



Government of South Australia

SA Health

Palliative care needs in South Australia

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Executive Summary

Population growth is inevitable. In addition to population growth, increased longevity in South Australians will contribute not only to a higher number of older people in the population but also change the nature of diseases together with the time and the way that people die. An increased period of ageing will be accompanied by the presence of multiple, incurable, long-lasting, and persistent chronic conditions which will contribute to a gradual deterioration of health, place greater demand on health services eventually causing death. This changing demographic is reflected in the shift in the leading causes of death whereby more people are dying of conditions typical of prolonged dwindling trajectory such as dementia.

Palliative care has proven to be highly effective for those patients who receive it. There is also a growing recognition that modern technologies (that can delay dying) do not always maintain or enhance the quality of the life being lived. Therefore, it becomes important to identify people who are in the last days of life earlier (not just in the last 12 months of life) as it can affect not only how, and potentially where, people die, but also what constitutes end of life care.

People with life-limiting illnesses have varying needs which can change over time. Different levels of service and different settings for care (community, residential care, hospital) are required to meet these needs at different times and not all people will require specialist palliative care services. Estimations based just on mortality data (14,426 SA deaths in 2017) indicate that about 41% to 72% of people in SA who die from a life-limiting condition each year (currently between 5,851 and 10,452) would benefit from some form of palliative care services.

People with non-cancer conditions do not access specialist palliative care as readily. The illness trajectories of non-cancer diseases may be longer and have unpredictable fluctuations both of which complicate the provision of cost-effective palliative care services.

Delivering integrated palliative care in the home and community makes sense as many patients prefer to be cared for at home and because acute care hospitals are busy and unfamiliar environments. The teams in the community help manage symptoms, provide education, coordinate care, and provide additional or enhanced support and care. Expanding such models in South Australia could reduce the impact and demand on in hospital Palliative Care services and improve access for palliative patients on non-cancer disease trajectories. Rapid response by specialist palliative care teams and extended care paramedics need to be integrated with routine home based community care to manage crisis and emergencies in the community settings.

End-of-life care should be core business for residential aged care providers but the quality of end-of-life care in residential aged care is not consistent across the sector and can be impacted by funding models. The literature highlights that people are transferred back and forth between hospitals and aged care facilities too often, as aged care facilities lack palliative care expertise and qualified staff to administer pain relief. General practitioners (GPs) play an important role in providing shared palliative care for adults who are patients of a Specialist Palliative Care Services to be cared for in a community setting. However, availability of GPs to provide active shared palliative care is challenging mainly due to financial challenges associated with the Medicare system which does not adequately remunerate the complex and time-intensive work of providing good end-of-life care at this stage.

There are also groups in the community who have special needs in relation to palliative and end of life care. These include people with complex needs, disabilities, children, Aboriginal Australians and those living in rural and remote areas and of different cultural or linguistic backgrounds. The needs of these specific groups are often difficult to meet adequately within the current service arrangements. Technological solutions, innovative practices, improving workforce capacity and development of new models of care are necessary to improve palliative care access for these populations.

Introduction

South Australia has population of over 1.7 million people, which accounts for 7.14% of Australia population. This represents a growth of 75,841 people (4.6% increase) from 2012 to 2017. The total population for South Australia (SA) is expected to reach 1,806,757 people by 2022, which is an increase of 9% from the Estimated Resident Population of 1,654,751 for 2012 (0.9% per annum). The Aboriginal population is projected to increase significantly by between 42,400 and 46,500 by 2021¹. It has a very different profile with a mean age of 23 in 2016, compared to 40 years for all people in SA, with 53% of the Aboriginal population being under 25².

In addition to population growth, South Australians have one of the longest life expectancies in the world, with life expectancy at birth between 2014 and 2016 for females estimated to be on average 84.5 years, and for males 80.4 years. Increased longevity contributes not only to a higher number of older people in the population but also changes the nature of diseases together with the time and the way that people die. The ageing population, and rising rates of cancer and other conditions such as dementia, has led to a rise in demand for palliative care services. Over the past four years, palliative care provided in Australian hospitals increased by 28%³. The impact of ageing, and a higher proportion of people living alone, will continue to place greater demand on health services. People aged between 65 and 75 years are twice as likely to be admitted to hospitals as the rest of the population, while those aged over 85 years are more than five times likely to be admitted to hospitals⁴. Those aged over 85 years account for less than 3% of population but 15% of bed days. The high levels of disadvantage and hospital admissions is also well established. In 2015–16, people living in areas classified as having the lowest socioeconomic status (quintile 1) accounted for a higher proportion of palliative care-related hospitalisations (22.3%) in public hospitals than those living in other areas.

Identification of the End of Life Stage

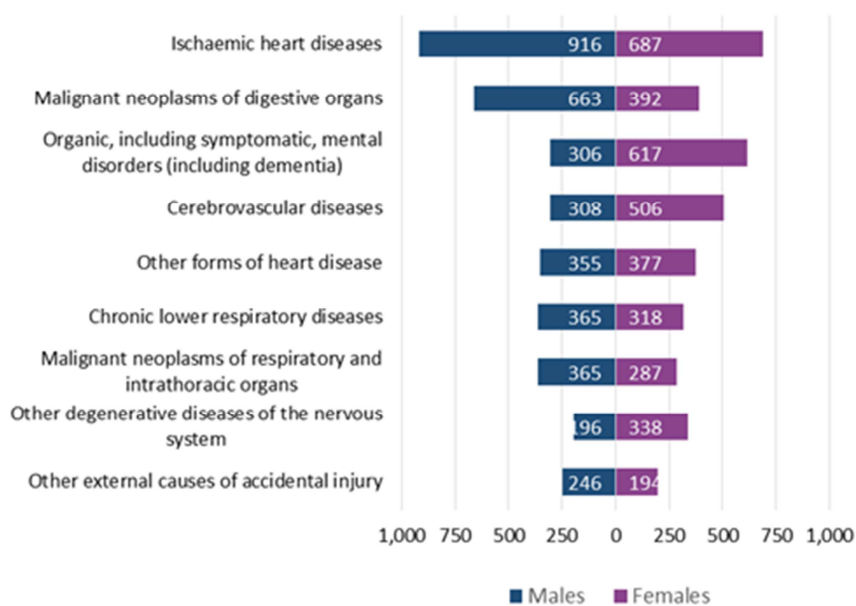
Each year in Australia, about 160,000 people die (50,000 occur in a residential care facility) and around 100,000 of these deaths are predictable. Of those, 40,000 patients receive specialist palliative care and 60,000 do not. Palliative care has proven to be highly effective for those patients who receive it⁵. Chronic diseases lead to a large proportion of deaths, yet people with chronic, terminal conditions are under-recognised by health services as entering the end of life stage. End of life is increasingly becoming 'medicalised' with a reduced emphasis on well-being. The widespread use of non-beneficial treatments (NBT) at the end of life in acute hospitals for patients aged 60 or older in their last six months of life potentially prevents patients from having access to a comfortable death, and prolonging suffering rather than survival⁶. Given the uncertainty of prognosis on time to death and the social and ethical pressures that exist it appears that a certain level of NBT must always be present, but reducing their prevalence can result in significant savings to the public health system.

There is now a growing recognition amongst clinicians and community members that modern technologies (that can delay dying) do not always maintain or enhance the quality of the life being lived — this can be true for patients of any age. Therefore, many people are now choosing to concentrate on the quality rather than the quantity of the remainder of their lives. Health services must accommodate these realities and identify people at end of life stage and clarify goals of care earlier as it can affect how, and potentially where, people die and the care they receive.

Review of South Australian Mortality Data

In 2016, there were 13,337 deaths in SA. The leading causes of death were ischaemic heart disease with 1,603 deaths, and malignant neoplasms of digestive organs (bowel cancer) with 1,055 deaths, both predominantly affecting males. Figure 1 details a breakdown of the leading causes of death in SA in 2016. Organic, including symptomatic, mental disorders which includes dementia, totalled 923 deaths with twice as many females as males being affected, and cerebrovascular diseases, including stroke, resulted in 814 deaths, predominantly affecting females. The top 10 leading causes of death were responsible for over one half of all deaths (61.0% and 59.3% for females and males respectively) in SA for 2017.

Figure 1: Leading Causes of Death, 2016 SA (Source: Underlying Cause of Death, ABS, 2016)



Generally the Standardised Death Rate (SDR) is declining across Australia. In SA, in 2016, the SDR equalled the National SDR at 5.4 deaths per 100,000. In 2016, the Aboriginal death rate in South Australia was 8.7 deaths per 1,000 Aboriginal population (age standardised)⁷. Males and Aboriginal Torres Strait Islanders also died younger. Over the past 10 years, the median age at death has increased by 1.6 years for males and 1.7 years for females at the national level. In 2016, the highest median age at death was in South Australia for both males (80.1 years) and females (85.9 years). The median age at death for Aboriginal and Torres Strait Islander Australians for total five state/ territory was 59.3 years in 2015-2017, up from 54.8 years in 2005-2007. Death can take place at any age, although the majority of deaths in SA occur among those aged over 65, which accounted for 83.5% (11,736) of all deaths in 2017.⁸

In South Australia, based on the review of mortality data and the utilisation of specific ICD-10 codes proposed by both Rosenwax⁹, Murtagh¹⁰ and their colleagues the estimated percentage of people who could benefit from some form of palliative care service (minimal estimate) ranges from 41 to 72% (5851 to 10452 people) respectively (Table 1). This palliative care could be delivered by non-specialists, for example, as advance care planning in a primary care setting or symptom management in secondary care. Specialist multidisciplinary palliative care teams deliver care for more complex needs in a variety of settings, including hospitals, hospices and in the community, although they can also provide more straightforward end-of-life care¹⁰.

Table 1: Deaths according to two groups of ICD-10 codes

	Rosenwax et.al	Murtagh et al.	SA total deaths in 2017
Number of deaths	5851	10452	14,426
Percent of total deaths	40.56	72.45	

Acute Care

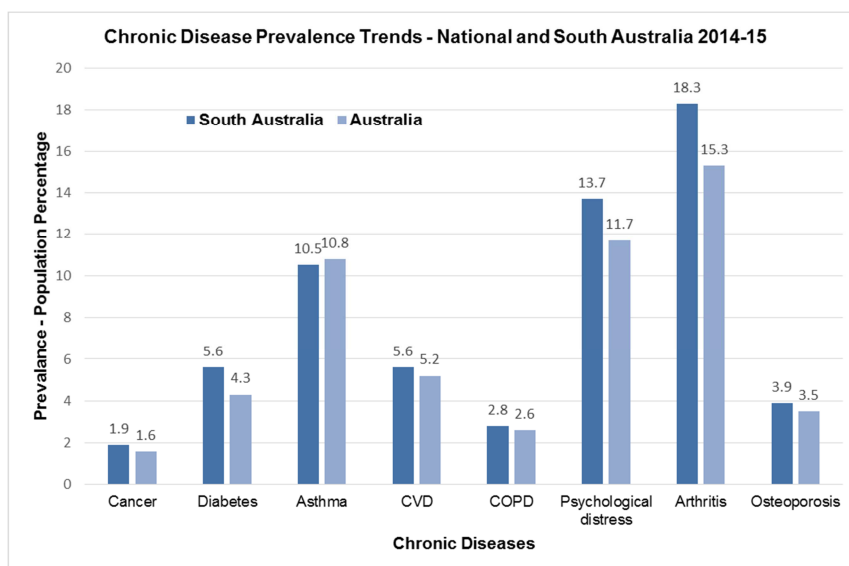
Evidence shows that specialist palliative care is more often provided to patients with cancer versus those without cancer because of the 'predictability' of decline and the history of hospice care for patients with cancer¹¹. The illness trajectories of non-cancer diseases may be longer and have unpredictable fluctuations¹² both of which complicate the provision of cost-effective palliative care services. Other complex factors such as patient and family awareness and preparedness also impact the provision of palliative care to people with non-cancer conditions¹³. The challenge for specialist palliative care services is to extend the skills and knowledge learnt from the cancer experience to cater for the needs of the non cancer disease group of patients. Leading international and national bodies have made an attempt to identify a list of diseases and conditions (Table 2) that may require palliative care input to assist patients to live fully until they die, noting that not all people with these conditions will require specialist palliative care input¹⁴.

Table 2: Diseases requiring palliative care

Adults	Children
<ul style="list-style-type: none"> Alzheimer’s disease and other dementias Cancer cardiovascular diseases (excluding sudden deaths) cirrhosis of the liver chronic obstructive pulmonary diseases diabetes HIV-AIDS kidney failure multiple sclerosis Parkinson’s disease Rheumatoid arthritis Drug-resistant tuberculosis 	<ul style="list-style-type: none"> cancer cardiovascular diseases cirrhosis of the liver congenital anomalies (excluding heart abnormalities) blood and immune disorders HIV-AIDS meningitis kidney diseases neurological disorders neonatal conditions

Non-Cancer Disease Trajectories: Coupled with an ageing population, Figure 2 shows that SA is also experiencing comparatively higher prevalence of chronic disease when compared nationally in all areas except asthma, which despite being lower than the National average prevalence, is still increasing significantly in SA. Data from the South Australian Monitoring and Surveillance System (SAMSS) provides a summary of the prevalence of a range of chronic diseases in SA. All major chronic disease areas have increased in prevalence between 2012-13 and 2016-17 with asthma increasing the most at 2.0%, followed by mental health conditions at 1.6% and COPD at 1.2%. In addition significant increases in the prevalence of dementia are projected both nationally and within SA with increases projected in SA of 2.9% per annum between 2011 and 2020. In 2017, around one in five (21.9%) South Australians aged 18 years or more were living with two or more of the following chronic health conditions: diabetes, asthma, cardiovascular disease, arthritis, osteoporosis and/or a mental health condition. Multi-morbidity increases the complexity of patient needs, which has implications for all health professionals- those providing disease-modifying therapies and those providing palliative care¹⁵.

Figure 2 - Summary of chronic conditions in SA compared to National; Source: ABS Causes of Death, 2014.



There has been an attempt in the literature to categorise the population potentially in need of palliative care into three “end-of-life trajectories” based on a detailed examination of ICD-10 codes by a panel of experts¹⁶. Reasoning in terms of trajectories has been an important step to overcome the one-size-fits-all and homogeneous model for palliative care and shown that people following different trajectories benefit from specific clinical approaches at the end of life, in different time frames, provided through different health-care services or professionals. Using this methodology to review the 14,426 deaths registered in SA for 2017, 9882 deaths (68%) were predictable and would have aligned to one of these trajectories and thus benefited from generalist or specialist palliative care services (Table 3).

Table 3: Deaths according to disease trajectories

End of Life Trajectories	SA Estimates
Trajectory 1- Short period of evident decline characterised by a long maintenance of good body functions but with a steady progression and rapid decline leading to the clear terminal phase. Includes: most cancer diagnoses	27% of all deaths
Trajectory 2- Long term limitations with intermittent serious episodes characterised with a gradual decline but broken up by acute episodes of illness and with an unexpected timing of death. Includes: Cardiovascular diseases, diabetes, chronic obstructive Pulmonary Disease (COPD), kidney failure, cirrhosis of the liver, HIV/AIDS, rheumatoid arthritis, and drug-resistant tuberculosis.	28% of all deaths
Trajectory 3 - Prolonged dwindling characterised by long-term, prolonged, and progressive decline. Includes: Dementias and Alzheimer’s disease, Parkinson’s disease, and multiple sclerosis.	13% of all deaths

This approach has revealed that most deaths particularly in high-income countries occur after a period of physical, psychological, and cognitive decline and that people with a wide range of chronic conditions would benefit from palliative care at the end of life. However, people with non-cancer conditions do not access specialist palliative care as readily¹⁷. Although only around 27% of all predictable deaths are for cancer in South Australia, a majority of referrals which come to the specialist palliative care services are for cancer patients (Table 4).

Table 4: Episodes by Main Diagnosis Group- Central and Southern Adelaide Specialist Palliative Care Services, Jan-Dec 2018.

	Central Adelaide	Southern Adelaide
Malignant referrals (e.g. Lung Cancer, Breast Cancer, Colo-Rectal Cancer, Pancreas Cancer, etc)	542 (76%)	375 (64%)
Non-Malignant referrals (e.g. Neurological Disease, Cardiovascular Disease, Respiratory Failure, Kidney Failure, Other Non-Malignancy)	171 (24%)	213 (36%)
Total	713	588

Clinical evidence demonstrates that there are commonalities in the prevalence of problems across cancer and non-cancer conditions¹⁸. However, the illness trajectories of non-cancer diseases may be longer and have unpredictable fluctuations both of which complicate the provision of cost-effective specialist palliative care service. Common needs of patients living with cancer include physiological, psychological and communication/information needs. Patients living with non-malignant conditions often have high rehabilitation needs that increase with disease progression¹⁹.

Care in the Community

Home Based Palliative Care: There is a growing body of evidence in the literature that demonstrates that home based palliative care teams help patients manage symptoms, improve quality of life and prevent avoidable hospitalisations. The community based teams involve a core group of interdisciplinary team members, specifically palliative care specialists, nurses, and general practitioners who provide integrated palliative care to patients in their homes²⁰. Care from these teams may help avoid unplanned use by anticipating clinical problems early and making care arrangements in advance. Teams expertly manage, monitor, and rapidly respond to complex symptoms and changes in the patient’s condition and prevent carer burnout. Moreover, patients and families can access the teams 24/7, a feature especially important on evenings and weekends. This reduces emergency department visits and hospitalisations late in life because of inadequate symptom control and failure to cope, among other factors. Expanding such models in South Australia could reduce the impact and demand on in hospital Palliative Care services and improve access for palliative patients on non-cancer disease trajectories.

Rapid response teams: Rapid response teams providing specialist palliative care in the UK complement home based palliative care services by responding quickly to crises and emergencies (e.g. due to uncontrolled symptoms, carer fear or stress, not having medication available). They provide intense care for a few days at a time and operate on a 24/7 on-call basis. They are available at a time when the patient and/or carer are most vulnerable and when no other service is available or able to manage the crisis. They have been found to improve patient outcomes, increase

the chance of the patient dying at home and are cost-effective in relation to less use of acute care and emergency services.

Extended Care Paramedics: The SA Ambulance Service (SAAS) established an Extended Care Paramedic (ECP) team in 2008. The ECPs provide 24 hour coverage across the Adelaide metropolitan region, providing out of hospital management of patients, one service of which is afterhours palliative care provision. ECPs manage approx. 25-35 palliative care patients per month (15% on weekends, 30% on weekdays, 55% afterhours on weekdays). The ECPs are built into the afterhours palliative care model. ECP resourcing is reduced after 1900hrs and there is only one ECP on between midnight and 0700hrs which limits timely access for palliative care patients. There are ECPs only located in the metropolitan area in SA. This is also not a model available in the regional areas which are supported by volunteer crews and paramedics in the larger regional areas. Over reliance on the ECP model as the only strategy for meeting needs of palliative care patients afterhours is insufficient in the long term. It needs to be further developed to co-exist with and be supported by other approaches such as home based community care and the rapid response teams mentioned above.

Grief and Bereavement Support: Over one in seven (14.7%) of the state's population are carers, and around a quarter of those are primary carers. Grief is a common and especially significant concern for many of the carers and family members. In addition to direct service costs, there are the indirect costs of grief and bereavement, the long-term impact on mental health and the associated losses to productivity and community capacity. While these costs may be more difficult to calculate, they are no less real for individuals impacted by them. Specialist palliative care services usually have a focus on bereavement care but if end of life care is to be everybody's responsibility, then care after death of those left behind grieving must also be addressed across the health system. There is opportunity to partner with non-government organisations to develop a statewide grief and loss strategy and build community capacity in this particular area.

Residential Aged Care

The incorporation of palliative care into residential aged care settings has been found to benefit the residents (with more dying in the aged care facility) and to reduce the use of acute health services resulting in cost benefits for health systems. However, identifying the need for palliative care in residential aged care facilities (RACFs) can be difficult as residents often have multiple morbidities with differing illness trajectories, varying levels of cognitive decline, complex symptom management, and time to death is often unpredictable.

The Aged Care Funding Instrument (ACFI) is a tool used to assess the core care needs of residents, including palliative care needs. The ACFI is not specifically designed to estimate palliative care needs, however it provides some insights on provision of palliative care in RACFs. In 2017-18 there were 242,027 permanent aged care residents in Australia and about 1 in 50 of these residents (4,793; 2.0%) had an Aged Care Funding Instrument (ACFI) appraisal indicating the need for end of life palliative care. The proportion of Aboriginal permanent aged care residents appraised as requiring palliative care was lower than that for other Australians (1.8% and 2.0% respectively). A significant number of RACF residents also do not have advance care directives (ACD) or a Resuscitation Plan - 7 step pathway (community version) for medical care. This results in residents often receiving inappropriate or unwanted medical treatment. Staffing levels in residential care also tends to be low, there are competing demands on nursing time, and medical care to residents largely provided by GPs is often unavailable and is very time limited. This creates challenges for the provision of high quality palliative and end-of-life care.

Primary Care

General practitioners (GPs) play an important role in palliative care as well as the health-care system more broadly. The GP Palliative Shared Care Program was established in 2015 by SA Health and GP partners Australia. The Program plays an important role in building the capacity and skills of general practitioners to support patients with a life limiting illness within the community setting. It provides adults who have a life limiting illness and have been referred to a SA Health public, metropolitan Specialist Palliative Care Service with the option to obtain shared palliative care with a participating GP. It is available to adults who are patients of a metropolitan Adelaide Specialist Palliative Care Service and being cared for in a community setting. This includes people living at home, being discharged into the community from hospital and living in residential aged care facilities.

So far over 400 GPs have been recruited. However, availability of GPs to provide active shared palliative care is challenging mainly due to financial challenges associated with the Medicare system which does not adequately remunerate the complex and time-intensive work of providing good end-of-life care at this stage.

Addressing the Unique Needs of Diverse Populations

Patients with Complex Needs: There is a smaller group of younger patients, under 65 years (which has many parallels with the care of people with disabilities in RACFs) with intermediate health care needs requiring more intensive nursing services, as well as a wide range of social supports to maintain health and functioning. Such patients often have high levels of dependency, and include

- Patients with relatively short prognosis (weeks) whose care needs cannot be adequately met in a standard RACF facility because of likely escalating symptom control needs
- Patients with longer prognosis whose nursing needs exceed RACF capacity but who do not need ongoing acute care (e.g patients with intensive nursing needs due to neurodegenerative disorders, such as Motor Neurone Disease, brain tumours, malignant wounds requiring intensive nursing, psychiatric comorbidities, morbid obesity and complex pain interventions such as intrathecal infusions).

When the patient's care needs becomes very demanding, it is beyond the capacity of even a well-resourced family and they cannot be cared for at home. While these patients often do not require ongoing medical care in an acute hospital or hospice, residential aged care facilities are not adequately resourced to provide the level and responsiveness of care needed. Even if the long and complex process of negotiating admission to a RACF is successful, these patients, particularly the youngest, do not fit into the RACF resident profile and facilities struggle to meet their needs. As a result they cannot be discharged to community care. Addressing the needs of these patients in the community with increased capacity for skilled nursing care, with additional multidisciplinary support tailored would enable patients requiring end-of-life care to be safely discharged from acute hospital beds, or admitted directly from the community avoiding unnecessary ED presentations.

People Living in Rural and Remote Areas: Mortality rates increase with increasing remoteness. People living in rural and remote areas have higher levels of illness and disease risk factors. End-of-life care for people regional SA has improved but is limited compared to those in metropolitan areas. Consultative or outreach palliative care services are generally provided from higher level palliative care services (Levels 4, 5 and 6) to lower level services (Levels 1, 2 and 3). Level 6 services have the capacity to manage the highest level of patient risk and/or complexity and is able to provide highly complex symptom management.

The concentration of level 6 services in the three metropolitan local health networks has maintained a urban focus, despite the service partnering arrangements and support that these services provide to the level 4 and 2 country palliative care services in their designated regions through an integrated service model. Consumers in rural and remote areas have less access to around-the-clock care, and to appropriately trained GPs, after-hours nursing, equipment and medications, than other consumers. This can especially be an issue if a person's condition deteriorates rapidly. Improving partnerships with primary healthcare providers are pivotal in palliative care provision in rural and remote South Australia.

The provision of multidisciplinary visits (face to face or through tele-health) by level 6 services to level 4 and 2 services has definitely been an area of increased need. Telehealth has the potential to have a positive impact on palliative care services in rural and remote areas. It can link people and their health care providers with specialist palliative care advice. Face-to-face consultation with a local health professional is important but a video consultation with a palliative care team or other specialist, facilitated and supported by local health professionals, can provide additional expertise and support. The establishment of six new Regional Local Health Networks provides an opportunity to consider the palliative care needs across regional SA and develop a country focused plan for the provision of services supported by a focus on increasing end-of-life care knowledge and expertise in the generalist health workforce.

Children: Palliative care for children differs from palliative care for adults across the dimensions of diagnosis, symptoms, age range, geographical vastness and the inherent burden of care and impact on families and communities of a child's death. Paediatric palliative care has continued to be delivered for the whole state, Northern Territory, Broken Hill and Mildura by the Women's and Children's Hospital (WCH), through the Statewide Paediatric Palliative Care Service. Paediatric hospice facilities do not exist in SA. However, there are plans to include 2 hospice style family units in the new WCH. More than 70% of the 50 new referrals per year to the paediatric service are for non-cancer life limiting conditions. The service age range covers perinatal palliative care from antenatal diagnosis through to newborn, paediatric ages and then adolescence to 18 years old. The combination of variable diagnosis and physical size of these patients require co-ordination across multiple service providers and health care partners potentially over years of uncertain life span.

Families generally express a wish for the majority of their care to be provided at home and this requires preparation and support of communities and health care providers in metropolitan, rural and remote communities in the care of patients. The relative rarity and burden of service provision has meant that in SA there has been no engagement of the Extended Care Paramedics or GP partnership programmes in Paediatric Palliative Care. Home care requires attention to the whole family as the unit of care and the provision of appropriate specialised support across the 24 hour timeframe. This includes access to expert care advice, supportive counselling and meticulous attention to care planning and co-ordination with capacity to anticipate and meet escalations in care needs. Increasingly the portfolio of families includes multiple cultural origins, religious complexity, and diverse family units which add to the requirement for complex, sensitive and timely assessments and service provision.

A study from the UK identified that 32 per 10,000 children aged 0-19 years old were in need of palliative care and also noted an increase of almost 30% over a 10-year period²¹. Further, a worldwide study reported that 68% of children living with life-limiting conditions require some type of palliative care, and it was estimated that 21 children per 10,000 require palliative care services in Australia²². The proportion of children with a life-limiting condition who have more complex needs is estimated to be 37.5% in high income countries such as Australia. In South Australia, the number of children requiring palliative care is estimated to be between 860 to 1310 with about 323 to 491 of them having more complex needs (Table 5).

Table 5: Need for palliative care, SA population under 19 years old, 2017

	Number of children requiring palliative care	Number of children with complex needs
Based on 21 per 10,000	860	323
Based on 32 per 10,000	1310	491

Aboriginal people: The rate of palliative care-related hospitalisations in public hospitals is about twice as high for Aboriginal Australians as for other Australians (45.6 and 23.3 per 10,000 population, respectively) with the rate of all public hospitalisations 3.8 times higher for Aboriginal Australians than other Australians²³. However, Aboriginal and Torres Strait Islander peoples maybe ambivalent toward western health care and underrepresented in the palliative and end-of-life care patient population. Major conditions such as cancer in Aboriginal people often come to medical attention only late in the course of the illness. They also use health care services reluctantly, and palliative and end-of-life care services rarely. This is confirmed by Palliative Care Outcomes Collaboration (PCOC) data showing that Aboriginal people received 1.0 per cent of specialist palliative care services in South Australia in July-December 2017, well below the population rate²⁴.

Aboriginal and Torres Strait Islander people also access aged care services at a younger age, consistent with poorer health status and lower life expectancy. SA Health's Palliative care services plan 2009-16 recognised that, for many dying Aboriginal people, returning to country was the highest priority. Understanding this, and other cultural obligations, and providing services closer to home, where possible, would make final stages of life more comfortable for patients and their families.

CALD: Composition of people from overseas continues to evolve with an additional 44,243 people reporting speaking a language other than English at home in South Australia between 2011 and 2016 creating challenges including communication and clear therapeutic goal setting in the context of life limiting diseases and chronic disease management. The process of dying, perhaps more than any other moment in the course of medical care, can accentuate cultural differences between patients, families, and providers. The consequences of culturally inappropriate care can include psychological distress and unnecessary suffering for the patient, family, carers and community. CALD patients and caregivers' experiences are multifaceted, particularly in negotiating linguistic difficulties, beliefs about treatment, and issues related to death and dying. Therefore, greater attention is needed to develop effective communication skills, recognise patients' cultural, linguistic and spiritual values and needs.

Disabilities: Palliative care has paid limited attention to the needs of disabled people nearing the end of life. It is often assumed that these individuals, like all patients with little time left to live, arrive at palliative care with various needs and vulnerabilities that by and large, can be understood and accommodated within routine standards of practice. However, people with longstanding disabilities continue to experience various forms difficulties in accessing palliative care services.

Workforce Capacity

The profile, skills and capabilities of the Australian health workforce is being shaped by changing patterns of disease, increasing demands for quality care at end of life, system-wide shortages of health professionals, and reforms to systems of care. A workforce with skills and capabilities to support emerging models of care is needed to meet community expectations of safe and quality care for all. A major challenge to equitable access to palliative care services is the uneven distribution of health professionals, particularly in rural and remote regions. Therefore, specific incentives and alternate models may be required to match the service challenges in regional, rural and remote locations. A systematic strategy for developing capabilities in end-of-life care for the whole health workforce and integrating learning at all levels of cultural competence and culturally safe practice have been found to be integral to the provision of high quality and sustainable services for people who are dying.

South Australia has about 1.1FTE/ 100,000 population palliative medicine specialists working in the health system²⁵ (Palliative Care Australia recommends 2.0FTE/ 100,000 population) with unmet need being greatest outside of metropolitan areas. The emerging role of nurse practitioners in palliative care in providing a model of care that reflects changing needs of the health system is evident, with a small number of palliative care nurse practitioners now accredited in South Australia. To date, analysis of the potential for such roles, and the training and support requirements for them to reach their potential is limited. In many instances, Advance Practice Nurses can be effectively utilised working to full scope of their practice in absence of NPs. People living in outer regional centres have access to about a half as many allied health professionals as people in metropolitan centres. Less access to Allied Health staff has implications for timely access to equipment, rehabilitation and receiving psychosocial support. Increasing access to health professionals in under-served communities requires a composite of incentives that are both financial and non-financial and well integrated 'hub and spoke' health service networks²⁶.

Conclusion

The literature searches have identified only a small body of work related to estimation of palliative care needs. In interpreting this literature, it is important to note that patients with life-limiting illnesses have varying and often complex needs which can change over time. Moreover, different levels of service capability and different settings for care (primary care, community, residential care, hospital) are required to meet these needs at different times, and not all people will require specialist palliative care (SPC) services. The current methods for estimation of palliative care demand that are available in the published literature do not clearly distinguish between need for specialist and non-specialist palliative care services. The paper has looked within the literature and used published methodologies to estimate need for palliative and end of life care at the population level. Further work needs to be done to map this work with what currently happens in the different settings of care (primary care, community, residential aged care and hospital).

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