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Palliative Care Needs Assessment - 2022

WentWest - Western Sydney PHN

Contents

Palliative care

Palliative care is an approach to treatment that focuses on reducing suffering and improving patient and family quality of life for those diagnosed with life-threatening illnesses (1). Palliative care is provided for those with advanced levels of disease, with little to no prospect of cure (2). The approach of palliative care treatment promotes improvements to quality of life through treatment and further prevention of pain and suffering for patients, as well as addressing other broader health contexts including spiritual, psychosocial, emotional and physical (4).

Palliative care differs from end-of-life care, which is more specific and is generally provided when a patient is likely to die in the next 12 months. To contrast, palliative care aims to increase quality of life and provide symptom treatment to assist in allowing people to live as comfortably as possible, and this can include episodic care over a longer period (3).

Importantly, within Australia's context of a growing and ageing population, the demand for palliative and end-of-life care is likely to continue to increase due to the changing demographics of the nation (1). In addition to this, increases in chronic disease rates nationally will see a continual increase in cohorts likely to require palliative care.

Palliative care is provided in a variety of health-based settings ranging from child and youth-based services, general practice, hospital settings, residential aged care facilities and other community-based services. As the demand for palliative care continues to increase, it is imperative that specialist services also increase to meet this demand and promote good quality of life for those suffering.

The NSW Health End of Life and Palliative Care Framework 2019-2024 highlights several priorities within the palliative care space including the importance of patient centred care, equitable access to care and ensuring there is a well support and skilled workforce (4).

Service demand and diagnosis

In the 2016-2020 period, the Western Sydney Primary Health Network region recorded 22,098 deaths. The top 10 causes of death during this period are detailed below (30):

Cause of death (ICD Classification)	Number of deaths	Percentage of all causes
Coronary heart disease (I20–I25)	2,417	10.9
Dementia including Alzheimer's disease (F01, F03, G30)	1,952	8.8
Cerebrovascular disease (I60–I69)	1,326	6.0
Lung cancer (C33, C34)	1,206	5.5
Chronic obstructive pulmonary disease (COPD) (J40–J44)	861	3.9
Diabetes (E10–E14)	823	3.7
Colorectal cancer (C18–C20, C26.0)	721	3.3
Breast cancer (C50)	461	2.1
Heart failure and complications and ill-defined heart disease (I50–I51)	447	2.0

Cancer of unknown or ill-defined primary site (C26, C39, C76–C80 excl. C26.0)	443	2.0

In 2019-2020, 52% of palliative care hospitalisations had a principal diagnosis of cancer. The next most frequently reporting diagnoses presenting in palliative care hospitalisations were cerebrovascular disease, septicaemia, and heart failure (10). In 2021, 66% of patients who participated in The Australian Palliative Care Outcomes Collaboration (PCOC) had a diagnosis of cancer (1).

The top causes of death in Western Sydney also align with the main presenting diagnosis for palliative care nationally, including high rates of cancer and cerebrovascular disease. This demonstrates that as the population continues to grow in Western Sydney, ongoing resources and infrastructure need to be invested into palliative care to provide quality care and support for persons affected by illness, to promote quality of life and to maintain patient dignity.

Service utilisation and barriers to access

Appropriate use of palliative care services enables community members to receive care and support to ease suffering. Survey results from Palliative Care Australia show that there are strong misconceptions in relation to palliative care, and results have also shown that the Australian population is not aware of the breadth and depth of palliative care services, and the benefits of accessing these (5). These common misconceptions can act as barriers to service utilisation in Western Sydney, and nationwide.

Palliative care services are provided in a range of settings in Western Sydney, including (6):

- Public hospital clinics at Mt Druitt Hospital
- Private hospital clinics at St Joseph's Hospital (Auburn)
- Community based services such as Silver Chain.

Whilst over 85% of Australians think it is important to consider their preferences for care if they developed a serious or terminal illness, half of all Australians have not made any actions regarding their end of life wishes, and 32% of the population have no plans in place including a will, power of attorney, advance care plan, or nominated person (5).

Estimates show that between 60-70% of Australians want to die at home, however only 14% do so (8). Increased uptake of appropriate and accessible palliative care services can help to promote and enable patient centred care.

Service system in Western Sydney

The main public hospital facility in the region is the Mt Druitt Hospital Supportive and Palliative Care Service. This 16-bed unit provides inpatient care, and outpatient clinics with a variety of services offered onsite including:

- specialist medical and nursing care
- occupational therapy
- oral health
- volunteers
- social work
- physiotherapy
- pastoral care
- bereavement
- counselling (26).

Westmead Hospital and Blacktown Hospital also provide some palliative care services.

St Joseph Hospital in Auburn has a 21-bed supportive and palliative care unit with a dedicated palliative care team including:

- A palliative medicine physician
- nurse practitioner
- hospice and palliative certified registered nurse
- social workers
- bereavement care specialists
- case managers
- chaplains
- volunteers (28).

Silver Chain Group provide community palliative care within Western Sydney Local Health District, in partnership with NSW Health. Silver Chain provides community care to allow patients to be cared for in a home setting, through the provision of 24/7 on-call access to care, as well as respite, pastoral and bereavement care and support for carers and families. This partnership began in 2017 and is to be delivered until July 2024 (27). Auburn Community Health Centre also provide community nursing services including palliative care (29).

Hospital based palliative care

Hospital based facilities are generally specialist palliative care inpatient units, such as the Mt Druitt Hospital Supportive and Palliative Care Unit. In 2019-2020, there were 86,900 hospitalisations where palliative care was provided as part of, or as the main purpose of care (10). Palliative care related hospitalisations are episodes of care for admitted patients in which palliative care services comprise a component of care given during hospitalisation. 16% of public acute hospitals in Australia had a specialised palliative care inpatient unit in 2019-20 (10).

Since 2015-16, there has also been an 18% increase in palliative-care related hospitalisations. This rate is much higher than the 5.8% increase for all hospitalisations in the same period (10).

General practice and community based palliative care

Within a primary care and community setting, GPs can provide support for patients, and offer palliative care. The true rates of palliative care being provided in a GP setting is not comprehensively understood as there is a lack of palliative care data in Australia and currently there is no nationally consistent data collection for reporting on palliative care provided by GPs (7).

Further development of the GP workforce is required, as 31% of GPs reported lacking in confidence to provide appropriate palliative care to their patients due to patient complexity, and inadequate or insufficient training and resources (9). Community palliative care services play an important role in bridging this gap and linking hospital palliative care teams and services to GPs.

GPs also play an important role in providing ongoing support and follow up for patients and can assist in the development of effective strategies and treatment plans for symptom management and psychosocial care, as well as ensuring continuity of care (9).

The Bettering the Evaluation and Care of Health (BEACH) survey collected and analysed GP data of general practice activity. The last BEACH survey conducted in 2015-16 highlighted that:

- 1 in 1,000 GP encounters were related to palliative care
- 90% of GP encounters were for those aged 65 and older
- 1.3% of encounters were recording as being with Indigenous Australians (11).

Studies investigating the role of general practice in palliative care, as commissioned by the Department of Health showed several key findings and recommendations including:

- Requirement of more resources for GPs, including those for educational and practical purposes
- There are varying views and levels of understanding of the concept of palliative care, and end of life care, which could be remedied by the introduction of a clear definition of palliative care
- GPs view in-home care as the most challenging environment to provide palliative care, however, also feel that they are not largely involved when patients are receiving hospital based palliative care
- Better integration and communication across palliative care services to allow for shared care and greater continuity of care (12).

Palliative care in residential aged care facilities

As Australia's population trends continuing towards growing and ageing, there is increasing demand for palliative care in residential aged care facilities (RACF). In 2015-16, only 9,144 residents in residential aged care facilities had an Aged Care Funding Instrument (ACFI) assessment that indicated the need for palliative care, equating to only around 4% of those

assessed. This small proportion shows an underestimation of those requiring palliative care, in addition to other concerns surrounding sub optimal palliative care in RACF contexts (15).

More recently, in 2020-21, only 1.9% of all residents with an ACFI assessment were indicated to require palliative care. This decrease in palliative care admissions is likely due to ACFI application. Funding under the ACFI is currently specifically for end-of-life care, rather than the more holistic approach of palliative care (16).

55% of palliative care related hospitalisations were aged 75 years and over, with an average age of admission of 74 years for men, and 75 years for women. Approximately only 1 in 10 palliative care hospital admissions were for those under 55 (32).

There are limited in reach services for RACF in the WSLHD region.

Palliative care workforce

There is a diverse range of health professionals who work together within the palliative care workforce including (but not limited to) general practitioners, pharmacists, palliative medicine specialists, related support staff and other medical specialists such as oncologists.

In 2020, there were 302 palliative medicine physicians and 3,798 palliative care nurses in Australia (full time equivalent), equating to around 0.8% of all specialist medical practitioners, and 1.1% of all nurses and midwives (17).

There has been a 29% increase in employed palliative medicine physicians and nurses between 2016 and 2020 (17).

Currently, national data only records information on health professionals who have a primary speciality of palliative medicine (palliative medicine physicians and nurses), despite the various other roles that work in the palliative care space (1).

Volunteers also play an important role within the palliative care workforce, through the provision of support including practical assistance and respite for carers, as well as companionship. Increasing workforce capacity through volunteers will assist in service delivery capabilities and can also act as a link to the community. Palliative Care NSW is currently implementing an NSW palliative care volunteer support initiative, focusing on the role of volunteers in terms of provision of physical, functional, emotional, psychological, social and spiritual care (33).

Medicare

There are some gaps in the Medicare Benefits Schedule (MBS) for GPs providing palliative care. Whilst there are MBS items for specialist palliative care services, there are no items for similar services provided by GPs or other medical staff who are not palliative care specialists, such as services commonly provided by oncologists (11). This also creates barriers to understanding the true prevalence of GPs providing palliative care to patients in a community-based setting. It is thought that there are more GPs working in this setting than current data shows or was previously thought (12).

Palliative medicine specialists are those who are eligible for MBS palliative care subsidies and must be a Fellow of the Royal Australasian College of Physicians who has completed the College training program in palliative medicine, or a Fellow of the Australasian Chapter of Palliative Medicine, or a Fellow of both (13). The MBS-subsidised specialist services for palliative medicine include case conferencing models and specialist consultations with patients including home and hospital visits.

In 2020-21, a total of $6.3 million was spent on MBS-subsidised palliative medicine specialist services (14).

Prescribed medications in palliative care

Prescribed medications are an important part of palliative care. Treatment of pain and discomfort is generally achieved through drug therapy and symptomatic control. 90% of prescriptions written by GPs for palliative care were for pain relief, with similar trends amongst clinicians (86%), and palliative medicine specialists (57%) (18). Throughout most of Australia during the 2020-2 period, over 90% of palliative care related prescriptions were written by GPs.

The medications within the Palliative Care Schedule can be categorised as:

- Analgesics – for pain relief
- Anti-epileptics – for treating seizures
- Anti-inflammatory and anti-rheumatic – for treating inflammation
- Drugs for functional gastrointestinal disorders
- Laxatives – for treating constipation
- Psycholeptics – to depress the central nervous system
- Stomatological preparations – for treating diseases of the mouth (19).

The increasing demand for palliative care is evidenced by increasing rates of palliative care related prescriptions. The overall number of related prescriptions rose by 28% in 4 years until 2020-21 (18).

During this period, 1.17 million palliative care related prescriptions were dispensed nationally, with most of these being for pain relief, followed by scripts for gastrointestinal symptoms (18).

During 2020-21, $22.9 million was paid across Australia for medications included on the Palliative Care Schedule, showing an increase of 61% from 2016-17. Pain relief constituted 86%, or $19.7 million of this cost (18).

Advance care planning

Advance care planning is the process of planning for prospective or potential future health care in terms of values, beliefs, and preferences to assist in maintaining respect and autonomy of choice. In addition, planning allows health care teams to deliver care in an

appropriate manner, and to help guide their clinical decisions (22). Advance care planning is important at any stage of life, but particularly in a palliative care and end-of-life care context.

An advance care directive is a formalisation of the advance care plan of a patient, and contains preferences, goals and beliefs. Directives cannot be overridden by health professionals and family members, so they ensure that patient wishes, and decisions can be followed if they are unable to make decisions (23).

Advance care directives can include information regarding a substitute decision maker, details such as preferred outcomes as well as guidance on treatment and care patients would prefer or would refuse.

In New South Wales, there is no specific advance care directive form template to be completed (24).

Studies in 2020 by Advance Care Planning Australia showed that only 25% of participants had at least one advance care directive in their health record. The prevalence of directives was highest in residential aged care facilities compared to general practice and hospital settings. The prevalence of advanced care directives has also declined from 29.8% in 2017 (25).

Performance of services

The Australian Palliative Care Outcomes Collaboration (PCOC) are the main body within Australia who analyse standardised clinical assessment tools to monitor and evaluate palliative care outcomes and benchmarking (20). The PCOC assessment framework incorporates clinical assessment tools including:

- Palliative Care Phase
- Palliative Care Problem Severity Score (PCPSS)
- Symptom Assessment Scale (SAS)
- Australia-modified Karnofsky Performance Status (AKPS) scale and
- Resource Utilisation Groups – Activities of Daily Living (RUG-ADL).

The PCOC play an important role in collecting Patient Reported Outcome Measures in addition to other palliative care data for reporting and benchmarking and providing guidance to clinicians and health professionals in their assessment of patient experience (20).

In 2021, over 58,000 patients received palliative care from 177 services nationwide that participated in the PCOC. Inpatient episodes were generally shorter with a median of 5 days, compared to a median of 20 days for community episodes. Similarly, the average length of each phase (stable, unstable, deteriorating and terminal) was longer in community settings (21).

Trends seen between 2017 and 2021 have shown that the number of services participating in the voluntary PCOC has increased, with an overall 36% increase during this period.

Palliative care episodes also increased, at a higher rate in inpatient settings. The increase was at a slower rate in 2020-21 for both services and episodes, likely due to the impacts of lockdowns and related COVID-19 restrictions (21).

One of the main indicators of performance of service is the percentage of patients who report a positive outcome. Even throughout the pandemic period, outcomes measures have generally remained steady or improved. There are some exceptions to this trend, as there has been a decline from 93% to 86% of those assessed as ready for care and then receiving it within 2 days (21).

Some performance measures from 2021 PCOC data include:

- 88% of unstable phases were resolved in 3 days or less
- 9 out of 10 palliative care phases that started with absent/mild patient pain remained absent/mild at the end of the phase
- 77% of palliative care closed episodes ended in a 30-day period, with 62% of these ending within 2 weeks (21).

Evaluation and learning

The demand for palliative care is predicted to increase with Australia's ageing and growing population and increasing burden of chronic disease, meaning that resources, support and planning is required to ensure that quality care is accessible equitably, and there is a skilled workforce in place to provide patient centred care.

WSPHN has completed a comprehensive needs assessment of our region, which showed the need for increased palliative care services particularly in The Hills Shire and Blacktown regions. Additionally, the importance of service mapping and collaboration was highlighted, as it promotes patient continuity of care.

The older population represent most admissions for palliative care hospitalisations and are also the main cohort who access aged care services. A major gap in the aged care space that relates to palliative care includes increased accessibility and usable information, both for consumers and for health professionals. The need to promote services as well as recognition of the importance of the role of palliative care and advance care planning is imperative to improve service utilisation and appropriate care for patients.

Increased navigation and support for Australia's older population is critical in promoting better health outcomes and engagement. This will be initiated through the Carefinder program, targeting those accessing the aged care system, with Care Finders providing specialist assistance to help with understanding and access of support (31).

More research and consultations will continue to be undertaken in Western Sydney, to understand what is already available in the aged care space, including palliative care services. This will allow for a comprehensive guide to be developed and accessible for residents in Western Sydney, as well as for Care Finders to recommend appropriate services for consumers.

The palliative care space is a new area for WSPHN, with the potential to commission relevant services to provide support to the community, as well as continue to develop applicable data collection methods to provide insight into palliative care service access, outcomes and engagement across Western Sydney. There is potential for collaboration across Western Sydney with stakeholders such as Western Sydney Local Health District, including existing palliative care hospital clinics, community organisations and general practices.

The focus of equitable access and quality of care is paramount, to promote better patient outcomes and quality of life. Further engagement in the palliative care sector will ensure that increasing burdens of chronic disease and ageing populations can be managed from a patient centred approach, to maintain patient dignity and provide appropriate support and care.

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