New South Wales Legislative Council
Portfolio Committee No 2 – Health

Inquiry into health outcomes and access to health & hospital service in rural, regional and remote New South Wales

Supplementary questions – palliative care

Dear Members

Thank you for the opportunity to provide a response to the supplementary questions.

As a rural Obstetrician & Gynaecologist, my exposure to palliative care has primarily been through the anticipated birth of a baby who is expected to die as a consequence of extreme prematurity or congenital abnormality and women who have terminal gynaecological cancer.

Both these situations involve a multidisciplinary approach including primary care providers such as general practitioners, palliative care nurses, general nurses, midwives, social workers and Aboriginal health practitioners.

There is no palliative care specialist or palliative care unit in the Eurobodalla.

There are palliative care nursing vacancies and no Aboriginal health practitioner.

Local staff are required in our region and need to have the flexibility of working arrangements to provide 24/7 palliative care.

Frequently volunteers are utilised to support the service.

Remote health care is unsatisfactory for palliative care except for the provision of advice to doctors and nurses.

Local palliative care providers require support to build capacity for care.

There are barriers to care including expense, inflexibility and lengthy administrative processes.

A common complaint is the failure of early referral to palliative care.

This can be overcome by medical, nursing and public education.

However, the clinical and infrastructure resources need to exist to allow early integration.

Small communities must be able to provide individualised, compassionate and personal care for the end of life as we provide for the beginning of life.

I attach three statements and references for the Committee’s information.

Yours sincerely
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Response to Health Outcomes & Access to Health and Hospital Services in Rural, Regional and Remote New South Wales

Palliative Care – Eurobodalla (Palliative Care Nurses, Community Nurses cover to North of the Wapengo Bridge Tathra/ Bermagui Road, Christopher's Road Quaama. Allied Health Services are from SERH)

Service Provision – In reach to MDH, BBH, Community Health, and RACF x 7 , Oncology Unit x 1 , Renal Unit x 1, Aged Care Package providers

Client

Currently provided by Nurse Practitioner 1 fte , Clinical Nurse Educator 0.5 , Clinical Nurse Specialist 1 fte . RN 0.5 fte. (Additional 0 .6 fte RN position to be advertised). Allied Health- Social Worker 0.5 fte. Aboriginal Health Practitioner 0.5fte –vacant

Current: 3 .5 fte

SNSWLHD Palliative Care Medical Support 0.4 fte provided by Hammond Care. After hours support to hospitals.

Eurobodalla Bimonthly visits – alternate month telehealth.

Gaps:

1. Midazolam is not on the PBS. Required for end of life. Midazolam 5mg/mL cost the consumer approx. $24 – $30 for 10 amps. Unnecessary cost at the End oflife
2. Support for Carers both in and after hours: Out of hospital Care Program does not meet the rapid response required to meet unpredicted demands of palliative patients and their carers to support a home death. It is a lengthy administrative process using valuable nursing hours, with a cost to the patient of $10 a week which is excessive when on pension. Total hours is 48 hours in total 6 weeks – don't provide hours which is completely inadequate without the flexibility to support someone after hours

1. completion of a CHOPS tool to identify if the person is eligible
2. complete a COSMOS (application for package) – wait for management approval ,
3. Open an encounter with central intake with ACC.
4. Weekly reports to the Community interchange and ACC which we have to attend if put clients are on the list

Given the whole process can take a week before a support person is in the home – there is carer confusion. This service does not meet the needs

Research

Allied Health – OT 1 fte

Existing relationship with clinicians

PERSPECTIVE / ONLINE FIRST (/JOURNAL/ONLINE-FIRST)

Reframing palliative care to improve the quality of life of people diagnosed with a serious illness

Peter Hudson, Anna Collins, Mark Boughey and Jennifer Philip

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An approach for reframing palliative care has been designed to help improve the wellbeing of people with serious illness

Most Australians can expect to die as the result of a chronic illness. The *Lancet* Commission on palliative care and pain relief estimated that annually, more than 61 million people experience chronic health conditions associated with suffering that could be significantly ameliorated through palliative care.[1] Given the increasing incidence of chronic illness, the role of palliative care, including its availability earlier in the course of an illness, will become increasingly prominent in health care across the world.[1,2,3]

Modern palliative care, originally framed as “hospice care”, began in the 1960s, with the term “palliative care” adopted from the 1970s.[4] Since then, palliative care has changed its focus from institutionally delivered hospice care for oncology patients to a broader purview encompassing care of patients suffering any serious illness from point of diagnosis and delivered at any site including home, hospice, residential aged care or hospital. There is also an increasing and proactive approach to early integration for improving quality of life.[4] This follows a robust body of evidence demonstrating the benefits of early access to palliative care for patients, their family caregivers and the health care budget.[5]

Despite this, palliative care is too often considered, in the minds of both health care providers and the public, as exclusively about death and dying, and associated with a loss of control or abandoning of hope.[6,7,8,9] This has significant negative consequences, including that many people are missing out on the benefits that palliative care can offer.

In addressing such misconceptions, we describe as a first step, the development of a framework to be used by our health service to help promote understanding of, and access to, palliative care. We also briefly highlight the definitional issues underpinning the rationale for such a framework and outline the steps required for systematic change.

Definition of palliative care and related terms

Arguably the most widely cited and accepted definition of palliative care is from the World Health Organization, which emphasises involvement of palliative care early in the illness course.[4,10] However, there are numerous other definitions of palliative care, including those created by various organisations and jurisdictions and incorporating a varied scope of practice.[11] These definitional changes are further compromised by using variable terms with different application across international settings, such as “advanced disease”, “life-limiting illness”, “end of life” and “progressive disease”. Nearly three decades after the World Health Organization first defined palliative care, we seem to be no closer to agreeing on what the term actually means.[12]

Based on a review of definitions[4] and palliative care standards in numerous countries, there seems to be a broad consensus that palliative care is:

- delivered by a suitably qualified multidisciplinary team;
- focused on quality of life of the patient and their family (including bereavement);
- holistic in nature (physical, emotional, existential and social);
- available to people of all ages and across a range of diagnoses or illnesses; and
- delivered across multiple care sites including hospital, home and residential aged care.

While there is less consensus around the precise timing for introducing palliative care, evidence suggests it should not be restricted to the final months of life (end of life). Rather, the benefits are evident for upstreaming palliative care much earlier in the illness.[5]

The implications of lack of definitional clarity

The language used to describe palliative care is important,[13] having significant implications for the care of people living with serious illness. Despite the mature, established evidence base for palliative care integration early in the course of illness (including for those still receiving curative treatment), palliative care tends to remain associated in the minds of both health care providers and the public as exclusively end of life care. This creates a failure in our health care system to present palliative care earlier in the disease trajectory as a highly beneficial holistic complementary approach. Instead, when conceived as synonymous with death and dying, there may be fear and refusal of this service by patients, resulting in poorer health outcomes.[4,6]

Should palliative care be renamed?

For the public and health professionals alike, palliative care has an identity crisis leading many to ask “why don’t we just change its name?”. The most frequently proposed change is to “supportive care”.[4] However more than 10 different definitions of supportive care have already been identified, with wide variations in focus from symptom management during cancer treatment to survivorship care.[4] It also appears that renaming of individual palliative care services may only lead to short term increases in referral rates.[4]

Thus, changing the name seems neither practical nor necessary,[2] and only likely to cause increased confusion.[4] Moreover, “Patients are not interested in the name … but in what we do, how compassionate we are, how well we communicate and whether we demonstrate concern for their relatives”.[14] While fearful of the term “palliative care”,[15] when made aware of its core activities, patients, families and community alike are keen to avail themselves of this form of care.[13] It therefore seems there are opportunities to reframe how palliative care is presented,[8] rather than overhaul what it is named. Creative and consistent approaches to the framing of palliative care are required to help health professionals describe palliative care to those who may benefit from access to this care.

There are also significant issues associated with access to specialist palliative care in Australia. Furthermore, it seems that much of the palliative care delivered is restricted to end of life care, commonly the last weeks or months. This is at odds with evidence supporting earlier integration of palliative care. A reframing of palliative care, based on its core activities and practices, simultaneously highlights the opportunity — indeed the necessity — within current resources for the delivery of palliative care to be “everyone’s business”.[5] For example, aspects of symptom relief or exploring preferences for care can be delivered by primary care teams or generalist providers. Hence, the responsibility for providing palliative care is not solely that of palliative care specialists (whose input should focus on more complex needs) but is a task of all health providers.[5] A reframing of palliative care must reflect this.

Our proposed framing of palliative care

Given this background, we sought to:

- agree on an operational definition of palliative care for use in our own clinical tertiary hospital setting;
- create a conceptual framework to underpin accessing of palliative care; and
- develop key messages that could be used by our health service and its health care professionals to describe palliative care to those who may benefit.

To achieve this, we assembled a lead group of local senior palliative care clinicians and academics to review the literature related to palliative care definitional issues along with online resources of key professional and non-government organisations in the field. We then convened a workshop comprising invited multidisciplinary health care professionals, consumers, a communications consultant, and a director of philanthropic funding. From this process, a framework evolved by consensus and was subject to further iterative development, arriving at the content for use within our hospital (Box 1 and Box 2).

Box 1

Framing palliative care and key messages

Box 2

Framework for contemporary integrated palliative care

Conclusion

Palliative care is an essential component of the goal of universal quality health coverage.[12] We have argued that a name change is not required but that attention should instead focus on how palliative care is framed. A national public palliative care education campaign in Australia is required.[17] We have set out one framework to help inform this in our own health service, in an attempt to locally influence the manner in which we talk about and conceptualise palliative care. While other models framing palliative care have been put forward,[18] we suggest our framework explicitly highlights the ways palliative care may be integrated to complement treatment intention, respond to varying prognoses, and facilitate a response to patient and family needs throughout the care process. Nevertheless, our approach has its limitations and will require subsequent work to refine and adapt it in a way that gathers further evidence and ensures it is acceptable to a broader range of health services. Importantly, application of the framework will require a response to the individual needs and preferences of patients and family carers.

While the implementation of an effective framework can open the door to palliative care, poor service experience can also close it.[2] To change the landscape, the quality of palliative care service delivery must match the promise of outcomes from consistent and evidence-based care. Naming and characterising the three access points to palliative care (Box 2) could assist in the development of a more standardised approach to entry criteria for specialist palliative care support, with triggers specific to a person's illness. Ultimately, this may foster better understanding of the minimum standard of palliative care expected from both specialist and generalist health care providers at each entry point.

Palliative care, effectively delivered, can restore choice regarding options for care in serious illness,[13] improve a sense of control and independence, and provide peace of mind that patients and families cherish.[2] When coupled with investment in public education, training, research and integration of palliative care principles earlier in an illness, the reframing of palliative care could bring us much closer to the goal of standardised high quality care for all people facing serious illness, and their families.

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AMA
Australian Medical Association

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SCHN Palliative Care

(Sydney Children's Hospital, Randwick (SCH) / Children's Hospital Westmead (CHW) / Bear Cottage, Manly)

SCHN Palliative Care consultative services (SCH and CHW) are available to support local health care providers (HCP) across NSW (includes regional, rural and remote NSW) who are caring for a child with a life limiting illness; the interdisciplinary paediatric palliative care services include Medical, Nursing, Allied Health (OT, Physio, Social Work, Child Life Therapy, Music Therapy, Bereavement Counselling), Volunteer Family Support Co-ordinator, and Aboriginal Health Worker

Due to the broad geography of NSW and relatively low numbers of paediatric palliative care patients, it is essential for specialist services from tertiary children's hospitals to be appropriately funded to provide and expand upon outreach services supporting primary care providers across the state; recognising that the local supports for children and families includes community nursing and/or community palliative care, local allied health, General Practitioners, Obstetricians (perinatal palliative care), General Paediatricians, local hospitals, NDIS care providers.

These consultative services increase local capacity in a range of different ways,

- Paediatric palliative care multidisciplinary care plans, including support for identifying family and medical goals of care
- Health care case conferences utilising different modalities: telephone, videoconferencing; face to face in some circumstances, although not currently feasible on a frequent basis due to travel distances. This can include "pre-briefs" to educate local staff on care a dying child, and advice on self-care processes.
- "Pop-up" model of care whereby the specialist paediatric palliative care service works collaboratively with local care providers and family – can be hybrid consultations with family, local HCPs and specialist PPC via telehealth.
- Individual clinician advice, support and education around specific patient care needs
- Outreach general education about interdisciplinary paediatric palliative care – limited face to face options, but these are possible periodically; other modes with videoconferencing, webinars and online learning opportunities
- In reach placement opportunities for HCPs across NSW to visit specialist paediatric palliative services in Sydney to increase knowledge and capacity, as well as promote networking and professional support
- Medical after-hours advisory service for any HCP in NSW (and ACT) to contact for advice about the care of a child with a life limiting illness (this is a collaboration of SCHN and JHCH, through NSW Paediatric Palliative Care Programme: www.nswppcprogramme.com.au)
- Death reviews with local care providers and debrief opportunities as an important component of service evaluation as well as addressing some staff support needs after the death of a child

Bear Cottage inpatient hospice facility (Manly) is available to children in NSW with a life limiting illness – respite, symptom management, and terminal care. Bear Cottage also includes an after-hours nursing advice line for families known to specialist paediatric palliative care services in NSW, with back up from the state-wide medical after hours service for paediatric palliative care.

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