

Cancer survivorship care at the time of the COVID-19 pandemic

During the pandemic, cancer survivors are lost in transition

In 2006, the United States Institute of Medicine published a seminal report entitled “From cancer patient to cancer survivor: lost in transition”,¹ which articulated the unique challenges faced by cancer survivors after completion of treatment. The report has since informed the delivery of survivorship care in many countries including Australia.² The emergence of the coronavirus disease 2019 (COVID-19) pandemic has now presented cancer survivors with new challenges, but also new opportunities to improve their care.

The pandemic has changed lives overnight, bringing a collective sense of grief, lack of control and fear of the unknown — feelings very familiar to those who have lived through cancer. The Australian health care system has quickly stepped up to develop a framework for rational planning of cancer care. Guidance on how to prioritise cancer treatment has been developed.³ Telemedicine was adopted to reduce face-to-face consultations. Patient resources conveyed a consistent message of “we are here for you”.⁴ Although many challenges remain, such as access to clinical trials, in general, acute cancer care in Australia seems like business as usual.

However, those who have completed their acute cancer treatment were not explicitly included in the new care delivery framework. Many survivorship care planning visits were cancelled as “not time critical”. Perhaps appropriately in the context of a crisis, these consultations were the lowest priority to maintain. Cancer survivors can experience psychological distress, persistent symptoms, and difficulties managing comorbidities. These may be appropriately managed in primary care; however, survivorship care has not necessarily been transferred to the primary care system, which has faced the same pandemic challenges. Somewhere along the way, cancer survivors were again lost in transition.

While there are valid reasons for this re-prioritisation of acute cancer services, the omission of planning for cancer survivors raises a question as to whether acute cancer services are best positioned to lead the delivery of care for cancer survivors in Australia. Not every cancer survivor needs rigorous follow-up but how do we decide who does? And what is the optimal way of doing so? Cancer survivors face significant challenges compared with the general population, and many of these are likely to be amplified in the context of the pandemic. They are more likely to suffer from chronic diseases such as cardiovascular disease, chronic pain and depression.⁵ They may not adhere to healthy lifestyle recommendations and may find adherence problematical in the context of social distancing.⁶ They are more likely to be unemployed and financially vulnerable.⁷ These concerns may be neglected during the pandemic, with potentially undesirable



consequences. Equally, these issues may not be well managed within acute cancer services and may require a complex approach, not easily delivered in a primary care setting. Perhaps survivorship care belongs somewhere in between, such as a special interest of internal medicine, similarly to palliative care?⁸ There is a pressing need for data on long term outcomes for cancer survivors that include not just cancer recurrence and survival but also long term non-cancer mortality and morbidity, to inform selection of appropriate care pathways.

For survivors who maintain contact with their health care provider, this is now delivered by telephone (or less frequently video) conference. The pandemic has allowed us to move to rapid implementation of technology that enables safe contact and avoids parking costs.⁹ It is hard to imagine going back to the old models of care. But in the haste of moving to telephone and online options, we have given little attention to engaging patients to see whether this approach is acceptable and achievable; that the survivor has a telephone line or internet access, and the skills to connect effectively. Like any other intervention, telephone or video consultation requires appropriate informed consent based on consideration of the merits of each option. Further, it has been assumed that health care providers have the skills to effectively navigate an online consultation without training. While this approach may be acceptable as a short term crisis intervention, training (and outcome monitoring) is needed to ensure a quality online consultation process that is effective and sustainable.

Telephone or online consultations should not be a band-aid substitute for a face-to-face consultation. It is important to identify what matters to patients and providers during the consultation and what modality delivers an optimal experience and outcome at a particular phase of a cancer trajectory. Telehealth may be of particular value for long term survivors, where the focus is less on cancer surveillance and more on transition to normal life. Digital technology

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potentially offers some exciting opportunities, such as shared online consultations allowing simultaneous engagement with the specialist and the primary care provider, allied health specialist or multiple family members in diverse locations. These options are not new, but before the COVID-19 pandemic there were limited drivers, including reimbursement, for their adoption. The pandemic has forced a fundamental rethink of health care delivery, presenting a once in a generation opportunity to consolidate and refine the content, method and appropriate use of these technologies in health care in general and in cancer survivorship.

Technology can also enable systematic collection of patient-reported outcomes that can be initiated by patients themselves.¹⁰ What online and telephone consultations cannot deliver is a physical examination, raising the question as to whether some examination parameters can be obtained using wearable devices that monitor vital signs and behaviour indices. The possibilities of technology are enormous but their development requires planned implementation and monitoring of outcomes well beyond the COVID-19 pandemic.

It is also worth reflecting on how dependent this technology is on the self-management capabilities of cancer survivors and the broader implications of this shift of control over care from the health care system to the patient. What in the past has been traditionally driven by the health care provider, for example exercise programs delivered face-to-face by an exercise physiologist or physiotherapist, has suddenly been replaced through necessity by walking or gardening — less technical but more feasible. Some of the face-to-face interventions for delivery of allied health support have transitioned to online and are likely to remain so well beyond the pandemic. A motivated and technologically aware survivor can now

access support from the local service or from across the globe — an international oncology community has shared many free professional services available to patients, ranging from exercise physiology in Canada to psycho-oncology counselling for Chinese-speaking patients in Hong Kong. However, there is currently no simple way of verifying the quality of these services, and the Australian Health Practitioner Regulatory Agency mandates that all services should be provided by a practitioner registered with the Agency. While the pandemic offers innovative ways for global connection, we are yet to find simple ways of ensuring that services that survivors can access are credible and safe.

The COVID-19 pandemic offers a unique opportunity to consider how we deliver value in survivorship care. Monitoring morbidity and mortality data now and over forthcoming months will shed light on the value of follow-up of cancer survivors. We have opportunities for global data collection where outcomes can be compared across different health care settings. Population-based data from the global financial crisis of 2008 showed that economic downturn closely correlated with mortality for curable cancers, presumably owing to lack of uptake of treatment.¹¹ To date, there is little knowledge regarding the impact of such major disruptions on the outcomes of cancer survivors. At this unprecedented time, as we all experience the feelings so familiar to cancer survivors — fear for the future and lack of control — let's channel these feelings to address some of the most pressing challenges of survivorship care to ensure that no person with cancer is ever lost in transition.

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