CANCER SURVIVORSHIP – AN OVERVIEW

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The number of people living after a diagnosis of cancer has grown with increasing rates of diagnosis, improved treatments and better supportive care. While more people are treated and live longer, many experience poorer general health outcomes, higher rates of comorbidities and complex late or long-lasting effects of their treatments. How the healthcare system, healthcare professionals and the broader community can work together to support those affected by cancer to achieve optimal health outcomes for the duration of their lives is a salient question.

There has been substantial development in the field of ‘cancer survivorship’, particularly since the Institutes of Medicine landmark report, Lost in Transition, was released in 2006. This report documented the poorly coordinated follow-up care of people completing primary treatment for cancer, with the healthcare and community support systems failing to meet their needs. In the intervening decade, cancer survivors and their caregivers have heard about new models of survivorship care proposed, late effects of treatment being given prominence and research into interventions to reduce the burden on survivors being increased. While we are still far from providing evidence-based care for all aspects of survivorship, things have improved for many. This edition of Cancer Forum presents a series of articles articulating the state of cancer survivorship in Australia and work to improve psychosocial and cancer outcomes for those living after a diagnosis of cancer.

Consumer and community voice

The first three articles in this Forum, befitting increased holistic care, are from cancer consumer advocates and a community-based organisation. There are differing experiences across the cancer survivor community, but a strong common drive to achieve optimal health.

Chapman shares his personal cancer experience and journey to wellness, articulating the principles of self-management and empowerment that helped him to thrive rather than just survive. We can learn much from these experiences to guide our thinking in developing strategies to engage and empower cancer survivors to seek the support they need at different times during their follow-up care.

Marker challenges all of us to understand the disruption and dislocation a cancer diagnosis brings to many individuals, families and communities. She highlights the gaps in knowledge and care for cancer survivors, with many struggling to access resources to better support them in adjusting to life after cancer. However, it is not all bad news. She also describes some important initiatives and areas for future development in supporting cancer survivors to live better.

Community-based organisations play an important role in supporting individuals and bringing community focus to cancer. Miller and Tang detail how the community and not-for-profit sector can be integrated into the cancer care team and community. Those reading this article will be rewarded with a greater understanding of how this sector works and the plethora of services provided to patients, caregivers, and survivors.

Collectively, these three articles demonstrate the complexity of how cancer survivorship is defined. The US National Coalition for Cancer Survivorship recognises the broadest definition of cancer survivorship: ‘An individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life.’ Family members, friends and caregivers are also impacted by the survivorship experience. While this broad definition is embraced by some organisations and individuals, from a policy and operational perspective the more common practice continues to define cancer survivorship from the completion of primary anti-cancer treatment. These differing definitions of cancer survivorship are apparent throughout the articles included in this issue. Marker, and Miller and Tang, referring to survivorship from the point of diagnosis, while Agar et al use a nuanced definition that includes people living long-term with incurable cancers, and others again refer to the survivor as the patient in the post-treatment phase. No one definition is right or wrong, rather the differing usage reflects the complexity of defining the experience of being diagnosed and living with a cancer diagnosis. We must always to remember that people impacted by cancer live with the disease, they do not become it.

International and local developments

As discussed above, the field of cancer survivorship has evolved due to the combined efforts of survivors, health professionals and researchers. The strong drive to address the needs of cancer survivors advances these
initiatives. Koczwara articulates the successes, challenges and strategies for improving survivorship care from an international perspective. Her insightful comments regarding the impact of these international developments work in the Australian context.

**Screening and support in survivorship care**

Girgis et al address the issue of screening cancer survivors for psychosocial needs and late effects of treatment. One of the challenges to implementing routine screening has been doing so efficiently, while ensuring the needs of survivors are appropriately managed where concerns are identified. Girgis and colleagues outline the framework used and their experience developing a patient-reported outcomes monitoring system within the NSW electronic medical record system. There is no doubt that their efforts will pave the way for greater integration and efficiency in the future.

While many people live for relatively long periods after their cancer diagnosis, we know a sizable proportion experience poor health and side-effects of cancer and its treatments. Agar et al remind us of the value of palliative care health professionals in achieving excellence in survivorship care. Their role in this context is underexplored; this timely article challenges survivors and healthcare professionals to recalibrate their bias toward palliative care and consider its role in supportive care for cancer survivors.

**Interventions to assist survivors**

The high rates of unmet needs and poor general health outcomes among cancer survivors have seen a rapid growth in the development of interventions to address these concerns. This issue includes three articles detailing research that aims to address three quite distinct survivorship concerns.

Fear of cancer recurrence is one of the most distressing unmet needs reported by cancer survivors. For many, such fear is a lifelong worry that ebbs and flows around the time of follow-up appointments and anniversaries, however for some it is intrusive and debilitating. Butow et al provide a review of the research into fear of cancer recurrence and detail an ongoing Australian randomised control trial, Conquer Fear, of a psychological intervention designed to address this concern.

People surviving after treatment for head and neck cancer commonly experience a high burden of treatment sequelae that seriously impede their ability to re-engage with their pre-cancer lives. Turner provides details of another ongoing Australian randomised control trial, ENHANCES, evaluating a tailored survivorship intervention in this population. Actively addressing the complex needs of head and neck cancer survivors using an intervention with a strong theoretical base is likely to provide lessons for other complex cancer scenarios.

The third in this set of articles is from a group of exercise physiologists, a profession that is a relative newcomer to the cancer healthcare team. Cormie and colleagues provide a detailed review of the evidence for exercise and cancer survivorship, something about which we will all have to learn. They also go on to describe the gaps in knowledge and translation of research findings into practice. There is no doubt that exercise has an important and increasing role to play in improving the outcomes of cancer survivors.

**State of play**

The growing international movement to improve follow-up care among cancer survivors is also evident in the Australian oncological community. In 2012, the Clinical Oncology Society of Australia (COSA) established a Cancer Survivorship Group to promote the concerns of survivors, their caregivers, and health professionals regarding the challenges of delivering high-quality care to cancer survivors, given their high level of morbidity and ongoing health concerns. Commitment from Australian healthcare professionals to improving the experience of cancer survivorship is clear from the number and range of individuals participating in this initiative, as well as in the varied projects underway around the country.

In the past 12 months, three major conferences have been hosted in Australia with a deliberate focus on cancer survivorship. COSA and the Union for International Cancer Control ran overlapping survivorship-focused conferences in December 2014 in Melbourne. These organisations brought together the diverse professionals working in the cancer survivorship field to celebrate what has been achieved, while inspiring the profession to greater achievements in the future.

The third conference was the Flinders Cancer Survivorship Conference, held in Adelaide under the auspices of the Flinders Centre for Innovation in Cancer, in February 2015. This Australian conference is unique, seamlessly involving cancer survivors, community organisations, healthcare professionals and researchers in robust discussions of how survivorship care can be implemented, the ongoing research and reflections on the future.

COSA led a national discussion among its members regarding a model of survivorship care suitable for the Australian healthcare system. COSA’s Model of Survivorship Care was launched at the conference and is now in a process of active stakeholder consultation. The model incorporates the concepts of recovery and wellness as being core to optimal cancer survivorship. At this point, the model focuses on services provided to people after completion of their primary cancer treatment...
– it by no means diminishes the impact of a cancer diagnosis on the family and friends of the individual, nor does it diminish the importance of addressing the physical, psychosocial and existential challenges confronting many people from the point of cancer diagnosis. Rather it is an acknowledgement of our limitations, that we cannot be all things to all people.

In order to achieve a national strategy for cancer survivorship that includes research, it is important to articulate a specific problem and how it can be addressed. The Victorian Department of Health Services Cancer Survivorship demonstration projects are an excellent example of policy that supports implementation of novel models of care. Cancer survivors, healthcare professionals and the system need more targeted support to undertake this work using an evidence-based approach.

We hope that this Forum provides readers with an insight into the diverse and active world of cancer survivorship in Australia. We have a wealth of active consumer advocates, dedicated health professional, and some of the leading researchers in this field among us. While much needs to be done to support cancer survivors, we have the drive and skill to achieve this.

References