ABSTRACT

This paper explores cancer survival experiences and offers the Heideggerian concept of temporality as a way of acknowledging and understanding the complex and pervasive nature of survivorhood. Firstly, despite demographic indicators, the process of cancer survival is under-reported in the research literature. Secondly, and embedded throughout this paper, is the notion that cancer survival is not an illness and requires its own analytic frameworks. Thirdly, this paper suggests temporality can assist to extend understanding of cancer survival beyond extant psychiatric diagnostic, disease trajectory, coping and adaptation, and illness narrative frameworks.

This study explored the lived experience of cancer survival with participants who defined themselves as survivors of cancer. Fifteen participants were interviewed in rural Australian towns using an in-depth interviewing technique guided by phenomenological principles. Fourteen participants were interviewed on a second occasion, three to four months following the first interview. Temporality emerged as a key finding and, for the purposes of this paper, can be understood as the experiences of changes to self and relationships through time. This goes beyond chronicity, and is concerned with the meanings ascribed to one’s past, present and future in light of a cancer diagnosis.

Findings demonstrate that cancer problematised temporality for survivors through forcing an awareness of uncertainty and possible death. This raised existential questions about self, others and relationships of care. Extending the existing psychosocial literature, findings suggest that survivorhood is an on-going process of meaning-making, rather than a developmental trajectory. The findings have implications for health care and social work protocols for post-discharge planning and longer term care for cancer survivors, including personal and family casework, group work and community development practice.

INTRODUCTION

According to the Australian Bureau of Statistics (ABS, 2001), in 1998 cancer caused 26.5% of all deaths in Australia making it the leading cause of death. The ABS (2001) estimated the lifetime risk of cancer as 1 in 3 for males and 1 in 4 for females. The optimistic trend, as reported by the South Australian and New South Wales cancer registries, is that 5-year survival rates were increased to 46% for men and 57% for women (ABS, 2001).

Despite some increases in survival rates, cancer still remains Australia’s leading cause of death for many diagnostic groups. However, it is no longer a death sentence for people with particular types of cancer, with some survivors living for a greater number of disease-free years than in previous decades. For example, estimates of breast cancer survival rates for women are up to 90.9% for 2 years...
and 65% for 10 years post-diagnosis (BreastScreen, 2000). According to the Anti-Cancer Council of Victoria, improved early detection and public health campaigns, particularly for breast and prostate cancer, are also attributed to increasing survival rates (ACCV, 2001). The demographic data clearly identifies an emerging trend of increased incidence of cancer survivors.

Clearly, cancer survival can be identified as a demographic trend. Although previous research, outlined above, has identified psychosocial complexity of cancer and illness experiences, few studies have focussed on the temporal lived experience of cancer survival. The aim of this study was to explore the temporal lived experience of cancer survival from the perspective of people who have experienced the phenomenon. The research question arose from the aims of the study and was broadly expressed as: “What is the nature of the lived experience of cancer survival?” Lived experience, with a particular focus on temporality, was explored through (a) revealing the phenomenon of cancer survival as it appeared in everyday life and (b) developing an understanding of the meanings survivors ascribed to their lived experience of cancer survival.

THE STUDY

Study design

This study employed qualitative methods and was underpinned by hermeneutic phenomenology (Heidegger, 2000). Phenomenology, as a theoretical framework, had implications for the research as both meaning and method, informing data analysis.

Setting and sample

The study was undertaken in regional Victoria, Australia where cancer rates are comparable to other parts of the developed world. The study received institutional ethics approval from La Trobe University, Bendigo campus. In keeping with an exploration of significant lived experience, a purposive non-probability sampling technique was used to access suitable participants with relevant experience (Grbich, 1999). To be eligible for inclusion in the study, participants needed to self-report a cancer diagnosis and self-define survivorship. It was important for survivors themselves to define their survivorship status, even if this contradicted medical prognosis, as the complexity of their perceptions and definitions was important to a study of lived experience. This kept the study iterative, and defined by the phenomena in the field.

Participants were recruited from cancer support groups, community health centres, community houses, general practitioner clinics and hospitals within regional Victoria, Australia. They were informed of the study through letters and advertising material sent to health and social work practitioners and agencies. All participants voluntarily gave informed consent to participate in the study, with 11 women and 4 men volunteering to participate. They ranged in age from 30 through to 80 years of age. The majority of participants were partnered (n=11) and parents and/or grandparents (n=12). Participants belonged to a range of diagnostic groups: breast cancer (n=7), prostate cancer (n=3) non-Hodgkin’s Lymphoma (n=2), ovarian cancer (n=1), invasive skin cancer (n=1) and dual diagnosis of lung and thyroid cancer (n=1).

Participants included long and short-term survivors with disease-free years ranging from 12 months to 15 years post-diagnosis. However, some had metastatic disease at the time of interview (n=2), whilst others were in remission after initial diagnosis with metastatic disease (n=3). Treatment regimes included adjuvant and palliative surgery, chemotherapy, radiotherapy, as well as complementary therapies.

Data collection

Interviews were semi-structured and in-depth, approximately eighty minutes in length, and conducted in a mutually agreed upon location affording privacy. During the interviews phenomena were explored from past, present and future perspectives, allowing the researcher access to a range of temporal perceptions and memories (Ellis & Bochner, 2000). All but one participant (who was too ill by the second interview) were interviewed on two separate occasions, approximately three to four months apart. Thus interviews were chosen for the phenomenological accord with temporal meaning-making. All interviews were one to one and confidential. Interviews took place between April and December 2003.

Data analysis

The interviews were audio-taped and transcribed verbatim. Data collection and preliminary analysis occurred concurrently. The transcripts were entered into the NVivo qualitative data analysis programme (QSR International, 2000) and thematically analysed using abductive data analysis techniques. Phenomenological theory, the participants' voices, as well as the researcher's process of intuition, indwelling, focus, immersion, illumination and explication (Moustakas, 1990) were used to develop free nodes, which were later typologised into key themes.
FINDINGS

The lived experience of cancer survival was a complex personal, social and meaning-making phenomenon for the participants and persisted beyond their patient and treatment experience (Pascal, 2006). Within the broader context of survivorhood, the findings in this paper focus upon the lived experience of temporality. That is, rather than dwelling on one’s individual story, self-identity or personal coping and adaptation, the temporality of survivorhood is characterised through the experience of understanding oneself within relationships of care. It is within the past, present and future contexts of care, rather than the context of the self, that experience and meaning-making is constructed.

The past: Family of origin

Family of origin played a significant role in how participants’ past lives shaped their present experiences of cancer survival. Older participants drew upon survival experiences gained from childhood adversity and positive parental role modelling. Several had lived through economic depression or rural hardship. For example, a participant recalled survival lessons gained in younger life:

“In my childhood I lived through the Depression and was lucky to have enough money to buy food, lucky to have a house. I think you learn to cope with things during that time.”

By contrast, for other participants there was a need to “re-learn” lessons from childhood to enhance understanding of themselves and their present family relationships. One participant told of her very strict upbringing that she fought hard to overcome. The message was:

“Things don’t go wrong with your body. You don’t rest, just work. So I had to have a complete mind shift.”

For some participants, family of origin provided a present connection that was supportive and enhanced the experience of survival; for others the relationships were painful reminders of the past. For some, despite the pain, there was an opportunity for learning and healing. Further, family of origin was often the site of genetic and lived experience of cancer. Many participants had the experience of losing a family member to cancer, and several had knowledge of genetic predisposition. This shared genetic/familial cancer experience had the capacity to affect past, present and future generations. A participant elaborated:

“It mightn’t’ve made any difference anyway because there’s cancer in our family anyway you know. My mother’s had 5 brothers and I think 4 of them have died of cancer. My granddaughter’s got a melanoma on her leg as well and she is only 30.”

Overall, past family of origin issues appeared significant to the way participants constructed their present survival experience in terms of a temporal connection to their past self.

The present: The wake-up call

The present temporal context was characterised by changes to participants’ Being-in-the-World (Heidegger, 2000). The call to conscience (Heidegger, 2000; Watts, 2001) of a cancer diagnosis facilitated significant shifts in attitude. Everyday life before cancer was reviewed in the light of a cancer diagnosis. In the words of one participant:

“We pay our mortgages off and we go off and have friends for dinner and that’s nice and for some people that’s enough. But it’s not for me. And I don’t know, perhaps that was always in me or and it’s just cancer’s brought it out or it’s come from the cancer, but yeah, something’s changed.”

Several participants described cancer as a wake-up call; a warning that aspects of life were not being lived in a healthy or meaningful way. Participants described this as:

“I would be focussing on the next three million dollar job, the budget, the time line and when it had to be finished. That was my 100% focus.” Another said: “I had two small children, I was socialising…working really hard and doing shift work. A lot of friends, a lot of everything to excess.”

Furthermore, the concept of a wake-up call was summed up with the statement:

“My outlook has been that what I was doing before couldn’t have been that beneficial to my health. It gave me a big wake-up.”

The present: Relationships of care

As with family of origin relationships, present day family, friends and supportive relationships were significant to participants’ understanding of survivorhood. Thus, relationships of care, (Heidegger, 2000), taken in this context to mean concern and solicitude (Watts, 2001) were the major focus of participants’ present “here and now” temporality.

Firstly, there were changes to the relationship with one’s self and what one is prepared to tolerate. This was expressed as:
"I was not willing to give up anything. This has made me think, you just have to loosen up a bit and go with the flow and don't be too judgemental of others."

But for others:

"I don't get involved with crap at work: I can't be bothered with things that are just so trivial: I have developed intolerance, which probably isn't very nice."

Secondly there were changes to the relationship with partners. Often there was a deepened sense of appreciation and a desire to reciprocate care. As one participant said:

"He was such a great support to me, whatever I can do to support him, I'm doing it now."

Partners also shared the insights of the survival experience. Another participant noted:

"I have got my husband to relax a bit more now because he realises he's been pretty close to not having me."

However, not all partners were supportive. As one participant forthrightly remarked: "He turned into an arsehole, all of a sudden."

Thirdly relationships with adult children were significant relationships of care. One commented that: "It has brought my boys closer to me."

As with partners, adult children shared the insights of survivorhood. On a pragmatic level, one participant explained:

"My son won't go out and get cooked in the sun. He doesn't undress; he's always got a hat on."

From a philosophical viewpoint, another participant recounted:

"It's made them more aware that everyone is vulnerable… your life can be changed in the blink of an eye."

Fourthly, there were changes to relationships with dependent children. Children and grandchildren represented temporal connections with the future. Survival afforded the opportunity of experiencing important life transitions. For one participant:

"I have seen my daughter go from a 13 year old, to a young lady… She has now got a boyfriend and a job."

Survivorhood also allowed for a contribution to children's well-being. As an outdoor person, one participant described:

"I love the grandkids. I just tell them to cover up, show them to keep themselves covered up."

The future: Dreams and hopes

Most had longer term goals, but there was variability in conceptualising future time, or datability. For example, some survivors planned for future years:

"I am looking forward and the project next door is keeping me at least looking at least two or three years ahead for that."

For others, there was a changed temporal proximity as present and future merged. This was expressed in the philosophy of taking one day at a time and being present in the moment. One account of the importance of everydayness was:

"I'm just recovering and I'm doing well, I'm peaceful, I'm hopeful, my birthday and Christmas are coming, the weather is warming up."

For others there was a sense of the anticipated future becoming immediate. This was explained as:

"I guess we just follow our gut feeling about what we want to do… The furthest is that we are going away in December, we don't have a financial five year plan… about our money or our life."

Thus, some participants had long-term plans; others lived in the immediate everydayness, with several participants not wishing to make plans.

Participants hoped for future cancer-free health and well-being. The most fundamental issue was to be alive. Contrary to the cultural norm of fearfully anticipating old age, and its implication of death, participants embraced the possibility of being old. Becoming older was a way of imagining a future for oneself. As one participant described:

"Just getting over the first hurdle will take me to old age: that's older than 52. I will be shorter, more shrunk, my voice all cracked: all the things I want to see for myself as an older woman. So, I'm looking forward to it."

The future: Anniversaries and milestones

Both medical and personal milestones marked survival. The first anniversary post-diagnosis was described as a significant milestone. For longer-term survivors, each passing year signified a reprieve from recurrence. However, for some survivors, tests were very anxiety provoking.
regardless of survival time and particularly if suspicious symptoms were identified. The milestone then had the possibility for celebration or commiseration.

Aside from medical time keeping, personal milestones such as birthdays were much anticipated events. Birthdays symbolised and celebrated another year of life and were in direct contrast to ‘death’. They were times for anticipating the future:

“I’m looking forward. My birthday’s next week, my third birthday after the initial outbreak, so I’m after eighteen more birthdays. That’s not asking a lot.”

As previously discussed, family of origin relationships were significant for participants as the historical connection and reconnection to a past self. Family of origin issues revealed past intergenerational losses so that participants were keen to maintain their intergenerational futures within their present family. This temporal reconnection was continued to the future through the anticipation of increased time with children. For some, time with children provided a long-term anticipated milestone for the future. As one participant explained:

“I was going to see my daughter’s 21st Birthday party. No matter what I did, that was the thing that kept me going. She was three months when I got diagnosed. That’s a long-term goal.”

Fourthly, and significantly, this shared experience created a space for survivors to transcend their own suffering by contributing to others and society. For most participants, becoming a survivor involved asking moral questions about living a good life (Morton, 1996). As one participant commented:

“It’s more of a case of looking at things morally perhaps, what’s right and what’s wrong.”

For example, this was enacted by several participants were actively volunteering in community cancer projects, Opportunity Shops, animal rights, organic farming, foster care and community leisure projects. One participant decided to become an organ donor. “I’ve donated very part of my body to whatever they want.” For most participants, community participation gave a sense of personal fulfillment and it was important to know that: “I haven’t been through this for nothing.”

These contributions can give enhanced meaning to survivors’ lives, and was essentially a moral project. As one participant explained:

“Making links and becoming involved in things, I know that I can live and get through bad patches… and it’s all going to pan out OK.”

DISCUSSION AND IMPLICATIONS

In keeping with the phenomenological notion of self as time (Heidegger, 2000) the present study is significant in its revelation of the everyday temporal Being-in-the-World of cancer survival. Participants discussed their temporal lived experience, but not necessarily chronological experiences, and their changed awareness, incorporating their past, present and future possibilities in the wake of a cancer diagnosis. When discussing their lives before cancer, most participants described a life that was busy, distracting and stressful, often being caught up with issues that seemed unimportant when compared with cancer. Often referred to were workplaces, family and social expectations that were unfulfilling, or even unhealthy. Since cancer, most participants had made significant and beneficial changes in their employment and family relationships. Making these changes was not unproblematic and required a revisioning of participants’ social roles and personal identities.

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Our study supports McGrath’s (2002) findings that present time expanded for participants, with a focus on the everyday here and now. In accord with McGrath’s concept of reconnecting with the normalcy of life, when reviewing their past roles and relationships, participants in the present...
study described cancer as a wake-up call, often a warning signal that life needed to change, and alerting participants to the absurdities and demands of socio-cultural expectations. As such, normalcy was revised, including changes to employment, relationships, and life’s meaning and purpose.

A key finding in the present study was the importance of relationships as a temporal anchor in participants’ present lives. Family of origin provided an historical connection, whereas present day family and friends provided a connection with the present here and now. These findings extend Breaden’s (1997)6 shared journey and McGrath’s (2002)20 notion of support and connection.

Similarly, adult children were important in providing support, care and connection for participants, although participants did not want to burden their children with their concerns. Again, this was a change in social role and identity, with adult children at times adopting the carer role. Adult children learned valuable lessons about their own Being-in-the-World from their parent’s cancer survival experience, thereby continuing the iterative nature of family of origin as meaning-making and survival as a shared journey.

Beyond the partner relationship, the family experience of cancer survival receives little mention in the research literature (Kornblith, 1998).15 Our findings demonstrate that dependent children, including grandchildren, also provided important relationships of care for participants’ present connection to the here and now, as well as enhanced social identity. Further, children represented future, as well as present possibilities, thereby enhancing participants’ temporal identities. Sharing in a child’s development allowed participants to contribute to children and grandchildren’s future well-being.

Beyond the family, friendships were an important source of temporal connection with the here and now. Long-term friendships, as well as those forged during the cancer survival experience, provided connection to participants’ Being-in-the-World and a sense of normalcy (McGrath, 2002).20 However, the process of participants revising their relationships of care resulted in certain friendships becoming disconnected through participants choosing to change the order of priority in their relationship world. Further, some friendships became isolated in the unfamiliarity of the survival experience. That is, roles and boundaries changed, but remained unspoken and unconscious for both participants and their friends. This resulted in misunderstandings, confusion and sometimes abandonment of the relationship. This was not a result of participants’ choosing. Isolation from friendship and social support created a diminished sense of identity, but at times was clarifying for participants, assisting them to relinquish certain relationships.

Relationships with other survivors also developed in the context of formalised support groups. Several participants were regular attendees or shared in leadership roles. Again, mutual support was of key importance. Further, participants felt able to contribute to assisting others. As well as caring about other survivors, contributing to support groups provided the opportunity to enhance the identity of survivors. Following Little et al. (2002),17 this facilitated participant reconstruction and incorporation of the experience of cancer survival into forging an enhanced identity.

Support groups were characterised in the literature as mutually beneficial or even longevity-enhancing (Bloch & Kissane, 2000;3 Speigal, 1990, 1995;20 Speigal et al., 199831). However, the present study found that not all participants experienced support groups as mutually beneficial. Some found support groups depressing and disempowering, whereas others did not feel they needed help. Of particular interest to the present study was the finding that several “survivor” support group members felt uncomfortable with support group members in palliative or treatment stages. This may be attributed to triggering fear and uncertainty, or survivor guilt, highlighting the differing needs of survivors and “patients”. This reflects Little et al. (2001)16 concerns that there be a clear recognition of the particular status and needs of survivors.

Overwhelmingly, and in accord with current literature (Breaden, 1997;6 Brennan, 2001;7 Little et al., 2001;16 McGrath, 1999, 2002;20 McGrath, Patterson et al., 1999b;21 McGrath, Patterson et al., 1999b;22 Nelson, 1996;25 Pascal, 2001;26 Thibodeau & MacRae, 199732), the future was characterised by uncertainty for all participants in the present study. Alongside this uncertainty, participants anticipated their futures with dreams and hopes for employment, travel, retirement, projects (such as renovating and quilt making), cancer-free health and longevity. Participants also hoped for greater self-understanding and continued relationships of care with partners, children and friends. Nonetheless, in the midst of anticipating a hopeful future, participants also imagined the future possibility of death. This was often highlighted at cancer anniversaries with the paradoxical capacity for celebration and commiseration.

Angst about future death created uncertainty and fear. However, Being-for-death (Heidegger, 2000)14 also
facilitated a focus on the here and now (McGrath, 2002) and a strengthened resolve to lead a good life (Morton, 1996; Taylor & White, 2001). This resolution raised moral, ethical and existential questions of life’s meaning and purpose (Benner, 1994; Frank, 1995; Mattingly, 1998). A key finding of the present study was participants' desire to transcend the socio-cultural demands of the everyday world. This included an ongoing process of redefining boundaries with self and others, deeper connection based on compassion, and transcending suffering through personal and community contribution. Through this process of transcending, participants were constructing, and reconstructing, meaning of the cancer survival experience within the context of their temporal lived experience.

It is clear that cancer problematises temporality for survivors as it forces an awareness of the uncertainty of temporal existence. This possibility of nothingness (Cohn, 2002; Watts, 2001) is revelatory and challenges normative definitions of what/who is a survivor. The question becomes not “How much time do I have?” although it may be this question initially, but rather, “What does this time mean?” Additionally, participants’ temporal self-definitions of survivorhood challenge (already complex and contested) medical definitions of survival. That is, participants in our study conflated self-defined survival status with recurrence, remission and active metastatic disease. These self-definitions suggest that temporality is experienced as internal, lived time and not as externally measured by clock time. Relationships of care with family of origin, partners, children, friends and others with cancer were all significant for participants’ connections to the here and now and represented a temporal phenomenon. Such relationships provided a sense of historical connection and future possibilities, assisting in alleviating the sense of temporal disruption inherent in the cancer survival experience.

Becoming a survivor: Implications for health and social care practice

Becoming a cancer survivor is a temporal experience involving the transition from illness and patient status, to a life that is at once similar and different from the “before-cancer” experience. If the illness experience was familiar, with its patient-carer socially constructed roles of receiving and giving care respectively, then survival posed challenges to these constructions. Participants experienced temporal and identity confusion, possibly even abandonment, in the transition to becoming a survivor. Further, the transition to survivorhood did not arrive immediately upon discharge, with the treatment phase completed and medical health restored. Rather, this was experienced as a confusing and frightening time.

Given the problematic nature of survivorhood, understanding the temporal context of cancer survival has broad implications for multidisciplinary health and social care practice in case work, group work and community care settings. Of importance for the casework practitioner is to acknowledge the complexity of temporal experience beyond treatment contexts. This may seem self-evident, but survivorhood status and needs are largely overlooked in the literature and practice contexts (Zebrack, 2000). Of particular importance for caseworkers is the understanding that Angst is inherent in the survival experience, and an impetus for insight and change, and not necessarily a clinical mental health disorder. Reconceptualising connections between fear and Angst could extend current practice frameworks focussing on problem solving, coping and other cognitive issues. Of particular significance is a critical deconstruction of ideological discourses of coping and hoping, such as “think positive”, and embracing reflexive and interpretive ways of rethinking developmental and normative assumptions and biases (Crapanzano, 2003; Del Vecchio-Good et al, 1990; Wilkinson & Kitzinger, 2000).

Given the demonstrated importance of family relationships, caseworkers could assist both survivors and family members to understand the changed family and relationship roles. Understanding these, at times problematic, changes as an inherent aspect of survivorhood could assist to alleviate feelings of distress, disconnection or family discord. Of particular significance here is a survivor’s relationship with children and grandchildren. Whilst more research is necessary than undertaken in the present study, it should be noted that the areas of parenthood may require sensitive casework practice.

Group work facilitation of cancer support groups may benefit from understanding the temporal complexity of survivorhood. Again, survivors need to be acknowledged as having different issues from those requiring palliative care. It is not appropriate for survivors, who have unmet existential and emotional needs of their own, to support people who are dying from cancer. Nonetheless, survivors do wish to make a contribution to others with cancer. It is recommended that survivors have a separate support group focussing on their specific needs. This does not preclude survivors from then joining to support others with cancer to their mutual benefit.

All participants in this study became involved in communities of care throughout their survivorhood; these included family gatherings, support groups, health...
promotion, environmental activism, organ donation, animal rights and other charitable and volunteer projects. Implications for community development workers include supporting cancer survivors to understand the pedagogy of survival. That is, the survival lessons of suffering and compassion could be used as a mutually beneficial skill for community work. When considering the ontology of care (Heidegger, 2000) as enhancing meaning-making, community development workers could assist survivors with the complex process of authentic temporal lived experience (Cohn, 2002; Watts, 2001) particularly revisiting everyday socio-cultural assumptions (Heidegger, 2000).

By way of conclusion, becoming a survivor poses challenges to normative definitions of the world before-cancer, temporality and care. The life world is questioned and revised in terms of socio-cultural expectations and family of origin relationships. Participants reconstruct their present selves in light of a cancer diagnosis with changes to the everydayness of their Being-in-the-World and relationships of care. These changes to self are experienced in the light of a life threatening cancer diagnosis and its accompanying temporal shifts.

CONCLUSION

Thus, understanding that survivorhood is an on-going process of temporal meaning-making, rather than a linear developmental trajectory, extends existing interpretations of the cancer experience. Relationships of care offer authentic possibilities for Being-in-the-World with survivorhood understood as a hermeneutic space for meaning-making that is both temporal and relational in process.

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