Understanding the long-term challenges of cancer survivorship

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Survivorship in the context of cancer is an expanding domain. It is important not just to eradicate the cancer but also to understand the implications of diagnosis and treatment. This may also include a fear of secondary malignancies and life-threatening complications.

Survivorship in the context of cancer is an expanding domain, due to earlier diagnosis and more effective treatments. However, as a result of the intensity and invasiveness of those treatments and experiences, it is a domain with issues that we are only really just beginning to address.

To discuss survivorship and relate it to quality of life we also need to look at other concepts.

What is survivorship?

There are a number of definitions of survivorship:

- The National Coalition for Cancer Survival defines cancer survivorship as: ‘Living through and beyond a cancer diagnosis’.
- The National Cancer Institute has the most holistic definition of survivorship, which takes on board the experience of the caregivers – ‘an individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life. Family members, friends, and caregivers are also impacted by the survivorship experience and are therefore included in this definition’.
- A fundamental concept related to survivorship is the concept of health and what that means in itself. Interestingly, many definitions found in the literature only relate survivorship to an absence of illness or to a level of fitness.
- Frank-Stromborg’s definition (1986) is useful as every one of us can aspire to this at whatever point we are on life’s trajectory – ‘The realisation of fullest human potential and the ability to fulfil one’s role’.
- Life is a dynamic trajectory, constantly changing, even though sometimes we may not think so. And just like life, survivorship is dynamic, it is a changing path and it is a very individual path. Hassey-Dow (1990) expresses this well in a paper exploring the concept of seasons of survival, explaining that ‘surviving is not a static concept, but one that is changing as individuals adjust to the physical, psychosocial, and spiritual aspects of their lives after illness’.

Measuring survival

We are all familiar with the traditional model of measuring cancer survival in a linear timeline, describing five-year or ten-year survival rates. This methodology is useful in quantitative analysis but arguably it becomes less meaningful in the light of screening.

Does the fact that we have diagnosed a cancer earlier in the disease process make the survival period longer or does it mean we have simply shifted the measuring stick? Importantly, time measurement in terms of time alone is only part of the story, as according to Wallwork and Richardson (1994) ‘measuring cancer survival in terms of time alone fails to describe how an individual copes after a diagnosis and the treatment of cancer’.

Therefore, to eradicate the cancer but ignore the implications of diagnosis and treatment and to ignore the disruption, change, and adjustment that accompanies a cancer diagnosis, is simply neglectful.

Fear of relapse

Koocher and O’Malley (1981) used the term ‘Damocles syndrome’ to describe a fear of relapse. In cancer survivorship today, this also includes a fear of secondary malignancies and life-threatening complications.

A recent article by Goldsmith (2004) highlights this issue. Two-thirds of the 2.3 million children who survive cancer in the US each year develop late adverse effects of treatment with chemotherapy or radiation, such as cognitive impairment, alterations in growth, and second malignancies. Additionally, some delayed adverse effects of treatment such as cardiac or pulmonary toxicity and secondary cancers, constitute the second most frequent cause of death in children who are commonly regarded as cancer survivors. These are a few of the many challenges that cancer survivors face.

Stages of cancer survivorship

Mullan (1985), a physician who underwent treatment for non-Hodgkin’s lymphoma, describes the problems of survivorship succinctly. ‘It is as if we have invented sophisticated techniques to save people from drowning but once they have been pulled from the water, we leave them to cough and splutter on their own in the belief that we have done all we can.’

I hope that we have improved since Mullan underwent his treatment for cancer but, in a world of medicine that strives for better treatments and diagnostic techniques, and that continues to set its sights on finding permanent cures, have we really become any better at providing care following treatment?
Mullan (1985) described three seasons of cancer survival (Box 1). I have often wondered how many people are in the permanent season. I believe I have met very few, but this could be the effect of them interacting with me, as I am a part of their cancer world. I have, however, picked up the telephone to be asked if a patient who had treatment 10 years previously should come to the leukaemia unit because he was having palpitations, not having thought of contacting his GP.

Survivorship and quality of life are dynamic and ever-changing experiences. In order to offer a service and care that acknowledges this aspect we must provide information to enable people to make choices about treatment options in the light of their own life choices and preferences and to do this we need to be informed.

The knowledge and information we have on today’s survivors must not remain static. We must periodically revisit and revise our own knowledge base in the light of a changing and growing body of evidence.

Only by doing this can we equip cancer patients with the knowledge and tools they need to master the new realities of their survivorship.

There are obvious implications for health care practice. With increasing numbers of individuals being cured or living for long periods of time after a diagnosis of cancer, oncology nurses and allied health professionals who work with cancer survivors must maintain their knowledge of the issues and practices that are critical to the well-being of the patient.

The definition of ‘meaning’

Another concept that is discussed in the survivorship literature is that of meaning. Frankl (1963) spoke of meaning as being a basic need necessary for human fulfilment, but he also said that the meaning of life differs from person to person, from day to day and from hour to hour. Traditionally, health care workers and perhaps the use of the medical model reinforce the link between meaning and patients getting back to normal after treatment.

The literature, however, in reflecting patients’ experiences, increasingly refers to finding a new wholeness and that is something quite different from what was the norm before diagnosis and treatment. This new wholeness embodies life on a physical, psychological, and spiritual level.

Changes in relationships

Changes in relationships vary from an increased closeness brought about by the shared experience, to a distancing of friends or family (Stephens, 2004). This change has been described as originating from a combination of experiences such as seeing those people with new eyes and increased clarity, intensely facing death together, and a realisation of what is important in life. This can bring about an intense closeness and intimacy.

Some have described a re-evaluation of friends and family relationships and have found disappointment, no longer wishing to spend time with acquaintances and finding small talk irrelevant and superfluous.

Relationships with family, friends, colleagues, and sexual partners are very often altered in some way as a result of surviving cancer (Loescher et al, 1990). Wilkie (1993) in a book describing experiences with ovarian cancer, looked back and mourned a time in the past: ‘I realised that everything came into my own personal timescale of BC and AD– before cancer and after diagnosis – and I went through a period of what I now think was true bereavement. I had to mourn the person I’d been before I got cancer, because there was no way back to being that person.’

Grieving and a sense of loss are described in the literature but this is not loss in the traditional sense. When we lose someone we experience a sense of loss and see our lives with a gap. However, life post-cancer treatment is life with the loss of something very dear, but it does not have the gap (Stephens, 2004).

Stephens (2004) explored in a study the lived experience post-transplant, and participants described this idea of a different new life, but described moving forwards, not looking back.

Follow-up

Should we offer surveillance and/or support, or neither to cancer survivors? Almost 10 years ago Brada (1985) questioned the value and efficacy of follow-up protocols in relation to the stress that they may cause.

How can we expect people to move into Mullan’s permanent season of survivorship, and to put their cancer behind them when we call them back annually for a computerised tomography scan in the vague hope that if relapse is going to occur, the cancer cells have a calendar?

We have made progress in addressing the needs of people following treatment, passing them tissues and saying a kind word as they cough and splutter, but I do think that we can do a bit more in supporting them as cancer survivors.

REFERENCES


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