

# **Cancer and Beyond:**

## **The Question of Survivorship**

submitted by

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the degree of Master of Nursing.**

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**DECLARATION**

**I certify that this thesis does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any university; and that to the best of my knowledge and belief, it does not contain any material previously published or written by another person where due reference is not made in the text.**

**Katrina Breden**

## ABSTRACT

In Australia, as in many other countries in the Western world, the five year survival rate for persons diagnosed with cancer is now approaching 50 per cent. Although there is a growing population of cancer survivors, little is known about what surviving entails. Nurses usually do not feature in survivors' lives, for survivors are mostly lost to our experience as they leave the treatment merry-go-round. Traditionally, a survivor has been defined as one who has been disease-free for a period of five years or more. However, this definition in terms of linear time, does not reveal the experience nor the process of survival. This process commences at the point of diagnosis of cancer and continues for life.

The aim of this thesis is to present a phenomenological exploration of the meanings and experiences of surviving cancer. Using a method of hermeneutic phenomenology (as described by van Manen 1990), the study draws on the stories of six women, who by their definition are surviving cancer. Through research conversations, the women describe what this experience has been like. A discussion of themes has been structured according to the everyday experiences of *living in a body* and *living in time*. The women describe a survival process that includes: *feeling whole again; the body as the house of suspicion; the future in question; changes in time; lucky to be alive; and sharing the journey*. The thrust of the work is to deepen nurses' understandings of survivorship.

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## Chapter 1

### THE QUESTION OF SURVIVORSHIP

#### The Starting Point

This study began with my professional experience as a nurse and an academic. As a nurse I have had a deepening interest over the years in the experience of people with cancer. I have both cared for and observed people in various stages of the illness, but rarely have encountered those who have survived. It was as though once the treatment merry-go-round had been completed, they ceased to exist. Unless the disease recurred I may never encounter these people again. As an academic involved in teaching, I have often been perplexed at the disease focus of curricula that left out the experience of surviving altogether. It appeared to me that survivorship was an unexplored and undervalued phenomenon. Given the silent nature of survivorship, it was indeed a wonder that it ever became such a compelling interest of mine. Reflecting on my past, there was one particular incident that stood apart from all previous incidents and provided the trigger from which I went on to imagine what the experience of surviving cancer might be like.

The trigger occurred in relation to a woman called Rachel and heralded for me the beginning of the question of survivorship. The following incident occurred more than two years ago:

*I was coordinating a particular unit in our undergraduate nursing program that involved the invitation of certain guest speakers. These people were asked to come and tell of their experience of illness. Rachel was one of the invited speakers. She commenced her story by saying that thirteen years ago she had surgery for breast cancer and now at 44 the disease had returned as metastasis in her shoulder. Rachel had often spoken to community groups about her cancer experience, but this was the first occasion since her recurrence, some six months previously. She organised her talk around what she termed as her experiences both 'in the bed' and 'out of the bed'.*

*Her 'in the bed' story centred around what it was like to be a patient again after so many years of wellness. She talked about how the nursing care was very different this time when compared with her previous hospitalisation and how she experienced her body as an object for "another" during the diagnostic tests that confirmed that the disease had spread. The 'out of bed' part of her story referred to Rachel as a member of the workforce, a wife and a mother and how the experience of cancer had affected these aspects of her life in very profound ways. As I, and the hundred or so students, sat in silence listening to her story, I gained the impression that she would survive this recurrence of her cancer in spite of the statistics, which if correct, gave Rachel a limited life expectancy.*

*Through the exploration of several women's stories and their experience of cancer as part of a project for my Master's degree, I came across Rachel again some six months later. This time I was invited to her home. She was still working part-time, "but not for much longer" were her words. Her appearance however did not betray the extent of the disease, nor did she have the cachectic look that I had so often associated with the terminal stages of cancer. I asked her a question about what it was like during those years after the initial cancer was treated when she was considered 'cured' by the medical profession and by those around her. She fell silent at this point, and after some time said to me; "No one has ever asked me that question before, what it was like to survive cancer, and I really did believe I had survived it, I thought I was invincible". Her reply struck a chord with me, however it was many months before I thought of her answer again. I stayed for some time listening to her story and we both shared our experiences of being women and mothers. Some months later Rachel died.*

I started to think back over her reactions and mine to the question of surviving cancer. There was something in her experience of survivorship that resonated with me. It was as though I understood in some way what that experience was like for her, and yet how could I have an understanding of her feelings when I was in a very different place? What was it about Rachel's story that enabled me to have such an immediate understanding of her survival, never having had cancer myself? Was it possible, as van Manen (1990) has suggested, that within Rachel's experience lay the experience of others?

These were some of the thoughts that emerged at that time and later crystallised into a question concerning the lived experience of survivorship. It was therefore Rachel's story that provided a starting point, a conversational space from which I was to recall other stories of survival (van Manen 1990:37).

Questions concerning the experience of survival have surfaced again and again in both my work as a nurse and also within my work related friendships. As a



student nurse, I recall a close friend who had a melanoma removed from her face. I remember the fear she expressed at the prospect of waiting for the all clear in five years, the time period when no reappearance of the disease meant a possible cure. I wondered about the fear that seemed to dominate her existence at that time, her preoccupation with time itself and I asked myself is this what survival is about— an obsession with the accumulation of months? As I dwelt on this and other similar incidences and listened to survivors of many illnesses, not just cancer, my question of what it might mean to survive cancer emerged. Although this question was framed to address survivorship in general, for the purposes of this study it was necessarily limited to the experience of cancer. I was also influenced by the ability of phenomenological research to speak to the experience of everyday living; and gained important insights from the work of Merleau-Ponty (1962), Benner and Wrubel (1989), Gadamer (1975) and van Manen (1990, 1984).

### **The Nature of the Question**

It was therefore Rachel's story in particular, and the other experiences of people I knew over time, that caused me to wonder about the nature of survivorship. The question concerning the experience of survivorship has involved a sense of commitment on my part and it was my project. This commitment reflected the phenomenological nature of the question I was posing. Unlike positivistic research where the question stands apart from the activities of those who carry out the research, the phenomenological question is said to be lived by the researcher (van Manen, 1990:44). The question therefore became part of the very fabric of my being, and as such, I was unable to stand outside the question in a detached way. It arose from the way I was and am in the world, as a nurse, a woman and a mother.

What is the nature of this survivorship, the meaning and experience of surviving cancer? Within this question there are perhaps a number of subsuming questions concerning the experience of survivorship. Is there a sense of

achievement involved, is it really ever possible to consider oneself cured, is survivorship accompanied by a feeling of abandonment and alienation as Wallace and her colleagues suggest? (Wallace, Reiter and Pendergrass, 1987; Welch-McCaffrey et al. 1989). These questions are not meant to be answered at this point, but they have served as useful guides for reflection as I reviewed the literature on survivorship.

An initial exploration of this literature has revealed that the majority of articles seem to confine themselves to the experience of cancer the disease as opposed to cancer as an illness experience. There were a few notable exceptions however, these being articles by such people as Leigh (1992a), Mullen (1985), Hassey Dow (1990), Wells (1991) and Parker (1981). These authors did address the lived experience of surviving cancer the illness. Exceptions aside, most of the remaining literature tended to centre around the functional losses that cancer sometimes caused, and how through rehabilitation these losses could be minimised; or they have provided a discussion on how people who are disabled by cancer were a minority group and hence an underserved population (Dudas and Carlson, 1988; Berry and Catanzaro, 1992; Conti, 1990; Mundy, Moore and Mundy, 1992; Watson, 1992).

Many popular books have provided a recipe like approach for 'surviving cancer', something that could be taught by the right attitude or diet. These books may in some way have touched on the experience of cancer (Gawler, 1984, 1987; Siegal, 1986). In popular women's magazines, articles have appeared from time to time on people who have undergone treatment for cancer, and these have given a personal perspective on surviving. These articles are valuable in that they have given an 'inside view' of the experience of illness. This experience has been missing from many of our nursing texts (Black and Matassarin-Jacobs, 1993; Erikson, 1986; and Kneisl and Ames, 1986).

In the medical and nursing literature, the metaphor of 'time as survival' has dominated the study of survivorship until recently. This literature has presented

a linear view of time, equating longevity with cure. This interpretation of survival has meant that the longer one has survived (in terms of months and years), the more likely it will be that one will be deemed cured. The five year mark has generally been accepted as the mark at which survival commences (Hassey Dow, 1990). This narrow definition of survival has left out the experience and process of survival. The literature review set out in Chapter Two provides a further discussion of this concept of time.

Wells (1991), provided a mandate to focus not only on survivorship, but the quality of that survivorship. This mandate is reinforced by Hassey Dow:

Nurses intending to conduct research in cancer survivorship would serve patients better by studying the process intact rather than assigning specifically defined stages to the experience (Hassey Dow, 1991:59).

Benner and Wrubel (1989) have suggested that cancer survivors have not been studied sufficiently to know what the impact of surviving cancer has had on subsequent health, morale, stress and coping. This study therefore has sought to explore the experience and meaning of survival as a whole experience. Its aim has been to uncover, through the stories of people with cancer, experiences and meanings of survivorship.

### **The First Person**

I have chosen to write mainly in the first person in recognition that within my experience lies the possible experience of others (van Manen, 1990). I was involved in the research process in such a way that it defied the myth of objectivity in academic writing (Webb, 1992). To write about what it might have been like to survive cancer in the third person would have been to distance myself from the women who entered into a special relationship with me. To talk of myself as the 'author' or the 'researcher' would make a mockery of the research method of hermeneutic phenomenology and also would distance you the reader from the research process. Statements such as 'the author thinks this' or, 'the writer believes that', imply that the ideas being expressed are neutral and

value free, and somehow apart from the person who writes the ideas. This way of separating the knower from what is known resembles scientific writing whereby “knowledge is treated as something outside rather than inside the minds or brains of individuals” (Chalmers, 1982). I acknowledge that I have been an active agent in the construction of knowledge and I agree with the following comments by Webb:

Writing in the third person is therefore a form of deception in which the thinking of scientists does not appear, and they are obliterated as active agents in the construction of knowledge (Webb, 1992:749) .

You, the reader, are entering into the hermeneutic process of interpretation and as such you are also implicated in the construction of knowledge.

### **Organisational Framework for the Study**

This first chapter has introduced the study and placed it against a background of detail that has arisen from my professional interest as a nurse and an academic. This chapter has placed the question of survivorship in a particular context and has provided a starting point. Chapter Two provides an historical perspective to the phenomenon of survivorship with reference to the current literature and further situates the significance of the study to nursing. Chapter Three provides the methodological orientation and a method of hermeneutic phenomenology (van Manen 1984, 1990). Chapters Four and Five present the thematic analysis and interpretation of the stories. The final chapter contains reflections on the research process and it ends with a personal reworking of the issue of survivorship.

## Chapter 2

### **SURVIVORSHIP: WHAT IS KNOWN**

Until recently, cancer and survival have been thought of in contradictory terms. Someone either has had cancer or has undergone treatment for cancer, but has rarely been spoken of as having survived cancer. Exploring the question of survival has required an investigatory process into what is already known about survivorship in general and surviving cancer in particular. Therefore, my intention in this chapter is to explore the question of survivorship from the perspective of the current literature.

Definitions of survivorship are presented followed by an historical view of the development of survivorship as a concept. One meaning of the experience of cancer and survival is explored through an examination of the prevailing metaphors that may have assisted in its construction. The literature review is then organised around classifications of health presented by Benner and Wrubel (1989). Health as a commodity, as a human potential and as personal attributes are discussed and extended to the phenomenon of survivorship. Finally, survivorship as a process is presented as an introduction to the research methodology underpinning this thesis.

#### **Definitions of Survivorship**

There are no definitions of survivorship as a universal phenomenon within the literature. Survivorship seems to mean different things to different people. For some, to survive is to conquer adversity, to outlast others. The idea of remaining behind after others have succumbed, is reminiscent of the Darwinian notion of survival of the fittest where natural selection plays a part in determining who survives and who does not. This term survival of the fittest was coined by

Herbert Spencer (Baradat, 1988:70), in an attempt to explain and justify the expansion of capitalism and the hierarchical class system during the mid 19th century in England. People who were rich and part of the higher classes in society were said to be not only biologically superior (through the process of natural selection), but also morally superior. These personal attributes enabled one to survive, according to Spencer (in Baradat, 1988). In linking this notion of 'survival of the fittest' to cancer survivors, it could be inferred that survival for some depends on genetic superiority as well as social and educational advantages.

The Macquarie Encyclopedic Dictionary has no definition for 'survivorship', however it does define 'survival' as "continuing on after the death of someone or the occurrence of some event" (1990:962). Hassey Dow (1990) wrote that the traditional view of surviving in Western society focused on the family that remains after the death of a family member.

The medical definition of cancer survival is generally couched in terms of the number of people who are still alive at the five year mark, though not necessarily free of cancer (Carnevali and Reiner, 1990; Hassey Dow, 1990). The most recent Australian statistics put the five year cancer survival rate for all sites and all ages at nearly 50 per cent (McMurchie, 1991:1444). For certain types of cancers, namely the haematological cancers, the number of long term survivors is increasing (Silverberg and Lubera, 1989). Medical views of surviving, represented as statistics and probabilities, equate longevity with cure from cancer. Survival and non-cure seem to be mutually exclusive and separate those who are deemed cured from those who are not. Mullen (1985) suggests that there is no moment of cure, but rather an evolution of survival beginning with diagnosis: "Survival is a much more useful concept [than cure], because it is a generic idea that applies to everyone diagnosed as having cancer, regardless of their point of illness" (Mullen, 1985:271).

## Historical Considerations

Historically, the term 'survivorship' has been associated with catastrophic life events such as aeroplane crashes and natural disasters (Lifton, 1980; Benner, Roskies and Lazarus, 1980; Erikson, 1986). For example, Mason Lee (1993) reported a true story of 13 people who survived a plane crash at the North Pole. In this account, the people who survived the plane crash became 'survivors' at the point of discovery instead of victims. It was as though the rescue and discovery operations turned a victim into a survivor. This perspective may have implications on how we view survivors of illnesses such as cancer. After all, one is 'rescued' from disease.

Lifton, who studied survivors of Hiroshima after the atomic bomb, defined a survivor as one who "has touched, witnessed, encountered, or been immersed in death in a literal or symbolic way and has himself/herself remained alive" (Lifton, 1979:54). The themes that Lifton and others (Titchener and Kapp, 1986; Erikson, 1986) have described as being common to the process of surviving disasters are a feeling of engulfment by death, a loss of a sense of invulnerability, a sense of guilt in remaining alive when others have died, a withdrawal from others who were not part of the experience, a feeling of being suspended in time and a search to find meaning in what has occurred.

Post traumatic stress is a modern day label for survivors of disasters such as road trauma and bushfires. Norman (1989) in the analysis of post traumatic stress disorder, found that there were similar bodily responses that occurred in the people affected by severe trauma and these were memory failure, inability to concentrate, irritability and recurrent nightmares. Recurrent nightmares were also reported to be part of the continued survival for adult survivors of incest (Brunngraber, 1986).

Survivors of serious illnesses such as cancer seem to share similar themes as those described by Lifton and others above (Smith, 1981; Hassey Dow, 1990; Welch-McCaffrey et al., 1989). Cancer survivors also seem to experience

recurrent dreams and nightmares; and a loss of a sense of being invulnerable, recognising their own mortality (Hassey Dow, 1990). This recognition may carry with it a changed belief in what is now important in life. They seem to be able to put the illness experience into perspective, finding meaning in what has occurred (Hassey Dow, 1990). In addition, cancer survivors are said to continue to deal with fears of recurrence of their cancer, adjustment to some level of physical compromise and isolation and difficulties in taking up life again in the community in which they live and work (Welch-McCaffrey et al. 1989).

This discussion has provided a perspective from which to examine the literature on survivorship. An additional approach to the study of cancer and survivorship has been through the examination of its metaphors. An examination of metaphors can often betray powerful, yet hidden ways of thinking about a subject (Proctor, 1991).

### **Survivorship and Metaphors**

The word 'metaphor' is derived from the Greek word to 'carry over' (Proctor 1991:63) and linguistically at their simplest level, metaphors can assist in our understanding of an unfamiliar concept by linking it with something familiar. Metaphors have been used to describe illnesses of all kinds. Susan Sontag (1991) in her book *Illness as Metaphor*, wrote that cancer has been a metaphor for deterioration and decay. Because of the uncertain nature of cancer's causality and the often difficult treatment regimes, cancer as a word has assumed a great deal of significance:

First the subjects of deepest dread (deterioration and decay ) are identified with the disease. The disease itself becomes a metaphor. Then, in the name of the disease (that is, using it as a metaphor), that horror is imposed on other things. The disease becomes adjectival (Sontag, 1991:60).

Feelings of decay have been projected onto cancer and the word 'cancer' now laden with constructed meanings, has been taken up by the world and used in everyday speech. For example, we often refer to corruption in government as a 'cancer in the system' (Sontag, 1991).



In her subsequent book, *Aids and its Metaphors*, Sontag (1991) still speaks of cancer as a metaphor for what is both feared and deplored. She does acknowledge however that cancer is now less feared than it was during the writing of her first book. One metaphor that has been used when describing cancer and its treatments has been, and still is, the military metaphor (Sontag, 1991). Cancer cells are said to invade, infiltrate and become alien, an 'other' as enemy in warfare. There is a national fight against cancer, and cells are bombarded during radiation. This terminology raises questions in the understanding of survivorship. How do these images of war and battle contribute to the experience of survivorship? Does survivorship become a metaphor for victory, the conquering of disease?

The dominant metaphor of survivorship within the literature has been 'survival as time' as a Western linear view (Greenwood and Nunn, 1992; Hassey Dow, 1990). Watching the months pass by is one of the objective parameters used by the medical community (and very often the sufferers themselves), to indicate the type and stage of the disease and the risk of spread. This information is then used in the attempt to control, predict and explain the course of a cancer. But as Hassey Dow states, "...within the context of surviving illness, where understanding is the priority, disease survival is just one indicator" (Hassey Dow, 1990:511). Understanding the disease process of cancer in terms of statistics and probabilities is one aspect of survival, understanding the illness experience from the person's perspective provides another.

For the environmentalist David Suzuki, the way someone views the passage of time plays a vital role in the shaping of the relationship with the world in which he or she lives (Knudtson and Suzuki, 1992). If one views surviving as an accumulation of time, then this view will affect one's relationship with friends, the space in which one lives, one's body and one's view of time itself. For many of us living in Western society, time is indeed linear, sequential and occurring in one direction. We differentiate between our past, our present and our future, and time does not go backwards. Our lives are dictated by an orderly sequence

of events that are “officially assigned its own measure of importance” (Knudtson and Suzuki, 1992:143). Other cultures have an experience of time that is vastly different from ours. For example, the Australian aboriginal people view time as cyclical, and as a people they are not interested in the differentiation between the past, present and the future (Mountford, 1975). Mountford wrote:

The Aborigines are not interested, as we are, in the episodes of the past. The important things to them are the cycles of life; the development of the individual from infancy to old age; the progress of the initiates from ignorance to knowledge; the rounds of the seasons, and the movements of the heavenly bodies (Mountford, 1975:21).

Cyclical time relates to the natural rhythms of the world, the seasons of the year, the familiar biological rhythms such as sleeping and eating, the cycles of birth, old age and death. The cycles simply move around and around, returning to the same starting point. Linear time on the other hand never returns to the same place, since it moves forward away from the past into an endless future (Greenwood and Nunn, 1992).

It seems that the Western world emphasises linear time and marginalises other views. This perspective of time may therefore influence how a person experiences survival. In a world that is mostly governed by clock time a transition to another way of thinking about time may be difficult for a person in the process of survival.

The word 'cancer' carries with it a myriad of metaphors that have influenced our thinking. Cancer survival may involve negotiating powerful constructions of bodily destruction and decay and challenging definitions of survival in terms of cure and linear time.

### **Health and Survivorship as Commodities**

Viewing survivorship through the notion of survivorship as a commodity is a way of thinking that extends the idea of health as a commodity that can be bought on the open market. This idea can also be seen as a metaphorical construction.

Viewing health as a commodity implies that health can be acquired through the process of trade. Access to health occurs through the process of buying medicine, surgery or some form of technical intervention (Seedhouse, 1986). In this trading process, the body is handed over to medicine to enable the restoration of health. The body becomes an object in the hands of the medical profession, a commodity that is exchanged for health as Seedhouse has illustrated:

According to this way of looking at life (health as a commodity) health can be given or purchased without personal involvement in the process. For example medical health can be purchased by buying surgery or drugs.... Health appears to be a thing which exists apart from people, which may be captured if the right procedure is followed. This sort of health can be lost if a person has a diseased organ, but with appropriate treatment it can be restored piecemeal (Seedhouse, 1986:34)

In extending this idea of health as a commodity to the term survivorship, it can be inferred that survival, like health, can be gained through the process of trade. In order for someone to survive, the deficit position in relation to the ideal state of health needs to be corrected by treatment (Benner and Wrubel, 1989). Health may be obtained by the object body by participating in treatment procedures and by being involved in routine checkups to monitor for delayed treatment effects or signs and symptoms of recurrence. Personal involvement in this process of trade is not required as the body becomes the consumable item.

This view of survivorship outlined above represents a medical and scientific approach to health care which leaves out the meaning of surviving cancer for the person concerned (Carter, 1989). Treatment for cancer is applied to the body as an object and the person inside the body and the way in which they experience treatment tends to be neglected. The inference that can be drawn from such an approach is that one's body and habitual way of doing things in the world cannot be trusted (Benner and Wrubel, 1989:154). Thomas suggested that as a society we have lost confidence in our bodies:

We are losing confidence in the human form. The new consensus is that we are badly designed, intrinsically fallible, vulnerable to a host of hostile influences inside and around us, and only precariously alive. We live in danger of falling

apart at any moment, and therefore we are always in need of surveillance (Thomas, 1975:1245-1246).

In applying this view of shoring up our ailing bodies, we need to exercise a form of control over them and follow a prescribed level of diet and/or exercise. Very often the changes required by vast numbers of lifestyle approaches are radical, as in the case of such diets as the Gerson Diet, the Macrobiotic diet and the Pritikin diet (Hunter, 1988; Brigdin, 1987). These diets are very popular with cancer patients because of the widespread opinion that diet is implicated in cancer and that therefore a good diet can help cure (Pietroni and Pietroni, 1991). However, it has been argued by Hunter (1988) and others (Anti Cancer Council of Victoria, 1994; Dreher, 1987) that these diets are in opposition to the needs of cancer survivors. Adoption of such dietary regimes may cause anaemia, physical discomfort, weight loss and depression (Hunter, 1988). Guilt may result if the survivor has to stop a diet or is unable to follow a strict regime (Pietroni and Pietroni, 1991).

Scheper-Hughes and Lock (1987) suggest that there is an obsessive concern for the healthy body in Western society. This obsession for a healthy body may provide an additional burden for the person who has undertaken treatment for cancer and this was evident in Rachel's story, as she related her search for remission during the early days of her cancer recurrence (Chapter One). She told of the tremendous guilt she carried (after attending a Gawler Clinic) in not being able to keep to the strict dietary regime that was advocated for her survival. She had been prescribed a diet that did not fit into her lifestyle; it had been ordered to make up for a deficit position in her health. Survival, like health, became for her, a commodity that was used as an object for trade. For Rachel, surviving may have been made all the more difficult due to our consumer society where the message is to:

stay young, stay beautiful, live longer. These are the catch phrases of today's hard living society....While the secret of longer life is still a long way off, many people are searching for a short cut - through health foods, yoga, gardening. Grab your survival kit and live longer (Featherstone, 1982:24).

Our bodies have become the passport to all that is good in life. Illich (1975) suggests that people are experiencing their bodies as commodities in Western society. Within a consumer society, such as ours, it is hardly surprising that death and dying, cancer and illness are viewed so negatively. They remind us of the inevitability of death and decay that is in store for us.

It can be argued that this view of survival as a commodity that can be bought through the process of trade represents a biomedical view of health and illness. Survivorship then is a construct that can be broken down into its constituent parts to derive causal connections (Capra 1982). In order to understand survivorship it needs to be broken down into smaller and smaller fragments for study. To date, most of the research and discussion of the parts has been limited to physical, psychosocial and demographic factors of long term survivors (Quigley, 1989; Welch-McCaffrey, et al., 1989; Loescher et al., 1989; Wroblewski, 1994; Bushkin and Bushkin, 1993). Some studies have focused on the needs of adult long term survivors (Gambosi and Ulreich, 1990; Halstead and Fernsler, 1994), while others have concentrated on survivors of childhood cancers (Wallace, Reiter and Pendergrass, 1987; DeLaat and Lampkin, 1992). To talk about the needs of cancer survivors assumes that universal needs exist and that all cancer patients are similar in cultural background and social status. A limitation of the biomedical model is therefore that individual differences are not taken into account and individual diversity may be lost.

Some writers argue that survivorship involves aspects of rehabilitation (Otto, 1994; Leigh, 1992b). Dudas and Carlson (1988) talk about rehabilitation enhancing an individual's quality of survival. These authors see cancer as a disruption in one's ability to meet needs and attain goals; and survival is to do with the restoration of physical and psychosocial functioning. Watson (1992) presents a model for cancer rehabilitation and again focuses on a restoration of physical functioning and psychosocial support. This approach to survivorship as restoration also reflects reductionistic thinking of the biomedical model where

rehabilitation and hence survivorship can be understood in terms of physical and/or psychosocial functioning.

### **Health and Survivorship as a Human Potential**

Benner and Wrubel (1989) suggest that health can exist in the presence of illnesses such as cancer. According to these authors, everyone has the potential for health, whether sick or well, based on one's ability to adapt to changing circumstances using the power within each person rather than relying solely on medical or technical intervention.

In extending this approach to health into the area of survivorship, it can be inferred that, even though one is again operating from a deficit model of health as a result of having had cancer, one has the potential for complete biological, spiritual and mental health (Benner and Wrubel, 1989:156). One can survive and one's full potential can be realised through recovery processes by increasing one's level of wellness. Psychological techniques such as visualisation, relaxation and guided imagery, often labelled as 'alternative', supposedly assist the cancer survivor in the pursuit of his or her full human potential (Anti Cancer Council of Victoria, 1994). In Australia, such techniques have been advocated by people such as Gawler (1984, 1987) and Meares (1980). There does seem to be some evidence of the efficacy of these techniques on the progression of cancer (Dreher, 1987; Spiegel et al., 1989).

Within the first chapter, the reader was introduced to Rachel, whose cancer returned 13 years after her initial cancer diagnosis. Rachel's years of living with cancer's remission, when looked at from the perspective of achieving one's full potential, suggests that she did take responsibility for her own health and survival. She was part of a support group for cancer sufferers, she exercised and meditated regularly and continuously strived towards an increased level of health and wellness. However, she was unable to follow the rigorous diet advocated for her recovery, and as such, wasn't perhaps living and surviving

according to what she could have accomplished, had she been able to achieve her full potential (my interpretation). This view of survivorship reflects the doctrine of liberal humanism, which assumes that human beings have some degree of freedom of choice and action in shaping their own lives (Fontana Dictionary of Modern Thought, 1988:396). Humanistic psychology, which grew out of the philosophy of humanism, has as its central theme, a belief that each individual has an inner drive to reach his or her full potential (Berger, 1988; Stewart, 1992). Within this approach (as in Rachel's case) a person will always be pursuing but will never quite arrive at a place of complete health or certain survival. There was no place for Rachel to just stand still. In her striving for survival, the actual process of surviving may have been lost and perhaps not even valued. The responsibility for survival very much lay with Rachel. The position ignored the community, social structures and relationships in which she lived.

### **Surviving as a Personal Attribute**

Many people believe that there is a cancer prone personality where an individual's susceptibility to cancer depends on personality characteristics such as anxiety or depression. Susan Sontag (1991) provides an interesting discussion of the psychological theories of illness. She talks about the often widely held belief that the person who develops cancer deserved it in the first place. Repressed emotions in childhood, the inability to form close relationships, tendency to self-sacrifice and self-blame are often cited reasons for the development of cancer at a later date (Sontag, 1991; Kissen, 1966; Schmale and Iker, 1971). Sontag (1991:59) further states that the "widely believed psychological theories of disease assign to the luckless ill the ultimate responsibility both for falling ill and for getting well". In addition, Frank, who also experienced cancer writes, "being sick, carries more than a hint of moral failure, I felt that being ill [with cancer] I was vaguely irresponsible" (Frank,

1991:58). The responsibility for getting well and perhaps surviving falls upon the unfortunate victim.

In considering survivorship as a personal attribute, it can be inferred that there may be certain personality characteristics that make it more likely that an individual will survive cancer. Bernie Siegal (1986) reviewed the studies of personal characteristics of people who survived devastating events such as wars, and he found that one of the most significant characteristics of a survivor was their complexity of character (Siegal, 1986:161). He saw that opposite personality characteristics such as tough/gentle, shy/aggressive coexisted in the character of the survivor. He suggested that this apparent paradox made these people more flexible than most and hence conferred upon them a survival advantage. In Siegal's experience, the personality characteristics of survivors of disasters and survivors of illnesses such as cancer were very similar. He suggested that cancer patients who did well and survived were those who:

[were] self-reliant and [sought] solutions rather than lapsing into depression. They interpret[ed] problems as redirections, not failures. They [were] the ones who read or meditate[d] in the waiting room instead of staring forlornly into space (Siegal, 1986:162-163).

Within this approach to survival there is an accountability for one's own illness and hence survival. Blaming the victim is a potential outcome of this type of an approach, as the responsibility for surviving rests solely with the person concerned (Keith, 1991). One may feel guilty if individual effort has not led to a prolongation of life:

The genius of the cancer personality argument is that it means nothing has to change. The fault and the fear are safely contained, locked up inside the cancer patient...those who enjoy good health can believe that they have earned it. Only the ill are left to feel guilty (Frank, 1991:113).

### **Surviving as a Process**

A review of the literature on survivorship has revealed very little actual research and what has been written tends to reinforce the biomedical model. There are also numerous anecdotal accounts and first person narratives of surviving that



present a generalised and representational view in contrast to an experiential or lived view (Shook, 1983; Gawler, 1984; Siegal, 1986; Keith, 1991; Mullen, 1985; Frank, 1991; Ferguson, 1990). The outstanding finding points to a dearth of studies around the individual's experience of surviving cancer.

The individual experience of surviving cancer is not revealed within five year survival estimates given for the various cancers. The binary opposites of cure and non-cure are also unhelpful when trying to understand the experience of survival. Two separate paths to survival do not seem to exist. According to Mullen (1985), survival for all begins at the time that cancer is diagnosed, and is not one condition but many:

It was desperate days of nausea and depression. It was elation at the birth of a daughter in the midst of the treatment. It was the anxiety of waiting for my monthly chest film to be taken and lying awake nights feeling for lymph nodes. It was the joy of eating Chinese food for the first time after battling radiation burns of the oesophagus for four months.... It was survival - an absolutely predictable but ill-defined condition that all cancer patients pass through as they struggle with their illness (Mullen, 1985:271).

Leigh (1992b), a survivor of both Hodgkin's disease and breast cancer, sees survival as a continuing ongoing event, a process of moving through and beyond the experience of cancer.

There is a rallying cry from various authors to study the phenomenon of survivorship from the perspective of the individual. Kondora (1993) states that nurses need phenomenologically based studies to reveal the personal journeys of survivors, to understand their difficulties, their endurance and their healing. Benner and Wrubel (1989) say that cancer survivors have not been studied sufficiently to know the impact that surviving has had on the various aspects of a survivor's life. Hassey Dow (1991) suggests that nurses intending to conduct research into cancer survivorship should do so by studying the process intact rather than assigning specifically defined stages to the experience. Gambosi and Ulreich (1990) provide the mandate for nurses to be at the forefront in shaping the cancer recovery experience.

There is an increasing interest in the nature of survival and the quality of that survival reflected in the numerous studies on 'Quality of Life' (Whedon and Ferrell, 1994; Andrykowski, Henslee and Farrall, 1989; Belec, 1992; Wyatt, Kurtz and Liken, 1993). These studies are important in cancer care, however Carter (1989) has argued that reducing the subjective experience of quality to separate domains for study is again a reflection of the biomedical model. This reduction excludes the experience of surviving for the person concerned.

The interpretive phenomenological approach includes the context in which a person survives. It involves "culture, language and context" (Lumby, 1991:480). It seeks to understand the meaning that experience has for an individual and rejects the notion of dualisms. Two such phenomenological studies that have been conducted in the area of survivorship are those by Clarke, Lavery and Ruffin (1993) and Carter (1989).

Clarke et al. (1993) interviewed 30 women who had been treated for breast cancer to discover repetitive themes that reflected the subjective experience of surviving. The time since diagnosis ranged from a few months to 18 years. The general themes centred around the stage when the cancer was diagnosed, time in the life cycle when the women were diagnosed and the support networks the women had around them at the time. They found that it seemed easier on the women concerned if the lump was found early because of the associations with less severe treatment options. Older women also seemed less concerned with body image and found immense support in grown children, especially daughters. These authors talked about survivors as winners "who overcome the cancer and continue on life's journey" (Clarke et al., 1993:2). This statement implies that it is a loser who is unable, for what ever reason, to overcome cancer. The survivors become almost glorified, "the unsung heroines who conquer their cancer to become healthy, revitalised members of our community" (Clarke et al., 1993:2).

Carter (1989) studied 25 survivors of breast cancer 40-78 years of age, with 5-26 years of survival time. She found that the women described a journey through several phases (sometimes simultaneously) of survival. These phases included interpreting the diagnosis, confronting mortality, re-prioritising, coming to terms, moving on and flashing back. This study by Carter (1989) drew on the medical definition of survival in terms of the five year mark for inclusion of the participants into the study but even though it was written from an interpretive perspective it did not reveal survival as a process.

It is interesting to speculate that the experience of cancer and the experience of survivorship may very well be one and the same phenomenon. For the purpose of this research I have adopted Mullen's (1985) view that survival begins at the point of diagnosis and although the experiences of living with cancer and survivorship may coexist I have chosen to pursue the experience of survivorship in contrast to the experience of living with cancer. I recognize, however, that this is a somewhat arbitrary distinction.

## Chapter 3

### METHODOLOGY: EXPLORING THE PHENOMENON OF SURVIVORSHIP

The preceding chapter focused on the literature surrounding survivorship and ended with an introductory discussion of a phenomenological approach and its application to the study of survival. The purpose of this chapter is to outline the research design and the procedure used for data collection and interpretation. It also introduces the women who participated in the study.

#### Research Design

There are a number of approaches to doing phenomenological research, and I have chosen that of van Manen (1984, 1990) because it appears to best suit my question. The methodology outlined here is based on his works, particularly *Practicing Phenomenological Writing* (1984) and *Researching Lived Experience* (1990).

Van Manen's method of hermeneutic phenomenology is drawn from the twin methodologies of phenomenology and hermeneutics, and has its roots in Husserlian phenomenology (Donalek, 1994). His view of hermeneutic phenomenology is that it is both descriptive (phenomenological) in that it is attentive to how things appear, and interpretive (hermeneutic) because how things appear is always interpreted first, for as he states, "there is no such thing as uninterpreted phenomena" (van Manen, 1990:180). van Manen acknowledges that while other philosophers such as Gadamer (1975) and Silverman (1984) differentiate between the description of lived experience and the interpretation of that lived experience, he uses the terms phenomenology and hermeneutics interchangeably because for him, describing *is* interpreting through the medium of language (van Manen, 1990). Phenomenological research for van Manen is the study of lived experience, the explication of phenomena as they present themselves to consciousness. It is an attentive practice of thoughtfulness as well as a poetising activity.

Following van Manen, my research approach has been to interpret through the medium of language as a poetising activity.

The key assertions from van Manen's (1984; 1990) hermeneutic phenomenology are outlined below:

**Phenomenology is the study of lived experience**

According to van Manen (1990), phenomenology is concerned with the study of the lifeworld or the world of lived experience to gain a fuller understanding of the meaning of our everyday existence. It offers a way of acquiring a more direct contact with our world. In this type of research, questions are concerned with finding out what particular experiences are like.

**Phenomenological research is the explication of phenomena as they present themselves to consciousness**

For van Manen (1990) consciousness is the only way we have to access our world of experience. Therefore, anything that presents itself in consciousness connects us with the world around us, for consciousness is always consciousness of something. If something does not present itself to consciousness, then it falls outside the boundaries of lived experience and is therefore unresearchable. In this sense, it appears that van Manen presents an Husserlian view of consciousness.

Lived experience is only available to us through reflection, from a position of looking back and it cannot be accomplished whilst still living through the experience. Van Manen (1990) provides the example of experiencing anger to illustrate this point; if one tries to reflect on anger whilst still in the grips of this emotion, one finds that the anger being experienced has already changed or perhaps lessened.

**Phenomenology is the study of essences**

The term 'essence' refers to the essential nature of something, what makes a thing what it is and not something else. An essence of a phenomenon is therefore those internal structures of meaning that make the phenomenon what it is and not something else. Phenomenology attempts to uncover and describe those particular structures of lived experience in order to gain a deeper understanding of what a particular phenomenon is like. I have not emphasised a study of essences in this research.

**Phenomenological research is the attentive practice of thoughtfulness as well as a search for what it means to be human**

For van Manen, 'thoughtfulness' is the word that most closely characterises phenomenology. This thoughtfulness is a mindful caring about life and living, a concern for the people with whom we share our world. It is a concern for what it means to be human, taking into consideration the social, cultural and historical conditions that provide meaning to how we are in the world. This search for what it means to be human aims to uncover the fullness of living so that we can become "more fully who we are" (van Manen, 1984:38).

**Phenomenological research as a poetising activity**

Phenomenology as a poetising activity is not like poetry in that it makes verses, instead it is an activity that engages language that speaks the world rather than speaking of it. As a poetising activity, phenomenology is unlike much research in that the link between the results and the means by which the results were obtained cannot be separated, for to do so would render the results almost meaningless. Nor does one ask for a summary of a poem, for the actual poem is the thing. It is therefore inappropriate to ask for a conclusion of a phenomenological study for the study in its entirety is the result.

Therefore, phenomenological research, as it has been described by van Manen (1984, 1990), is a creative process. Its aim is to understand lived experience and what it means to be human, to uncover some of the complexity and context of the nature of everyday life.

## **The Activities of Phenomenological Research**

Carrying out phenomenological research involves a set of activities that are inseparable according to van Manen (1984, 1990). These activities are turning to a phenomenon of concern and interest to the researcher; investigating the experience as it is lived; reflecting on the essential themes that emerge from the investigation; and lastly, describing the phenomenon through the art of writing and rewriting (van Manen, 1984).

### **1. Turning to a phenomenon of concern and interest to the researcher**

The phenomenon of interest in this research was survivorship; this was approached by asking what the experience of survivorship is like. The focus was on the meaning and experience of surviving cancer through the examination of the context in which the experience is lived. Gadamer suggests that 'the essence of the question is the opening up of ourselves to an infinite array of possibilities' (Gadamer, 1975:266). Thus the question of what it might mean to survive cancer is one of infinite possibilities that one must remain open to. However, to remain open to these possibilities van Manen (1990) suggests that first we must suspend our own assumptions and preconceived ideas concerning the phenomenon under investigation. This suspension is attempted because it is seldom the case that we know too little about the phenomenon under investigation, but rather the opposite, we usually know too much, preventing us from seeing the phenomenon in a new light. Therefore it is important to address our preconceived ideas and assumptions, not by ignoring previous knowledge but instead we can use it "against itself, as it were, thereby exposing its shallow or concealing nature" (van Manen, 1990:47).

In this research I have rejected the notion of suspending assumptions and preconceived ideas but have attempted to bring them into play, acknowledging that complete objectivity is impossible as the researcher is a part of the process. and thus necessarily influences the shape of the research. There is no knowledge out there in the objective sense that is separate from the assumptions made in relation to the world or the people in it. This position is reinforced by Sir Peter Medawar (1990) who states:

There is no such thing as unprejudiced observation. Every act of observation we make is biased. What we see or otherwise sense is a function of what we have seen or sensed in the past (cited in Davey, 1992:43).

This idea of unprejudiced observation perhaps needs further clarification. If there is no such thing as unprejudiced observation, then the way we approach the world, with our prejudices and biases, must have a part to play in our understanding of the world in which we live. For Gadamer, our prejudices are important. The way we judge the world before all the conditions are known enables us a certain openness in the way we understand the "things themselves" (in Bernstein 1983:138). We do not come to understanding by forgetting all our prejudices, but rather, by being open to our biases, we can begin to come to a point of understanding. Gadamer points out that our prejudices open us up to the world:

prejudices are not necessarily unjustified and erroneous, so that they inevitably distort the truth ... Prejudices are biases of our openness to the world. They are simply conditions whereby we experience something - whereby what we encounter says something to us (cited in Bernstein, 1983:127).

As a researcher I have both influenced and shaped the research. I am also revealing myself as I interact with the data through the process of interpretation.

### **Selection of the participants for the study**

The main aim of participant selection for the study was to include those people who had a direct knowledge of the experience of cancer survival. People known to the researcher through prior work or professional contacts were invited to participate. The six participants were invited because they had finished active treatment for cancer, i.e. chemotherapy, surgery or radiotherapy. The reason completion of active treatment was chosen as the entry point for the study was initially one of convenience, however I also believed that the ability to be truly reflective on the process of survivorship came as a result of being able to look back to the point of diagnosis. I felt that while still in the midst of active treatment, the focus for the people concerned was on increasing the chance of their survival. The consuming nature of the treatment process may have meant that outside interests or concerns were severely curtailed.



## 2. Investigating the experience of survivorship as it is lived

Bernstein (1983), again drawing on the work of Gadamer, suggests that:

We must learn the art of being responsive to works of art, texts and traditions (other persons or forms of life) that we are trying to understand. We must participate in them, listen to them, open ourselves to what they are saying and to the claims of truth that they make on us (Bernstein, 1983:137).

Investigating the experience of survivorship as it is lived is therefore accomplished by being immersed in a world of relationships and shared situations. The approach I have taken draws on the term 'research conversation', described by Winning (1991), rather than the term 'interview' to describe the actual data gathering process that took place. An interview implies a formal asking of questions and whilst it is "directed toward understanding informants' perspectives on their lives, experiences or situations as expressed in their own words" (Taylor and Bogdan, 1984:77), it does not lend itself to the easy exchange of ideas. People participating in an 'interview' do so with clearly defined roles with the researcher usually directing the interview (Winning, 1991:12). The term 'conversation' better described the data collection process as it implies an everydayness and acknowledges my presence and influence in the research process. In addition, a conversation between two people often has little direction or purpose, whilst a research conversation implies a direction and purpose towards the proposed research (Winning, 1991). Gadamer calls this latter form of conversation a 'true' conversation:

To conduct a conversation requires first of all that the partners to it do not talk at cross purposes. Hence its necessary structure is that of question and answer.... Dialectic is the art of asking questions, proves itself only because the person who knows how to ask questions, is able to preserve his orientation towards openness.... The first condition of the art of conversation is to ensure that the other person is with us.... To conduct a conversation means to allow oneself to be conducted by the object to which the partners in the conversations are directed (1975:367).

In order to obtain a 'true' conversation, the focus of the survivorship experience guided the conversations. Each of the research conversations began with a discussion of the nature of the cancer experience. The conversations then turned to the nature of survival and the question of 'what it might be like to survive cancer?' The women seldom required prompting, and many began their stories of survival well before the actual diagnosis of cancer. Little interjection was required by me except for the occasional, 'can

you tell me a little more about what that was like?' I concluded each conversation with the question, 'do you believe you have survived cancer?'; and without exception, all the women said 'yes!'

I met with the women at a mutually agreed upon location. Five of the interviews took place in the women's homes and one in a place of employment. At the first face-to-face meeting informed consent was obtained. Each conversation lasted for about an hour, to an hour and a half. A return visit was made to discuss individual transcripts with each of the women; these meetings lasted about an hour. The age range of these women was between 33 to 69 and the type of cancers they had varied. All the research conversations were tape recorded and later transcribed. The tapes were stored in a locked cabinet according to the University's policy for data storage. The ethical considerations for this study have been presented in the appendix.

The language of the conversations between the women and myself was preserved as text through the use of a tape recorder and research conversation transcripts. In this way, the 'lived experience' of survivorship was captured in the text, preserved and made available to others. This 'fixing of the text' does not imply that the text is outside the world as a disembodied thing that can be viewed in an objective way. The text is located within a world that contains historical, social and cultural dimensions as a segment of time. It is through language that understanding occurs, through the process of interpretation (Gadamer, 1975). This research has been an interpretive process and it can be argued that I have helped to construct the women's stories of what it might mean to survive cancer thus bringing the very nature of the phenomenon into question.

People with cancer are not an homogeneous group, and neither are those who survive cancer all the same. To celebrate difference and not lose sight of the women as individuals I have chosen to introduce them so that they can be kept alive in the pages of this text as their stories merge with mine for the purpose of this thesis. These women, referred to by pseudonyms, are Kate, Sue, Edna, Joan, Dawn and Laura.

### Kate

Kate was 28 when her cancer of the cervix was discovered. Married for a year, Kate and her husband had not yet started a family. She had a complete hysterectomy and at the time her doctor said to her on the subject of prognosis, *well, nobody's guaranteed a long life, we think we've got everything*. Today she horse rides and is involved in the Army Reserve. Despite the loss of a dream of ever having children, Kate returned to work, maintaining a very positive and enthusiastic view of her future. As she states, *well, there's worse people off than me*. Kate is now five years post cancer diagnosis.

### Sue

Like Kate, Sue had a complete hysterectomy for cancer of the cervix. She inferred that there seemed to be a silence surrounding her prognosis all those years ago and said, *I would really have liked more information*. Sue's experience as a patient 15 years ago filters through into her present work and in some ways seems to enhance her sensitivity to others in her everyday world. Sue had two children, both boys, prior to her cancer diagnosis and in this aspect differs from Kate. For Sue, a regret she still carries is the idea that she will never have another baby, a daughter. Many years have now passed and yet the loss of this possibility is still felt.

### Edna

Edna, 69, experienced two growths; cancer of the breast and a brain tumour. Whilst undergoing tests for her suspected breast cancer, Edna suffered from a particularly bad migraine attack, something that had plagued her for many years. A subsequent scan showed a large benign tumour in her brain. For Edna, the discovery of a second growth upset her more than the breast cancer diagnosis. As she said *when they mention the brain, well it worries you doesn't it?* Surgery to both her breast and her brain was undertaken within a short time period of each other. She cannot remember how the prognosis was presented to her at the time, but knows that she has to have regular checkups. It has now been 12 months since her initial breast cancer diagnosis. She still has some residual soreness over her chest wall but she maintains a positive outlook and

says, *you don't worry other people with your problems*. Edna lives on her own and has some family living close by.

### **Joan**

Somewhat like Edna, Joan experienced two completely unrelated cancers nearly 30 years apart. The first cancer, cancer of the cervix, was detected during the early trial of Pap smears. She was 28 and her only child was then three years old. She underwent a hysterectomy which at that time was the usual treatment for cancer of the cervix. At the time, the surgeon said, *I left your ovaries so you are going to be all right*. She cannot remember being given a time period in relation to survival, and as far as she was concerned the cancer was gone. The years that followed were disease-free. Her second cancer of the kidney was discovered, almost by accident, 18 months ago. Joan's right kidney was removed and she gained support and strategies for survival from a complementary therapist. She said of the medical profession this time: *they've chopped it out, they've sent me away, to come back in 6 months,... I was just told that they could only guarantee five years, which I knew anyway*. Now living on her own, she meditates regularly and is careful with her diet. Joan has worked all her life and maintaining employment seems important to her.

### **Dawn**

Five years prior to Dawn's breast cancer diagnosis, a mammogram and subsequent fine needle biopsy for a breast lump turned up nothing suspicious. Less than a year ago, she returned to her doctor and mentioned in passing that the lump in her breast had never really gone away. Repeated tests revealed a malignancy and she then had a mastectomy. She said her oncologist had given her a 95 per cent chance of survival and that she *had more chance of being run over by a bus*. Today she wears a prosthesis and like many others, has a positive outlook on life. She says of her cancer, *I don't really think about it*.

## Laura

Unlike the other women in this study, Laura had bowel cancer. It is now over 12 months since her initial surgery. The subsequent chemotherapy was to use her words, *worse than the actual operation*. She thinks her doctor gave her a time period of five years in relation to her prognosis, but pragmatically says, *if it's going to happen, it's going to happen*. Laura has a strong religious faith and says that this, along with the support of her family and friends, got her through the experience. Survival for Laura is will power and determination, however thoughts of cancer are *something you don't put out of your mind*. Today Laura exercises regularly, watches what she eats, and maintains a colourful garden.

### 3. Reflecting on essential themes

Following van Manen (1990) I utilised thematic analysis to make sense of the research conversations. However prior to this step, the transcripts had to be managed and collated in some way. Data management involved having all the transcriptions and journal entries entered into a qualitative computer program called N.U.D.I.S.T (Latrobe University, 1992). This program allowed for management and retrieval of vast amounts of textual conversations according to the themes identified.

The transcripts were read and reread several times to get a general sense of the whole. This step occurred in conjunction with ongoing data collection, enabling focused questions in subsequent research conversations. Following the reading of the whole text, a 'highlighting approach' was used to isolate thematic statements (van Manen, 1984:61). The transcripts were read several times, each time asking *what phrase seemed particularly essential about the experience of surviving cancer?* Thematic statements in the women's own words were isolated and themes that seemed to make up the experience of surviving cancer were identified. Additional themes were added and many were deleted as the transcripts were revisited time and time again in a constant back-and-forth process. The themes identified were not exhaustive but they did allow for a systematic investigation of the text.

The lifeworld themes of lived time, lived space, lived body and lived relations (van Manen, 1990) were used to guide reflection around the phenomenon of survivorship. These four themes have been considered by Merleau-Ponty to be part of the basic structure of the lifeworld or the world we experience everyday, and as such are common to all human existence (Merleau Ponty, 1962). These themes above have been labelled by van Manen (1990) as 'existentials' so as to differentiate them from the particular themes of the phenomenon under investigation. It is important to note here that not all lifeworlds are the same, nor do we inhabit the same lifeworld everyday. Our lived worlds differ experientially according to whether we are as child or as adult and to whether we are at work or at play (van Manen, 1990:101).

Thematic analysis was used to determine the "experiential structures that made up the experience" of survivorship (van Manen, 1984:59). This step of thematic analysis was concerned with bringing to the forefront, things in the experience of survivorship which tended to be hidden. Van Manen describes these themes as "knots in the web of our experiences, around which certain lived experiences are spun and thus lived through as meaningful wholes" (1990:90). A theme or a thematic phrase according to van Manen (1990) is therefore not an abstract concept, but hints at some aspect of the phenomenon under investigation – in this case survivorship. In this sense, van Manen appears to ground the phenomenon in consciousness, that is, in the mind of the knower and he suggests that survivorship exists in some essentialist way. This aspect of phenomenological research is somewhat problematic particularly in the sense of the researcher claiming an insider perspective and a role in interpretation. In coming to terms with this problem, I chose to move away from van Manen's essentialist treatment of the data and from the foundational descriptions of survivorship towards his notion of phenomenology as a poetising activity. The thematic analysis was, however, helpful in theorising around and working with the text. I became interested in attempting to engage a language that 'speaks the world' in phenomenology as a poetising activity.

The steps of data collection and analysis or interpretation were not mutually exclusive activities. The two steps intertwined uncovering themes or thematic phrases involving many forays into the transcripts as my understanding deepened. This to-and-fro process

with the transcripts served to keep the findings close to the original data and allowed the reader to participate in the process of interpretation through the medium of language (Gadamer, 1975).

#### **4. Describing the phenomenon of survivorship through the art of writing and rewriting**

The aim of phenomenological description and interpretation (as it has been described by van Manen 1990; 1984) is to permit us to see the deeper structures and significance of the lived experience of the particular phenomenon under investigation. In describing the phenomenon of survivorship, I have attempted to use examples and descriptions that hopefully illuminate its deeper structures. In a sense, I am constructing the text as interpreter/writer, theorising around the women's and my conversations.

Phenomenological research allows for a great deal of freedom in how the results are organised. Van Manen (1990:167-173) identifies at least five possible ways this can be accomplished: thematically, analytically, exemplificatively, exegetically and existentially. In this research, the text has been theorised and poetised with four lifeworld themes interwoven.

#### **Criteria for Precision, Exactness and Rigor**

It is generally acknowledged that phenomenological research operates under a different set of criteria for precision, exactness, and rigor than quantitative research (Sandelowski, 1993; Lincoln and Guba, 1985; Koch, 1994). In the latter form of research, the terms 'precision' and 'exactness' usually refer to the reliability of a measurement tool used to collect data and the overall research design (van Manen, 1990). In contrast, phenomenological research uses 'precision' and 'exactness' to refer to the interpretive descriptions being as full and complete as possible, remaining faithful and as close to the phenomenon under investigation (van Manen, 1990). Van Manen (1990) suggests that phenomenological research is rigorous in its stance to be sensitive to the fact that our lifeworlds are far more complex than can ever be fully or finally revealed and that an interpretive description is only ever at its best an approximation. In addition, he suggests

that objectivity and subjectivity are not mutually exclusive categories, as they are in quantitative research (van Manen, 1990:20). Objectivity for the phenomenological researcher is the ability to remain true to the object under investigation without being sidetracked or misled into other directions. Subjectivity on the other hand, involves maintaining a strong orientation to the phenomenon under investigation. This is accomplished by the researcher being perceptive, insightful and discerning throughout the research process.

Lincoln and Guba (1985:300) suggest that there are four terms involved in interpretive inquiry that replace the more conventional research terms of internal validity, external validity, reliability and objectivity. These terms are credibility, transferability, dependability and confirmability. A number of authors have used these criteria in an attempt to establish rigor in qualitative research (Koch, 1994; Porter, 1994; Beck, 1992).

Lincoln and Guba (1985) suggest that credibility of the research study refers to the likelihood that believable findings and interpretations will be produced as a result of the research. The most crucial step according to these authors in the establishment of credibility is member checking, through the return of the transcripts to the participants for clarification of meanings (Lincoln and Guba, 1985:314). Member checking was undertaken informally by returning the transcripts of the conversations to the women concerned, and asking them to read and discuss the interpretations derived from the text. At the second interview, the women were given the opportunity to add anything resulting from readings of the transcript. It was also an opportunity for debriefing.

Transferability replaces the notion of external validity, or the probability that the results can be transferred over time and across different contexts. Sandelowski (1986) uses the term 'fittingness' as part of the evaluation of qualitative research findings. I have included as much detail as possible, including the time and the contexts in which the interviews took place, to assist potential users of this research to make such judgements about its transferability.

Dependability and confirmability replace the notions of reliability and objectivity. A number of techniques are possible according to Lincoln and Guba (1985) to ascertain the



dependability and confirmability of the inquiry. The technique used in this project was the keeping of a reflexive journal (Lincoln and Guba, 1985:327). Throughout the course of the research, I kept a journal recording, very often on a day-to-day basis, my thoughts and feelings in relation to the interviews I was conducting and the decisions concerning method, that I made along the way. Reviewing my journal has provided me with not only a source of data, but also an opportunity to uncover some of the assumptions and biases, which were influencing my interpretation.

In this chapter, van Manen's hermeneutic phenomenological research approach has been described and specific methods for data collection and analysis have been discussed. It is my hope that the inclusion of the information contained within this and subsequent chapters provides an invitation to the reader to be a part of the validating process for this research (Benner, 1984).

## Chapter 4

### LIVING IN A BODY

My body is the means and medium of my life; I live not only in my body but also through it. No one should be asked to detach his mind from his body and then talk about this body as a thing, out there.

(Frank, 1991:10-11)

"I live not only in my body but also through it!" (Frank, 1991:10). These powerful words speak to a mind and body separation that arose for Frank as a result of medical treatment. Both the treatment and diagnostic processes of cancer silenced his embodied voice, objectified his body, placing it outside the realm of his existence. What was once 'my body' became 'the body', the object of medical scrutiny. He also talked about the labelling of his cancer, and what it was like to have his diagnosis placed on the door of his room. He became "*the seminoma in room 53*" (Frank, 1991:52). The process of labelling the cancer may have moved Frank from a person to a patient, and his body could then be spoken of as something apart from the man who was living the illness, his body was elsewhere, the seminoma in room 53. Of course, for the nursing staff and the doctors, the body and the cancer it contained, was indeed elsewhere, but a medical understanding of cancer had little to do with Frank's experience of his illness.

As a nurse, I have been what Lawler (1991) has described as a 'body worker'. I have worked primarily with the outside of people's bodies, objectively measuring physiological parameters of a person's embodied illness. Of course this was not all I did, but a large part of any day was taken up in such a manner. I remember wondering what it must have felt like for the person in the bed, to have so much attention paid to the physical body. The body that was subjectively feeling my ministrations, lay beyond the blood pressure cuff, the thermometer, the wash cloth, and the label of 'cancer'. At times I felt I was

purposely objectifying the body in an attempt to cope with the awfulness of disease. Seymour (1989) has suggested that this practice of objectifying the body may lead to a disembodied conception of self, a disruption in the unity between the body and the mind. I certainly had a view of a separate mind and body in my work as a nurse and I wondered if this practice of objectifying the body occurred for the person in the bed as they too attempted to cope with bodily destruction.

The separation between mind and body has pervaded Western thought for thousands of years. In the 17th century, a philosopher named Descartes extended this notion of a separate mind and body by suggesting that the mind was not only separate from the body, but from nature as well (Grosz, 1994). The body then could be seen to be like any other object in the natural world and subject to the same physical laws. As a result, the body as machine metaphor flourished. This has meant that the body as an object could be, "tested experimentally and blueprinted in detailed anatomical study" (Leder, 1984:30). Dualism, the legacy of Descartes (Cartesian Dualism) assumed that there were two distinct mutually exclusive categories – mind and body. The result of these categories was that the mind was hierarchically positioned outside the body and a gulf existed between the two (Grosz, 1994). These Cartesian categories have led to a devaluing of bodily intelligence.

Merleau Ponty (1962), a French philosopher advanced the view of the 'lived body'. He critiqued the Cartesian portrayal of a separate mind and body saying that our bodies cannot be reduced to the mere workings of a machine (Leder, 1984), for it is the 'lived body' that ultimately constitutes our being in the world (Merleau-Ponty, 1962). There is no mind that is housed in a mechanical body, for the body is not a container for 'things'.

The English language has only a single word for the body, and that is 'the body'. It does not differentiate in language between the body as an object and the body as it is lived, whereas in both German and French, there are separate words for the differing realities of the body (Emden, 1991). Thus the term 'lived body' has

been used to represent the body through which and in which the world is experienced.

### **Feeling Whole: From an Experience of Disembodiment to Embodiment**

Living in a body for the women in this study has meant, not only that they initially experienced this feeling of separation between mind and body, but that survival for them involved regaining a sense of feeling whole and becoming 'embodied' again. Embodiment refers to an intimacy between the body as an object and the body as it is lived, and it is this lived body that enables us to be able to experience situations, interpret them, and interact with the world in a meaningful way (Benner and Wrubel, 1989). On the other side of the coin, there is *disembodiment* which refers to a rift between the body we *have* and the body we *are*, a separation between the body and the self (Seymour, 1989). This intimacy between the body and the self (or the mind) may be disrupted by major changes to the body's appearance or functioning state, leading to a feeling of disembodiment.

Cancer is an uncontrolled growth of disordered cells. It impacts at a cellular level on the body, extending into bodily spaces where it was never meant to be. Internally, a person may never know of this erratic division, until a symptom emerges and he or she has it investigated. During the initial phases of cancer diagnosis and treatment, the women in this study became very aware that the easy, taken for granted way in the world, an embodied way, had been disrupted. When they were well, the body passed by unnoticed, but when a lump arose or a disturbing symptom occurred, the body became the object of their scrutiny. There was an awareness that something was wrong and this awareness disrupted the body's harmony. For Edna, the awareness that something may be wrong occurred in the form of a sore breast:

*I went for a normal visit to my [doctor] and he has a habit of just when we've finished all our normal business, he puts his hands behind his head, and he'd say, now is there anything else troubling you ..... and I said I don't know if it's anything or not but I've got a sore breast. I said there's no lump - I've a sore breast. So he said, OK. A mammogram for you young lady, he said. So I went and had it, and it wasn't a lump, it was what they call a thickening, it was definitely a tumour.*

For Laura, the awareness arose as a result of constipation and a swollen belly that went on for months. Something was not right:

*I had constipation that went on for months and months and I thought I just couldn't use my bowels. I'd get something to work them [the bowels] and the pain was just like labour pains and I was always swollen in the stomach... So I said I can't cope with this anymore and I went to see [the doctor].*

Kate had felt unwell and uncomfortable, Dawn had a pain in her side, Audrey found a lump in her breast. Sue was the only one whose cancer was discovered by routine medical examination. For all except Sue, the heralding symptoms of cancer began the process of disembodiment, the loss of the unity between the body and the self.

Treatment for cancer depends on many things such as the age of the person, the type of cancer and its stage of growth (Otto, 1994). The treatment will be a great deal more aggressive if the person affected is relatively young, and the cancer is small and localised, meaning it is likely that it hasn't spread as yet. It is the doctors who usually decide on the best course of treatment, although people with cancer may choose from a number of options presented to them by the medical profession. During treatment, the body as a commodity is handed over to medicine to be 'fixed'. Edna talked about handing control of her body over to the doctor to be treated. This relinquishing of the territory of the body occurred within the context of treatment options:

*Then they [the oncologist and the surgeon] made up their minds that they were going to take the lymph gland. So I went into hospital again...they made arrangements for me to have radiotherapy and I rang the doctor - I said "what happens now",... and he said "leave it to me, we'll sort this out between us". I said fine, you doctors can sort it out.*

Even the decision to have either a partial or a full head shave prior to surgery was left to the doctor to decide. As Edna said, *I left that to [the doctor] too*. For Frank part of the process of survival involved relinquishing the territory of the

body, for a short while at least; "I, my body became the passive object of this necessity, the investigation" (Frank, 1991:51). This process of handing the body over to medicine for treatment seemed to objectify the body, making it passive, as Joan so aptly describes:

*I got no help from the medical profession in that they chopped a piece out and then said come back in six months or twelve months and have your smears or whatever, and that was it I was still left, and I did not realise it then but I do so now, I was just left to look after myself spiritually and mentally; so they fixed the body yes, and the rest is left to me.*

Joan in the above conversation extract spoke to a separation between her body as an object, and the spiritual and mental part of herself. Kate too, spoke of a similar separation and implied that *there's more to it than six months and then you're right*:

*Yes, you've got your physical state and your mental state, and your adjusting [to surviving] because your whole life has been turned around, and there's more to it than 'six months and then you're right'.*

Audrey found a lump in her breast and had it investigated four years before it was diagnosed as being malignant. During our conversation, the force with which she described her hatred of her cancer surprised me. Her breast turned into some sort of 'alien other', and her body became an 'it' in the few minutes it took to relate her experience to me. She couldn't wait to get into hospital to have her breast removed:

*I used to really hate the thing [the cancer]. I'd get out of the shower and think, oh you awful thing, you're eating away at me. So by the time I went into hospital I was glad that it was time to get rid of it [the breast].*

She was speaking in a way that separated herself from her cancer and the body part it had invaded. Lawler (1991), who studied how nurses dealt with patients' bodies, tells this story about a nurse she interviewed who was asked if she had ever seen patients objectify parts of their bodies, for example calling the diseased foot **the** foot instead of **my** foot. This was the nurse's reply:

*I didn't take any notice of that ... because they're probably trying to dissociate it from the body aren't they. If they're calling it **the** instead of **mine**. They don't want it as theirs, they don't want that part of them (Lawler, 1991:164).*

It may well have been that speaking of the body as an object separate from the mind was part of coping with the initial shock of the cancer diagnosis and may therefore be an integral part in the process of survival.

Recall Joan's story earlier on, when she said, *I was just left to look after myself spiritually and mentally, so they fixed the body yes, and the rest is left to me*. I believe she was inferring that the 'fixing' of the object body did not reconstitute embodiment, make a person whole again. Kate, in the next extract, is describing the experience of regaining a feeling of being whole in her body once again. I had just made the statement to her that resuming life again after cancer was not like putting back the pieces of a jigsaw in many people's experience, and this was her reply:

*Now I know that the last year I've been really good, but some things you find are real ... [difficult]. I mean, after about three years I went off on an army camp and I walked for miles and miles and I was a cripple. My legs blew up and here's me thinking that the exercise will be really good, and so I can't have too much exercise and I can't have too little, I've got to have just an in-between, ... and the same with my riding. One day I obviously rode too much, I was having all this instruction and I rode and rode and I was really bad after that. My legs blew up and it was really awful and I could hardly walk because of the fluid and it was shocking. I'd cry because all those sorts of things were a nuisance.*

For Kate, regaining an embodied self involved finding a balance between too much exercise and too little, one that was just right for her. Rereading her words I also get a strong sense of her frustration. Her body was not behaving as she thought it should, perhaps reinforcing the separation between the body she *has* and the body she is *living*. Edna's story picks up on this theme of frustration:

*I can't do as much as I want to do, but that frustrates me a little bit too and I'm just getting out and trying to clean up the yard.... The only thing is my legs get tired so I'll come in and put my legs up and have a cup of coffee and have a spell and away I'll go again .*

Many of the women, as Kate and Edna have just illustrated, had to adjust to a level of activity during survival that they had previously taken for granted. Both Kate and Edna found a level of activity that they could live with, and in some ways regained a sense of feeling whole, even though they acknowledged that they felt different. Kate continues with her story:

*I'd find with my horses, I couldn't even get up in the stirrups to get up on my horse. All these things that were so frustrating and there were things I found a long time afterwards were difficult, you know different stretching muscles that I probably hadn't used before my operation, and all of a sudden I was putting them into practice again and they weren't ready and they were screaming out at me. Well everything...like going to the toilet ... it is not the same any more ... for the first year you feel your body's healing. I know what I can do now and with Army of a night time, I just undo my boots and put my legs up in the air. They say you lazy old cow and I say that's it, I've got to do it, that's all I'm saying so carry on without me...*

*It is not the same anymore*, the pain of these words recalls a time for Kate when things were different. Like parts of a jigsaw, once treated for cancer, the body is never again quite as it was before. Perhaps Kate was mourning this loss of a united comfortableness. As Pellegrino states, [e]ven when one is 'cured' the experience of [cancer] leaves its imprint. Body and self are never the same again quite so comfortably united (Pellegrino, 1982:159).

As the women began to feel at home again in their bodies, they resumed activities that they had engaged in prior to the diagnosis of cancer. Kate took up horseriding again, Edna continued to clean up the yard, Laura gardened, Dawn mowed the lawn, Joan continued to exercise and keep fit, Sue kept teaching. However, they were left with constant physical reminders. Cancer had left its trace on their bodies and their bodies became a text which could be read. Kate's legs 'blew up', Laura had scars on her abdomen and had put on weight, Edna became tired easily and had an incredible itch over the area of her chest that had been treated with radiotherapy, Dawn's physical reminder of cancer was her sore arm. Most of the time she didn't think about it, but the soreness that resulted from strenuous activity forced her to once again dwell on the seriousness of her disease:

*When I first got home, I used to look at the scar and think that's horrible, but I don't even notice it now. I went down the river and did some mowing and it made my arm sore - it still gets sore where the glands went if I do hard work, but other than that I don't even think about it. ...I try to still exercise it as much as I can and I keep an eye out for the lymph oedema, but I'm pretty careful. But the Breast Cancer book that they gave me tells you not to go gardening and get thorn scratches or anything and make sure you've long sleeves so I'm always pretty careful that I don't get sore if I'm doing gardening.*



Feeling embodied again in the process of survival seemed to be mediated through physical reminders, such as the sore arm in Dawn's case. The soreness served a dual purpose. It reminded Dawn that she has had surgery for cancer, and it also reminded her that the cancer could return at any moment. To survive was to live with these reminders, meaning that cancer and its threat could never be completely forgotten as Kate reminds us:

*Some stages I'd go through a day and the next day I'd be sore, I'd know I blew it. Even now I have a lot of fluid, without having the lymph glands there. I'd go and have a massage once a week. I tried five times a week, but once a week is enough to keep it moving and I have to put my feet up when I get home. While I was at work, if I went a whole day, I'd be bloated and sore and aching, all that sort of stuff.*

Regaining a sense of an embodied self during the process of survival was not always a smooth process. It involved dealing with the anguish that *things [were] not the same anymore* to use Kate's words, implying that things were now different. Looking different was one aspect of this feeling not the same. Seeing herself through the eyes of another reinforced a feeling of being different for Dawn. She saw herself through the eyes of her friends, and was made conscious that she only had one breast. She said, *I notice people say hello and immediately drop their eyes to see what I look like*. Being asked where her cancer was, or knowing that other people knew where her cancer was, altered Dawn's experience of her body. She moved from *being* her body to *having* a body and has become the object of another's gaze. According to Sartre (1966), it is the look of this *Other* that dissipates an unreflective way of being in the world. Dawn became alienated from her body to the extent that she lived it reflectively. Van den Berg (1955) depicts the phenomenon of alienation with the following words:

*When excluded we see ourselves and our bodies as undesirable, unwanted and we cannot inhabit our bodies easily and freely as we would when we feel accepted and confirmed by others. There grows a split between mind and body, we become embarrassed, ashamed, self-conscious (Van den Berg 1955:55).*

Most of the time Dawn tells us that she did not think about her cancer, but *there grows a split between mind and body* when she was reminded that she looked different, only having one breast, and when this happened she became at some level alienated from the body she was living.

Looking normal in the eyes of others also seemed to be important in the survival process for some of the other women. Edna wore a scarf over her bald head during the six months it took for her hair to regrow following radiotherapy. Laura put herself on a diet to lose weight because she didn't like feeling and looking different to how she was prior to surgery. Picking up again with Dawn's story, she said:

*once you get the prosthesis in and you look normal again, really I don't think about it.*

For Edna, Laura and Dawn, regaining a sense of embodiment involved regaining a sense of looking and feeling normal. It is after all, the outside of our bodies that exists as a visible covering for all to see:

"See yourself in wool." Yes, I would like that. I see myself in that wool, heavy, thick, warm, swinging around my legs in rippling caresses.....But who is this coming up behind me? ..... Don't look back, I can't look back, his gaze is unidirectional, he sees me but I can't see him. But no - I am seeing myself in wool seeing him see me. Is it that I cannot see myself without seeing myself being seen? So I need him there to unite me and my image of myself? ....So I am split. I see myself, and I see myself being seen (Young, 1990:177).

It may be that the body in survivorship is reflected in these words above by Young (1990). The body in this sense was both an object, the basis of the gaze of others, and a lived body; the body in which and through which the world was experienced. During the early stages of survivorship, the object body assumed a dominant status, and the embodied self or the lived body lost its sense of unity and harmony for an interim period. The loss of the lived body is mourned, reflected in the words of both Kate and Edna when they said earlier; *things are not the same anymore* (Kate), and *I can't do as much as I want to* (Edna). The loss of a sense of embodiment comes powerfully through in the next extract by Sacks, who told of a devastating leg injury he suffered while walking:

I once had a violin as a child which got brutally smashed in an accident. I felt for my leg, now, as I felt long ago for that poor broken fiddle. Admixed with my happiness and renewal of spirit, with the quickening music I felt in myself, was a new and sharper and most poignant sense of loss for that broken musical instrument which had once been my leg. When will it recover, I thought to myself? When will it sound its own tune again? When will it rejoin the joyous music of the body? Oh, *when* ? (Sacks, 1984:14).

How do the women in this study reclaim the territory of the body during the process of recovery and survivorship? For Edna, it seemed to be tied up with her hair growing back, and being able to go out again, not looking different:

*It took six months for the hair to grow back, ... and it feels good, it's soft. I wouldn't go out anywhere till then. Oh I had a scarf when I went to Kings Meadows, but not often [went out].*

Radiotherapy was also a process that controlled Edna's body:

*every day for five weeks,... that really knocked me, it seemed to drag every little bit of energy from me.*

She finally seemed able to feel whole again when she looked well in the eyes of those around her:

*my son said when we were going down to Hobart , "Mum I don't say much, but I love you, you look real well". When he said I looked real well, I thought , well I must have come through it. But everyone says I've got over it really well.*

The regaining of a sense of self in embodiment did not seem to be always an easy thing. Feeling whole again for the women also involved regaining a sense of being in control over a body that had previously been handed over to medicine to be treated. Loss of control over one's body was not an uncommon feeling according to some authors after the experience of a serious illness (Eakes, 1993, Frank, 1991). Frank (1991) suggested that control was a much valued attribute in our society today. Advertisements advocate control over the body by diet or exercise or some other form of prescription. To lose bodily control, as sometimes happens in cancer, could be seen as a failure both socially and morally. For Dawn this latter point may have been true. In the following conversation extract, she was talking about a friend who had also been recently diagnosed with cancer:

*... she has been so hopeless, and I thought goodness me, I don't know whether I'm hard or peculiar, or what, but I just couldn't go to pieces like she did - you know, crying for a week or ten days or something.*

Dawn remained in control whilst her friend did not. Perhaps she saw the loss of control as failure, both socially and morally? The struggle it took to regain

control over an aberrant body came through powerfully in the next conversation extract by Kate:

*I can't remember how long, but I was house-bound for a while. I got like a phobia where I couldn't leave home. Dan would help me out of bed and help me to sit down straight after the operation and when I got out of hospital...I could walk for a bit and then I'd have to sit down, but I'd need help to sit down and then Dan was always around and I gave up smoking ... I was too scared to have a smoke while I was stuck up there and could hardly move, because I thought if I dropped a cigarette, I'd burn to death....He didn't leave me for quite a while and then I realised that he couldn't even go round to the shops. Because I remember the first time he said I'll just pop round to the shop are you all right? I said that's all right, everything's fine and he went out the door and I had this massive anxiety, I could hardly breathe and my heart was thumping and I just called out to him. He didn't hear me, he'd gone. I got up and managed to walk to the front near the window to see if I could catch him, so I went and lay on the bed and I was heaving all the time because I wasn't used to getting around on my own and I lay down and was trying to breathe easy so I didn't faint...And when he came back I was howling my eyes out. It happened all the time and he had to gradually go away a little bit longer and that was awful. And then it got to the stage that I was all right and then when I was allowed to drive again... I was going down the southern outlet, and I really freaked out, so I put my foot down and came flying back home again... it was after that I couldn't go anywhere out of town, couldn't drive anywhere out of town. Couldn't drive anywhere. So I started going anywhere but up the southern outlet and he'd [husband] go somewhere and I drive towards him and that was always good....it was something that happened to me while I was on my own. ... It really worried me because I thought I should go and see a psychiatrist or something and [the doctor] said it's something when you've had a really frightening experience, you know that you've had a life and death situation and it's just suddenly dawned on you what's happened to you.*

Kate was describing here just how frightening it was to be on her own. She was very much afraid of something happening to her whilst she felt she was so vulnerable. It was so frightening that for a while she thought she was going mad. I sensed her panic was still close to the surface, nearly five years after this experience had taken place, a feeling that at any moment her body could again act in a bizarre way. It may be that the feeling of being out of control for Kate was related to her contracted space of illness. Sacks suggests that the world of illness can be a contracted world, "with each step, each advance, one's horizons expanded, one stepped out of a contracted world - a world one hadn't realised was so contracted" (Sacks, 1984:154). Kate was house-bound for a while, and later was geographically bound to an area close to home that she felt she could not venture beyond. This contracted feeling of space may be related to the

feeling of disembodiment, for as Merleau-Ponty (1963) suggests, the body is our means of access to the space around us, and it haunts space unlike other objects:

it applies itself to space like a hand to an instrument, and when we wish to move about we do not move the body as we move an object. We transport it without instruments ... since it is ours and because, through it we have access to space (Merleau-Ponty, 1963:5).

The reconstituting of embodiment, the regaining of bodily control, and the re-expanding of a previously contracted world of illness, all focus on the body as it is lived during survival.

### **The House of Suspicion**

In addition to cancer being a disease of disordered cell growth, it has the potential to spread and regrow in any area of the body. This potential for spread, or metastasis as it is known, is one of cancer's most dangerous properties (Otto, 1994; Kneisl and Ames; 1986). A secondary cancer can be found years after an apparent cure in organs and body sites far distant from the original growth. This threat of recurrence is never far from the thoughts of people who have had cancer (Carnevali and Reiner, 1990; Welch-McCaffrey et al., 1989). The threat of recurrence and spread occurs in the body and in this sense it may be that the body becomes for those who survive cancer, a constant source of suspicion, the house of suspicion.

As I sat listening and talking with the women involved in this research, I was repeatedly struck by their sense of alertness and watchfulness for the possibility of cancer's return. It was as though they all knew of the statistical information that placed them at an increased risk of developing a second cancer. For example, it is well documented that procedures such as biopsies, chemotherapy and radiotherapy all increase the likelihood of a secondary growth occurring at a later date (Otto, 1994). Prior to this research, the significance of this threat did not really mean anything to me, nor did it seem to mean anything to the nurses I worked alongside. It was listening to Kate, Sue and the others tell of repeated checkups and return appointments that threw me back to another time and

another place. A number of years ago, I worked as a nurse in doctor's surgery in a small rural community. A large part of what I did each day was to arrange for people to come back and see the local doctor on a regular basis. Many of the people I met through this process had had treatment for cancer and their progress was being monitored at six month or yearly intervals, alternating visits between the oncologist and the local doctor. These return visits came around like clockwork and the people concerned never missed any of these monitoring appointments; appointments that I could only describe as a tedious and perhaps unnecessary intrusions in people's lives. At the time, I obviously misread the nature of these return visits and the importance that people with cancer may have placed on this continual monitoring process.

One of the key features of surviving cancer for the women in this research seemed to be that they had to make sure that cancer did not re-emerge in the body. It was the body that became for them the house of suspicion, harbouring a potential threat, the threat of cancer's return. To combat this suspicious potential of the body, the women all participated in self monitoring behaviours, such as breast self-examinations and underwent repeated checkups and tests conducted by the medical profession. The importance of continued checkups and the necessary vigilance required, reinforced in the women the notion of the body as an object of suspicion, the house of suspicion. In addition, the suspicious potential of the body to house the invader 'cancer' seemed to be tied up with the language of discipline and punishment. The body became something that couldn't be trusted.

Laura was determined to have regular checkups as a sort of insurance against her cancer reappearing:

*I had it [the checkup] six months and then I'm due for one at the end of the year. So they're going to have it every 12 months now. They wanted three years, and I said no, that's a bit too long to wait, anything could happen before that ... I'd always have them [the checkups]. When the doctor said no, I said I prefer to have one every 12 months because for the women at the Cancer Chat, its been six years and one of hers is in secondary now. So you never know.*

Laura knew the potential of the body to harbour a secondary cancer, and was quite adamant that she would always have regular checkups with the doctor. Three years between return appointments was just too long for her to wait for the reassurance that at least for the time being there was no sign of cancer, for as she said 'anything could happen before that'.

During these return appointments with the oncologist, many tests were performed to detect recurrence and/or spread, and the type of test depended on the original cancer treated. As Laura had had bowel cancer, she had to undergo repeated bowel examinations, which were not pleasant, but were tolerated as they seemed for her to be an integral part of the survival process:

*I had to have the stuff you have to drink before you have it [the examination] and you've got to have a bowel examination and you're half awake because you can feel the tube going through the passage. But it's just one thing you've got to do to find out whether it's spread further. When they did the other tests last fortnight, they had a good look around and they said there's no sign of cancer. So maybe I beat it, I don't know, but only the future can tell.*

A sense of the body as the house of suspicion, never seemed to fade for Joan, who had her first cancer diagnosed and treated 30 years earlier. She continued to be monitored via a yearly vaginal examination. But these yearly appointments did not allay for her the fear that cancer could return at any moment. And it did. Eighteen months ago, another cancer surfaced in her kidney, reinforcing for her just how right she had been to remain so vigilant over all those years. Again, this cancer was caught early, however, she did not lapse in her determination to remain on guard. A sudden back pain of unknown but suspicious origin sent Joan back to the oncologist. The subsequent bone scan revealed 'hot spots' on her spine. For Joan, a 'hot spot' was a metastasis and confirmed for her that cancer had indeed returned, in spite of her attempts to remain vigilant. But the doctors had another interpretation of the word 'hot spot', meaning instead what they had found on her spine was an arthritic spot, and not necessarily a secondary growth. However, the doctor was cautious, reinforcing for Joan the uncertain cause of the pain she was experiencing:

*He said that we're not sure what it is, we don't think it is a metastasis, but he said we can't say for sure that it's not. So I thought - oh I've really got it and it's in my spine, and that's all there is to it... I've insisted that I read [the x-ray report] in front of them, and I feel that it's my right, and once I do that I feel as if, I've seen it and it registers up here, and then I'm OK. And it said that I had this "hot spot" on whatever it is here, my vertebrae, but they [the doctors] didn't think it was a metastasis - but they couldn't rule it out.... I said, but I want some answers and he [the doctor] said, you'll just have to realise that the tests showed nothing, so as far as we're concerned there's nothing there. He said, go home, and get better, he said, just forget about it.*

Joan did just that, she went home and got better, but the thought of a 'hot spot' on her spine did not leave her over the next 12 months reinforcing for her the ability of her body to harbour a potential enemy. She continues her story:

*I went back to the doctor when 12 months was up and asked him could I have another bone scan, and he said no ...why do you want a bone scan?, and I said because that 'thing's' still there, and I want to know if it's progressed or whether it's disappeared or whatever, and he said no he won't order it, but perhaps your GP will. So I went to see [the doctor] where I worked and he said, "oh Joan, you don't want to have a bone scan", and I said, yes I do, I really want to have a bone scan, and he said "leave it to me ... and I'll think about it" .... So next week I went down to see him and I said, well, what about this bone scan, and he said, "you're really insistent aren't you", and I said, Yes I am, and he said, "well I'm not in agreement with it, but if you insist, I'll order it for you". ... I really had to fight to get that scan, that bone scan. And of course, the next 12 months I'm going back, and I'm going to insist on the same thing again, and we'll go through the whole process again.*

This extract is testimony to Joan's determination to remain on guard over her body. Sitting with Joan as she told of her determination to fight for continued bone scans reinforced for me the metaphor of the body as a machine that required constant and continual maintenance to remain in working order. Featherstone (1982) suggests that our bodies within the consumer culture in which we live, are seen as machines, and "like cars and other consumer goods, bodies require servicing, regular care and attention to preserve maximum efficiency" (1982:24). These women have been persuaded to assume responsibility for their own survival, participating in a ritual of constant surveillance, perhaps reinforcing the feeling of an object body. Surviving for Joan, meant the acknowledgment of the possibility of cancer's recurrence. But what about the other women in this study? Did they also participate in this ritual of constant surveillance? It appears as though they did.



Dawn returns to the doctor twice a year, and has a yearly mammogram. Sue still thinks of cancer each time she gets an unknown twinge and regards each mole with suspicion, but laughingly says, *well, I'm still here and I do what is necessary*. She was referring to the fact that she still has her yearly checkups. For Kate the return visits are at six monthly intervals. Her suspicion manifested in anxiety, the seeking of assurances that everything was all right:

*[J]ust a little while before I was to go back again, I'd get really anxious and not myself and I put it down to that was what was happening. I needed to be getting assurances that I was all right, so my appointments got a bit closer together for a lot longer than what they were meant to be.*

Kate was given hints that her cancer may return. She continued her story:

*[T]hey put my ovaries sort of up in my ribs somewhere, so if I had to have chemo at a later date or radiation or whatever they call it, then my ovaries were out of the way and he just said, "well nobody's guaranteed a long life" or whatever and "this is really good, we think we've got everything, and each time you come along here we're just checking to make sure that nothing comes back".*

Rereading her words, I can still hear her voice and see the expression on her face as I remember the conversation. I am struck yet again by the tenuous nature of survival. For these women, cancer and its threat could never be forgotten. The body remained throughout life, a constant source of worry and suspicion. Living in the world in an embodied way continued on one level, but just below the surface of the everyday existence, a fear lurked. As Laura explains:

*I mean every time something happens, I think it's back. It's just something you don't put out of your mind.*

This feeling is not uncommon for cancer survivors by all accounts:

*If I wake up in the morning and I have a headache or my joints hurt, or if I have a sore throat, I probably will just shrug it off and go about my day. If a patient with cancer wakes up in the morning with any of those symptoms however, they mean possible brain tumour, possible brain metastasis, possible throat cancer. Every little twitch and twinge assumes ominous and threatening proportions. In weeks, months, even years after a brush with cancer, your body's sensations conspire to inflict a kind of emotional Chinese water torture on you (Wilbur in Leigh, 1992a:1478).*

Thinking about all these return appointments and repeated tests, I can't help but wonder that the women were battling with the myths and stigma associated

with cancer as they dealt with the suspicious nature of their bodies. One powerful myth was that cancer was a punishment for the way they had led their lives. The language of punishment perhaps reinforced the notion of the body as *the house of suspicion*. Laura and some of the other women illustrated this point:

*I think when we came here just over two years ago, well he didn't have work and I was worried that we were going to lose the house, I mean I own it, but it's just the worry of bills coming in and that was the stress that I reckon caused the cancer. Because it was only after that that this all happened.. I mean it was probably always there, but it aggravated it.*

*It's just the stress that I reckon caused the cancer*, said Laura. The thinking that stress causes cancer is not new. As Leigh (1992a:1476) states, "when society fails to understand the biology of a disease, it opens the door to mythologic speculation and oversimplification, that in turn define sickness". The exact nature of causation is an unknown quantity and it is this unknown quantity that can give rise to mythological speculation. The results of studies that link certain things such as stress to cancer are inconclusive and even controversial (Lowenthal, 1990). However, the belief that in some way a person caused his or her disease is widespread in our society, oversimplification or not. For Joan, her cancer arose as a direct result of carrying a burden of guilt and the way she led her life:

*I must have known, there must have been something up here, telling me that something was going to happen again, and I had this feeling that my life was totally out of control. I had no time to myself, I had an aged mother who was 82 then, who had told three brothers not to go near her anymore, and I was the only one who was to go near her and help her. It was just one continual rushing backwards and forwards, you know, in the middle of the week, ..... and when I look back, I had no time to myself, and my life was totally out of control, so I think now, that something had to happen to pull me up, that's what happened I think. I had no time to myself, and my life was totally out of control, so I think now, that something had to happen to pull me up and that's what happened I think.*

Joan was in no doubt that she had caused her cancer. Perhaps it was even seen as a punishment. The language of punishment was manifested in the following words by Dawn:

*obviously I'm doing something wrong with me, otherwise the cancer wouldn't have got me twice.*

For Edna it was a punishment sent by God:

*I'm not terribly religious, but I said God must have thought I could handle this or he wouldn't have done it to me, would he?*

Cancer as a punishment directly affects the body. Foucault (1979) suggests that historically, punishment was seen as a way of compelling people to act in a certain fashion by disciplining the body:

[P]unishment was seen as a technique for the coercion of individuals; it operated methods of training the body - not signs - by the traces it leaves, in the form of habits, in behaviour[s] (Foucault, 1979:131).

Survivorship, seen as a stay of the sentence of death, may involve disciplining the body as a form of punishment through the instigation of the rituals of surveillance and self monitoring behaviours.

The belief that cancer was sent as punishment, infers that during survivorship the person concerned lives out the sentence. However, for an unknown period of time the women have been given a reprieve, a stay in the sentence of death. Again, like the mythology surrounding cancer causation, there has been a widely held belief in our society that cancer equals death. The idea still lingers today, as Kate illustrated:

*And you don't rush home and tell your parents something like that. I wanted to tell my husband and it might have been just something that could be fixed up and then continue on instead of getting everyone concerned about it. Every time anyone mentions cancer, well, that's death.*

Kate continues, after having told me that she subscribed to the view that cancer equalled death, to say that she had been given a reprieve:

*I sort of feel really pleased that I've been given a reprieve I guess.*

Dawn too felt that she had been given a reprieve in the sentence of death:

*I can always remember that Sister saying to me "you've had a reprieve". I had a reprieve from 1989-1993.*

For these women surviving cancer involved living in a body with all that that entailed. Out of the ashes of disembodiment a new sense of embodiment arose, different to that which had existed prior to the diagnosis of cancer. Feeling at

home again in one's body, after the disruption of treatment was something that seemed to take time. Part of the process of reconstituting a sense of embodiment may have involved regaining a sense of control over one's body and the situation one found themselves. In addition, the threat of cancer's return remained forever in the minds of the women concerned. The threat may be forgotten for a time, but it never left the women completely. The potential for the body to harbour this threat is one that was coped with by ongoing checkups and self monitoring behaviours, disciplining the body to act in a certain way.

Living in a body during the process of survival, may also involve living in time, for the body, time and space are intimately connected in a way that make separation impossible (Merleau-Ponty, 1963).

## Chapter 5

### LIVING IN TIME

What could be more easily grasped than time? We regulate our lives by time. We carry the time around on our wrist. We divide the day into morning, afternoon, evening and night time. And we reflect on past time and anticipate the time to come. We even talk about time going by, sometimes fast, and at other times more slowly. And yet when someone asks us "what is time anyway?" we are quickly at wit's end to describe it.

(van Manen, 1990:77)

Time it seems is an elusive concept, and yet the experience of time, like the body, plays an important part in the phenomenon of survival. I have already mentioned elsewhere my surprise that survival seemed, for one person at least, to be about keeping track of time, an obsession with the accumulation of months. Each month, day and year were carefully stacked up, and survival was directly related to the height of the stack. This thinking reflects the popular view of survival being equated to the length of time since diagnosis; the longer the elapsed time, the more likely it is that one has survived. This is one definition of survival, but as a definition it excludes all those people who do not live for the required amount of time. It is therefore a very limited linear definition (Hassey Dow, 1990; Greenwood and Nunn, 1992).

Linear time contains within it many facets. The notion of cause and effect is one such aspect that warrants further discussion. Cause and effect refers to the idea that one event in time can give rise to another event, but only as time moves forward in one direction (Knudtson and Suzuki, 1992:152). For example, it is well documented in the literature that early detection of cancer increases one's chance of survival (Otto, 1994). The event of early detection gives rise to the likelihood of increased survival time measured by the accumulation of disease-free months. The earlier a cancer is found, by luck or by design, the easier it is to treat, and the more likely it is that a person will be 'cured'.

How we think and experience time today has its roots in the historical and philosophical traditions of the past. The following discussion is based on the review of time presented by Boyle and Morris (1987: 171-197).

### **Looking Back: Time's History**

#### **Ancient Greece:**

Going back as far as ancient Greece, time was linked to the whims of the gods, fickle and unpredictable. Humans did not control time, it was controlled by the outside forces of the gods. But gradually, in the hands of philosophers such as Plato and Aristotle, time came to be seen as something that was stable, providing an order to the universe. It was Aristotle who defined time as a linear measuring of external events. This model has influenced our thinking of time for more than two thousand years and is evident in the medical definition of survival (Chapter Two).

#### **From Enlightenment onwards:**

During the period of Enlightenment (the name given to the Age of Reason during the 18th century), the world was seen as something that could be analysed and controlled by breaking it down into smaller and smaller fragments for study. The assumption underlying this reductionist focus was that the whole was the sum of its parts. Logical laws of the universe were sought in an attempt to solve the problems of disease and death. Disease became simply a breakdown in a mechanical body. Time, based on Newton's definition of absolute time, was objective time, "devoid of human experience" (Boyle and Morris, 1987:175). This absolute time had no connection to the material world (Capra, 1982). The future was seen as something that was predictable and the past, present and the future were separate entities. There arose a split between objective clock time and the inner subjective world of the self.

The disadvantages in the Newtonian model of time are many, suffice it to say that within this model there is no distinction made between the time of people and the time of things. Linear time, discounting individual differences, sets up artificial categories and standards

such as the popular definition of survival that begins at a fixed point (5 years). One advantage of the Newtonian model is that it does allow standardisation, and has had considerable success in the area of cancer epidemiology and the statistical analysis of survival data. This information is obtained from groups of survivors and not individuals, and is used to measure the end result of cancer treatment and to indicate improvements in cancer management as time progresses (Otto, 1994). Many of our current cancer treatment programs are based on this type of information.

However, not all philosophers have adopted Newton's view of time. Heidegger, for instance, rejected the Newtonian division between past, present and future. He recognised that it was the self that gave unity to these aspects of time, for dying and living were inseparable. Heidegger (1989) said this of time:

Time is thus an unfurling whose stages stand in relation of earlier and later to one another. If we approach an event with a clock, then the clock makes the event explicit, but more with respect to its unfolding to the now than with respect to the how-much of its duration. What primarily the clock does in each case is not to indicate the how-long or how-much of time in its present flowing, but to determine the specific fixing of the now (Heidegger, 1989:5E).

Clock time therefore only indicates the present moment, it does not show the future, nor does it reveal the past. Measuring time only indicates the 'how-much' of time, and not how it is experienced by the self.

### **The Future in Question**

The women in this study seemed to experience time as something to be religiously measured and something to be experienced. They kept careful watch over the accumulation of months and because their future was so uncertain, past, present and future seemed all the more connected.

Most of us have plans for the future, a vision of things we might be doing in five or ten years time. For people diagnosed with cancer, plans for the future are temporarily arrested. As Frank (1991:64) wrote, "what was it like to be told I had cancer? The future disappeared. Loved ones became faces I would never see again". Cancer disrupts the ordinary continuity of our experience of time. How can a future be planned when there

may be no future. There appears a fault line in the sequence of time. Merleau-Ponty (1962:83) suggested that a traumatic experience can arrest our sense of personal time. Impersonal time may continue its path, like the days of the week or hours of the day, but lived time stops for a while. The profound shock of finding out that one has cancer can lead to an experience of time standing still. The following extract from Joan's story gives a strong sense of time stopping. Joan had just received the news that she had cancer of the kidney, 30 years after she had had cancer of the cervix, and this was her experience:

*there was silence behind the screen and I said, "well have I got it or haven't I", and he said yes you have.... I can remember I had one foot just about in the pantyhose and the other one just wouldn't go in, and I got dressed somehow and came out and sat down in the chair...and from then on other things seemed to take control. I was sitting there, and I can remember feeling as if my whole stomach and my whole body was just like a lump of ice, it was a horrible feeling, its hard to explain, but I felt as if [time] stopped working.*

Sacks's (1984:8) experience of time was not so different it seems to Joan's. He described how time altered for him when he injured his leg while out walking. He had just splinted his own injured leg and said this of time:

*By now about twenty minutes had elapsed since my injury, or possibly less. Could all this have occurred in so short a time? I looked at my watch to see if it had stopped, but the second hand was going round with perfect regularity. Its time, abstract, impersonal, chronological, had no relation to my time – my time which consisted solely of personal moments, life-moments, crucial moments.*

For Sacks and for Joan, clock time continued, but it had no relation to *my* time, the time that was being experienced. There was a sense of disorientation and thoughts of the future were temporarily arrested. However, this sense of disorientation did not last for ever. Plans for a future time began to re-emerge out of the devastation that the diagnosis of cancer can bring. The women in this study seemed to have an expectation that some sort of a future would be there for them, the future was no longer in question. Dawn, for example imagined a future that contained a much loved grand daughter:

*probably more than anything I thought of my grand daughter, and I thought I want to be around to see her grow bigger, so probably every one of her birthdays I'll thank my stars that I'm here for another one.*



Future possibilities for Laura involved taking up new activities and planning for projects around the home:

*I got to the stage where I thought what's the use and then I thought this is not me and even bought myself an organ. ... Yes and I've learnt to play Amazing Grace and Laura Goodnight because they're two of my father's favourites. I think about what I'm going to do, because in ten years I want to extend the house. I'm getting the house painted outside next week.*

Joan wanted to finish many of the things she had already started at some point in the past. However, within these next few sentences what comes powerfully through, is a sense of urgency and desperation:

*I'm nearly 60, but I've got so much I want to do myself, there are so many things I want to try, so many things I've started that I haven't finished.*

Joan, who now has had two cancers, seemed all the more aware that at any moment the future might indeed be in question again.

As each of the women told their story, I was amazed at the level of detail that they could remember about their whole experience of survival. As their stories unfolded, I noticed that many of the events that went into making the story were often not told in terms of linear time. Selective things were remembered depending on the significance they had for the women concerned. Kate's cancer occurred just over five years ago now and she remembered the time around her diagnosis, the point at which many of the women began their stories. Kate said she couldn't remember everything about that time, yet was able to provide detail about the events surrounding the time of her cone biopsy:

*I can't really remember everything. It [the diagnosis of cancer] was something that was so vivid that my whole world revolved around it.....there are a lot of things I forget ...but I remember my cone biopsy....I was in a room with another person. I'm a private patient, so I expected to be on my own, so I was not ready really to hear anybody next door to me crying or even laughing. Any emotions from somebody else when I was dealing with what I was dealing with – I didn't like that and then the person went and so that was all right and I could cry on my own and then I was told [the diagnosis].*

The past was remembered by Kate as it impacted on the present, and may have even been changed under the influence of the present telling. Memories long forgotten have left their trace on her by the way she related her story to me. The emotions that existed for her five years ago were again evoked under the strength of the present telling. She

seemed to experience again the time around her cone biopsy and appeared angry as she did so.

Cancer is a serious life threatening illness and it confounded the women's capacity to expect a lengthy future. There is a very real possibility of dying as a result of the disease process itself and/or its long term effects on the body. The future could be *in question*. The women in this study were all aware of this fact, and the possibility of dying was something that they seemed to work through in the process of survival. Joan was very articulate when it came to talking about the possibility of death and dying. In the next extract she described the time when she was recovering in hospital after the operation to remove her cancerous kidney:

*I can remember one morning, and it was winter when it happened, and it had been raining, and I looked out the window and there was a cobweb hanging on a tree and it had all this rain, this dew and stuff on it, and I looked out and I thought, I don't want to die, it just hit me, you know how beautiful it was, and how the grass was beautiful, everything seemed to look different, but that cobweb was something and it was just enough to start me off crying, just as one of the sisters came in. She was a lovely person, she came in and she sat down on the bed.*

Joan's words have a sense of poignancy about them and I recall a softening in her voice as she spoke them. She did not want to die, but at that point in her life, the future was in question. Laura, on the other hand viewed the possibility of death with a sort of fatalistic acceptance:

*I said if it's going to happen it's going to happen isn't it. I even told my husband, I said look, in that drawer is my nightie, everything's ready. I said we've got to go and this is the time for me. I wasn't frightened*

*If it's going to happen, it's going to happen.* Laura recognised that her future was in question, and yet seemed to accept the possibility that she might die. Her fatalistic outlook did not prevent her from planning for the future as illustrated earlier on. Thoughts of dying and thoughts of the future seemed to coexist for her. It was Heidegger (1962) who suggested that we are always future directed, meaning that we are always living towards the point of our death. It is this knowing that we will die, and being thrown towards this point in the future, that enables us to interpret the world in which we live, and the possibilities within it:

When, by anticipation, one becomes free for one's own death, one is liberated from one's lostness in those possibilities which may accidentally thrust themselves upon one. Anticipation discloses to existence that its uttermost possibility lies in giving itself up, and thus it shatters all one's tenaciousness to whatever existence one has reached (Heidegger, 1962:309).

Perhaps for Laura, the knowledge that she was going to die enabled her to live more fully in the present, and at the same time she was able to expect and plan for a future.

As the women went about the business of surviving, linear time remained important, but perhaps less so than it did before the diagnosis of cancer. It was the cycles of anniversary dates and birthdays that became the focus, rather than the accumulation of years. Each of the women had the exact date of the anniversary of their cancer diagnosis or treatment in the foreground, as though these were milestones to be remembered at all costs. At times in our conversations, I forgot how long it had been since they had been diagnosed and treated for cancer. I asked them at least a few times during the course of the discussion, just how long it had been, but the women did not suffer any such amnesia when it came to remembering such important dates. Laura corrected me yet again as I fumbled with the years since her diagnosis.

Katrina:

*And as the anniversaries pass, you have had two ?*

Laura:

*No, I have had one. Its twelve months this August. I had an anniversary 25th August this year.*

Joan was overseas at the time of her first anniversary since her kidney operation:

*I can remember I was driving the car in Ireland and I said to my friend, it was the 23rd of June, and I said – "you know, this time 12 months ago I was on the operating table [for cancer]".*

The exact date of either the cancer diagnosis or the operation to remove the cancer had been etched in the memories of the women. In effect, this date became a new birth date that returned in cycles, time and hopefully time again. Our birth dates are something we usually celebrate each year, and they mark the passing of clock time. The new birth dates

for the women were the dates their cancer was discovered or a time very close to this day, It was not just a year's passing that they celebrated however, I believe they celebrated both a new beginning and the reclaiming of *the future in question*, taken for granted by most of us as we go about the business of daily living.

Even though the cycles of birthdays were looked forward to, being here-in-the-moment took on a new meaning, perhaps because the future for the women was so uncertain when it came to extended survival. In our conversations, Laura and I discussed many things, but one of the most memorable was perhaps our discussion on the philosophy of life. This was Laura's view:

*Day to day. Never put off till tomorrow what can be done today. There is a song and I call it my song, "One day at a time", I think Little Jimmy sings it. I reckon it was written for me because I just take one day at a time.*

Laura lived one day at a time, even though she had made plans for the future, as she said earlier, *in ten years I want to extend the house*. These plans however did not seem to overshadow the importance she placed on living one day at a time. I got a sense talking to Laura that this philosophy was something new for her and that she had not always thought this way. It was as though the diagnosis of cancer had changed the way she viewed time. The date of her cancer diagnosis, now her new birth date, signified for her a new beginning, a new experience of time as living for the present moment.

### Changes in Time

The metaphor of a Phoenix has been used by May (1991) to describe the change that a person like Laura, often undergoes as a result of experiencing a life threatening illness such as cancer:

If the patient revives after such [life threatening] events, he [sic] must reconstruct afresh, tap new power and appropriate patterns that help define a new existence. One cannot talk simply of a new accessory [prosthesis] here, a change of venue there, but ... of a new Phoenix that must emerge from the ashes (May, 1991:22).

A Phoenix was a mythical bird that was said to have burnt itself on a funeral pyre, only to rise from the ashes restored in youth and beauty to live through another cycle of years (Macquarie Encyclopaedic Dictionary, 1990). The Phoenix imagery was related to time

in that this change referred to by May occurred in time, and to use Heidegger's definition, "Time is that within which events take place. ... Change is in time" (1989:3E).

May's Phoenix imagery pervades the stories of many people's illness narratives. For example, Sacks talked about personal changes that occurred as a result of his injury. "But I knew that something momentous had happened, which would leave its mark, and alter me, decisively, from now on" (1984:152). The Phoenix metaphor was also evident in the survival stories of the women in this research. Joan experienced a new self in relation to herself and others in the process of surviving:

*[The experience of cancer] has really made me sit up and take notice of myself. I can actually talk to myself in the mirror now and I couldn't, I couldn't look at myself in the mirror before, except to put makeup on or do your hair or something. Now everything's changed, ... And of course this was something I had to learn to do [express love]. So it got to the stage where I'd go up North there and see [my daughter] and I get out of the car now, and she'll say well aren't you going to give me a cuddle. I've got her to the stage you see where she's able to accept me and I can accept her, and we give each a cuddle before we leave or whenever we see each other, and that is a big step too. I mean, for me to be able to express love, I've never been able to do that before, it was all sort of tight in here somewhere. So I've been able to do that, and that for me is going ahead in leaps and bounds .*

Katrina:

*And that's very much part of your recovery?*

Joan:

*Oh, definitely. I couldn't do it before, I'd never even entertain the thought of doing it before. I can even now, when I see patients that I know very well, I can say to them, give me a cuddle sort of thing, and everything just changes, and of course, this is one thing people are not used to.*

Joan's Phoenix claimed a radically new self that still seemed to be in the process of becoming. She exemplified what Frank referred to as "Who I might become" (Frank, 1991:44), and found new resources in survivorship, living in time, being here for the present. Laura's Phoenix was a much stronger person. My impression of Laura was that she had always been very strong, but in the process of survival she had become much more resilient:

*My faith pulled me through I think. I mean I had my faith, but it grew stronger when I had it [the cancer] because when it was all over, I got up at mass one Saturday night and I said in front of everyone I just told them what had happened and I just thanked*

*them and I just burst out crying.... One women came up to me and she said, that took a lot of guts and I said yes, but you helped me through it and a lot of them didn't even know I had cancer at the time.*

There was another category of Phoenixes that Frank referred to, and these were the “reluctant Phoenixes” (Frank, 1993:47). A ‘reluctant Phoenix’ was someone who was ambivalent about whether the experience of survivorship had changed them at all. Kate, Sue, Dawn, and Edna did not refer to a personal change in their stories of surviving cancer. They did not talk about how surviving cancer had changed them into someone new, nor did they talk about becoming more fully who they already were. Kate for example, did not refer to a better Kate, or a Kate that was fulfilling her potential, but I got the impression she has been able to assimilate the experience of surviving cancer within the life she had always led, and she did this quietly without any shouting or missionary zeal. The very fact that each of these women volunteered to participate in this research was witness, I believe, to the fact that “*the self must be told*” (Frank, 1993:47). They were perhaps publicly witnessing their own survival, and the implication this survival was having on their lives. And they were doing this quietly.

Time is something in which the events of survivorship take place (Heidegger, 1989). The women seem to find a new sense of time as they cope with new anniversary dates and the loss and regaining of future plans. Yet in all they do, they are conscious of death at their shoulders, as Audre Lorde, who also faced cancer, described:

*Living a self conscious life, under the pressure of time, I work with the consciousness of death at my shoulder, not constantly, but enough to leave a mark upon all of my life's decisions and actions (Lorde 1980:16).*

### **Lucky to be Alive**

The language of luck and chance ran as a thread through many of the women's stories. To be lucky from the women's point of view seemed to be related to an acknowledgment that their cancer was caught early, or it was related to a gratefulness that they had remained alive when others that they knew had not. Time played a key role in the thinking of how lucky they were to be alive.

It is generally known that some cancers, such as breast and prostate cancer, have a tendency to run in families. This means that they have a demonstrated pattern of inheritance (Otto, 1994). Just what causes these cancers to run in families is uncertain. It could be due to inherited faulty genetic material, or it could be due to a shared environmental exposure to a particular cancer-causing substance (Kneisl and Ames, 1986).

Dawn, Laura and Joan had a strong family history of cancer which automatically placed them at an increased risk of developing cancer. These three women all knew of the increased risk this history had placed upon them. For Dawn, this prior knowledge perhaps led her to go back to the doctor a few years after she had had her original breast lump investigated. Laura said that her cancer was caught early, meaning that she had presented herself to the doctor during the early stages of the cancer's growth. Joan's medical knowledge, coupled with the strong family history, made her all the more willing to participate in an experimental test for cancer of the cervix more than 30 years ago. Her story extract illustrates this point:

*At the time I was a theatre sister at the [hospital] and I was twenty eight years old. I had one child who was three years old and at that stage pap smears had only just arrived in and I went to my specialist. There was only one contraceptive pill then and I needed a contraceptive pill so I had to go to him and because the pap smear had just arrived, he just decided he would do it, not for any reason but just as a trial. ... I had a cone biopsy and in those days there was no talk of just a cone biopsy and leave it at that, it was a hysterectomy and that was it. There was nothing else you know, you just had the hysterectomy and [the doctor] said when that came back as positive he said I could come home and have another baby if I wanted to and something stopped me dead in my tracks and I said no, I have got one and I don't want another, and since then I can see that if I had gone and had another baby that would have probably been the end of me. Then I had that feeling so I said no and within a fortnight they put me into hospital and took my uterus out.... I was so grateful that cancer had been found early because there is so much cancer in my family on my father's side of the family especially, they have all died of cancer and I had an aunt, my father's sister, who died of cancer of the cervix as well as the uterus.*

Luck for Joan occurred in the context of discovering cancer early and making the right decision not to have another baby. Dawn's luck in survivorship occurred in her reluctance to accept a verdict of all clear:

*Well, I first found the lump [in the breast] in 1989 and I had a mammogram and that didn't show anything, so then they did a needle biopsy which was dreadful and then from that they said I'd better have the lump removed so I went to day surgery and had*

*the lump removed and they said well you've had a reprieve, it's all clear so that was fine. But when I got home and got to looking at it I thought well that's funny thing to me because it was still there, the lump. You could actually physically see the lump.*

Dawn used the term 'all clear' to signify that for the medical profession there was no cancer to worry about. All clear, perhaps reinforces the military metaphor, where cancer was said to invade, likening it to the enemy, and the body to a war zone (Sontag, 1991).

Dawn went on to talk about how wrong the tests had been in 1989:

*Time went by until 1993 and I had to go to the doctor for something else and I said I suppose I should tell you I've still got a lump and he looked at it and at the papers they'd sent him which said it was all clear, and he said we'd better start again. So I went and had another mammogram which showed nothing and I went through that awful needle biopsy again.*

The needle biopsy conducted in 1993 showed Dawn's lump to be malignant and although she said the news nearly made her fall off the chair, deep down she had suspected all along that something was not right. Luck for Dawn was perhaps this intuitive knowledge that led her back to the doctor:

*I just couldn't believe it, but I think I always knew it was there.... I don't know. My doctor down here reckons that I did have a feeling about it that it was there ... I don't know.*

Probability is the likelihood or chance of a particular event occurring. Survival has been equated with the mathematical language of probabilities by the medical community when it has wanted to convey the likelihood of a person surviving beyond the five year mark. For some cancers, namely pancreatic cancer, the probability of surviving beyond five years is very poor, but those people that do, tend to survive the following five years. This information is based on epidemiological evidence (Otto, 1994). Dawn used this language of probabilities when she was describing what the doctor had said to her on the subject of survival. Dawn's story continues:

*He said he would give me an 85 per cent chance of cure, he said I can't give you more than 85 per cent, but he said we'll send you along to the oncologist, so I went and he [the oncologist] said I'd give you 95 per cent and he said I think you've got more chance of being run over by a bus.*

This mathematical language used by Dawn's doctor and subsequently Dawn herself, was inconsistent with the language of luck she used earlier. Dawn may have attributed her



survival to luck, however she was also citing the statistics, which seemed to reinforce for her, her chance of surviving.

Laura continued with the theme of luck. Even though she had lost three quarters of her bowel, she considered herself lucky because the cancer was caught in its early stages, probably meaning that the cancer had had little chance to spread to distant sites in the body:

*I was very lucky. It [the cancer] was only in the first stages, they got it pretty early ... they got it in time I suppose.*

*They got it in time I suppose*, these words of Laura's were spoken in such a way as to cast doubt on the luck she had just mentioned. It was as though she was crossing her fingers against the possibility of bad luck.

Luck for Kate came with the nature of her cancer, and its location.

*I thought for a while, well I've had mine and I'm really lucky because it was where they could rip it out and I didn't have to have any radiation or anything afterwards.*

Although Kate said she had been lucky, she went on to show some ambivalence about how she regarded this luck. At first she thought that because her cancer was somewhere accessible to the surgeons knife, she was indeed lucky; luckier perhaps than someone who had inoperable cancer. Her cancer was *where they could rip it out*. But with time, she realised that extended survival depended not just on the surgeon's skill. This realisation came as somewhat of a shock. Her story continued:

*Then I suppose the realisation that that [I've had good luck] wasn't the case was another bit of a shock and now I don't dwell on it. I go off and I have my examination and I just think when I'm going along there, well I've got this far, so if something horrible happened, I just imagine that I would start thinking how I'm going to deal with this.*

I believe she dealt with these ambivalent thoughts concerning the continuation of her luck by taking on a talisman, her husband:

*I had a chat to my husband and he went with me [to the checkup appointments] and everytime I go for my checkups he still goes with me - I still think he is my good luck charm, if I take him, well, then I'm still clear. I think that the day I don't take him along with me when I go and have my checkup, well, I might get bad news.*

Seeing survival in terms of luck also occurred for some of the women as they compared their experience with other people who had also had cancer. Dawn compared her luck with the bad luck she considered others were having:

*I go up there [support group] every last Thursday in the month and I see how bad some of the other people are and how lucky I am.*

Kate likewise compared herself to someone who she considered was worse off:

*I ran into a girl today, who at the time when I had my operation and before that, she'd had a tumour of some kind, it was about seven pounds or something like that and she was really in a bad way and she had two or three little kids and how she survived I'll never know....I kept thinking that there are people worse off than me.*

Cancer survivors are often reminded by those around them just how lucky they are to be alive, and this attitude may in fact make the person concerned hesitant about bringing up worries or concerns for fear that they may be labelled as demanding or ungrateful (Leigh, 1992a). Edna kept a great deal of her worries and concerns to herself about how she was coping in survival. In this next conversation extract she talked about not troubling other people with her problems, perhaps out of fear that she might be labelled as being ungrateful:

*Another lady that's in the Cancer Group comes around.... But everytime she came here she used to say "I don't know, you're a marvel, you're always bright and happy when I come". I said "Oh yes it pays to be that way". Maybe by midnight I'd be bawling my eyes out, but ... you don't worry other people with your problems. ...I've always been fairly independent. It's usually when I'm here on my own that I let my guard down, there's no one here to see me.*

For Edna, it paid to keep on a mask in front of other people. When she was on her own however she took the mask off. It may have been that she was reluctant to appear ungrateful in the eyes of others because she was after all, so *lucky to be alive*.

Reflecting on this theme of *lucky to be alive* I wonder about those people who do not survive cancer in terms of the medical definition of survival, all those people who do not live for the required amount of clock time. Are these people seen as being unlucky by those around them? For Kate at least, this seemed to be so. I can't help but think that the use of the language of luck and probabilities creates yet another dichotomy for those in the process of surviving.

## Sharing the Journey

As I have discussed up to this point, living in time was one aspect of surviving cancer for the women in this study. The experience of living in time occurred in a world with other people, it did not occur in isolation. As Heidegger wrote, "Being in the world is also being in the world *with* others and *for* others" [my emphasis] (1989:7E).

The theme of sharing the journey implies that the women in the study have been on some sort of a journey in the process of survival. A journey implies movement along a path from A to B. It is a term that is perhaps reminiscent of the path of linear time, only ever moving in one direction. However, the shared journey that each woman in this study took was anything but linear. It was a journey that had unlit alley ways and dead end streets. And it wasn't a journey that had to go anywhere in particular. There was no path *to* survival as this would imply an end to the journey. Each of the women were already surviving and would continue to do so for as long as they lived. They did not have to wait for a specified end point to be considered a survivor. Sharing the journey of survivorship was about relationality or "the lived relation we maintain with others in the interpersonal space we share with them" (van Manen, 1990:105). For cancer survivors, this relationality with others was expressed through the sense of support and caring that surrounds them as they negotiated their seasons of survival.

The point of commencement of survivorship and the beginning of the shared journey has been identified as the bestowing of the diagnosis. Once this event had occurred, the news of it may then be passed onto others. For some of the women in this study, the telling of others that they had cancer had been easy, whilst for others, it had been more difficult. For example, Kate found it extremely distressing to tell her husband that she had cancer of the cervix:

*I just told my husband ...and we'd only been married a year, so it really wasn't very nice telling him something like that.*

Dawn talked about the devastation her news of cancer brought upon her husband:

*I came home and told my husband and he was just devastated.*

For Edna, it was hard enough telling her family that she had one cancer, let alone two:

*I was in hospital when they told me about the thing in my head and I got her to ring my niece and her husband and my daughter and they came and she told them about it, because I was just hopeless, I couldn't tell them about [the second cancer]..I had enough trouble telling them about the first cancer [of the breast].*

Listening to these women relating the anguish of telling another person the bad news, I felt they were living a double agony. Not only did they have to deal with bad news themselves, but they also had to make it palatable for others. Laura, for example, tried to bring up the subject of cancer with her son, but found this very difficult:

*I used to bring it up [the subject of cancer] at the table and my son did not want to talk about it, he used to shut it out.*

The telling of friends and acquaintances was important because these people mattered to the women concerned. It is because of this concern that they became involved in the world in the first place. This *in* the world is not the same as the way objects are said to be *in* the world. We are in the world in such a way that people matter, friends and family matter (Heidegger, 1962). Therefore telling friends that they had cancer was an important part in the process of survival. Kate couldn't stand the thought that the people she worked with would speculate as to the reasons she was absent during the treatment phase, and why she did not have any children:

*At work, .. I went and made a general announcement because I couldn't stand people wondering what was going on. I knew that I would be in hospital for two weeks and it would be six weeks before I'd be back at work and that upset me because I really like work. I was even thinking about rehabilitation, so I had to tell someone at work that after I had my operation I really expected to come back, even if I only came in for an hour, I didn't know how I'd feel, or how long it would take me to get better, but the minute, I felt like I could, I wanted to go in just for an hour or something so people would see me when I wasn't at my best, so I just told everyone - I just went around a few really close people at work and just said to them - this is what's happening. They looked a bit uncomfortable, but I can't have them saying you'll be right and talking about children later in years to come. It was no use hiding anything and I didn't want anyone to be uncomfortable, so that's why I did that.*

Kate went to some lengths to make the bad news comfortable for others. Although she said she told everyone, the *everyone* was limited to a few close people she knew well. The above conversation extract also highlights the importance that Kate placed on returning to work. Some authors (Leigh, 1992a; Welch-McCaffrey et al., 1990, 1989) suggested that returning to work again after cancer treatment could be especially difficult

for some people because of the discrimination that they might face from employers. Dawn, Sue and Kate were all working at the time of their cancer diagnosis and none of them reported to me any difficulty with employers on the subjects of leave, or discrimination because of time taken off for treatment. It was generally the opposite that seemed to be the case, employers went out of their way to help in any way they could.

For Dawn the result of the telling seemed to initially affect her relationships with those around her:

*In the beginning, they [friends] didn't know what to say to me.... We were at a function, and a friend, she just ignored me all the time and I thought oh, heavens, and then she told my husband a couple of days later that she didn't know what to say to me.*

Sue found she could talk to close friends about her cancer, but not to general acquaintances:

*I had difficulty in saying to people oh yes, I'm going to have a hysterectomy for cancer,....my close friends I had at work, they knew of the diagnosis and they were very supportive, and so was my husband.*

Being able to talk about cancer with people other than friends seemed also difficult for Joan:

*All those years ago we never talked about it...my friend knew I had cancer of the cervix, but people never talked about it... it was sort of hush hush thing thirty years ago, not like it is today.*

Joan seemed to think that some of the mystery surrounding cancer today was somewhat less than it was thirty years ago, when it was a sort of hush hush thing.

The support of friends and family seemed therefore to be a major component in feelings of survival for the women in this project. As Edna said:

*I came on leaps and bounds with love and care.... there were three people I could never have got through without... my neighbour and my friends from church, they were always there with me, they kept me going.*

In addition to family and friends, support groups seemed to play a part in the shared journey of survival for the women in this study. Most of the women who attended a group (Dawn, Laura and Edna) found them to be extremely beneficial, however Joan was not so keen in joining a group:

*I was very anti about going to the cancer support group because I didn't want to get involved with a whole group of people who looked as if they were dying, because I considered I wasn't dying. I'd go along to lectures and things like that, but I just didn't feel that I, and I still don't feel as if it's right for me to be in with a group of people like that.*

Maintaining hope was important for Joan and being reminded of cancer's precariousness was not helpful to her as she went about the business of surviving. But for others like Laura, Dawn and Edna, a support group was a great source of comfort. Laura valued being able to talk openly about the problems she was experiencing in survival:

*We have our cancer chat every month at the clinic run by the Cancer Support Group in town and its great there because you can talk openly to each other [about] your problems.*

For Dawn, her sense of comfort from a support group came from the information it provided:

*I go up there [cancer support group] once a month. I went to them before, because I didn't know the first thing about breast cancer or prosthesis, or anything else and someone told me to go up there and I did and they were very helpful. I really felt much better after talking to them.*

Edna also experienced a similar sense of support from a cancer group. A lady from a cancer support group came to visit Edna on a regular basis because she had difficulty in driving the car to attend meetings.

There have been reports in the literature of studies investigating the relationship between support groups and the quality of life (Brown et al., 1993; Hundleby et al., 1993). It may be that cancer patients who regularly attend a cancer support group may live longer and have a better quality of survival than those who do not (Clarke et al., 1993). Support groups obviously have a role to play in cancer survival, however, they may not be for everyone as Dawn attested.

A few of the women attributed their survival to something existential that they called *God*. Perhaps a belief in something outside of themselves helped to provide meaning in their experience of survival. This search for meaning is a common human trait according to van Manen (1990).

In a larger existential sense human beings have searched in this experience of the other, the communal, the social for a sense of purpose in life, meaningfulness, grounds for living, as in the religious experience of the absolute Other, God (van Manen, 1990:105).

Laura talked about her faith in *God*;

*Yes it was [my faith] that pulled me through I think, I mean I had my faith, but it grew stronger when I had it because when it was all over I got up in mass one Saturday night and I said in front of everyone I just told them what had happened and I just thanked them*

Perhaps this recognition of God by Laura was part of her search for meaning in the events that had taken place in her life and part of the way she coped in survival. In their study of 59 cancer survivors, Halstead and Fernsler (1994) found that over two thirds of the people thought that prayer or a belief in God was a very helpful strategy in survival. Given this information, it was a surprise to me therefore that more of the women in this study did not refer to a belief in a God in our conversations, but then again this finding might reflect no more than the number of people in the population who would make the same statement about living life in general.

In addition to gaining support from a variety of sources, some of the women also seemed to gain the support of a person who had also experienced cancer. For Kate, Sue was a support, *"Sue was good because she'd had a similar operation, but even she had two children, so even she was different, and she wasn't just married"*. Sue, on the other hand, told of a friend that used to come around in her early convalescent days and bully her out of her dressing gown. In the study conducted by Clarke et al. (1993), the single most important factor in assisting women to cope with breast cancer was social support, such as friends, family, church groups or support groups. Social support also seemed to be an important factor in the survivorship of the women in this study, thereby illustrating the theme; survivorship as a shared journey. This point was highlighted for me by the following quote, *"thus every step [towards recovery] had the quality of miracle - one that might never occur without the urging of others* (Sacks, 1984:154).

## Chapter 6

### THE POETISING OF SURVIVORSHIP

I allow myself eddies of meaning:  
yield to a direction of significance  
    running  
like a stream through the geography of my work:  
    you can find  
    in my sayings  
    swerves of action  
    like the inlet's cutting edge:  
    there are dunes of motion,  
  
...but the Overall is beyond me: is the sum of these events  
I cannot draw, the ledger I cannot keep, the accounting  
    beyond all accounts.  
    ....  
I have reached no conclusions, have created no boundaries,  
shutting out and shutting in separating inside  
    from outside: I have  
    drawn no line:  
    as  
  
    manifold events of sand  
change the dune's shape that will not be the same  
    shape  
    tomorrow,  
so I am willing to go along, to accept  
    the becoming  
thought, to stake off no beginnings or ends,  
    establish  
no walls:.....

Adaptation of A. R. Ammon's "Corson's Inlet".  
(in Lather, 1991:151-152)

I have set out in this study to make some sense out of what might be seen as a certain aspect of human existence, namely survivorship. In this process, the lived experiences of seven women (myself included) joined together in the layering of meaning around survivorship as a process. I have reached no conclusions and I have hopefully created no boundaries. For in this final chapter, it would be an antithesis to finish with a summary or a conclusive statement, for like poetry, the study itself has been the 'thing'. Van



Manen (1990) suggests that phenomenology is a poetising activity, a language that “speaks the world” (van Manen, 1990:13). In this final section, in addition to reflecting on the method I have used, I have attempted to poetise survivorship, engaging language in “a primal incantation ... which harkens back to the silence from which the world emanates” (van Manen, 1990: 13).

### **Survivorship: Looking Forward, Looking Back**

Few studies have addressed the lived experience of survivorship, and those that have still seem to focus on the narrow definition of survival in terms of clock time. But, for the women involved in this study, statistics and probabilities provide only part of the picture. They seemed to have intuitively used Mullen’s (1985) definition of survival in living from the point of diagnosis, for as long as each of them shall live.

Cancer and survival may have been seen in contradictory terms in the past, reinforced by the myths and metaphors of our time. The thought that cancer equalled death still lingered in the minds of some of the women, as Kate reminds us:

*Anytime you mention cancer, well that’s death isn’t it?*

Thoughts of continued survival coexisted with thoughts of a possible recurrence. Recall Laura’s words:

*I mean every time something happens, I think it’s back. It’s just something you don’t put out of your mind.*

Strategies for survival seemed to include bodily maintenance and surveillance. Laura again reinforces this strategy with her comments:

*I had it [the checkup] six months and then I’m due for one at the end of the year. So they’re going to have it every 12 months now. They wanted three years, and I said no, that’s a bit too long to wait, anything could happen before that ... I’d always have them [the checkups]. When the doctor said no, I said I prefer to have one every 12 months because for the women at the Cancer Chat, it’s been six years and one of hers is in secondary now. So you never know.*

The women who generously gave of their time to this study and shared in the research conversations, may eventually die of the disease. This knowledge continues to haunt me today, as it did all those months ago as I sat in various armchairs around the state,

listening and sharing in their stories. Laura, Kate, Sue, Edna, Joan and Dawn all said that they had survived cancer were surviving cancer. However, they also seemed to live with a sense of crossed-fingers, aware of a questionable future.

### **Reflections on Method**

I chose the method described by van Manen (1990) to explore the phenomenon of survivorship. This choice was deliberate, and it is timely now to reflect on the limitations and strengths of this choice.

In studying survivorship as a process, I have been studying the experience of women as they go about living with cancer. However, is what I have written a true reflection of what it has been like for these women? What is a 'true reflection' anyway? Or is what we have before us a construction of survivorship: a construction created by our experiences of history and culture; a construction created by the women and myself? There is a problem in drawing on phenomenology as method when meaning is seen to be located in subjective understandings. The phenomenological method tends to locate the subject "as an autonomous individual capable of full consciousness and endowed with a stable 'self' constituted by a set of static characteristics such as sex, class, sexual orientation" (Lather, 1991:5).

However, we are not the authors of our lives, for as Lather (1991) suggests, the "author is inevitably in discourses created by others, preceded and surrounded by other texts" (Lather 1991:9). The method has not allowed for an exploration of the discourses created by others within this thesis, nor does it challenge the location of knowledge within the subject.

I have used the major headings of 'living in a body' and 'living in time' as guides for reflection. The identification of themes, at best, are only ever a simplification of the whole, and are therefore perhaps inadequate when being used solely to interpret the phenomenon of survivorship. In this area, I have perhaps been inconsistent with the method of van Manen in that I have not reduced the women's stories to abstract generalisations in deriving themes. The women remain alive in the text as their stories

and personal moments are woven through the discussion. My voice has been added to their voices in the creation of the text.

I have interpreted the conversations with the women in this study, and I recognise that the conversations are open to an infinite array of further possible interpretations. I have provided only one interpretation, but as van Manen (1990) suggests:

... A phenomenological description is always *one* interpretation, and no single interpretation of human experience will ever exhaust the possibility of yet another complementary, or even potentially *richer* or *deeper* description (van Manen, 1990:31).

As a nurse interested in the field of oncology and palliative care, my knowledge and experience have been used in the interpretation of the conversations. My own experience has been added to the material collected. Rather than considering my own subjectivity a limitation as it would be from within a positivist framework, it becomes a strength. The voices and the stories of six women became seven as I participated in the narration of survivorship. These shared understandings have removed the distance between myself as the researcher and the women with whom I was researching. The method has allowed me to explore the phenomenon from within an interpretive paradigm which has facilitated these shared understandings (Habermas, 1971).

The narration of survivorship has been of particular importance to the women. They all said in their own way how helpful it had been to be able to tell of their experiences. It was as if the conversational space had not previously been available to them for a variety of reasons. Perhaps the telling of the story has provided a sense of validation of experience for each of the women in the study.

Just as I cannot be separated from the women in this study, the women themselves cannot be separated from the world in which they live. Their stories have shed light on the phenomenon of survivorship in a limited way, but this study will add to the cumulative understandings of survivorship as a process.

## The Poetising of Survivorship

Rereading this study, I am aware that I do not appear very often as a participant in the text, and yet the overwhelmingness of this sharing with the women within the research process lingers today. Our conversations have left their trace on my memory, like a comet's tail leaves its trace on the night sky. I wonder why I see this distance between myself and the pages of this text. My method of surviving the feeling of being constantly overwhelmed may have been to distance myself somewhat in the writing of this thesis, allowing for its completion.

I have chosen to bring this thesis to a close through a joining of voices.

**The voices in bold type can be viewed as the voice of science, based on the scientific knowledge that surrounds cancer and survival; drawn from Otto, (1994).**

*Between the bold type, I have presented the multiple voices of people surviving cancer. The voice fragments form a life play voices in the poetry of survivorship.*

**Cancer is a logical, coordinated process in which a normal cell undergoes changes and acquires special capabilities:**

*I remember there was silence behind the screen and I said,  
"well have I got it  
or haven't I",  
and he said "yes you have".  
I had one foot just about in the pantyhose and the other one just wouldn't go in,  
everything stopped working.  
With the diagnosis of cancer, the music of my body stopped.  
I looked at my watch.  
Had I only been here for twenty minutes.  
Could all of this have occurred in such a short time.  
Time seemed to have stopped for me,  
but the second hand was going round with perfect regularity.  
What was it like to be told I had cancer?  
The future disappeared.  
Will I be around ,  
to watch my grand daughter grow up?*

**The diagnosis period can be confusing and frightening for both patient and family:**

*I don't want to die.  
I was in hospital when they told me about the thing in my head.  
I can remember one morning,  
It was winter when it happened,  
it had been raining,  
and I looked out the window  
there was a cobweb hanging on  
a tree and it had all this rain, this dew and stuff on it, and I looked out and I  
thought, I don't want to die, it just hit me, you know how beautiful it was, and  
how the grass was beautiful, everything seemed to look different,  
but that cobweb was something  
and it was just enough to start me off crying.  
Will I die?*

**Prevention, screening and early detection are amongst the best strategies available in the quest to conquer cancer. If it is diagnosed early enough and remains localised, surgery can effect a cure. Of the 40 per cent of cancer patients who are treated by surgery alone, a third are cured:**

*Well, I first found the lump in 1989.  
I had it removed  
and they said  
well you've had a reprieve,  
it's all clear  
so that was fine.  
It might have been just something that could be fixed up*

**Whatever causes cancer, the result is an irreversible change in the cellular genetic code:**

*My life was totally out of control. Something has to happen to pull me up,  
that's what happened I think.  
I caused my cancer.  
Even if I am deemed 'cured', cancer has left its imprint.*

*Body and self are never the same again quite so comfortably united.*

*I know that;*

*you've got your physical state and your mental state,*

*and your adjusting to*

*surviving*

*because your whole life has been turned around,*

*there's more to it than 'six months and then you're right'*

*I once had a violin as a child which got brutally smashed .*

*I felt for my body now,*

*as I felt long ago for that poor broken fiddle.*

*After all, my body is the means and medium of my life.*

*So, I am split.*

*It's not the same anymore*

**Survival analysis is the observation over time of persons with cancer and the calculation of their probability of dying over several time periods. The five year survival rate for breast cancer diagnosed early is 90 per cent:**

*He said he would give me an 85 per cent chance of cure,*

*I can't give you more than that.*

*But he said we'll send you along to the*

*oncologist,*

*So I went and he said:*

*I'd give you 95 per cent*

*I think you've got more chance of being run over by a bus.*

*I'm lucky*

**The five year survival rate has become almost a standard term:**

*The possibility of death was always present.*

*I was, in fact, surviving, struggling physically and mentally,*

*the large scale disruption of my life.*

*It was survival*

*Survival, in fact, begins at the point of diagnosis.*

*They got it in time*

*I suppose...?*

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## APPENDIX

### Ethical considerations

The proposal for this study was submitted to the University's ethics committee and approval was received. Prior to the first interview, the women received over the phone a verbal explanation of the study, its purpose and what would be involved should they choose to participate. Assurances were given that the information that they gave would be confidential and that they could withdraw from the study at any time. They were informed that the data would be stored in a locked cabinet, according to the University's policy for data storage. In addition, a written explanation of the study was provided at the first face-to-face meeting and a signed consent form was obtained (see the Attachment). All the women were provided with a card with my full name, where I worked and a telephone number where I could be contacted both at work and at home.

The purpose of the study was clearly articulated to the women at the outset. Research conversations, like any human interaction, have their inherent risks and dangers. Embarrassment, anger, invasion of privacy, and misunderstandings are possible as a result of the research process (May 1989:198). The type of research conversations I used may have had certain effects on the participants in the research project. They may have felt uncomfortable with the discussion about issues and memories that were part of a long forgotten past. Keeping this fact in mind, I was sensitive to how I responded to the participants. Through the provision of telephone contacts, an avenue for debriefing was built into the research project where concerns and issues for the participants could be aired and discussed. Support was therefore available long after the project had been completed.

## ATTACHMENT

### CONSENT

DEAR

I am a registered nurse interested in the field of cancer nursing. As part of my Master's degree, I am proposing to conduct a study into what it might mean to survive cancer. In order to gain some understanding about this experience, I am interested in hearing your story. I invite you to participate in this project. If you do not wish to be part of the interviewing you may withdraw at any time. I would like to stress that withdrawal from the project will not prejudice you in any way.

With your consent, the sessions will be audio taped. Audio tapes are confidential and will be destroyed at the end of the study. I anticipate that two interviews will be needed, lasting for about an hour each time.

If at any time you wish to discuss the study or if you have any questions please do not hesitate to contact me at the University of Tasmania, School of Nursing on the following number:

Katrina Breaden (003) 24 3318

#### Statement by the participant

"I have read the information above and any questions I have asked have been answered to my satisfaction. I agree to participate in this investigation and understand that I may withdraw at any time without prejudice.

I agree that research data gathered for the study may be published provided that I cannot be identified as a subject."

Signature of subject ..... Date

#### Statement by the investigator

"I have explained this project and the implications of participation in it to this volunteer and I believe that the consent is informed and that he/she understands the implications of participation."

Signature of investigator ..... Date