

At the time of the pandemic cancer survivors are getting lost in transition.

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***The Medical Journal of Australia* – Preprint – 29 May 2020**

In 2006, the US Institute of Medicine published a seminal report entitled “From Cancer Patient to Cancer Survivor. Lost in Transition” [1] which articulated 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 2020 COVID19 pandemic has now presented cancer survivors with new challenges, but also new opportunities to improve their care.

The pandemic has changed lives overnight bringing on the 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. Guidelines how to prioritise cancer treatment were developed. [3] Telemedicine was adopted to reduce face-to-face consultations. Patients resources conveyed a consistent message of “we are here for you”. [4] While many challenges remain, such as access to clinical trials; in general, in Australia, acute cancer care seems like business as usual.

But 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. Problems faced by cancer survivors can include psychological distress, and symptoms and comorbidity management that may be very appropriately managed in primary care. But survivorship care has not necessarily been transferred to the primary care system, facing 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 care delivery 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 to the general population and many of these are likely to be amplified in the context of 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 problematic 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 the acute cancer services but may require complex approach, not easily delivered in a primary care. 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 those survivors who continue contact with their health care provider, this contact is now delivered by phone (or less frequently video) conference. The pandemic allowed us to move to rapid implementation of technology that enables safe contact and avoids the dreaded parking costs. [9] It is hard to imagine going back to the old models of care. But in the haste of moving to phone/online; we have given little attention to engaging the patient to see whether this approach is acceptable *and* achievable i.e. the survivor has a phone line/internet to connect *and* the skills to do that effectively. Like any other intervention, phone or video consultation requires appropriate informed consent that considers merits of each options. 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 quality online consultation process as effective and a sustainable.

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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 optimal experience and outcome. The digital technology potentially offers some exciting new opportunities such as shared online consultations allowing simultaneous engagement with the specialist and the primary care provider, or an allied health specialist, or multiple family members in diverse locations. Technology can also enable systematic collection of patient reported outcomes that can be initiated by the patient themselves.[10] What an online/phone consultations cannot deliver is a physical examination; raising a question 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 require planned implementation and monitoring of outcomes well beyond the pandemic.

It is also worth reflecting on how dependent this technology is on the self-management capabilities of cancer survivors and what are 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 physiologists or a physiotherapists, have disappeared overnight and was 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 stay well beyond the pandemic. A motivated and tech savvy survivor can now access support from the local service or from across the globe – an oncology community has shared may free professional services available to patients ranging from exercise physiology in Canada to psychooncology counselling for Chinese speaking patients in Hong Kong. But 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 an Australian based

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practitioner. 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.

This 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 the light on whether follow-up of cancer survivors makes much difference. 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 had shown that economic downturn closely correlated with mortality for curable cancers presumably due to lack of uptake of treatment. [11] To date, there is little knowledge as to 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 – the fear for the future and the lack of control - let's channel these feeling to address some of the most pressing challenges of survivorship care so no person with cancer is ever lost in transition.

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