Inquiry into End of Life Choices

August 2015

Introduction

The VHA welcomes the opportunity to contribute to Legislative Council’s Legal and Social Issues Committee “Inquiry into End of Life Choices”. The VHA agrees to this submission being treated as a public document and being cited in any reports that may result from this consultation process. This submission will focus on the health sector’s perspectives in relation to the Terms of Reference:

1. How current medical practices and palliative care can assist a person manage their end of life;
2. How this issue is managed in other Australian and international jurisdictions; and
3. Potential changes to our legislative framework.

How current medical practices and palliative care can assist a person manage their end of life

What is Palliative Care?

At least half of all deaths annually in Australia are related to advanced disease, and are clinically expected. Palliative care is derived from the Latin word meaning “to cloak”, or to protect, and much of the focus of palliative care is on symptom relief and comfort. The provision of palliative care must be appropriate to a person’s needs at the right time and in the place of their choice. Despite the definition, there is a common perception that palliative care refers to the provision of care without curative intent, and it is this concept that can make the initiation of palliative care difficult for healthcare professionals, patients and patients’ families to accept. Palliative care teams report that palliative care can be perceived as “giving up”, as there is poor understanding of the role these teams can play in symptom management. Regardless of perceptions, palliative care must be available to all who require it, irrespective of location, income, age, social and cultural background, diagnosis or prognosis.

There are many factors in Australia that influence access to services and choice of care. Rising rates of chronic disease, the changing needs and expectations of society, an ageing population and increasing survival rates from previously un-survivable injury and illness have impacted the demand for palliative care services. Workforce challenges, fragmented funding arrangements and scarce resources have made the capacity to meet ongoing demand with supply problematic. Consequently, there are population groups who often miss out.

In healthcare, end of life preferences and choices are most keenly dealt with by palliative care teams. Palliative care is commonly delivered in four key areas – inpatient sub-acute, consultancy acute services (also known as “consult”), outpatient services, and in the community. Each of these areas of practice has a slightly different focus, ranging from end of life comfort, to pain and symptom management, or prioritisation of service provision with the patient’s best interests in mind.

In order to effectively deliver palliative care, it is imperative that appropriate funding arrangements acknowledge the priorities of providing palliative care and do not overlook patient preferences. Effective palliative care arrangements exist when healthcare service consumers can access a flexible system with services close to home and a range of choices. The benefits of appropriate palliative care include better quality of life and longer survival\(^2\), and reduced costs in delivering effective care with reduced intensive care unit admissions\(^3\).

**Funding of Palliative Care Services**

Feedback from health service based palliative care experts indicates that a number of specific service areas are chronically underfunded. Specifically, consultancy services in hospitals receive little focus. Consultancy palliative care services can provide support for clinical decision making, particularly in regards to avoiding futile and costly treatment with no benefit to the patient, and has been demonstrated to provide more efficient and cost effective care in comparison to usual treatment\(^4\). This aspect of palliative care is focused on holistic patient care, particularly in regards to patient wishes and symptom management, and is not only for end of life care.

Examples of appropriate consult palliative care input include referring patients with complex medical needs requiring care from multiple medical and surgical units, where the consult palliative care team can make recommendations on consolidating medications, prioritising care, and ensuring the patient’s wishes are met with regards to clinical care and outcomes.

Other functions of consult palliative care services in acute care include the important role of education, particularly to staff, which is vital in ensuring that health services are geared towards providing holistic end of life care for patients. Education topics include communication skills, and early identification of indicators for referral to palliative care services. Consult palliative care is generally underfunded, with clinicians unable to consistently participate in unit meetings, and therefore unable to help teams to look at patient goals, which often include referral to palliative care and proper end of life care planning.

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The Value of Consultancy Services – Case Study

The structure of hospital care is such that an individual medical or surgical unit of care is responsible for each patient's admission and care based on their acute medical condition. Consultation occurs with other units external to the admitting unit when issues arise outside of the admitting unit’s expertise. This leads to delivery of care based on individual systems, and can lead to fragmented care where patients are seen through a “disease-based” lens, rather than with holistic care in mind.

Mr. Smith, a 36 year old man from rural Victoria, was admitted to a major metropolitan health service with an aggressive, metastatic abdominal tumour, for which high-risk surgery was discussed as an option. Consequently, he met with the anaesthetics team, surgical team, and nutrition and dietetics team to discuss nutrition options following the planned operation. As a result of his significant pain issues, the consult palliative care team was introduced to Mr. Smith, and all his treatment options were discussed.

Mr. Smith indicated his reluctance to under-go high risk surgery, given the impact it would have on his ability to eat and enjoy the food and drinks he truly enjoyed, and also the poor prognosis of his metastatic disease. In conjunction with the consult palliative care team, Mr. Smith’s discharge home was facilitated with access to palliative services in his home town to manage his pain, and his end of life choices were respected by the care team. In facilitating Mr. Smith’s decision, the hospital was able to avoid performing high-risk surgery, and prevent a costly ICU admission for a patient whose medical outcomes would not meet his expectations.

Community-based palliative care services are another aspect of palliative care that is considered under-funded and under-resourced. A number of different bodies are involved in community based delivery of palliative care, including hospitals and community palliative care organisations. This sector provides palliative care services to those in their own home, which is often the preferred place to receive care, and to die, for patients requiring end of life care. Additionally, receiving home-based palliative care is associated with a greater likelihood of dying at home. However, waiting lists vary significantly between services, and this can be attributed to the different ways in which services choose to deliver care, as well as the resources they are able to access.

Greater investment and appropriate funding mechanisms need to be in place to support the right care being provided at the right place and at the right time for the right person. Continuity of care depends on the integration and coordination of service and organisations involved in a person’s care. The delivery of appropriate care at the right time and place provides an effective structured framework that should allow patients to move between services (such as hospital and community based care). However, this is not viable without flexible funding that fosters collaboration and partnership. This ought to be part of the work explored by the Victorian Government’s new ‘Better Care Victoria’ body, which when established, will be tasked to drive improvements in patient care and treatment in a manner that optimises hospital capacity across the Victorian health system.

Palliative Care Workforce

Central to the delivery of high quality care is a skilled and experienced workforce. Australians and the Australian health workforce are ageing rapidly. Approximately 36 per cent of the medical palliative care workforce and over 28 per cent of the nursing palliative care workforce is aged over 55 years.\(^6\) Average ages for each profession are 51 and 47.4 years respectively. Australian government bodies have examined the impact of an ageing workforce, and recognise that an ageing workforce, compounded by general population ageing, will lead to fewer people of working age who will effectively contribute to the health workforce, as well as increased numbers of older Australians who will require greater access to healthcare services through an increased burden of disease.\(^7\)

Any shortage of healthcare professionals will have a profound impact on the composition of the specialist workforce required for the provision of quality palliative care. Palliative care in Australia is delivered by a range of professionals in a range of settings, from GPs and community nurses to large tertiary referral specialist palliative care services. A skilled multidisciplinary team is essential in providing appropriate holistic palliative care that includes medical, nursing, allied health, spiritual care, and also grief and bereavement support for families and carers. The development of multidisciplinary teams requires enhanced learning and training for clinicians and support staff so that they are able to provide the necessary physical, emotional and spiritual support for a person’s end of life care.

Further, the development of innovative workforce strategy is critical to meeting the demand for healthcare professionals in palliative care over the next decade. This strategy must clearly identify the cost and return on investment of maintaining a skilled workforce and ways to maximise the use of appropriately trained health professionals.

Recommendation:

3. Multi-disciplinary training for palliative care service provision must be embedded at all levels of education for health professionals to address perceptions, recognising appropriate referrals, and increasing confidence to discuss palliative care with patients, and to develop an appropriately skilled workforce.

Social and Cultural Barriers

Additional funding and workforce education are only part of the answer to the challenges in access and availability of choice to appropriate palliative care. Cultural change and enhanced training and education for healthcare professionals are also vital to remove the stigma of palliative care being considered equivalent to terminal care. There continues to be a lack of understanding both within the

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community and health professional groups around the benefits of palliative care being simultaneously delivered with disease-focused treatment. Consequently, the belief that palliative care is terminal care deters clients and healthcare providers from the option of early referral. However, early referral to palliative care can allow for better care management and coordination that reduces inappropriate and avoidable hospitalisation.

Adding to the complexity within the palliative care space are factors external to healthcare services. Population health literacy levels in Australia are considered to be at least “adequate” for only 41 per cent of the population. With regards to end of life choices, inadequate health literacy is likely to limit a patient’s awareness of available options and their ability to ask questions. Without these two skills, a patient’s ability to self-advocate is limited. In order for the broader population to be more involved in health care, and specifically end of life choices, there is a need for interventions and community education campaigns focusing on health literacy to empower individuals to make informed choices.

Recently there have been awareness campaigns to promote organ donation awareness, emphasising the need to register decisions and initiate discussions with loved ones to know each other’s wishes. A similar but separate campaign is needed for advance care planning (see below) to promote discussion, understanding and acceptance of each family member’s decision. This needs to occur irrespective of where in the life stage a person is – healthy and active, recently diagnosed, chronically ill, or approaching their end of life. This is particularly important because illness and incapacity can be sudden and unforeseen, leaving no capacity for care planning.

**Recommendation:**
4. Governments should support efforts to raise public awareness of the benefits of palliative care and advance care planning, noting the importance of maintaining the distinction between them. Campaigns could be modelled on those undertaken for organ donation, and should be available for a range of culturally and linguistically diverse populations.

**Advance Care Planning**

In Victoria, healthcare workers are supported to engage patients in discussions about end of life care through the Victorian Government’s 2014 Advance Care Planning – have the conversation strategy. Also known as Advance Care Directives, the strategy is underpinned by a National Framework for Advance Care Directives, which is supported by the Australian Health Ministers’ Advisory Council – the health advisory body to the Council of Australian Governments.

Advance care planning encourages individuals to make informed decisions with healthcare providers and loved ones about their future healthcare wishes, preparing for if they were to become incapable of making such decisions in future. This process involves ensuring the patient understands their illness and treatment options, the healthcare provider understands a patient’s values, beliefs and care goals, and identification of potential decision makers who may act if the patient is incapable of making decisions about their treatment.

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The discussion around future care needs at the end of life is a difficult one. There is a risk that health professionals may avoid raising the subject particularly when communication or cognitive problems also exist, or in the presence of the emotions that families experience when their loved ones are ill and possibly dying. Health professionals recognise that the conversation about end of life choices can be difficult, and identify barriers such as lack of education on the topic and confidence as barriers to their uptake.

Despite a long history of advance care planning in Victoria, it is difficult to quantify the number of people who have used such frameworks to document their end of life care wishes. However the effectiveness of such plans has been demonstrated in a number of trials, with patients much more likely to receive end of life care in accordance with their plans if an advance care planning intervention had been completed. This has been well established in residential aged care settings.

The Victorian Department of Health and Human Services is currently working in partnership with health providers to implement and embed the Victorian advance care planning strategy across health services, and this important work needs to continue.

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**Advance Care Planning in Health Services – Case Study**

A large metropolitan health service in Melbourne has undertaken an audit of the number of ACPs completed for their patients. During 2014, a total of 33,000 patients were seen, with only 45 patients completing Advance Care Plans during their admission.

A service-wide strategy on advance care planning implementation was introduced, including:

- Introducing and embedding a service-wide policy with support from executive management,
- Focusing on a "values-based" approach to Advance Care Planning, where patients outline what they consider to be acceptable and non-acceptable outcomes in relation to health, physical and cognitive performance (rather than their desire for specific medical interventions),
- Education with all staff, and
- Encouraging and providing computer permissions for nursing staff to utilise the “ACP” function of the health service’s electronic health record

Following the introduction of the strategy, 67 advance care plans were completed in the first quarter of 2015, and 83 in the second quarter, already a threefold increase on the previous year in a six month period.

The Victorian Department of Health and Human Services is currently working in partnership with health providers to implement and embed the Victorian advance care planning strategy across health services, and this important work needs to continue.

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How this issue is managed in other Australian and international jurisdictions

The VHA for some time has argued there ought to be nationally consistent legislation across all jurisdictions. In addition, information and communication technology (ICT) is an important component of strategies to support consistency of approach across health services and jurisdictions.

Role of Information and Communication Technology

Initiatives such as the Personally Controlled Electronic Health Record (PCEHR), soon to be renamed My HealthRecord (MyHR) have the potential to work across ICT systems of different sectors in different jurisdictions, to allow better sharing of assessment and treatment information of palliative care clients, including ACPs. This would avoid assessment duplication and enable clients to more easily navigate through service and treatment options. Information sharing initiatives can facilitate the growth of strong, cross-sector, multidisciplinary teams that are able to effectively manage the complex health needs of clients.

Increasing web-based information sharing strategies enables service providers to share valuable knowledge including patient information as well as effective models of practice, innovation, lessons learnt and mistakes made, which can contribute to a more efficient and effective delivery of palliative care services. However implementation of ICT strategies to support access and distribution to information will take time and needs to be well planned and well resourced. This includes the consideration of the barriers associated in the implementation and execution, such as a lack of supportive funding models. The VHA is pleased to acknowledge plans by the Commonwealth to trial opt-out access to the PCEHR in 2016-17, and looks forward to working with governments and our members to ensure that full functionality of health ICT can be realised through this and other initiatives.

Recommendation:

5. Methods to embed advance care planning approaches to care must continue to be supported by the Government in all health services, primary care facilities, and residential aged care facilities to ensure that patient centred care can be delivered in accordance with an individual’s end of life choices. Training for health professionals to communicate with patients effectively during difficult conversations ought to be prioritised.

6. End of life choices documents, such as medical Power of Attorney and Advance Care Planning documents, should be supported to link to the PCEHR and the electronic medical records of health services to avoid duplication and ensure all health services involved in patient care have access to this information.

14 2012 VHA Position Paper on Advance Care Planning.
Potential changes to our legislative framework

Legislative Matters

The provision of medical care relies on legislation in the form of the Medical Treatment Act 1988 (Vic). This assists in identifying Agents and Guardians who may act on behalf of the patient (in line with the Guardianship and Administration Act 1986 (Vic)), and outlines criteria to be fulfilled for refusal of treatment. If concerns arise regarding decisions made which are not in the patient’s best interests, under the Guardianship and Administration Act, health services can utilise the Office of the Public Advocate to access a statutory guardian in an emergency situation where an appointed Agent or Guardian is not acting in the best interests of the patient. The VHA does not have specific concerns regarding legislative matters that need to be addressed to support current practice and delivery of palliative and end of life care.

In regards to any future legislation, it is critical that the drafting related to the provision of medical services is clear and consistent.

**Recommendation:**
7. Any future legislation must be clear to ensure that health services and clinicians have certainty with respect to the legal framework and are not unduly placed at risk when delivering healthcare in a manner that meets the patient’s wishes.

Further information

Background

The Victorian Healthcare Association (VHA) is the peak body representing the public healthcare sector in Victoria. Our members include public hospitals, rural and regional health services, community health services, aged care facilities and primary care organisations. Established in 1938, the VHA promotes the improvement of health outcomes for all Victorians, from the perspective of its members.

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