-141.
- Weisman, A. D., & Worden, J. W. (1976). The Existential plight in cancer: Significance of the first 100 days. *The international journal of psychiatry in medicine*, 7(1), 1-15.