

Health Psychology and life after cancer: Recognizing the need for continued support

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Increased longevity and the success of medical treatments for all manner of physical illness mean that more and more people are living with chronic conditions. Looking at the

World Health Organisation's (WHO) website relating to cancer (<http://www.who.int/cancer/en/>) we see that great care is taken to provide information on cancer as a disease, on national cancer control programmes, prevention, early detection, treatment and palliative care. Research and clinical practice in oncology has focused on prevention, detection and the improvement of cancer treatments. However, there is something missing from this representation of the cancer trajectory. There is little attention given to life after treatment has ended, that period when the patient moves into what is termed 'long-term survivorship'. There is a growing interest within Health Psychology in the quality of life of those whose lives have been prolonged by early detection and successful treatment of cancer and indeed, health psychologists have much to offer in this domain.

The NCCS and the NCI use a wide definition of survivorship stating that it begins at the point of diagnosis and includes "anyone touched by cancer" (National Coalition for Cancer Survivorship, 2012). The American Society for Clinical Oncology (ASCO) characterises survivorship into different phases from new diagnosis and treatment (acute survivorship) to early post-treatment (extended survivorship) and beyond (permanent survivorship) (IOM, 2006). In this article, we focus on the period of extended survivorship and the transition into permanent survivorship.

The need to give attention to cancer survivorship was acknowledged by the National Coalition for Cancer Survivorship (NCCS) and the National Cancer Institute (NCI) when they established the Office of Cancer Survivorship in 1996. In 2004, the US Centres for Disease Control and Prevention (CDC) and the Lance Armstrong foundation (LAF) launched a National Action Plan for Cancer Survivorship. That plan highlighted a number of common myths about cancer survivorship, including the belief that "the need for care of survivors ends once treatment is complete" (CDC & LAF, 2004, p.7).

Due to earlier detection and more effective therapies, the majority of those diagnosed can now expect to live long term after diagnosis (Rowland & Bellizzi, 2014). According to De Angelis et al. (2014) the number of adults surviving for at least 5 years after diagnosis has increased for all European regions with some cancers having over 80% survival rates.

Unfortunately, surviving cancer does not necessarily mean that life returns to 'normal'. Lives are forever changed by the diagnosis of this disease and by its treatment. While most survivors do have a good quality of life after their treatment is over, there is accumulating evidence that about 20% of long-term survivors who are disease free are living with negative physical and psychological side effects caused both by the disease and its treatment (Aziz, 2007; Bloom et al., 2007; Ganz, 2007; Ivers et al., 2009). Some leading survivorship experts have even suggested that up to 75% of survivors will experience some health-related consequence of their treatment (Aziz & Rowland, 2003).

Individuals are at increased risk for long-term morbidity and premature mortality. This may be related directly to the cancer itself, to pre-existing co

morbidities, surgery or exposure to a variety of therapies including radiotherapy, chemotherapy and hormone therapies. Long-term effects include physical effects, such as fatigue and pain, psychological effects such as fear of recurrence, anxiety and depression (Ivers et al., 2009; Rowland, 2007; Stanton et al., 2006). People can experience a number of other psychosocial problems including impaired body image and sexual dysfunction, loss of fertility, social and vocational stigmatisation and discrimination and financial difficulties (Daly 2003; Ivers et al., 2009). As a result of their illness, people may find it difficult to slot back into their previous social roles and fatigue, pain or other symptoms may lead to a reduced capacity to work leading to financial strain. Not only are there long-term and late-emerging effects of cancer and its treatment, but cancer survivors are at increased risk for developing a range of other health issues including secondary cancers, cardiovascular disease, osteoporosis and other chronic illnesses (Aziz, 2007; IOM, 2006).

It is important to note that many individuals gain positive meaning from their experience with cancer. Such individuals often report more meaningful interpersonal relationships, a deeper appreciation for life, increased personal strength and spirituality, changes in their life priorities and goals, and they give greater attention to positive health-promoting behaviours (Stanton, 2006).

When a cancer survivor appears to be well and returns to the usual activities of life, assumptions are made that the cancer experience is over. Individuals have reported feeling that they need to 'justify' or explain any negative symptoms they may have, suggesting that those around them often fail to realise that the effects of cancer can often extend beyond the treatment phase. Kaiser (2008) highlights the common perception of the cancer 'survivor' as a person who demonstrates exceptional health and strength in the face of adversity. Within the narrative of survivorship, cancer is 'beaten' or 'conquered', and often linked to the use of terms such as 'fighting spirit'. Pertl et al. (2012) suggest that survivorship

discourses can place idealistic expectations and pressure on patients to live up to these ideals. Those who fail to get better within a socially prescribed time frame may not be understood by others, even being considered hypochondriacs who refuse to move on (Sinding & Gray, 2005). This can leave patients alone to exist in a medical limbo between sickness and health (Pertl et al., 2012). For those who struggle to cope with lingering physical issues after cancer, it can be difficult to communicate the extent of the symptoms. These individuals often voice frustration that their symptoms are not recognised or are delegitimized by others. For people who have lived through cancer, there is often a lack of awareness about whether they should consider their symptoms an ongoing side effect of a cured disease or as an independent medical condition (Pertl et al., 2012).

Leaving the often "safe cocoon" of cancer treatment to transition into survivorship can be a difficult time for individuals. Suddenly there are less frequent interactions with healthcare providers and less contact with others who are also experiencing cancer. In a qualitative study by Ivers et al. (2009) survivors described feelings of being "set adrift" after treatment ended. People sometimes experience high levels of stress and anxiety after treatment when the busyness of dealing with the trauma of diagnosis and treatment is over and the reality of the life threatening experience begins to hit home. Stress and anxiety are often associated with a fear of cancer recurrence (Lee-Jones et al., 1997). If there are lingering physical symptoms this fear can be exacerbated. The difficulties associated with this period are aggravated by the sense of being 'lost in transition' (IOM, 2006) with limited resources to provide support.

It is clear that those who survive cancer are likely to require continued medical and psychological care subsequent to their cancer-related care (McCabe et al., 2013). Much of the traditional follow up care is focused on monitoring disease status to avoid and detect recurrence of the disease. However, there is a need for attention to be paid not just to cancer

recurrence, but to focus on the health concerns of cancer survivors, health promotion and symptom management of common long-term and late effects (Siegel et al., 2012). Patients may not be equipped with the necessary skills or information about how to appropriately deal with any persistent problems.

The IOM report (2006) states that the period that follows primary treatment for cancer is "uncharted territory in terms of evidence-based guidance for providers of survivorship care" (p. 60). Consequently, there are very few services and resources that are specifically designed for post-treatment cancer survivors. There are a number of inpatient rehabilitation programmes in Europe, the US and Canada, most of which focus on the immediate post-treatment phase and concentrate primarily on recovery of musculoskeletal function and distress management. Efforts have been made to establish evidence-based clinical practice guidelines, assessment tools, and screening instruments to identify and manage late effects of cancer and its treatment. For example, the American Society for Clinical Oncology first established a Cancer Survivorship Task Force in 2004 to address the growing issues related to cancer survivorship and a partnership between the UK NHS and MacMillan Cancer Support developed the National Cancer Survivorship Initiative in 2008 (for further information see: <http://www.ncsi.org.uk/>). Gao and Dison (2013) propose that it is the responsibility of oncologists, cancer clinics, and cancer centres to provide expertise and assistance for issues following a cancer diagnosis and they advocate the implementation of survivorship care plans.

The IOM report (2006) recommended the development of cancer care plans noting that patients should be able to access any available resources for follow-up of specific issues that may arise, including local, national, and Web-based resources to assist in the transition from treatment to follow-up (Hewitt et al., 2005). The EU's 2009 Partnership for Action against Cancer aimed to have integrated care plans in place by 2013 in all member countries (Gorgojo,

Harris, & Garcia-Lopez, 2012). A few have achieved this aim but much needs to be done (Grassi & Watson, 2012). A recent international examination of national cancer programmes and cancer care plans coordinated by the International Psych-Oncology Society (IPOS) reported very little integration of psychosocial care into such programmes (Grassi & Watson, 2012). The development of evidence-based, comprehensive cancer survivorship programmes and survivorship care plans is absolutely necessary given the increasing numbers of cancer survivors (Hudson et al., 2009).

Not only are there few post-treatment services but there is still a serious lack of information available to survivors and to health service providers about the post-treatment period (Ivers et al., 2009). Khan et al. (2011) found that although a subset of cancer survivors did report specific emotional and physical needs, many cancer survivors did not look to their GP for their long-term cancer-related care yet participants expressed a need for psychological services and information on possible long-term effects. A recent study by Susanibar et al. (2014) found that less than 30% of medical residents had any formal training in cancer survivorship care.

As well as the development of cancer care plans, the provision of information to cancer survivors and their families and the training of health professionals, there is a need for preventive interventions that focus on cancer survivors' lifestyle behaviours to support maximum recovery and quality of life (Ganz, 2007). Enhancing quality of life requires not just attending to symptoms and functional issues but also to reducing risky health behaviours such as smoking, poor diet and low levels of physical activity and to reduce stress and distress associate with the whole experience of having cancer. As the number of survivors of cancer continues to increase, identification of the best methods for promoting the well being of long-term survivors is essential (Stanton et al., 2006). Health psychologists' skills in health promotion and intervention development may be valued in such contexts.

One example of how Health Psychology can be

applied to this area was the CANSURVIVOR Project conducted by Ivers et al. (2009) in Ireland. The findings of this research indicated that many cancer survivors have a range of needs, which may only emerge in the late-survivorship phase after completion of treatment. Most of the participants in the study had recovered very well after cancer treatment, however over 25% had significant difficulties with quality of life issues and on-going symptoms. In particular, issues relating to physical, emotional and social functioning were cited. A third of the group had anxiety levels above the normal range. In terms of health-behaviours, 51% were overweight, with many having reduced their physical activity levels since the time of their diagnosis. The majority of these survivors also had a poor diet. The authors identified a need for a specific post treatment service and the provision of information about what happens 'after cancer', including post-treatment effects as well as specific support in relation to stress management and anxiety reduction, lifestyle changes, diet and physical activity.

The findings of this study led to the implementation of a multidisciplinary pilot intervention programme including a dietician, psychologist and physiotherapist. The overall aim of the intervention was to improve the quality of life of cancer patients who had completed their treatment. The intervention focused on assisting survivors in terms of anxiety reduction, promoting a lifestyle behaviour changes, and improving activity levels, fitness strength and diet. The researchers reported significant increases in quality of life (physical and emotional functioning) and a reduction in symptom difficulties. This is just one example of the contribution that health psychologists can make to the growing area of cancer survivorship.

Health psychologists can help individuals to work through the psychological and emotional challenges associated with illnesses such as cancer (applied health psychology) or guide the development of services more sensitive to survivors needs (e.g. through consultancy). As patients work towards

resuming life roles and activities that may have been suspended during active treatment, health psychologists can help cancer survivors to enhance symptom awareness and can facilitate adaptive coping behaviours. These skills can be used to promote healthy lifestyles after cancer treatment, while also using their knowledge and skills to work with those within the healthcare system. With the accumulation of evidence base on impact of survivorship and effects of various interventions, it is hoped that the difficulties associated with life after cancer will be recognised and acted upon by health providers and health service planners/policy makers. This can guide consultations and boost a sense of validation for patients and above all, that approaches to alleviate these difficulties will be developed.

Key supports that health psychologists have skills to deliver for cancer survivors include: 1) the development of information resources about life after cancer and potential late and long-term effects, 2) educating health professionals about survivorship, 3) developing interventions to help reduce anxiety, 4) developing interventions to support health behaviour change and, 5) advocating for comprehensive survivorship care plans in our health services.

In conclusion, the quality of long-term follow-up care for cancer survivors has implications for their future physical and mental health, their overall quality of life and their health service needs into the future. At the very least, survivors should be prepared for the possibility of experiencing common late effects of their cancer and its treatment and advised about lifestyle behaviours that enhance quality of life (Ivers et al., 2009). Ganz (2007) points out that it is necessary for health service providers to become knowledgeable about the longer-term impact of cancer at a physical and psychosocial level so that they can help survivors to maximize their quality of life and that health services are utilized most effectively and efficiently. Health psychology as a discipline has knowledge and skills to support such endeavours. We, as health psychologists, have a role to play in recognising the needs of cancer survivors

and contributing to the development of support resources and interventions to reduce the impact of cancer and its treatment and enhance survivors' quality of life.

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