

# CANCER SURVIVORSHIP – LESSONS FROM AROUND THE GLOBE

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## Abstract

The discipline of cancer survivorship has evolved as a result of the concerted effort of survivors, supported by clinicians and researchers aiming to address the unmet needs of survivors resulting from cancer and its treatment. Nearly 30 years later, there is much to celebrate, but still much to be done. Delivering quality cancer care to survivors is not just about delivering good cancer care, but rather improving overall health care for the growing numbers of people affected by cancer. Ensuring that care is evidence-based, cost-effective and adaptable to different health settings remains a constant challenge in the continually changing health care environment. International collaborations have potential for strategic advancement of the field through data sharing, priority setting and large scale research initiatives to make a lasting impact at the population level.

It is hard to believe that the field of cancer survivorship is nearly 30 years old. Its birth can be dated to the seminal publication by Fitzhugh Mullan, *The Seasons of Survival*, published in the *New England Journal of Medicine* in 1985.<sup>1</sup> Mullan, a physician and a cancer survivor, reflected on his and others' experience of cancer survival and the resulting unmet needs of survivors, and called for a "coordinated national research enterprise in the area of cancer survival". It was then that the term 'survivorship' was used for the first time, referring to the experience of survival commencing from the time of the diagnosis and having distinct biomedical and psychosocial dimensions. The article was a call to action articulating next steps needed to be taken by the cancer profession and survivors themselves. Only a year later, it was followed by Mullan convening a small group of 25 individuals in Albuquerque, New Mexico. This meeting led to the creation of the National Coalition for Cancer Survivorship, which has been instrumental in the development and progress of survivorship ever since. These events were indeed revolutionary and visionary – at the time cancer advocacy was still in its infancy, and it had only been 30 years since the first use of chemotherapy and just over 10 years since the declaration of the 'war on cancer' by President Nixon in 1971.

This paper examines key developments in cancer survivorship care and research across the globe from the perspective of how they may impact on and inform care and research in Australia, with particular emphasis on challenges that are best addressed by international efforts and the opportunities for international collaborations. It is outside the scope of this paper to offer a systematic

review of all advances in the field, but rather it will focus on those that are most pertinent to the Australian setting and to the question of how survivorship care and research in Australia relates to the global effort on cancer control.

## Beginnings – consumer voice in action

Cancer survivorship is the only field of oncology which originated to a significant extent as a result of concerted effort of survivors themselves and their plea to the cancer profession to acknowledge, recognise and address significant challenges experienced as a result of cancer and its treatment. As cancer treatment outcomes continue to improve and survival rates rise, this plea is only gaining in significance. In the US, the establishment of the National Coalition for Cancer Survivorship has led to the creation of the Office of Cancer Survivorship at the National Cancer Institute in 1996, which has since provided a strategic approach to the care and research relating to cancer survivorship. To this day, one of the key drivers in the area of survivorship is through the Livestrong Foundation, which has been instrumental in collecting data on unmet needs of survivors, developing minimum standards and advocating for their adoption. The foundation has supported innovative approaches to care delivery and research through research funding and support of the Livestrong Survivorship Centres of Excellence.<sup>2</sup> While originating in the US, the reach of Livestrong Foundation extends beyond the US, with support of the Global Cancer Summit in Dublin, Ireland in 2009, and establishment of connections with similar organisations around the globe. Likewise in other countries, for example the UK, the major support for survivorship initiatives originates from

MacMillan Cancer Support – one of the largest charities in UK dating back to 1911. Unlike other aspects of cancer care, cancer survivorship has not been primarily driven by oncologists focused on the biomedical model of care and research, but rather cancer clinicians and researchers representing diverse disciplines including psychology, sociology and health services research.

The origins of the field of survivorship may explain some of the challenges that the discipline is facing today. It is possible that its origins from outside of the traditional domain of oncology, have led to its relatively slow integration into mainstream oncology. For some cancer clinicians, survivorship as a field can be an uncomfortable reminder that their well-intended efforts to eradicate cancer may have undesirable consequences. For many, addressing undesirable consequences of cancer and its treatment requires skills in general medicine, psychology and care coordination, which are not necessarily embraced equally by all oncologists. As such, survivorship not only came to oncology from outside, it forces oncology to reach out in order to reconnect with the outside world – the world of community and primary care and general medicine – in order to gain the expertise required to address the problems that survivors grapple with.

## **Price of success – managing growing demand**

While the beginnings of the survivorship movement and its impetus from consumers have largely focused on the recognition of unmet needs of survivors, the practicalities of delivering survivorship care on a large scale have identified additional drivers for change relating to the capacity of the system to manage growing numbers of survivors. At present there are approximately 14 million survivors in the US, two million in the UK and about 32.5 million globally, with the majority representing breast, prostate and bowel cancer survivors. As the numbers increase exponentially, in the setting of a limited cancer workforce, the question that is being asked is will the cancer health care system have the capacity to deliver care to survivors within the acute cancer service?<sup>3</sup>

This concern was not a major issue at the initial stages of development of survivorship care, where the discipline was the domain of selected expert centres and maybe less so in the US, where a national approach to health care delivery is more limited than in other countries. In the UK, the issue of meeting demand within the limited capacity has been recognised from the outset as part of the national strategy for cancer. This recognition led to the development of risk stratification approaches and a focus on enhancing self-management strategies for those survivors considered low risk.<sup>4,5</sup> The recognition of growing demand has led to exploration of how survivorship care can engage with primary care providers for delivery of care for cancer survivors, an approach that

is yet to be wholeheartedly embraced by cancer survivors themselves.<sup>6</sup>

## **Models of care delivery – one size does not fit all**

The delivery of survivorship care in the context of cancer and overall health care of an individual is operationalised differently across clinical settings, depending on the predominant models of care and reimbursement, and the drivers that influence them. In the US, where the fee for service predominates and the cancer care models include comprehensive cancer centres, the Survivorship Centres of Excellence and the large academic centres are the mainstay of innovation in the area of survivorship care. The delivery of so-called essential elements of cancer care is very much dependent on creation of a reimbursement structure that supports care delivery.<sup>7</sup> Having said that, the recent introduction of the Affordable Healthcare Act and the movement to capitation payment is likely to lead to a change to this model. In the UK and Canada, with their universal public health care system and high level of reliance on primary care, there is greater scope to deliver care as part of general practice, although the details on how that can be done are yet to be defined. Within these different health systems, a range of models of care are emerging, including nurse-based follow-up clinics, one-off consultation by specialist physicians and shared care with primary care and others.<sup>8,9</sup> To date, little data exist on which of these is more appropriate. What is likely, is that different models may best fit different contexts. A common theme emerging from all models is the inclusion of a treatment summary and a survivorship care plan. Although the content of the survivorship care plan can vary dramatically. Interestingly, the American Society of Clinical Oncology has moved from a very detailed template to a simplified two-page template, while the UK has managed a one page patient-driven care plan. More importantly, there is little data on their utility or cost effectiveness.

## **The challenge – the diversity of survivorship experience**

While there is a wealth of information regarding survivorship care in the US, the UK, Canada and few other developed countries, notably the Netherlands and Scandinavia, in many parts of the world cancer survivorship is not identified as a distinct entity or priority. There are many reasons for this, including less developed advocacy networks of consumers, and greater priorities for immediate cancer care delivery. For example, in parts of Europe where the profession of medical oncology remains unrecognised and where access to cancer drugs is the key priority, cancer survivorship may take second stage. There are only limited data on approaches to care of cancer survivors in low and middle income countries. Again, this may reflect conflicting priorities, limited resources, or other considerations.

It is not only low and middle income countries where the progress in survivorship is lagging behind. There is scarcity of data on the needs of cancer survivors in disadvantaged communities within developed countries with otherwise excellent survivorship credentials. In a recent provocative paper, the survivorship experience has been described as if seen through the lens of ‘breast cancerisation’ – positive, successful and breast cancer focused, an experience far removed from the reality of the majority of cancer survivors.<sup>10</sup> In fact, survivors themselves have been struggling with the construct of survivorship – many uncomfortable with the term ‘survivorship’ and challenged by the medicalisation of their experience, where the development of survivorship care as a distinct discipline creates the concept of a new disease, that of being a cancer survivor.<sup>11</sup>

All of which raises a question of whether survivorship should be managed as a distinct entity within the specialised field of cancer medicine. Many problems that survivors identify are not unique to those treated with curative intent, but rather represent a more personal dimension of living with cancer (neither Mullan, nor the National Coalition for Cancer Survivorship definition of cancer survivor draw a distinction between survivorship as applying in the curative setting and after the treatment has finished, but for practical reasons of service delivery, many service providers apply this distinction). Furthermore, nearly half of cancer survivors die of other causes, emphasising the importance of good general medical care outside of oncology as fundamental to good survivorship care. The shift to delivery of survivorship care by primary care providers aligns with these considerations, but many issues regarding how best to deliver care in the primary care setting are yet to be addressed.<sup>12</sup>

The issue of the chronic illness and survivorship interface deserves particular attention. Firstly, because cancer may be considered a chronic illness and strategies for managing it require skills in chronic illness management, including building self-management capacity, health promotion and care coordination, which are not yet incorporated into models of care. Secondly, many cancer survivors suffer from other health problems. Data from Medicare beneficiaries in the US (i.e. for patients 65 years or older) indicate that more than 90% of patients with cancer have at least one other chronic condition and approximately a quarter have five or more.<sup>13</sup> Given that management of co-morbidity is a major health priority for many health care systems, management in the context of cancer survivorship is an important, yet relatively unexplored area.

### **Survivorship research – need for strategy and collaboration**

Similarly to diversity of survivorship care, there is a rich diversity of survivorship research, both in terms of scope and quality. The research output is growing exponentially

and there are now opportunities for dedicated research funding in this field. Most importantly, survivorship research is increasingly integrated into existing cancer research programs. For example, in early 2014, the European Organisation for Research and Treatment of Cancer convened a meeting to identify priority areas for survivorship research and considered how data from existing trials could be used to contribute to survivorship research. But gaps in research remain. Its scope remains polarised in the direction of psychosocial research, with less work being done in pre-clinical, laboratory and biomedical research related to survivorship. Similarly, little high level evidence exists on utility of diverse models of health care delivery, implementation research relevant to different clinical contexts, and health economics of survivorship care.

A recent UK study reported the results of a scoping analysis of survivorship research from the last 20 years, concluding that there was paucity of data on later phases of survivorship, most of the evidence was derived from breast cancer studies and there was limited data on rehabilitation and self-management.<sup>14</sup> The authors offered a priority list for future research, which included focus on where research findings have a high likelihood of being ‘implementation ready’ in a reasonable timeframe and where existing groups with strong track record already exist. They proposed the following as examples of such priority areas: large-scale prospective cohort studies that sufficiently describe needs of long-term survivors and to predict those most at risk; robust randomised trials of well-specified ‘delivery ready’ interventions and research to determine the most effective and efficient ways to organise care. The second aspect of their recommendation – the existence of the established research group, underscores the fundamental importance of growing national and international collaborations in the area of survivorship to take advantage of collective knowledge and skill, but also to develop a strategic approach to research planning and priority setting. One area where international collaborations would be of great value is that of registries and clinical databases, where international comparisons would be valuable.

### **Next 30 years – the journey continues**

As we enter the next 30 years of survivorship care and research, there is much to celebrate. And there is much to be done. Delivering quality cancer care to survivors is not just about delivering good cancer care, but improving overall health care of the growing numbers of people affected by cancer. Ensuring that care is evidence-based, cost-effective and adaptable to different health settings remains a constant challenge in the continually changing health care environment. The journey continues.

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