

WHAT CONSTITUTES IDEAL SURVIVORSHIP CARE?

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Abstract

There is increasing recognition that cancer survivors require continued care, beyond diagnosis and treatment. They are at increased risk of second and recurrent cancers, treatment related side-effects, other co-morbid health conditions, as well as psychological and social difficulties. However, current care is suboptimal and does not adequately meet the needs of this vulnerable population. In this paper, the principles of optimal survivorship care are discussed, including: prevention and detection of new cancers and recurrent cancer; surveillance for cancer spread, recurrence or second cancers; interventions for consequences of cancer and its treatment and; coordination between specialists and primary care providers. Barriers to achieving optimal care are discussed and recommendations made for improving survivorship care.

Importance of continued care for cancer survivors

The number of people completing curative cancer treatment is increasing, with over 60% of cancer patients in Australia surviving more than five years.¹ This has led to the recognition of cancer survivorship as a distinct phase in the cancer trajectory.² Despite the expectation that survivors will 'return to their normal lives', the transition into the survivorship phase can be difficult due to the physical, psychological and social consequences of cancer and its treatment.³ Cancer survivors report issues managing long-term side-effects and late effects, fears of recurrence, uncertainty about the future, difficulties returning to work/social situations, financial problems and feelings of abandonment by the treatment team.³ Furthermore, survivors are at an increased risk of second or recurrent cancers, as well as co-morbidities that affect older populations, such as heart disease and arthritis.⁴ Continued care, beyond the acute treatment phase, is essential to ensure that these issues are appropriately managed and to improve survivor outcomes.⁵

Current survivorship care

Despite the complex issues around treatment completion, survivorship care is suboptimal. Follow-up care may be fragmented between oncology specialists (surgeon, medical and radiation oncologists) and general practitioners. There can be considerable duplication of effort, or alternatively, major gaps in follow-up resulting from poorly coordinated care. Follow-up generally tends to focus on surveillance for cancer recurrence, metastases or new primary cancers, with little attention given to physical and psychosocial late effects. Health promotional advice and psychosocial strategies to improve wellbeing are rarely discussed, and when they are, this is usually ad hoc, inconsistent and lacking a sound evidence base.²

Patients commonly report a lack of necessary information and ongoing support.⁶ Hewitt examined perspectives

on post-treatment cancer care with survivors, nurses and physicians.⁷ Most survivors reported that they were satisfied with current medical care, but felt their psychosocial needs were not met. In addition, they reported being overwhelmed at the end of treatment, but were rarely given any written information.⁷ This has been identified as a significant problem, nationally and internationally, with few resources available for patients in this phase.² This is currently being remedied in Australia, with the development of several key resources, including a DVD and information booklet for people completing treatment.⁸ Further consideration of the content and delivery of survivorship care is critically needed.

Principles of ideal survivorship care

The push for improved services for cancer survivors has gained considerable momentum over the past 10 years. In 1996, the National Coalition for Cancer Survivorship established 12 principles for delivering quality cancer care.⁹ In 2001, the US Institute of Medicine (IOM) also released a report *Crossing the Quality Chasm*,¹⁰ which recommended several factors for the delivery of quality care. Together with the growing body of survivorship work, there is now broad consensus that ideal survivorship care should be:

- comprehensive, high quality health care that is accessible to all cancer survivors, including specialised survivor services
- patient-centred and tailored to meet individual needs, whilst empowering survivors to take an active role in their own health management, to the extent that they desire
- multidisciplinary and collaborative, involving a range of oncologists, primary care providers, nursing and allied health staff, as well survivors and their families
- continuing medical care that is focused on the transition from the acute setting to the community, using effective communication strategies to promote planned and coordinated follow-up

- holistic care which addresses psychological and social needs in addition to physical issues; attention should also be given to preventive, rather than solely reactive management strategies
- evidence-based and supported by appropriate guidelines, policies and research, ensuring that service delivery is outcomes focused, cost-effective and sustainable.

In 2006, the IOM released a pivotal report, *From Cancer Patient to Cancer Survivor: Lost in Transition*,² advocating for planned and coordinated care to manage the medical and psychosocial difficulties experienced by cancer survivors after completing treatment. The report attempted to further describe and 'operationalise' the content of what survivorship care should involve. Four key components were identified.

Prevention of new cancers and recurrent cancer

Although survivors remain at a heightened risk of developing new cancers, many risk factors are modifiable.⁵ There is growing evidence to support many adjuvant medical treatments (not reviewed here) to reduce the likelihood of secondary cancers.² In addition, the period after treatment can be seen as a teachable moment, where changes to health and lifestyle may be more readily adopted in an attempt to prevent disease and ill health.² Improved diet, maintaining a healthy weight, ceasing smoking and increasing physical activity may prevent secondary and recurrent cancers, and may also reduce many of the physical and psychosocial consequences of cancer treatment.¹¹ Information on recommended health and lifestyle strategies should be provided to all cancer survivors.^{2,11}

Surveillance for cancer spread, recurrence or second cancers

Ongoing surveillance is an essential component of follow-up care to ensure that new or recurrent cancers are detected at a time when treatment may be most effective.¹² Guidelines are not available for all cancer types and vary considerably in terms of their comprehensiveness. Many emphasise detection of cancer recurrence, but place little emphasis on the prevention, detection and amelioration of the consequences of cancer treatments. Many of these guidelines provide inconsistent recommendations about the frequency, duration and type of follow-up that is required for different survivor groups.¹²

Nevertheless, surveillance is an ideal opportunity to monitor treatment efficacy and any physical or psychosocial consequences and also to provide continuing information and support. Surveillance may also help survivors to feel less anxious about the possibility of cancer returning and more confident about what will happen to them in the future. Surveillance should be tailored, with high-risk individuals requiring a higher degree of surveillance.¹² Surveillance also provides an added opportunity to screen general health issues, as many patients neglect other areas of health due to a heavy focus on cancer and recurrence.¹³

Interventions for consequences of cancer and its treatment

Cancer survivors may require further assistance managing the physical and psychosocial effects of cancer diagnosis and treatment. Patients may have persisting, even long-term effects and also be at risk of developing problems at a later time, referred to as 'late effects'.⁴ Patients frequently report ongoing physical issues with fatigue, pain, urinary/bowel issues and hot flushes,³ many of which can often be managed with medical interventions or self-care strategies. It is unknown to what extent advice regarding these strategies is provided. Furthermore, it has been suggested that a full review of psychosocial and adjustment issues should be incorporated into an optimal model of survivorship care.⁴ A growing number of psychosocial interventions may improve symptom management and psychological issues as they arise, and should be discussed as part of a tailored survivor consultation.¹⁴

Coordination between specialists and primary care providers

Follow-up care is often provided by a group of oncology specialists and primary care providers. This system has a number of strengths, if used effectively. Cancer screening services are received more reliably when specialists are involved, however preventive services for other medical illnesses tend to be neglected.⁴ This may be greatly improved when a primary care provider is also involved.⁴ Coordinated care between oncologists and primary care providers is essential for ensuring that all health needs are met.² Regular, effective communication strategies are crucial to the success of such an arrangement. Care plans may assist in this matter and are discussed below. Clear delineation of roles is essential. Comprehensive care means that each of the above principles (detection, surveillance and intervention) should be undertaken, however it is less clear how to optimally allocate these responsibilities in a shared care model.

Barriers to optimal care

While survivors may receive follow-up care that achieves some of these components, such as adequate surveillance for cancer recurrence, there are several reasons why survivorship care may be less than comprehensive.

Firstly, there are currently insufficient means for identifying and addressing many of the diverse issues which are crucial for cancer survivors. Review appointments are often very brief such that it may not be possible to adequately address the broad range of survivorship issues, particularly in the setting of busy clinics. This problem is compounded by the lack of sound assessment tools available to clinicians that can be administered in such an environment.

Secondly, it is often unclear to both patients and health professionals exactly who is responsible for follow-up and how it should be provided. Although both oncologists and primary care providers are usually involved, the system is fragmented and it is often unclear who is accountable for each of the components of care, resulting in unmet needs

for cancer survivors or being lost to follow-up.² Even when these roles are delineated, primary care providers may not have adequate training in survivorship issues, and are generally unable to rely on communication and advice from specialists.²

Thirdly, although attempts are being made (eg. American Society of Clinical Oncology guidelines),¹⁵ there is a lack of evidence to guide the frequency and content of review appointments. Existing guidelines are generally limited to detecting recurrence and second cancers and are not always readily available to clinicians. Furthermore, there is a lack of evidence for recommending self-care strategies to manage treatment side-effects.¹⁶ Intervention research to date has focused almost solely on limited health promotional strategies, particularly exercise programs and the reduction of physical side-effects.^{11,17} Further evidence-based support for psychosocial treatments would greatly improve their recommendation and uptake. The IOM report also recommended the development and testing of strategies to improve both physical and psychosocial outcomes.²

Recommended strategies to promote ideal survivorship care

There is much work to be done to improve survivorship care. The IOM report made several recommendations, most of which are directly adaptable in an Australian setting. Several priority areas and strategies have been identified to implement the above principles.

Clinical guidelines for follow-up

It is clear that there is a need for long-term continuous follow-up for cancer survivors. The IOM report suggested that progress had been limited in terms of evidence-based guidance for providers of survivorship care and recommended the development of “evidence-based clinical practice guidelines, assessment tools and screening instruments to help identify and manage late effects of cancer and its treatment.”² Such guidelines would include ongoing, repeat assessments and would assist clinicians with the management of the complex range of survivor issues, ensuring that any changes to health, cancer or non cancer, are detected at a time when treatment or intervention is most likely to be effective.¹²

Screening and management of psychosocial issues

In addition to routine physical screening, there is a need to screen all cancer survivors for distress and unmet needs, and to identify mechanisms for matching these needs to interventions and other treatments. Tailoring interventions to the level of distress experienced may further improve psychosocial outcomes and efficient use of health resources.¹⁸ Work, finances and other social difficulties should be discussed, and referral pathways developed, to assist survivors to manage these issues.

Education and training

There is a need to incorporate survivorship issues into the training of all health professionals, and to upskill the current workforce. Educational opportunities should be provided to better equip health professionals to address

the physical and psychosocial issues pertinent to cancer survivorship.² Awareness of the medical and psychosocial needs that may follow cancer treatment will ensure that appropriate assessments are completed and available interventions employed. In combination with a system of increased accountability for follow-up, this strategy may enhance clinician confidence to identify and manage survivor issues directly, rather than allow patients to be lost in a system of referrals.

Survivorship care plans

Central to overcoming the communication barriers in survivorship care, the IOM report recommended that all patients completing primary treatment should be provided with a comprehensive care summary and follow-up plan, written by those who coordinate oncology treatment.² Such a medical summary would include all diagnosis and treatment information, as well as details regarding any toxicities and complications experienced.⁴ The care plan should also include recommendations regarding frequency and duration of follow-up, as well as a schedule for appointments, particularly if a shared care model is applied. It would also include information on strategies to deal with current consequences of cancer and its treatments, strategies to remain well and a list of available support services. The care plan is intended for the cancer survivor as well as their GP and all other specialists. A structured care plan has the potential to significantly improve communication between specialists and primary care providers, who often must rely on patient recollection and understanding of their care. There is widespread support for tailored care plans from survivors, nurses and physicians, although further investigation is required regarding their preparation and implementation.^{7,19}

Conclusion

Cancer survivors require ongoing follow-up care that focuses on prevention and detection of new cancers and recurrent cancer, surveillance for cancer spread, recurrence or second cancers, interventions for consequences of cancer and its treatment and coordination between specialists and primary care providers. The delivery of survivorship care is currently inconsistent and fragmented, with many survivors reporting unmet needs and being lost to follow-up. Survivorship care needs to be patient-centred, flexible, tailored to individual needs, cost-efficient and sustainable. Currently, there are several barriers to achieving this, including poor communication, unstructured follow-up schedules, lack of clarity around roles and responsibilities, and a deficit in evidence-based strategies to address the range of issues faced by survivors. Further development of new initiatives such as care plans, screening tools, education and training programs, and the development of evidence-based guidelines are crucial to improving the care that can be provided to this vulnerable population.

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