

Cancer and beyond: the question of survivorship

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Today, more people are surviving cancer as a result of improved treatment and early diagnosis. In Australia, the 5-year survival rate for persons diagnosed with cancer is now approaching 50%. Although there is a growing population of cancer survivors, little is known about what surviving entails. Traditionally, a survivor has been defined as one who has been disease-free for more than 5 years. However, this definition does not take into account the experience nor the process of survival and the aim of this article is to document the process of surviving cancer as reflected in the experiences of cancer survivors. Using a method of hermeneutic phenomenology (as described by van Manen), the study draws on the stories of six women, who by their definition, are surviving cancer. 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'.

Keywords: survivorship, phenomenology, cancer

INTRODUCTION: THE QUESTION OF SURVIVAL

Until recently 'cancer' and 'survival' have been thought of as contradictory terms. It is usual to speak of someone as having had cancer or having undergone treatment for cancer, but rarely as having survived cancer. Why do 'cancer' and 'survival' appear to be mutually exclusive terms? Do people pass over an invisible line that demarcates surviving from not surviving? Could the many years of hoped-for survival be wiped out in an instant, because of a returned malignancy? It is these questions that prompted a study into the nature of survivorship.

THE LITERATURE

Historically, the term 'survivorship' has been associated with catastrophic life events such as aeroplane crashes and natural disasters (Lifton 1980, Benner *et al.* 1980, Erikson 1986). Lifton, who studied survivors of the atomic bomb

in Hiroshima, 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 1980 p. 54). This definition provides some insight into the experience of survivorship in general.

Survivors of serious illness such as cancer seem to share similar qualities to those described by Lifton and others (Smith 1981, Welch-McCaffrey *et al.* 1989, Hassey Dow 1990). Like survivors of other serious illnesses, cancer survivors also experience recurrent dreams and nightmares and a loss of the sense of being invulnerable, recognizing their own mortality (Hassey Dow 1990). However, cancer survivors differ from other survivors in that they 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).

The dominant metaphor of survivorship within the literature has been 'survival as time' in accordance with the Western linear view (Hassey Dow 1990, Greenwood &

Nunn 1992). 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 an 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 p.511). Understanding the disease process of cancer in terms of statistics and probabilities provides part of the picture of survival; understanding the illness experience from the person's perspective provides another. According to Mullen (1985), survival for those diagnosed with cancer begins at the point of diagnosis and not at some pre-determined period in the future.

A review of the nursing and medical literature on survivorship has revealed very little research in this area and what has been written tends to reinforce the biomedical view of health and illness. From the perspective of the biomedical model, the concept of survivorship has been studied as isolated fragments, and by doing so, loses sight of survivorship as a whole process. To date, most of the research and discussion of the parts has been limited to physical, psychosocial and demographic aspects of long-term survivors (Quigley 1989, Welch-McCaffrey *et al.* 1989, Loescher *et al.* 1989, Bushkin & Bushkin 1993, Wroblewski 1994). Some studies have focused on the needs of adult long-term survivors (Gambosi & Ulreich 1990, Halstead & Fernsler 1994), while others have concentrated on the needs of survivors of childhood cancers (Wallace *et al.* 1987, DeLaat & 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, which is clearly not so. A limitation of the research from within this paradigm is that individual differences are ignored and diversity may be lost.

Benner and Wrubel (1989) believe that, because there has been insufficient study of cancer survivors, the impact of surviving on various aspects of a survivor's life is largely unknown. There is a need to study the phenomenon of survivorship from the perspective of the individual. For example, Kondora (1993) states that nurses need phenomenologically-based studies to reveal the personal journeys of survivors, in order to begin to understand their difficulties, endurance and healing. 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, such as 'early, middle or late' survival. This study, therefore, has sought to explore the experience and meaning of survival as a whole experience and does not attempt to divide survival into stages. Its aim has been to uncover the nature of survivorship, through listening to the stories of people with cancer.

METHODOLOGY

This research employs van Manen's (1984, 1990) method of hermeneutic phenomenology. The key assertions of this methodology are that phenomenological research is the study of lived experience; it is the explication of phenomena as they present themselves to consciousness, and it is the attentive practice of thoughtfulness.

Carrying out phenomenological research involves a set of activities that are inseparable according to van Manen (1984, 1990). These activities include: 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 describing the phenomenon through the art of writing and rewriting (van Manen 1984). These activities have provided the structure for this research.

Participant selection: six women

People diagnosed with cancer, and who were known to the researcher through prior work or professional contacts, were invited to participate in this study. Six women volunteered to be involved. They had all finished active treatment and were all at least 8 months post-cancer diagnosis. The age range of these women was between 33 and 69 and the type of cancers they had varied.

The women met individually with the researcher at a mutually agreed location and at the first face-to-face meeting informed consent was obtained. The conversations with each of the participants lasted for about an hour to an hour and a half and a return visit was made to discuss individual transcripts with each of them. The conversations were tape recorded and later transcribed. The ethical considerations for this study complied with the generally accepted policy for the University of Tasmania. These women, referred to by pseudonyms, are Kate, Sue, Edna, Joan, Dawn and Laura.

Reflecting on themes of survivorship: data analysis

The process of thematic analysis (van Manen 1990) was used in this research to make sense of the conversations. The transcripts were read and re-read several times to get a general sense of the whole. This step occurred in conjunction with ongoing data collection, which enabled the researcher to ask more focused questions in subsequent conversations. Following the reading of the transcripts, a 'highlighting approach' was used to isolate thematic statements (van Manen 1984 p.61). Each time the transcripts were read, the question was asked: what phrase seemed particularly essential about the experience of surviving cancer? As a result, thematic statements in the women's own words were isolated, and recurring themes that seemed to make up the experience of surviving cancer were identified.

Criteria for precision, exactness and rigor

Lincoln and Guba (1985 p. 300) suggest that four terms describe an interpretive inquiry: credibility, transferability, dependability and confirmability. These replace the more conventional research terms of internal validity, external validity, reliability and objectivity.

A crucial step in establishing credibility in this study was 'member checking' or returning the transcripts to the participants for clarification of meanings (Lincoln & Guba 1985 p. 314). This was accomplished at the second interview where the women were given an opportunity to expand or clarify anything contained in the original transcript. Dependability and confirmability were attempted through the use of a reflexive journal (kept by the researcher) in which reactions and feelings were recorded (Lincoln & Guba 1985 p. 327).

DESCRIPTION AND INTERPRETATION: THE STORIES OF SURVIVORSHIP

The women in this study described experiences of surviving cancer that can be clustered around two central everyday themes of 'living in a body' and 'living in time'.

Living in a body

Our bodies provide us with our access to the world in which we live:

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 pp. 11–11)

'I live not only in my body but also through it' (Frank 1991 pp. 10–11). These powerful words speak of a mind and body separation, not unlike the experience of those women in the present study. Their experience of their bodies in survivorship was one that moved from disembodiment to embodiment, and one that dealt with the body as a house of suspicion.

Feeling whole: from an experience of disembodiment to embodiment

For the women in this study, living in a body has meant not only that they initially experienced the feeling of separation between mind and body (as described by Frank 1991), but that survival 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 experience situations, interpret them, and interact with the world in a meaningful way (Benner & Wrubel 1989). Disembodiment, on the other hand, refers to a

perceived 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) was disrupted for each of the women in this study, leading to a feeling of disembodiment, 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 6 months or 12 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.

Kate too spoke of a mind/body separation:

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 '6 months and then you're right'.

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'. In Kate's words:

There were things I found a long time afterwards that 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 the Army [Reserve] 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'.

Once treated for cancer, the body is never again quite as it was before the diagnosis. Perhaps Kate was mourning this loss of a united comfortableness. As Pellegrino states (1982 p. 159), '[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'.

The body as the house of suspicion

One of cancer's most dangerous properties is its ability to spread and regrow in any area of the body (Otto 1994). Years after an apparent cure, a secondary cancer can be found in organs and body sites far distant from the original growth. The threat of recurrence is never far from the thoughts of people who have had cancer (Welch-McCaffrey *et al.* 1989, Carnevali & Reiner 1990), and in this sense it may be that the body becomes for survivors a constant source of suspicion.

For the women in this research a key feature of surviving cancer was the need to ensure that cancer did not re-emerge in the body. To combat this potential threat, all the women participated in self-monitoring behaviours, such

as breast self-examinations, and underwent repeated check-ups and tests conducted by the medical profession. Laura was determined to have regular check-ups as a sort of insurance against her cancer reappearing:

I had it [the checkup] 6 months ago 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 3 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]... You never know.

Kate made her return visits to the oncologist at 6-monthly intervals, seeking assurances that everything was alright:

Just 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.

These conversational extracts illustrate the tenuous nature of survival. For these women, the recurrent threat of cancer was never far from their minds.

Living in time

For many people living in Western society, time is linear, sequential and occurs in one direction only. We differentiate between our past, our present and our future, and time never goes backwards. Other cultures have a vastly different experience of time. For example, the Australian Aboriginal people view time as cyclical:

The Aborigines [sic] 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 p. 210)

Cyclical time relates to the natural rhythms of the world, the seasons of the year, the cycles of birth, old age and death. The cycles simple move around and around, returning to the same starting point (Greenwood & Nunn 1992).

A western view of survival has in the past emphasized clock time and marginalized other experiences of time. Clock time, however, 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. It does not reveal time as it is experienced by the self (Heidegger 1989 p. 5). This latter perspective of time may therefore influence how a person experiences survival.

For the women in the present study who are involved in a process of survival, clock time only presents a part of the whole experience of survivorship. They experience time as something to be questioned, a concept in which

change and chance take place, and as part of a shared journey.

The future in question

Most of us have plans for the future, a vision of things we might be doing in 5 or 10 years' time. For people diagnosed with cancer, plans for the future are temporarily arrested. As Frank (1991 p. 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? 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:

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, it's hard to explain, but I felt as if [time] stopped working.

For Joan, clock time continued, but it had no relation to 'self' time, the time that was being experienced by the self. For the women in this study, 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 the future began to re-emerge. Dawn, for example, imagined a future that contained a much loved granddaughter:

Probably more than anything I thought of my granddaughter, 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.

As the women went about the business of surviving, measuring the 'how much' of time remained important, but it was the cycles of time that became paramount. Their new birth date became the anniversary date of the cancer diagnosis or treatment. These dates were etched in their minds, and returned in cycles, year after year. It was not just a year's passing, but a new beginning and a reclaiming of the future in question.

Changes in time

The 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). May (1991) used the metaphor of the phoenix to describe the

change that a person often undergoes as a result of a life threatening illness. 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 look at myself in the mirror before, except to put makeup on or do your hair or something... now everything's changed.

Joan's phoenix represents a radically new self that still seems to be in the process of becoming. She exemplifies what Frank refers to as 'Who I might become' (Frank 1993 p. 44), and finds new resources in survivorship.

Frank (1993 p. 47) identified another category of phoenixes, namely the 'reluctant phoenixes', to refer to those survivors who were 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 who was fulfilling her potential, but the impression she gave was that she has been able to assimilate the experience of surviving cancer within the life she had always led, and she did so without any shouting or missionary zeal. The very fact that each of these women volunteered to participate in this research was witness to the fact that 'the self must be told' (Frank 1993 p. 47). They were publicly witnessing their own survival, and the implication this survival was having on their lives; and they were doing this quietly.

Lucky to be alive

The element of luck ran as a recurring theme through the women's narratives. This theme is related to acknowledgement of having had a cancer caught early, as Laura illustrates:

I was very lucky, the cancer was only in its first stages, they got it pretty early... they got it in time I suppose.

Kate's luck came with the cancer's location, in addition to its early detection:

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 did not have to have any radiation or anything afterwards.

Cancer survivors are often reminded by those around them just how lucky they are to be alive, and this attitude may make them hesitant to bring up worries or concerns for fear that they may be labelled as demanding or ungrateful (Leigh 1992). Edna kept most of her worries and concerns about how she was coping in survival to herself. In

this next extract she talks about not troubling other people with her problems, perhaps out of fear that she might be labelled as 'ungrateful':

Another lady that's in the Cancer Group comes around... But every time 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.

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.

Sharing the journey

The experience of living in time occurs in a world with other people, it does not occur in isolation. As Heidegger (1989 p. 7) wrote, 'being in the world is also being in the world with others and for others'. Sharing the journey of survival with others was an important part of living in time for the women in this study.

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 suggests 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 each one of them lived. They did not have to wait for a specified end-point to be considered a survivor.

The support of friends and family was 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 it to be extremely beneficial; however, Joan was not so keen:

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 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.

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 p. 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 Laura's recognition of God 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.

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.

Limitations

The major headings of 'living in a body' and 'living in time' have been used as guides for reflection in this study. 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. The women's stories have not been reduced to abstract generalizations in the derivation of themes. These women remain alive in the text as their stories and personal moments are woven through the discussion. The researcher's voice has been added to their voices in the creation of the text.

The conversations have been interpreted by the

researcher in consultation with the women involved in the study, and it is recognized that these conversations are open to an infinite array of further possible interpretations:

... 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 p. 31)

SURVIVORSHIP: LOOKING FORWARD, LOOKING BACK

This study set out to make some sense out of what might be seen as a certain phenomenon of human existence, namely survivorship. In this process, the lived experiences of seven women (including the researcher) joined together in the layering of meaning around survivorship as a process. The women in this study 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. Laura, Kate, Sue, Edna, Joan and Dawn all said that they had survived cancer, were surviving cancer. Their stories have shed light on the phenomenon of survivorship, adding to the cumulative understandings of survivorship as a process.

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