



Australian Government Department of Health

Exploratory Analysis of Barriers to Palliative Care

Literature Review

July 2019

Acknowledgments

Australian Healthcare Associates (AHA) would like to thank the many people who contributed to this project. These included palliative care and other health and social care providers, academics, and peak organisation and government representatives. In particular, we thank the people from the under-served populations who shared their thoughts and experiences with us.

AHA Australian Healthcare Associates

Level 6, 140 Bourke St, Melbourne VIC 3000

Locked Bag 32005, Collins Street East, VIC 8006

(03) 9663 1950

aha@ahaconsulting.com.au

www.ahaconsulting.com.au

Contents

1	Introduction	1
2	Aboriginal and Torres Strait Islander peoples.....	8
3	Care leavers and those affected by forced adoption	19
4	People from culturally and linguistically diverse backgrounds	21
5	Refugees.....	31
6	People with disabilities	34
7	People experiencing homelessness	43
8	People who are incarcerated	51
9	People who identify as lesbian, gay, bisexual, transgender or intersex	58
10	Veterans.....	64
	Appendix A. Literature review method..	98

Figures

Figure 1-1: Suite of reports.....	ii
Figure 8-1: Comparative rates of incarceration (per 100,000 people).....	51

Tables

Table 1-1: Population group definitions	5
Table 7-1: Key principles of person-centred palliative care	49

1 | Introduction

Background

Patterns in the continuum of life, dying and death in Australia have shifted rapidly in the last 50 years. A combination of longer life expectancies, increased incidence of chronic disease, and advances in health care have contributed to more people requiring palliative care to ensure quality of life and wellbeing is maintained during the last years of life (1).

In line with these trends, demand for palliative care services has increased dramatically over recent years (2). While Australia is a global leader in the provision of palliative care (3), inequalities remain for a number of population sub-groups (1).

For some populations, experiences of palliative care can vary considerably (4), services can be difficult to access (5), and life circumstances can result in exclusion from services (6).

In 2017-2018 the Australian Government Department of Health (the Department) engaged Australian Healthcare Associates (AHA) to undertake nine separate policy development activities through an exploratory analysis of barriers to accessing quality palliative care for under-served populations in Australia (the project). The following populations were identified by the Department:

- Aboriginal and Torres Strait Islander peoples
- Care leavers (including Forgotten Australians, Former Child Migrants and Stolen Generations) and people affected by forced adoption

- People from culturally and linguistically diverse (CALD) backgrounds
- People with disabilities
- People experiencing homelessness
- People who are incarcerated
- People who identify as Lesbian, Gay, Bisexual, Transgender or Intersex (LGBTI)
- Refugees
- Veterans.

This document

To gain a better understanding of the barriers to and enablers of access to palliative care for these populations, AHA has conducted nine literature reviews focusing on the specified under-served populations. The purpose of the literature reviews is twofold:

- To inform understandings of current barriers and enablers of access to quality palliative care for each under-served population group
- To inform the development of effective stakeholder engagement strategies for each under-served population group to be explored through the project.

The methodology utilised for the reviews is outlined in *10/Appendix A*.

This document represents a summary of the literature reviews which were originally conducted in March–April 2018 and updated in January 2019, with minor final amendments made in July 2019. It is part of a suite of documents developed through the project, as shown in *Figure 1-1*.

Figure 1-1: Suite of reports



What is palliative care?

Palliative care is a person- and family-centred approach to care. Palliative care services are provided for a person with an active, progressive, advanced disease, who has little or no prospect of cure and who is expected to die, and for whom the primary treatment goal is to optimise quality of life (7). It improves quality of life for individuals and families through the prevention and relief of suffering by means of early identification and correct assessment and treatment of pain and other physical, psychosocial or spiritual problems (2).

Palliative care:

- Should be strongly responsive to the needs, preferences and values of people, their families and carers
- Should be available to all people with an active, progressive, advanced disease, regardless of diagnosis
- Affirms life while recognising that dying is an inevitable part of life.

This means that palliative care is provided during the time that the person is living with a life-limiting illness, but it is not directed at either bringing forward or delaying death.

Palliative care can be provided in a range of settings, including:

- At home
- At a hospital
- In a hospice
- In an aged care facility
- In an institutional setting (such as a correctional facility or accommodation for people living with a disability).

Palliative care involves a range of clinical and other supports delivered by different providers,

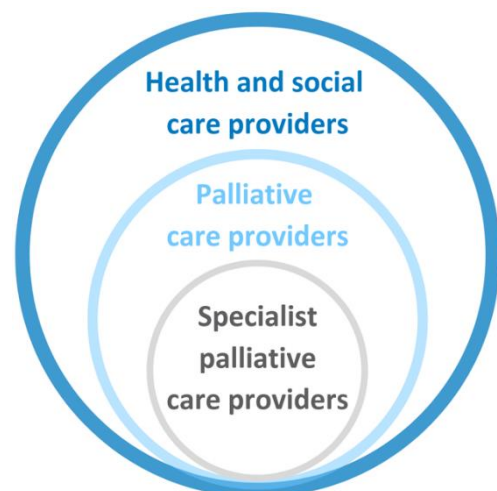
including volunteers, depending on the patient's needs. These may include:

- General practice and primary care
- Other specialist medical, nursing and allied health practitioners
- Community, disability, aged and social services
- Grief and bereavement services
- Specialist palliative care services (comprising multidisciplinary teams with specialised skills, competencies, experience and training in palliative care), for patients with complex needs.

This project adopts a broad view of palliative care, as outlined above, and is not limited to the provision of specialist palliative care services.

Therefore the term 'palliative care provider' is used in this document to refer to all health and social care providers involved in the delivery of palliative care.

Where relevant, the term 'specialist palliative care provider' is used to differentiate this group of professionals. More broadly, the term 'health and social care providers' is used to represent those within this category for whom palliative care is not considered core business.



Advance care planning

Advance care planning is a process of planning for future health and personal care, whereby an individual's values and preferences are made known to guide decision-making at a future time when the person cannot make or communicate their decisions. Formal advance care planning programs usually operate within a health, institutional or aged care setting after a life-limiting condition has been diagnosed, and frequently require the assistance of trained professionals to develop. However, people can choose to discuss their advance care plans in an informal family setting (8).

Formal components of advance care planning include appointing a substitute decision-maker and completing an Advance Care Directive (9). It should be noted that legislation concerning advance care planning and medical power of attorney varies between jurisdictions.

Australian policy and service delivery context

The provision of palliative care services is undertaken primarily in the context of state and territory health systems (1) and service delivery frameworks. Patterns of use vary between states and territories (10). In addition, different state and territory legislation applies to legal elements of advance care planning in each jurisdiction (11). These issues contribute to the complexities of care provision across the country (12).

Despite differences, national approaches to palliative care are supported by the National Palliative Care Strategy (the Strategy) and a number of Australian Government-funded programs and projects (13).

The National Palliative Care Strategy provides an overarching vision that 'people affected by life-limiting illness get the care they need to live well' (14: p.5). A guiding principle of the Strategy is that 'all Australians will be able to access quality palliative care' (p.11), recognising that a number of populations are under-served and the needs of these population groups should be identified and respected. Person-centred care and a public health approach (in which 'everyone has a role to play in palliative care') are also guiding principles.

These principles are echoed in other documents that guide current delivery of palliative care services in Australia, such as Palliative Care Australia's National Palliative Care Standards (14) and Service Development Guidelines (15) and the 2015 National Consensus Statement on Essential Elements for Safe and High-Quality End-of-Life Care developed by the Australian Commission on Safety and Quality in Health Care (8).

Identified populations

As highlighted earlier, access to and experiences of palliative care can vary considerably for specific populations.

The under-served populations identified for this project, and their definitions, are detailed in *Table 1-1*.

Table 1-1: Population group definitions

Population	Definition
Aboriginal and Torres Strait Islander peoples	<p>According to the National Aboriginal Community-Controlled Health Organisation, the following definition (used by the federal government, state legislation and the High Court) should be ‘the only acceptable definition of Aboriginality’. The definition requires three conditions to be established:</p> <ul style="list-style-type: none"> • Descent (i.e. a parent is of Aboriginal or Torres Strait Islander descent) • Self-identification (i.e. the individual identifies as an Aboriginal or Torres Strait Islander) • Community recognition (i.e. the individual is accepted as such by the Aboriginal or Torres Strait Islander community in which he/she lives) (16).
People from culturally and linguistically diverse (CALD) backgrounds	<p>The term ‘culturally and linguistically diverse’ (CALD) is a broad and inclusive descriptor for communities with diverse language, ethnic background, nationality, dress, traditions, food, societal structures, art and religion characteristics (17).</p> <p>More specifically, CALD may be used to refer to people from non-English speaking backgrounds (18).</p>
Care leavers and people affected by forced adoption	<p>A care leaver is ‘a person who was in institutional care or another form of out-of-home care, including foster care, as a child or youth during the 20th century’, including:</p> <ul style="list-style-type: none"> • Forgotten Australians • Former Child Migrants • Stolen Generations (19). <p>Forced adoption refers to ‘adoption where a child’s natural parent, or parents, were compelled to relinquish a child for adoption’ (21: p.6).</p>
People with disabilities	<p>Disability is an umbrella term that encompasses any or all of the following components (all of which also may be influenced by environmental and personal factors):</p> <ul style="list-style-type: none"> • Impairment—problems in body function or structure • Activity limitation—difficulties in executing activities • Participation restriction—problems an individual may experience in life situations (21).

Population	Definition
People experiencing homelessness	<p>A person is defined as homeless if they are living in either:</p> <ul style="list-style-type: none"> • Non-conventional accommodation or ‘sleeping rough’, or • Short-term or emergency accommodation due to a lack of other options (22).
People who are incarcerated	<p>All persons remanded or sentenced to adult custodial corrective services agencies in each state and territory in Australia (23).</p>
People who identify as LGBTI	<p>Including individuals who are lesbian, gay, bisexual, transgender or intersex, the umbrella term LGBTI refers to those of diverse sexual orientation, sex or gender identity (24).</p>
Refugees	<p>Any person who, owing to a well-founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group or political opinion, is outside the country of his/her nationality and is unable, or owing to such fear is unwilling, to avail him or herself of the protection of that country (25).</p>
Veterans	<p>All former members of the Australian Defence Force (ADF), irrespective of whether they were deployed or undertook war or warlike service (26).</p>

Of these groups, Aboriginal and Torres Strait Islander peoples, people from CALD backgrounds, people who are experiencing homelessness, LGBTI people, veterans, and care leavers and those affected by forced adoption are designated in the *Aged Care Act 1997* as ‘people with special needs’ (27). Two other special needs groups—people who live in rural and remote areas and people who are financially or socially disadvantaged—are not explicitly captured in the scope of this project. It is acknowledged, however, that these characteristics ‘cut across’ all nine populations highlighted within the project’s scope.

Similarities, diversity and crossover

Some of the potential barriers to access and uptake of palliative care services may be common to more than one under-served population. For example, language and communication issues are likely to contribute to access barriers for groups including Aboriginal and Torres Strait Islander peoples and those from CALD backgrounds (including refugees) (28).

Of particular note, the nominated under-served populations are at increased risk of historical trauma and associated or independent mental health issues (29–32).

However, it is also important to acknowledge that there is significant diversity both between groups and within each population, and that many individuals are likely to belong to more than one of the identified under-served populations.

These complexities illustrate the importance of a person-centred approach to palliative care service delivery. Contemporary palliative care recognises that life experiences, including those related to culture and ethnicity, influence people’s preferences for end-of-life care (14).

2 | Aboriginal and Torres Strait Islander peoples

According to the National Aboriginal Community-Controlled Health Organisation, the following definition (used by the federal government, state legislation and the High Court) should be 'the only acceptable definition of Aboriginality'. The definition requires three conditions to be established:

- Descent (i.e. a parent is of Aboriginal or Torres Strait Islander descent)
- Self-identification (i.e. the individual identifies as an Aboriginal or Torres Strait Islander)
- Community recognition (i.e. the individual is accepted as such by the Aboriginal or Torres Strait Islander community in which he/she lives) (16).

Introduction

Aboriginal and Torres Strait Islander people over the age of 50 are considered 'aged', compared with 75 years and older for the non-Indigenous community, and life expectancy within the Indigenous community is considerably less (33). The mortality rate among Aboriginal and Torres Strait Islander peoples is 1.6 times that of non-Indigenous Australians, and cardiovascular disease and cancer are the leading causes of death (34).

While cancer diagnosis rates are overall lower than for the general population, Aboriginal and Torres Strait Islander people are less likely to participate in cancer screening, are less likely to receive adequate treatment for cancer, and have a higher age-standardised mortality rate from cancer that is increasing (35).

More broadly, given the gap in mortality rates, Aboriginal and Torres Strait Islander people experience the death of family, friends and community members far more frequently than the general population (36), and for some communities, death is so frequent that they 'are in either acute or chronic shock from constant bereavement' (38: p.48).

In a broader sense and through complex mechanisms, Aboriginal and Torres Strait Islander communities' history of dispossession, racism and systemic discrimination has contributed to barriers to health care access and significant health disparities (38).

The rate of palliative care-related hospitalisations across public hospitals in Australia is about twice as high for Aboriginal and Torres Strait Islander people as for other Australians (39), but only 1.3% of palliative care-related encounters in general practice were recorded as being provided to Indigenous people. Given that Aboriginal and Torres Strait Islander peoples comprise 3.3% of the Australian population, this suggests that these populations are under-represented in general practice-based palliative care (40).

Literature review findings

For this review, international literature relating to Indigenous populations was excluded (given cultural differences and availability of Australian literature), as were articles relating to broader care considerations for Aboriginal and Torres Strait Islander peoples (e.g. aged care, cancer care).

Although conducted some time ago (2003), a specific National Indigenous Palliative Care Needs study is of particular relevance to this review (41). The study found very few Indigenous-specific services or initiatives in the palliative care area at that time, and suggested that key barriers included referral issues, shame, fear, lack of knowledge and eligibility issues for non-cancer clients (41).

Key findings from the literature review are summarised below.

Barriers to palliative care

Individual and family barriers

At a broad level, a **lack of understanding and awareness** regarding palliative care, and/or **fear of Western medicine and healthcare providers and services** may be a common barrier to accessing palliative care for Aboriginal and Torres Strait Islander people (42–47). This may include a misconception that palliative care only relates to the last few days of life (48).

Other individual and family-related barriers are summarised below.

Language and communication

Among Aboriginal and Torres Strait Islander people, English language skills range from zero to full proficiency (49). Although language is only one factor in communication, it is of obvious importance. In the Northern Territory, for example, more than 40 Indigenous languages are known to exist and, while 70% of Aboriginal people (in 2000) spoke a language other than English at home, limited availability and use of interpreters in health service delivery has been reported (37,50). Where interpreters are available, there may be little or no understanding of palliative care (and no education regarding these concepts) among those individuals (51).

Even for Aboriginal and Torres Strait Islander people fluent in English, communication difficulties can result from different understandings of health and disease, and a lack of direct translation: Western ‘clinical talk’ can be seen as a foreign language (49,52). As often highlighted in the literature, there is no Aboriginal word for ‘cancer’, and biomedical explanations regarding the development and progression of disease are often not congruent with Aboriginal cultural understandings (see *Community/cultural barriers*). In addition, ‘cultural shyness’ may mean Aboriginal and Torres Strait Islander people do not speak openly and/or assertively (49), and conversations regarding death and dying may be considered ‘bad talk’ by some people and communities (48).

A lack of effective communication, particularly between mainstream service staff and Aboriginal and Torres Strait Islander people and their families, can be a significant issue in the provision of effective and appropriate palliative care, fostering fear for individuals and families and

creating problems such as obtaining informed consent (48,52). While Aboriginal and Torres Strait Islander people may consider communication sub-optimal in palliative care delivery (37), language and communication barriers also represent a source of frustration for non-Indigenous healthcare practitioners (48,49,52). Health professionals who may find it stressful to speak to any family about death may find it even more difficult when language and cultural barriers exist (53).

While language and communication issues present key challenges in the provision of palliative care, for many Indigenous people native language has strong emotional and spiritual value, especially at the end-of-life. As noted by O'Brien et al. (2013), 'the inability of clinicians and patients to be able to speak the same language, particularly at the [end-of-life] is another limitation to providing appropriate, culturally competent and person-centred care' (55: p.5).

Kinship and caring

Relative to a Western model of palliative care, kinship and the extended family network are elements of increased importance in effective palliative care delivery for Aboriginal and Torres Strait Islander peoples (43). Caring for unwell and dying family members is considered an important family responsibility (55). Aboriginal families' care for dying family members might include the preparation of bush food and music and singing (56). Traditionally, **kinship rules may determine who is the right person to provide care** (56), and care by a person of the opposite sex may bring shame or embarrassment (48). These and other factors may have an impact on palliative care providers' ability to deliver appropriate services.

However, caring for a dying loved one has been described as 'hard work not suited to some individuals' (57: p.5) and the experience can be 'fraught with challenges of **distance, social isolation, poverty, and overcrowding**, as well as different cultural needs' (p. 1). Family members (as well as patients) may feel 'stuck at home' in settings where there is no access to respite services (43,57), and may be unwilling to administer end-of-life medicines for fear of poisoning (and associated blame and payback) or because interfering with suffering might be considered inappropriate for a culturally-determined sickness (58).

In some cases, **social breakdown and substance abuse** can adversely affect the way families and communities look after the dying, and the introduction of services (where available) can have a negative impact by interrupting traditional kinship roles (37).

Cost

Finally, **financial cost** is also referred to in the literature as a barrier, particularly relating to logistical issues for those living in rural or remote communities, with expenses relating to cost of visits, palliative care staff time, provision of equipment, transport and power (43,59). Although clearly not universal, McGrath (2000) noted in the context of palliative care that 'the lack of publicly-funded health services is compounded by the material poverty of Aboriginal people' (44: p.60).

Community and cultural barriers

O'Brien & Bloomer (2012) highlighted that 'while there is no doubt Aboriginal people have taken on aspects of the non-Aboriginal culture in the last 200 years, their expectations and rituals around end-of-life...still arguably extend from their

connection to the land, culture and tradition' (61: p.39).

There are many significant cultural differences between the dominant Anglo-Australian culture and that of Aboriginal and Torres Strait Islander peoples (61,62). While it is outside the scope of this literature review to describe all such differences, it is clear that these can create barriers to access to palliative care for Indigenous populations.

Such barriers include differences in **fundamental understandings** of health, disease and dying—e.g. beliefs such as 'cancer is contagious' (63), and illness and dying being embedded in beliefs about curses and payback for past misdeeds (43). It was reported that individuals sometimes held both traditional Indigenous and Western belief systems simultaneously (53).

While acknowledging wide variation among Aboriginal communities and individuals, O'Brien et al. (2013) noted that Aboriginal perspectives on death and dying commonly incorporate:

- A whole-of-life outlook which not only focuses on the social, emotional, spiritual and cultural wellbeing of the individual, but also of the entire community
- A cyclical life-death-life concept, so that death is not feared but seen as the time when a person's spirit leaves their body and returns to the Dreaming to await reincarnation
- Mourning and grieving customs.
- Ceremonies that assist the spirit to leave the physical body and return to its sacred place (55).

There may be a perception that non-Indigenous health professionals are not aware of the importance of an Indigenous

person's spiritual beliefs in their end-of-life care, and patients may therefore be **reluctant to talk** with them about such things. In other cases, health professionals may not be aware of the prevalence of Christian beliefs among Aboriginal and Torres Strait Islander people, which sometimes coexist with traditional spirituality and understandings (62).

A **preference for traditional healing** (63) and the importance of '**dying on country**' for Aboriginal and Torres Strait Islander people is clearly a key consideration for palliative care services (see below). However, this is balanced in some instances by the fact that, if a person dies in the family home, the family may not be willing to live there for some time following the death (64).

Health professional barriers

Referral issues

A 2003 report noted that 'probably the most significant factor influencing access (or lack of access) to palliative care services is the question of referral'—finding that Aboriginal and Torres Strait Islander people were either not referred at all to palliative care, or were referred 'late' (42: p.4).

A recent study found that there was a greater likelihood of delayed commencement of specialist palliative care for Aboriginal and Torres Strait Islander people, particularly for younger individuals, those presenting for a first episode of palliative care, and those living outside major urban centres (65). Late referral presents a number of complications and added difficulties and can make relationship-building and discussion of palliative care issues and practices even more difficult for non-Indigenous health professionals (48).

Lack of palliative care/cultural awareness

In some cases, a lack of knowledge and awareness about palliative care among Aboriginal and Torres Strait Islander health service providers (e.g. Aboriginal Health Workers (AHWs) and those serving remote communities), as well as communities more generally (41,43,54) may contribute to access issues.

Many contributors to the 2012 Senate inquiry into palliative care in Australia 'attributed the relatively poor engagement by Aboriginal Australians with palliative care services to health professionals' lack of cultural knowledge around death and dying' (11: p.153). Within mainstream services, even well-meaning health professionals 'may be so afraid of doing the wrong thing that they are struck by... "cultural paralysis" when confronted by unfamiliar cultural circumstances' (38: p.48). While 'cultural brokerage' is required, it can be particularly difficult when service providers from outside the community are working with people from cultures in which not all knowledge can be shared with all people (37).

The 2003 National Indigenous Palliative Care Needs Study highlighted that 'generalist cultural awareness training of the kind that many health professionals receive is not adequate for the sort of cross cultural practice required of palliative care workers' (42:p.13).

As well as individual healthcare providers, a lack of cultural awareness and sensitivity can apply to organisations and services more broadly (see below).

Organisation/service-side barriers

Lack of available services where Aboriginal and Torres Strait Islander people live

While the majority of Aboriginal and Torres Strait Islander people are based in Australian cities and towns, a significant proportion of the published literature relates to the difficulties in providing care to remote Aboriginal communities. For example, one paper noted that 'palliative care and respite services in central Australia are vastly complex, with issues of remoteness, a high proportion of Indigenous people in the population, high levels of chronic diseases, and high levels of poor living conditions needing to be factored into the development of a service' (58: p.7).

Particularly in remote areas, palliative care services simply may not exist—either for Aboriginal and Torres Strait Islander or non-Indigenous people—with geographical distance and isolation a major challenge in providing home-based palliative care (45,57). In such cases, Aboriginal people may have to rely on acute and other care settings (hospital accident and emergency wards, health clinics, community nurses, general practitioners, respite care, and care for the aged) for palliative care services (43).

This brings about a particular issue for Aboriginal and Torres Strait Islander people in remote areas who are often committed to '**dying on country**' (56,66). Many practical barriers to dying on country exist, including issues relating to equipment, facilities, transport, telephone service, access to medicines, carer supports and access to specialised care (37,45,58).

While many Indigenous people living in remote communities must travel to a metropolitan hospital to access specialist palliative care services or respite, such relocation is fraught with fears about a broad range of factors including leaving their home, family and community, the mainstream hospital environment, cultural alienation, communication barriers, disempowerment, and financial issues. Patient escorts may experience similar distress (43,57).

Although geographical distances may present major challenges in delivering home-based palliative care in remote areas (45), White et al. suggested that 'an over reliance on a simplistic and binary view of remote cultures, has shifted attention away from an examination of the real capacity of remote communities to aid in developing their own palliative care service' (68: p.29). It was suggested throughout the literature that building community capacity to deliver local palliative care services is essential to ensuring appropriate care (60).

Beyond the broad cultural considerations highlighted above, there was a lack of literature retrieved through this review relating to specific barriers for urban populations of Aboriginal and Torres Strait Islander peoples.

Appropriateness of palliative care services

'Mainstream' palliative care services are often not suited to care for Aboriginal and Torres Strait Islander people either culturally, geographically or logistically (55).

Even when appropriately located to allow a person to die within their own community (see above), services may not be able to

facilitate an appropriate death. For example:

- Room size or hospital policies and regulations may not allow for large family gatherings (60), or for ritual cleansing (smoking ceremonies) to take place (45)
- A lack of privacy may not facilitate the cultural practice of passing on sacred information to family members (45)
- There may not be access to outside areas and seating, or cultural artwork (55).

Workforce issues

Both a **lack of Aboriginal and Torres Strait Islander people trained to provide community-based palliative care** (60) and a **lack of education and cultural awareness or respect among non-Indigenous staff** were mentioned in the literature as limiting services' ability to provide culturally-appropriate palliative care. While 'the inclusion in a palliative care team of an Indigenous health worker will usually be of great value in facilitating team and personal interactions with Indigenous people' (69: p.519), elsewhere it was noted that in some cases AHWs (and others) were reluctant to become involved in the care of a dying person, for fear of blame or association with that death (37,53,69).

Staffing issues also included **inadequately staffed health clinics** (particularly in remote areas) where acute issues may take priority and a lack of palliative care trained people to undertake care of the terminally ill in these settings. Staff **turnover** was also identified as an issue for Aboriginal and Torres Strait Islander people and their families, for whom a trusting relationship was vital to care provision (57).

Enablers of access to palliative care

Given the number of barriers described above, it is unsurprising that there are a vast number of recommendations in the peer-reviewed and grey literature to support improvement in access to palliative care for Aboriginal and Torres Strait Islander peoples. While addressing each barrier individually should presumably lead to improved access, it is perhaps most useful to consider them together to re-imagine services that are acceptable and appropriate for Aboriginal and Torres Strait Islander individuals, families and communities—although a number of key individual factors are addressed briefly below.

Holistic models

McGrath et al. (43,61) described the development of a model for Aboriginal palliative care service delivery based on consultations with a variety of stakeholders in the Northern Territory and review by a national panel of experts. Importantly, the model summarised and addressed many of the barriers highlighted in the literature. The model was based on key principles of equity, autonomy and empowerment, trust, humane, non-judgemental and seamless care, an emphasis on living and cultural respect (61).

In a more practical sense, the model addressed many of the barriers to access highlighted above by recommending:

- Employing AHWs
- Ensuring effective communication/respect for language
- Addressing psychosocial and practical problems

- Building services in the communities
- Encouraging family meetings
- Organising consumer and professional educational activities
- Addressing relocation issues, with a focus on staying at home
- Understanding and supporting cultural practices
- Developing culturally-appropriate healthcare facilities
- Offering carer and escort support
- Providing respite (43).

Similarly, the 2003 National Indigenous Palliative Care Needs Study identified a large number of issues affecting the accessibility of palliative care for Aboriginal and Torres Strait Islander peoples, and the literature published since suggests that many of these remain priorities. Elements of ‘good practice’ articulated in the report included:

- Early referral
- Cultural advocacy and brokerage
- Good communication and relationship development
- Clear coordination
- Regular case management meetings, including cultural advocates
- Continuity of care
- Flexibility and responsiveness which recognises individual needs (41).

The associated practice principles highlighted a number of factors affecting—and organisational and personal strategies for addressing—the principles of **involvement** of Aboriginal and Torres Strait Islander people, **communication** and **training**.

Queensland Health's 'Sad news sorry business' resource provides practical guidance to clinicians around developing cultural capability (including cultural respect and recognition, communication, relationships and partnerships and capacity building) and providing appropriate care for Aboriginal and Torres Strait Islander people in the final stages of life (50).

Though not palliative care-specific, the National Safety and Quality Health Service (NSQHS) Standards include six actions specifically relating to Aboriginal and Torres Strait Islander peoples, including partnership with communities, safety and quality priorities that address the specific health needs of Indigenous people, improving cultural awareness and competence within the workforce, providing a welcoming environment and routinely asking about and recording Aboriginal and/or Torres Strait Islander identity (70).

In its position statement, Palliative Care Australia noted the disparities in service provision between urban and remote areas, and that 'the heterogeneity of Aboriginal and Torres Strait Islander culture means models of care need to be flexible to address the specific needs of different culture groups' (71).

A number of jurisdictions have developed specific guidelines or frameworks to promote the delivery of appropriate palliative care services to Aboriginal and Torres Strait Islander people and communities—e.g. Queensland (72), Victoria (73), NSW (74) and the ACT (75)—and a national guideline has been developed by the Program of Experience in the Palliative Approach (PEPA) (76). These have been further explored with jurisdictional representatives as a part of the broader project.

Responsive, dedicated local service design

O'Brien & Bloomer (2012) suggested that 'providing patient care in the community rather than in mainstream facilities is essential to ensuring appropriate care: when embedded in mainstream services there is some concern culture and community are not addressed' (61: p.39).

An example of a service developed according to local need is reported in Alice Springs, where a flexible, community-based, and culturally-appropriate respite house was developed. Importantly, staff provided transport to and from the facility. An evaluation of the service (after ten months of operation) suggested the service brought improvements in daily living for respite patients and their carers and improved case management of patients with chronic and complex issues (57). Flexibility, as well as a whole-of-service approach, was noted in a 2018 review as a feature of models attempting to reduce barriers to palliative care for Indigenous populations In New Zealand, Canada and the US, as well as Australia (77).

Cultural respect

Across the literature, the centrality of cultural respect is clear.

Maddocks & Rayner (2003) noted that the word 'respect' encompassed 'many aspects of the appropriate approach to health care and palliative care for Indigenous Australians: respect for the terrible history of displacement, dispossession and violence that characterised white-black relations over generations; respect for different meanings of "family"; respect for the suspicion and discomfort commonly felt by Indigenous people required to enter major healthcare institutions, and the need for

Indigenous ownership, management and staffing of more acceptable healthcare facilities; and respect for the need to “sit down” with patients and family members, giving enough time and space to hear how needs are expressed and to bring family-based decisions into professional-led care plans’ (69: p.519).

Respecting the importance of dying on country is perhaps ‘the most important issue to be taken into consideration when developing palliative care for Indigenous communities’ (47: p.190).

Effective and appropriate communication

In some cases, it was suggested that an interpreter or advocate may be necessary for effective communication with an Indigenous patient in the palliative care setting, particularly for ‘difficult’ end-of-life situations, although finding one (in particular with the right kinship relationship to the patient) can be a difficult process (49,52).

Beyond ‘pure’ language considerations, communication with Indigenous patients, their families and communities must be undertaken in a culturally-sensitive way. Persistent or direct questioning, reflection, sharing perceptions, eye contact and touch, and use of particular terms such as ‘death’ and ‘dying’ may not be appropriate for all Aboriginal and Torres Strait Islander people (47).

More broadly, ‘the central concept informing communication with Aboriginal people is that the right story must be told to the right person: that is, full and culturally appropriate information (properly translated, with the opportunity given for feedback to ensure comprehension) must be communicated to a person selected in

recognition of the importance of family and community relationships’ (44: p.2).

Workforce development: Aboriginal healthcare professionals and workers and cross-cultural teams

To ensure appropriate palliative care delivery to Aboriginal and Torres Strait Islander peoples, the literature suggested a ‘compelling need to build the Aboriginal community capacity to train and sustain Aboriginal palliative care Indigenous clinicians’ (61: p.39). Indigenous Liaison Officers and AHWs within community palliative care services can advise the palliative care team on culturally-appropriate care for Aboriginal and Torres Strait Islander individuals and play a significant role in community liaison (58). In presenting a case for AHWs in palliative care, McGrath et al. (2007) noted that ‘Aboriginal people can interpret not only the spoken but also the non-verbal language of Indigenous people’ (79: p.433).

Relevant education and training for both Indigenous workers in communities and non-Indigenous palliative care providers was recommended as a high priority (58,66), as improving access to palliative care for Aboriginal and Torres Strait Islander peoples requires a workforce with the relevant knowledge and skills (42), including knowledge of Aboriginal spiritual beliefs relating to death and dying (62).

In the Northern Territory, a Rural Community Palliative Team (including a clinical nurse manager, Indigenous Liaison Officer/AHW and palliative care doctor) visits patients and supports primary care professionals in remote community clinics, and PEPA provides remote workshops for community health staff as well as

facilitating visits to the Darwin-based palliative care team for rural and remote clinic staff (42,58,66). This type of ‘two-way’ cross-cultural education can help medical and nursing staff to improve their understanding of Indigenous peoples’ views, and Indigenous people to learn more about prevention and treatment of cancer from a biomedical perspective (69).

Consistency of staffing is an enabler of access to palliative care for Aboriginal and Torres Strait Islander peoples, as trusting relationships help communities engage with services (57).

Community engagement

The literature suggests that while there may be a lack of knowledge of the role of palliative care and the services available, once this is addressed—and communities gain some experience of palliative care services—there is often a positive reaction from Aboriginal and Torres Strait Islander individuals and communities (37,43,46).

Meaningful engagement with communities and families has been highlighted as a fundamental prerequisite for progress in the design and implementation of improvement strategies (77).

Partnerships

Partnerships between service providers, consumers and communities are considered a key element of quality healthcare provision, with the user guide for Aboriginal and Torres Strait Islander health associated with the NSQHS Standards recommending that health service organisations discuss customs and practices with the local community, to determine strategies that can be used to meet local and individual needs (70). For example, cancer services across Australia highlighted the importance of working with local health networks (e.g.

Aboriginal Community Controlled Health Services and Primary Health Networks as well as palliative care services and Indigenous community members) in delivering best-practice care (79).

Other partnerships (e.g. between state/territory health departments and palliative care services and relevant media channels) are also considered important in engaging Aboriginal and Torres Strait Islander communities in discussions and initiatives relating to palliative care (48).

Advance care planning

Not a great deal of information regarding use of advance care planning by Aboriginal and Torres Strait Islander people was uncovered by this review, perhaps simply because it is not common practice for most of this population (80). As noted by a Tasmanian project, ‘experience of death is widespread, but preparation for it is uncommon’ (82: p.9). However, Waran et al. (2017) noted that early discussion of end-of-life preferences, with the use of advance care directives, ‘could play an important part in preventing unnecessary displacement of patients by allowing those who wish to die in their community to do so’ (83: p.377).

Sajiv (2013) noted that ‘challenges in creating advance directives include factors involving trust, uncertainty, hope, presence of multiple clinicians, communication issues including adequacy of communication, the willingness of clinicians to follow patient preferences, patient and family misunderstandings about the process, [and] documents not available when needed’ (81: p.4). As for more general aspects of palliative care, the inclusion of (the right) family members and effective communication are considered paramount

(80,83). Other potential barriers to advance care planning include taboos surrounding talk of death, the involvement of multiple clinicians (but none singly responsible for advance care planning), uncertainty around an individual's prognosis, the availability of family locally, the scarcity of Aboriginal Health Practitioners (AHPs) and the formal, structured nature of (in particular) advance care directives (82). Waran et al. (2017) noted that in the Northern Territory, despite the high proportion of Aboriginal and Torres Strait Islander people in the population, training in advance care directives is not part of the curriculum in AHP training, even though these practitioners are the ones asked to help Aboriginal people prepare the documentation. It was suggested that less formal discussions and processes, along with educational efforts, may be key strategies for overcoming the barriers (82).

In a study from Western Australia, Aboriginal and Torres Strait Islander community members were given information about advance care planning by an AHW and a palliative care researcher at community events or home visits. The study found that the role of the AHW was important in this context, and that a **whole-of-community approach** was useful in promoting the use of advance care planning (83).

A 2015 scan of Australian online resources found five palliative care resources that specifically referred to advance care planning for Aboriginal and Torres Strait Islander peoples (84), such as that produced by Austin Health, which includes a step-by-step guide for advance care planning (85). A number of other resources have been developed across Australia for this purpose in recent years, including a brochure from

the Department of Health (86) and an app developed in Queensland (87).

3 | Care leavers and those affected by forced adoption

A care leaver is ‘a person who was in institutional care or another form of out-of-home care, including foster care, as a child or youth during the 20th century’, including:

- Forgotten Australians
- Former Child Migrants
- Stolen Generations (19).

Forced adoption refers to ‘adoption where a child’s natural parent, or parents, were compelled to relinquish a child for adoption’(21: p.6).

Introduction

Care leavers and those affected by forced adoption (as defined above) have been identified as special needs groups in the *Aged Care Act 1997* (88), and may also face considerable barriers in accessing palliative care.

It is estimated that, throughout the 1990s, more than half a million children in Australia (**Forgotten Australians**) were placed in institutional and out-of-home care under various arrangements (89). Also in the mid-20th century, more than 7,000 children from the UK and Malta were sent to Australia as **Child Migrants** (90).

Between the late 1800s and the 1970s, many Aboriginal and Torres Strait Islander children were forcibly removed from their families—so many that ‘almost every Aboriginal family today can identify one or more family members lost’ as part of the ‘**Stolen Generations**’ (91: p2).

While it is not possible to enumerate the number of people affected by **forced adoptions**, ‘tens of thousands’ of people have been affected, and the associated trauma can be inter-generational (91).

Literature review findings

No relevant literature was found using the search methodology outlined in *Appendix A*, with palliAGED noting on its website (in April 2018) in relation to care leavers that ‘there is limited published research or supports in Australia to inform aged care and palliative care practice in this evolving area’ (92).

However, information of relevance to this project includes:

- There is some evidence that care leavers may have higher rates of chronic health conditions than the general population (93).
- Many care leavers were physically or sexually abused in their settings of ‘care’.

- Homelessness, drug and alcohol misuse and mental health issues are more prevalent in this group than among the Australian population overall (90).
- Those affected by forced adoption may have complex mental health issues including depression, anxiety, complex and/or pathological grief and loss, post-traumatic stress disorder (PTSD), abandonment, identity and attachment disorders, and personality disorders (94).

Barriers to access to health care

Fear and mistrust of government agencies and services—along with a **history of trauma**—may be key barriers to access to care (in general) for many care leavers and people affected by forced adoption (89,90,93). Shahid et al. (2013) noted that mainstream palliative care providers may have ‘little understanding that many Aboriginal people do not want non-Aboriginal people coming to their homes for reasons which may include memories of the past when Aboriginal children were removed’ (49: p.4). Fear and mistrust of professionals and agencies associated with former forced adoption practices was also noted among the affected cohort (95).

A **lack of family support** may also be an issue for Forgotten Australians, with relationship difficulties and isolation at least in part attributed to their childhood experiences (93). Many have lived alone all their lives, have broken marriages, and/or have chosen not to have children (89).

Research involving around 700 Australian care leavers suggested that barriers to accessing services in general also included **cost**, a **lack of services or information** about them, **stigma**, and **lack of transport** (93).

Enablers of access to health care

Although not specifically relating to provision of palliative (or even aged) care, it has been recommended that service providers utilise **trauma-informed approaches** for care leavers and those with a forced adoption experience (93,94). **Training** of health professionals across the healthcare sector was recommended to help the workforce identify and meet the needs of those with histories of complex trauma, as well as mitigate the risks of vicarious trauma (93).

4 | People from culturally and linguistically diverse backgrounds

The term ‘culturally and linguistically diverse’ (CALD) is a broad and inclusive descriptor for communities with diverse language, ethnic background, nationality, dress, traditions, food, societal structures, art and religion characteristics (17).

More specifically, CALD may be used to refer to people from non-English speaking backgrounds (18).

Introduction

More than one-third of people in Australia aged 65 and over were born overseas, and most of these (61%) were born in non-English speaking countries. People from CALD backgrounds may experience a range of barriers to accessing and engaging in a range of health and community support services (96).

Almost half of the Australian population is either first or second generation Australian, and more than 20% speak a language other than English at home: most commonly Mandarin (2.5% of the population), Arabic (1.4%), Cantonese (1.2%) and Vietnamese (1.2%) (97).

It is unsurprising that CALD patients and their families report greater communication problems than non-CALD patients, but

international and Australian research also suggested that they often receive less adequate palliative care (98). International research suggests that they might, at least, have different experiences of care compared with other patients. For example, some populations may experience different rates of more aggressive end-of-life care compared with comfort-focused treatment, or be more or less likely to have an advance directive documented (99).

Huang et al. (2009) noted that ‘culture plays a critical role in the different perceptions of end-of-life needs by patients, their families and healthcare providers’, affecting people’s beliefs about health and illness and death and dying, their health-seeking behaviour in general, and their emotional responses to life-limiting illness and palliative care (101: p.E13).

Literature review findings

Barriers to palliative care

Individual and family barriers

Language and communication

Given the diversity in first languages of CALD populations and English-language proficiency between individuals, communication is an obvious barrier to

access to palliative care for CALD populations (101–103), compounded by a lack of non-English information and interpreting and advocacy services (104,105).

In some cases, the words used in the area of palliative care do not translate well: as an example, for Spanish-speaking people in the US, ‘hospice’ may be taken to mean an orphanage, a nursing home, or a mental institution (106). Similarly, Western terms related to death and dying might not be compatible with diverse cultural beliefs and practices (107). In a number of cultures, however, the whole subject of death or dying is considered uncomfortable or even taboo (102). In cultures with Chinese-based roots, there is little agreement on what ‘palliative care’ means (108).

Preferences and beliefs

Crawley (2005) noted that ‘patient and family beliefs, values, customs, languages, and immigration status may influence end-of-life decision making, preferences for treatment (including alternative and complementary medicine), communication with providers, trust, and satisfaction with care’ (110: p.S-64).

Again noting the heterogeneity within cultures and individuals, individual and family-related barriers might include a **focus on curative care** with maximal medical treatment (110) or conversely a **preference for ‘less aggressive’ end-of-life care** (111), **negative views or mistrust of palliative care services** (104,111,112), a **preference for dying at home** (104), and for **being cared for by family members** (113). This is especially evident in Confucian philosophy, which forms the basis of behaviours and transitions in Chinese-based cultures, where filial piety (respect for and obedience to parents, elders and ancestors) is much

valued (114). However, the **burden of caring** borne by family members may be great. If the family cannot cope, unwanted hospital admissions and death in the hospital may result (102,115). There may also be reluctance on behalf of an individual to burden their family, despite a preference to die at home (116), and some cultures do not support dying at home (117).

Religious and spiritual beliefs may also affect individuals’ palliative care preferences. For example, concepts and understandings regarding pain and suffering (e.g. viewing these as a ‘test of faith’ that should not be interfered with) may be incongruent with symptom management in palliative care (105,118), or faith may provide hope in the context of ‘medical futility’ (119).

Lack of awareness/knowledge

As with other under-served populations, there may be a lack of knowledge or understanding of palliative care in general or available services in particular, especially among more recent arrivals (102,104,111,120). In some cases, palliative care (as it is understood in Australia) may not exist in a person’s country of origin (98), and a **lack of information in appropriate languages and formats** (104) may contribute to the issue.

Community and cultural barriers

As for each of the under-served populations addressed in this review, there is great diversity among CALD populations and individuals, and no consistent set of values or beliefs (98,109,111). Interestingly, it has been suggested that understandings and experiences of palliative care across CALD and non-CALD populations are characterised by more similarities than differences (98,102). Nyatanga (2018) noted

that while there may be a significant degree of ‘acculturation’ throughout life, rituals at birth and death tend to remain largely unaffected, passing on from one generation to the next (103). Similarly, Bray et al. (2018) described migrants’ ‘dual possession of a new hybrid identity developed in their adoptive country, and an inner ethnic and cultural identity, in varying degrees of harmony with each other’ that may require some degree of resolution at the end-of-life (123: p.2647). Among Sudanese communities in Australia, different preferences around death and dying may be expressed by older and younger members (123).

In addition, there may be a **variety of understandings about palliative care and attitudes and beliefs about illness, suffering and dying** between patients and their families and healthcare professionals (111), and such differences can translate to a barrier to access palliative care services (116). Common differences may include:

- A desire to carry the burden collectively
- Reluctance to speak about death and dying
- A preference to be cared for and die at home
- Use of traditional medicines or healers (98).

A recent Australian study found that CALD families were often concerned by their loved one’s lack of food consumption, while providers were in turn concerned about families ‘force feeding’ patients—although there was no comparison to other patients’ families (124).

When differing world views (e.g. those related to health and health care) are not understood or respected, ‘tension arises in

the relationship with the minority culture feeling disempowered and vulnerable’ (126: p.111).

Despite these issues, traditional cultural beliefs and traditions are not necessarily incompatible with Western medical theory and practices, as noted for Chinese-Australian people utilising both Western and Chinese medicine (116).

As with Aboriginal and Torres Strait Islander populations, an increased emphasis on family involvement in care is described in the literature for CALD populations (126), and **exclusion of family in decision-making processes** is highlighted as a barrier to culturally-sensitive care (111).

In some cultures there may also be **ingrained values of denial or secrecy**—for example a tendency among families to not share a serious diagnosis or poor prognosis with the patient themselves, limiting the palliative care options that are possible without alerting the patient to the truth (101,102,127). Some communities may prefer to withhold bad news until community supports can be ‘wrapped around’ individuals and families (123). A 2005 review noted that despite this, most people of Chinese origin living in a number of major cities around the world (including Sydney) indicated that they wanted to be informed about their diagnosis, prognosis and treatment options at the same time as their families (128). Green et al. (2018) noted that ‘the role of family members as intermediaries between patients and providers may be in conflict with the Western medical emphasis on patient autonomy’ (125: p.7). Understanding the ‘rules of engagement’ with patients and families around diagnosis as well as navigating the important role of family members while prioritising patient preferences represent key issues for

providers providing palliative care to CALD individuals (129).

Different issues around truth-telling may be apparent in paediatric palliative care.

Wiener et al. (2013) noted that in many cultures nondisclosure of life-threatening diagnoses to children is acceptable, but a cultural reluctance to discuss death with a child (in an age-appropriate manner) may interfere with access to palliative care and cause conflict between health professionals and family members (130).

Health professional barriers

A key barrier to palliative care may be a **lack of understanding** among health professionals about the cultural and spiritual needs of CALD individuals, and how to address these (111).

As with Aboriginal and Torres Strait Islander populations, evidence from Australia and the UK suggests that **referrals** to palliative care for CALD individuals may not be made (102) or may not be 'timely', sometimes because of a lack of awareness of services and referral processes among healthcare professionals who are not palliative care or cancer specialists (104). In other situations, referral may not be made (or be made late) if referring professionals did not think their patients would receive culturally-appropriate care (101). Racial stereotyping and assumptions (e.g. regarding a preference for family care, or the availability of services from within a minority community) may lead clinicians to provide inappropriately differential treatment and effectively create a barrier to palliative care (117,123,129,131).

A recent systematic review suggested that intensive care unit clinicians 'lack the knowledge to enable effective interaction with culturally diverse patients and families

at the end-of-life' (133: p.1), and experience from a Queensland project led to a recommendation that hospital doctors and local GPs be targeted and 'convinced' of the importance of providing information regarding a local culturally-sensitive in-home hospice service—and referrals—to CALD families (102).

Organisation/service-side barriers

In the UK (with particular reference to end-of-life care for minority groups), it was noted that services were '**disproportionately needed in areas of social deprivation** [with higher proportions of minority populations], and disproportionately present in areas of social affluence' (105: p.5). Similarly, a **focus on palliative care for cancer patients** observed in Australia and other countries may be less relevant for other communities or put patients with other diagnoses at risk of sub-optimal care, as cancer rates may be lower among migrant populations (101,133).

Some of individual and family barriers noted earlier affect professional interpreters as well as patients in the palliative care setting. Kirby et al. (2017) noted the challenges of translating the meaning of 'palliative care', interpreting in the presence of family members, communicating sensitively while maintaining professionalism and the emotional burden of difficult clinic encounters (134).

In some cases, palliative care facilities may find it **difficult to accommodate cultural practices** (e.g. cultural rituals, burning of oils or candles (100,111).

It was noted that in some contexts, **healthcare funding models** did not support the provision of culturally-appropriate palliative care, for example by not allowing primary care doctors to claim remuneration

for in-depth discussions regarding a person's faith-based practices (111). In the US, at least, cost, finance and insurance issues were often reported to present barriers to palliative care for CALD populations (99,135).

At the broadest level, **institutional racism** may be a key barrier to access (128,136).

Enablers of access to palliative care

As summarised by Crawley (2005), 'understanding and serving the needs of specific populations requires us to apply a framework of equity and to consider strategies to eliminate disparities. These include identifying sources of bias and discrimination in health care; enhancing the collection of racial, ethnic, and other demographic data; and increasing the representation of a range of diverse population groups in well-designed qualitative and quantitative research' (110: p.558).

In a 2011 appraisal of literature reviews related to end-of-life care in the UK, the authors noted 'the complexity and interrelatedness of factors leading to low service use was recognised and reflected in reviews' recommendations for service improvement' (104).

Fang et al. (2016) suggested that 'guidelines and recommendations can proceed from our academic understandings as a first step towards improved and more equitable practices' (p. 11), especially where they promote person- and family-centred end-of-life care as a process that engages with the experiences of all persons in receipt of care (111).

Individual enablers of note are summarised below.

Cultural competence

Cultural sensitivity and **cross-cultural communication strategies** are described as important features of cultural care (100,126). Cultural competence 'is an amalgam of skills, abilities, capabilities, and competencies necessary for the establishment of respectful and culturally appropriate relationships' (127: p.211), and cultural awareness and sensitivity can help individual healthcare providers 'to actively recognise and meet their patients' cultural needs' (101: p.E16).

It was noted that 'in contrast to the frequent recognition that services need to provide culturally competent care, few reviews provided recommendations about how to achieve this' (105: p.7), and the concept is complex and ambiguously expressed (137). Interpretation of 'culturally-appropriate care' often 'views culture as static and unchanging', 'fails to account for diversity within groups', and leads to 'stereotyping and a failure to identify the needs of the individual receiving care' (139: p.761). In addition, there is 'a paucity of research that involves service users as experts in defining their own needs and assessing their experiences related to cultural care' (138: p.220).

Provider education is one strategy for improving the cultural competence of palliative care services (105). As an example of assisting health professional cross-cultural understanding, the Migrant Information Centre in Melbourne has published a resource to assist providers in caring for people from CALD backgrounds by highlighting key cultural issues for local Cambodian, Chinese, Indian, Iranian, Sri Lankan and Vietnamese communities (112).

Similarly (and more specifically), Partners in Culturally Appropriate Care (PICAC) NSW/ACT provides a summary of cultural attitudes towards palliative care and end-of-life considerations for a large number of cultural groups (139).

At the same time, Nyatanga (2018) notes that 'although cultural competence will remain a noble aspiration for community nurses, this should be placed in the context of the changing cultural world of mass immigration, cross-cultural fertilisation and inter-racial marriages' (104: p.307). Therefore culturally-appropriate care requires consideration of the patient as an individual, rather than a 'cultural being'. As noted by Brown et al. (2018), 'cultural care should be integral to holistic patient care, irrespective of a person's race or ethnicity' (138: p.220). Fostering trust may be a key tenet of providing quality end-of-life care, including to elderly people from culturally diverse backgrounds (140), and conversations about end-of-life conducted with 'humility and openness' may be more constructive than cultural competence per se (118).

Clark & Phillips (2010) outlined key questions GPs might use to explore patients' cultural beliefs relating to end-of-life, relating to communication preferences and comprehension, cultural values and customs, concluding that 'taking the time to understand each patient's unique cultural needs, values and beliefs is the most respectful way of delivering palliative care and facilitating a dignified death' (127: p.213).

Incorporating culturally-dictated needs and preferences into treatment plans may be a way of ensuring culturally-appropriate end-of-life care (105) and, at the organisation level, accommodating the needs of CALD palliative care patients may include

consideration of culturally-determined daily living practices (e.g. relating to diet and hygiene) or the use of alternative therapies (100).

Creating a culturally-sensitive workforce

Workforce development initiatives, in particular training, could help to bolster the cultural awareness and capabilities of palliative care providers (104). Flexible training, aligned with the particular needs of staff, may be helpful (141), although it has been suggested that both **education and training** and **positive experiences** caring for individuals in a particular community, as well as support in the everyday context, are important in determining health professionals' confidence in their cultural competence (115,142,143).

While 'even the best training cannot cover all aspects of care nor deal with the myriad of ways in which values and norms interact and adapt before finally being enacted in the hospital, surgery, or home' (p. 177), understanding various cultures' attitudes to death and dying and cultural rituals is important for palliative care providers (144).

Training could occur at a number of levels across the spectrum of palliative care provision—from training at undergraduate and postgraduate levels for generalist and specialist medical staff to training in palliative care for interpreters and advocates (104). Inter-professional educational programs incorporating critical reflection and dialogue could promote understanding of diverse needs for CALD populations (111).

Recruitment of staff from different cultural backgrounds (i.e. those matching patients'

cultural backgrounds and speaking their native language) is also a key enabler of culturally-appropriate care and promoter of linkages between other health services and palliative care (117,118,145). A small study of doctors in the UK found that the majority felt palliative care services could not be sensitive to religion and culture without this (101).

Language and communication

In a number of cases, the importance of good communication was emphasised above all other factors (104), and it was suggested that **identifying the key decision-maker** in the family may be helpful in identifying patient and family needs (100).

Translation and interpretation have obvious roles in overcoming language barriers, and professional interpreters can improve discussions about and provision of end-of-life care (146). However, the availability and capability of interpreters may be variable, and concepts can quite literally be 'lost in translation', complicating clinical work. Patients from small communities may also be reluctant to use an interpreter known to them or their families (98). Even where available and utilised, interpreters and clinicians face challenges such as balancing accuracy and understanding, pure translation and cultural advocacy, and professionalism and support (147,148). Meetings between clinicians and interpreters before patient discussions may be helpful (146).

In some cases, the involvement of English-speaking family members may be useful in connecting and communicating with patients (98,100), although this can also carry risks—in particular uncertainty about how much information is being provided to the patient (101,104,149).

Aside from the use of interpreters, other techniques for overcoming language barriers include learning some of a patient's language, use of other staff from different cultural backgrounds, and the use of non-verbal cues (informal sign language, facial expressions and symbols) (100). Abunafeesa & Elsayem (2017) described end-of-life care discussions as a critical component of physician training to facilitate the conversation in a culturally-appropriate manner (150).

Awareness

Information about terminal illnesses and the types of palliative care services offered in local communities may increase social acceptance of palliative care for CALD communities (115).

Fang et al. (2016) noted the need for 'intercollaboration, community cooperation [and] experiential knowledge synthesis in order to drive effective [end-of-life] care for ethnocultural groups' (p.5), involving **mobilisation initiatives, public agencies, grassroots organisations and healthcare professionals** (111). Engaging community organisations and religious leaders and church communities may be an effective strategy for improving awareness (117,151), and 'patient navigators' could also have a role in facilitating community engagement through outreach and education activities (see 'other' below) (106).

The availability of **culturally-appropriate resources** (e.g. online, in print) for those approaching end-of-life and their families may be useful to support planning and decision-making about palliative care (111), although elsewhere the potential lack of literacy in an individual's own language was noted as a challenge (101). Ethnic media, including radio and newspapers, may be

useful in communicating about palliative care to broader CALD communities (102).

Other

An article from the US described the potential use of **'patient navigators'** to improve end-of-life outcomes for Latino people. While the role of patient navigators is not consistent across the literature, in general they 'build trust with the community they serve to provide one-on-one, culturally appropriate, patient empowering interventions' (107: p.2014).

A more 'grassroots' intervention, delivered through partnering with African American churches, involved an education program for church leadership, an intensive education and training program for church-based lay companions, and messages and materials targeting the general congregation (151). Providing education using non-threatening language in face-to-face discussions with patients and family members in their homes, and using personal testimonials, are examples of culturally competent intervention strategies a navigator could use to address cultural barriers and increase palliative care access. Once care has been accessed, a navigator may continue to assist with practical and other barriers to care that might arise throughout the patient journey.

Similarly, McGrath et al. (2001) suggested services **create links with volunteer or community organisations** to access volunteers with relevant ethnic language skills, and highlighted the importance of (positive) community experience with services and communication with the younger generation to engage the broader community (102).

In the US, a screening tool applied in the setting of ageing services providers (with

largely African American and Latino clients) found that more than a third of participants might benefit from palliative care services, with most accepting referrals to outpatient palliative care clinics. The authors noted that the tool 'has the potential to increase palliative care utilisation among underserved community-dwelling older adults and may improve their quality of life, potentially in communities worldwide' (153: p.929).

An evaluation of the Culturally Appropriate Palliative Care Strategy (2013—2015) in Victoria highlighted the importance of collaborative efforts from both CALD communities and palliative care services in promoting and providing culturally-appropriate care, including community engagement and long-term, committed relationships and partnerships (153).

Advance care planning

A 2009 review found that, while published evidence is limited, what is available suggests that people belonging to minority cultural and linguistic groups are less likely to be involved in advance care planning than the 'mainstream' population (and may reject the concept outright) (154). However, those with any type of illness may be more likely to engage in advance care planning than other members of their community, and increasing age, income and education may be sociodemographic factors that contribute to awareness and/or completion of advance care planning among some CALD groups, at least in the US (155).

Cultural barriers to advance care planning may be similar to those for palliative care, such as religiosity, preferences for curative therapy, family (rather than individual) decision-making and mistrust of the healthcare system (154–157). However,

these views are not universal, as demonstrated in an Australian study that found while first-generation Italian migrants preferred family decision-making, the opposite was true for Dutch migrants (158).

Again, as with general aspects of palliative care, barriers such as awareness and language are relevant to advance care planning (155), and cultural understanding and sensitivity were considered key in promoting and facilitating advance care planning among CALD communities (159). While for some individuals and communities advance care planning may not fit with their cultural understandings and beliefs around death and dying (160,161), others may experience barriers to access through distance, language or discrimination (160).

Awareness of advance care planning may be low among CALD communities, and some groups may be less supportive (154,161,162), but in other cases interest in and acceptance of the principles may be high (160,161,163). Education and culturally-appropriate community engagement about advance care planning may be needed to increase knowledge and awareness and 'serve and empower' patients (81,155,164), rather than representing 'an imposition of directives by (usually white) healthcare professionals' (156: p.1286). Despite this, a 2015 scan of Australian online resources found no palliative care resources for CALD groups that specifically referred to advance care planning (84). A lack of assistance in preparing medical directives may be a significant barrier for CALD populations (135).

Improving the cultural competence of healthcare professionals may be an enabler of advance care planning among CALD populations (157,165). The [ACPTalk website](http://www.acptalk.com.au)¹, funded by the Australian Government Department of Health, provides 'informational support for health professionals conducting advance care planning with people from different religious and cultural backgrounds' and may also be used by community members. It provides information about advance care planning in the context of Buddhist, Christian, Hindu, Islamic, Jewish, Sikh and secular communities. Within the first nine months, ACPTalk received 12,957 page views in 4260 sessions (primarily from Australia), and the website has been received positively by healthcare professionals (166).

Sudore et al. (2018) suggested that the right resources can overcome literacy, language and cultural barriers to assist CALD (and mainstream) populations in progressing their own advance care planning (i.e. without clinician or system-level intervention) (167), and McDermott & Selman (2018) advocated more informal, communication-based approaches to meet the needs of culturally diverse populations (157). Indeed, there is some suggestion that certain ethnicities (e.g. African Americans) may prefer less formal methods of advance care planning, rather than formal legal directives (118).

In a recent US review, Hong et al. (2018) suggested that efforts to engage diverse communities in advance care planning may be assisted by recruiting more CALD healthcare professionals who are well-

¹ www.acptalk.com.au

informed about advance care planning
(155).

5 | Refugees

The 1951 *Convention Relating to the Status of Refugees* (and its 1967 Protocol)—to which Australia is a signatory—defines a refugee as ‘any person who owing to a well-founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group or political opinion, is outside the country of his/her nationality and is unable, or owing to such fear, is unwilling to avail himself/herself of the protection of that country’ (25).

Introduction

According to the United Nations High Commissioner for Refugees (UNHCR), approximately 68.5 million people worldwide were forcibly displaced at the end of 2017—the highest level in the post-World War II (WWII) era (168). Approximately 25.4 million of those forcibly displaced were considered to be refugees (defined above). Refugees may be forced to leave their home or country for a range of reasons, including exposure to conflict, violence, war, persecution, natural disasters or serious environmental changes (169).

Every refugee is initially an asylum seeker—a person whose claim for international protection is yet to be accepted by the country to which it has been submitted (170).

Australia’s population includes refugees from post-WWII Europe, Central and South America, Lebanon, Laos, Cambodia, the

former Yugoslavia and Africa, with a recent pattern of refugees originating from Asia and the Middle East (171). Approximately 750,000 people have been accepted under Australia’s Humanitarian Program since WWII, with refugees in the country at the end of 2017 numbering almost 50,000 (172). In addition to those recognised as refugees, there are substantial numbers of people seeking asylum in Australia, either on bridging visas in the community, in community-based detention, or in detention facilities located offshore (on Nauru or Manus Island, Papua New Guinea) (173).

Refugees often face a range of health and social challenges as a result of the ‘interplay of language and cultural issues, the disruption associated with the refugee and resettlement experiences and adverse conditions in the community’ (175: p.11). Refugees in Australia may have relatively poor health and complex needs (174) and have higher rates of mental health problems, some infectious diseases, and disabilities compared with the general population (175).

Literature review findings

Very little information regarding the delivery of palliative care services to refugees (outside emergency humanitarian contexts) was found in the current review. As noted by CareSearch, ‘the literature on the health of asylum seekers and refugees may not be easy to find. The relevant literature may be found using terms such as “multicultural” rather than their immigration status’ (176). A 2018 review noted that ‘research on end-of-life experiences among refugees is sorely lacking in the global literature’ (178: p.4).

Barriers to access to health care

While more general considerations for CALD populations are somewhat relevant (see *Chapter 4*), refugee populations in particular face ‘considerable’ barriers to accessing health care in general (173). Beyond language barriers and cultural differences, refugees also have:

- Experiences of trauma and torture that may have ongoing impacts on access to care
- Limited access to transport and other geographical barriers in accessing health care, particularly in rural and regional areas and for people with low or no income
- Varying access to Medicare (for asylum seekers rather than refugees) and other financial barriers (including financial disincentives for service providers)

- A lack of familiarity with Australian healthcare systems and difficulty accessing complex service pathways and appointment systems (174,175).

Similarly, a systematic review of the literature relating to barriers to access to medication and pharmacy services found that communication and language barriers, navigating healthcare systems, different cultural beliefs (including use of traditional medicine) and issues of trust were common barriers to access described in the literature (178).

Hiruy & Mwanri (2014) describe the life experiences of African refugees and associated disadvantages—including mental disorders and stigma along with limited education, poor health, low English language proficiency and employment skills—as barriers to access to palliative care for this population in the Australian context (179).

Healthcare professionals can find caring for refugees challenging (175), and have identified a number of needs including multilingual information on health topics and conditions, education about available services and Medicare eligibilities, and cultural awareness and knowledge of an individual’s experiences before arriving in Australia (180).

A 2013 review found that permanently settled refugees in Australia have inadequate access to primary health care, and that there is limited availability of refugee-focused health services as well as a lack of coordination between services (175).

Enablers of access to health care

Again, although little specific literature was identified relating to palliative care for refugees, some of the enablers of access to palliative care for CALD populations will be relevant to refugees.

Madi et al. (2018) noted that what literature was available stressed ‘the importance of integrating cultural aspects in the delivery of medical and palliative care services to refugees’ (178: p.4).

A recent study seeking to improve the care of refugees in the hospital setting (not palliative care related) suggested that those providing care for this population required greater support, information and education and access to interpreting services in order to overcome barriers to care (180). To improve refugees’ access to primary care, Russell et al. (2013) noted that ‘improved integration is needed between Commonwealth and state-supported services, refugee focused and mainstream health services, health and non-health sectors, and with consumers and carers, supported by robust research and evaluation’ (176: p.16).

A 2018 workshop in Italy involving health professionals and government representatives (from Italy and countries of origin for refugees in Italy) suggested that an approach based on palliative care models, with its holistic focus, may be particularly helpful in improving the health care of refugees (in a far broader sense than end-of-life care), as it encompasses relief of suffering and management of cultural and emotional stress (181).

Cultural mediators—individuals who understand refugees’ faiths, traditions and

beliefs and speak refugees’ own language as well as that of the host country—conduct group awareness and education sessions to familiarise refugees with their host country’s health services. Through ‘innovative styles in communication and cultural products that involve the refugee community...host communities may share the task of integration’ of refugees (182: p.1).

Advance care planning

No literature relating to advance care planning among refugee populations was found in the current search. Again, many considerations for CALD groups are likely to apply.

6 | People with disabilities

Disability is an umbrella term that encompasses any or all of the following components (all of which also may be influenced by environmental and personal factors):

- Impairment—problems in body function or structure
- Activity limitation—difficulties in executing activities
- Participation restriction—problems an individual may experience in life situations (21).

Disability is diverse and can be understood as a continuum from no impairment or limitation, to the complete loss or absence of functioning or ability to complete a task. Almost one in five Australians is living with a disability, and of these, one in three will have severe or profound limitation (182).

Causes of disability include genetic disorders, illnesses, accidents and ageing, or any combination thereof.

Introduction

Almost one in five Australians is living with a disability—and over half of those are aged 65 years and over.

While there is significant diversity among those living with a disability, the literature concerning palliative care barriers primarily focused on the following conditions:

- Neurodegenerative diseases (dementia, Alzheimer’s disease, Motor Neurone Disease)
- Intellectual disability.

For both of these foci, unique barriers to access were uncovered. Further, the literature relating to palliative care for those living with an intellectual disability also comprised paediatric settings, introducing greater complexity to service provision (in particular concerning communication between the child and healthcare provider).

In Australia, resource use related to dementia is expected to increase markedly (183,184), and health professionals will therefore require a more sophisticated understanding of palliative care needs for this population.

Literature review findings

It is well established that those living with a disability are at a significant disadvantage when trying to access high-quality palliative care services (185–187). Barriers primarily relate to individual, family, organisational and healthcare professional characteristics (188).

Barriers to palliative care

Individual barriers

Individual barriers to accessing quality palliative care were considerable for those living with a disability. The primary barrier faced by those living with a disability was **difficulties in communicating** with health professionals and family members during end-of-life care. In some cases, access to palliative care may be delayed because of communication problems between the patient and clinician, especially in the case of palliative care for children with an intellectual disability (189,190). However, the primary concern revolves around the inability of the clinician to understand the patient's needs, the 'patient's ability to articulate symptoms and concerns, and the care provider's ability to communicate' (192: pp.513-4) to the patient. Further challenges in communication may include:

- A person not fully understanding his/her condition
- Cognitive and motor deficits impeding a person's ability to express his/her needs
- Individuals being unable to communicate their levels of pain or discomfort (192–196).

A second key individual-specific barrier described is that of '**overshadowing**'. Overshadowing can be defined as 'a phenomenon in which a person's presentation is attributed to their underlying condition, thereby potentially delaying identification of other problems and referral to hospice and/or palliative care' (192: p.514). In the case of those living with a disability, their presentation to health services may be attributed to the disability they have, rather than recognising the individual may be at the end-of-life and subsequently needing palliative care (191,194,197). In particular, overshadowing is a contributing factor in the premature mortality and high rates of avoidable death among people with intellectual disabilities (198).

Many people with a disability who are facing end-of-life also have complex mental and physical health comorbidities (199). Still, it has been reported that few individuals receive multidisciplinary care at end-of-life such as appointments with geriatricians, psychiatrists, or community psychiatric nurses (199).

Family barriers

Family members and caregivers may display a degree of **avoidance** of the topic of death and dying that may be unwanted by those living with disability and unhelpful in the context of person-centred palliative care service delivery (200).

Families often **lack adequate support** from health professionals and associated service providers during the end-of-life stage when caring for someone with a disability. This is particularly the case for those families caring for a loved one with dementia, as the prognostication of the disease can be extremely difficult (191,201). In a white paper detailing what optimal palliative care

for those living with dementia looks like, van der Steen et al. (2014) detail several factors to consider when supporting families, including:

- Families may suffer from caregiver burden
- Families will need continued support, from diagnosis through to major decline in health status
- Education should be provided to families regarding disease progression and palliative care options
- Families should be encouraged if they wish to take part in the care of a loved one
- Families will need support from clinicians as to their role in future decision making
- Clinicians should be cognisant of the effects of sustained grief felt by families when caring for someone with dementia
- Bereavement support should be explored
- When the person dies, families and fellow residents (if in care) should be given time to adjust to life without the person they have been caring for (202).

The role of **families as decision-making surrogates**, and advocates for quality palliative care for those living with a disability, is significant. This is particularly the case for parents of children living with disabilities, whereby parents and primary caregivers may take on the role of decision making concerning end-of-life care (189,191). In these cases, ensuring the individual has adequate input into the type of care received is important. In a Dutch study of 47 people with intellectual disability in a residential facility, 27 had

decisions made for them by healthcare staff about end-of-life care, with half of those not having any family involvement to advocate on their behalf (191). It has also been highlighted that there is a need to support decision-making surrogates/substitute decision makers/caregivers due to the stress and struggle that is often associated with navigating end-of-life decisions and care (203,204).

A **lack of knowledge** among families concerning disease trajectories and available palliative care options may be another barrier for those living with disabilities. Hertogh (2006) noted that ‘family members often experience a lack of information not only with regard to the specific decisions to be made but also with regard to the natural course of the disease’ (188: p.553). With greater knowledge and education for carers of people with dementia comes increased likelihood that they will choose ‘comfort care’ over more invasive, unnecessary life-sustaining medical intervention (186). Finally, in a qualitative study, people with dementia emphasised it was important to be cared for ‘in place’, stay at home for as long as possible, and be comfortable at end-of-life (205).

Health professional barriers

Barriers associated with health professionals revolved around a lack of knowledge in how to provide palliative care to those living with a disability, difficulties in prognostication regarding neurodegenerative diseases, and beliefs held by staff, particularly concerning neurodegenerative diseases.

In defining optimal palliative care for people with dementia, van der Steen et al. (2014) stressed that healthcare teams should be

adequately trained to provide care (202). Education and upskilling of staff, including volunteers, is necessary for providing quality palliative care to those living with a disability (206). In many cases, health professionals exhibited little experience in working with people with an intellectual disability.

The difficulties concerning prognoses, particularly for neurodegenerative diseases, present significant barriers to accessing palliative care for those living with such conditions. For example, the disease trajectory of dementia is often unpredictable, making it difficult for health professionals to determine an accurate prognosis, and by extension, determine when palliative care is appropriate (201,202,207,208). Furthermore, healthcare professionals working in nursing homes may experience emotional distress while caring for residents with dementia, due to a lack of knowledge and understanding of how to cope with behavioural changes, as well as difficulties coordinating care with family members (209).

Health professional beliefs concerning the terminal nature of dementia were also cited as barriers to accessing palliative care for those with the condition. A number of published papers raised concerns that health professionals may not view dementia as a terminal illness that requires access to palliative care (186,192,210). Similarly, others report that the symptom burden of Alzheimer's and other types of dementia are comparable to those of cancer, yet people with dementia tended to receive poorer quality end-of-life care, based on a range of clinical indicators (prescription of medications, bereavement support offered to next of kin, assessment for pain, and specialist palliative care consultations) (211).

Organisation/service-side barriers

Barriers at the organisation/service level include a lack of planning about where people with intellectual disabilities will live at the end of their lives, including the transitions from family to agency care settings (196). Wark et al. (2017) investigated barriers to providing end-of-life care for people with an intellectual disability in Australia by interviewing direct care staff from a sample of metropolitan and rural locations (212). The following qualitative themes were reported:

- Perceived staff isolation
- Frustration experienced by staff due to awareness of available supports and services but a perceived inability to gain consistent access to them
- Potential isolation from medical services/doctors
- Lack of access to generalist health support
- Internal staffing issues/attracting and retaining suitable staff
- lack of available funding to support individuals with other healthcare needs (212).

In the setting of group homes, O'Hehir (2018) found that palliative care services reported a lack of referral from group homes to palliative care services, while group home staff reported a need to identify residents who would benefit from palliative care in a more timely manner and difficulty advocating for their residents in acute and primary healthcare settings in the context of (changing) healthcare needs (213).

Finally, O'Hehir (2018) briefly discussed the impact of the National Disability Insurance Scheme (NDIS) on funding models for palliative care in group homes, noting that

‘the line between what is funded by the NDIS and what is supposed to be funded by the health system is not yet fully clear’ (214: p.10).

Enablers of access to palliative care

Individual/family enablers

Enablers of access to quality palliative care for those living with a disability revolved around the type of support provided by families, characteristics of the individual, and the ability of service providers to collaborate effectively in providing holistic care. The most important enabler of access was the presence of family to assist with decision making at the end-of-life.

In the case of a person living with an intellectual disability, ‘assisted capacity’ has been proposed as a method of ensuring an individual’s wishes are effectively communicated and they receive the palliative care they desire (214). Assisted capacity involves support being provided from multiple people involved in the individual’s life which may include immediate family members, friends, health advocates and healthcare providers (214). Further to assisted capacity is the process of ‘best respect’, whereby those closest to the person and those involved in their health care engage in an informed dialogue about how to proceed with end-of-life care (215).

Whilst not as prominent in the literature as the support of families, characteristics of the individual themselves may determine whether they are able to easily access palliative care. Lindley et al. (2017) detailed that children with intellectual disabilities with complex comorbid health conditions were more likely than other children with

intellectual disability to enrol in palliative care (189).

Organisation/service-side enablers

Collaboration between services to provide care can enable quality palliative care—e.g. disability services and group homes collaborating with specialist palliative care providers—although such collaboration are not without their difficulties (200,208,213). In Tasmania, a service provider has identified ‘a clear need for a sector-specific strategy which strives to enhance services’ understanding of the role, availability and pathways for accessing palliative care and best practice principles for supporting people at end of life stage’ (201: p.3).

In a mixed-methods study of end-of-life care being delivered in disability community living services in Victoria, Grindrod & Rumbold (2017) found that organisational structure and culture both influenced end-of-life practices in community supported living (216). The authors found that collaboration between disability and palliative care professionals was important in enabling greater access to palliative care for those living with a disability. Similarly, McCleary et al. (2018) expressed that the establishment and continuation of meaningful interrelationships are vital for providing quality end-of-life care for people with dementia in long-term care home settings (217). For people with dementia, a new palliative care model was trialled and evaluated (in the UK), which drew on partnerships between a peak body (Alzheimer’s Society) and a hospice (South Wales) to deliver services by a specialist community palliative care nurse and dementia support worker (218). Education and training sessions were also delivered to health professionals, volunteers and members of the community. The program reportedly enabled support and coping for

carers, as well as allowing a greater number of people to be cared in their place of choice (218). In Tasmania, a 'community of practice' has arisen to 'strengthen the community sector by offering opportunities for organisations to share knowledge, resources and support each other as we strive to enhance the life and death experiences for people with disability' (201: p.6).

Others have suggested strategic and interdisciplinary research is needed to advance and translate palliative care into practice, specifically in the context of dementia (219).

In relation to people growing older with learning disabilities, NICE guidelines (UK) recommend that 'mainstream' end-of-life or palliative care services should, wherever practical, make reasonable adjustments to support people/family/friends/carers and other people they live with, throughout palliative care and bereavement phases (220). Tuffrey & Davidson (2018) reviewed best practice initiatives in end-of-life care for people with an intellectual disability (UK). Key themes included:

- Individual and organisational commitment is required
- Good practice is dependent on 'champions', and being supported by committed organisations/managers
- Collaboration is essential, including continuing relationships between those who provide care at home and the palliative care team
- The individual's story must be at the heart of care – i.e. person-centred care (195).

A tool for identifying palliative care needs among people with intellectual disabilities has been developed in the Netherlands (the

PALLI) (221). While it was reported that the tool was considered to be feasible and useful, further research is needed, including in the Australian healthcare context. However, O'Hehir (2018) noted that signals such as changes in a group home resident's behaviour or repeated access of acute services may be indicative of a need for palliative care assessment (213).

A study from the UK adapted a palliative care program and resource to enable identification, assessment, and management of the psychosocial needs of people living and dying in a care home (222). Staff demonstrated improvements in the identification of, and response to, patients' physical health needs and planning for declines in their illness trajectory (including initiating advance care planning) as a result of the program (222).

For people with severe physical disabilities such as amyotrophic lateral sclerosis, emerging technology such as high-tech augmented and alternative communication (HT-AAC)—i.e. eye tracking computer systems to enable communication—may be useful as part of routine palliative care (223). Such technology may help overcome communication barriers as speech deteriorates, enable and enhance decision-making capacity, and maintain social supports and quality of life (223), but further research is needed.

In Australia, Wark et al. (2017) provided recommendations to improve end-of-life care for people with an intellectual disability, including consideration of:

- The roles and responsibilities of state and commonwealth healthcare services, and the role of the NDIS

- The need for further education/training for doctors and other healthcare staff to better understand the needs of people with an intellectual disability during end-of-life
- The need for disability services to establish links within the local palliative care nursing teams and wider health system
- The need for increased external funding
- Establishing realistic/flexible management plans for people with an intellectual disability during end-of-life, including the allocation and utilisation of additional support hours and access to specialist healthcare services (212).

Also in Australia, the *Talking End of Life ...with people with intellectual disability* online toolkit has been developed to assist disability support workers (and others) in talking to people with intellectual disabilities about end-of-life issues (224).

Advance care planning

Several themes emerged regarding advance care planning by those living with a disability, including:

- Lower rates of advance care planning
- Individual/family characteristics
- Health professional characteristics
- Organisational/service-side factors.

Lohiya et al. (2002) identified that, in a developmental centre that provided care for 850 residents with intellectual disability, only two had an advance care directive, a rate significantly lower than the general population (225). Similar low rates have

been observed in males with Duchenne muscular dystrophy (226). Relatively low uptake of advance care planning has also been reported among people with dementia and/or their families and caregivers (187,207,227,228).

Various individual characteristics affected whether people were likely to have an advance care plan in place, including their prior life experiences and communication styles. Chen & Habermann (2013) found that those with employment backgrounds in healthcare professions may be more likely to have an advance care plan in place (229). Also, the communication styles between individuals and their families might influence how they make advance care planning decisions (205,230–233). Poole et al. (2018) found that although many people with dementia felt confident that their families could express their wishes on their behalf, many had not communicated their preferences regarding their care at end-of-life (205). Rather, there was a tendency to discuss practical arrangements such as organising a funeral and making financial decisions. Another study reported that decisions about how to plan and manage end-of-life situations commonly emerged from ‘ordinary/everyday’ conversations between people with dementia and their families (231) or ‘emergent planning’ (232).

For those with an intellectual disability, poor health literacy and cognitive capacity made it difficult for them to complete an advance care plan (189). For those with dementia, van der Steen et al. (2014) detailed a number of options to assist with end-of-life care planning, including:

- Prioritising explicit global care goals
- Anticipating progression of disease, and completing advance care planning at point of diagnosis

- Providing flexible formats of advance care plans, tied to available resources for the individual
- Revisiting care plans over time (individual and family or caregivers)
- Storing care plans and ensuring they are accessible to all providers of care (202).
- When to enact the advance care plan: delays in initiating a care plan, due to a lack of clarity around who should be responsible and the required paperwork, would often result in advance care plans being considered too late in the progression of disease, when the patient was no longer capable of contributing to its development (234).

Finally, health professionals may have an element of influence over whether a person with a disability completes an advance care directive. Robinson et al. (2013) detailed that health professionals involved in primary and acute care, and volunteer and legal institutions in the UK, had doubts about putting advance care directives into practice, in particular relating to:

- Who should be responsible for implementing an advance care plan: a number of health professionals that did not identify as palliative care specialists felt ill-equipped to take on board advance care planning as part of their professional responsibility, which was primarily attributed to a lack of time and resources
- What documentation was to be used: healthcare providers were often overwhelmed by the amount of and variation in documentation required to implement an advance care plan, often putting them off initiating one with a patient

Whilst reservations about advance care planning in these service groups was evident, the small sample size may not be representative of the broader health, legal and volunteering sectors.

Other studies highlight the aforementioned issues including uncertainty about when to initiate advance care planning—for example in relation to prognosis and cognitive capacity, particularly for people with dementia (230,235–238). In the primary care setting, there may be a ‘disconnect’ between GP attitudes regarding the importance of advance care planning, and the levels of actually completed documents among patients with dementia (239). Perceived barriers were reported to include lack of time, lack of GP/patient/family knowledge and awareness, discomfort concerning having the discussion, and lack of available resources (239).

The literature also describes enablers and ‘practice points’ addressing advance care planning among people with dementia. These include:

- Educating family members regarding morbidity and mortality associated with dementia
- Summarising psychiatric and medical treatments to date

- Enhancing conversations/effective communication
 - Consulting about whether family members (if any) should be involved in discussions
 - Finding a quiet/private place to have the discussion
 - Using open-ended questioning to inquire about family knowledge regarding disease process, and identify any unhelpful coping behaviours (patient and/or family)
 - Providing clear explanations and options
 - Avoiding burden/judgment-laden statements that put pressure on decision making; rather, using empathy and comfort statements (e.g. ‘we will hope for the best but plan for the worst’)
 - Avoiding medical jargon
- Collaborating with other specialists/teams to develop comprehensive and shared assessments of illness trajectory (239,240).

Still, Piers et al. (2018) conducted a review of existing guidelines for advance care planning with people with dementia (in Belgium), and suggested there are no ‘high quality’ guidelines available for advance care planning in dementia care in the literature (241).

Others emphasise the importance of initiating advance care planning discussions early in illness trajectories (242), with a recent review synthesising and compiling informational resources that may be helpful in supporting advance care planning conversations for people with early-stage dementia and the people close to them (237). Systematic reviews and randomised controlled trials examining the effectiveness of advance care planning among people with dementia in various care settings have

also been published and described elsewhere (243–246).

McGinley & Knoke (2018) developed a conceptual framework that describes a range of barriers to advance care planning that people with an intellectual disability may face at end-of-life (247). The authors propose that in order to facilitate person-centred advance care planning, people with intellectual disabilities should not be excluded from discussions about values, wishes, and care. Of relevance, the ADVANCE toolkit has been developed to support health professionals in having conversations with young people with a learning disability and their families/friends/professional caregivers to plan for end-of-life care, including strategies to involve the young person in the discussion (i.e. person-centred dialogue) (248).

Finally, a systematic review examining the effectiveness of advance care planning to improve end-of-life care for people with a disability and their carers reported that overall, most forms of advance planning are generally associated with improved outcomes. Still, elucidating the active or effective components/elements of advance care planning are not well understood, and further research is needed (243). There also may be challenges associated with the intersection between law, ethics, and practice across different jurisdictions (249).

7 | People experiencing homelessness

A person is defined as homeless if they are living in either:

- Non-conventional accommodation or 'sleeping rough', or
- Short-term or emergency accommodation due to a lack of other options (22).

Introduction

Homeless populations exhibit complex barriers to health care in general (and particularly primary care) (250), and by extension, access to palliative care is challenging.

People experiencing homelessness face significant multi-morbidity in chronic health concerns, and in some cases the proportion of homeless persons living with complex and numerous chronic diseases has increased in the previous decade (251). People who are homeless 'often have lives characterised by complex trauma, adverse childhood experiences and tri-morbidity; the combination of physical ill-health, addiction and mental health issues' (253: p.433). This population is diverse, with significant cross-over with other under-served populations including Aboriginal and Torres Strait Islander peoples (251), LGBTI people (253) and veterans (254). This diversity can compound the barriers faced in accessing quality palliative care for an already under-served population.

Literature review findings

The literature review uncovered significant barriers to palliative care access for the homeless population. Unlike the prison and veteran populations, literature originating from countries outside of the US was more prevalent. Significant barriers were observed across individual and family domains, at the organisational level, among health professionals and the health system more broadly.

Barriers to palliative care

Individual barriers

The primary barrier to accessing palliative care services for homeless populations related to the characteristics of individuals, including mental health issues and experiences of death and loss (255). Of most concern was current **use and/or abuse of alcohol and drugs** by people who are homeless and needing access to palliative care (256–258). Mental health and substance use issues may lead to avoidance of medical care, and those affected may lack insight into their condition, be less able to navigate the health system and have difficulty communicating their needs (255).

The use and/or abuse of alcohol and drugs may also result in palliative care providers refusing to administer drugs for pain relief, resulting in some of those who are homeless self-medicating during end-of-life (256). In

other circumstances, palliative care providers may have policies in place requiring individuals to be alcohol and drug free, which may prevent some who are homeless from accessing services, or the drug and alcohol use itself may reduce motivation to access services (259–261). On the other hand, homeless individuals themselves may have concerns about the use of narcotics, addiction and relapse in the context of palliative care (255).

Much like prisoners, homeless populations often exhibit a **lack of trust** in the healthcare system more broadly, which may prevent them from seeking out palliative care services (258). Krakowsky et al. (2013) found in their study that those experiencing homelessness did not trust health professionals to respect their wishes (262). Similar concerns were reported by Webb (2015) when discussing palliative care barriers for homeless persons with emergency hostel accommodation staff (263). While not universal (264), this lack of trust may also present as **fear and anxiety** of accessing health services, particularly as the circumstances those who are homeless find themselves in at the end-of-life may be traumatic and lonely (257,258,260).

A lack of trust may stem from the **discrimination** experienced by homeless persons when accessing services and the **stigma** felt by this population in relation to their personal circumstances. This discrimination and stigma may arise from their socioeconomic status, race, HIV-positive status or substance use (255,265,266).

More broadly, homeless populations may exhibit a lack of compliance with recommended care and a de-prioritisation of healthcare needs relative to more immediate concerns such as food and shelter (255,267). A tendency towards not seeking treatment and/or lack of knowledge about the palliative

care services may also contribute to poorer access (268).

There are obvious practical barriers to providing palliative care to homeless individuals, including the **lack of a stable environment**, lack of transport, and concerns around loss or theft of belongings (255), and a **lack of available finances** may present a significant barrier to palliative care access for homeless populations (255,261).

Finally, aggressive or challenging behaviour may make accessing health services (including palliative care) more difficult, and inhibit development of long-term relationships with services and health professionals (267,269).

Family barriers

One major barrier existed in the family domain for people experiencing homelessness: many **no longer have contact with their immediate family**, and as a result, lack support to access appropriate palliative care (257,259,270). Lack of family to provide support and substitute decision making becomes particularly problematic as a homeless person's health deteriorates, or if they are experiencing significant mental health issues (261). While some individuals may desire reconciliation with estranged family members before dying, others remain strongly opposed to family being contacted in the event of serious illness or death (255,264).

Organisation/service-side barriers

The incongruity of current models of palliative care with the realities of homelessness has been noted throughout the literature (255). Giesbrecht et al. (2018) noted that 'those experiencing structural vulnerability at the end-of-life simply do not 'fit' into public/formal healthcare environments, yet have no place else to go to

access needed care' (272: p.49). 'Mainstream' clinical guidelines may not account for the specific challenges that affect access to care or the ability to participate in a care plan. This has prompted clinicians in the US to develop specific guidelines for end-of-life care for those experiencing homelessness (272). Conversely, for organisations that provide assistance to people experiencing homelessness, palliative care does not readily fit into their service provision structure and capabilities (81).

Attitudes to death and dying, the general focus of many homelessness services (e.g. on access to mental health and/or addiction services, working towards independent living), and uncertainty regarding prognoses and illness trajectories can all affect palliative care access for homeless populations by inhibiting the relevant conversations between those who are homeless and those who provide care to them (260).

Specific organisational barriers identified include:

- The policies held by organisations (e.g. concerning providing palliative care to those with alcohol or substance use histories)
- A lack of specialists embedded in or engaged with homelessness services
- A lack of planning to provide appropriate palliative care.

Restrictive organisational policies

McNeil et al. (2012) report that some organisations held anti-drug policies that disproportionately exclude homeless persons from accessing palliative care, finding that these policies prioritised 'privileged normative patients' (260: p.4). In some cases, these policies stemmed from genuine safety concerns, and in others, arose from discriminatory behaviours (265). These policy

barriers were not just faced in homeless organisations, but across healthcare providers more generally (259,261,273).

More broadly, risk management policies may prevent the delivery of palliative care in settings such as hostels, supportive housing or shelters, denying homeless populations the option of 'dying in place' (274).

Lack of specialist resources

In other cases, a lack of specialist resources, or the ability to link up with specialists, created barriers to accessing palliative care for homeless persons. In their systematic review of qualitative research, Hudson et al. (2016) highlighted that some homelessness organisations found it difficult to access specialised support services, especially given organisations had limitations on what prior medical history they could ascertain from homeless persons (257). This was most apparent in homeless hostels, where the environment was not conducive to providing care at end-of-life (e.g. having a lack of private spaces for palliative care to be provided, and a lack of resources to dedicate toward linking up with external services) (257,275).

In a Canadian study, while health and social care service providers reported offering palliative care services, most had not received any formal training in the area (268).

Lack of planning

Finally, a lack of planning for palliative care provision is a major organisational barrier faced by homeless populations. In an in-depth case study of a homeless person in Melbourne, MacWilliams et al. (2014) detailed the significant lack of planning for multi-disciplinary care between service providers, resulting in multiple late-stage hospitalisations rather than appropriate

palliative care (256). It was noted elsewhere that poor communication between health providers resulted in a lack of continuity of care for individuals, including poor discharge planning from hospitals (259), and that late referral and access also presented key challenges (269). Contributing to the lack of planning may be the prioritisation of the most immediate needs, not only by those experiencing homelessness but also the services that support them, and the 'unexpected' nature of death from life-limiting conditions (as opposed to drug overdose, accidents, or other causes of sudden death) (274).

Health professional barriers

Key health professional-related barriers to accessing palliative care for homeless populations included a lack of knowledge, experience and/or training in providing care for homeless persons, and negative provider attitudes and behaviours (258,276). For many health professionals, the extent of training in respect to working with homeless and marginalised populations is minimal (258). Further, as homeless persons access primary care at a much lower rate and at later stages of ill-health than the general population, many primary care providers have little experience in working with this population (257).

This lack of experience or knowledge of the complex health issues associated with homelessness may result in health professionals not recognising the need for palliative care in a homeless person. Difficulties in providing accurate diagnoses and prognoses in this population may also contribute (255,269).

Health professionals may lack knowledge in two specific areas: not knowing how to talk about death and dying comfortably, and not

being knowledgeable about the unique issues facing homeless populations (256,262).

Cagle (2009) detailed that discrimination experienced by homeless persons when accessing palliative care services often originates from health professionals themselves, particularly those who may be ill-equipped to deal with significant mental health issues and drug dependence in homeless populations (261).

Finally, health providers may experience significant 'ethical and jurisdictional' challenges in caring for and making decisions affecting those who are homeless and approaching end-of-life. These might include decision-making for those without a formal substitute decision-maker, and determining and upholding professional role-boundaries. West et al. (2018) noted that the emotional burden of such issues may be significant (276).

Enablers of access to palliative care

The literature review uncovered a number of ways in which access to palliative care for homeless populations could be improved. The principles of **shelter-based** care provision were highlighted as key enablers of access (266). Collier (2011) detailed that up-skilling shelter-based staff in provision of palliative care can be a cost-effective way of increasing access for the homeless (258). Providing care within shelters is also beneficial for homeless persons in terms of their comfort, as they may be more trusting of service providers in this environment, as opposed to a mainstream healthcare environment (261,277). Indeed, trusting relationships were highlighted throughout the literature as key enablers of access to palliative care in this context (278) and provision of flexible, quality care (279). Henry et al. (2017) noted that

‘caring communities can be created from supports currently in place: shelters, soup kitchens, out-of-the-cold programs...needle exchanges, drop-ins, emergency departments, street-involved agencies and supports, and religious groups’ (281: p.190).

However, the current discourse on place-of-choice for providing palliative care for people who are homeless may be based more on assumptions and practicalities than the wishes of individuals in this population group (281).

Other options noted in the literature include ‘home-like’ facilities, outreach initiatives (to streets as well as shelters), relaxing admission requirements for hospices, and providing long-term residential beds with 24-hour nursing care (255).

Recent work in the US and Canada has provided recommendations and guidelines to support end-of-life care for homeless and vulnerable populations (268,272,274).

Greater **multidisciplinary and collaborative** approaches to palliative care for the homeless may enable access to services (255,274,278,279). Shulman et al. (2018) suggest that in-reach of palliative care services into homeless shelters and hostels (i.e. external specialist services working within homeless organisations to provide early intervention) will assist in building trust with healthcare providers (282). Similarly, Klop et al. (2018) found that reciprocal consultations between social and palliative care workers had the potential to better link the disciplines, support professionals and enable the provision of appropriate palliative care to homeless populations (283).

Regardless of the model of palliative care delivery, increased **support and training** for relevant staff—including healthcare providers, shelter staff and social workers—

was highlighted in the literature as an enabler of access to, and delivery of, more appropriate services (278,282,284), as well as improved knowledge and confidence (285).

De Veer et al. (2018) recommended developing a network of palliative care specialists for those experiencing homelessness (269). Education for service users may also enable access to palliative care (268).

Håkanson et al. (2016) suggested that a service delivery model based on **person-centred care** is able to overcome some of the barriers faced by homeless persons accessing palliative care (286). This person-centred care is based on four key principles which are illustrated in

Table 7-1, along with the specific barriers they overcome.

Table 7-1: Key principles of person-centred palliative care

Key principle	Barrier addressed
Building trustful and family-like relationships	A homeless person's lack of trust of health providers
Re-dignifying the person	The stigma felt by homeless persons when accessing services
Reconsidering communication about illness and dying	Low levels of health literacy among homeless persons
Re-defining flexible and pragmatic care solutions	The transient nature of homeless persons

Source: Håkanson et al. 2016 (286)

A **harm reduction approach** to providing palliative care was also seen as a way to decrease access barriers for homeless populations (259,287,288). Such an approach involves not denying services based upon the individual's alcohol or drug use, and instead taking that initial contact with a health service as an opportunity to provide information, advice and support in reducing alcohol or drug dependence (259). Harm reduction approaches can also assist in developing trusting relationships with those experiencing homelessness, and express 'a commitment to serving homeless persons and awareness of this population's life circumstances' (260: p.5).

Finally, innovative practice by the Footprints organisation in Brisbane North describes a model for enabling access to palliative care for those experiencing homelessness (and other vulnerable population groups). The Footprints model drew on several key initiatives including:

- Creating a new position within the organisation, a designated 'Linkage Worker', to collaborate with external organisations

- Creating relationships with local hospice services to link Footprints clients with these services toward the end-of-life
- Creating linkages with local hospital and health services
- Promoting knowledge exchange between services
- Developing staff training and guidelines to drive patient-centred care (289).

To address the physical barriers to home-based palliative care for homeless populations, a 'housing first' approach may be particularly useful to provide prioritised and holistic support to those requiring palliative care (268). Recognition and support of 'families of choice' (e.g. street families, homeless support workers) are also relevant in the context of those experiencing homelessness (274).

Advance care planning

Key issues regarding advance care planning among those experiencing homelessness related primarily to the characteristics, beliefs and attitudes of the homeless person themselves. This included prior thoughts about death, and sociodemographic characteristics.

Leung et al. (2015) found that those experiencing homelessness who had completed an advance care plan were more likely to have thought about death and dying, and believe that thinking about family was important (290). Ko & Nelson-Becker (2014) reported that some homeless persons felt that what was spoken about in everyday life reflected what would actually happen, preventing them from discussing or thinking about death (291). Song et al. (2008) reported that females and those with a higher level of education evidenced a higher completion rate of advance care planning (270).

A study of homeless veterans in the US found that although most (70%) reported they had thought about end-of-life care, less than half had discussed these issues with a trusted person or identified a substitute decision maker, and only one-quarter (26%) had an advance directive in the medical record (292). Similar patterns were reflected in a recent study in which people who were homeless who had potential 'confidants', those with three or more chronic conditions, and those with a recent primary care visit were more likely to have advance care planning documentation, as were those with adequate (rather than 'limited') literacy. Greater duration of homelessness and illicit drug use were associated with lower likelihood of documented advance care planning (293).

A lack of access to primary care may be a barrier to advance care planning if this is the setting in which it is most likely to occur (rather than acute/emergency healthcare settings) (264,294). A lack of continuity of care, mistrust of providers, and resource limitations within settings and organisations providing care to homeless populations are also likely to contribute. It is also possible that healthcare providers may assume those who are homeless are not interested in advance care planning, and subsequently fail

to initiate the relevant conversations. However, clinician-guided interventions (and even self-guided interventions) to assist people who are homeless with advance care planning have led to completion rates that are similar to or greater than those in the general population, and may provide some comfort and peace of mind for members of this population group (255,264). A review of the literature suggested that public health nurses may be well-placed to support advance care planning among homeless populations by providing information, engaging in conversations and assisting with completion of advance directives in settings such as respite care, transitional housing facilities, shelters, and day programs (264).

Fear of loss of autonomy, a perception of advance directives as paternalistic and controlling, distrust of healthcare professionals, feeling misunderstood by family, and discomfort with the topic of end-of-life care may all present barriers to advance care planning (255).

Those experiencing homelessness may prefer to talk about end-of-life issues outside of formal healthcare settings (255). Collaborations between health services and community organisations working with homeless populations may show promise in engaging these groups and facilitating advance care planning discussions and documentation in familiar and supportive settings. Challenges may remain, however, in ensuring the resulting information is available to all relevant agencies (294).

Recent US guidelines recommend that opportunities for advance care planning be identified across the healthcare spectrum, and assistance for completing advance directives be provided. Education materials and 'easily executed' forms should be developed to support these activities, and optimal storage should be considered (272).

8 | People who are incarcerated

People who are incarcerated are those remanded or sentenced to adult custodial corrective services agencies in each state and territory in Australia (23).

Introduction

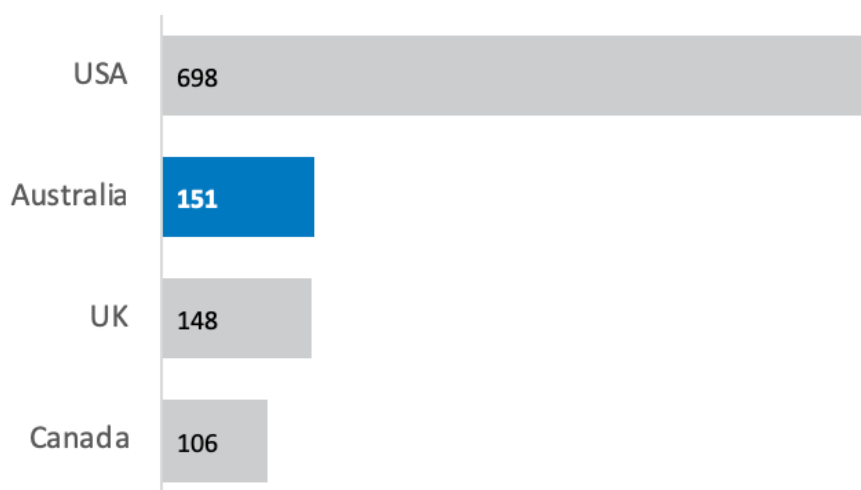
The purpose of incarceration of an individual for criminal offences is to punish, which primarily involves separating that individual from their family, community and society (295). The withholding of health care, or provision of sub-standard health care, is not the punishment, and this view has persisted across judicial rulings, medical ethicists and healthcare providers (296,297). Therefore, quality palliative care should be accessible for incarcerated populations, just as the community would expect to access such care at the end-of-life (298).

Internationally, research on palliative care in the prison setting 'is still emerging and largely absent in Australia' (300: p.29). The origin of

literature related to palliative care service delivery for incarcerated persons was overwhelmingly from the United States (US). This is unsurprising given that the US has the second highest rate of incarceration in the world behind Seychelles (300), and one significantly higher than Australia, the UK and Canada (see *Figure 8-1*).

Literature was also sourced from the UK and New Zealand, with limited peer-reviewed information originating from Australia. It has been identified in the grey literature that more research on ageing prisoner issues is needed in Australia, as international literature is currently relied upon to inform prison health care for the aged in Australia (301–303). This is particularly important as the prison population across Australia continues to age—e.g. in NSW, a third of the prison population is projected to be older than 65 by 2036 (304). Older prisoners are now the group most frequently dying in custody, with death from natural causes overtaking self-inflicted deaths since 2000 (299).

Figure 8-1: Comparative rates of incarceration (per 100,000 people)



Source: Walmsley 2016 (300)

A high incarceration rate has placed heavy demands on the US correctional system, with significant healthcare costs associated with an ageing prison population (305,306).

Similarly, in France, it was estimated that the annual prevalence of prisoners requiring end-of-life care was higher than expected, at approximately 15.2 per 10,000 prisoners (307).

As discussed later, the high incarceration rate and ageing prison population has resulted in the development of sophisticated and innovative palliative care service delivery for prisoners in the US, both within and outside the prison walls (306). These prisoner-specific services have been designed to overcome significant barriers faced in accessing palliative care by this population.

Another major challenge in providing palliative care for prisoners is the significant health challenges this population faces when compared with the general population. In the US, prisoners are considered to be of old age at 50 years due to the various deficiencies in health faced by this population (308).

There is an age differential at death between those who are incarcerated and the general public of approximately 10 years (309). At one US prison, average age of death was just 56 years (310). An ageing population within the prison system means a population that will on average die sooner than the general community, and face significant co-morbid medical conditions, requiring sophisticated and responsive palliative care services (310).

Literature review findings

Barriers to palliative care

A number of barriers prisoners face in accessing palliative care were identified in the literature. These include characteristics and past behaviours of the individual, staff reluctance to provide or facilitate access, poor access for families and the high security nature of the prison system. These barriers are presented below, separated into individual, family and organisational barriers.

Individual barriers

One of the major individual-related barriers to quality palliative care described in the literature was a **lack of knowledge** about end-of-life care. The literature highlighted that it was common for prisoners to have low levels of health literacy in general, which can result in misunderstandings between prisoners and health professionals/staff (311). Prisoners often lacked knowledge of what hospice services were, and did not know about end-of-life care and the treatment options available to them (312). Similar concerns were observed in a female prison, with a lack of information creating barriers to palliative care (306).

Distrust in staff and health professionals was also a significant barrier to palliative care access (313–315). It has been reported that prisoners do not feel health professionals are acting in their best interests, and at times questioned a health professional's decision to stop treatment (308). This distrust may be exacerbated in prisoners of minority backgrounds, due to prior history of breaches of human rights of those incarcerated (308).

In other cases, a prisoner's **prior drug use** may cause health professionals to be apprehensive about providing opioids for pain relief, or the prisoner themselves may resist delivery of pain relief medications for fear of relapsing (296,316). Still, reasons for palliative care consultations and interventions for prisoners have been shown to be similar to 'free-living' individuals in the community, which include recommending opiates for pain/dyspnoea (317).

High levels of frailty, multimorbidity, vulnerability, and fear are reported to be experienced by older prisoners facing end-of-life in prison (299,318), as well as perceived lack of control and agency (308), and grief and loss (319)—all of which have implications for palliative care in the prison setting.

Family barriers

Two major family-related barriers were evident within the literature: the **restrictions placed upon family** visiting prisoners at the end-of-life, and the **absence of family** to provide support to prisoners at end-of-life.

The restrictions placed on family access to their loved ones may be based around risk involved, restrictive visitation hours, and the 'cold bureaucratic response' of staff to grief experienced by family members at the end of a prisoner's life (306,311,320). Further, prisoners may be located within a prison a considerable distance away from their family, making transportation and accommodation costs prohibitive for families desiring to be there at a prisoner's end-of-life (296,311).

The absence of family or the unwillingness of family to provide support at end-of-life is another key barrier to accessing quality palliative care. Loeb et al. (2014) detailed that 'quality of care depends on whether anyone on the outside is showing any love and concern' (313: p.7). In some cases, prisoners

may be estranged from family, given their criminal past (296). Older prisoners may fear the prospect of dying following release, in part due to a lack of adaptive social resources (318).

Organisation/service-side barriers

By far the greatest barriers to quality palliative care access for prisoners could be found at the organisational level, with the prisons themselves being difficult environments in which to deliver end-of-life care. Of primary concern were issues of **risk and security** in relation to palliative care service delivery (299,313). Stensland & Sanders (2016) explain that due to the nature of many prisoners' crimes, the prison environment is heavily steeped in a rigid, hierarchical structure, inflexible to the demands of compassion and always mindful of security measures (308). This focus on risk and security can have very specific impacts, for example, withholding of information from terminally ill prisoners:

'Due to the prison's overall priority of maintaining the highest degree of security possible, medical staff are not allowed to inform Jerry if and when he will be taken to the hospital for his treatments, as known, pre-planned exits from the prison compound pose significant security threats if he or fellow offenders in his cell unit were made aware of these trips' (309: p.264).

This withholding of information from the prisoner can cause distress at end-of-life and engender further distrust between prisoners and prison staff.

Concerns regarding security and risk also affect the ability to provide compassionate palliative care. In some cases where prisoners

are admitted to hospice care outside the prison, hospice staff have been reluctant to have prisoners admitted, citing that safety of the staff, other patients and visitors is of primary concern (321). Further, the presence of guards within a palliative care environment is 'paradoxical to the hospice image' (322: p.135), and the availability of security staff to supervise palliative care nurses may not align with the immediate palliative needs of prisoners (297).

Prison staff attitudes are also clear barriers to quality palliative care access for those who are incarcerated. Loeb et al. (2014) described evidence of staff indifference toward dying prisoners, whereby they are seen as another prisoner that will be gone soon, and they will no longer be the prison's problem (312). Negative attitudes toward prisoner health in general and prisoners at the end-of-life in particular were also cited by Wright & Bronstein (2007), detailing that some staff believed prisoners did not deserve to die with dignity, and some staff were not in favour of 'coddling' prisoners (313).

Finally, the **prison setting** itself is generally not conducive to the provision of quality palliative care. Often prisoners are removed from the general prison population at end-of-life, separating them from the people they may have spent a large proportion of their lives with (322). Further, the design and layout of a prison may not be appropriate for movement or housing of prisoners at the end-of-life stage (297,323)—for example, the layout of a building may restrict movement of a prisoner in a medical bed. Other aspects of the prison environment that might be particularly challenging for older and frail prisoners at end-of-life include the need to climb stairs, reduced mobility to access toilet and shower facilities, and inappropriate bed sizes for fitting pressure mattresses (318). The transfer of prisoners between prisons, or

to external hospitals for palliative care, has been viewed as costly and difficult to coordinate, increasing barriers to quality palliative care (309).

In Australia, there are provisions for compassionate release in the event of a prisoner being diagnosed with an end-of-life illness, in which case palliative care may be easier for them to access (324). However, barriers related to 'compassionate' or 'medical release' have been identified in the literature (307,325–327). Many prisoners are deemed ineligible, often due to the nature of their offence (i.e. sex/violent offences). Others who are eligible for compassionate/medical release do not go on to submit a request (307,328), and many are not aware of relevant policies or how to apply (327). Other structural and organisation-level barriers reported by an Australian study include restrictions on the provision and place of care (limited access to palliative care unit), suitability/adequacy of pain management, and late recognition of dying (329).

Enablers of access to palliative care

Key enablers of access to palliative care for incarcerated populations identified in the predominantly US-based literature included the development of prison hospice programs, the involvement of prisoners as palliative care volunteers, attitudes of staff and partnerships formed with health providers. In addition, a review of prison healthcare models (primarily from the US) provided some insights into the types and levels of palliative care available in the prison setting, including hospice care (330).

A number of agencies have developed guidelines and recommendations regarding

the provision of palliative and end-of-life care in correctional settings (299).

Prison hospice programs

Prison hospice programs began to emerge in the US in the late 1990s, with Louisiana State Penitentiary opening the first program delivering palliative care to prisoners at the end-of-life stage in 1998 (331). Concurrent work through the Guiding Responsive Actions in Corrections at End of Life (GRACE) project provided much-needed momentum in developing prison hospice programs (332). Lum (2004) made several recommendations for the development of hospice programs in New Zealand, many of which tackle the aforementioned barriers to accessing quality palliative care for incarcerated populations (321). These recommendations are detailed in the box to the right.

A key and defining characteristic of the emergence of prison hospice programs in the US was the engagement of **prisoners as peer supporters** for those at end-of-life. The roles incarcerated volunteers engage in vary from prison to prison, but primarily involve providing support to hospice staff and emotional, non-clinical support to those prisoners at the end-of-life (309,333). The effect on the prison volunteers themselves was seen to be transformative, helping the incarcerated to ‘feel compassion and to consider the feelings of others’ (p. 402) and providing ‘important opportunities to reflect on their own lives’ (p. 396), with subsequent therapeutic benefits (313).

Information regarding what motivated prisoners to volunteer in prison hospice programs was scarce, however Loeb et al. (2013) reported that a prisoner’s past experience with formal or informal caregiving prior to incarceration contributed to decisions to engage in volunteering roles in prison hospice environments (333). It was

also reported that prisoners commonly felt motivated to participate in a prison-based end-of-life program as a means to help others, give back/make amends, and to find meaning or purpose in life (334).

Recommendations for prison hospice programs (New Zealand)

- Prison medical unit personnel will receive training in basic palliative care, and will liaise closely with existing community providers
- An interdisciplinary team approach will be adopted, including medical, nursing, chaplaincy, and corrections staff as a minimum
- Strategies will include effective symptom control, allowance for high drug tolerance where there has been previous drug abuse, and extreme care in the administration of drugs with abuse potential
- Resuscitation policies will be reviewed when a terminal illness is diagnosed, and may be amended to ‘allow natural death’
- Visiting rules will maximize access by families, including significant others from both inside and outside the prison
- Consideration may be given to training long-term inmate volunteers to assist with non-clinical aspects of care
- Where compassionate early release is a feasible option, this process will be streamlined to minimise delays. Some prisoners, for whom release is not an option, may elect to remain in the place that has become ‘home’.
- The provision of bereavement care for custodial staff and other prisoners must be addressed; prison chaplains may be instrumental in this (321).

Staff education and attitudes

Staff education and staff attitudes also contributed to enabling greater access to high-quality palliative care in prisons. An interdisciplinary approach to prison palliative care was seen as an essential ingredient for success (306,316). For prison staff, appropriate training around end-of-life care, and training in the delivery of hospice care in the correctional setting were seen to improve prison staff attitudes toward caring for prisoner health (320).

Other approaches, such as computer-assisted technology, may enable delivery of training in geriatric and end-of-life care to staff in correctional settings (335).

Partnerships

Partnerships were the final major theme arising from the literature describing enablers of access to palliative care for incarcerated populations. Brostein & Wright (2006) stated that prison staff found partnerships with external organisations were important to the success of prison hospice programs (336). These partnerships may involve collaboration with community hospice programs, workshops with other prisons and connections with local healthcare providers (306,336,337). Evidence of the effectiveness of partnerships between Australian correctional facilities and other health providers was not found in the peer-reviewed literature.

Compassionate/medical release

For those that are eligible, compassionate release of prisoners with a life-limiting illness may make palliative care easier to access. For those who may not have eligibility for compassionate/medical release, the 'Dying Well in Custody Charter' was developed in the UK to guide and support staff who are

involved in the end-of-life care of people in prisons (338).

Advance care planning

Barriers to effective advance care planning for prisoners followed similar themes as barriers to palliative care, with slight differences. These included low health literacy levels and a lack of substitute decision makers, and lack of knowledge among healthcare providers and correctional staff, as outlined below.

Prisoner knowledge and health literacy

Stone et al. (2012) found that low health literacy levels among prisoners contributed to a lack of effective advance care planning (339). As prisoners had little understanding of medical terminology and what was normal and abnormal regarding health states, they were limited in the questions they could ask health professionals. This lack of knowledge caused concerns among health professionals, as some lacked confidence in a prisoner's ability to make sound decisions about their care at the end-of-life (296).

A recent study examined the differences between incarcerated and non-incarcerated individuals who died in community hospitals in the US (340). Incarcerated individuals had a greater number of chronic health conditions but fewer hospitalisations and were less likely to have completed an advance directive than non-incarcerated individuals (340). It was highlighted that further research is needed to examine and understand palliative care needs of incarcerated people according to the diverse range of demographic profiles of those in the prison system (340).

Lack of substitute decision makers

Just as prisoners may lack family to advocate for access to quality palliative care, a lack of family to act as a surrogate decision maker for the prisoner at end-of-life impedes processes of advance care planning. Sanders et al. (2014) noted that a lack of desire of the family or even the prisoner to involve family as a surrogate decision maker in advance care planning was a key challenge (320). Regardless of prisoner age or health status, engaging an appropriate surrogate decision maker was a considerable barrier.

Lack of correctional/health professional knowledge

A lack of knowledge about advance care planning among correctional and health professionals, and questions about the legal validity of advance care planning documentation within the prison setting have been reported as barriers (341). Other barriers include a lack of understanding about prisoners' end-of-life wishes and how they view their dying process (342). Dying inmates reportedly feel reduced personal agency when engaging in advance care planning, which may be associated with perceived lack of control regarding their 'fate' of death in prison, as well as mistrust of prison staff (342).

To overcome barriers, it has been suggested to include advance care planning in existing intake protocols in correctional settings, which may facilitate uptake, particularly if there are staff who demonstrate a willingness to learn about the process (343).

9 | People who identify as lesbian, gay, bisexual, transgender or intersex

Including individuals who are lesbian, gay, bisexual, transgender or intersex, the umbrella term LGBTI refers to those of diverse sexual orientation, sex or gender identity (24).

Introduction

While notably difficult to estimate, it has been suggested that up to 11% of the Australian population may be of diverse sexual orientation, sex or gender identity (24).

LGBTI people have a higher incidence of life-limiting disease (including a number of cancers) and mental illness—at least partially due to risk behaviours linked to the experience of homophobic discrimination—and tend to present to palliative care services with more advanced disease than other groups (344,345).

However, ‘there is significant diversity amongst people who are lesbian, gay, bisexual, of transgender experience and people with intersex characteristics’ (347: p.1).

Literature review findings

Overall, there was only a small amount of literature relating specifically to palliative care for LGBTI people. Some authors noted that much of the literature available related to end-of-life and bereavement in the context of HIV/AIDS (344,345), which may be less relevant in the modern context. A more recent review (not dated, but including references from 2016) identified a need for better understanding of LGBT people dying from diseases other than cancer (347).

Although a number of commentaries and frameworks related to LGBTI people as a group, the literature reflected a focus on lesbian and gay (and to a lesser extent bisexual) people, with very little found relating specifically to gender diverse individuals (344,347). Some of the literature related more specifically to lesbian and gay (LG), lesbian, gay and bisexual (LGB) or lesbian, gay, bisexual and transgender (LGBT) populations. To reflect this, these acronyms are used as relevant throughout this section.

Barriers to access

LGBTI people (particularly transgender people) may have additional or different palliative care needs (including social support needs) than other population groups. However, more basic needs (i.e. comfort and safety) are universal (345), and LGBTI people need access to safe and inclusive care (348).

Individual and family barriers

It has been suggested in a recent synthesis that navigating the transitions involved in moving from a curative care to a palliative care setting may invoke particular challenges for LGBTI people and their families, particularly around **lack of (or poor) communication**, disclosure or non-disclosure of sexual and/or gender identity, and perceptions of family and spirituality (349).

A key barrier to access to palliative care for LGBTI people is a **perception that services are not appropriately sensitive or safe**, specifically relating (at least in part) to fear of discrimination and lack of recognition of family of choice. It should be noted, however, that where these exist, they are clearly barriers related to health professionals and service providers/organisations, rather than LGBTI individuals.

Fear of discrimination and stigma

Many LGBTI people have experienced bias and discrimination in their lives in healthcare (and other) settings (345,348). Although perhaps more prevalent among older LGBTI people (350), actual experience or fear of discrimination is a key barrier to access to services in general (351)—particularly in as vulnerable a setting as palliative care (352), and perhaps particularly regarding services provided by religious or faith-based organisations (81,344,350).

These ‘internalised’ barriers (345) may affect not only access but the decision to disclose sexual orientation or gender identity to services and healthcare professionals. **Non-disclosure** of sexual orientation may result in an assumption of heterosexuality (344), which may go unchallenged (345), and some transgender individuals may not want to be identified as such (353). However, withholding this information can:

- Delay or deny the provision of person-centred care (352)
- Prevent the involvement of ‘family of choice’ (see below) (354)
- Affect clinical and health care (e.g. by preventing appropriate sexual health discussions, denying hormone therapy for transgender people, and preventing identification of various risk factors (352).

Family of choice

LGBTI people are more likely than the general population to be single, living alone, not have children, and hold more distant relationships with biological family in later life (347,348).

For many LGBTI people, ‘family of choice’ includes individuals who are not biologically related to, but rather designated by, the individual, recognising that ‘many LGBTI people have been ostracised or abandoned by their relatives, and that a strong network of friends and loved ones are as intrinsic and equally valid in the life of an LGBTI person with life-limiting illness’ (349: p.2). However, non-disclosure of sexual or gender identity can prevent LGBTI people from being surrounded and supported by their loved ones up to and at the time of death (355), and disenfranchisement for partners (354). It remains unclear whether the Australian *Marriage Amendment (Definition and*

Religious Freedoms) Act 2017 has influenced these barriers.

In many cases, families defined by marriage or blood are prioritised in healthcare settings or at end-of-life generally (352,354) and in some cases, this may lead to people being cared for by family members who may not support their gender identity or sexual orientation and therefore may make inappropriate healthcare decisions (352).

On the other hand, Almack et al. (2010) found that LGB social networks may be more limited for older LGB people, and that those dependent on such networks may find that they may ‘shrink’ as they age (354).

Carer burden

LGBT carers (or carers of LGBT people) may experience increased pressure and burden if their loved one does not access palliative care services, or accesses them late, and bereavement care for partners has been identified as a key unmet need (347).

Health professional barriers

LGBTI people report experiencing **bias** across a range of healthcare settings and in palliative care in particular (355), if not clear **discrimination** (344,345).

Heterosexual healthcare providers may display ‘implicit’ preferences for heterosexual people (345), and may have difficulty communicating with people about their sexuality and/or recognising people with diverse sexual orientations and gender identities (352).

Organisation/service-side barriers

There may, in general, be a **lack of LGBTI inclusive or supportive support services**, or a **lack of awareness** of these if available (345).

As mentioned, the fear of discrimination experienced by many LGBTI people may be, in many cases, based on past experience or current knowledge of services. In the UK, a survey found that ‘although many end-of-life care providers were confident that there was no active discrimination against LGBT people...more active steps are needed to ensure indirect discrimination is avoided’ (355). For LGB people, **heteronormativity** within services is a key issue (356).

A lack of **recognition of family of choice** can also be a key barrier to appropriate care for LGBTI people (see above). For family and carers, ‘**disenfranchised grief**’, or bereavement marked by stigma and a lack of social recognition of loss, may be experienced by family and carers if services are seen to be unsupportive—e.g. communicating **heteronormative assumptions**, or using **language, materials and resources that do not acknowledge and represent LGBTI experiences** (349,355). Compounding this, partners and caregivers can experience barriers to accessing bereavement support, if partners are not recognised (352) or services are (or are felt to be) non-inclusive or unsupportive (349).

Enablers

As with many populations highlighted in this review, **cultural competence** among healthcare professionals was considered necessary to provide appropriate care to LGBTI people, and ‘clinicians can work to reduce barriers by maintaining an open and affirming approach with all patients and assuring confidentiality, privacy, and high levels of professionalism in all interactions’ (p. 99) as well as including family of choice in decision making (350). **LGBTI-inclusive education and training** for providers was suggested to improve outcomes for these population groups (349,357). Another specific

recommendation was to encourage service providers to explore their own potential implicit bias towards population groups other than their own (357).

Harding et al. (2012) noted that avoiding assumptions about sexual orientation and 'providing an open, non-judgemental environment' is needed (345: p.608), requiring an acknowledgement of potential discrimination among staff and ensuring sensitive assessment. **Promoting disclosure** (e.g. by ensuring services are perceived as 'safe') may lead to higher perceived levels of support (344).

According to the (US) National LGBT Cancer Network, along with relevant data collection and further research, 'best and promising' practices in palliative care for these populations include:

- Open-access registries with ratings of hospices' and healthcare organisations' cultural competence in caring for LGBT people
- Creating individualised plans (at initial encounter) in regard to disclosure or nondisclosure of sexual orientation and gender identity to others
- Providing face-to-face or virtual access to culturally competent and/or LGBT-specific bereavement programs for family of choice
- Addressing the increased risk of mental health problems and unique psychosocial barriers that exist for some LGBT people
- Providing ongoing training to all palliative care providers and staff to ensure culturally competent care to LGBT people and families of choice in all care settings

- Addressing the complex spiritual needs of LGBTI individuals and families of choice with awareness of potential distrust of faith-based communities experienced by many LGBT people
- Facilitating dignity at end-of-life (including 'unique' topics such as continuation of hormone therapy for transgender people)
- Discussing and formalising surrogate decision-making during the initial encounter
- Providing LGBT cultural competence training for palliative care providers (358).

These are similar to recent recommendations by Stevens & Abraham (2018) and a position paper from Palliative Care Australia and the National LGBTI Health Alliance that called for person-directed care for all people with life-limiting conditions, including recognition of partner and family of choice, inclusive service delivery, efficient case management, protection from medical abuse and effective procedures for addressing discrimination and breaches of privacy (348,353).

Practical changes, such as **changing language and avoiding heteronormative assumptions** may 'make all the difference' (350,355). Similarly, a UK study suggested that asking about and **overtly acknowledging partners** (and their importance) is a simple way to show respect (345). Asking about gender identity can be broken down into questions that avoid assumptions—e.g. asking both the gender an individual was assigned at birth and how that individual identifies (359).

At the service level, **visible signs of respect and support** for LGBTI communities, including **partnerships** with relevant organisations—as well as a clear position and policy on

discrimination—may facilitate access to care for these populations (345).

As with other populations with ‘special needs’ (particularly CALD populations), recent commentary has suggested that rather than attempting to recognise and respond to the generalised characteristics of a specific population, a more person-centred approach should be adopted. This means that rather than providing ‘special’ care to LGBTI people, inclusive and appropriate care should be provided to all people, including those who are LGBTI (359).

Advance care planning

Throughout the literature, the particular importance of advance care planning for LGBTI people was highlighted (356,360,361), commonly to protect against the possibility of family members and health professionals disregarding their wishes (344). It was noted that advance care planning can also reduce the perceived burden on (356) and minimise the disenfranchisement of (362) partners. Motivations for planning may include a desire for a sense of agency, life experiences (e.g. watching others go through illness and death), opportunities to learn from professionals (e.g. lawyers, doctors, organisations who promote advance care planning), and reducing conflict and confusion for loved ones (363).

Although many LGBTI individuals may discuss their end-of-life preferences with someone, only a proportion of these will complete formal components of advance care planning (350,362,364). For example, in an Australian sample of LGBT people, 45% preferred their partner to be their substitute decision maker. More than half had communicated their end-of-life preferences to their partner, but only 29% had an enduring power of attorney, 18% an enduring guardian and 12% an advance

care directive (364). Interestingly, a US survey (in 2006) found that respondents in a legally-recognised same-sex relationship were more likely to have completed an advance care directive and a power of attorney for health care than those who were not (360). Gay and lesbian couples may be more likely than heterosexual couples to have informal planning conversations as well as formal end-of-life plans, perhaps due to differences in legal protections and concerns about discrimination from families (365).

This is perhaps validated by a recent Australian survey of medical specialists most frequently involved in end-of-life decisions (e.g. those working in emergency medicine, geriatrics, intensive care, medical oncology, palliative care etc.). In a scenario-based question, less than one-third of doctors surveyed correctly identified an individual’s same-sex partner as the legally-authorized decision maker (in the absence of an advance care directive or appointed substitute decision maker, where a son had been appointed attorney for financial matters, and where the woman had a husband from whom she had been separated for many years) (366). In a US study, one-quarter of ‘key nurse informants’ reported difficulties regarding advance care planning for LGBTI people, including identifying who had a legal right to make decisions on an individual’s behalf (367).

In a review of international data (including two surveys from Australia), transgender people were found to be 50-70% less likely than lesbian, gay or bisexual people to have a living will or have appointed a healthcare proxy (368).

Many of the barriers to palliative care access described above also related to advance care planning among LGBTI populations, including discrimination, stigma and disenfranchised grief as well as lack of knowledge, lack of

close social connections and a reluctance to think about issues related to death and dying (351,362).

Some of the literature suggested that a lack of knowledge about advance care planning and relevant processes may contribute to a lack of uptake (351,364). In Australia, confusion may be caused by differing options, processes and terminology used in each jurisdiction (360,361).

A key issue highlighted in the literature in relation to advance care planning is the recognition of an individual's chosen substitute decision-maker (often partner) as opposed to 'next of kin'—particularly in cases of discord between the dying person's family of origin and their same-sex partner (362). Health professionals—including those in Australia—may often be uncertain or make incorrect assumptions regarding who the legally-authorized decision maker is (366). Leinert et al. (2010) noted that, especially 'when relationships have been kept secret due to fear of discrimination or recrimination, specialist legal advice is needed to assist GLBT people to protect rights and property and assert their end-of-life care wishes' (352: p.44).

Greibling (2016) noted that the recent legalisation of same-sex marriage in the US is likely to have a positive effect on palliative care issues for LGBT people (350). In 2014, Hughes & Cartwright stated that 'because same-sex couples cannot be legally married in Australia, there remains confusion among some people about their legal status' (361: p.546), suggesting that recent marriage equality legislation is likely to ease this confusion for same-sex couples who marry.

Another key issue noted in the literature was the need for individuals and family members to engage in conversations regarding advance care planning with healthcare professionals.

Authors of a recent Australian study highlighted 'the importance of education strategies to raise awareness of the end-of-life care planning options among LGBT people, as well as strategies for increasing health providers' preparedness to discuss these issues with LGBT patients' (361: p.545). Similarly George et al. (2018) recommend improvements in both clinical education and clinical practice to promote advance care planning among same-sex couples, with the latter including consideration of gender orientation and relationship status and registration with LGBTI provider networks (369).

In the Australian context, Leinert et al. (2010) highlighted the need for LGBT people to engage with advance care planning and recommended:

- Initiatives to promote better understanding of current legal rights
- Advocacy for additional legal rights and recognition for these populations
- Relevant education for service providers and the wider community
- Interventions to reduce social isolation
- Development of appropriate information resources (351).

10 | Veterans

Veterans include all former members of the Australian Defence Force (ADF), irrespective of whether they were deployed or undertook war or warlike service (26).

Introduction

Veterans face unique circumstances in relation to palliative care. Barriers to palliative care access were not prevalent in the peer-reviewed or grey literature, and it was evident in the literature that access to care that was appropriate and tailored to the unique needs of this population was the primary concern, as opposed to low rates of palliative care utilisation.

For ADF veterans there are two major routes for healthcare compensation as a result of service. The first involves access to a white card, which entitles the veteran to health care for a specific condition. The second is a gold card, which entitles the veteran to health care for all medical treatment (370). In each case, the Department of Veterans' Affairs (DVA) pays for health care accessed under a white or gold card scheme. In other cases, DVA may pay for health care regardless of whether it is related to the veteran's service. This is referred to as 'non-liability health care' (370).

As was the case with palliative care literature related to incarcerated populations, literature relating to veteran populations predominantly originated from the US. This is not surprising given the significant involvement of the US in military action over the last century. In the US approximately 6.3% of the population are veterans (371),

compared with 1.6% of Australians (approximately 371,000 people as at 2013) (372).

Literature review findings

When compared with other under-served populations, the veteran community in general had greater access to palliative care. It is hypothesised that this may be the case due to the healthcare benefits received by this population, making pathways to health care easier than for other under-served populations. In the one Australian study comparing a small sample of veterans and non-veterans, access to DVA benefits reduced financial stress on veterans accessing palliative care (373), with the paper indicating that access may be on par with the general population. Nevertheless, there were some barriers faced in accessing quality palliative care that was specifically tailored to and took into account the unique experiences of this population.

Barriers to palliative care

Individual barriers

The primary concern regarding palliative care access for veterans was the increased incidence of **mental illness** as a result of prior experiences in the armed forces. This impacted upon the provision of quality palliative care for this population. In a review of veteran hospice patient mental health, Holland et al. (2014) identified one study (374) in which 88% of the cohort 'experienced at least one neuropsychiatric syndrome' (376: p.708). Ganzini et al. (2010)

earlier highlighted that quality palliative care can be impeded by the presence of schizophrenic symptoms, primarily due to the difficulties of establishing a therapeutic relationship between the health professional and the individual (376).

Further, in a retrospective review of veteran medical records undertaken in the US, Garrido et al. (2014) found no association between reported psychological distress by veterans in palliative care and subsequent receipt of mental health care (377). This suggests that whilst assessment for mental health concerns took place, action upon any subsequent mental health reporting was non-existent.

In Australia, O'Connor et al. (2014) analysed a number of qualitative palliative care reports of veterans who had accessed home-based palliative care. They suggested that palliative care services would benefit from considering veteran status and service history, as this may improve linkages between palliative care and any mental health care veterans may be receiving (373).

Homelessness among veteran populations is also a barrier to accessing quality palliative care. As was discussed in *Chapter 7* there are significant barriers faced by homeless populations in accessing palliative care, many of which would also challenge homeless veterans (378). In Victoria and NSW, it is estimated that up to 12% of the homeless population are veterans (254).

Finally, veteran populations who are **LGBTI** may have specific health needs (as discussed in *Chapter 9*) that possibly remain under-recognised in end-of-life care, and health care more broadly (379).

Family barriers

There was very little information regarding family-related barriers to accessing quality palliative care for veteran populations. What was evident was that, similar to prison populations, in many cases veterans **lacked family support** at the end-of-life, which resulted in palliative care taking place in healthcare environments rather than at home (380). In other cases, where family was present for palliative care, some families caring for a veteran at the end-of-life felt they received **inadequate emotional support** from healthcare professionals (375).

Organisational/service-side barriers

At the organisational and health system levels, veterans in the US faced challenges in navigating the veterans affairs health system, finding it **too complex** and difficult to source appropriate information (381). This was also observed in the Veterans Administration Demonstration Project investigating palliative care management, with the complexity of navigating multiple services difficult for both individuals and health professionals (382).

It has been identified that there is currently a **shortage of specialist palliative care providers** for the veteran population in the US (383). Other barriers experienced in accessing quality palliative care included waiting lists to access Veteran Affairs health care (381) and a lack of continuity in care received (382). At present there is little indication of whether these service shortages are similar in Australia.

Enablers of access to palliative care

Three key areas contributed to veterans receiving high-quality palliative care, and greater access to palliative care relative to other under-served populations, and in some cases, the general population. These enablers include:

- Legislation and funding
- Veteran healthcare benefits
- A mature model of service delivery.

In the US, significant legislation was enacted in 2003 mandating ‘universal access to multidisciplinary palliative care teams comprising nursing, medicine, social work, and chaplains involved in end-of-life care’ for veteran communities (385: p.742). This legislative push provided the impetus for heavy investment in veteran access to palliative care, resulting in greater resources in the sector (384,385), and ensuring palliative care for veterans was included in veteran healthcare benefit packages (386). This investment has seen the number of veterans accessing end-of-life care from veteran health services tripling between 2006 and 2009 (385).

By virtue of this investment, the current model of service delivery can be considered ‘mature’ in nature, with over a decade of sustained investment and work in building visibility and knowledge of palliative services within the veteran population. This maturity is exemplified in the Hospice and Palliative Care program by US Veterans Affairs, which is detailed in the box on page 67 (387).

Homeless veterans

Hutt et al. (2018) reported on barriers and recommendations concerning access to palliative care for homeless veterans in the

US, which emerged from a national consultation process (388).

In a separate qualitative study, involving in-depth interviews and focus groups with homeless veterans, Gruenewald et al. (2018) identified barriers for homeless veterans. An overarching sentiment of ‘meet me where I am’—was described by the authors to reflect what many homeless veterans felt they wanted most from their care at end-of-life (389).

The themes from both of these articles were largely consistent with the literature concerning homeless populations presented in *Chapter 7*.

Psychosocial programs/approaches

Recent studies demonstrate that psychosocial-based programs may reduce physiological stress and mental health symptoms among veterans with a life-limiting illness (390–392).

A recent pilot study from the US trialled a psychological group-based program (the Life Program) to address mental health symptoms among veteran populations with a life-limiting illness (392). The authors reported that veterans who participated in the pilot program (which targeted personal values, mindfulness, and psychological flexibility) showed meaningful reductions in their mental health symptoms (392). A separate study trialled an animal-assisted intervention (i.e. time spent with a therapy dog), and reported that when combined with structured discussions with a palliative care psychologist (veteran’s choice of topics), veterans showed reductions in physiological markers of stress (391).

Finally, the Integrate Multidisciplinary Palliative Care into the Intensive Care Unit (IMPACT-ICU) is a communication skills

training program that is designed to integrate palliative care into intensive care units to upskill nurses (393). This program was trialled in a military-based hospital in the US with acute care registered nurses working with ageing veterans requiring palliative care (390). Findings included improvements in skills and confidence among nurses (having palliative care conversations with individuals, families and physicians)—which were maintained at follow-up (390).

While these studies highlight that psychosocial approaches might complement or enhance currently available palliative care services for veterans with a life-limiting illness, the findings are preliminary in nature, and the available evidence in the Australian context remains sparse.

Hospice and Palliative Care program by the US Veterans Affairs

The Hospice and Palliative Care (HPC) program is a highly-integrated network 'of interdisciplinary palliative care teams in all 153 Veterans Affairs medical centres. Each team is guided by regional palliative care leaders and national program office staff. The HPC has transformed the culture of care through sweeping changes in policy, legislation, and practice' (388: p.49).

Key aspects of this model include:

- Measuring quality outcomes
- Education of Veterans Affairs staff and community organisations
- Partnerships with community hospice providers and national peak bodies for palliative care.

Advance care planning

There was very little recent peer-reviewed literature discussing advance care planning in veteran populations, despite this population being identified as having low advance care planning completion rates (394).

A study by Patel et al. (2016) investigated the acceptability of advance care planning in veteran populations (384). The research found that in a sample of 246 veterans diagnosed with cancer, 53% had an advance care plan, with 22% of those being made before the diagnosis. The rate of advance care plans within this sample was greater than the general population rate of advance care planning, suggesting that veterans may have more awareness of these processes, though the higher rate may have been explained by the veteran sample having a diagnosis of cancer, and therefore more imperative to complete an advance care plan (384).

David et al. (2018) suggest that veterans with a serious physical illness who have higher levels of health activation (i.e. levels of taking an active role in health from being 'engaged' to 'actively maintaining health behaviours') had higher levels of engagement in the advance care planning process (395). Fried et al. (2018) developed the Sharing and Talking about My Preferences (STAMP) protocol, which uses a behavioural approach to enhance engagement and improve communication among veterans and their families/surrogate decision makers (396)—however results from the trial are not yet available.

Bekelman et al. (2018) examined the role that patient navigators (i.e. trained laypersons/volunteers/health professionals) may have in improving palliative care outcomes for veterans with cancer (397). One component of the trial involved motivating individuals to pursue advance care planning. Of the veterans who had not completed an advance care directive at the start of the trial period, 45% had completed one by the end of the study. However, veterans' levels of satisfaction with intervention were mixed, suggesting it is not yet clear whether patient navigators are appropriate or effective enablers for advance care planning. Still, it was suggested that patient navigator models might be particularly useful when there are access issues to palliative care or where service needs are greatest.

Abbreviations

Abbreviation	Definition
AHA	Australian Healthcare Associates
AHMC	Australian Health Ministers Conference
AHP	Aboriginal Health Practitioner
AHWs	Aboriginal Health Workers
CALD	Culturally and Linguistically Diverse
COAG	Council of Australian Governments
Department	Australian Government Department of Health
DVA	Department of Veterans' Affairs
GRACE	Guiding Responsive Actions in Corrections at End of Life
LGBTI	Lesbian, gay, bisexual, transgender or intersex
NDIS	National Disability Insurance Scheme
NSQHS	National Safety and Quality Health Service
PEPA	Program of Experience in the Palliative Approach
PICAC	Partners in Culturally Appropriate Care
PTSD	Post-Traumatic Stress Disorder
the Strategy	National Palliative Care Strategy
UK	United Kingdom
UNHCR	United Nations High Commissioner for Refugees
US	United States of America
WWII	World War II

Glossary

Advance care directive (ACD):

An advance care directive is a type of written advance care plan recognised by common law or specific legislation. An ACD can only be completed and signed by a competent adult. It may record the person's values and preferences for future care, and/or include the appointment of a substitute decision-maker to make decisions about health care and personal life management. Forms and requirements vary between states and territories (398).

Advance care planning: The process of planning for future health and personal care needs. It provides a way for a person to make their values and preferences known in order to guide decision-making at a future time when they cannot make or communicate their decisions (398).

Carers: People who provide personal care, support and assistance to people with a disability, medical condition, mental illness, or frailty due to age. Carers may include family members, friends, relatives, siblings or neighbours. The term 'carer' does not include people who provide care for payment (such as a care or support worker), as a volunteer for an organisation, or as part of the requirements of a course of education or training (399).

End of life: The period when a patient is living with, and impaired by, a fatal condition, even if the trajectory is ambiguous or unknown. This period may be years in the case of patients with chronic or malignant disease, or very brief in the case of patients who suffer acute and unexpected illnesses or events, such as sepsis, stroke or trauma (8).

End-of-life care: Includes physical, spiritual and psychosocial assessment, and care and treatment delivered by health and social care providers. It includes the support of family and carers, and care of the person's body after death. People are 'approaching the end-of-life' when they are likely to die within the next 12 months (2).

Family: Includes people identified by the person as family and may include people who are biologically related and people who joined the family through marriage or other relationships, as well as family of choice and friends (7).

Life-limiting illness: Describes illnesses where it is expected that death will be a direct consequence of the specified illness. The term incorporates the concept that people are actively living with such illnesses, not simply dying (7).

Overshadowing: A 'phenomenon in which a person's presentation is attributed to their underlying condition...potentially delaying identification of other problems and referral to hospice and/or palliative care' (192: p.514).

Palliative care providers: Health and social care providers involved in the clinical management and coordination of care for people living with a life-limiting illness. Palliative care providers may include general practitioners (GPs), geriatricians, oncologists, physicians, paediatricians, renal specialists, cardiologists and other specialists. Other team members will include nurses, allied health professionals and pharmacists (7).

Person-centred care: Care that is 'respectful of, and responsive to, the preferences, needs and values of patients and consumers' (401: p.7).

Specialist palliative care

services: Multidisciplinary teams with specialised skills, competencies, experience and training in palliative care. Care provided through these services is targeted at people with more complex needs, and is referred to as 'specialist palliative care' (7).

Substitute decision-maker: A person appointed or identified by law to make decisions on behalf of a person whose decision-making capacity is impaired. A substitute decision-maker can be:

- Someone chosen (and appointed) by the person. Depending on the state or territory, they may be called an enduring guardian, a medical enduring power of attorney, an agent or a decision-maker.
- Someone assigned as a decision-maker for the person by law, in the absence of an appointed substitute decision-maker. The hierarchy for appointing a substitute decision-maker varies by jurisdiction. They may be a spouse or de facto spouse, carer, relative or friend.
- A substitute decision-maker appointed for the person (e.g. a guardian appointed by a guardianship tribunal) (398).

Trauma-informed care: 'An organisational structure and treatment framework that involves understanding, recognising and responding to the effects of all types of trauma' (402: p.2).

References

1. Commonwealth of Australia. Supporting Australians to live well at the end of life: National Palliative Care Strategy 2010. Canberra: Commonwealth of Australia; 2010.
2. Australian Government Department of Health. National Palliative Care Strategy 2018.
3. Urbis. Evaluation of the National Palliative Care Strategy 2010 final report. Prepared by Urbis for the Commonwealth Department of Health; 2016.
4. Davidson PM, Phillips JL, Dennison-Himmelfarb C, Thompson SC, Lockett T, Currow DC. Providing palliative care for cardiovascular disease from a perspective of sociocultural diversity. *Curr Opin Support Palliat Care*. 2016 Mar;10(1):11–7.
5. Stinchcombe A, Smallbone J, Wilson K, Kortess-Miller K. Healthcare and end-of-life needs of lesbian, gay, bisexual, and transgender (LGBT) older adults: A scoping review. *Geriatrics*. 2017;2(1):13.
6. Lipmann B. Elderly homeless men and women: Aged care's forgotten people. *Aust Soc Work*. 2009;62(2):272–86.
7. Palliative Care Australia. Palliative Care Service Development Guidelines. 2018.
8. Australian Commission on Safety and Quality in Health Care. National consensus statement: Essential elements for safe and high-quality end-of-life care. Sydney: ACSQHC; 2015.
9. Advance Care Planning Australia. What is advance care planning? [Internet]. 2018 [cited 2018 Apr 2]. Available from: <https://www.advancecareplanning.org.au/individuals/what-is-advance-care-planning>
10. Australian Institute of Health and Welfare (AIHW). Palliative care services in Australia. Canberra: AIHW; 2019.
11. The Senate Community Affairs References Committee. Palliative care in Australia. Canberra: Commonwealth of Australia; 2012.
12. Australian Commission on Safety and Quality in Health Care (ACSQHC). End-of-life care in acute hospitals: A background paper. Sydney: ACSQHC; 2013.
13. Oechsle K. Palliative care [Internet]. *Internist*. 2018 [cited 2017 Dec 6]. Available from: <http://www.health.gov.au/internet/main/publishing.nsf/Content/Palliative+Care-1>
14. Palliative Care Australia (PCA). National palliative care standards. 5th ed. Canberra: PCA; 2018.
15. Palliative Care Australia (PCA). Palliative care service development guidelines. Canberra: PCA; 2018.
16. NACCHO. Definitions [Internet]. Aboriginal health. 2017 [cited 2018 Feb 27]. Available from: <http://www.naccho.org.au/about/aboriginal-health/definitions/>
17. Ethnic Communities' Council of Victoria (ECCV). ECCV glossary of terms. Melbourne: ECCV; 2012.

18. Commonwealth of Australia Department of Social Services. National Ageing and Aged Care Strategy for people from Culturally and Linguistically Diverse (CALD) backgrounds. Canberra; 2015.
19. Australian Government Department of Health. People from diverse backgrounds [Internet]. 2018 [cited 2018 Apr 18]. Available from: <https://agedcare.health.gov.au/older-people-their-families-and-carers/people-from-diverse-backgrounds>
20. Senate Community Affairs Reference Committee. Commonwealth contribution to former forced adoption policies and practices. Canberra: Commonwealth of Australia; 2012.
21. Australian Institute of Health and Welfare. Disability - overview [Internet]. 2018 [cited 2019 Apr 16]. Available from: <https://www.aihw.gov.au/reports-data/health-conditions-disability-deaths/disability/overview>
22. Australian Institute of Health and Welfare. Homelessness services glossary [Internet]. Canberra; 2017 [cited 2018 Feb 26]. Available from: <https://www.aihw.gov.au/reports-statistics/health-welfare-services/homelessness-services/glossary>
23. Australian Bureau of Statistics. 4517.0 - Prisoners in Australia, 2017 [Internet]. 2017 [cited 2018 Mar 20]. Available from: [https://www.abs.gov.au/ausstats/abs@.nsf/Lookup/bySubject/4517.0~2017~MainFeatures~In this issue~2](https://www.abs.gov.au/ausstats/abs@.nsf/Lookup/bySubject/4517.0~2017~MainFeatures~In%20this%20issue~2)
24. Australian Human Rights Commission. Face the facts: Lesbian, gay, bisexual, transgender and intersex people [Internet]. 2014 [cited 2018 Feb 27]. Available from: <https://www.humanrights.gov.au/education/face-facts/face-facts-lesbian-gay-bisexual-trans-and-intersex-people>
25. Refugee Council of Australia. Background information on refugees and asylum seekers [Internet]. [cited 2018 Feb 22]. Available from: https://www.refugeecouncil.org.au/docs/news&events/RW_Background_Information.pdf
26. Foreign Affairs Defence and Trade References Committee. Mental health of Australian Defence Force members and veterans. Canberra: Commonwealth of Australia; 2016.
27. Australian Government. Aged Care Act 1997 [Internet]. Federal register of legislation. [cited 2018 May 14]. Available from: <https://www.legislation.gov.au/Details/C2018C00141>
28. Palliative Care Australia. Palliative care and culturally and linguistically diverse communities. Canberra: Position statement, PCA;
29. Victorian State Government Department of Health and Human Services. Equity in participation: Towards a new healthcare policy framework. State Government of Victoria Department of Health and Human Services;
30. McSherry B, Carroll A. Hospitals or prisons? Treating offenders with severe mental health conditions [Internet]. 2015 [cited 2018 Feb 27]. Available from: <https://socialequity.unimelb.edu.au/news/news-archive/hospitals-or-prisons-archived>

31. Mental health of those suffering with physical or learning disabilities. Newark, UK: The Shaw Mind Foundation; 2016.
32. Sacred Heart Mission. Trauma and homelessness initiative [Internet]. 2014 [cited 2017 Dec 11]. Available from: <https://www.sacredheartmission.org/understanding-homelessness/trauma-homelessness-initiative>
33. Brooke NJ. Needs of Aboriginal and Torres Strait Islander clients residing in Australian residential aged-care facilities. *Aust J Rural Health*. 2011;19(4):166–70.
34. Australian Institute of Health and Welfare. The health and welfare of Australia’s Aboriginal and Torres Strait Islander peoples 2015. Canberra: Cat. no. IHW 147. AIHW; 2015.
35. Cancer Australia. National Aboriginal and Torres Strait Islander Cancer Framework. Surry Hills, NSW: Cancer Australia; 2015.
36. Anderson I, Devitt J. Providing culturally appropriate care to Aboriginal and Torres Strait Islander peoples: discussion paper. The National Palliative Care Program;
37. McGrath CL. Issues influencing the provision of palliative care services to remote Aboriginal communities in the Northern Territory. *Aust J Rural Heal*. 2000;8(1):47–51.
38. Awofeso N. Racism: A major impediment to optimal Indigenous health and health care in Australia. *Aust Indig Heal*. 2011;11(3):1–13.
39. Australian Institute of Health and Welfare (AIHW). Palliative care services in Australia. Canberra: AIHW; 2017.
40. Australian Institute of Health and Welfare (AIHW). Palliative care in general practice. Palliative Care Services in Australia. Canberra: AIHW; 2017.
41. Sullivan K, Johnston L, Colyer C, Beale J, Willis J, Harrison J, et al. National Indigenous Palliative Care Needs Study. Canberra: Australian Government Department of Health and Ageing; 2003.
42. Shahid S, Ekberg S, Holloway M, Jacka C, Yates P, Garvey G, et al. Experiential learning to increase palliative care competence among the Indigenous workforce: An Australian experience. *BMJ Support Palliat Care*. 2019;9:158–63.
43. McGrath P. The living model: An Australian model for Aboriginal palliative care service delivery with international implications. *J Palliat Care*. 2010;26(1):59–64.
44. McGrath P. “The biggest worry..”: Research findings on pain management for Aboriginal peoples in Northern Territory, Australia. *Rural Remote Heal Heal*. 2006;6(3):549.
45. Dembinsky M. Exploring Yamatji perceptions and use of palliative care: An ethnographic study. *Int J Palliat Nurs*. 2014;20(8):387–93.
46. McGrath P, Patton MA. Indigenous understanding of hospice and palliative care. *J Hosp Palliat Nurs*. 2007;9(4):189–97.
47. Yates P. Palliative care for specific populations. *Aust Fam Physician*. 2006;35(10):776–9.
48. Shahid S, Bessarab D, Van Schaik KD, Aoun SM, Thompson SC. Improving palliative care outcomes for Aboriginal Australians: Service providers’

- perspectives. *BMC Palliative Care*. 2013.
49. McGrath P, Anne M, Patton S. The right story, to the right person: communication issues in end-of-life care for Indigenous people. *Aust Heal Rev*. 2005;29(3):306–16.
50. Queensland Health. *Sad news sorry business: Guidelines for caring for Aboriginal and Torres Strait Islander people through death and dying*. Brisbane: State of Queensland (Queensland Health); 2015.
51. Stewart S, Holloway L. *Palliative care for renal clients living in a remote setting*. Darwin: Northern Territory Government Department of Health and Families; 2010.
52. McGrath P, Holewa H. End-of-life care of Aboriginal peoples in remote locations: Language issues. *Aust J Prim Health*. 2007;13(1):18–27.
53. Weeramanthri T. “Painting a Leonardo with finger paint”: Medical practitioners communicating about death with Aboriginal people. *Soc Sci Med*. 1997;45(7):1005–15.
54. O’Brien AP, Bloomer MJ, McGrath P, Clarke K, Martin T, Lock M, et al. Considering Aboriginal palliative care models: The challenges for mainstream services. *Rural Remote Health*. 2013;13(1):1–10.
55. O’Brien AP, Bloomer MJ, McGrath P, Clarke K, Martin T, Lock M, et al. Considering Aboriginal palliative care models: The challenges for mainstream services. *Rural Remote Health*. 2013 Jan;13(1):1–10.
56. McGrath P. Family care giving for Aboriginal peoples during end-of-life: Findings from the Northern Territory. *J Rural Trop Public Heal*. 2008;7:1–10.
57. Carey TA, Schouten K, Wakerman J, Humphreys JS, Miegel F, Murphy S, et al. Improving the quality of life of palliative and chronic disease patients and carers in remote Australia with the establishment of a day respite facility. *BMC Palliat Care*. 2016;15(1):1–10.
58. Waran E, O’Connor N, Zubair MY, May P. ‘Finishing up’ on country: Challenges and compromises. *Intern Med J*. 2016;46(9):1108–11.
59. To T, Boughey M. Referral patterns to a palliative care service in rural Australia servicing Indigenous Australians. *Intern Med J*. 2010;40(11):772–6.
60. O’Brien A, Bloomer M. Aboriginal palliative care and mainstream services. *Aust Nurs J*. 2012;20(6):39.
61. McGrath P, Holewa H. Seven principles for Indigenous palliative care service delivery: Research findings from Australia. *Australas J Cancer*. 2005;5(3):179–86.
62. McGrath P, Phillips E. Aboriginal spiritual perspectives: Research findings relevant to end-of-life care. *Illness, Cris Loss*. 2008;16(2):153–71.
63. Shahid S, Finn L, Bessarab D, Thompson SC. Understanding, beliefs and perspectives of Aboriginal people in Western Australia about cancer and its impact on access to cancer services. *BMC Health Serv Res*. 2009;9:132.
64. Stewart S, Manager P, Holloway L, Aboriginal R, Officer L. *Palliative Care for Renal Clients Living in a Remote Setting*.
65. Woods JA, Johnson CE, Ngo HT, Katzenellenbogen JM, Murray K, Thompson SC. Delay in commencement of palliative care

- service episodes provided to Indigenous and non-Indigenous patients: Cross-sectional analysis of an Australian multi-jurisdictional dataset. *BMC Palliat Care*. 2018;17:130.
66. McGrath P. "I don't want to be in that big city; this is my country here": Research findings on Aboriginal peoples' preference to die at home. *Aust J Rural Health*. 2007;15(4):264–8.
67. White K, Wall D, Kristjanson L. Out of sight out of mind: Reframing remoteness in providing palliative care in remote Australia. *Collegian*. 2004;11(3):29–33.
68. Maddocks I, Rayner RG. Issues in palliative care for Indigenous communities. *Med J Aust*. 2003;179(6 Suppl):S17-19.
69. McGrath P, Holewa H, Ogilvie K, Rayner R, Patton MA. Insights on Aboriginal peoples' views of cancer in Australia. *Contemp Nurse*. 2006;22(2):240–54.
70. The Wardliparingga Aboriginal Research Unit of the South Australian Health and Medical Research Institute. National Safety and Quality Health Service Standards user guide for Aboriginal and Torres Strait Islander health. Sydney: Australian Commission on Safety and Quality in Health Care; 2017.
71. Palliative Care Australia. Improving access to quality care at the end of life for Aboriginal and Torres Strait Islander Australians - Position statement. Canberra: Palliative Care Australia; 2015.
72. Queensland Health. Sad news, sorry business: Guidelines for caring for Aboriginal and Torres Strait Islander people through death and dying (version 2). Brisbane: State of Queensland (Queensland Health; 2015.
73. Victorian State Government Department of Health and Human Services. Victoria's end of life and palliative care framework. Melbourne, Victoria; 2016.
74. Building partnerships: A workbook for implementing best practice palliative care for Aboriginal and Torres Strait Islander peoples in NSW. Sydney: NSW Department of Health; 2005.
75. ACT Health. Best practice palliative care for Aboriginal and Torres Strait Islander people in the ACT [Internet]. 2006 [cited 2018 Apr 2]. Available from: https://www.caresearch.com.au/Caresearch/Portals/0/Documents/WhatisCaresearch/NationalPCProgram/ACT_Best_Practice_Palliative_Care_Workbook.pdf
76. PEPA Project team. Cultural considerations: Providing end of life care for Aboriginal peoples and Torres Strait Islander peoples. 2017.
77. Shahid S, Taylor EV, Cheetham S, Woods JA, Aoun SM, Thompson SC. Key features of palliative care service delivery to Indigenous peoples in Australia, New Zealand, Canada and the United States: A comprehensive review. *BMC Palliat Care*. 2018;17:72.
78. McGrath PD, Patton MAS, Ogilvie KF, Rayner RD, McGrath ZM, Holewa HA. The case for Aboriginal Health Workers in palliative care. *Aust Heal Rev*. 2007;31(3):430–9.
79. Taylor E V, Haigh MM, Shahid S, Garvey G, Cunningham J, Thompson SC. Cancer services and their initiatives to improve the care of Indigenous Australians. *Int J Environ Res Public Health*. 2018;15:717.

80. Sajiv C. Cultural considerations when providing care to Aboriginal and Torres Strait Islanders (ATSI) opting for conservative care. *Nephrology* (Carlton). 2013;Apr 16.
81. Wilson B. Enhancing advance care planning in specific communities project – CALD, LGBTI, Aboriginal, homeless: Final report. Hobart: Palliative Care Tasmania; 2016.
82. Waran E, Wallace S, Dodson-Jauncey J. Failing to plan is planning to fail: Advance care directives and the Aboriginal people of the Top End. *Med J Aust*. 2017;206(9):377–8.
83. Sinclair C, Williams G, Knight A, Auret K. A public health approach to promoting advance care planning to Aboriginal people in regional communities. *Aust J Rural Health*. 2014;22(1):23–8.
84. Pereira-Salgado A, Mader P, Boyd LM. Advance care planning, culture and religion: An environmental scan of Australian-based online resources. *Aust Heal Rev*. 2018;42:152–63.
85. Austin Health. Advance care planning with Aboriginals and Torres Strait Islanders. Melbourne; 2006.
86. Australian Government Department of Health. Caring for your mob at the end of their life [Internet]. [cited 2019 Jan 7]. Available from: [http://www.health.gov.au/internet/main/publishing.nsf/content/4BA0E8B093C5CFB0CA258270007C2D14/\\$File/D OH_PC013_A4_Brochure_DOH WEBSITE_Aboriginal&TorresStraitIslander_digita....pdf](http://www.health.gov.au/internet/main/publishing.nsf/content/4BA0E8B093C5CFB0CA258270007C2D14/$File/D OH_PC013_A4_Brochure_DOH_WEBSITE_Aboriginal&TorresStraitIslander_digita....pdf)
87. Queensland Government. New palliative care app for Aboriginal and Torres Strait Islanders [Internet]. 2018 [cited 2019 Jan 10]. Available from: <https://www.health.qld.gov.au/darlingdowns/news/may-2018/new-palliative-care-app-for-aboriginal-and-torres-strait-islanders>
88. Australian Government Department of Health. Aged Care Diversity Framework - relevant legislation [Internet]. 2017 [cited 2018 Apr 24]. Available from: <https://agedcare.health.gov.au/support-services/people-from-diverse-backgrounds/aged-care-diversity-framework-relevant-legislation>
89. Harrison EJ. Forgotten Australians: Supporting survivors of childhood institutional care in Australia. Alliance for Forgotten Australians; 2014.
90. Department of Health. Caring for Forgotten Australians, Former Child Migrants and Stolen Generations: An information package for aged care services. Canberra: Department of Health; 2016.
91. National Archives of Australia. Overview of forced adoption practices in Australia [Internet]. [cited 2018 Apr 18]. Available from: <http://forcedadoptions.naa.gov.au/content/overview-forced-adoption-practices-australia>
92. palliaged. Care leavers [Internet]. 2018 [cited 2018 Apr 18]. Available from: <https://www.palliaged.com.au/tabid/5097/Default.aspx>
93. Fernandez E, Lee J-S, Blunden H, McNamara P, Kovacs S, Cornefert P-A. No child should grow up like this: Identifying long term outcomes of Forgotten Australians, Child Migrants and the Stolen Generations. Kensington: University of New South Wales; 2016.
94. Kenny P, Higgins D, Morley S. Good practice principles in providing services to those affected by forced

- adoption and family separation. Melbourne: Australian Institute of Family Studies; 2015.
95. Higgins D, Kenny P, Sweid R, Ockenden L. Forced adoption support services scoping study. Canberra: Report for the Department of Social Services by the Australian Institute of Family Studies; 2014.
 96. Australian Institute of Health and Welfare. Older Australia at a glance [Internet]. 2017 [cited 2018 Apr 4]. Available from: <https://www.aihw.gov.au/reports/older-people/older-australia-at-a-glance/contents/diversity/culturally-and-linguistically-diverse-people>
 97. Australian Bureau of Statistics. 2016 census: multicultural [Internet]. 2017 [cited 2018 Apr 24]. Available from: <http://www.abs.gov.au/ausstats/abs@.nsf/lookup/Media+Release3>
 98. Broom A, Good P, Kirby E, Lwin Z. Negotiating palliative care in the context of culturally and linguistically diverse patients. *Intern Med J*. 2013;43(9):1043–6.
 99. Gardner DS, Doherty M, Bates G, Koplow A, Johnson S. Racial and ethnic disparities in palliative care: A systematic scoping review. *Fam Soc J Contemp Soc Serv*. 2018;99(4):301–16.
 100. Huang Y, Yates P, Prior D. Accommodating the diverse cultural needs of cancer patients and their families in palliative care. *Cancer Nurs*. 2009;32(1):E12–21.
 101. Karim K, Bailey M, Tunna K. Nonwhite ethnicity and the provision of specialist palliative care services: Factors affecting doctors' referral patterns. *Palliat Med*. 2000;14(6):471–8.
 102. McGrath P, Vun M, McLeod L. Needs and experiences of non-English speaking hospice patients and families in an English-speaking country. *Am J Hosp Palliat Care*. 2001;18(5):305–12.
 103. Nyatanga B. Culture, palliative care and multiculturalism. *Int J Palliat Nurs*. 2002;8(5):240–6.
 104. Evans N, Mēaca A, Andrew EVW, Koffman J, Harding R, Higginson IJ, et al. Appraisal of literature reviews on end-of-life care for minority ethnic groups in the UK and a critical comparison with policy recommendations from the UK end-of-life care strategy. *BMC Health Serv Res*. 2011;11.
 105. Gustafson C, Lazenby M. Assessing the unique experiences and needs of Muslim oncology patients receiving palliative and end-of-life care. *J Palliat Care*. 2019;34(1):52–61.
 106. Fischer SM, Sauaia A, Kutner JS. Patient navigation: A culturally competent strategy to address disparities in palliative care. *J Palliat Med*. 2007;10(5):1023–8.
 107. Wong S, Tsang B, Mortensen A, Lim S. Caring for Asian children. Auckland: Waitemata District Health Board, eCALD Services; 2018.
 108. O'Connor M, Poon EWH, Hsu JC-Y. The complexities of communicating palliative care in Chinese-based languages. *Prog Palliat Care*. 2015 Apr;23(2):85–7.
 109. Crawley LM. Racial, cultural and ethnic factors influencing end-of-life care. *J Palliat Med*. 2005;8(suppl. 1):S58–69.
 110. De Graaff FM, Francke AL, Van Den Muijsenbergh ME, Van Der Geest S. "Palliative care": A contradiction in terms? A qualitative study of cancer

- patients with a Turkish or Moroccan background, their relatives and care providers. *BMC Palliat Care*. 2010;9:19.
111. Fang ML, Sixsmith J, Sinclair S, Horst G. A knowledge synthesis of culturally- and spiritually-sensitive end-of-life care: Findings from a scoping review. *BMC Geriatr*. 2016;16(1):1–14.
 112. Migrant Information Centre. *Palliative care for culturally and linguistically diverse communities: Cultural profiles to assist in providing culturally sensitive palliative care*. Melbourne: Migrant Information Centre; 2009.
 113. De Graaff FM, Francke AL. Barriers to home care for terminally ill Turkish and Moroccan migrants, perceived by GPs and nurses: A survey. *BMC Palliat Care*. 2009;8:3.
 114. O'Connor M, O'Brien AP, Griffiths D, Poon E, Chin J, Payne S, et al. What is the meaning of palliative care in the Asia-Pacific region? *Asia-Pacific J Clin Oncol*. 2010;6(3):197–202.
 115. Hanssen I, Pedersen G. Pain relief, spiritual needs, and family support: Three central areas in intercultural palliative care. *Palliat Support Care*. 2013;11(6):523–30.
 116. Hsu C-Y, Lee S, O'Connor M. Issues affecting access to palliative care services for older Chinese people in Australia. *J Community Nurses*. 2005;10(3):9–11.
 117. Lau R, O'Connor M. Behind the rhetoric: Is palliative care equitably available for all? *Contemp Nurse*. 2012;43(1):56–63.
 118. Cain CL, Surbone A, Elk R, Kagawa-Singer M. Culture and palliative care: Preferences, communication, meaning, and mutual decision making. *J Pain Symptom Manage*. 2018;55(5):1408–19.
 119. Kirby E, Lwin Z, Kenny K, Broom A, Birman H, Good P. "It doesn't exist...": Negotiating palliative care from a culturally and linguistically diverse patient and caregiver perspective. *BMC Palliat Care*. 2018;17:90.
 120. Doorenbos A. Hospice access for Asian Indian immigrants. *J Hosp Palliat Nurs*. 2003;5(1):27–33.
 121. Nyatanga B. Cultural competence in palliative care and a world of multiculturalism. *Br J Comm Nurs*. 2018;23(6):307.
 122. Bray Y, Wright-St Clair V, Goodyear-Smith F. Exploring the lived experience of migrants dying away from their country of origin. *Qual Life Res*. 2018;27:2647–52.
 123. Sneesby L, Satchell R, Good P, van der Riet P. Death and dying in Australia: Perceptions of a Sudanese community. *J Adv Nurs*. 2011;67(12):2696–702.
 124. Green A, Jerzmanowska N, Thristiawati S, Green M, Lobb EA. Culturally and linguistically diverse palliative care patients' journeys at the end-of-life. *Palliat Support Care*. 2018;1–7.
 125. Prior D. Palliative care in marginalised communities [Review]. *Prog Palliat Care*. 1999;7(3):109–15.
 126. Clark K, Phillips J. End of life care: The importance of culture and ethnicity. *Aust Fam Physician*. 2010;39(4):210–3.
 127. Kreling B, Selsky C, Perret-Gentil M, Huerta EE, Mandelblatt JS. "The worst thing about hospice is that they talk about death": Contrasting hospice decisions and experience among immigrant Central and South

- American Latinos with US-born White, non-Latino cancer caregivers. *Palliat Med.* 2010;24(4):427–34.
128. Payne S, Chapman A, Holloway M, Seymour J, Chau R. Chinese community views: promoting cultural competence in palliative care. *J Palliat Care.* 2005;21(2):111–6.
129. Green A, Jerzmanowska N, Green M, Lobb EA. ‘Death is difficult in any language’: A qualitative study of palliative care professionals’ experiences when providing end-of-life care to patients from culturally and linguistically diverse backgrounds. *Palliat Med.* 2018;32(8):1419–27.
130. Wiener L, McConnell DG, Latella L, Ludi E. Cultural and religious considerations in paediatric palliative care. *Palliat Support Care.* 2013;11(1):47–67.
131. Migala S, Flick U. Cultural and individual barriers to palliative care from different angles: Data triangulation in practice. *Qual Inq.* 2018;1–13.
132. Brooks LA, Bloomer MJ, Manias E. Culturally sensitive communication at the end-of-life in the intensive care unit: A systematic review. *Aust Crit Care.* 2018;1–8.
133. Worth A, Irshad T, Bhopal R, Brown D, Lawton J, Grant E, et al. Vulnerability and access to care for South Asian Sikh and Muslim patients with life limiting illness in Scotland: Prospective longitudinal qualitative study. *BMJ.* 2009;338(7693):1–11.
134. Kirby E, Broom A, Good P, Bowden V, Lwin Z. Experiences of interpreters in supporting the transition from oncology to palliative care: A qualitative study. *Asia Pac J Clin Oncol.* 2017;13(5):e497–505.
135. Periyakoil VS, Neri E, Kraemer H. Patient-reported barriers to high-quality, end-of-life care: A multiethnic, multilingual, mixed-methods study. *J Pall Med.* 2016;19(4):373–9.
136. Molassiotis A. Supportive and palliative care for patients from ethnic minorities in Europe: Do we suffer from institutional racism? *Eur J Oncol Nurs.* 2004;8(4):290–2.
137. Brown E, Franklin A, Coad J. A concept analysis in relation to the cultural competency of the palliative care workforce in meeting the needs of young people from South Asian cultures. *Palliat Support Care.* 2018;16(2):220–7.
138. Williamson M, Harrison L. Providing culturally-appropriate care: A literature review. *Int J Nurs Stud.* 2010;47:761–9.
139. PICAC NSW & ACT. Bridging cultures: A guide to the diverse cultures in Australia for aged care service providers. 3rd ed. Partners in Culturally Appropriate Care (PICAC) NSW & ACT; 2016.
140. Johnstone MJ, Rawson H, Hutchinson AM, Redley B. Fostering trusting relationships with older immigrants hospitalised for end-of-life care. *Nurs Ethics.* 2018;25(6):760–72.
141. Ekblad S, Marttila A, Emilsson M. Cultural challenges in end-of-life care: reflections from focus groups’ interviews with hospice staff in Stockholm. *J Adv Nurs.* 2000;31(3):623–30.
142. Gunaratnam Y. Intercultural palliative care: Do we need cultural competence? *Int J Palliat Nurs.* 2007;13(10):470–7.
143. McNamara B, Martin K, Waddell C,

- Yuen K. Palliative care in a multicultural society: Perceptions of health care professionals. *Palliat Care*. 1997;11:359–67.
144. Gatrad AR, Brown E, Notta H, Sheikh A. Palliative care needs of minorities. *BMJ*. 2003;327:176–7.
145. Randhawa G, Owens A, Fitches R, Khan Z. Communication in the development of culturally competent palliative care services in the UK: A case study. *Int J Palliat Nurs*. 2003;9(1):24–31.
146. Silva MD, Genoff M, Zaballa A, Jewell S, Stabler S, Gany FM, et al. Interpreting at the end of life: A systematic review of the impact of interpreters on the delivery of palliative care services to cancer patients with limited English proficiency. *J Pain Symptom Manage*. 2016;51(3):569–80.
147. Butow PN, Lobb E, Jefford M, Goldstein D, Eisenbruch M, Girgis A, et al. A bridge between cultures: Interpreters' perspectives of consultations with migrant oncology patients. *Support Care Cancer*. 2012;20(2):235–44.
148. Norris WM, Wenrich MD, Nielsen EL, Treece PD, Jackson JC, Curtis JR. Insights from medical interpreters. *J Palliat Med*. 2005;8(5):1016–25.
149. Kemp C. Cultural issues in palliative care. *Semin Oncol Nurs*. 2005;21(1):44–52.
150. Abunafeesa H, Elsayem AF. Cultural diversity and barriers to high-quality end of life care. *Ann Palliat Med*. 2017;6(2):183–6.
151. Johnson J, Hayden T, Taylor LA, Gilbert A, Jones CH, Mitchell MPH, et al. Engaging the African American church to improve communication about palliative care and hospice: Lessons from a multilevel approach. *J Palliat Care*. 2019;34(3):168–74.
152. Ghesquiere A, Gardner DS, McAfee C, Kenien C, Capezuti E, Kozlov E, et al. Development of a community-based palliative care screening tool for underserved older adults With chronic illnesses. *Am J Hosp Palliat Med*. 2018;35(7):929–37.
153. Palliative Care Victoria. Culturally responsive palliative care strategy 2013-2015: Final evaluation summary. 2015.
154. Johnstone M, Kanitsaki O. Ethics and advance care planning in a culturally diverse society. *J Transcult Nurs*. 2009;20(4):405–16.
155. Hong M, Yi EH, Johnson KJ, Adamek ME. Facilitators and barriers for advance care planning among ethnic and racial minorities in the U.S: A systematic review of the current literature. *J Immigr Minor Heal*. 2018;20(5):1277–87.
156. Menon S, Kars MC, Malhotra C, Campbell A V., van Delden JJM. Advance care planning in a multicultural family centric community: A qualitative study of health care professionals', patients', and caregivers' perspectives. *J Pain Symptom Manage*. 2018;56(2):213–21.
157. McDermott E, Selman LE. Cultural factors influencing advance care planning in progressive, incurable disease: A systematic review with narrative synthesis. *J Pain Symptom Manage*. 2018;56(4):613–36.
158. Sinclair C, Smith J, Toussaint Y, Auret K. Discussing dying in the diaspora: Attitudes towards advance care

- planning among first generation Dutch and Italian migrants in rural Australia. *Soc Sci Med*. 2014;101:86–93.
159. Jeong S, Ohr S, Pich J, Saul P, Ho A. “Planning ahead” among community-dwelling older people from culturally and linguistically diverse background: A cross-sectional survey. *J Clin Nurs*. 2015;24(1–2):244–55.
 160. Con A. Crosscultural considerations in promoting advance care planning in Canada. Vancouver: CIHR Cross-Cultural Palliative NET; 2008.
 161. Ko E, Lee J. Completion of advance directives among Korean American and non-Hispanic white older adults. *Res Aging*. 2010;32(5):618–44.
 162. Kwak J, Haley WE. Current research findings on end-of-life decision making among racially or ethnically diverse groups. *Gerontologist*. 2005;45(5):634–41.
 163. Michael N, O’Callaghan C, Sayers E. Managing ‘shades of grey’: A focus group study exploring community-dwellers’ views on advance care planning in older people. *BMC Palliat Care*. 2017;16(1):1–9.
 164. Belisomo R. Reversing racial inequities at the end of life: A call for health systems to create culturally competent advance care planning programs within African American communities. *J Racial Ethn Heal Disparities*. 2017;5:213–20.
 165. Inoue M, Hughes Rinker C, Vargas-Jackson R. Advance care planning in Medicare/Medicaid-funded agencies: Providing a training in cultural competence. *Gerontol Geriatr Educ*. 2018;Dec 8:1–12.
 166. Pereira-Salgado A, Mader P, O’Callaghan C, Boyd L. A website supporting sensitive religious and cultural advance care planning (ACPTalk): Formative and summative evaluation. *JMIR Res Protoc*. 2018;7(4):e78.
 167. Sudore RL, Schillinger D, Katen MT, Shi Y, Boscardin WJ, Osua S, et al. Engaging diverse English- and Spanish-speaking older adults in advance care planning. *JAMA Intern Med*. 2018;94121(12):1616–25.
 168. The UN Refugee Agency Australia for UNHCR. 2017 Annual Report. Sydney; 2017.
 169. Refugee Council of Australia. Who is a refugee? [Internet]. Get the facts. 2016 [cited 2019 Apr 30]. Available from: <https://www.refugeecouncil.org.au/who-is-a-refugee/>
 170. United Nations High Commissioner for Refugees. UNHCR master glossary of terms rev. 1. Geneva; 2006.
 171. Karlsen E. Refugee resettlement to Australia: What are the facts? Research Paper Series, 2016–17. Canberra: Parliament of Australia; 2016.
 172. United Nations High Commissioner for Refugees. Global trends - forced displacement in 2017. Geneva: UNHCR; 2017.
 173. Paxton GA, Cherian S, Zwi KJ. The Royal Australasian College of Physicians position statement on refugee and asylum seeker health. *Med J Aust*. 2015;203(4):176–7.
 174. Department of Health and Human Services. Refugee and asylum seeker health services: guidelines for the community health program. Melbourne: DHHS; 2015.

175. Russell G, Harris M, Cheng I, Kay M, Vasi S, Joshi C, et al. Coordinated primary health care for refugees: A best practice framework for Australia. Dandenong, Victoria: Report to the Australian Primary Health Care Research Institute; 2013. <https://www.aihw.gov.au/reports-data/health-conditions-disability-deaths/disability/about>
176. CareSearch. Refugees and asylum seekers [Internet]. 2018 [cited 2018 Mar 14]. Available from: <https://www.caresearch.com.au/caresearch/tabid/2385/Default.aspx>
177. Madi F, Ismail H, Fouad FM, Kerbage H, Zaman S, Jayawickrama J, et al. Death, dying, and end-of-life experiences among refugees: A scoping review. *J Palliat Care*. 2019;34(2):139–44.
178. Bellamy K, Ostini R, Martini N, Kairuz T. Access to medication and pharmacy services for resettled refugees: A systematic review. *Aust J Prim Health*. 2015;21(3):273–8.
179. Hiruy K, Mwanri L. End-of-life experiences and expectations of Africans in Australia: Cultural implications for palliative and hospice care. *Nurs Ethics*. 2014;21(2):187–97.
180. Ross L, Harding C, Seal A, Duncan G. Improving the management and care of refugees in Australian hospitals: A descriptive study. *Aust Heal Rev*. 2016;40(6):679–85.
181. Silbermann M, Baider L, Respini D, Tralongo P, Daher M, Obeidat R, et al. Palliative care is a useful means to overcome intercultural barriers faced by refugees in their new host countries. *J Palliat Care Med*. 2018 Jun 26;8(3):334.
182. Australian Institute of Health and Welfare. Disability - about [Internet]. 2017 [cited 2019 Apr 16]. Available from:
183. Brown L, Hansnata E, La HA. Economic cost of dementia in Australia 2016-2056. Canberra: NATSEM; 2017.
184. Standfield LB, Comans T, Scuffham P. A simulation of dementia epidemiology and resource use in Australia. *Aust N Z J Public Health*. 2018;42:291–5.
185. Ryan KR, McQuillan R. Palliative care for disadvantaged groups: People with intellectual disabilities. *Prog Palliat Care*. 2005;13(2):70–4.
186. Sampson EL. Palliative care for people with dementia. *Br Med Bull*. 2010;96:159–74.
187. Hertogh CPM. Advance care planning and the relevance of a palliative care approach in dementia. *Age Ageing*. 2006;35(6):553–5.
188. Grindrod A, Rumbold B. End of life care for Victorians with intellectual disability living in residential services. Melbourne: La Trobe University Palliative Unit; 2015.
189. Lindley LC, Colman MB, Meadows JT. Children with intellectual disability and hospice utilization. *J Hosp Palliat Nurs*. 2017;19(1):28–33.
190. Disability Services. Disability residential services palliative care guide. Melbourne; 2009.
191. Friedman SL, Helm DT, Woodman AC. Unique and universal barriers: Hospice care for aging adults with intellectual disability. *Am J Intellect Dev Disabil*. 2012;117(6):509–32.
192. Ryan T, Gardiner C, Bellamy G, Gott M, Ingleton C. Barriers and facilitators to the receipt of palliative care for

- people with dementia: The views of medical and nursing staff. *Palliat Med.* 2011;26(7):879–86.
193. Tuffrey-Wijne I, Mcenhill L. Communication difficulties and intellectual disability in end-of-life care. *Int J Palliat Nurs.* 2008;14(4):189–94.
194. Hahn JE, Cadogan MP. Development and evaluation of a staff training program on palliative care for persons with intellectual and developmental disabilities. *J Policy Pract Intellect Disabil.* 2011;8(1):45–52.
195. Tuffrey-Wijne I, Davidson J. Excellence in palliative and end-of-life care provision for people with intellectual disability. *Int J Palliat Nurs.* 2018;24(12):598–610.
196. Moro TT, Savage TA, Gehlert S. Agency, social and healthcare supports for adults with intellectual disability at the end of life in out-of-home, non-institutional community residences in Western nations: A literature review. *J Appl Res Intellect Disabil.* 2017;30(6):1045–56.
197. Higginson IJ, Costantini M, Silber E, Burman R, Edmonds P. Evaluation of a new model of short-term palliative care for people severely affected with multiple sclerosis: A randomised fast-track trial to test timing of referral and how long the effect is maintained. *J Postgrad Med.* 2011;87:769–75.
198. Trollor J, Srasuebkul P, Xu H, Howlett S. Cause of death and potentially avoidable deaths in Australian adults with intellectual disability using retrospective linked data. *BMJ Open.* 2017;7:e013489.
199. Sampson EL, Candy B, Davis S, Gola AB, Harrington J, King M, et al. Living and dying with advanced dementia: A prospective cohort study of symptoms, service use and care at the end of life. *Palliat Med.* 2018;32(3):668–81.
200. Holliday A. Quality end of life care for people with disability, a Tasmanian perspective. *Liviende Veranto*; 2016.
201. Chang E, Hancock K, Harrison K, Daly J, Johnson A, Easterbrook S, et al. Palliative care for end-stage dementia: A discussion of the implications for education of health care professionals. *Nurse Educ Today.* 2005;25:326–32.
202. van der Steen JT, Radbruch L, Hertogh CM, de Boer ME, Hughes JC, Larkin P, et al. White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care. *Palliat Med.* 2014 Mar 4;28(3):197–209.
203. Cresp SJ, Lee SF, Moss C. Substitute decision makers' experiences of making decisions at end of life for older persons with dementia: A systematic review and qualitative meta-synthesis. *Dementia.* 2018;Sep 25:1471301218802127.
204. Vick JB, Ornstein KA, Szanton SL, Dy SE, Wolff JL. Does caregiving strain increase as patients with and without dementia approach the end of life? *J Pain Symptom Manage.* 2019;57(2):199–208.
205. Poole M, Bamford C, McLellan E, Lee RP, Exley C, Hughes JC, et al. End-of-life care: A qualitative study comparing the views of people with dementia and family carers. *Palliat Med.* 2018;32(3):631–42.
206. Tuffrey-Wijne I, Whelton R, Curfs L, Hollins S. Palliative care provision for people with intellectual disabilities: a questionnaire survey of specialist

- palliative care professionals. *Palliat Med.* 2008;22(3):281–90.
207. Harris D. Forget me not: Palliative care for people with dementia. *Postgrad Med J.* 2007;83:362–6.
208. McCarron M, McCallion P, Fahey-Mccarthy E, Connaire K. The role and timing of palliative care in supporting persons with intellectual disability and advanced dementia. *J Appl Res Intellect Disabil.* 2011;24:189–98.
209. Midtbust MH, Alnes RE, Gjengedal E, Lykkeslet E. Perceived barriers and facilitators in providing palliative care for people with severe dementia: The healthcare professionals' experiences. *BMC Health Serv Res.* 2018;18:709.
210. Hughes JC, Jolley D, Jordan A, Sampson EL. Palliative care in dementia: Issues and evidence. *Adv Psychiatr Treat.* 2007;13:251–60.
211. Martinsson L, Lundström S, Sundelöf J. Quality of end-of-life care in patients with dementia compared to patients with cancer: A population-based register study. *PLoS One.* 2018;13(7):1–11.
212. Wark S, Hussain R, Müller A, Ryan P, Parmenter T. Challenges in providing end-of-life care for people with intellectual disability: Health services access. *J Appl Res Intellect Disabil.* 2017;30(6):1151–9.
213. O'Hehir S. Palliative care for people living in group homes 2018. Southern Metro Region Palliative Care Consortium; 2018.
214. Stein GL. Providing palliative care to people with intellectual disabilities: Services, staff knowledge, and challenges. *J Palliat Med.* 2008;11(9):1241–8.
215. Martyn SR. Substituted judgment, best interests, and the need for best respect. *Cambridge Q Healthc Ethics.* 1994;3:195–208.
216. Grindrod A, Rumbold B. Providing end-of-life care in disability community living services: An organizational capacity-building model using a public health approach. *J Appl Res Intellect Disabil.* 2017;30(6):1125–37.
217. McCleary L, Thompson GN, Venturato L, Wickson-Griffiths A, Hunter P, Sussman T, et al. Meaningful connections in dementia end of life care in long term care homes. *BMC Psychiatry.* 2018;18(1):1–10.
218. Harrop E, Nelson A, Rees H, Harris D, Noble S. The challenge pathway: A mixed methods evaluation of an innovative care model for the palliative and end-of-life care of people with dementia (Innovative practice). *Dementia.* 2018;17(2):252–7.
219. Fox S, Fitzgerald C, Harrison Denning K, Irving K, Kernohan WG, Treloar A, et al. Better palliative care for people with a dementia: Summary of interdisciplinary workshop highlighting current gaps and recommendations for future research. *BMC Palliat Care.* 2017;17(1):1–12.
220. National Institute for Health and Care Excellence. Care and support of older people with learning disabilities: NICE guideline NG96. 2018.
221. Vrijmoeth C, Echteld MA, Assendelft P, Christians M, Festen D, van Schroyen Lantman-de Valk H, et al. Development and applicability of a tool for identification of people with intellectual disabilities in need of palliative care (PALLI). *J Appl Res Intellect Disabil.* 2018;31(6):1122–32.

222. Kinley J, Denton L, Scott S. Development and implementation of the Steps to Successful Palliative Care programme in residential care homes for people with a learning disability. *Int J Palliat Nurs*. 2018;24(10):492–502.
223. Linse K, Aust E, Joos M, Hermann A. Communication matters – pitfalls and promise of hightech communication devices in palliative care of severely physically disabled patients with amyotrophic lateral sclerosis. *Front Neurol*. 2018;9:603.
224. CareSearch. Talking End of Life...with people with intellectual disability [Internet]. 2018 [cited 2018 Jan 27]. Available from: <https://www.caresearch.com.au/TEL/>
225. Lohiya G-S, Tan-Figueroa L, Kohler H. End-of-life decisions in a developmental center: A retrospective study. *West J Med*. 2002;176(1):20–2.
226. Arias R, Andrews J, Pandya S, Pettit K, Trout C, Apkon S, et al. Palliative care services in families of males with Duchenne muscular dystrophy. *Muscle Nerve*. 2011;44:93–101.
227. Tjia J, Dharmawardene M, Givens JL. Advance directives among nursing home residents with mild, moderate, and advanced dementia. *J Palliat Med*. 2018;21(1):16–21.
228. McCreedy E, Loomer L, Palmer JA, Mitchell SL, Volandes A, Mor V. Representation in the care planning process for nursing home residents With dementia. *J Am Med Dir Assoc*. 2018;19:415–21.
229. Chen H, Habermann B. Ready or not: Planning for health declines in couples with advanced multiple sclerosis. *J Neurosci Nurs*. 2013;45(1):38–43.
230. Bosisio F, Jox RJ, Jones L, Rubli Truchard E. Planning ahead with dementia: What role can advance care planning play? A review on opportunities and challenges. *Swiss Med Wkly*. 2018;148:w14706.
231. de Vries K, Drury-Ruddlesden J. Advance care planning for people with dementia: Ordinary everyday conversations. *Dementia*. 2018;Jan 1:1471301218764169.
232. Ryan T, McKeown J. Couples affected by dementia and their experiences of advance care planning: A grounded theory study. *Ageing Soc*. 2018;1–22.
233. Givens JL, Sudore RL, Marshall GA, Dufour AB, Kopits I, Mitchell SL. Advance care planning in community-dwelling patients with dementia. *J Pain Symptom Manage*. 2018;55(4):1105–12.
234. Robinson L, Dickinson C, Bamford C, Clark A, Hughes J, Exley C. A qualitative study: Professionals' experiences of advance care planning in dementia and palliative care, "a good idea in theory but..." *Palliat Med*. 2013;27(5):401–8.
235. Tilburgs B, Vernooij-Dassen M, Koopmans R, van Gennip H, Engels Y, Perry M. Barriers and facilitators for GPs in dementia advance care planning: A systematic integrative review. *PLoS One*. 2018;13(6):e0198535.
236. Tilburgs B, Vernooij-Dassen M, Koopmans R, Weidema M, Perry M, Engels Y. The importance of trust-based relations and a holistic approach in advance care planning with people with dementia in primary care: A qualitative study. *BMC Geriatr*. 2018;18(1):1–11.
237. Cotter VT, Spriggs M, Razzak R.

- Advance care planning in early stage dementia. *J Nurse Pract.* 2018;14(3):142–7.
238. Kiriaev O, Chacko E, Jurgens JD, Ramages M, Malpas P, Cheung G. Should capacity assessments be performed routinely prior to discussing advance care planning with older people? *Int Psychogeriatrics.* 2018;30(8):1243–50.
239. Lee L, Hillier LM, Locklin J, Lee J, Slonim K. Advanced Care Planning for Persons With Dementia in Primary Care: Attitudes and Barriers Among Health-Care Professionals. *J Palliat Care.* 2018;082585971881246.
240. Parker D, Lewis J, Gourlay K. Palliative care and dementia: Paper number 43. *Dementia Australia;* 2017.
241. Piers R, Albers G, Gilissen J, De Lepeleire J, Steyaert J, Van Mechelen W, et al. Advance care planning in dementia: Recommendations for healthcare professionals. *BMC Palliat Care.* 2018;17(1):1–17.
242. Katwa AP, Jenner C, MacDonald K, Barnett N. Improving advance care planning for care home residents with dementia: Evaluation of simulation training for care home workers. *Dementia.* 2018;Jan 1:1471301218788137.
243. Dixon J, Karagiannidou M, Knapp M. The effectiveness of advance care planning in improving end-of-life outcomes for people with dementia and their carers: A systematic review and critical discussion. *J Pain Symptom Manage.* 2018;55(1):132–50.
244. Brazil K, Carter G, Cardwell C, Clarke M, Hudson P, Froggatt K, et al. Effectiveness of advance care planning with family carers in dementia nursing homes: A paired cluster randomized controlled trial. *Palliat Med.* 2018;32(3):603–12.
245. Mitchell SL, Shaffer ML, Cohen S, Hanson LC, Habtemariam D, Volandes AE. An advance care planning video decision support tool for nursing home residents with advanced dementia: A cluster randomized clinical trial. *JAMA Intern Med.* 2018;178(7):961–99.
246. Bryant J, Turon H, Waller A, Freund M, Mansfield E, Sanson-Fisher R. Effectiveness of interventions to increase participation in advance care planning for people with a diagnosis of dementia: A systematic review. *Palliat Med.* 2019;33(3):262–73.
247. McGinley JM, Knoke V. Conceptualising person-centered advance care planning for people with intellectual disabilities: A multifaceted theoretical approach. *Ethics Soc Welf.* 2018;12(3):244–58.
248. Gallagher A, Peacock M, Arber A. Helping young people who have learning disabilities and their families to plan end of life care: the ADVANCE toolkit. *Learn Disabil Pract.* 2018 Nov 27;21(6):33–41.
249. Blake M, Doray ON, Sinclair C. Advance care planning for people with dementia in Western Australia: An examination of the fit between the law and practice. *Psychiatry, Psychol Law.* 2018;25(2):197–218.
250. Riley C. The homeless community: Breaking down the barriers to primary care. *Int Paramed Pract.* 2017 Aug 2;7(2):26–30.
251. Arnold-Reed D, Troeung L, Brett T, Ping-Delfos WCS, Strange C, Geelhoed E, et al. Increasing multimorbidity in an Australian street health service: A 10-year retrospective cohort study.

- Aust J Gen Pract. 2018;47(4):181–9.
252. Webb WA, Mitchell T, Snelling P, Nyatanga B. The spiritual concerns of people experiencing homelessness at the end of life. *Int J Pall Nurs*. 2018;24(9):428–35.
253. Andrews C, Carlile S, McNair R. A vicious cycle: The lack of LGBTIQ homelessness data and policy. *Parity*. 2017;30(3):46.
254. Kelly F. Thousands of Iraq and Afghanistan veterans homeless [Internet]. ABC. 2015 [cited 2018 Mar 28]. Available from: <http://www.abc.net.au/radionational/programs/breakfast/thousands-of-iraq-and-afghanistan-veterans-homeless/6285252>
255. West KJ, Wrobel B, Pallotta S, Coatsworth A. Bearing witness: Exploring the end-of-life needs of homeless persons and barriers to appropriate care. *OMEGA - J Death Dying*. 2018;0(0):1–29.
256. MacWilliams J, Bramwell M, Brown S, O'Connor M. Reaching out to Ray: Delivering palliative care services to a homeless person in Melbourne, Australia. *Int J Palliat Nurs*. 2014;20(2):83–8.
257. Hudson BF, Flemming K, Shulman C, Candy B. Challenges to access and provision of palliative care for people who are homeless: A systematic review of qualitative research. *BMC Palliat Care*. 2016 Dec;15:96.
258. Collier R. Bringing palliative care to the homeless. *Can Med Assoc J*. 2011;183(6):E317-8.
259. McNeil R, Guirguis-Younger M, Dilley LB. Recommendations for improving the end-of-life care system for homeless populations: A qualitative study of the views of Canadian health and social services professionals. *BMC Palliat Care*. 2012;11:14.
260. Hudson BF, Shulman C, Low J, Hewett N, Daley J, Davis S, et al. Challenges to discussing palliative care with people experiencing homelessness: A qualitative study. *BMJ Open*. 2017;7:e017502.
261. Cagle JG. Weathering the storm: Palliative care and elderly homeless persons. *J Hous Elderly*. 2009;23(1–2):29–46.
262. Krakowsky Y, Gofine M, Brown P, Danziger J, Knowles H. Increasing access—A qualitative study of homelessness and palliative care in a major urban center. *Am J Hosp Palliat Med*. 2013;30(3):268–70.
263. Webb WA. When dying at home is not an option: Exploration of hostel staff views on palliative care for homeless people. *Int J Palliat Nurs*. 2015;21(5):236–44.
264. Hubbell SA. Advance care planning with individuals experiencing homelessness: Literature review and recommendations for public health practice. *Public Health Nurs*. 2017;34(5):472–8.
265. Tarzian AJ, Neal MT, O'Neil JA. Attitudes, experiences, and beliefs affecting end-of-life decision-making among homeless individuals. *J Palliat Med*. 2005;8(1):36–48.
266. Podymow T, Turnbull J, Coyle D. Shelter-based palliative care for the homeless terminally ill. *Palliat Med*. 2006;20:81–6.
267. Klop HT, De Veer AJEJ, Van Dongen SI, Francke AL, Rietjens JAAC, Onwuteaka-Philipsen BD. Palliative care for homeless people: A

- systematic review of the concerns, care needs and preferences, and the barriers and facilitators for providing palliative care. *BMC Palliat Care*. 2018;17(1):67.
268. Palliative care for vulnerable and underserved populations: Needs assessment report. Ontario: Dilico Anishinabek Family Care; 2018.
269. De Veer AJE, Stringer B, Van Meijel B, Verkaik R, Francke AL. Access to palliative care for homeless people: Complex lives, complex care. *BMC Palliat Care*. 2018;17(1):119.
270. Song J, Wall MM, Ratner ER, Bartels DM, Ulvestad N, Gelberg L. Engaging homeless persons in end of life preparations. *J Gen Intern Med*. 2008;23(12):2031–45.
271. Giesbrecht M, Stajduhar KI, Mollison A, Pauly B, Reimer-Kirkham S, McNeil R, et al. Hospitals, clinics, and palliative care units: Place-based experiences of formal healthcare settings by people experiencing structural vulnerability at the end-of-life. *Heal Place*. 2018;53:43–51.
272. O’Sullivan A, Jean M, Catalaon L, Basara D, Borne D, Dosani N. Adapting your practice: Recommendations for end-of-life care for people experiencing homelessness. *Health Care for the Homeless Clinicians’ Network*; 2018.
273. Huynh L, Henry B, Dosani N. Minding the gap: Access to palliative care and the homeless. *BMC Palliat Care*. 2015;14(1):62.
274. Stajduhar KI, Mollison A. Too little too late: How we fail vulnerable Canadians as they die and what to do about it. Victoria, British Columbia: University of Victoria Institute on Aging & Lifelong Health; 2018.
275. Woolley E. How do people experiencing homelessness get palliative care? [Internet]. Homeless Hub. 2016 [cited 2018 Mar 28]. Available from: <http://homelesshub.ca/blog/how-do-people-experiencing-homelessness-get-palliative-care>
276. West K, Wrobel B, Coatsworth A, Pallotta S. Palliative care for the homeless: a scoping review. *Innov Aging*. 2018;2(S1):529.
277. Nikouline A, Dosani N. Benefits and Barriers to the Homeless by In-Shelter Palliative Care: A Qualitative Study [Internet]. Canadian Virtual Hospice. 2017 [cited 2018 Mar 28]. Available from: http://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home/For+Professionals/For+Professionals/The+Exchange/Current/Benefits+and+Barriers+to+the+Homeless+by+In_Shelter+Palliative+Care_+A+Qualitative+Study.aspx
278. Petruik CR. Social work practices in palliative and end-of-life care for persons experiencing homelessness: A scoping review. *Fam Soc J Contemp Soc Serv*. 2018;99(4):317–28.
279. Kushel M, Miaskowski C. End-of-life care for homeless patients: “She says she is there to help me in any situation.” *J Am Med Assoc*. 2006;296(24):2959–66.
280. Henry B, Dosani N, Huynh L, Amirault N. Palliative care as a public health issue: Understanding disparities in access to palliative care for the homeless population. *Curr Oncol*. 2017;24(3):187–91.
281. Webb WA, Mitchell T, Nyatanga B, Snelling P. How to explore the end-of-life preferences of homeless people in the UK. *Eur J Palliat Care*. 2018;25(2):59–62.

282. Shulman C, Hudson BF, Low J, Hewett N, Daley J, Kennedy P, et al. End-of-life care for homeless people: A qualitative analysis exploring the challenges to access and provision of palliative care. *Palliat Med.* 2018;32(1):36–45.
283. Klop HT, van Dongen SI, Francke AL, de Veer AJE, Rietjens JAC, Gootjes JRG, et al. The views of homeless people and health care professionals on palliative care and the desirability of setting up a consultation service: A focus group study. *J Pain Symptom Manage.* 2018;56(3):327–36.
284. Song J, Ratner ER, Bartels DM, Alderton L, Hudson B, Ahluwalia JS. Experiences with and attitudes toward death and dying among homeless persons. *J Gen Intern Med.* 2007;22:427–34.
285. Shulman C, Hudson BF, Kennedy P, Brophy N, Stone P. Evaluation of training on palliative care for staff working within a homeless hostel. *Nurse Educ Today.* 2018;71:135–44.
286. Håkanson C, Sandberg J, Ekstedt M, Kenne Sarenmalm E, Christiansen M, Öhlén J. Providing palliative care in a Swedish support home for people who are homeless. *Qual Health Res.* 2016;26(9):1252–62.
287. Hwang S, Dowbor T, Devotta K, Pedersen C. Palliative care services for people experiencing homelessness in Toronto: A preliminary needs assessment. Toronto: Centre for Urban Health Solutions Survey Research Unit, St Michael's Hospital; 2017.
288. McNeil R, Guirguis-Younger M, Dilley LB, Aubry TD, Turnbull J, Hwang SW. Harm reduction services as a point-of-entry to and source of end-of-life care and support for homeless and marginally housed persons who use alcohol and/or illicit drugs: A qualitative analysis. *BMC Public Health.* 2012;12:312.
289. Yates P, Brown C, Gain W, Harrison D, Rosenberg J. Strengthening partnerships between health and aged care services to achieve better end-of-life care for older Australians: The Decision Assist Linkages Project Case Studies. Brisbane; 2017.
290. Leung AK, Nayyar D, Sachdeva M, Song J, Hwang SW. Chronically homeless persons' participation in an advance directive intervention: A cohort study. *Palliat Med.* 2015;29(8):746–55.
291. Ko E, Nelson-Becker H. Does end-of-life decision making matter? *Am J Hosp Palliat Med.* 2014;31(2):183–8.
292. Dubbert PM, Garner KK, Lensing S, White JG, Sullivan DH. Engagement in steps of advance health care planning by homeless veterans. *Psychol Serv.* 2017;14(2):214–20.
293. Sudore RL, Cuervo IA, Tieu L, Guzman D, Kaplan LM, Kushel M. Advance care planning for older homeless-experienced adults: Results from the Health Outcomes of People Experiencing Homelessness in Older Middle Age study. *J Am Geriatr Soc.* 2018;66(6):1068–74.
294. Cortez DM, Harding K, Koutouratsas L, Pietras C, Meyer J. Advance care planning for the homeless: A community collaboration. *Narrat Inq.* 2017;7(1):E14–5.
295. Linder JF, Enders SR, Craig E, Richardson J, Meyers FJ. Hospice care for the incarcerated in the United States: An introduction. *J Palliat Med.* 2002;5(4):549–52.
296. Linder JF, Meyers FJ. Palliative care for

- prison inmates. *JAMA*. 2007;298(8):894–901.
297. Turner M, Peacock M. Palliative care in UK prisons: Practical and emotional challenges for staff and fellow prisoners. *J Correct Heal Care*. 2017;23(1):56–65.
 298. Burles MC, Peternelj-Taylor CA, Holtslander L. A ‘good death’ for all?: Examining issues for palliative care in correctional settings. *Mortality*. 2016;21(2):93–111.
 299. Baidawi S. Managing the health of an ageing prison population: A review of the challenges to be addressed by effective models of care. An Evidence Check rapid review brokered by the Sax Institute for the Justice Health and Forensic Mental Health Network; 2015.
 300. Walmsley R. World prison population list. 11th ed. Institute for Criminal Policy Research; 2016.
 301. McInerney M. Westernised systems of palliative care can be problematic, conference is told [Internet]. Croakey. 2017 [cited 2018 Mar 28]. Available from: <https://croakey.org/westernised-systems-of-palliative-care-can-be-problematic-conference-is-told/>
 302. Aged Care InSite. Call to act on ageing prisoners [Internet]. APN Educational Media. 2012 [cited 2018 Mar 28]. Available from: <https://www.agedcareinsite.com.au/2012/05/call-to-act-on-ageing-prisoners/>
 303. Palliative Care NSW. Within prisons – Palliative Care NSW Volunteer Support Services Programme [Internet]. VolunteerHub. 2016 [cited 2018 Mar 28]. Available from: <http://volunteerhub.com.au/volunteer-support-services/palliative-care-volunteers-and/palliative-care-volunteers-in-prison-settings-lessons-from-the-us/>
 304. Wiseman H. Frail elderly put new pressure on prisons to provide palliative care [Internet]. Palliative Care Australia. 2016 [cited 2018 Mar 28]. Available from: <http://palliativecare.org.au/frail-elderly-prisoners-put-new-pressure-on-prisons>
 305. Williams BA, Goodwin JS, Baillargeon J, Ahalt C, Walter LC. Addressing the aging crisis in U.S. criminal justice health care. *J Am Geriatr Soc*. 2012;60(6):1150–6.
 306. Maschi T, Marmo S, Han J. Palliative and end-of-life care in prisons: A content analysis of the literature. *Int J Prison Health*. 2014;10(3):172–97.
 307. Pazart L, Godard-Marceau A, Chassagne A, Vivot-Pugin A, Cretin E, Amzallag E, et al. Prevalence and characteristics of prisoners requiring end-of-life care: A prospective national survey. *Palliat Med*. 2018;32(1):6–16.
 308. Stensland M, Sanders S. Detained and dying: Ethical issues surrounding end-of-life care in prison. *J Soc Work End Life Palliat Care*. 2016;12(3):259–76.
 309. Yampolskaya S, Winston N. Hospice care in prison: General principles and outcomes. *Am J Hosp Palliat Care*. 2003;20(4):290–6.
 310. Cloyes KG, Berry PH, Martz K, Supiano K. Characteristics of prison hospice patients: Medical history, hospice care, and end-of-life symptom prevalence. *J Correct Heal Care*. 2015;21(3):298–308.
 311. Craig EL, Craig RE. Prison hospice: An

- unlikely success. *Am J Hosp Palliat Med*. 1999;16(6):725–9.
312. Loeb SJ, Penrod J, McGhan G, Kitt-Lewis E, Hollenbeak CS. Who wants to die in here?: Perspectives of prisoners with chronic conditions. *J Hosp Palliat Nurs*. 2014;16(3):173–81.
313. Wright KN, Bronstein L. An organizational analysis of prison hospice. *Prison J*. 2007;87(4):391–407.
314. Reviere R, Young VD. Aging behind bars: Health care for older female inmates. *J Women Aging*. 2004;16(1–2):55–69.
315. Bedard R, Metzger L, Williams B. Ageing prisoners: An introduction to geriatric health-care challenges in correctional facilities. *Int Rev Red Cross*. 2016;98(3):917–39.
316. Linder JF, Meyers FJ. Palliative and end-of-life care in correctional settings. *J Soc Work End-of-Life Palliat Care*. 2009;5(1–2):7–33.
317. Stephens SL, Cassel JB, Noreika D, Del Fabbro E. Palliative care for inmates in the hospital setting. *Am J Hosp Palliat Care*. 2019;36(4):321–5.
318. Turner M, Peacock M, Payne S, Fletcher A, Froggatt K. Ageing and dying in the contemporary neoliberal prison system: Exploring the ‘double burden’ for older prisoners. *Soc Sci Med*. 2018;212:161–7.
319. Lillie K, Corcoran M, Hunt K, Wrigley A, Read S. Encountering offenders in community palliative care settings: Challenges for care provision. *Int J Pall Nurs*. 2018;24(8):368–75.
320. Sanders S, Stensland M, Dohrmann J, Robinson E, Juraco K. Barriers associated with the implementation of an advance care planning program in a prison setting. *J Soc Work End-of-Life Palliat Care*. 2014;10(4):322–37.
321. Lum KL. Palliative care behind bars: The New Zealand prison hospice experience. *J Pain Palliat Care Pharmacother*. 2003;17(3–4):131–8.
322. Loeb SJ, Penrod J, Hollenbeak CS, Smith CA. End-of-life care and barriers for female inmates. *J Obstet Gynecol Neonatal Nurs*. 2011;40(4):477–85.
323. Turner M, Payne S, Barbarachild Z. Care or custody? An evaluation of palliative care in prisons in North West England. *Palliat Med*. 2011;25(4):370–7.
324. Corrections Victoria Commissioner. Prisoners with an end of life illness. Melbourne: Victorian Government; 2016.
325. Holland MM, Prost SG, Hoffmann HC, Dickinson GE. U.S. Department of Corrections compassionate release policies: A content analysis and call to action. *OMEGA - J Death Dying*. 2018;August 6:30222818791708.
326. Mitchell A, Williams B. Compassionate release policy reform: Physicians as advocates for human dignity. *AMA J Ethics*. 2017;19(9):854–61.
327. Kanbergs A, Ahalt C, Censer IS, Morrison RS, Williams BA. “No one wants to die alone”: Incarcerated patients’ knowledge and attitudes about early medical release. *J Pain Symptom Manage*. 2019;57(4):809–15.
328. Inspector of Custodial Services. Old and inside: Managing aged offenders in custody. Sydney: State of New South Wales through Inspector of Custodial Services, Department of Justice; 2015.

329. Panozzo S, Philip J, Bryan T, Lethborg C. Insights into end-of-life care provision for hospitalised patient groups experiencing vulnerability. *J Pain Symptom Manage*. 2018;56(6):e66–7.
330. Redemske D. Providing healthcare in the prison environment. HDR; 2018.
331. Evans C, Herzog R, Tillman T. The Louisiana State Penitentiary: Angola prison hospice. *J Palliat Med*. 2002;5(4):553–8.
332. Ratcliff M, Craig EL. The GRACE project: Guiding end-of-life care in corrections 1998-2001. *J Palliat Med*. 2004;7(2):373–9.
333. Loeb SJ, Hollenbeak CS, Penrod J, Smith CA, Kitt-Lewis E, Crouse SB. Care and companionship in an isolating environment. *J Forensic Nurs*. 2013;9(1):35–44.
334. Depner RM, Grant PC, Byrwa DJ, Breier JM, Lodi-Smith J, Luczkiewicz DL, et al. “People don’t understand what goes on in here”: A consensual qualitative research analysis of inmate-caregiver perspectives on prison-based end-of-life care. *Palliat Med*. 2018;32(5):969–79.
335. Loeb SJ, Penrod J, Myers VH, Baney BL, Strickfaden SM, Kitt-Lewis E, et al. Enhancing care of aged and dying prisoners: Is e-learning a feasible approach? *J Forensic Nurs*. 2017;13(4):178–85.
336. Brostein LR, Wright K. The impact of prison hospice. *J Soc Work End Life Palliat Care*. 2006;2(4):103–6.
337. CareSearch. Issues for prisoners [Internet]. Palliative Care Knowledge Network. 2017 [cited 2018 Mar 28]. Available from: <https://www.caresearch.com.au/cares>
338. Dying well in custody charter: Self-assessment tool. Ambitions for Palliative & End of Life Care Partnership; 2018.
339. Stone K, Papadopoulos I, Kelly D. Establishing hospice care for prison populations: An integrative review assessing the UK and USA perspective. *Palliat Med*. 2012;26(8):969–78.
340. Rothman A, McConville S, Hsia R, Metzger L, Ahalt C, Williams BA. Differences between incarcerated and non-incarcerated patients who die in community hospitals highlight the need for palliative care services for seriously ill prisoners in correctional facilities and in community hospitals: A cross-sectional study. *Palliat Med*. 2018;32(1):17–22.
341. Ekaireb R, Ahalt C, Sudore R, Metzger L, Williams B. “We take care of patients, but we don’t advocate for them”: Advance care planning in prison or jail. *J Am Geriatr Soc*. 2018;66:2383–8.
342. Sanders S, Stensland M, Juraco K. Agency behind bars: Advance care planning with aging and dying offenders. *Death Stud*. 2018;42(1):45–51.
343. Akouegnon F. Initiation of an advance care planning protocol for inmates within the Delaware prison system. Ann Arbor: ProQuest LLC; 2018.
344. Harding R, Epiphaniou E, Chidgey-Clark J. Needs, experiences, and preferences of sexual minorities for end-of-life care and palliative care: A systematic review. *J Palliat Med*. 2012;15(5):602–11.
345. Bristowe K, Hodson M, Wee B, Almack K, Johnson K, Daveson BA, et al. [earch/tabid/1202/Default.aspx](https://www.caresearch.com.au/cares)

- Recommendations to reduce inequalities for LGBT people facing advanced illness: ACCESSCare national qualitative interview study. *Palliat Med.* 2018;32(1):23–35.
346. National LGBTI Health Alliance and Palliative Care Australia, National LGBTI Health Alliance. *Palliative Care for Lesbian, Gay, Bisexual, Transgender People and People with Intersex Characteristics (LGBTI) Position Statement.* 2015. 4–6 p.
347. Marie Curie UK. “Hiding who I am”: The reality of end of life care for LGBT people. London: Marie Curie; 2016.
348. National LGBTI Health Alliance and Palliative Care Australia. *Palliative care for lesbian, gay, bisexual, transgender people and people with intersex characteristics (LGBTI) position statement [Internet].* 2015 [cited 2018 Mar 28]. Available from: <http://palliativecare.org.au/wp-content/uploads/2015/04/LGBTI-Position-Statement.pdf>
349. Cloyes KG, Hull W, Davis A. Palliative and end-of-life care for lesbian, gay, bisexual, and transgender (LGBT) cancer patients and their caregivers. *Semin Oncol Nurs.* 2018;34(1):60–71.
350. Griebing TL. Sexuality and aging: A focus on lesbian, gay, bisexual, and transgender (LGBT) needs in palliative and end of life care. *Curr Opin Support Palliat Care.* 2016;10(1):95–101.
351. Leinert T, Cartwright C, Beck K. The experiences of gay, lesbian, bisexual and transgender people around end-of-life care: Scoping study report. Coffs Harbour: Aged Services Learning and Research Centre, Southern Cross University; 2010.
352. Paterson S. End-of-life preparation and the role of online technology: A comparison of older gay men and lesbians. Halifax, Nova Scotia: A thesis submitted in partial fulfillment of the requirements for the degree of Master of Arts in Family Studies and Gerontology; 2017.
353. Stevens EE, Abraham JL. Adding silver to the rainbow: Palliative and end-of-life care for the geriatric LGBTQ patient. *J Palliat Med.* 2019;22(5):602–6.
354. Almack K, Seymour J, Bellamy G. Exploring the impact of sexual orientation on experiences and concerns about end of life care and on bereavement for lesbian, gay and bisexual older people. *Sociology.* 2010;44(5):908–24.
355. Dying Matters. LGBT people “let down” by end of life care services [Internet]. 2018 [cited 2019 Aug 6]. Available from: <https://www.dyingmatters.org/page/lgbt-people-let-down-end-life-care-services>
356. Almack K, Yip A, Seymour J, Sargeant A, Patterson A. The last outing: Exploring end of life experiences and care needs in the lives of older LGBT people: A final report. Nottingham: The University of Nottingham; 2015.
357. Maingi S, Bagabag AE, O’Mahony S. Current best practices for sexual and gender minorities in hospice and palliative care settings. *J Pain Symptom Manage.* 2018;55(5):1420–7.
358. National LGBT Cancer Network. LGBT best and promising practices throughout the cancer curriculum [Internet]. 2018 [cited 2018 Mar 27]. Available from: <https://cancer-network.org/reports/lgbt-best-and-promising-practices-throughout-the-cancer-curriculum/>

359. Lawton AJ. LGBTQ-inclusive hospice and palliative care: A practical guide to transforming professional practice. *J Palliat Med*. 2018;21(1):114–5.
360. Hughes M, Cartwright C. LGBT people’s knowledge of and preparedness to discuss end-of-life care planning options. *Heal Soc Care Community*. 2014;22(5):545–52.
361. National LGBTI Health Alliance. 2nd national lesbian, gay, bisexual, transgender and intersex ageing and aged care roundtable report. Sydney: National LGBTI Health Alliance; 2014.
362. Rawlings D. End-of-life care considerations for gay, lesbian, bisexual, and transgender individuals. *Int J Palliat Nurs*. 2012;18(1):29–34.
363. Seelman KL, Lewinson T, Engleman L, Allen A. Motivations for advance care and end-of-life planning among lesbian, gay, and bisexual older adults. *Qual Soc Work*. 2018;doi:10.1177/1473325018792396 .
364. Hughes M, Cartwright C. Lesbian, gay, bisexual and transgender people’s attitudes to end-of-life decision-making and advance care planning. *Australas J Ageing*. 2015;34(Suppl. 2):39–43.
365. Thomeer MB, Donnelly R, Reczek C, Umberson D. Planning for future care and the end of life: A qualitative analysis of gay, lesbian, and eeterosexual couples. *J Health Soc Behav*. 2017;58(4):473–87.
366. Cartwright C, White B, Willmott L, Parker M, Williams G. Australian doctors’ knowledge of and compliance with the law relating to end-of-life decisions: Implications for LGBTI patients. *Cult Heal Sex*. 2018;
367. Carabez R, Scott M. ‘Nurses don’t deal with these issues’: Nurses’ role in advance care planning for lesbian, gay, bisexual and transgender patients. *J Clin Nurs*. 2016;25:3707–15.
368. Kcomt L, Gorey K. End-of-life preparations among lesbian, gay, bisexual, and transgender people: Integrative review of prevalent behaviors. *J Soc Work End Life Palliat Care*. 2017;13(4):284–301.
369. George M, McLawhorn JM, Azhar G, Jarrett D, Knight D. Advance care planning in same-sex couples. *Case Reports Intern Med*. 2018;5(1):26.
370. Gill GF, Bain R, Seidl I. Supporting Australia’s new veterans. *Aust Fam Physician*. 2016;45(3):102.
371. U.S. Department of Veterans Affairs. Veteran Population [Internet]. National Center for Veterans Analysis and Statistics. 2017 [cited 2018 Mar 16]. Available from: https://www.va.gov/vetdata/veteran_population.asp
372. Department of Veterans’ Affairs. Snapshot of the veteran community [Internet]. Annual reports 2017-18. Canberra; 2017 [cited 2019 May 31]. Available from: <https://www.dva.gov.au/about-dva/accountability-and-reporting/veterans-affairs-portfolio-annual-reports/annual-reports-2-11>
373. O’Connor M, Brennan B, Bloomer MJ, Shimoinaba K, O’Connor M, Brennan B, et al. Vulnerability at the end of life: Australian veterans requiring home-based palliative care. *Home Health Care Manag Pract*. 2014;26(3):134–40.
374. Goy ER, Ganzini L. Prevalence and natural history of neuropsychiatric syndromes in veteran hospice patients. *J Pain Symptom Manage*.

- 2011;41(2):394–401.
375. Holland JM, Currier JM, Kirkendall A, Keene JR, Luna N. Sadness, anxiety, and experiences with emotional support among veteran and nonveteran patients and their families at the end of life. *J Palliat Med*. 2014;17(6):708–11.
376. Ganzini L, Socherman R, Duckart J, Shores M. End-of-life care for veterans with schizophrenia and cancer. *Psychiatr Serv*. 2010;61(7):725–8.
377. Garrido MM, Penrod JD, Prigerson HG. Unmet need for mental health care among veterans receiving palliative care: Assessment is not enough. *Am J Geriatr Psychiatry*. 2014;22(6):540–4.
378. Hutt E, Whitfield E, Min S-J, Jones J, Weber M, Albright K, et al. Challenges of providing end-of-life care for homeless veterans. *Am J Hosp Palliat Care*. 2016;33(4):381–9.
379. Hinrichs KLM, Christie KM. Focus on the family: A case example of end-of-life care for an older LGBT veteran. *Clin Gerontol*. 2019;42(2):204–11.
380. Hallenbeck J. Toolkit for developing hospice and palliative care programs in the Department of Veterans Affairs medical centers. Palo Alto, California: Department of Veterans Affairs; 2001.
381. Casarett D, Pickard A, Amos Bailey F, Ritchie C, Furman C, Rosenfeld K, et al. Important aspects of end-of-life care among veterans: Implications for measurement and quality improvement. *J Pain Symptom Manage*. 2008;35(2):115–25.
382. Rosenfeld K, Rasmussen J. Palliative care management: A Veterans Administration demonstration project. *J Palliat Med*. 2003;6(5):831–9.
383. Snyder S. Palliative care in the US military health system. *Mil Med*. 2015;180(10):1024–1026.
384. Patel MI, Bhattacharya J, Asch SM, Kahn J. Acceptance of advance directives and palliative care referral for veterans with advanced cancer. *Am J Hosp Palliat Med*. 2016;33(8):742–7.
385. Frahm KA, Barnett SD, Brown LM. Trends in hospice utilization across age among the veteran population. *Am J Hosp Palliat Med*. 2011;28(6):424–8.
386. Lu H, Trancik E, Bailey FA, Ritchie C, Rosenfeld K, Shreve S, et al. Families' Perceptions of End-of-Life Care in Veterans Affairs versus Non-Veterans Affairs Facilities. *J Palliat Med*. 2010 Aug 16;13(8):991–6.
387. Shreve S. Hospice and palliative care by the VA, beyond the VA. *Generations*. 2010;2:49–56.
388. Hutt E, Albright K, Dischinger H, Weber M, Jones J, O'Toole TP. Addressing the Challenges of Palliative Care for Homeless Veterans. *Am J Hosp Palliat Med*. 2018;35(3):448–55.
389. Gruenewald DA, Doan D, Poppe A, Jones J, Hutt E. "Meet me where I am": Removing barriers to end-of-life care for homeless veterans and veterans without stable housing. *Am J Hosp Palliat Med*. 2018;35(12):1483–9.
390. Blackman V, Hipszer S, Milic M, Puntillo K. Recruiting the military to IMPACT-ICU palliative care. *Crit Care Med*. 2019;47(1):393.
391. Krause-Parello CA, Levy C, Holman E, Kolassa JE. Effects of VA facility dog on hospitalized veterans seen by a palliative care psychologist: An

- innovative approach to impacting stress indicators. *Am J Hosp Palliat Med.* 2018;35(1):5–14.
392. Ramos K, Hastings SN, Bosworth HB, Fulton JJ. Life Program: Pilot testing a palliative psychology group intervention. *J Palliat Med.* 2018;55(2):625–6.
393. VitalTalk, The Regents of the University of California. IMPACT-ICU (Integrating Multidisciplinary Palliative Care into the ICU) [Internet]. 2017 [cited 2019 Jan 25]. Available from: <https://www.vitaltalk.org/resources/impact-icu/>
394. Pearlman RA, Starks H, Cain KC, Cole WG. Improvements in advance care planning in the Veterans Affairs system: Results of a multifaceted intervention. *Arch Intern Med.* 2005;165(6):667–74.
395. David D, Barnes DE, McMahan RD, Shi Y, Katen MT, Sudore RL. Patient activation: A key component of successful advance care planning. *J Palliat Med.* 2018;21(12):1778–82.
396. Fried TR, Redding CA, Martino S, Paiva A, Iannone L, Zenoni M, et al. Increasing engagement in advance care planning using a behaviour change model: Study protocol for the STAMP randomised controlled trials. *BMJ Open.* 2018;8:e025340.
397. Bekelman DB, Johnson-Koenke R, Bowles DW, Fischer SM. Improving early palliative care with a scalable, stepped peer navigator and social work intervention: A single-arm clinical trial. *J Palliat Med.* 2018;21(7):1011–6.
398. Advance Care Planning Australia and National Ageing Research Institute. Advance care planning in aged care: A guide to support implementation in community and residential settings.
399. The Parliament of Australia. Carer Recognition Act No.123, 2010. 2010.
400. Australian Commission on Safety and Quality in Health Care. Patient-centred care: Improving quality and safety through partnerships with patients and consumers. Sydney: ACSQHC; 2011.
401. Victorian Government Department of Health & Human Services. Trauma and mental health: 10-year mental health plan technical paper. Melbourne: DHHS; 2015.
402. Bronfenbrenner U, Morris PA. The bioecological model of human development. In: Lerner R, Damon W, editors. *Handbook of Child Psychology: Theoretical models of human development.* Hoboken, NJ: Wiley & Sons Inc; 2006. p. 793–828.
403. McCabe MP, Mellor D, Ricciardelli LA, Mussap AJ, Halford DJ. Ecological model of Australian Indigenous men's health. *Am J Mens Health.* 2016;10(6):NP63–70.
404. Sallis JF, Owen N, Fisher E. Ecological models of health behavior. *Heal Behav Theory, Res Pract.* 2015;5:43–64.

Appendix A. Literature review method

Conduct of the literature reviews was standardised to ensure consistency in approach between the two reviewers. The original search and review were undertaken in March-April 2018. Reviewer One undertook the literature search and coding process for Aboriginal and Torres Strait Islander, CALD, care-leavers/forced adoption, LGBTI and refugee populations, while Reviewer Two conducted the search and coding process for incarcerated, veteran, homeless populations and those living with a disability.

The literature review process was conducted as follows:

- Peer-reviewed and grey literature search
- Compiling and coding of literature
- Analysis and synthesis of coding
- Reporting of findings.

Peer-reviewed and grey literature search

Database searches

The peer-reviewed and grey literature searches were conducted utilising the same keyword criteria (see *Table A-1*). Peer-reviewed literature was searched using Google Scholar and CareSearch's automated PubMed search database. Grey literature was accessed via a Google search.

Two searches were conducted for both peer-reviewed and grey literature using the following key words:

1. 'Palliative care' AND 'Access or needs or barriers or engagement or strategies or reach'
2. 'Advance care planning'

Exclusion criteria

AHA reviewers considered the relevance of each resource and, when considered necessary, conferred and jointly decided whether or not an article was to be included.

Subjects considered not (or less) relevant included:

- Evidence relating to disease-specific palliative care
- Barriers/engagement strategies relating to socioeconomic disadvantage (although this may be covered in introduction/overlap).

Expert advisor and stakeholder input

In addition to Google Scholar, CareSearch and Google database searches, AHA's expert advisors were consulted to ensure relevant literature had been captured by the search process.

Table A-1: Literature search keywords

Population	Keywords
Aboriginal and Torres Strait Islander peoples	<ul style="list-style-type: none"> • Aboriginal and Torres Strait Islander • Aboriginal • Indigenous
Care leavers and people affected by forced adoption	<ul style="list-style-type: none"> • Care leavers • Forgotten Australians • Former child Migrants • Stolen Generation • Forced adoption
People from CALD backgrounds	<ul style="list-style-type: none"> • Culturally and linguistically diverse/CALD • Migrants • Immigrants • Ethnic
People with disabilities	<ul style="list-style-type: none"> • Disability/disabilities • Disabled • Dementia
People experiencing homelessness	<ul style="list-style-type: none"> • Homeless
People who are incarcerated	<ul style="list-style-type: none"> • Incarcerated • Prisoners • Inmates • Jail • Detention • Correctional
People who identify as LGBTI	<ul style="list-style-type: none"> • LGBTI • Each term separately • Gender diverse
Refugees	<ul style="list-style-type: none"> • Refugees • Asylum seekers
Veterans	<ul style="list-style-type: none"> • Veterans • Soldiers • Defence force • Ex-serving

Peer-reviewed literature

Peer-reviewed literature was downloaded and compiled in Mendeley reference manager software. Subsequently, full-text articles were imported into NVivo for coding. Articles were coded to pre-determined coding themes which are illustrated in *Table A-2*. Codes were pre-determined based on Bronfenbrenner's ecological model of human development

(402). In this model, multiple 'levels' of an individual's life are said to have an impact upon their development, and these levels may also interact to shape development. To understand the barriers to accessing palliative care for the nine varied populations, this model affords a general scaffolding with which to code the literature review data. Bronfenbrenner's ecological model has previously been applied in health-related research (403,404).

Table A-2: Coding structure and definitions

Codes and themes	Definition
Barriers and enablers	Barriers and enablers were coded discretely
Individuals	Patient related barriers and enablers may include individual circumstances, personal health (mental or physical), and characteristics of the individual that may impede or promote access to palliative care
Families	Family related barriers and enablers refer to family specific issues preventing or promoting access to palliative care, e.g. a lack or absence of family to assist in service access
Communities	Community related barriers and enablers refer to barriers concerning the broader 'community' an individual may be a part of. In some cases, this also specifically included cultural factors
Health professionals	Health professional barriers and enablers refer to characteristics of the health professional providing health care to the population group. This may include a health professionals attitude toward the person under their care
Services or organisations	Service or organisational related barriers and enablers refer to the organisational context in which the individual finds themselves within. A key example for this coding category is the prison system

Codes and themes	Definition
Healthcare system	Healthcare system related barriers and enablers refer to the broader healthcare system, which may encompass the extent to which services integrate and work together to improve palliative care access
Advance care planning	Advance care planning was coded at a single level, and contains any references to advance care planning barriers and enablers

The two reviewers coded the literature to the point of data saturation, e.g. where no new information was being uncovered in the collated literature.

Grey literature

Grey literature was analysed independently of the peer-reviewed literature against the same coding structure. Information from grey literature was used to supplement peer-reviewed findings, and to inform any gaps identified in the peer-reviewed literature.

Analysis and synthesis of coding

Once all literature had been coded under the major and sub-themes, data was exported by theme into individual documents and printed. The extracted data was then re-read to ensure alignment of coding to specified themes, and to uncover any further detail that could inform the literature review findings.

Literature review update

Given the length of time over which the project was undertaken, the literature reviews were updated in January 2019 to consider evidence published since the original review. Google Scholar, CareSearch and Google were again searched for more recent relevant materials using the original search strategy, and this document updated accordingly.

References recommended by stakeholders throughout the consultation process were also considered, where they fit into the specific focus of the review.

Reporting of findings

The literature review findings (including the amount of information uncovered by the search and the themes reported) varied across the identified population groups. As such, the structure of each chapter differs depending on the unique barriers and enablers of palliative care for each underserved population group. In general, reporting of findings includes:

- Barriers to access and unmet needs
- Enablers of access to palliative care
- Evidence relating to use/potential use of advance care planning.

The review was designed to inform the broader project, rather than a representing a comprehensive and systematic review of the evidence. Therefore, analysis continued until 'thematic saturation' was considered to have been reached. In many cases, references are provided to illustrate the themes presented, rather than provide a complete list of all relevant literature in every instance.