

ISSUES FOR CANCER SURVIVORS IN AUSTRALIA

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Abstract

As the number of people surviving cancer continues to increase, the need to know about the issues they face and how to support them becomes more urgent. Cancer is a life-changing diagnosis, with many survivors experiencing a range of both positive and negative outcomes attributed to cancer. While most survivors adjust well over time and experience relatively high quality of life, issues persist for some. Many survivors experience ongoing physical effects such as fatigue, pain and sexual problems. Some experience elevated levels of anxiety, depression or mood impairment and ongoing disruptions to daily living and social activities. New issues that emerge can include employment problems, insurance difficulties and worries about health, including cancer recurrence. Positive effects include changed values and goals, enhanced appreciation of life, improved close relationship with others, altruism and lifestyle changes. This article provides a brief overview of the psychological, physical, social and existential impact of cancer, with an emphasis on the issues faced by survivors after the completion of primary treatment.

"Two years after diagnosis, it is hard getting used to the new me." I don't have the strength, flexibility or stamina that I used to, and have to adjust to achieving less each day than my mind expects me to... Still, I am generally not in pain and happy to still be here with my family and friends. I have down-sized my career, which has had a financial impact, but I think has achieved a better work/life balance for this stage in my recovery."

The past three decades have seen significant improvements in the survival outcomes of those diagnosed with cancer, with more than 60% expected to be alive at least five years after their initial diagnosis.¹ It is estimated that about 340,000 people in Australia are living with a history of cancer, representing about 2% of the Australian population.² Many more will have an experience of cancer as a partner, family member or friend of someone with cancer. Given the multicultural nature of the Australian community, many survivors will be from culturally and linguistically diverse backgrounds (CALD). While most survivors are considered cured and/or cancer-free, others live with active disease and for many, cancer becomes a chronic disease.

The term cancer 'survivor' has varied definitions and has been used to describe those diagnosed with cancer who are alive and/or disease-free after five years, diagnosed patients who have completed primary treatment, as well as patients at any point from diagnosis.³ This article adopts the widely accepted National Cancer Institute Office of Cancer Survivorship definition of a cancer 'survivor' to encompass anyone diagnosed with cancer, from the time of diagnosis to the end of life.⁴ Mullan (1985) described survival as a three phase process: acute survival includes the diagnosis and treatment phases often dominated by fear and anxiety; extended survival starts at the

completion of active treatment or remission of disease and is characterised by fear of recurrence, physical limitations such as fatigue and monitoring for recurrence and late effects of treatment; permanent survival evolves from extended survival when the risk of recurrence is low and patterns of normal life may be re-established.⁵

A diagnosis of cancer is typically experienced as very distressing. Cancer treatments are often invasive and prolonged, placing significant demands on the person diagnosed, as well as their family and loved ones. While acknowledging that each individual's experience is unique, it is well accepted that cancer may have a significant psychological, physical, social and existential impact upon survivors with both positive (eg. feelings of gratitude) and negative sequelae (eg. distress, fatigue) reported. Although there are relatively few longitudinal studies, it is also known that some effects are long-term or permanent (eg. infertility) and others manifest some time after treatment completion (eg. lymphoedema). The extent to which these effects are experienced by survivors is known to vary according to characteristics such as age, gender, ethnicity, type of cancer, stage of disease, treatment modality, social support and coping style.⁶

In order to help the growing population of cancer survivors in Australia to 'thrive', it is important to understand the range of issues they face. Although most studies have focused on survivors in the acute survival phase, there is an emerging body of evidence describing the experience of those who have completed potentially curative treatment. Drawing on Australian research where possible, this article provides a selective and brief overview of the issues faced by cancer survivors, with an emphasis on the extended and permanent phases of survival.

Psychological

Estimates of the prevalence of psychological morbidity experienced by cancer survivors vary widely across studies. However, it is generally agreed that distress is most common in the acute survival phase and declines over time since diagnosis; studies have found that cancer survivors' levels of distress typically return to a level comparable to the general population and individuals with no history of cancer, around two years post-diagnosis.⁷ Consistent with international research, a recent study conducted in Australia indicated that long-term survivors of cancer often report levels of psychological wellbeing that matches or exceeds population levels.⁸

Nonetheless, areas of concern may persist for some survivors. For example, many survivors report a heightened sense of vulnerability, loneliness, worries about their health, concerns about burdening their loved ones, and anxiety about the possibility of cancer recurrence. Studies undertaken in Australia consistently report fear of cancer recurrence and uncertainty about the future as the most common concerns survivors need help to manage,⁹⁻¹¹ and are associated with an inability to make future plans. Adverse psychological outcomes tend to be more prevalent among female survivors compared to male survivors, and younger survivors (less than 50 years) compared to older survivors.¹²

Although many survivors find follow-up testing stressful, they also feel anxious about leaving the safety of the hospital system when they transition from the end of treatment to long-term follow-up.¹³ When cancer does recur, it is often experienced as more traumatic than the first diagnosis and reinforces the importance of periodic screening for distress across the cancer trajectory, including the survivorship phase.¹⁴ Anecdotally, some survivors report experiencing feelings of guilt because they survived and someone else they knew with cancer didn't, although this is not well documented in the scientific literature.

Despite the absence of evidence to support this notion, it is common for those who have experienced cancer to adopt a 'positive attitude' in the belief that this may contribute to longer survival. For some individuals, this strategy may confer a sense of control and optimism, while for others it represents a burden, especially if there is pressure, either overt or covert, to avoid discussing painful or confronting issues. Furthermore, the belief that one's force of will and attitude can influence the course of cancer poses a burden if cancer recurs, with the implication being that the individual "has not tried hard enough".

Research undertaken in Australia reveals that there are a number of issues specific to CALD communities that are an additional source of distress to CALD cancer survivors. In the Chinese, Greek and Arabic communities, cancer is perceived as incurable, sometimes connoting 'certain' and 'imminent' death, and a source of stigma for self and family that should be kept a private matter. In some parts of the Greek and Chinese communities, cancer is still viewed as contagious.¹⁵⁻¹⁷ Survivors and their families from Arabic, Chinese and Greek backgrounds also report feelings of loss of power and control, and consequent

difficulties navigating the health system due to difficulties with both written and verbal language.¹⁸

Physical

Fatigue is commonly experienced by survivors and can be profoundly debilitating: "At its worst, cancer-related fatigue is a draining, unrelenting exhaustion that impedes the ability to enjoy life and carry out daily activities".¹⁹ Unlike other visible markers of cancer treatment such as hair loss, fatigue is not apparent to others, and survivors may be reluctant to discuss fatigue because they 'look well', or intuitively believe that rest will help. Given the evidence about the benefits of exercise in reducing fatigue in cancer survivors, exploration of fatigue and provision of information about strategies to deal with this should be part of routine clinical care.²⁰

Although pain in advanced cancer is recognised as a management concern, there is emerging evidence that cancer survivors may experience chronic pain, and given its association with depression, is an area that merits closer attention.²¹ Survivors' reluctance to report pain may be due to fear that the pain represents residual or recurrent cancer.

It is now recognised that cognitive changes occur in those who have been treated with chemotherapy,²² although there is insufficient evidence about the precise mechanism of this, and risk factors for its development. The nature of the deficit is often subtle and not evident in casual social contact, but problems with new learning, organisation and ability to self-monitor and self-correct are commonly identified on neuropsychological testing, and can be disabling to the point of interfering with the ability to return to work. In Australia, research is being initiated to assess the effectiveness of computer-based programs designed to "retrain" affected individuals (Vardy J, personal communication).

There is an extensive literature describing the adverse impact of cancer treatment on body image and sexuality, and the former focus on breast cancer has expanded to include other cancers such as prostate cancer. Sexual difficulties are common and can impact upon other aspects of intimacy and relationship functioning. Sexual difficulties can be due to direct effects of treatment, such as gynaecological cancers treated with surgery and radiotherapy, and indirect effects such as chemotherapy-induced menopause, pain and fatigue. Effective treatments are available however, once established, problems tend to persist in the absence of active intervention.²³ An active approach to management is now promoted and interventions should take into account interpersonal and relationship issues, self-esteem and body image in addition to biological factors.²⁴

The loss of fertility following treatment may represent a major setback and be associated with significant psychological distress and relationship difficulties.²⁵ The impact is obvious for a young woman or man, however for those who already have children the impact may not be apparent to extended family members or social contacts. Even women who have regarded their family as "complete" prior to the development of chemotherapy-

induced menopause may express grief and regret about the choice of future pregnancies being taken away from them.

Social

Social relationships may change as a consequence of diagnosis; some may not provide anticipated support, others may decrease over time, while new relationships and sources of support may emerge.²⁶ Family members may rate the cancer experience as more stressful than patients,²⁷ highlighting the importance of attention to the adjustment of family members. Divergence in priorities and attitudes can result in tensions in relationships emerging, with the cancer survivor being expected to “move forward”. A strong attempt to “get back to normal” can represent the desire of family members and significant others to avoid contemplating the risk of recurrence or a less certain future.

Although most survivors function effectively in a work environment following the completion of cancer treatments, a minority may take a number of years to return to work, or will return to work in a diminished capacity. Studies indicate employment discrimination, difficulties with re-entry into the workforce, dismissal, demotion and lack of career advancement can be experienced by some cancer survivors.^{28,29} Adverse socioeconomic and financial effects may be partly due to such difficulties in addition to out-of-pocket medical costs and difficulties borrowing from financial institutions. Access to insurance coverage for health care, sickness, disability, life and travel can also be problematic following a diagnosis of cancer.³⁰

Some of these difficulties (eg. relationship changes) may be accentuated in CALD survivors because of the stigma and taboos surrounding cancer, and the associated reluctance to discuss this outside of the family.^{15,16} Feelings of isolation may also be compounded by a sense of cultural isolation. Regardless of English ability, CALD survivors have described experiencing an additional level of comfort, support, and familiarity when treated by people from their own culture, and feelings of separation, isolation, and difficulty building relationships when this is absent.

Existential

Most survivors report that life is never the same after a cancer diagnosis. Many re-evaluate and change their values, goals, priorities and outlook on life as a result of facing their own mortality.³¹ Little et al described the process of ‘liminality’ commencing at the first experience of malignancy, whereby “each patient constructs and reconstructs meaning for their experience by means of a narrative. This phase persists, probably for the rest of the cancer patient’s life.”³² Learning to adjust to a new ‘normal’ can be challenging and two recent studies conducted in Australia identified that many survivors struggle to cope with changes to their self-identity and expectations of themselves as a cancer survivors.^{10,13} The obvious relief of survival may be tinged with sadness about the cost at which this has been achieved, for example limited functioning or inability to parent children.

Numerous positive outcomes and improvements in wellbeing have been reported in both the empirical and popular literature on cancer survivorship. Several studies have found that most survivors, including CALD survivors, perceive benefits from their cancer experience such as personal growth, enhanced appreciation for life, living fuller and more meaningful lives, closer relationships with others, existential gains, increased faith and positive lifestyle changes such as increased exercise and healthier diet.^{10,13,17,33,34} There is some evidence suggesting that women and younger survivors are more likely to identify personal growth and other positive aspects of cancer, while men and older survivors are more likely to minimise its impact and perceive it as just a part of living.³⁵ Researchers advocate the inclusion of positive change items in outcome assessments to capture the breadth of individuals’ experiences and to identify opportunities for improving outcomes.³⁶

Future directions

A key perspective missing in our understanding of the issues faced by cancer survivors is longitudinal studies that follow survivors with repeated assessments to see how they fare over time. Further research exploring the specific needs of CALD survivors is also required. Recognition of the importance of this type of research has increased with the high profile report *From Cancer Patient to Cancer Survivor: Lost in Transition*,⁵ recommending large-scale population-based studies conducted with the diversity of cancer survivors be undertaken as a matter of priority. Two studies addressing these priority areas are currently underway in Australia; the Cancer Survival Study undertaken by the Centre for Health Research and Psycho-oncology (CHeRP) is following 1455 survivors from six months to five years post-diagnosis, while the Psycho-Oncology Co-operative Research Group (PoCoG) is conducting a population based study which aims to recruit 1000 survivors from Arabic, Chinese, Greek and English speaking backgrounds from two years to five years post-diagnosis. Among other outcomes, both studies are assessing survivors’ anxiety, depression, perceived needs and quality of life. The PoCoG study will provide the first population based estimates of these outcomes in cancer survivors from CALD communities in Australia, while the CHeRP study will identify the duration, onset, frequency and severity of the positive and negative effects of cancer over the disease trajectory.

It is imperative that we are able to identify the difficulties experienced by cancer survivors and develop effective approaches to help survivors manage them. The results of these two landmark studies will make a substantial contribution to providing an evidence base upon which to develop culturally appropriate policies and practices to improve the health and wellbeing of cancer survivors in Australia.

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