

CANCER SURVIVORSHIP: RESEARCH PRIORITIES AT THE NATIONAL AND INTERNATIONAL LEVELS

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Abstract

With an increasing number of people living with and beyond a cancer diagnosis, research addressing the needs of this population has consistently been identified as one of the key priorities for a global survivorship agenda. Within an international context, US, UK and Canada have been key players in priority setting activities, with the consistency across these nations lending support for a global survivorship research agenda. Priorities identified include: development of tools and instruments for use in survivorship research; development of effective care models and interventions; investigation of long-term effects of cancer diagnosis and treatment on patients, their families and caregivers; and needs and characteristics of unique or disadvantaged populations. An overview of the research being undertaken in Australia suggests a high level of congruency with international priorities, with a wide spectrum of research addressing issues across the whole survivorship continuum. However, support is needed for further work to progress our understanding of survivorship issues within an Australian context, particularly in the areas of unique populations, lifestyle factors and effective care models.

A brief scan of international survivorship research priorities

Due to advances in early detection and treatment, the number of people living with and beyond a cancer diagnosis is growing annually and it is imperative we increase our understanding of the unique needs of this population. Research addressing the health and life of a person with a history of cancer has consistently been identified as one of the key priorities for a global survivorship agenda. The Institute of Medicine's seminal report, *From Cancer Patient to Cancer Survivor: Lost in Transition*,¹ includes among its 10 recommendations, three specific to survivorship research. First is a recommendation to increase support for survivorship research, including research initiatives focused on patient follow-up to help guide effective survivorship care. The second relates to the development of evidence-based clinical practice guidelines for survivorship care and the third, to the development and implementation of measures of quality of survivorship care.¹

From an international perspective, the US, UK and Canada have been key players in guiding current research priority setting activities. Following is a brief overview of the survivorship areas identified for priority research from these three countries.

From the US

In recognition of the large number of individuals now surviving cancer for long periods of time and their unique and poorly understood needs, the National Cancer Institute established the Office of Cancer Survivorship (OCS) in July of 1996. Since its inception, the OCS has spearheaded major funding initiatives geared towards the stimulation of research on long-term cancer survivorship.

The mission of the OCS is to enhance the quality and length of survival of all people diagnosed with cancer and to minimise or stabilise adverse effects experienced during cancer survivorship. This is accomplished through: a variety of funding mechanisms; liaisons with researchers health professionals and the public to build common research agendas; and through assistance to the National Cancer Institute and other organisations concerned with the educational, medical and supportive care needs of survivors.

The OCS conducts and supports research that both examines and addresses the long and short-term physical, psychological, social and economic effects of cancer and its treatment among paediatric and adult survivors of cancer and their families. As well as supporting exploratory levels of research, the OCS is seeking to expand its research portfolio to include descriptive and analytical studies documenting the physiologic, psychosocial and economic effects of cancer and its treatment on survivors, as well as intervention studies to develop and test new strategies to prevent or reduce adverse outcomes and promote optimal health and well-being after cancer treatment.

Currently, the OCS has identified a number of priority areas.² These include:

- understudied cancer sites, such as colorectal, lung, and head and neck
- health disparities in cancer survivorship among minority or disadvantaged populations
- the impact of cancer treatment, and the sequelae of cancer survivorship on family or caregivers
- economic outcomes relating to the impact of survivorship on work and financial status

- access to, and the impact of, patterns of care on the morbidity and mortality among survivors
- research addressing healthy lifestyle and behaviours such as those affecting cancer risk, promoting well-being and improve health and surveillance practices
- communication initiatives aiming to develop educational and training programs for cancer survivors and their families and friends, and exploring the information needs of cancer survivors
- development of instruments for assessing needs and health-related outcomes suitable for use with long-term cancer survivors, which permit cross-comparison with healthy or chronically ill populations.

From the UK

In 2008, the Department of Health and Macmillan Cancer Support launched the *National Cancer Survivorship Initiative*. A think tank event, Making the Cancer Survivorship Agenda a Reality, attended by a wide variety of stakeholders including researchers, consumers and research funding organisations, highlighted that survivors of cancer have a range of physical, psychological, social, spiritual, financial and information needs. The think tank identified the following as priority areas:

1. Research

Further extensive review is required to inform and improve the future assessment and outcomes for patients, including service planning and commissioning. Activities incorporated into this work stream will include:

- prevalence modelling
 - determination of the natural history for each site specific cancer
 - linking of databases and cancer registries to enable healthcare analysis
 - systematic review of existing survivorship literature
 - cohort studies
 - methodology for evaluating new service models.
2. Survivorship care plans and testing and evaluating new service approaches.
 3. Expert patient program - evaluation of new and existing approaches to care.
 4. Late effects of treatment.
 5. Management of active and progressive disease.
 6. Survivors of childhood, adolescent and young adult cancer.
 7. Work and finance.

A summary report of the think tank is available.³ Seven work streams were subsequently set up to look into the health care services and support available and how these may be improved, extended and adapted to best serve the needs of survivors. The research work stream is working to bring together partners, representatives of other cancer charities, researchers and consumers in

order to identify the knowledge gaps and define the future research agenda.

From Canada

Most recently, an environmental scan of cancer survivorship across Canada recommended identifying topics for a national research agenda as a key priority for cancer survivorship research.⁴ The Canadian Partnership Against Cancer, an independent organisation funded by the Federal Government to accelerate action on cancer control, determined priorities in survivorship through a comprehensive approach which included an invitational workshop held in March 2008 involving 84 participants, around one-third of whom were cancer survivors. The workshop identified seven priorities for a Canadian survivorship agenda, one of which was research, including the development of stronger collaborations across institutions.⁵

A second workshop held in November 2008 focused on advancing the research agenda and included attendees from community treatment agencies, community-based organisations, academic institutions, policy oriented organisations and cancer survivors. Importantly, funders were invited to be involved in the planning process. An iterative process was used to prioritise unanswered questions in survivorship research identified by the participants. In total, 30 priorities were agreed from an initial pool of 250 questions identified by participants as unanswered at this stage. Strategies to address each of the priority areas were then developed.

The top five priorities identified for cancer survivorship research were:

- measurement and development of relevant and appropriate tools for use in survivorship research (seen as underpinning all the other research priorities)
- effective care models across a range of issues
- effective interventions across a range of issues
- mechanisms underlying long-term effects of cancer diagnosis and treatment (including behavioural, psychological and physical effects)
- needs and characteristics of unique populations.

Strategies recommended to address these priorities are outlined in detail in the report of the workshop.⁶ However, some overarching themes which were seen as important for the advancement of these priority areas included:

- identification/collation of current knowledge and further refinement of key areas of investigation
- targeted funding for survivorship research
- forging partnerships across institutions to encourage collaboration between researchers/clinicians, and multidisciplinary/multi-site research
- access to clinical trials data and establishment of clinical trials groups for survivorship.

A key outcome of the workshop was identification of the need for a coordinated program of research incorporating translational aspects, to ensure best practice is implemented in the long-term.

It was recognised that the difficult task ahead was to maintain the momentum of priority setting and create action in advancing the identified priorities. While future work in this area is characterised by opportunities as well as barriers, national recognition for the importance of research in cancer survivorship is at an unprecedented level, with major funding bodies for cancer research in Canada having embraced survivorship as a key priority.

Australia: punching above its weight in addressing survivorship research priorities

International cancer survivorship research priorities and current focus areas reveal a high level of consistency across the main players involved, lending support for a global survivorship research agenda. It is vital that Australian research is congruent with such an agenda, and that the research being funded helps to address the identified priorities.

Survivorship is recognised as a critical issue in most Australian cancer plans, sometimes implicitly, at other times explicitly. For example, the *National Services Improvement Framework for Cancer* states a guiding principle behind the framework is that cancer care should span “the continuum of care and life course for the condition – embracing where required prevention, screening, diagnosis, management, rehabilitation, living with the condition and palliation”.⁷ In its conclusion regarding management and support after and between treatment, it states: “The absence of research about good practice, guidelines for service provision or data about current practice in Australia illustrates the relative lack of attention outside the treatment context. There is an urgent need for increased research data and the development of organised and co-ordinated approaches to care.”

To date, there have been no integrated Australian efforts to develop a survivorship research agenda. Individual researchers have conducted a wide spectrum of research on survivorship, ranging from qualitative to epidemiological research, addressing issues across the survivorship continuum. These have included studies on the:

■ **Meaning of survivorship**

A number of qualitative studies have been conducted identifying the subjective experience of cancer survivorship. For example, concepts of liminality, hope and awareness of death as central themes to the survivorship experience have been identified.⁸ Liminality is a state of being on the “threshold” of or between two different existential planes. In one study,⁸ an initial acute phase of liminality was identified, marked by disorientation, a sense of loss and of loss of control, and a sense of uncertainty, followed by an adaptive, enduring phase of suspended liminality, in which each patient constructs and reconstructs meaning for their experience.

■ **Unmet needs and distress in survivors and their caregivers**

Several Australian research groups have developed and validated measures of unmet needs for survivors and their carers,⁹⁻¹¹ and documented the nature,

prevalence and severity of distress and unmet needs in cancer survivors.¹²⁻¹⁶ Australian research funded by the National Health and Medical Research Council and Cancer Council NSW is underway, exploring the impact of cancer over the first five years post-diagnosis, for cancer survivors and for their partners/caregivers.

■ **Fear of recurrence**

Several groups have documented the prevalence of fear of recurrence in cancer survivors. For example, in one study fear of recurrence was reported as the most common unmet supportive care need in a large cohort of patients in NSW, concurring with the results of many other studies.¹⁷ Australian research funded by the National Breast Cancer Foundation is underway, exploring the prevalence, predictors and outcomes of high levels of fear of recurrence.

■ **Long-term side effects of cancer treatment**

Australian groups are working on the prevalence, causes and intervention to improve long-term side-effects of cancer treatments, such as cognitive dysfunction after chemotherapy,^{18,19} lymphoedema²⁰⁻²³ and infertility.^{24,25}

■ **Occupational and insurance issues in survivorship**

Work in occupational and insurance issues has been undertaken both in the context of those at high risk of cancer,²⁶ and those who have been diagnosed with cancer.²⁷

■ **Lifestyle interventions to improve survival and quality of life**

Several groups have explored the relationship between lifestyle factors, such as exercise and diet, and outcomes for people with cancer.^{28,29} Studies evaluating interventions to increase exercise in cancer survivors are underway in Queensland²⁹ and NSW.

■ **Models of follow-up care**

There is increasing interest in survivorship care plans and follow-up in the Australian context,^{15,30-31} with studies underway piloting interventions to improve these.

■ **Supporting patients with advanced cancer**

A small number of Australian studies have investigated strategies to support and inform patients with advanced cancer and manage their pain.³²⁻³⁵

■ **Needs of specific populations**

Australian studies have explored the needs of specific populations experiencing cancer survival, such as migrants³⁶ and rural patients.³⁷ Other studies have explored patterns of care in Indigenous patients,³⁸ but without a specific focus on survivorship.

Conclusions

The above summary highlights that the research currently undertaken nationally is well within the scope of survivorship research priority areas identified internationally. However, further work is needed to progress our understanding of

survivorship issues within an Australian context, particularly in the areas of survivorship issues in unique populations, the influence of lifestyle factors and behaviours on the health and wellbeing of survivors, and flexible and cost-effective models for providing survivorship care. Studies in these areas are underway in Australia and these need to be supported.

While it is important that our national research agenda assists in advancing our knowledge and understanding of issues faced by cancer survivors in an Australian context, it is imperative that research priorities are guided by those identified through international priority setting activities.

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