

# Improving the Care of Adult Cancer Survivors

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## ABSTRACT

Internationally, there are growing numbers of cancer survivors. Survivors report a range of persistent symptoms and unmet needs, which are quite consistent, internationally. Current models of post-treatment survivorship care are suboptimal, and unsustainable given the number of survivors, and limited health workforce. The most appropriate model of care for an individual will depend on a range of patient, disease and

treatment factors. Alternatives to traditional follow up have been evaluated including nurse led follow up, follow up led by a primary care physician and formalized models of shared care. There should be greater focus on implementation of proven models.

**Key words:** Cancer survivors, model of care, surveillance

## Introduction

With respect to the optimal care of adult cancer survivors, internationally, we have a number of shared challenges. There are large and growing numbers of survivors. Survivors may experience a broad range of issues, concerns, and needs. These are currently poorly identified and addressed. Most health-care systems have a limited and constrained health workforce, insufficient to deal with the growing number of survivors. There is a need to provide improved care within resource constraints. We need to develop and embed improved models of care. Some models

have been evaluated in randomized controlled trials and are appropriate for broad dissemination.

## Numbers of Survivors

In Australia, at the beginning of 2018, there were estimated to be 1.1 million cancer survivors, that is, people with a personal history of cancer.<sup>[1]</sup> One in 22 Australians is a cancer survivor. As with other countries, this number is projected to increase substantially so that by 2040, there will be an estimated 1.9 million survivors

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in Australia. The majority (64%) will have survived cancer for more than 5 years, and the majority (58%) will be over the age of 70 years. The vast majority of survivors have comorbidities.<sup>[1]</sup>

Data from the US show a similar profile of survivors, compared to Australia. Absolute numbers are much greater.<sup>[2]</sup> At the beginning of 2019, there were 16.9 million survivors in the US, projected to increase to 22.2 m by 2030.

## Issues for Survivors

The issues that survivors experience are quite consistent internationally.<sup>[3-5]</sup> While the majority of adult cancer survivors adjust well to life after cancer, there are a set of issues that are commonly experienced. Many people report feeling lost or abandoned after cancer treatment, particularly after a period of intense treatment. Many report persisting side-effects from treatment, including issues such as fatigue, pain, and concerns with sleep and with cognition. Emotional and psychological issues, particularly fear of cancer recurrence, are very common. Some survivors are at risk of side effects that develop later (“late effects”), such as the risk of becoming infertile, of developing organ damage and the risk of developing another cancer as a result of prior cancer treatments. Of course, cancer and cancer treatments also impact family, friends, and others. Psychological distress can be common in carers and family members.<sup>[4]</sup> Many survivors report difficulties resuming work or study, may experience loss of income, and long-term financial toxicity. Some, however, report benefit and growth through the cancer experience.<sup>[3-5]</sup>

A recent systematic review of unmet needs in cancer survivors showed that the most commonly endorsed unmet needs were psychosocial, including the need for assistance to manage worries about cancer recurrence or progression, feeling uncertain about the future and assistance to reduce stress.<sup>[6]</sup> Survivors also reported unmet needs in the supportive care domain, including the need for more information about support services and affordable hospital car parking. Survivors also reported unmet needs in the physical domain, including help with feeling tired and having a lack of energy and not being able to do usual things.

A survey of almost 2000 patients from Australia and nine high-, middle-, and low-income Asian countries found that many symptom issues and unmet needs were shared across these diverse settings.<sup>[7]</sup> Commonly reported physical symptoms included fatigue, loss of strength, pain, sleep disturbance, and weight changes. The most common unmet need across all patients related to fear of cancer recurrence. This was followed by needs relating to comprehensive cancer care. Patients also reported significant unmet informational needs.

## Issues with Current Survivorship Care

As noted, survivors often have symptoms and other issues that are under-recognized and undertreated, are often unprepared for the posttreatment phase, may be unaware of health risks, and may have poorly coordinated follow-up care.<sup>[3-5]</sup> The current care is associated with insufficient health promotion and attention to health risk factors and management of unhealthy behaviors, such as smoking, lack of exercise, and management of overweight and obesity. Primary care providers are not adequately engaged in the care of survivors and often state that they do not have the information and support that they need. There may be underuse of existing services, including rehabilitation and services provided by nongovernment and not-for-profit organizations. Specialist-led review appointments may not represent the best use of their time, and there may be underuse of nurse and allied health reviews in both the cancer setting and in the community. There are limited metrics and key performance indicators to describe, report, and manage optimal survivorship care.<sup>[3]</sup>

The landmark report from the US Institute of Medicine (IOM), “from cancer patient to cancer survivor: lost in transition” recommended four essential components of survivorship care.<sup>[4]</sup> These include prevention of recurrent and new cancers, as well as late effects; surveillance not only for cancer spread and recurrence but also assessment for possible medical and psychosocial late effects. Survivorship care must identify and appropriately manage the consequences of cancer and its treatment, including symptom management, management of distress in caregivers and family members as well as survivors themselves, and respond to concerns related to work, insurance, and disability. Care should be well-coordinated between all providers, including those in the community.

## Exploring New Models of Care

Soon after the IOM report, England’s National Cancer Survivorship Initiative was launched and ran between 2008 and 2013.<sup>[5]</sup> A key component of redesigned care is the notion of risk-stratified pathways, with care being responsive to survivors’ issues and concerns, and risk of developing later problems. Some people require complex care, managed through a multidisciplinary team, at least for a period; many survivors may be able to self-manage, with appropriate support, alongside recommended surveillance testing. Some survivors need an intermediate level of care, combining support for self-management, evidence-based surveillance testing, and perhaps shared management between oncology and primary care providers. Stratified follow-up pathways are progressively being rolled out in

England. This is combined with the “recovery package,” which includes needs assessment, provision of a treatment summary and care plan, and a cancer care review in primary care. It has been estimated that rolling out stratified cancer pathways will result in significant cost savings for England’s National Health Service. Stratified pathways of care are emphasized within Australia’s recommended model of survivorship care and have been recommended within the US.<sup>[3]</sup>

The recommended and most appropriate model of care will depend on a number of factors, including the type of cancer and type of treatments, current survivors’ issues, concerns, and needs as well as the risk of developing recurrence, late effects, or another cancer.<sup>[3]</sup> As an example, the care that might be required for somebody who has recently completed combined chemoradiation to treat a cancer in the head and neck region may be quite different from the care required by somebody treated for an early-stage melanoma. The most appropriate model of care will also depend on comorbidities/concurrent illness, personal circumstance, and practical issues such as the availability of, distance to, and relationship with various care providers. The time since completing treatment will also influence the issues and needs of survivors and impact on the most appropriate model of care.

Primary care is often the best setting for at least some aspects of posttreatment survivorship care including the management of health risk factors such as smoking, obesity and physical inactivity, as well as preventive interventions and the management of comorbid illnesses. Many survivors are already consulting with primary care providers. Primary care providers often express a willingness to be involved in survivorship care so long as they are provided with necessary guidance and support.

Several randomized controlled trials have examined primary care led follow-up compare to the traditional hospital or cancer center led follow-up. A systematic review showed no statistically significant differences with respect to patient well-being, recurrence rates, survival, diagnostic delay or patient satisfaction, though noted that primary care-led follow-up is likely cheaper.<sup>[8]</sup>

Shared care involves a formalized plan to share follow-up care between oncology and primary care providers. A recent systematic review has suggested similar effectiveness with respect to quality of life, mental health outcomes, unmet needs, clinical outcomes, and again may be cheaper.<sup>[9]</sup> Nurse-led care may also be an appropriate model. A systematic review showed no statistically significant differences in survival, recurrence or psychological morbidity, though generally higher satisfaction with nurse-led, versus traditional follow-up.<sup>[10]</sup>

These models point to flexibility in follow-up models of care. The studies have generally considered survivors of breast, prostate and colorectal cancers and melanoma and generally have recruited people considered to be a low-to-medium risk of recurrence and complications. These models may not be applicable in other circumstances. It is uncertain whether these models can be applied with the same outcomes, internationally. Notably, the studies have not necessarily considered all possible survivorship outcomes such as symptom management, unmet needs, management of comorbid illnesses, and return to optimal well-being, for example, return to work.

We now have considerable evidence to support the implementation of a number of models of care. A reasonable focus is on the successful implementation of these models.

## Immediate Next Steps for Providers

For the individual healthcare provider, there are a number of steps we can all take to improve the care of cancer survivors [Box 1]. Preparing survivors early for the posttreatment phase and providing survivors with information about this phase are strategies that respond to known unmet needs. Linking survivors to other services and resources and empowering patients and survivors to self-manage are also useful strategies. As we know that survivors have issues and concerns that are not systematically identified using prompt lists for patients, considering the use of patient-reported outcome measures

### Box 1: Useful survivorship-focused resources

#### Information for patients

Macmillan Cancer Support, [www.macmillan.org.uk](http://www.macmillan.org.uk)

American Cancer Society, [www.cancer.org](http://www.cancer.org)

Cancer.Net (from the ASCO)

Australian Cancer Survivorship Centre, [www.petermac.org/cancersurvivorship](http://www.petermac.org/cancersurvivorship)

Survivorship information for patients in 9 languages (“On the road to recovery”)

<https://www.petermac.org/languages>

Online survivorship care plan generators

[www.mycareplan.org.au](http://www.mycareplan.org.au)

<https://oncolife.oncolink.org>

[www.journeyforward.org](http://www.journeyforward.org)

Free online education in cancer survivorship for health professionals

<https://education.eviq.org.au/courses/cancer-survivorship-introductory-course>

<https://www.futurelearn.com/courses/cancer-survivorship>

ASCO survivorship compendium

A repository of tools and resources to support oncology providers to implement or improve survivorship care within their practices

<https://www.asco.org/practice-guidelines/cancer-care-initiatives/prevention-survivorship/survivorship/survivorship-compendium>

ASCO: American Society of Clinical Oncology

and clinical note templates may assist with recognition and management of concerns.

Many health-care professionals report the need for additional education and training around cancer survivorship. A suggested educational curriculum has been developed,<sup>[11]</sup> and there are a number of resources available [Box 1].

The vast majority of survivors wish to receive a treatment summary and care plan.<sup>[12]</sup> There are online resources which can enable people to quickly generate a care plan [Box 1]. A number of organizations have developed survivorship guidelines, which may be disease-specific, or symptom-based. Linking primary care providers with care throughout the cancer journey, and providing primary care providers with information and guidance will support holistic, coordinated, shared care.

Another individual strategy might be to consider the current follow-up care: consider who might be the most appropriate health-care provider to coordinate survivorship care and consider whether there are opportunities to reduce review appointments or discharge patients from ongoing follow-up. Importantly, we need to develop and embed metrics of quality cancer survivorship care.<sup>[13]</sup>

## Conclusion

There are large and growing numbers of cancer survivors. Survivors have significant issues, concerns, and unmet needs. Our current models of care are suboptimal and are not sustainable. We need to develop and implement better models of care. There is considerable experience to draw on. There are many opportunities to improve the care of cancer survivors.

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## Conflicts of interest

There are no conflicts of interest.

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