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Editorial

Survivorship research for people with metastatic or advanced cancer: A time for action



Over recent decades, survival outcomes for people diagnosed with cancer have changed dramatically, with approximately 20% improvement in five-year relative survival rates in high-income countries including the United States and Australia. Regardless of regions, there is a decrease in overall cancer mortality rate of about 1% per year. Likewise, the cancer disease trajectory has changed. The traditional linear cancer trajectory in which a patient moves from cancer diagnosis through to a binary outcome (cure or death)—is no longer applicable and does not adequately describe the complexity of experience for many people. Indeed, the availability of targeted therapies and immunotherapies has meant that people diagnosed with cancers once rapidly fatal in the advanced or metastatic stages, such as prostate, breast, ovarian, melanoma, myeloma, and non-small cell lung cancer, are now being treated over relatively long periods of time with treatments that slow the progression of their cancer, prolong life and control cancer symptoms.¹ However, despite the ability of these novel therapies to extend life, most patients with an advanced or metastatic cancer diagnosis will never be cured. For these patients, cancer is often a chronic and complex illness that is, often unpredictable and requires ongoing monitoring, treatment, care, and support.

Over the years, there has been considerable debate about the definition of survivor, who counts as a survivor and whether it even matters.² We strongly suggest that it does matter. The way we label, categorise, and define people with cancer determines who is included in survivorship research, and ultimately, who will benefit from improved care.³ Many researchers, clinicians, and organisations acknowledge the historically inclusive definition of survivor as an individual from the time of cancer diagnosis through the balance of his or her life. However, in practice, the operationalised use of survivor typically refers to those post-treatment. In doing so, a large proportion of people with cancer are tragically omitted from survivorship research and dedicated survivorship services, as people with advanced or metastatic cancers may never complete treatment. An opportunity has been missed to build the evidence base necessary to inform the development of meaningful guidelines and much-needed survivorship services appropriate to the needs of those with advanced or metastatic cancer.

One author (ALS; a cancer health services and implementation science researcher) knows first-hand that gaps in services for those living long-term with a metastatic cancer diagnosis exist, and that these gaps can be directly traced back to the lack of focus on people living with advanced cancer in survivorship research. Having been diagnosed with *de novo* metastatic breast cancer in 2016, ALS did not have access to a breast care nurse for the first six months of her treatment, despite there being several breast care nurses at her cancer centre. Similarly, she was informed that it *'would not be inappropriate'* for her to attend the cancer

centre's supportive care workshops as they were designed for people with early breast cancer. And finally, having completed six months' cytotoxic chemotherapy, but facing a lifetime of treatment to keep the cancer under control, she was told she was ineligible to enrol in the diet and exercise supportive care survivorship program run by the state-based cancer organisation as she had not completed active treatment. ALS is glad to report things have changed at the cancer centre and at the cancer organisation since then; however, many more recent or current examples continue to exist.

There is a certain irony in the under-representation of people with advanced or metastatic cancer in survivorship research and services. One of the original drivers of the survivorship movement was Dr Fitzhugh Mullan's resistance to 'the dominant view that there are two different paths for people diagnosed with cancer: a path for those who are cured, and a separate path for those who are not. In his view, there was one path for people diagnosed with cancer, that of survival, dominated by dealing with the physical and psychological effects of diagnosis and treatment'.² If the point of the survivorship movement was to draw attention to the immediate and ongoing care needs of those with cancer, then the time has come for those working in cancer survivorship research and care delivery to pay greater attention to those with perhaps the most significant survivorship needs. It is no longer sufficient to argue that their time is limited, and that their needs can be met by palliative care services alone.

Adjusting to a diagnosis of advanced or metastatic cancer is challenging. Adjustment means dealing with prognostic uncertainty, the capricious disease trajectory, the unpredictable chronic versus acute nature of the disease and the ever-present existential threat. It requires the patient to make frequent treatment-related and lifestyle-related decisions (to work or not? access your superannuation (or pension fund) or not? disclose your diagnosis with whom and when?), to deal with financial hardship, and to cope with the complex interplay of side-effects, late-effects, and long-term effects of current and past treatments. In addition, it has been reported that many people with advanced or metastatic cancer 'feel alienated and misunderstood by their oncologists, their families, and their communities because no one is quite sure how to navigate this place where cure is not an option'.⁴ Thankfully, the tide is turning. Consumers, advocacy organisations and clinicians who have experienced first-hand the challenges of supporting those with an advanced or metastatic diagnosis are calling out for urgent change.^{1,3,4}

Until recently, despite concerted efforts, advocates of those with advanced or metastatic cancer have struggled to gain traction or generate sufficient momentum to improve funding for research and care delivery in advanced and metastatic survivorship. A critical factor was the challenge of defining and quantifying this sub-population. A

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recent, major advance has arisen in the UK, through the work of Macmillan Cancer Support in defining and quantifying those living with cancer as a long-term illness. They have proposed and rigorously defined, with input from consumers and stakeholders, the term treatable but not curable as being the 'sub-group of people with cancer who, although ultimately their cancer is very rarely cured (eradicated completely), have the option to receive treatments that can slow the progression of their cancer, prolong life and control symptoms'.¹ Through an innovative data linkage project they have recently estimated that there are between 100,000 and 200,000 people living with treatable but not curable cancer in England, representing 8% of England's total cancer population.¹ They have identified the most prevalent treatable but not curable cancers to be prostate, breast, colorectal, lung and haematological cancers.

Call to action

Greater diversity and inclusivity within the field of cancer survivorship research is urgently needed so that everyone living post-cancer diagnosis gets to benefit from the resulting guidelines, models of care and survivorship services, not just those who are post-treatment and ostensibly 'cured'. We agree with Mollica et al on the five broad priorities to address evidence gaps in 'epidemiology and surveillance, symptom management, psychosocial research, healthcare delivery, and health behaviours'.⁵ In addition, we propose specific efforts as areas of priorities for the cancer nursing, cancer survivorship and supportive care communities for consideration:

- Reach a consensus on the terminology to define this emerging and significant population; currently, terms such as 'advanced and metastatic' or 'chronic cancer' can be troublesome as they can evoke nihilism on one hand, or complacency on the other
- Continue to find innovative ways to use existing data sets to quantify the size of this population, as well as to understand patterns of symptoms, issues and concerns, longitudinally
- Prioritise a portion of cancer research funding to those living with advanced and metastatic cancer, in particular managing advanced and metastatic cancer as a long-term illness
- Recognise the complexity of the supportive care needs of those with advanced or metastatic cancer, including the early, late- and long-term effects, and their often extensive psychosocial and practical needs
- Develop research that investigates effective mechanisms of support and advocacy in relation to the needs of those living with advanced or metastatic cancer
- Optimise clinician-patient communication relating to discussion of prognosis and the reality of the diagnosis and the limitations of what the clinician can accurately predict
- Optimise care coordination and supportive care across oncology teams, palliative care teams, primary care providers, cancer charities, non-government organisations, and family and friends
- Optimise self-management support taking into consideration unique needs of people with advanced or metastatic cancer and their carers.

While those providing clinical cancer care are increasingly recognising this important subgroup of people, more research is required to further enable a greater appreciation of the issues and needs that individuals experience. Appropriate interventions and models of care urgently need to be developed to address such needs. Furthermore, there needs to be continued generation of knowledge and data to measure improvements in patient outcomes (e.g. quality-of-life and overall survival) and patient experiences. The key to survivorship is not only how long, but also how well, patients live. The time has come for survivorship research to move beyond the rhetoric to generate actionable findings that will result in improvements in care for those patients grappling with how to live well with incurable cancer.

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Declaration of competing interest

None declared.

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