

Position Statement

Quality *End-of-Life* Care – Part 1

Essential elements for quality, safety, and appropriate clinical care at the end of life

Preamble

This position statement is the first in a series of two documents, designed to guide and encourage clinicians, health planners and agencies that set and monitor standards for safety and quality pertaining to the provision of Quality End-of-Life Care (EoL Care) for patients, families, loved ones and carers. These statements will help guide clinicians who are managing issues associated with their patients' last 6-12 months of life. Some of the elements outlined would be applicable even earlier in a patient's journey, at diagnosis of a life-limiting illness.

Part 1 specifically outlines evidence-based guidance for Quality EoL Care assessment and planning. Emphasis must be placed on the individual and their specific needs, to ensure that the process enhances patient preferences and involves family, loved ones and carer engagement in the health planning and care support processes.

Part 2 will be developed over the next few months and focus on evidence-based implementation strategies aimed at delivering quality EoL Care in the setting of patient choice, where possible.

Background

The Australian and New Zealand Society of Palliative Medicine Incorporated (ANZSPM) is a specialty medical society that facilitates professional development and support for its members. ANZSPM promotes the discipline and practice of Palliative Medicine in order to improve the quality of care of patients with palliative diagnoses, and support their families.



ANZSPM members are medical practitioners. They include Palliative Medicine Specialists, doctors training in the Palliative Medicine discipline, General Practitioners (GPs) and doctors who are specialists in other disciplines such as oncology.

Introduction

Modern medicine has a long history aimed at “curing” disease and “prolonging life”. Clinicians, scientists and public health officials have been extraordinarily successful at prolonging life in many countries with advanced health systems in place; achieving major improvements in longevity for many populations. Notable exceptions have of course been in indigenous, lower socio-economic and rural and remote sub-populations. The remarkable achievements of increased longevity have also been accompanied by the creation of new patient sub-populations that are medically more complex and burdened with chronic disease and/or “advanced frailty”. Managing this EoL sub-population under the “traditional models-of-care” with a focus solely on “curative” or “life-prolonging” intent, rather than having a concurrent goal of “enhancing quality of life for patients and their families”, leaves many patients and families enduring unnecessary and prolonged suffering at the end of life. This “traditional model of care” may also leave many clinicians feeling that they are “failing” their patients. Alternative and concurrently applied EoL Care models could help with enhancing patient choice and Quality of Life (QoL) as well as increasing family and clinician satisfaction.

“...our species’ epochal success in staving off death impacts contemporary individual and communal life in ways we have yet to understand. Prolonged serious illness, physical dependence, senescence and senility are now common facts of late life. Our society and culture must factor this new normal “waning stage of life” into our expectations and plans. It isn’t easy to “die well” in modern times. Because so many treatments work, many people survive longer with several previously lethal conditions. Clinicians now talk of a patient’s “illness burden”, a term for the accumulated aches, pains and disabilities that come with diseases and the side-effects of treatment. As odd as it may sound people are sicker before they die today than ever before”

Author - Dr. Ira Byock “Best Care Possible” (Penguin 2012)

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Essential Elements for quality, safety and appropriate clinical care at the end of life
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In response to an increasing burden of chronic disease and an ageing population, there has been an emergence of new models of interdisciplinary care, termed subacute care (Rehabilitation, Geriatrics Evaluation and Management, Psychogeriatrics and Palliative Care). Geriatrics and Palliative Medicine share in common the management of patients in both acute and subacute phases of their illness episodes. In these sub-populations, a shared decision-making approach is important and it is essential that goals of care are discussed and negotiated with patients, families, loved ones and carers. However it is necessary to recognise that in the absence of consensus it is the decision of the patient (or patient's guardian or "person responsible" if the patient is "incompetent") that must prevail. It is also important that QoL be understood from the perspective of the patient. Any EoL Care Plans need to be clearly documented with appropriate and transparent outcome measures put in place, even when they involve concurrent, time-limited trials of active disease-modifying management. However, the predominant culture throughout much of our healthcare system and society in general, continues to focus on "curative" care and "life prolongation" exclusively, at almost any cost. Many clinicians, patients and their families see adopting a concurrent "palliative approach" or a referral to Specialist Palliative Care even for 'shared care' as an "admission of defeat". Instead, a referral for Specialist Palliative Care advice at the EoL should be seen as a way for patients, families, loved ones, carers and clinicians to ensure that "best care possible" is being delivered when there is natural progression of a chronic disease process. In other words - **Right Care**, in the **Right Place**, at the **Right Time**:

- **Right Care** – EoL Care that focuses on enhancing the **Quality of Life** for patients and families facing issues associated with the end-of-life.
- **Right Place** – EoL Care can often be provided in the patient's "**Preferred Place of Care**" if coordinated care and support infrastructures are put in place across clinical teams, settings and time.
- **Right Time** - in the **last 6-12 months of life** multidisciplinary and coordinated EoL Care focusing on QoL enhancement is vital and this can be given in conjunction with disease modifying treatments to achieve the best patient-centred outcomes.

Definitions

Various definitions for ‘Care Types’ need to be clarified to avoid confusion for patients, their families/loved ones, carers and clinicians facing the final phases of a patient’s illness journey. Some of these terms can be confusing if they are used interchangeably, without clarification and are not clearly focused on outcomes. These outcomes need to be measured to ensure that “best practice care” is being delivered at any time. Three areas that need clarification are:

1. Palliative Care
2. Quality End-of-Life Care
3. Specialist Palliative Care

1. Palliative Care

Palliative Care even applies to non-specialist care and is defined by WHO (2013)ⁱ as:

“...an approach to care that improves the quality of life of patients (adults and children) and their families who are facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual. Palliative care also respects the choice of patients and helps their families to deal with practical issues, including coping with loss and grief throughout the illness and in case of bereavement.”

Quill & Abernethy (NEJM 2013)ⁱⁱ suggest that Primary Level or Non-Palliative Medicine Physician delivered Palliative Care should be able to manage:

- Basic pain and other symptoms
- Basic depression and anxiety
- Basic discussions about: Prognosis, Goals of Treatment, Suffering, Resuscitation Code Status

2. End-of-Life Care

End-of-Life Care is defined:

- a) by the Health Performance Council of South Australia (2010):

“...as care provided to people who are experiencing a condition which will eventually be fatal. EoL Care can be provided by all health care professionals and is not limited to Specialist Palliative Care services. Quality EoL Care is realised when strong networks exist between Specialist Palliative Care providers, primary generalist providers, primary specialists, support care providers and the community – working together meets the needs of people requiring EoL care.”

and

b) by the National Council for Palliative Care (UK - 2006):

“...Care which helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.”

3. Specialist Palliative Care

Specialist Palliative Care is defined:

a) by Palliative Care Australia (2008) as:

“...services provided by an interdisciplinary team of specialist palliative care professionals whose substantive work is with patients who have an eventually fatal condition. Specialist palliative care services are provided in various care settings including community, home, hospitals, aged care homes and hospices and palliative care units.”

b) more specifically by Quill & Abernethy (NEJM 2013) as:

- Management of refractory pain or other symptoms
- Management of more complex depression, anxiety, grief and existential distress
- Assistance with conflict resolution regarding goals or methods of treatment: within families, between staff and families, among treatment teams
- Assistance in addressing cases of *inappropriate care that some may define as ‘near futility’*

And

c) in the New Zealand Palliative Care Glossary (January 2012)ⁱⁱⁱ as:

“palliative care provided by those who have undergone specific training and/or accreditation in palliative care/medicine, working in the context of an expert interdisciplinary team of palliative care health professionals. Specialist palliative care may be provided by hospice or hospital based palliative care services where patients have access to at least medical and nursing palliative care specialists.

Specialist palliative care is delivered in two key ways in accordance with New Zealand definition of Palliative Care.

- *Directly – to provide direct management and support of patients and families/whānau where more complex palliative care need exceeds the resources of the generalist provider. Specialist palliative care involvement with any patient and the family/whānau can be continuous or episodic depending on the changing need. Complex need in this context is defined as a level of need that exceeds the resources of the generalist team – this may be in any of the domains of care – physical, psychological, spiritual, etc.*
- *Indirectly – to provide advice, support, education and training of other health professionals and volunteers to support the generalist provision of palliative care provision.”*

d) In addition, the Society of Palliative Medicine (U.K.) states that expected deaths make up 62-83%^{iv} of all deaths and that the Specialist Palliative Medicine workforce is currently too small to be able to care for all of these patients and their families, loved ones and carers, even though this would be highly desirable. Hence, a significant part of the role of any Palliative Medicine Physician (30-50%) needs to encompass many non-clinical components including capacity building of the Generalist EoL Care Workforce (G.P.s and Non-Palliative Medicine Specialists).”

Statement

ANZSPM believes that Quality EoL Care requires both integration and coordination of our health care system and the delivery of quality, appropriate, safe, holistic care at the end-of-life. Best practice care must always include the measuring of clearly defined patient and family-centred outcomes. Palliative Care and Quality EoL care are *everybody's business*.

The Four Essential End-of-Life Care Processes

ANZSPM emphasises that some overarching principles should be applied to guide all EoL Care and these should include the following four processes:

1. **Delivery of EoL Care that is holistic and interdisciplinary in nature** that:
 - a) focuses on enhancing QoL for the patient as perceived by the patient and their family, their loved ones and carers;
 - b) is based on impeccable assessment of symptoms that include physical, cognitive, psychological, social and spiritual domains; and
 - c) includes documented Care Plans for families, loved ones and carers.
2. **Development and documentation of proactive, individualised/flexible Care Plans** that can be easily accessed by relevant treating teams across time and settings.
3. **Frequent and timely re-assessment with documentation of reviewed Care Plans.**
4. **Measurement and documentation of appropriate and agreed outcomes** –as it is essential to know that ‘quality outcomes’ are being delivered and that referral to Specialist Palliative Care takes place in a timely manner where necessary.

The Five Domains of End-of-Life Care

Further to this, ANZSPM has conducted an extensive literature review looking for major evidence-to-practice gaps in EoL Care.^{vi, vii, viii} The goal was to develop a suite of generic EoL Care Clinical Indicators with clear outcome measures focused around ensuring that EoL Care was of the quality necessary to be delivering appropriate patient and family outcomes in the last 6-12 months of life, irrespective of the EoL Care provider (Generalist or Specialist). Where desired outcomes were not being achieved then timely referrals would become a natural process to ensure “best care”. The five major domains of current EoL Care evidence-to-practice gaps that were identified are:

1. **Symptom management (holistic & multidisciplinary)** – especially focusing on pain, shortness of breath, anxiety and depression, plus managing spiritual and/or existential distress. This process should be evidence-based and include a careful search for treatment side-effects or drug interactions and putting mitigating strategies in place (e.g. proactively manage constipation, nausea, cognitive impairment, fatigue, decreased function; reduce the risks of poly-pharmacy and institute rational de-prescribing processes based on harm/burden vs. benefit in the context of a realistic prognosis).
2. **Advance Care Planning** – especially identifying patient-selected *Substitute Decision Makers*, documenting shared ‘goals-of-care’, patient preferences for treatment options and *Preferred Place of Care*, documenting appropriate Resuscitation Plans.
3. **Carer Support** – documenting a list of close family members, loved ones & carers and developing documented, evidence-based support plans for them that include bereavement follow-up plans, by use of appropriate validated bereavement risk assessment processes.
4. **Coordination and Integration of Care** – across clinical teams, care-settings and time; instituting processes for safe, easily accessible and timely Clinical Handover; Regional Registration of EoL Care and/or Palliative Care Patients – to allow for optimal tracking and coordination of care by identified care planning teams; more timely access by all treating teams (primary care and non-palliative care specialists) to Specialist Palliative Care for advice when needed. It should also include any currently applicable clinical and care planning documentation; this process must also include plans for adequate access to appropriate community pharmacy services in a timely manner (e.g. opioid and other essential EoL Care pharmaceutical supplies and appropriately skilled Home Medicines Review).
5. **Terminal Phase (last 7-10 days of life)** - timely recognition of the “dying phase” and developing documented Terminal Phase Plans to adequately manage patients in their Terminal Phase and support their families, loved ones & carers.

It is ANZSPM’s belief that any Quality EoL Care management process must include documented interdisciplinary or holistic Care Plans that cover the first four of these domains and when the “Terminal Phase” is suspected, should also include plans documented in this last evidence-to-practice gap domain for providing timely and quality Terminal Care as well.

Conclusion

ANZSPM feels very strongly that Quality EoL Care is of the utmost importance and achievable for all patients, carers and families in Australia and New Zealand. All primary care and specialist providers, patients and families should have access to Specialist Palliative Care Services in all settings when Quality EoL Care outcomes are not being achieved. All clinicians (generalist to specialist) should be able to have easy access to regular, ongoing up skilling in “best practice” EoL Care management. As life comes with a 100% guarantee of mortality, we believe that basic Quality EoL Care management should be a mandatory part of the training and periodic re-validation process for any Specialist or Primary Care Physician who is likely to manage EoL Care patients, their families, loved ones and carers.

It is ANZSPM’s firmly held belief that any Quality EoL Care management process must include documented Care Plans that cover the outlined major EoL Care evidence-to-practice gap domains.

In this EoL Care position statement we have outlined some current major evidence-to-practice gap domains for Quality EoL Care; we believe that EoL Care should be evidence-based and outcome focused.

ANZSPM believes that the five domains outlined should form the basis for further development of Quality EoL Care standards, minimum data sets, outcome measures, clinical indicators and clinician performance measurement sets to ensure “best practice and up-to-date” EoL Care is being delivered to all patients, families, loved ones and carers facing the last 6-12 months of life.

ⁱ *Strengthening of palliative care as a component of integrated treatment throughout the life course* WHO Exec Board Report EB 134/28 Dec 2013

ⁱⁱ Quill TE and Abernethy AP. *Generalist plus Specialist Palliative Care – creating a more sustainable model* NEJM Mar. 2013; 368:1173-1175

ⁱⁱⁱ *New Zealand Palliative Care Glossary January 2012*, Published by The Palliative Care Council of New Zealand, Hospice New Zealand & the Ministry of Health

^{iv} Hughes-Hallet T, Craft A, Davies C, Mackay I, Nielsson T. *Palliative Care Funding Review: Funding the Right Care and Support for Everyone*. 2011.

^v Wee B et al RACP *Palliative Medicine* 2013

^{vi} ANZSPM Clinical Indicators for EoL and Palliative Care 2010

^{vii} Lorenz K, Lynn J, Dy SM, Shugarman LR, Wilkinson A, Mularski RA, et al. *Evidence for improving palliative care at the end of life: a systematic review*. Annals of Internal Medicine. 2008 Jan 15;148(2):147-159.

^{viii} Qaseem A, Snow V, Shekelle P, Casey DR Jr, Cross JT Jr, Owens DK, et al. Evidence-based interventions to improve the palliative care of pain, dyspnea, and depression at the end of life: a clinical practice guideline from the American College of Physicians. Annals of Internal Medicine. 2008 Jan 15;148(2):141-146.