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FOCUSING ON SURVIVORSHIP: LIFE AFTER CANCER

Focusing on survivorship: improving our knowledge of life after cancer

Dr Mary Ivers, Dr Barbara Dooley, Ms Ursula Bates

KEY POINTS

• The post-treatment period should be viewed as a distinct phase of the cancer journey
• Cancer and its treatment have long-term and late-emerging effects on quality of life
• There is a need to develop survivorship services
• Health providers need to improve their knowledge of survivorship
• Survivors need information about life after cancer.

INTRODUCTION

Although the latest figures from the National Cancer Registry of Ireland predict that the number of new cancer cases in Ireland will more than double between 2010 and 2030, advances in early diagnosis and improvements in cancer treatments have resulted in greatly increased survival rates for many cancers. With increasing expectations for survival, attention is now turning to focus on “survivorship”. There is now a need to improve our knowledge of survivorship issues to enable us meet the needs of cancer survivors.

In 2002, there were an estimated 22.4 million cancer survivors worldwide who had been diagnosed in the previous five years and there were an even greater number who were living more than five years post-diagnosis. In Ireland, the National Cancer Forum report estimated that, in 2002, there were approximately 120,000 cancer survivors in Ireland.

In this article, we aim to briefly introduce the reader to the topic of survivorship and present some examples of the physical, psychological and social issues that can have a detrimental impact on quality of life after cancer and highlight the need to develop appropriate and effective services to enhance the survivorship phase of the cancer trajectory.

THE EMERGENCE OF ‘SURVIVORSHIP’

Most of the focus of research and clinical practice in oncology and psycho-oncology has been on the patient in the initial phases of the cancer trajectory. Medically, the focus has been on prevention, detection and the improvement of cancer treatments. Psycho-oncological efforts at understanding and improving the experience of having cancer have concentrated on the impact that a cancer diagnosis has on the individual and their family, on the management of symptoms such as distress and anxiety, coping with treatment, or coping with a terminal prognosis.

The overriding impact of advances in cancer treatment has been the shift in the focus of attention from quantity to quality of life. With more and more patients surviving their cancer diagnosis there is now a growing concern about the quality of these prolonged lives.

While the majority of survivors go on to lead happy and productive lives, survival does not necessarily mean a return to “normal” life. Recent research has found that a significant number of post-treatment cancer survivors experience long-term and late-emerging physical, psychological and social effects as a result of their cancer and its treatment. Long-term effects refer to side-effects or complications of the treatment that continue beyond treatment while late effects refer to toxicities that were not evident at the time treatment ended but became evident years later. These effects have a detrimental impact on quality of life long after treatment is completed.

A DISTINCT PHASE OF THE CANCER JOURNEY

Over 20 years ago the National Coalition for Cancer Survivorship (NCCS) was formed in 1986 with survivorship issues as its driving force. The National Cancer Institute (NCI) established the Office of Cancer Survivorship 10 years later and, 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.”

Recently, the Institute of Medicine (IOM) produced an influential report, From cancer patient to cancer survivor: lost in transition, which the authors believe was the result of a convergence of trends in medical science, health service research and public health awareness. That report recommended that cancer survivorship be established as “a distinct phase of cancer care.”

These recent developments are indicators of a growing concern about the quality of life of those who are post-treatment and an interest in the development of cancer-related health and welfare services that will meet cancer survivors’ needs after treatment completion. Building the knowledge base about the factors impacting on the post-treatment period and developing interventions to ameliorate the impact of cancer and its treatment are the focus of current survivorship research and practice.

QUALITY OF LIFE AFTER CANCER

A recent review of quality of life in long-term survivors found that, in general, the longer the time since treatment ended, the better the reported quality of life. However, it also found that a substantial number of long-term survivors continue to
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experience issues associated with their cancer and its treatment. While the majority of survivors may enjoy a good quality of life there is accumulating evidence that up to 20% of long-term survivors who are disease-free continue to experience negative treatment side effects and psychological sequelae.\textsuperscript{1,5} In fact, leading survivorship experts suggest that up to 75% of survivors will experience some health-related consequence of their treatment.\textsuperscript{14} These consequences include physical effects, such as fatigue and pain and psychological effects including fear of recurrence, anxiety and depression. There is also evidence of sexual, vocational and financial difficulties after cancer.\textsuperscript{17,18,19,20} Such effects impact on functioning in many life domains.\textsuperscript{21}

PHYSICAL IMPACT

There are numerous physical effects experienced in the post-treatment period. These are often cancer site specific, they directly impact on functioning and may result in reduced mobility and interfere with activities of daily living (ADLs).\textsuperscript{2} For example, there is evidence that 12% to 25% of breast cancer survivors will develop lymphoedema and its onset can be up to four years post-treatment.\textsuperscript{11} Weight gain is another late effect of treatment with up to 50% of females who received chemotherapy reporting weight gain, which is also a risk factor for cancer recurrence.\textsuperscript{12} For prostate cancer survivors, urinary and bowel dysfunction are long-term problems resulting from all of the available treatments,\textsuperscript{9,22} while some of the late effects for colorectal cancer survivors include bowel dysfunction and pain.\textsuperscript{12,23}

There is evidence that as many as 80% of survivors still have ambulation problems three years after treatment as a result of pain.\textsuperscript{24} Fatigue is one of the most commonly reported effects with estimates that 30% to 43% of survivors are not able to carry out their usual ADLs due to post-treatment fatigue, resulting in reduced activity to conserve energy and leading to loss of muscle mass, weight gain and a reduction in cardiorespiratory fitness.\textsuperscript{25,26} This reduction in activity levels puts the survivor at further risk of other health problems. In addition, fatigue may prevent survivors from returning to work and being able to lead a normal life, resulting in reduced activity, loss of a sense of control, loneliness and isolation.\textsuperscript{27}

Physical symptoms cannot be isolated in terms of their effect as they can have a very powerful impact on psychological, social and emotional adjustment, affecting body image, role functions and a return to "normality".\textsuperscript{28}

PSYCHOLOGICAL IMPACT

Many psychological consequences as a result of cancer and its treatment have been identified in the literature including fears about recurrence, distress, anxiety, depression, alterations in body image, loss of control and anger, to mention but a few.\textsuperscript{9,13,30}

Fear of recurrence is the most commonly reported psychological impact of cancer with prevalence rates ranging from 10% to 89% across a number of published studies.\textsuperscript{22,33} There is a close link between fear of recurrence and anxiety which is also common in cancer survivors.\textsuperscript{2,4} The stresses of late or long-term physical effects, changes in family roles, problems with employment and other difficulties may place a huge demand on the survivors' coping resources and a failure to adapt may result in anxiety and/or depression.\textsuperscript{32} There are reports that up to 34% of post-treatment survivors have significant levels of distress\textsuperscript{36} and a recommendation for its measurement as the "sixth vital sign" at every follow-up visit.\textsuperscript{30}

Cognitive dysfunction is also an outcome for some survivors.\textsuperscript{7} This phenomenon, known as "chemo-brain", is reported by many breast cancer survivors and results in memory loss, poor concentration and deficits in executive functioning.\textsuperscript{12} There is a question over whether this effect is in fact due to chemotherapy or due to the cancer itself, as one study reported cognitive impairment in 35% of their sample before the beginning of systemic therapy for breast cancer.\textsuperscript{16} Cognitive dysfunction has also been reported in prostate cancer survivors treated with androgen deprivation therapy for more than two years.\textsuperscript{7} There is the possibility that anxiety is also implicated in cognitive dysfunctions such as poor concentration and memory loss.

SOCIAL IMPACT

The social impact of cancer and its treatment may include social isolation, disruption to work and family life, changes to social and personal relationships, sexual difficulties as well as vocational and financial difficulties.\textsuperscript{26} In breast cancer survivors, sexual difficulties may result from the early onset of menopausal symptoms or changes in body image. Sexual relationships and quality of life are also affected in those with prostate and colorectal cancers, with sexual dysfunction becoming a major concern.\textsuperscript{13,30}

Survivors often experience unsupportive behaviours towards them, which are risk factors for distress.\textsuperscript{39} Marginalisation and stigmatisation are other possible impacts of cancer and its treatment.\textsuperscript{31} Furthermore, many cancer survivors experience employment problems due to their cancer and the resultant strain and additional financial burden increases their psychological burden.\textsuperscript{39}

ENHANCING POST-TREATMENT SURVIVORSHIP

The IOM report states that the period that follows primary treatment for cancer is "uncharted territory in terms of evidence-based guidance for providers of survivorship care".\textsuperscript{12} Consequently, there are very few services and resources that are specifically designed for post-treatment cancer survivors.\textsuperscript{40} However, as the body of literature has grown and our knowledge is increasing, attention is turning to the development of interventions for moderating the effects mentioned earlier.

There are a few inpatient rehabilitation programmes in Europe, the US and Canada. These tend to focus on the immediate post-treatment phase and concentrate on recovery of musculoskeletal function and distress management. The development of survivorship services has not progressed due to the lack of an evidence base regarding the details of who needs
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what, when and where. Given this lack of an evidence base, the provision of appropriate interventions to tackle the late and long-term effects of cancer and its treatment is a challenge.

In conjunction with comprehensive cancer survivorship programmes that deal with late- and long-term effects, there is a need for preventive interventions with the aim of maximising recovery and quality of life post-treatment. The survivor's lifestyle behaviours may exacerbate the overall impact of cancer and its treatment on quality of life and future health. 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.

CONCLUSION
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 health difficulties including secondary cancers, cardiovascular disease, osteoporosis and other chronic illnesses. The evidence that has accumulated to date regarding the impact of cancer and its treatment, and the post-treatment care needs of survivors highlighted above, shows that a number of initiatives are required to maximise quality of life after cancer. The quality of follow-up care for cancer survivors can have implications for future physical and mental health, and for overall quality of life.

Not only is there a lack of a post-treatment service, but there is a serious lack of information available to survivors and to health service providers about the post-treatment period. Given the rise in survival rates and greater expectations about survivability, Ganz 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 maximise their quality of life and that health services are utilised most effectively and efficiently.

At the very least, survivors should be prepared (by their health providers) for the possibility of experiencing common late effects of their cancer and its treatment and advised about lifestyle behaviours that enhance quality of life.

REFERENCES AVAILABLE ON REQUEST

Dr Mary Ivers, lecturer in health psychology at the School of Psychology, University College Dublin, recently completed her doctoral dissertation on survivorship in Ireland.
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