

ROLE OF PALLIATIVE CARE IN SURVIVORSHIP

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Abstract

There is consensus that survivorship care should be integrated, risk or needs stratified, individualised, coordinated and multidisciplinary. But further research is needed to determine the service models that can best deliver optimal outcomes in the most cost-effective way. Model heterogeneity and diversity is needed to address issues that are disease, treatment or symptom specific, and account for other modifying influences such as comorbid illness and lifestyle. Further work is needed to determine the key elements within models of care configured to support cancer survivors that positively influence outcomes, and how these elements can be best delivered across a diverse range of care settings. In the meantime, adopting a needs based approach to care at the individual patient level will ensure that those in most need have access to relevant support and care from specialist palliative care services. Fortunately, current Australian health reforms provide a climate of plasticity and innovation that is conducive to the paradigm shifts required.

Increasingly, people diagnosed with cancer are living longer as a result of early diagnosis, more advanced technology and the advent of more targeted treatments.^{1,2} The survival rate for many common cancers has increased by 30 per cent in the past two decades, with two thirds (66%) of people diagnosed with cancer alive five years after their initial diagnosis.¹

But, in reality, does cancer survivorship include those where the goal or outcome of treatment is not complete cure? While it could be considered paradoxical to integrate palliative care principles into survivorship care, we would argue that it is not, because palliative care can and does include care to people with potentially curable cancer. Moreover, we suggest that specialist palliative care brings particular expertise that, in some cases, is not readily available from other cancer services. The purpose of this paper is to describe the potential role of specialist palliative care in the provision of supportive care for cancer survivors.

Defining survivorship

While survivorship has been variously defined, it has generally come to be accepted that a 'cancer survivor' is someone who has been diagnosed with cancer and is still alive.⁷ For many cancers there is no longer a clear 'post-treatment' period or specific time-point where cure can be declared. Treatment advances mean that many people with overt or covert disease may even remain relatively well for many years.¹⁴ The survivor population is essentially composed of three sub-populations: people

who have been effectively 'cured' and are disease free; people living with recurrent disease; and those who have been living with cancer from the time of diagnosis and are either undertaking curative treatment, undergoing active monitoring, or living with incurable disease.^{15,16}

Care needs of cancer survivors

Across the cancer survivor sub-groups, there are many similarities in the physical, psychosocial and economic sequelae faced.¹⁴ These include impacts on employment and activities of daily living, physical symptoms, psychological distress, and need for support by family carers.¹⁴ Many cancer survivors also share an ongoing need for health services to provide them with information, monitoring and supportive care.

Importantly, as the patterns of cancer survival change in response to new treatments, and for specific tumour types such as haematological malignancies, there often is uncertainty about prognosis and projected future needs, such that patients, families and providers cannot predict what type or duration of services patients will need.^{17,18} While many people who have completed treatment will remain disease free, they will require ongoing support to manage disease recurrence fears, long-term treatment side-effects and a range of co-morbidities.¹⁹ The diversity of these needs necessitates input from a wide range of disciplines with appropriate expertise to address them.²⁰

We argue that, while the population and underlying intent of treatment may differ, the same key competencies

and skills are required to deliver excellent survivorship, supportive and/or palliative care. Indeed, in some situations, specialist palliative care may bring particular expertise that is not readily available from other services. This view is aligned with the elements outlined in definitions of both survivorship and supportive care. In its broadest definition, supportive care has been defined as: “The provision of the necessary services for those living with or affected by cancer to meet their informational, emotional, spiritual and social, or physical needs during their diagnostic, treatment or follow-up phases, encompassing issues of health promotion, survivorship, palliation and bereavement.”²⁰ In turn, the essential elements of survivorship care have been identified as: 1) prevention and detection of new cancers and recurrent cancer; 2) surveillance for cancer spread and recurrence, or second cancers; 3) intervention for the consequences of cancer and its treatment, including symptoms such as pain and fatigue, medical problems such as lymphedema and sexual dysfunction, psychological distress for either cancer survivor or caregiver, and concerns about employment and return to work; and 4) coordination between primary care and specialist providers specifically involving survivorship care, but also including health promotion, immunisations and care of concurrent conditions.²¹

How palliative care can help

Contrary to popular belief, palliative care has an established philosophy that aims to help people focus on ‘living with’ rather than ‘dying from’ progressive advanced illness.²² As eloquently articulated by the palliative care pioneer, Dame Cicely Saunders: “We are there to help people to live as fully as they can within the confines of their illness, until natural death occurs.”²² This philosophy is reflected in the World Health Organisation (WHO) definition of palliative care as “an approach that improves the quality of life of patients and families who face life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”²³

Importantly, palliative care has expanded from purely delivering care in the last days of life, to care that is appropriate much earlier in the disease trajectory. This development is reflected in the most recent WHO definition (2002), which emphasises that palliative care is “...applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.”²³ While many palliative care services already provide care for people who have potentially curable cancer, there is a need to ensure that all services are responsive to the needs of other populations, such as cancer survivors who may benefit from specialist palliative care input. Barriers for

access to specialist palliative care include service models being limited by prognosis-based referral criteria, funding models and community myths about palliative care being only appropriate for those who are imminently dying.

Designing models of care to meet the needs of 21st Century Australian cancer survivors

For the last decade, specialist palliative care services have been encouraged to adopt a population-based approach to care, but the lack of strong policy drivers means that many services continue to provide a model of care shaped by prognosis as opposed to need. Just as palliative care services were reluctant to extend care to people with non-malignant disease due to restrictive funding models and for fear of being overwhelmed by clinical demands which could not be met with existing resources, the same could be said for extending care and support to cancer survivors, another population with unmet needs.

Despite these barriers, there are numerous opportunities to successfully integrate palliative care principles and access to this skillset across the various essential elements of survivorship care described above. Achieving this integration requires the development of novel models of care or reorientating services to be focused on integration, earlier timing and services tailored to address unmet need.²⁴

Like palliative care, survivorship care needs to be patient-centred and responsive to patients’ needs, and is underpinned by good communication, information sharing and the encouragement of patient participation.²¹ Successful models need to recognise that supportive care needs fluctuate over the course of anti-cancer treatment and beyond.²⁵ Where cancer is incurable, these needs will tend to increase over time, but fluctuations may still continue.

Internationally, definitions of ‘palliative care’ versus ‘supportive care’ lack clarity,^{20,26} presenting an opportunity to influence vocabulary and concepts to optimise the client-centredness and continuity of cancer care. One argument has been that use of the term ‘supportive care’ throughout the disease trajectory may promote symptom management and psychosocial care across cancer stages, and encourage earlier referral to specialist services, including palliative care services if they are best placed to address the patient’s needs.^{27,28}

It is worth noting that European standards for the provision of supportive and palliative care, published by the European Society of Medical Oncology, in large part do not distinguish stages of disease and emphasise flexible and continuous care via expert multi-disciplinary care from either provider.²⁹ The society has also established a continuing care section to better integrate supportive and palliative care in patients undergoing chemotherapy.²⁹

Emerging evidence from randomised trials is also supportive of specific benefits, which may be achieved with early referral to palliative care, including improved symptom control, satisfaction with care, quality of life and possibly improved survival.^{6,30-32} There are several hypotheses as to how these benefits are mediated, which include improved symptom control (including management of anti-cancer treatment related symptoms and toxicities), provision of counselling, greater social support, improving illness understanding and assistance with treatment decision making.⁶

Survivorship programs need to determine minimum standards that allow routine screening for physical and psychological symptoms and adequacy of social support, treatment of physical symptoms with best evidence approaches, access to psychological and spiritual care for the patient and their family, and ongoing care planning considering the benefit/burden of any treatment strategy.²⁰ Supporting people to remain in the community and to effectively manage their symptoms depends on clinicians partnering and building strong collaborative relationships with patients and their caregivers to promote self-management, which lies at the core of community palliative care services.

Self-management is a person-centred paradigm referring to a person's ability to manage the consequences of living with a chronic condition, including treatment, physical, social and lifestyle changes.² An essential

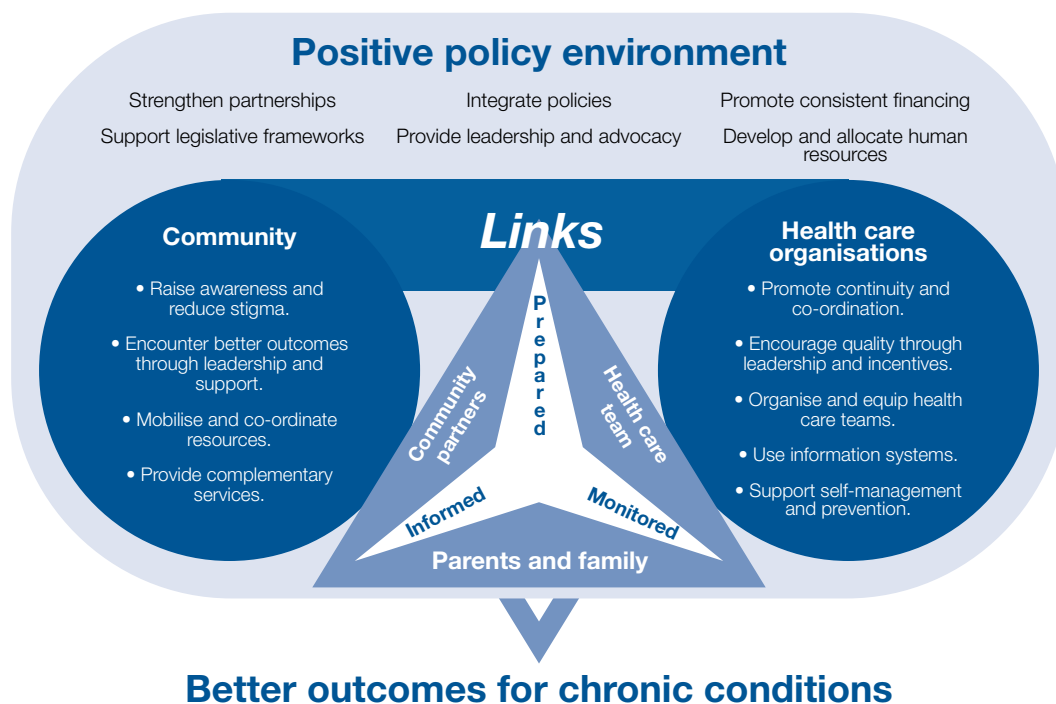
element of effective self-management is building strong collaborative relationships with patients and their family caregivers.³ Interventions for supporting self-management are well established for other chronic diseases like arthritis and diabetes, but are relatively nascent for cancer. One example where these principles are clearly applicable is in cancer pain management,⁵ where patient self-management and education can be particularly effective.

Increasingly, the benefits of a chronic care framework are being recognised for people living with cancer and its consequence (figure 1).³³⁻³⁵ The key principles of this framework are that patients are empowered to self-manage in the community and that services are configured around the patient and their individual needs rather than around specialty and disciplinary silos.³⁵

The American Society of Clinical Oncology has instigated a survivorship task force to develop guidelines focused on supportive and palliative care issues important to survivors, such as fertility preservation and cardiac and pulmonary late-effects.³⁶ It could be that Australia should consider similar initiatives aimed at better integrating expertise to meet patient needs.

Consideration also needs to be made for when patients are no longer able to attend a tertiary centre for ongoing care, and in this context palliative care is making ongoing progress in developing flexible, rapid response models

Figure 1: World Health Organisation's (2002) Innovative care for chronic conditions framework.



Source: World Health Organisation's *Innovative care for chronic conditions: Building blocks for action*. 2002. Geneva (p48).³⁵

of care in the community, especially at the end of life.³⁷ But integrating palliative models of care or services which are configured around the patient in the community with secondary and tertiary cancer services represents a particular challenge.^{38,39} Moreover, specialist palliative care services as they are currently resourced and configured, would struggle to cope with providing care to people with cancer across the disease trajectory, without some clear planning around better matching resources with patient need and targeted service enhancements.

Re-orientating services

While a variety of evidence-based models exist for integrating generalist and specialist care for people with advanced cancer, fewer are available for earlier in the disease trajectory or for supporting disease-free survivors.⁴⁰ Designated oncology and palliative care specialist nurses already play a key role coordinating care and providing education to patients/caregivers and primary healthcare professionals.⁴¹⁻⁴⁵ There is considerable scope for these nurses, along with the growing number of cancer and palliative nurse practitioners and practice nurses, to play an even larger role in supporting cancer survivors to manage their persisting symptoms, disabilities and to provide psychosocial support. Models that provide sequential oncology-palliative care, oncology-based supportive/palliative care or concurrent care from different providers, all have potential to deliver high quality care.^{38,46} Coordination, communication and clarity of roles are the keys to success.^{47,48} In addition to the need for good evidence that these new care models are effective and address the unmet needs of cancer survivors, policy reform supported by funding acceptance of such models by other clinicians providing survivorship care, and a willingness from consumers to engage with palliative care services while they identify as being a cancer survivor, will be required to embed these models into palliative care practice.

Although communication technology can undoubtedly facilitate multi-disciplinary healthcare, especially in rural and remote areas, a 'virtual' working environment may present psychological barriers to collaboration.⁴⁸ Online and/or patient-held medical records have important potential to support the integration of care between different services and settings, however an evidence-base is lacking.⁴⁹

While there is much hope that palliative care and other cancer services can work together to provide care for cancer survivors in the future, challenges exist. Barriers or stigma to accessing or referring to palliative care services remain, and these may be stronger deterrents when the patient has less advanced disease.⁵⁰ Different philosophical perspectives between palliative care professionals and those in oncology can exist – for example regarding the point at which cancer directed

treatments becomes medically futile.^{51,52} Fundamental to all survivorship programs will be the ability for all specialties and disciplines to consider how patient and family needs are best served by integrating available expertise, which will require in some cases creation of new interdisciplinary relationships and breaking down of silos.^{53,46} In taking this work forward, the elements of specialist palliative care which may offer most value add to survivorship programs are summarised in box 1.

Box 1: Elements of specialist palliative care which may offer most value add to survivorship program.³

- Promoting communication and collaboration between specialist, primary care and community providers.
- Contributing to systematic care planning and negotiating treatment goals based upon a multifaceted assessment of physical, psychological, social and spiritual needs (which degree of contribution varying dependent on disease status).
- Integrating evidence-based, palliative non-pharmacological and pharmacological interventions for specific symptoms (including cancer pain, cancer treatment-related pain, breathlessness fatigue), and maintenance of function/activities of daily living.⁴
- Supporting self-management approaches.⁵
- Supporting patients and their families in making decisions and care planning.⁶
- Assisting in modifying interventions to better suit the patients' needs (for example exercise program for someone with more advanced illness⁸⁻¹¹, lower limb lymphedema treatment).¹³
- Contributing to the ongoing robust evaluation of models of care.
- Flexibility in location of care delivery (allowing continuity of care if the person is no longer able to attend the hospital clinic or survivorship centre, in-reach into residential care).

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