



## Palliative and end-of-life care for LGBTIQ+ people

A scoping review of the barriers to and facilitators of inclusive care.

LGBTIQ+ Palliative Care Project 

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## Abbreviations

<b>ACD</b>	advance care directive
<b>ACP</b>	advance care plan
<b>CALD</b>	culturally and linguistically diverse
<b>EG</b>	enduring guardian
<b>EPoA</b>	enduring power of attorney
<b>HIV</b>	human immunodeficiency virus
<b>LGBTIQ+</b>	lesbian, gay, bisexual, transgender, intersex and other diverse genders and sexualities



# Executive summary

**The Commonwealth Department of Health funded LGBTIQ+ Health Australia to undertake a three-year national project on LGBTIQ+ inclusion in palliative care. This scoping review was conducted to understand the experiences of LGBTIQ+ people who have accessed palliative and end-of-life care services. It explores the barriers preventing access to inclusive care and the factors facilitating safe, appropriate and timely palliative care in Australia and internationally. This research provides an overview of current approaches supporting healthcare professionals to increase their knowledge and confidence in delivering inclusive care. The report includes empirical research studies and grey literature from the past five years.**

Research in this space has grown considerably in the last few years. LGBTIQ+ inclusive palliative care is of increasing concern to researchers and, anecdotally, to Australian healthcare providers.

The barriers most mentioned were discrimination, distrust of healthcare providers, ageing and ageism, legal issues, reduced access to advance care planning, social isolation and lack of recognition of families of choice. The most frequently referenced facilitating factors and strategies were, in order: LGBTIQ+ inclusive training for palliative care staff, end-of-life decision-making support, inclusive healthcare provider policies and legal advice for end-of-life documentation.

Cohorts within LGBTIQ+ communities have been studied to different extents. There is limited research about the palliative care experiences of people who are intersex. Only seven of the 100 publications reviewed included intersex people. Given this small sample size, this review is not conclusive or representative of intersex people. Although bisexual people were frequently included in LGBTIQ+ scopes, research on the barriers experienced by people who are bisexual or bi+ is limited.

More research is needed to understand how intersectional identities may compound LGBTIQ+ individuals' barriers when accessing palliative and end-of-life care. There is little evidence of how an individual's culture, disability and geographical location contribute to their experiences of palliative and/or end-of-life care.

It is crucial to acknowledge the changing health landscape shaped by the COVID-19 pandemic. Some early research identified additional barriers that minority groups, including LGBTIQ+ people, may encounter when accessing palliative and end-of-life care services in the COVID-19 context. Practice guidelines have been developed to support health care workers to consider how to be inclusive in these challenging times.

Encouragingly, a range of initiatives have been established to increase health professionals' understanding of the importance of including LGBTIQ+ people in service delivery. Examples include the London Hospices LGBT Network established by the Royal Trinity Hospice (RTH) in 2017 with nine other hospices. The network promotes equality, diversity and inclusion of LGBT people by providing leadership, support, education and raising awareness of hospice care in LGBT communities (Hospice UK, 2021). A pilot training program was established for health and social care professionals providing oncology and palliative care to LGB clients in Ireland. More than 200 staff participated in the training, resulting in enhanced familiarity with LGB-related language and terminology (Reygan & D'Alton, 2013, as cited in Henderson & Almack, 2016).

Consistent data collection by healthcare providers that could help demonstrate LGBTIQ+ palliative care needs is missing. In Australia, adopting the Australian Bureau of Statistics' 2020 Standard for Sex, Gender, Variation of Sex Characteristics and Sexual Orientation Variables would create a more consistent and appropriate approach to help fill the gaps in this area (Australian Bureau of Statistics, 2021).

### **What we know about this topic**

- barriers to people who are LGBTIQ+ accessing inclusive palliative care include high rates of healthcare discrimination in Australia and internationally
- barriers to inclusive palliative care are exacerbated by pre-existing mental health, financial and housing precarity, discriminatory policies and systems, and lifelong minority stress
- patients' distrust of palliative care providers can cause them to delay or avoid care or choose not to disclose their LGBTIQ+ status, reducing overall care outcomes
- research identifies a range of strategies and facilitating factors to increase the inclusivity of palliative care for LGBTIQ+ people; however, there is no research into their effectiveness.

### **What this review adds to this topic**

- the most referenced barriers in the literature were, in order: discrimination, distrust of healthcare providers, ageing and ageism, legal issues, reduced access to advance care planning, social isolation, and lack of recognition of families of choice
- the literature's most referenced facilitating factors and strategies were, in order: LGBTIQ+ inclusive training for palliative care staff, end-of-life decision-making support, inclusive healthcare provider policies and legal advice for end-of-life documentation
- people who are LGBTIQ+ sitting at the intersection of multiple identities such as disability, Aboriginal and Torres Strait Islander (Indigenous) and culturally and linguistically diverse (CALD) may have more specific palliative care needs
- insights and data were mostly available from case studies and practice examples from Australia, the United States (US), Canada, Britain and Ireland.

### **Implications for practice, theory, or policy**

- training and education for health professionals is a key strategy for improving palliative care for people who are LGBTIQ+
- training should be supported by inclusive organisational policies, practices, forms and documentation. Consistent data collection by healthcare providers will add to the evidence base of how to meet LGBTIQ+ palliative care needs and inform policy agendas
- there is a need to develop, implement and evaluate the strategies and facilitating factors for inclusive palliative and end-of-life care for LGBTIQ+ people.

## Introduction

**As part of a three-year federally funded national project on LGBTIQ+ inclusive palliative care, this scoping review provides an evidence base to inform the development of resources and e-modules. These resources aim to increase the confidence and knowledge of health professionals engaged in supporting LGBTIQ+ people who access palliative care in Australia.**

This review maps international LGBTIQ+ palliative care research, including academic and 'grey literature' (i.e., not published in scholarly peer-reviewed journals) from the past five years.

### Literature from 2005 to 2015

The literature and systemic reviews from 2005-2015 that mentioned LGBTIQ+ palliative and end-of-life care included similar themes as those reflected in this scoping review. The most prevalent barriers identified were discrimination, refusal of care, bias, assumptions, derogatory statements and low levels of trust of healthcare providers (Haviland, 2021). Healthcare professionals' agency to provide positive experiences in palliative care settings was also a key discussion point (Stinchcombe et al., 2017).

The literature reflected that older LGBTIQ+ people have low trust that their end-of-life wishes will be carried out. Older LGBTIQ+ people with cognitive impairment may face additional barriers to exercising their

palliative care preferences and end-of-life care plans. LGBTIQ+ individuals lack knowledge about the legal provisions to ensure their end-of-life decisions are known and hopefully respected (Valenti et al., 2020).

Much of the literature from this period referenced the experiences of gay men impacted by the HIV-AIDS epidemic in the 1980s-90s, documenting the prevalent stigma and discrimination (Farmer & Yancu, 2015). Strategies recommended to increase the inclusivity of palliative care included cultural sensitivity training for healthcare professionals delivered by LGBTIQ+ people. Training should incorporate the historical and political context of LGBTIQ+ communities, stigma and discrimination and current barriers to inclusive palliative care. One study showed that LGBTIQ+ ageing sensitivity training produced short-term positive change in service providers (Farmer & Yancu, 2015).

Compared with the 2005-2015 literature, the 2015-2021 literature focused more on understanding the experiences of transgender and gender diverse people who require palliative or end-of-life care. Intersectional perspectives and identities have also been considered more in the past five years.

## Key definitions

### Palliative and end-of-life care

We used the following definition of palliative care and end-of-life care:

**Person and family-centred care 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 goal is to optimise the quality of life. End-of-life care is the last few weeks of life in which a patient with a life-limiting illness is rapidly approaching death. The needs of patients and their carers is higher at this time. This phase of palliative care is recognised as one in which increased services and support are essential to ensure quality, coordinated care from the healthcare team is being delivered. This takes into account the terminal phase or when the patient is recognised as imminently dying, death and extends to bereavement care. (Palliative Care Australia, 2021)**

### LGBTIQ+

When referring to LGBTIQ+, we consider people who are lesbian, gay, bisexual, transgender, have intersex variations or describe themselves as having a diverse gender, sexuality or body (e.g., queer, gender diverse, non-binary, gender nonconforming).

### Publications about people who are intersex

It is important to acknowledge that people who are intersex are often included in LGBTQ+ research without important distinctions.

This scoping review found seven publications that included intersex people within an LGBT/Q+ context. No publications spoke solely about intersex palliative and/or end-of-life care experiences. Given the small sample size, limited conclusions can be drawn about this population's palliative and end-of-life care needs.

It is important to note that intersex people can be heterosexual and cisgender. This should be kept in mind when we refer to LGBTIQ+ people in relation to sexuality and gender identity. In these cases we are referring to intersex people who have a diverse sexuality or gender identity.

More research on intersex populations in palliative and end-of-life care is required. Best practice guidelines on research with people who are intersex are available at Intersex Human Rights Australia [here](#).

## Language disclaimer

At LGBTIQ+ Health Australia, we acknowledge that language is constantly evolving and that some people who are LGBTIQ+ may not use any of the terms noted above. For example, many older LGBTI people consider 'queer' derogatory. In all contexts, including healthcare settings, recognising all individuals' autonomy to self-identify is of utmost importance.

This report refers to LGB, LGBTQ, LGBTI and other abbreviations, depending on the research and literature source.

## Inclusion and exclusion criteria

The review considered English-language publications from Australia and internationally within the past five years, including grey literature. Publications were eligible if about (1) people who are LGBTIQ+ and (2) palliative care.

People who are LGBTIQ+ were included with associated terms such as lesbian, gay, bisexual, transgender, intersex, homosexuality (male) and homosexuality (female). Associated palliative care included end-of-life care, terminal care, hospice care, advance care planning, life support and bereavement care.

We included literature about barriers experienced by people who are LGBTIQ+ who access palliative care services and enabling factors that facilitate inclusive palliative care. Literature on LGBTIQ+ inclusive palliative care training approaches and outcomes was covered.

The search included some books and chapters; however, books were not screened exhaustively due to time and resource constraints.

The following were excluded from this review:

- non-empirical papers (e.g., essays, opinion and reflective pieces, editorials)
- literature about barriers LGBTIQ+ people experience accessing general health care, including aged care where palliative care or end-of-life care is not mentioned
- literature concerning LGBTIQ+ inclusive training in general healthcare spaces
- literature concerning best practices in palliative care not specific to LGBTIQ+ people.

### Additionally, the following were excluded from the review:

- book reviews, media articles, grant proposals, meeting abstracts and minutes
- articles and book chapters when the full text was unavailable (abstracts alone were not included)
- search results in languages other than English
- conference and poster presentations.

## Research questions

Three questions were codesigned with LGBTIQ+ experts in palliative and end-of-life care.

1. What are the barriers and facilitating factors that LGBTIQ+ communities experience when accessing palliative care?
2. What strategies have been developed to address barriers?
3. How effective are current LGBTIQ+ focused palliative care training approaches or initiatives addressing these barriers?

## Limitations

- the risk of bias or quality of included studies was not assessed and the full research articles were reviewed rather than each article's individual findings.
- the full text was only sought if eligibility could not be determined from the abstract or title; therefore, information on genders, sexualities, intersex variations and topics in the included publications were based on abstracts and titles alone
- the initial search included articles from 2010; however, to retrieve the most relevant information, we narrowed the search to 2015–2021 when removing duplicate materials.

## Methodology and search strategy

Multiple databases were searched between October 2020 and August 2021.

The search strategy focused on electronic databases followed by internet searches for grey literature. Titles and abstracts were scanned to assess eligibility in relation to the inclusion criteria.

## Databases

The following databases were searched: Medline (including Ageline), PubMed, CINAHL, PsycINFO, Web of Science, Google Scholar, OVID, Embase, Emcare, CAB Direct, Scopus, EMBASE, Ageline, the Cochrane Collaboration and the Joanna Briggs Institute.

The following journals were searched: Journal of Palliative Care, Palliative Medicine, BMJ Supporting and Palliative Care, BMC Palliative Care, Journal of Psychosocial Oncology and Australasian Journal on Ageing. Reference lists of articles selected for the final sample were also searched.

Searches were conducted using CareSearch's search filters in PubMed. The Palliative Care Search Filter combined with the Specific Needs—Lesbian, Gay, Bisexual, Transgender and Intersex filter and relevant search terms (e.g., Terminal Care, End-of-Life Care) was applied.

CareSearch's databases and resources section, grey literature section, and Systematic Review Collection were also searched using the LGBTI filter (and associated terms).

Duplicates were removed using manual searches of the publications; two research team members conducted a final check for duplicates in Excel.

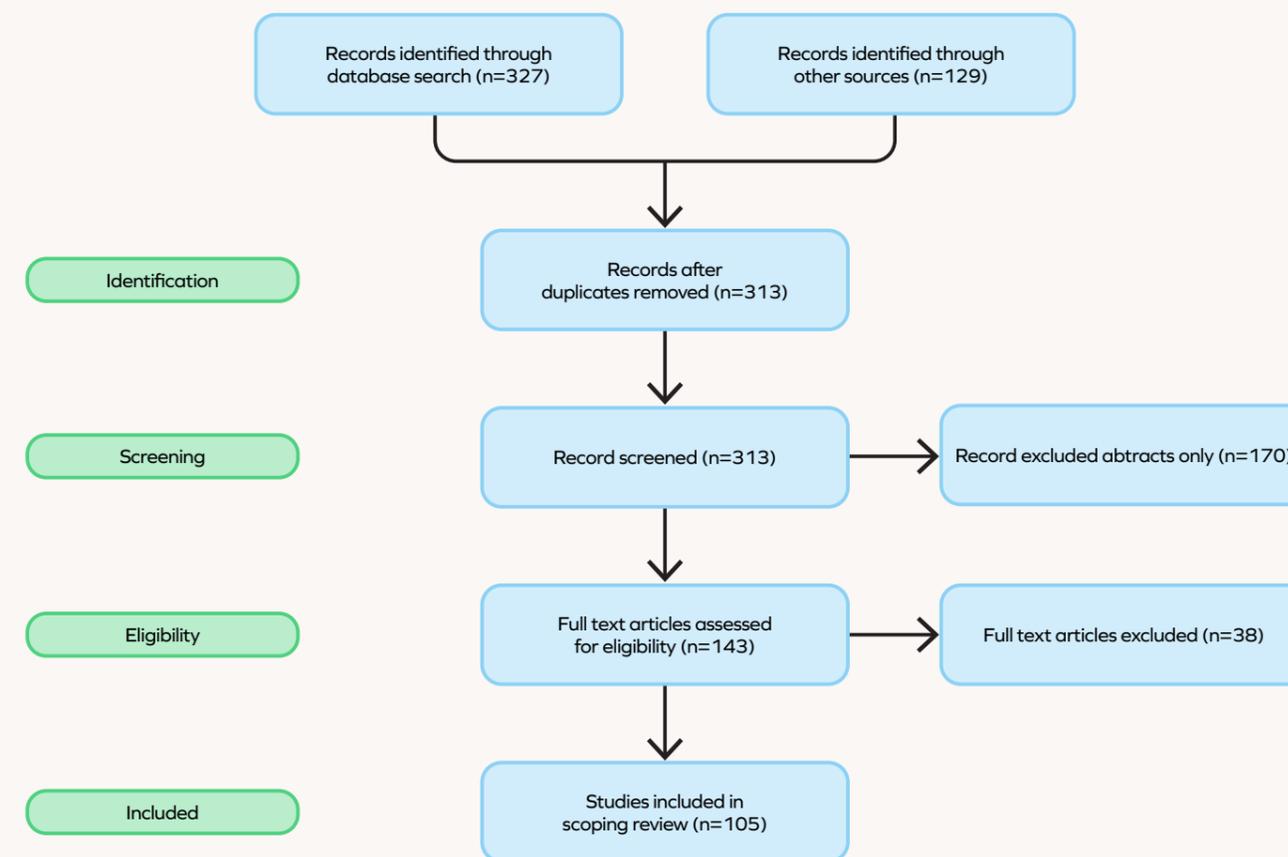
The following search terms were used with minor modifications to suit each search engine:

(Agender OR Asexual OR Bisexual OR BrotherBoy OR Diverse bodies OR Diverse genders OR Diverse relationships OR Gay OR Gender Queer OR Gender questioning OR Gender identity or Gender diverse OR GLBT OR Homophobia OR Homosexual OR Intersex OR Lesbian OR LGBTI OR LGB OR LGBTI+ OR LGBTI OR LGBTIQ OR LGBTIQ OR LGBTIQ+ OR LGBTIQA OR LGBTIQQ OR Non-binary OR Pansexual OR Sexual orientation or SisterGirl OR Trans\* OR Transgender OR Two-spirit OR 2-spirit OR Queer) AND (End-of-life OR End-of-life OR Palliative OR Palliative care OR Terminal care).

The initial search strategy produced 456 publications (inclusive of 2010–2021 publications). Results were then limited from July 2015 to September 2021, providing 143 publications for assessment. The research team crosschecked all literature and systemic reviews to ensure that there were no missing journal articles. The research team also consulted with an expert project Advisory Group in the subject matter regarding any missing papers. This did not result in the inclusion of any additional publications.

The 143 articles were manually assessed and entered into a Microsoft Excel document; 38 of these publications did not meet the inclusion criteria. The final sample comprised 105 publications (see Figure 1).

**Figure 1: Flow diagram of identification of studies**



## Summary of results

The characteristics of the 105 included publications were extracted and summarised in a table. The table is publicly available on request via the LGBTIQ+ Health Australia website: [www.lgbtiqhealth.org.au/palliative\\_care](http://www.lgbtiqhealth.org.au/palliative_care)

### This table includes:

- year of publication
- study location
- study type
- genders and sexualities explored, including whether studies grouped LGBTIQ+ people or examined identities separately.

Figure 2 shows the number of publications in the past five years. The number of publications has increased in the past two years.

**Figure 2: Publications by year**



Note: only the last six months of 2015 were considered, as this research commenced mid-2020.

Figure 3 shows the publications by region. Most publications originated from the US, followed by Canada, the United Kingdom (UK) and Australia.

**Figure 3: Publications by region**

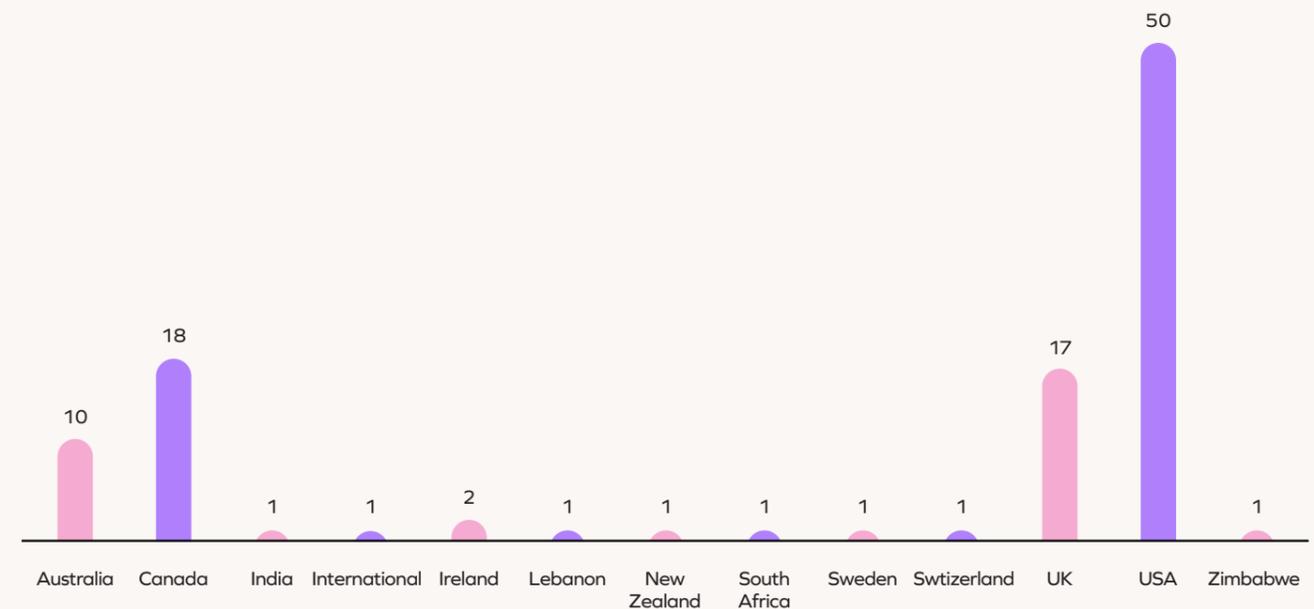


Figure 4 shows the publications by type.

**Figure 4: Publications by type**

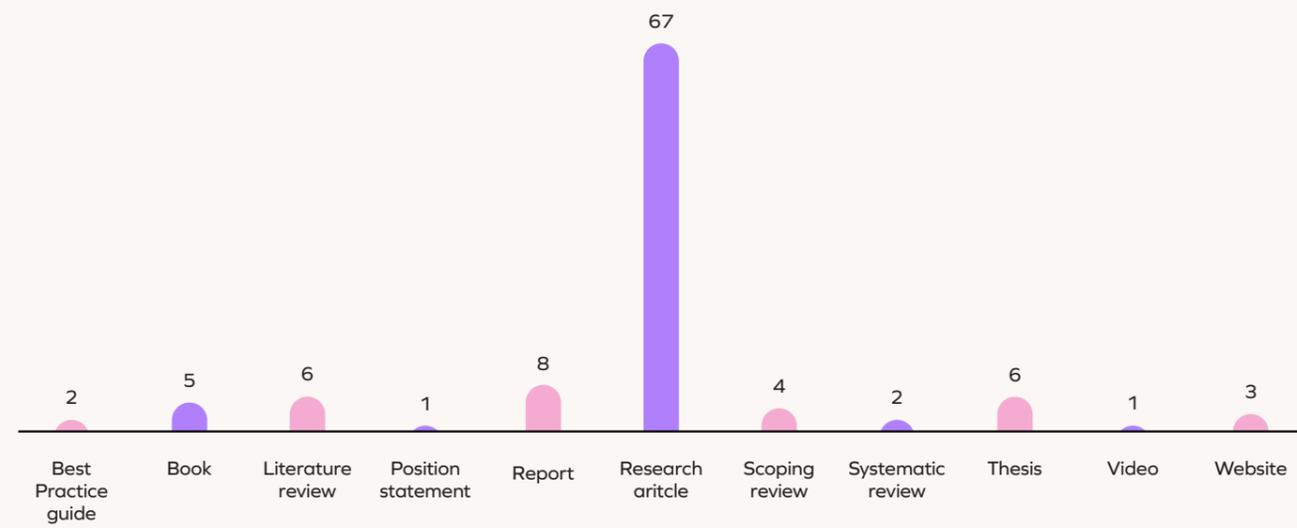
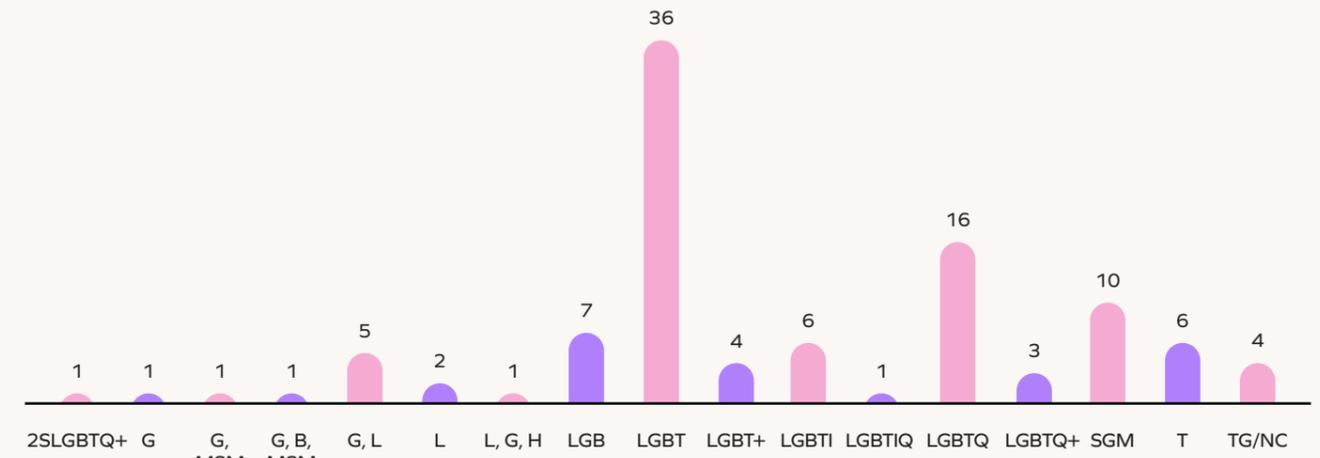


Figure 5 shows the groups in the LGBTIQ+ population represented in the publications.

**Figure 5: Publications by status**

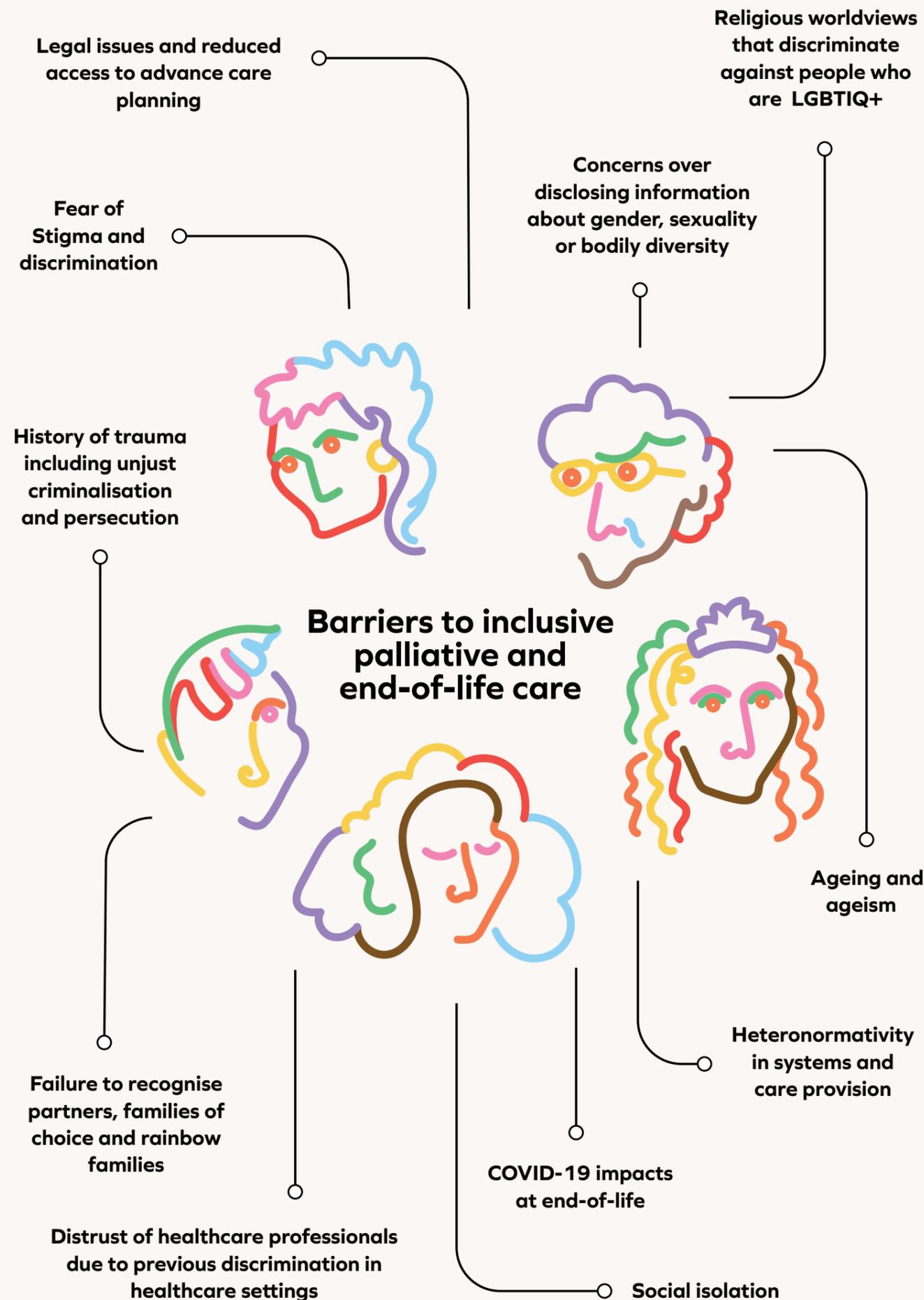


2SLGBTQ+ = Two spirit LGBTIQ+  
 G = Gay  
 MSM = Men who have sex with men  
 B = Bisexual or bi+  
 L = Lesbian  
 H = Heterosexual

T = Transgender  
 I = Intersex  
 Q = Queer  
 SGM = Sexuality or gender minorities  
 TG/NC = Transgender non-conforming

# Part I: Barriers experienced by LGBTIQ+ people accessing palliative care

Overt and covert discrimination by providers can include refusal of care biases, physical and psychological victimisation, incorrect assumptions about an LGBTIQ+ person's gender, sexuality or body diversity (Kaiser Health News, 2019)



## Barriers to inclusive palliative and end-of-life care

**There is considerable research evidence nationally and internationally of LGBTIQ+ people's disadvantage for appropriate palliative care. People who are LGBTIQ+ are frequently unable to access safe, timely palliative care that meets their needs. This exclusion is due to a range of factors, including stigma, non-recognition of partner relationships, social isolation and reduced rates of medico-legal planning, including advance care planning. Many LGBTIQ+ people avoid, delay or defer accessing palliative care due to their concerns about discrimination and non-recognition of their relationships, lives and identities (Almack, 2018). Failure to access palliative care may occur when people who are LGBTIQ+ who previously faced discrimination in health care carry their experiences forward into palliative care (Bristowe et al., 2017). This section explores the barriers reducing LGBTIQ+ people's access to palliative care.**

### Heteronormativity

Society's heteronormativity compounds many barriers to receiving inclusive palliative care. Heteronormativity is the unconscious bias that assumes all patients are heterosexual, cisgender (not transgender or gender diverse) and endosex (not intersex). At an organisational level, heteronormative assumptions can shape policies, processes, documentation and forms (e.g., intake forms), marketing and publicity materials, and interpersonal communications with healthcare providers and administration staff (Australian Health Care Associates [AHCA], 2019).

Healthcare providers' heteronormative presumptions about gender, sexuality and bodies do not reflect the LGBTIQ+ community's diversity. In Stonewall's (2015) Unhealthy Attitudes survey, almost 60% of social and healthcare professionals reported thinking a person's sexuality had nothing to do with their healthcare. Some providers reported not needing to ask their clients about sexual orientation or gender identity. Either they assume or think they do not have LGBTIQ+ patients, or they already know who is LGBTIQ+ and, therefore, do not need to ask (Arthur, 2015).

Providers often do not understand the importance of gender, sexuality and bodily diversity to patients. Therefore, providers do not understand the effect of not asking these questions. Providers may deliberately avoid conversations about sexuality or gender, assume that their patient is heterosexual, and/or that the patient's sexuality has nothing to do with their healthcare (Marie Curie Cancer Care [MCCC], 2017). By not asking, providers do not know the specific needs of their LGBTIQ+ patients and have a reduced ability to meet their patients' needs. Incorrect assumptions can also minimise the unique challenges faced by LGBTIQ+ people.

LGBTIQ+ palliative care patients may face greater challenges balancing sexual health needs and expression with social roles, pleasure, mood, and other components that affect quality of life (Javier & Oswald, 2019).

Heteronormativity can lead to assumptions about the sexual lives of LGBTIQ+ people. Healthcare professionals may assume that

LGBTIQ+ people accessing palliative care do not engage in sex or that they prefer emotional intimacy over sex. These and other assumptions may limit or reduce sexual health care for LGBTIQ+ people at end-of-life (Griebing, 2016). According to Hjalmarsson and Lindroth (2020), holistic, person-centred palliative care should include sexuality and sexual health. Inclusion of sexuality in general healthcare is often deficient and there are knowledge gaps in how sexuality is addressed in palliative care.

### Stigma and discrimination

**'In the US, a VA (Veterans Affairs) hospice unit [saw] an older, lesbian veteran who was cared for by her wife who was struggling to meet care needs at home. Over time it became clear that the wife was emotionally and financially dependent on the veteran and would face many psychosocial and financial challenges when the veteran died; however, the wife was reluctant to accept referrals for help or services due to past discrimination from social agencies. The interdisciplinary team collaborated to care for the veteran's medical needs, and the wife's emotional and psychosocial needs, until after the veteran's death' (Hinrichs & Christie, 2019 p204).**

Stigma and discrimination result in mistreatment and disrespect of LGBTIQ+ people. Stigma can have an isolating and negative effect, create feelings of difference, reduce health and wellbeing, and affect the type of palliative care received.

Overt and covert discrimination by providers includes physical and psychological victimisation, incorrect assumptions about an LGBTIQ+ person's gender, sexuality or body diversity, derogatory statements and refusing admissions (Selix et al., 2020). Discrimination includes denial of service or clinically appropriate pain management, non-consensual religious encounters (e.g., nurses praying for patients) and refusal of visitation and access by families of choice or designated health proxies (Kaiser Health News, 2019).

One research report noted that 70% of transgender patients experienced discrimination in healthcare settings (Wicks et al., 2018). In a survey of 865 US palliative care providers, 54% of healthcare provider respondents thought LGB patients were more likely than non-LGB patients to experience discrimination at their institution (Stein et al., 2020). In the same survey, 64% of respondents thought that transgender patients were more likely to face discrimination than cisgender patients (Stein et al., 2020).

Transgender people in particular face a high degree of stigma and discrimination and are concerned about the safety and appropriateness of end-of-life bodily care (e.g., whether care providers will support trans women in their gender expression by assisting them with shaving and ensuring access to hormones) (Pang et al., 2019). Transgender people are also concerned about being refused medical services based on gender (Pang et al., 2019). One researcher also cited transphobic violence leading to higher mortality as a reason to engage in end-of-life planning (Weaver, 2020).

Candrian and Cloyes (2020) noted that service providers lack accountability. Lack of accountability perpetuates the potential for discriminatory treatment and failure by hospices to routinely assess LGBTIQ+ patients' end-of-life wishes and decisions.

Stein and Berkman (2019) also noted that healthcare providers might be uncomfortable with gender, sexuality and bodily diversity. Hence, they may not enquire about these and may fail to recognise, acknowledge and address health care issues and disparities.

## **Distrust of health professionals**

People who are LGBTIQ+ can be reluctant to disclose personal information due to past negative experiences in healthcare systems - for instance, people may have experienced psychiatric interventions such as conversion therapy which may affect their views of the health system and providers (Almack, 2018).

Distrust of healthcare providers means that people who are LGBTIQ+ are reluctant to seek palliative care that they feel is inaccessible or inappropriate. Anticipatory discrimination is the fear of future overt or covert discrimination, mistreatment or exclusion by a service. Anticipatory discrimination means people who are LGBTIQ+ may delay or avoid general medical and palliative care treatment (Harrison, 2017). They may choose not to disclose their LGBTIQ+ status to palliative care providers, which can, in turn, reduce care outcomes (Harrison, 2017).

Patients fear that health professionals' ignorance of LGBTIQ+ specific needs may lead to intrusive questioning and the need for them to educate each staff member. Some patients also distrust palliative care services with a church affiliation; they may refuse to come out if they need to rely on church-based services (Higgins & Hynes, 2019).

## **The closet**

'Coming out of the closet' is not a universally accepted concept. For example, people who are LGBTIQ+ from CALD backgrounds may relate more to the idea of 'inviting in' people they trust regarding their sexuality, gender or bodily diversity. Transgender people may not relate to the concept of the closet but may refer to 'passing', that is, being assumed to be cisgender (Arthur, 2015). Being closeted and seeking to 'pass' relates to non-disclosure of LGBTIQ+ identities for safety reasons.

Some people who are LGBTIQ+ may go back into the closet when facing coming out repeatedly to different healthcare staff or providers and fearing discrimination, especially in aged care, hospital or hospice settings. Selix et al. (2020) described this as 're-closeting'. Decreased independence and decision-making capacity, increased vulnerability and exposure to unsafe social and physical environments can also create fear of disclosure.

Older LGBTIQ+ adults' safety concerns may increase near the end-of-life when they encounter new caregivers, medical providers or living circumstances (e.g., long-term care). LGBTIQ+ people who generally feel comfortable and unconcerned about discrimination may fear being discriminated against during end-of-life care (Harrison, 2017).

Non-disclosure of LGBTIQ+ status can affect partners and families of choice. Almack (2018) noted that partners might not be recognised by healthcare staff and providers. Partners may be prevented from visiting and sharing affection (e.g., holding hands) for fear of being judged. This situation reduces the comfort and increases grief at the end-of-life for the patient and their partner. The surviving partner may be at risk of disenfranchised grief (Almack, 2018). Cloyes et al. (2018) described disenfranchised grief as 'a mourning process marked by stigma and a lack of social recognition and validation that the bereaved person has suffered a significant loss, and subsequent lack of support' (p.64).

'The closet' is a barrier to advance care planning. Research shows that people who are not open about their sexuality may be less likely to nominate a partner as a substitute decision-maker (Hughes & Cartwright, 2015). They may be less likely to have spoken openly about end-of-life issues with their preferred substitute decision-maker (Hughes & Cartwright, 2015).

A 2010 study found that discrimination and abuse by healthcare providers could cause LGBTIQ+ patients to fear displaying personal items, go back into 'hiding' and even plan suicide (see Stevens & Abrahm, 2019).

### **Ageing and ageism**

Ageism is a barrier to quality health care for people who are LGBTIQ+ in general health care and palliative care settings. Older people who are LGBTIQ+ face the same risks in palliative care as in in-home care or aged care, including the threat of elder abuse and mistreatment by care staff (Stein et al., 2020).

The end-of-life stage can exacerbate general barriers to inclusive health care. Age and worsening illness(es) exacerbate the vulnerabilities of disadvantage and social inequalities that many people who are LGBTIQ+ face in their lives (Kortes-Miller et al., 2018). Minority stress—the ongoing stress that comes from poorer treatment as a member of a minority group—also worsens.

Minority stress particularly affects older LGBTIQ+ people because of cumulative disadvantage and ageing, including health risk behaviours such as higher rates of smoking and alcohol and drug use (Selix et al., 2020). People who are LGBTIQ+ are more prone to certain types of cancer (including but not limited to lung and liver cancer), chronic illness, poor nutrition, mental health conditions including

depression and anxiety and premature mortality (Baril et al., 2020). They may experience specific complexities related to dementia; for example, a transgender person forgetting that they have transitioned or a gay person forgetting that they have come out (Baril et al., 2020).

Ageism can sideline older people, and LGBTIQ+ older people can feel invisible due to social isolation (Stinchcombe et al., 2017). They are less able to participate in the LGBTIQ+ community as they did when they were younger (Stinchcombe et al., 2017). For example, Waling et al. (2019) noted that ageism undermines LGBTIQ+ identities. Transgender identity is often attributed to younger people, silencing older transgender people within the mainstream and LGBTIQ+ communities (Waling et al., 2019).

Vulnerabilities at the end-of-life stage include poverty, employment and housing challenges, especially for transgender people. Older people who are LGBTIQ+ are, on average, more financially vulnerable than older non-LGBTIQ+ people (Farmer & Yancu, 2015). Housing insecurity increases the vulnerability of people who are LGBTIQ+ at the end-of-life stage. Financial precarity increases the end-of-life care requirements of partners if additional healthcare support is not affordable, which creates greater carer stress (Gardiner et al., 2020).

Older LGBTIQ+ women who have lost a spouse or partner may make similar end-of-life planning decisions to non-LGBTIQ+ women. However, their distinct support needs are often unmet (Valenti et al., 2020). While they do not report perceiving overt healthcare discrimination, it is unclear whether they experience covert discrimination. Valenti et al. (2020) found a lack of communication about end-of-life options, including hospice, and providers could better support LGBTIQ+ women's knowledge and preparation.

Financial precarity means that older people who are LGBTIQ+ may be more dependent on their families of origin and/or choice, homes and communities, decreasing autonomy and leaving them vulnerable to elder abuse (Banerjee & Rao, 2021).

### **Criminalisation and persecution**

Many people who are LGBTIQ+, especially those who are older, may have grown up in oppressive times and environments, where diverse sexualities, genders and bodies were criminalised, medicalised or outlawed as deviant, or pathologised as mental illness (Bristowe et al., 2017). As a result of criminalisation and persecution, some older LGBTIQ+ patients and carers may be reluctant to engage with support and end-of-life services (Stein et al., 2020). Older people who are LGBTIQ+ may return to the closet fearing poor treatment or loss of privacy (Selix et al., 2020). They may fear being outed by healthcare providers (e.g., a transgender person asked to answer

questions related to their gender or name near other patients) (MCCC, 2017).

### **Legal issues**

People of all ages who are LGBTIQ+ face legal issues at end-of-life. Laws and policies about end-of-life planning can be more complex for people who are LGBTIQ+; complexity is due to heterosexist assumptions favouring biological, adoptive or affinity families (i.e., people related by marriage) (Godfrey, 2016). Legal marriage for most Australians who are LGBTIQ+ only became available at the end of 2017. Marriage is still not fully available to all transgender people.

Previously, basic family law rights and protections were denied to many people who are LGBTIQ+. Many older adults have a long history of ineligibility for most protections provided by safety nets, such as tax and legal recognition (Godfrey, 2016). Heterosexist assumptions can also affect care decision-making, visitation rights, health insurance and benefits, and retirement plans (Godfrey, 2016).

Legislative progress does not necessarily mean that healthcare providers are aware of upholding the rights of people who are LGBTIQ+ at the end-of-life (Bristowe et al., 2016). Major gaps exist in specialist medical practitioners' knowledge of who has the legal authority to make medical decisions for an LGBTIQ+ patient who has lost capacity. Fewer than 30% of the doctors surveyed were able to identify a same-sex

partner as having power under Australian law to make decisions about their partner's medical treatment (Cartwright et al., 2017). Biological family members were more likely to be given priority by doctors in these decisions (Cartwright et al., 2017).

LGBTIQ+ community members may need a working knowledge of the law to self-advocate effectively in a healthcare setting. Sometimes partners' visitation rights are not honoured, so they cannot see LGBTIQ+ patients, even if married or legally partnered. Partners may face direct challenges with end-of-life decision-making from biological family members, who question the partner's authority and rights. Healthcare providers may not provide appropriate assistance with these challenges, especially if they take a 'one size fits all' approach and do not ask about patients' gender, sexuality or bodily diversity status (Cathcart-Rake et al., 2020).

Therefore, healthcare providers may be unaware of their patients' specific needs or risks (Cathcart-Rake et al., 2020).

Even when LGBTIQ+ couples and chosen families discuss end-of-life plans and prepare legal documents, documents may not be guaranteed legally binding, respected or adhered to by healthcare providers or the validity of such documents may be challenged by families of origin. (Farmer & Yancu, 2015). There are risks in end-of-life legal planning using legal document templates rather than engaging a family lawyer specialising in elder law (Godfrey, 2016).

One study showed that approximately 33% of LGBTIQ+ participants believed advance care planning documents would be enforced by health professionals more for heterosexual people than themselves (Marsack & Stephenson, 2017). This belief indicated that stigma might be a barrier to legal documents being utilised for people who are LGBTIQ+ (Marsack & Stephenson, 2017). The researchers noted that laws and policies should clearly address and protect the utility of end-of-life documentation for LGBTIQ+ persons, especially in stigmatising healthcare contexts.

### Case study

The American Geriatrics Society Ethics Committee [AGSEC] (2015) cited the case of Sam, a gay man whose partner had Alzheimer's disease:

**Sam...made the decision to be open about their relationship to the staff of the home his partner was in. Although Sam had power of attorney [legal authority to make financial decisions for his partner], he had difficulty getting recognition as the most appropriate person to make decisions about his partner's affairs, with health workers and other professionals continually querying who he was.**

### Reduced access to advance care planning

Access to and use of advance care planning (ACP) is a particularly challenging issue for people who are LGBTIQ+. Many LGBTIQ+ people, including older people, are unaware of ACP. They are also unaware of the current legal mechanisms to protect themselves and their families (including unmarried partners) should they become incapacitated and cannot make medical decisions.

An Australian study found that only 29% of people who are LGBTIQ+ had an enduring power of attorney (EPoA), 18% had appointed an enduring guardian (EG), and 12% had made an advance care directive for end-of-life care (Cartwright et al., 2017). Having all three is the best practice for ensuring that wishes are upheld.

In a recent US study, most of the 107 LGBTQ participants had heard of ACP documents but had not used them (Marsack & Stephenson, 2017). People who are LGBTIQ+ are more reluctant than people who are not LGBTIQ+ to initiate conversations related to death and dying. However, all people need to have conversations and make plans about end-of-life.

One Australian study found that only 52% of people had spoken about their wishes to their preferred alternative end-of-life decision-maker and 31% of people reported that they were not sure their wishes would

be respected (Hughes & Cartwright, 2015). Not having an end-of-life planning conversation means risking not knowing if the preferred alternative or substitute decision-makers understand the person's wishes.

However, there is some contradictory evidence about people who are LGBTIQ+ engaging with ACP. One study found that same-sex spouses spent more time and attention in informal planning conversations and making formal end-of-life plans due to few legal protections and concerns about family interference. In comparison, heterosexual spouses reported minimal formal or informal planning. While ACP documents had relatively low take-up by people who are LGBTIQ+, their rates of completion of EPoA and EG documents were higher than the population average (Thomeer et al., 2017).

Commonly reported barriers to comprehensive ACP by people who are LGBTIQ+ include not knowing ACP is necessary and not knowing what documents are essential and how or where to complete them (Hughes & Cartwright, 2015).

Pet care is another consideration for LGBTIQ+ people during end-of-life planning. LGBTIQ+ people may consider their pets to be part of their chosen family and may not have a loved one to care for their pet after their passing. There can be anxiety around what will happen to their pet after they die (de Vries et al., 2019).

Carabez and Scott (2016) noted that nurses' knowledge and attitudes about ACP can significantly affect whether or not LGBTIQ+ people complete advance care directives. The study also indicated 50% of nurses have a lack of knowledge about ACP and 25% were unsure who the legal decision-maker would be in an LGBTIQ+ context.

### Social isolation

People who are LGBTIQ+ are more likely to lack support from biological family due to estrangement or rejection, are much more likely to be single, are three times more likely to live alone and are less likely to have children to offer support (Arthur, 2015).

At the end-of-life of LGBTIQ+ people, their social networks often include families of choice, such as close friends and ex-partners. One study showed that many same-sex couples who mentioned not having family support were not concerned. They anticipated support from friends, whereas heterosexual couples rarely mentioned support from friends (Thomeer et al., 2017).

Challenges lie in the amount and length of palliative care support that friends can provide. Additionally, friends are unlikely to have any authority regarding medical or end-of-life decisions. Legally married spouses tend to be the default decision-makers for healthcare at end-of-life life. This situation may disadvantage LGBTIQ+ older people, who could have been in long-term relationships for many decades but could only legally wed in Australia from 2017.

Social isolation contributes to delays in end-of-life decision-making and ACP. It may increase mental health pressures and reduce motivation for timely end-of-life preparations. For example, isolation can prevent completing EPoA and EG documents if people do not know whom to name as an alternative decision-maker (Hughes & Cartwright, 2015). ACP and advocating for the patient's wishes involve end-of-life conversations often situated within non-traditional family ties and communities. These include meaningful conversations about end-of-life wishes and legal documentation with loved ones and friends, which is more complex if the patient does not have a social circle.

People who are LGBTIQ+ requiring end-of-life carers are often supported by their partners who are also LGBTIQ+. Their partners also face ongoing minority stress. They are under increased pressure from providing longer and more intensive care if their partners avoid or delay care due to fear of stigma and discrimination (Hospice UK, 2021; MCCC, 2017).

Some people who are LGBTIQ+ who have lost partners describe feeling that, by losing their loved one, they have lost their visible LGBTIQ+ identity (MCCC, 2017). They may not be referred to appropriate bereavement support. They may need to come out to have a chance of receiving inclusive support such as LGBTIQ+ friendly bereavement counselling.

### Failure to recognise partners, families of choice and rainbow families

*A small qualitative study of 15 older gay and lesbian adults in the United Kingdom described the complex nature of the familial relationships of participants including a mix of biological and non-biological members. The article suggests that LGBT individuals may prefer a close friend to have legal rights regarding their end-of-life care and decisions rather than a biological relative (Stinchcombe et al., 2017 p.4).*

End-of-life issues are often family issues (Godfrey, 2016). Confusion from health professionals and a lack of legal clarity result in a lack of recognition of relationships during palliation, and after death, with partners, chosen family and friends overlooked. Patients may also fear being unsupported by medical professionals if families of origin push reconciliation at end-of-life. Healthcare professionals must recognise partners in critical discussions. They should be aware that reconciliation

with families of origin may or may not be welcomed or needed; it should be discussed and pursued per the patient's wishes.

Healthcare providers often prioritise biological families (or families of origin) as making end-of-life decisions for LGBTIQ+ people who have lost capacity. When not recognised or respected, the same-sex partner or family of choice face significant challenges in ensuring the LGBTIQ+ person's preferences. Some families of origin may not be aware that their relative is LGBTIQ+ (and the relative may not wish them to know). They may reject their relative's identity and deny partners and friends access or visitation (Cartwright et al., 2017).

Their partner's family of origin can exacerbate the LGBTIQ+ partners' disenfranchised grief and bereavement if not supportive of the relationship. For example, excluding the partner from important, socially recognised grief rituals by taking over funeral arrangements. The partner's exclusion may be compounded if not automatically acknowledged at funerals or unable to access bereavement leave from work (Higgins & Hynes, 2019).

Although the literature showed that family rejection is common, many people who are LGBTIQ+ have strong relationships with their family of origin alongside their chosen family (Godfrey, 2016). LGBTIQ+ people are less likely to have children (Cottrell, 2020). However, many have children, grandchildren and extended family who may have different ideas about their

relative's end-of-life experience (Godfrey, 2016). Healthcare providers must recognise the interests of the chosen family even if the LGBTIQ+ patient has a positive relationship with their biological family.

### Religious worldviews

**Changing the way LGBTQ individuals with chronic or life-limiting illnesses are cared for requires a paradigm shift in the way we (collectively, as healthcare professionals) approach the conversation about what it means to be inclusive in our compassion. You don't need to change your religious or moral beliefs to provide good care to LGBTQ individuals (Acquaviva, 2017, p. xiii).**

Health professionals with conservative religious beliefs or in religious-owned palliative care or hospice facilities could knowingly or unknowingly discriminate against people who are LGBTIQ+. People who are LGBTIQ+ frequently anticipate that different belief systems will impose on them when they need palliative care in ways that could be discriminatory.

Acquaviva (2017) offered a vision for how healthcare professionals and faith-based organisations could approach inclusive palliative care. Supporting individuals and institutions to think differently about reconciling their own conservative beliefs is key to reducing the adverse effects religion could have on the provision of inclusive care (Acquaviva, 2017).

### COVID-19 impacts

COVID-19 disproportionately affects the seriously ill and marginalised groups. It reduces the quality of palliative care for LGBTIQ+ patients (Harding et al., 2020). Palliative care for LGBTIQ+ populations during COVID-19 has not been researched at length. However, many people who are LGBTIQ+ are at high risk of COVID-related mortality. (Harding et al., 2020) Available research showed that LGBTIQ+ people felt that people like them were 'dying fast', especially those with pre-existing conditions and comorbidities, including HIV, diabetes and other conditions that lead to being immunocompromised (Allen & Craven, 2020). The research also noted that transgender people with HIV are at particular risk (Allen & Craven, 2020).

People who are LGBTIQ+ are particularly vulnerable to health inequalities, including at the end-of-life, compounding physiological, emotional and financial pressures. Therefore, COVID-19 is likely to exacerbate the chronic minority stress many LGBTIQ+ individuals already experience from marginalisation and inequality. For example, LGBTIQ+ patients may experience increased fear or distress related to potential separation from loved ones and/or their families of choice (Rosa et al., 2020).

Rosa et al. (2020) provided practical recommendations that clinicians can immediately implement to ensure inclusive LGBTIQ+ palliative care under COVID-19.

#### These recommendations include:

- o assuming every patient infected with COVID-19 may be LGBTIQ+
- o assuming every LGBTIQ+ patient infected with COVID-19 may need a surrogate decision-maker
- o asking relevant questions and listening, acknowledging and responding empathically to the answers.

Rosa et al. (2020) provided inclusive questions for practitioners to ask during an initial encounter with a patient and about inclusive LGBTIQ+ health care decision-making.

A recent report on LGB older adults and COVID-19 sampled 4,380 Canadians aged 55 and over to identify if they had been affected by previous pandemics, including polio, tuberculosis, HIV/AIDS and SARS (de Vries et al., 2021). The survey found that LGB people are more likely to have experience with the HIV/AIDS pandemic than heterosexual people. Overall, men and LGB people with previous pandemic experiences indicated they were more likely to feel prepared, understood the need to act and that they have been here before (de Vries et al., 2021). The mental health impact of COVID-19 was greater on LGB older adults, who were more likely to report feeling depressed, anxious and sad. Another key finding was that LGB people were more likely to have completed ACP documents since the pandemic began in comparison to non-LGB participants.

## Specific challenges of L/G/B/T/I/Q+ subsets

**Some distinctions were made in the literature between L, G, B, T, I and Q+ people around the particular barriers they face. Importantly, there was inconsistency in how different parts of LGBTIQ+ communities were discussed in the literature. The following section highlights the specific barriers associated with different groups.**

### Intersex people

There is no specific research about the experiences of intersex people in palliative care. The Australian Government Department of Health (2019) report on barriers to inclusive palliative care noted service providers' lack of knowledge around intersex health care.

### Bisexuals

Bisexual people face a high degree of invisibility ('bi invisibility') when healthcare providers 'treat everyone the same'. Bisexual people face different experiences and issues from those who are gay or lesbian. A lack of knowledge and understanding of bisexual people's identities and relationships can widen the gap in addressing their needs and creating services to support their particular life experiences (MCCC, 2017). The lack of services and support is compounded as bisexual people may encounter discrimination within lesbian and gay health support networks. This discrimination affects bisexual people's approach to and relationship with health and social care services (MCCC, 2017).

Bisexual women report a lack of and need for intergenerational friendships with other people who are LGBTIQ+ (de Vries et al., 2019). Bisexual women who have lost same-sex partners may struggle alone and feel isolated and excluded—navigating visibility centred on how homophobia/biphobia led to a lack of recognition for their grief. Research showed that bisexual women might find new places to be authentic and need new relationships to be themselves (Ingham et al., 2016).

Bisexual men may struggle with ACP due to social isolation and being unable to identify a person in their lives whom they trust to make medical decisions for them (Furlotte, 2018). Bisexual men may be less 'engaged with the end-of-life process' (Furlotte, 2018 p 85).

Bisexuals in same-sex relationships may face similar discrimination to lesbians and gay men (e.g., healthcare providers assuming their partner is their sibling or friend) (Almack, 2018). Bisexuals in opposite-sex relationships may be wrongly assumed to be heterosexual—it is not clear from the research how this affects their end-of-life care experience.

Bristowe et al. (2016) note the lack of research into the bereavement experiences of bisexual people.

### Transgender people

The literature reflects extensively on the unique challenges transgender people face at end-of-life. Many transgender people have a particularly challenging end-of-life experience compared to cisgender LGBTIQ+ people (Stein et al., 2020).

Some transgender older people described their concerns and plans for later-life care as 'dealing with the day-to-day of their financial precarity, fractured family and community support'. (Pang et al., 2019 p.45) They also reported that 'the gap between principle and practices' (i.e., finding services claiming to be LGBTIQ+ inclusive are not inclusive) creates mixed experiences of healthcare services. (Pang et al., 2019 p.45) Transgender elders face higher rates of psychological distress than other LGBTIQ+ people, lower rates of social support, reduced capacity to pay for appropriate care and higher rates of employment discrimination and disability. They are twice as likely to live in poverty. One research participant in Canada said:

*...we struggle so much with our everyday lives, of where we're going to eat, where we're going to sleep, we're under-housed, we're underemployed ... whether our teeth hurt or whether we're being attacked, just our everyday, everyday lives that it's really really difficult to plan ahead, especially, in fact it's not even on the radar for many people ... (Pang et al., 2019 p.45)*

Kcomt and Gorey (2017) found that transgender people are the least prepared for the end-of-life stage and at the greatest

risk of experiencing poor end-of-life care. They are 50%–70% less likely to engage in end-of-life planning than other cisgender LGBTIQ+ people. They face more barriers, including financial precarity and reliance on providers to initiate end-of-life conversations and provide information about legal options. Kcomt and Gorey found that only 10% of transgender people had had end-of-life conversations with their healthcare providers. Communication problems between transgender patients and health professionals need to be understood. Healthcare practitioners need to become comfortable initiating and engaging in end-of-life discussions and know about the laws governing end-of-life options.

Gott et al. (2020) found that transgender and non-binary people's experiences of gender-based discrimination contributed to their distrust of palliative care services and limited their use of ACP and hospice care services. However, a lack of data about transgender and non-binary palliative care patients limits the discussion of gender-inclusive palliative care. There is an urgent need to consider how gender operates beyond a binary system by foregrounding the experiences of transgender and non-binary people at the end-of-life.

Ageing and social isolation may be barriers to transgender people engaging with ACP. Many transgender people never expected to reach old age. They feel like they are living on unexpected time and are enjoying 'catching up on life' focused on new personal and social experiences rather than

end-of-life experiences (Pang et al., 2019). Some transgender people struggle with planning due to difficulty identifying a close person they feel comfortable calling upon to care for them when needed, drive them home from the hospital, or speak at their funeral (Pang et al., 2019). Even for those with community links or well-known via a public role, struggle (Pang et al., 2019).

Transgender people face a high degree of discrimination and stigma in hospital settings. For example, they may fear being 'deadnamed' (i.e., being referred to by their name before transition). They may also fear being misgendered in official health documents and conversations with clinicians or forced to use the wrong bathroom (Higgins & Hynes, 2019). Transgender people have trouble accessing care due to a lack of understanding and cultural competency around trans issues. They can face concerns regarding dignified treatment and may not disclose their trans status during oncology treatment for fear of being treated disrespectfully (Cathcart-Rake et al., 2019). Transgender and non-binary people, along with people assigned female at birth, are more likely to prefer a partner as their alternative decision-maker and are less likely to have completed an EPoA for their financial decisions. ACP is an important tool for transgender individuals to prepare for their end-of-life through key legal documents. Without ACP, unsupportive family members may take charge of medical care and funeral arrangements. Without these protections, the individual's

pronouns, name and physical appearance may be incorrectly identified or represented, including the deceased's appearance at a viewing, wake or funeral service.

Torres et al. (2019) introduce the 'queering the funeral space' by creating new cultural practices. These practices centre on queer identity, celebrate the deceased's life and give memorial attendees real opportunity for grieving. Queering the funeral space contrasts with the history of memorials and end-of-life celebrations as instances of symbolic violence against LGBTIQ+ people. Symbolic violence includes erasing same-sex partnerships and/or gender fluidity, accusing the deceased of immorality and/or refusing to allow fellow members of LGBTIQ+ communities to attend.

Weaver (2020) described 'post-mortem detransitioning' as the verbal, visual and material rejection of a person's gender identity by their family of origin after they die. This detransitioning can shape 'contentious memorialisation'. Post-mortem detransitioning can affect gendering in historical records, obituaries, death notices and grave markers. The prospect of post-mortem detransitioning can be distressing to transgender people as they seek to have their end-of-life intentions upheld. Weaver warns that 'unless legal documents have been compiled and can contest detransitioning, the dead are powerless to make their desires, wishes and voices known' (Weaver 2020 p.58). Post-mortem detransitioning can also contribute to disenfranchised grief in survivors when their

loved ones are misnamed and misgendered after death. Weaver referred to the case of Jennifer Gable, an American woman in her thirties who died suddenly in 2014 and was deadnamed. Her family presented her at an open-casket funeral, much to her friends' distress.

A transgender patient described her healthcare provider and funeral preferences:

**'[I] would have really liked to have a care provider who could have seen her as she was and who could have been affirming of her identity... and hopes her end-of-life memorial is an opportunity for others to remember, honour and celebrate her journey. Above all, she hopes she is represented as she truly is and knows herself to be' (Torres et al., 2019 p. 192).**

Some transgender and gender nonconforming adults at the end-of-life stage may struggle with retrospection or feel it is unfair that their life is ending too soon (Torres et al., 2019).

### Case study

Stevens and Abrahm (2019) presented the case of a man diagnosed with a life-limiting illness (ovarian cancer) who was assigned female at birth but did not feel any connection to the notion of being transgender. The man required palliative care at a hospice. The man's wife was aware that he had been assigned female at birth, but their children were unaware. The man did not want his children to know that he was assigned female at birth. The palliative care/hospice team upheld his privacy and confidentiality, and they provided an excellent palliative care experience for him. He died with his family by his side, with his assigned sex at birth never discussed.

### Lesbians

**Cathy said 'Don't say anything about being married anymore', which is really hard to hear because you know, she's dying. It's like 'oh, God'. Esther, lesbian, mid-60s, USA (Candrian & Cloyes, 2020 p.1198).**

The end-of-life experiences of older sexual and gender minority women and women who have lost a spouse or partner may be specific; however, these needs are under-researched. Older women grieving a same-sex partner may face specific challenges, but research is scarce (Kcomt & Gorey, 2017).

Candrian and Cloyes' (2020) paper focused on one woman's story to illustrate how end-of-life care can be compromised if an open discussion about who or what matters to patients is avoided. Esther lost her wife Cathy to cancer and faced covert discrimination by hospital staff when she indicated that they were married. They noticed subtle changes in how the nurse interacted with them. The nurses came less frequently to their room, spent less time, asked fewer questions than before (and asked about medical needs rather than emotional ones) and avoided eye contact. The discriminatory treatment became more overt and negative as Cathy became sicker than before. She grew anxious about how this behaviour might influence the care she would receive. Esther began checking the box for emergency contact so that staff would think they were friends, not spouses. Esther was regarded as her best friend when Cathy died, not a grieving widow.

Esther faced disenfranchised grief, social isolation and lack of family support. Esther's mother and brother had never met Cathy in the 33 years she and Esther had been together and did not understand same-sex relationships well. Esther believed referrals for bereavement care were affected due to bias. Esther eventually found an LGBTIQ+ support group that provided her with the recognition and the affirmation she needed.

In de Vries et al.'s (2019) study, lesbian and bisexual women identified the need for friendships with younger people who are LGBTIQ+ as a protective end-of-life factor. They recognised a lack of intergenerational contact (de Vries et al., 2019). Existing understanding of partner bereavement may provide a useful framework for understanding the experiences of older women who have lost same-sex partners and report being left alone and feeling isolated, excluded as though their grief is unrecognised due to homophobia (Valenti et al., 2020). Covert discrimination in healthcare interactions may also be a factor in women's needs not being met.

### Gay men

Gay men fear stigma and discrimination, particularly when needing institutionalised care, including being treated badly in religious hospice care (MCCC, 2017).

Some gay men may live under 'the shadow of HIV' in relation to death and dying (Bristowe et al., 2016). Gay men are more likely to have experienced the death of a partner at a young age from HIV-AIDS complications. This experience may still inform their perception of end-of-life care. Older people who are LGBTIQ+ who have been involved in caregiving or HIV-related healthcare may have experienced heterosexist assumptions, homophobia and systemic problems. Therefore, they may fear receiving undignified care and declining quality of care throughout the progression of an illness.

Patients fear suboptimal in-home care or care in nursing homes, hospitals or hospices. Conversely, one report noted that a gay man longed for the community health support and spirit felt during the AIDS crisis (Catalan et al., 2020). Healthcare professionals may play a role in chronic care education. They should be aware of the complex partnered caregiver needs of gay men with HIV (Kia, 2015).

Gay men, in particular, face issues of social isolation. Isolation is partly due to older gay men having reduced social networks from losing friends to HIV and having a lower chance of being partnered or having children. Weak community links between younger and older gay men, and ageism in the gay community, may contribute to older gay men feeling socially isolated at their end-of-life (Furlotte, 2018).

Social isolation can be compounded by reduced independence, declining health, housing issues and coming to terms with the need for institutionalised care (de Vries et al., 2019). Compared with LGB+ people, gay men particularly fear institutionalised care (de Vries et al., 2019). Gay men may struggle with ACP due to social isolation and the inability to identify a caregiver (Cottrell, 2020).

Gay men may be 'less mindful and engaged with the end-of-life process' (Furlotte, 2018 p. 85). Furlotte found that gay male activists have low efficacy in their end-of-life planning, noting that being politically engaged does not necessarily mean being personally engaged at this stage of life.

Additionally, Furlotte noted that gay men who were activists might engage with services in their older age that they previously advocated against (e.g., medical assistance in dying).

## Case study

Opening Doors London (ODL) is the largest provider of information and support services for older LGBT people in the UK (Hospice UK, 2018). ODL wants all older LGBT people to have access to the right information to make informed choices about their care. ODL frequently supports members reaching the end of their lives via a befriending service.

Trevor, a gay man in his eighties, was referred to the ODL Befriending Service by his social worker. Trevor had recently returned home from having cancerous tumours removed from his stomach. However, he still had terminal lung cancer. Trevor had been very independent and lived alone for many years until his cancer diagnosis. He went to the gym regularly and was very socially engaged. He lived on an upper floor of a housing association property without a lift.

A Befriender was placed with Trevor within a couple of months and visited weekly. The Befriender supported Trevor throughout a period of chemo, which Trevor said made all the difference:

‘You cannot imagine what a difference it made to have a friendly face come visit me and allow me to talk through everything I was feeling, which wasn’t always positive, over a cup of tea. It was a huge distraction from the awful treatment I was going through.’

Trevor’s relationship with his Befriender continues, [spending] a lovely evening at Trevor’s home while Trevor read him some love letters from an old lover. Working with ODL’s Befriending Coordinator, Trevor talked about the importance and relevance of the ODL Befriending Service. He was so grateful for his Befriender and didn’t think he could have gotten through this period without his smiling, friendly face turning up at his door once a week for a chat and a cup of tea (Hospice UK, 2018 p 32-33).

## Queer people

There is no specific research related to the particular end-of-life experiences of queer people or where the term queer is used.

### LGBTIQ+ carers caring for non-LGBTIQ+ individuals

In addition to considering the needs of LGBTIQ+ patients and their carers who may also be LGBTIQ+, we must consider different caring constructs where the patient is not LGBTIQ+, but the carer is LGBTIQ+. There is little research on the end-of-life experiences of LGBTIQ+ people and their caregivers and minimal discussion of the implications for these types of caring relationships and the barriers to quality end-of-life care. Any carer of someone who is LGBTIQ+ may be vulnerable to increased pressure and caring responsibilities because LGBTIQ+ patients access care later or not at all (MCCC, 2017). Any LGBTIQ+ person involved in the care of someone not LGBTIQ+ may encounter and be affected by the lack of awareness and potential discrimination and stigma in healthcare settings when caring for someone accessing palliative or end-of-life support.

### Rainbow families

There is little research into the specific needs of LGBTIQ+ families and palliative care, including hospice and palliative care settings. However, many of the same characteristics colouring the experience of LGBTIQ+ partner bereavement may

apply to the loss of a child in a rainbow family (Wheat & Thacker, 2019). Issues may include contested wills, legal battles, challenges recognising parental status, fear of discrimination within the healthcare system, microaggression from care workers and disenfranchised grief, especially when not well-supported socially.

Wheat and Thacker (2019) noted that people who are LGBTIQ+ raising families are not always supported socially by other members of the LGBTIQ+ community or by the mainstream community. LGBTIQ+ parents who lose a child may not find many avenues for recognition and assistance from inside or outside the LGBTIQ+ community. They may feel invisible, receive less social support, face stigma and cultural silence around pregnancy and child loss and/or deal with judgemental assumptions about parenting and families.

Bereaved LGBTIQ+ families may be helped by support focused on family resilience, queer resilience and acknowledging and valuing LGBTIQ+ experiences of child loss as a valid part of queer family-making (irrespective of homophobic responses to LGBTIQ+ families) (Allen & Craven, 2020).

There is no research evidence of inclusive palliative care for LGBTIQ+ youth.

## People who are LGBTIQ+ with specific morbidities: Cancer, dementia and HIV

**LGBTIQ+ individuals have increased rates of certain physical diseases, and they are at greater risk of stress-related mental health issues. Stigma exposes LGBTIQ+ people to serious illnesses, increasing the need for palliative care and reducing health and social care access and outcomes (Harding et al., 2020). They have worse healthcare experiences than others, particularly for cancer, dementia, and mental health provision (Westwood, 2020). Serious illnesses are often underdiagnosed, as healthcare workers fail to explore LGBTIQ+ status (Harding et al., 2020). People who are LGBTIQ+ are also at higher risk of a sedentary lifestyle, smoking and cardiovascular disease than non-LGBTIQ+ people (Selix et al., 2020).**

The end-of-life experiences of people who are LGBTIQ+ differ depending on the disease (e.g., motor neurone versus dementia) (MCCC, 2017). The difference is partly because treatment and support for some conditions, such as cancer care, is better funded than other conditions (Gardiner et al., 2020).

Transgender people have the highest risk of depression, suicidal attempts and death from suicide. Older LGBTIQ+ people, especially those from racial and ethnic minorities, face particularly high depression and suicidality, substance use disorders, sexually transmitted infections and interpersonal violence (Selix et al., 2020). Healthcare professionals need to consider the mental health needs of people who are LGBTIQ+ in their palliative care or end-of-life care journey.

### Cancer

Inclusive cancer care is vital. People who are LGBTIQ+ are at higher risk of certain cancers, including Hodgkin and non-Hodgkin lymphoma, anal, colon/colorectal, genital cancers and breast cancer (Selix et al., 2020). They may seek cancer care later than non-LGBTIQ+ people (Selix et al., 2020). Delays can result in reduced information, poorer prognoses, worse quality of life and end-of-life outcomes, and higher psychosocial support needs.

All cancer care, including palliative, needs to support transgender people. For example, transgender men need to access care that prevents and treats breast, ovarian and cervical cancer. Transgender women need the option of inclusive care for prostate and testicular cancer. Transgender people are especially concerned that they will not receive respectful, dignified care during oncology, palliative care and end-of-life treatments (Cathcart-Rake et al., 2020).

Cisgender women who have sex with women may be at risk of gynaecological cancer being less frequently detected (Candrian & Cloyes, 2020).

This oversight is due to their reduced chance of accessing health services for contraception (Candrian & Cloyes, 2020).

The mental health effects of cancer treatment, including longer periods of depression and more and more frequent side effects, are greater for older LGBTIQ+ patients. One older transgender man struggled to find a gender-affirming, non-gynaecological oncology appointment in an acceptable environment to receive cancer care for a life-threatening malignancy (Cathcart-Rake et al., 2019). Similar situations are likely occurring quietly at cancer centres everywhere (Cathcart-Rake et al., 2019).

### Dementia

Access to tailored, integrated palliative care is crucial to ensure that older people who are LGBTIQ+ with dementia die with dignity. Transgender people may face complex issues in relation to dementia, death and dying. A change in cognitive capacity may lead to an older person detransitioning because they have forgotten their present-day gender identity (Baril et al., 2020).

Baril et al. (2020) noted that end-of-life planning assumes that participants are 'cognormative (a normative system based on cognitive abilities)' (p. 367). When applied to transgender people with dementia, this assumes that gender identity is stable. It also assumes that a pre-dementia self is better equipped to make end-of-life decisions than the 'demented' self. Baril et al. recommended an intersectional, trans-affirmative and 'crip-positive' (disability positive) approach to respect

the agency of transgender people with dementia. Services may employ a 'trans-affirmative fluid approach' to care for transgender people as they wish to be cared for, as their capacity and self-perception change (Baril et al., 2020 p.368).

### HIV

People with HIV may face stigma, homophobia and systemic issues related to their fear of receiving undignified hospital-based palliation. Their concerns may grow as homophobia may be more common with the progression of an illness (Kia, 2015). Gay men who have HIV may live under 'the shadow of HIV' (Bristowe et al., 2016). They may have lost a partner or close friends to HIV previously or 'survived the darkest days' of HIV, the experience of which may influence their views on ageing and end-of-life care (Godfrey, 2016).

There is a 'greater perception of 'normalisation' of HIV-related disease and a focus on how to live, rather than how to die with HIV, which has paradoxically reduced access to palliative care treatment for people with HIV' (Harding, 2018, as cited in Catalan et al., 2020, p.1562). Managing disclosures of HIV status can be a barrier for some thinking about end-of-life care, let alone talking about it. Building support, community and connections may help facilitate ACP discussions among men with HIV (Dube et al., 2021).



## International evidence beyond Western countries

People with HIV may have multiple comorbidities, including cardiovascular disease, cancer (smokers with HIV have a lung cancer risk four times higher than those without HIV) and neurodegenerative conditions (AHCA, 2019). HIV, diabetes, chronic disease and other chronic medical condition compounded by neglect can lead to persistent immunocompromised states, especially in transgender people. Transgender people with HIV have a high risk of getting and dying from COVID-19 (Banerjee & Rao, 2021).

### Case study

The following case study is from the perspective of healthcare provider Noelle Marie C, Javier MD:

One of the most memorable patients that I took care of in palliative care and subsequently in hospice was a gay man with HIV/AIDS who wilfully decided to stop taking antiretroviral therapy because he was 'fed up with the world' and 'ready to die'. The biggest challenge in taking care of him was establishing good rapport. He was mistrustful of the health care system at large, owing to feelings of abandonment and judgment. As an advocate and provider [of] LGBTQ medicine, I only wanted what was best for this population, [which] collectively has been pushed to the sidelines and not necessarily receive[d] the best

quality of care afforded to the general population. One night in the hospice unit, as he was dying, it was found out that not even his mother, his only known family, knew of his illness. Up to the last few moments of his life, he felt alone. I took refuge in hospice being there for him and in a sense became a surrogate support. I was moved by images of a mother grieving and crying at the bedside and a son who felt betrayed by society. I felt like there was a hint of vindication in that he at least received the best medical and psychosocial care possible at that stage of his life. But did he really? The truth is that there continue to be gaps in knowledge and skills in taking care of the palliative care and hospice needs of the seriously ill in this population (Acquaviva, 2017 p119).

Research into LGBTIQ+ palliative care experiences is predominantly from the US, UK, Canada and Australia. The accessibility and quality of palliative care for LGBTIQ+ people has not been investigated in low- and middle-income countries where civil rights are weak (Hunt et al., 2019). The exceptions are reports from Zimbabwe, India and Lebanon, where criminalisation, persecution and marginalisation are significant barriers to LGBTIQ+ palliative care and overall wellbeing and safety.

Research conducted by Hunt et al., (2019) in Zimbabwe, referred to LGBTIQ+ people fearing being 'burnt alive as animals' if they were discovered to be LGBTIQ+ and receiving palliative care. (p. 689) Participants described their unmet needs and barriers to the most basic elements of palliative care, such as pain management. The care they received was entirely contingent on family and community. Other issues included risk of misdiagnosis, self-diagnosis and morbidities not recognised early, fear of being killed, fear of a painful, undignified, humiliating and lonely death, minimal understanding of and access to palliative care services, risk of transmission of infectious diseases, being told that a terminal illness is payback for going against God, disenfranchised partner relationships and disrespect for inheritance wishes, and partners denied shared property after the patient's death (Hunt et al., 2019).

Banerjee and Rao's (2021) recent research in India focused on the impact of COVID-19 on older transgender people. Barriers

included social inclusion, lack of awareness related to COVID-19, insufficient or no mental health care and no audience to their distress. Older transgender people felt fearful and like their 'voices [are] unheard', and that stigma, marginalisation, 'losing priority' and facing uncertainty under COVID-19 kept them on the 'back foot' for healthcare (Banerjee & Rao 2021 p.7).

They faced job insecurity and depended on families, homes and communities, which increased the risk of abuse. Social rituals, spirituality, hope and acceptance of their gender were major coping factors. Policy implementation and community awareness were vital to improving this minority's health and wellbeing. (Banerjee & Rao 2021)

Chidiac (2020) found that LGBTIQ+ people in Lebanon face challenges and receive suboptimal palliative end-of-life care. This suboptimal care was due to assumed heterosexuality, lack of knowledge and understanding of LGBTIQ+ issues and specific healthcare needs, discrimination, homophobia and transphobia, lack of legal and institutional support, stigma, marginalisation, fragmented services and a focus on sexual health and mental health. Care did not meet the broader needs of LGBTIQ+ people living with a life-limiting illness. A workshop was developed in response to these limitations, the first of its kind in Central, East and North Africa. The workshop was attended by 32 nurses and doctors. They reported an overall increase of knowledge of palliative care, general LGBTIQ+ issues and needs, specific LGBTIQ+

end-of-life care needs and confidence in providing care. The workshop highlighted the need for further training in health and social care. The participants' eagerness to provide culturally sensitive care reflected the gradual shift in social attitudes towards LGBTIQ+ in Lebanon.

### **Under-researched LGBTIQ+ communities**

American lawyer Kimberlé Crenshaw coined the term *intersectionality* in 1989. (Holman et al., 2021) The term was originally a critique of how gender had been neglected in critical race theory. Intersectionality provides a framework to examine how social justice issues (e.g., racism, sexism, homophobia, transphobia, ableism) overlap and how this can result in multiple layers of social injustice. An intersectional lens can help us better understand the privileges and disadvantages a person may experience (Holman et al., 2021). Intersectionality informs the concept of the social determinants of health. Individual wellbeing and the wellbeing of certain groups is largely affected by wider social forces, including access to services (Wicks et al., 2018).

Researchers have not explored the intersectional experiences of people who are LGBTIQ+ in end-of-life care to a great degree. Gott et al. (2020) noted that intersections at the end-of-life between gender (including transgender identity), disability, serious mental health problems and poverty have been neglected. LGBTIQ+

people can hold more than one rainbow identity. For example, a person may be gay and transgender, or bisexual and intersex; therefore, they may face increased stigma and discrimination when accessing palliative and end-of-life care.

The end-of-life needs of intersex people are specific yet under-researched, with no focus on their palliative care needs. A 2019 government report noted that service providers' lack of knowledge on intersex health care is a barrier to inclusive palliative care (Australian Government Department of Health, 2019).

Throughout their lifetimes, intersex people may have complex relationships with medical providers, which may include harmful, violating and unnecessary healthcare experiences. As intersex relates to bodily diversity and not diverse sexualities or genders, many intersex people may be heterosexual, cisgender but not identify with LGBTQ+ communities or culture. However, there may be erroneous assumptions that intersex people are sexual or gender minorities.

LGBTIQ+ Aboriginal and Torres Strait Islander people, brother boys and sister girls and people who are LGBTIQ+ from CALD backgrounds have specific needs that warrant more research (Gardiner et al., 2020). In a paper on cisgender and transgender people's experiences of aspects of end-of-life, Gott et al. (2020) noted that hospices could be perceived as resources for white, middle-class populations.

Evidence from New Zealand indicated that palliative care services are not always fit for structurally disadvantaged populations, including indigenous people (Gott et al., 2020).

It is especially important to consider the end-of-life requirements for LGBTIQ+ people living with disability. The recent LGBTIQ+ Australian survey *Private Lives 3*, which documented the health of LGBTIQ+ people, indicated that LGBTIQ+ people have a higher incidence of disability or long-term health conditions than the general population (Hill et al., 2020).

LGBTIQ+ people who are homeless, in prison, veterans or have had an asylum seeker or refugee experience (including those currently in detention) face significant barriers to care (Gott et al., 2020). Vulnerably housed and homeless people experience particular end-of-life challenges and are highly resilient (Gott et al., 2020). More marginalised communities are likely to face the same barriers as the wider LGBTIQ+ population, plus additional barriers preventing service access, culturally appropriate care and inclusive public health communication. An intersectional lens aids in acknowledging that the end-of-life inequalities experienced by minorities (e.g., homeless people) are exacerbated by inequalities based on gender, sexuality, immigration status and more (Hospice UK, 2021).

LGBTIQ+ people who live in poverty or face socio-economic disadvantage bear disproportionately higher carer time costs, out-of-pocket costs and employment-related costs of informal end-of-life caregiving (Gardiner et al., 2020). Various informal end-of-life carers are systematically disadvantaged financially (Gardiner et al., 2020). Poor LGBTIQ+ people's end-of-life wishes are likely to be affected as people living in poverty are more likely to die in hospitals and alone than at home (Gott et al., 2020).

People who are LGBTIQ+ living in rural and regional areas, including remote regions of Australia, may face significantly different challenges than people who are LGBTIQ+ in metropolitan areas. Geographical barriers such as distance lead to reduced service provision, access and options. In places with only one palliative care service provider, LGBTIQ+ people face a greater risk of discrimination if that service is not inclusive.

Geographical isolation can lead to premature institutional care, reducing LGBTIQ+ people's community resources and ability to 'age in place' (at home), which is the preference for many people. A partnership between Victoria's Thorne Harbour Health and Bolton Clarke provides volunteer-based palliative care support for LGBTIQ+ people with a life-limiting illness who wish to die at home (AHCA, 2019). These services are vital for rural and regional people (AHCA, 2019).

# Part II: Inclusive palliative and end-of-life care factors for LGBTIQ+ people

Being inclusive is not the same as treating everyone the same. In fact, treating everyone the same is an approach that rarely benefits patients, regardless of whether they are LGBTQ, because patients aren't all the same. (Acquaviva, 2017, p.xv)



## What does inclusive palliative and end-of-life care look like?

**There are a range of measures, facilitating factors, and strategies that healthcare professionals and organisations could employ to make palliative care more equitable. The most commonly mentioned enabler in the literature was training and education for healthcare professionals. Other enablers were: inclusive healthcare policies and practices, signals of inclusivity in the healthcare environment (e.g., the rainbow flag and LGBTIQ+ specific resources), ensuring all patient forms and questionnaires are inclusive of diverse sexualities, genders and bodies, appropriate religious and spiritual supports if required, and non-mainstream supports (e.g., death doulas). These strategies and facilitating factors reflect a vision of affirmative, compassionate and exemplary palliative care.**

Research shows that people who are LGBTIQ+ approaching the end-of-life have a clear idea of what good care is. The two most important indicators of good care are whether they are receiving care centred around them as individuals and if their partner is accepted as such (MCCC, 2017). People who are LGBTIQ+ may need to expend much energy to ensure their wellbeing in long-term care. They express a yearning for 'nuanced care' involving mutual comfort among residents and care providers (Kortes-Miller et al., 2018). They also desire to be around other older people who are LGBTIQ+ in care settings (Kortes-Miller et al., 2018). There are many

ways LGBTIQ+ patients may feel included; for example, being referred to LGBTIQ+ inclusive support groups, appropriate language in person-centred assessment and care planning and inclusive approaches to support networks and relationships (Henderson & Almack, 2016).

Overall, there is little evidence in the literature about the relative effectiveness of facilitating factors and strategies in LGBTIQ+ palliative care. However, in *LGBTQ inclusive Hospice and Palliative Care: A Practical Guide to Transforming Professional Practice*, Acquaviva (2017) argued:

**'Providing LGBTQ-inclusive hospice and palliative care requires changes at two levels: the individual and the institutional. At the individual level, hospice and palliative care professionals can shift toward providing more LGBTQ-inclusive care by adopting a structure of self-awareness and changing the way they interact with and support the patients and families they work with. At the institutional level, organisations can strengthen their inclusion of LGBTQ individuals and their families' (p. xx).**

For example, Barwon Health (Victoria, Australia) recently created a project officer role specialising in LGBTIQ+ palliative care to increase the organisation's capacity to provide appropriate care to LGBTIQ+ patients.

## Health, wellbeing and psychosocial needs of LGBTIQ+ people

People who are LGBTIQ+ have a range of health, wellbeing and psychosocial needs. Addressing these needs could increase the quality of care individuals receive. The approaches highlighted in the literature were:

- providers can spend quality time with patients, listening, identifying and addressing their needs, which may be complex. This quality time will maximise effective health promotion and treatment interventions for older people who are LGBTIQ+ (Hunt & Bristowe, 2019)
- providers are encouraged to take a medical history that is inclusive of transgender people. When medically appropriate, healthcare professionals can inquire sensitively about a transgender person's history and understand the effect of hormones or surgery on diagnosing and screening for medical conditions (AGSEC, 2015)
- providers take a patient history in a non-discriminatory manner, contextualised in social history that includes the patient's LGBTIQ+ experience (AGSEC, 2015). Providers can use health/medical history forms with culturally appropriate terminology to explore sexual orientation, gender identity, bodily diversity and relationships (Hunt & Bristowe, 2019)
- healthcare professionals are encouraged to perform dignified, sensitive person-centred assessment and care planning that recognises transgender people's specific needs and addresses behaviours to prepare for ageing (e.g., it may be important for transgender women to keep shaving as part of maintaining their end-of-life physical appearance) (Johnson et al., 2018). Other topics may include wound care, burial rights and whether and when to discontinue hormone treatment (Stevens & Abrahm, 2019)
- staff providing end-of-life care must be prepared to deal with the added layers of concerns uniquely connected to personal identities, neglect and the societal oppression that transgender older adults face (Torres et al., 2019)
- healthcare professionals can understand and share chronic care education; for instance, awareness of the complex partnered caregiver needs of gay men with HIV (Kia, 2015)
- healthcare providers can proactively screen for financial distress and offer referrals for financial planning assistance (Stevens & Abrahm, 2019)
- healthcare professionals can provide referrals to support planning and recognise and advocate that ACP documents follow patients across multiple care settings (Stevens & Abrahm, 2019). ACP documentation is especially important if patients have concerns about their family of origin

- o providers can educate LGBTIQ+ communities about increased cancer risks and screening and early detection (Arthur, 2015). Oncologists can be mindful of being LGBTIQ+ inclusive (Arthur, 2015)
- o LGBTIQ+ individuals can be educated, empowered and helped to complete appropriate state healthcare representative documents, including referral to support planning services. Some people may need help completing these documents in some clinical settings (AGSEC, 2015)
- o life (and end-of-life) experiences can be different for diverse LGBTIQ+ groups. Inclusive LGBTIQ+ palliative care must factor in experiences of homophobia, transphobia, racism, classism, poverty and stigma for other reasons (e.g., HIV positive status) (Allen & Craven, 2020).

### Relationships and social support

Inclusive and quality care incorporates an understanding and recognition of an individual's relationships and available supports. The literature highlighted the following key considerations for healthcare professionals:

- o healthcare professionals can consider the potential for an LGBTIQ+ patient's lack of social support (Barrett & Wholihan, 2016) and diverse social and family support types

- o healthcare professionals must recognise the patient's legal right to include their family of choice with reference to the changing laws and regulations at national, state and institutional levels (Stevens & Abrahm, 2019)
- o clinicians must recognise LGBTIQ+ partners and address misunderstandings about next of kin, including not using the term next of kin. They can consider the role of partners or other chosen family in healthcare decision making and caregiving and the individual's right to choose a healthcare proxy who may be a partner or friend (AGSEC, 2015). It is key that clinicians know the important role friend and partner caregivers may play for an LGBTIQ+ person with a serious illness
- o providers can discuss and formalise surrogate or substitute decision-making for end-of-life care as early as is reasonable, including medical proxy documentation, custody of dependent children, burial right forms and hospital visitation (Stevens & Abrahm, 2019)
- o providers can engage in behaviours that increase safety for same-sex partners and their chosen family to be open about their relationships, even if they decide not to disclose (Arthur, 2015)
- o healthcare practitioners can learn and teach about resources to improve referrals that support LGBTIQ+ patients and their chosen families, including where to find further specialist support, advice and information (Cottrell, 2020).

### Health care professionals' training on LGBTIQ+ inclusive palliative care

The research literature indicated that training is one of the most important considerations for improving the quality and inclusiveness of care for people who are LGBTIQ+:

- o education, training, practice and impact evaluation helps healthcare providers improve inclusive end-of-life practices for people who are LGBTIQ+. Inclusive care can enhance the outcomes of LGBTIQ+ patients and their caregivers (Cloyes et al., 2018)
- o many providers lack experience in knowingly caring for LGBTIQ+ patients. However, higher education and extensive time working in hospice are associated with more positive provider attitudes towards people who are LGBTIQ+ (Cloyes et al., 2018)
- o health professional students in cancer care do not receive adequate LGBTIQ+ health training (Radix & Maingi, 2018). Nursing student evaluations have shown inadequate LGBTIQ+ knowledge, and medical students exhibited an explicit and implicit bias towards people who are LGBTIQ+ (Radix & Maingi, 2018). The median time dedicated to teaching LGBTIQ+ content in medical schools is only five hours and is heavily focused on sexual health, STIs and HIV, with gaps in chronic disease, transgender and intersex health (Radix & Maingi, 2018)

- o all healthcare providers, including interdisciplinary providers, working with patients in palliative/end-of-life care can educate themselves and others about LGBTIQ+ specific issues and needs and focus on dignity, equality and respect for patients. Health professionals' contact and positive interactions with LGBTIQ+ patients are strongly associated with lower bias rates, which has important implications for the efficacy and value of training (Radix & Maingi, 2018). Training promoting 'cultural humility' can build on health professionals' experience and training by influencing attitudes, reducing bias and improving competency, including patient communication (Sprik & Gentile, 2019)
- o training helps health professionals increase their cultural competency to create safe spaces for and build rapport with LGBTIQ+ patients (Stinchcome et al., 2017). Cultural competency helps minimise fear of discrimination and mistreatment in patients' end-of-life care and reduces the occurrence of discrimination (Stinchcome et al., 2017). Training can highlight the need to eliminate unconscious assumptions and behaviours that make people who are LGBTIQ+ less inclined to approach, use or feel comfortable using palliative care services. For example, providers may learn to avoid heteronormative bias (assuming that everyone is heterosexual and cisgender and that heterosexuality is the 'normal' orientation)

- o training helps healthcare providers provide more LGBTIQ+ inclusive care, builds trust, encourages disclosure and facilitates ACP conversations and planning by people who are LGBTIQ+. While discussing end-of-life care and ACP issues can seem like a private matter, most people who are LGBTIQ+ would be comfortable with a healthcare provider raising these issues (Hughes & Cartwright, 2015)
- o new graduate training is important, as is ongoing education regarding the specific end-of-life concerns and issues of people who are LGBTIQ+ (Arthur, 2015). Training and education can promote awareness of LGBTIQ+ patients even if healthcare providers do not know who these patients are (Arthur, 2015)
- o there are challenges in assessing the outcomes of healthcare provider training on LGBTIQ+ inclusive care. Little research has examined the effects of such training on patient satisfaction or health outcomes. Additionally, it is easier for researchers to demonstrate changes in health professionals' knowledge than their attitudes, making changes in bias hard to measure
- o no research was found on the relative efficacy of different facilitating factors (e.g., whether training is a more effective intervention than inclusive policies and practices). However, researchers propose that more than one enabler increases the chances of successfully increasing LGBTIQ+ inclusive palliative care (Westwood & Knocker, as cited in

Waling et al., 2019). Change processes can be embedded within organisations to address disadvantages, celebrate diversity and complement training and awareness-raising courses, which may not be sufficient on their own (Westwood & Knocker, as cited in Waling et al., 2019)

- o training provides opportunities for healthcare professionals to test the assumption that they 'treat everyone the same,' assess how this translates into communication behaviours and practice approaches and explore beliefs (e.g., whether 'treating everyone the same' reflects patient-centred care) (Arthur, 2015)
- o training can connect provider attitudes and associated demographic and experiential characteristics of LGBTIQ+ patients and their families, including symptom management, caregiver burden and satisfaction with care (Cloyes et al., 2020). Providers may also become more aware of intersectionality, including evidence of palliative care disparities and risks for poorer people who are LGBTIQ+ (Gardiner et al., 2020).

### **Proposed and current training initiatives in LGBTIQ+ palliative care**

The research literature provided examples of proposed and current training initiatives in the LGBTIQ+ palliative care space:

- o Acquaviva (2017) outlined an in-depth approach for inclusive palliative care. This approach looked at the individual healthcare practitioner's values and beliefs and an organisational approach to LGBTIQ+ cultural competency in palliative care. Acquaviva developed this approach by drawing on nursing and medical competencies and social work and chaplaincy certifications
- o a current three-part study intends to build a mini video-based curriculum to help cancer healthcare providers ask patients with cancer about LGBTIQ+ status to potentially improve end-of-life care for LGBTIQ+ patient subgroups (Cathcart-Rake et al., 2019)
- o Devon Hospicecare in the UK developed training to increase staff and volunteer knowledge and understanding of LGBTIQ+ end-of-life issues. The project increased support for all carers and provided new open and respectful communication skills. (Hospice UK, 2021)

- o Willis et al. (2020) noted current initiatives to increase professional education for doctors in England and Wales via the creation of e-modules on gender identity and healthcare by the Royal College of Physicians in 2019. However, they noted that the training and education of social workers in trans inclusion was unaddressed. This gap creates anxiety and uncertainty among middle- to older-aged trans and gender diverse people

- o Royal Trinity Hospice (RTH) established the London Hospices LGBT Network with nine other hospices in 2017. The network promotes equality, diversity and inclusion of LGBT people by providing leadership, support and education; and raising awareness of hospice care in LGBT communities (Hospice UK, 2021). RTH also established an LGBT Friends group to inform service provision and have engaged local LGBT groups in this work
- o St Ann's Hospice in Manchester, UK, implemented a multifaceted approach to engage with transgender people. It built links with trans communities and local advocacy groups and promoted support and education. Transgender people are supported to share what matters to them regarding palliative and end-of-life care (Hospice UK, 2021)
- o Devon Hospicecare focused efforts on working with LGBTIQ+ people and their carers, including supporting people to engage in ACP. Workplace training focused on how LGBTIQ+ people's needs can be better addressed by initiating conversations about needs and concerns (Hospice UK, 2021).

### **Health professionals roles in inclusive care**

Specific healthcare professions may have distinct roles in the provision of inclusive care. These roles include:

- o training for all types of healthcare workers, including doctors, nurses and nursing assistants, can help create a culture of respect for people who are LGBTIQ+ in supported living (e.g., assisted living, nursing homes) (AGSEC, 2015)
- o palliative care specialists and long-term care home staff can address the unique health needs of older LGBTIQ+ adults nearing the end-of-life by allaying their fears and creating supportive and inclusive long-term care environments (Kortes-Miller et al., 2018)
- o general practitioners and gerontologists can improve care for people who are LGBTIQ+ by considering how sexual orientation reflects their experiences, not making assumptions and showing acceptance of sexual, gender and bodily diversity (Stinchcombe et al., 2017)
- o nurses and social workers can address the specific challenges associated with LGBTIQ+ patients' family and social support, unique relationships and sexuality. Nurses would benefit from being aware of the lack of community resources, housing (including long-term care), minority stress and end-of-life and palliative care disparities for people who are LGBTIQ+ (Cottrell, 2020)
- o nurses are uniquely positioned to improve service delivery and healthcare outcomes for LGBTIQ+ people once they are aware of the needs of LGBTIQ+ populations (Selix et al., 2020)
- o social workers with a social justice and trauma-informed approach can apply compassion as a major therapeutic tool to reduce traumatic loss and disenfranchised grief in individual client care and broader community social justice and healthcare work (Allen & Craven, 2020)
- o home care service providers, especially personal support workers, may be the least likely to have access to LGBTIQ+ education and training (Daley et al., 2020).

## What does best practice LGBTIQ+ Inclusive care training look like?

All palliative care training and service implementation must include information regarding the health and human rights of LGBTIQ+ patients to promote person-centredness and values-based care and comprehensively address the needs of all patients and their loved ones (Hunt & Bristowe, 2019). Cultural competence and individualised, patient-centred care are widely acknowledged as central to effective medical care (AGSEC, 2015). This type of care helps build a safe, open and affirming environment in which LGBTIQ+ patients feel that they can trust their healthcare providers (Torres et al., 2019).

Training material and activities must include inclusive and appropriate language. Formats may include educational videos, webinars/e-modules, in-person training, mixed in-person/online training, and apps (often referred to as blended learning).

The ACCESS Care study (Bristowe et al., 2017) found five sound practice principles for all individual healthcare providers:

1. avoid using heterosexually framed or assumption-laden language
2. demonstrate sensitivity in the exploration of sexual orientation or gender history
3. respect individuals' preferences regarding disclosure of their sexual identity or gender history

4. carefully explore intimate relationships and significant others, including biological and chosen family (friends)
5. explicitly include partners and/or significant others in discussions.

### Provider attitudes

Provider attitudes can fundamentally affect the provision of inclusive and culturally safe palliative and end-of-life care and should be addressed in training. Key findings from the literature included:

- o training addresses provider discomfort and lack of experience with LGBTIQ+ patients directly and provides structured support (Cloyes et al., 2018). Providers may then increase their relational skills and open, friendly attitudes towards diverse people who are LGBTIQ+
- o providers can learn about the possibility of discrimination (noting that the absence of discrimination is not equality) and how to identify abuse and practise empathy with LGBTIQ+ patients (Stein et al., 2020)
- o providers can create welcoming, accepting and culturally sensitive attitudes and environments, safe care and sensitivity to unique multidimensional issues that improve care for LGBTIQ+ patients (Barrett & Wholihan, 2016). To do so includes recognising the diversity of the life journeys, history, experience, life-course perspectives and end-of-life experiences of diverse LGBTIQ+ groups and people

- o training can teach 'cultural humility' as part of LGBTIQ+ cultural competence, including the history and context of people who are LGBTIQ+ (Sprick & Gentile, 2019). This understanding helps recognise needs, names, gender identities, bodily diversity and chosen families, and the importance of emphasising the strengths and resilience of people who are LGBTIQ+ (Cloyes et al., 2018).

### Safe, appropriate patient communications

The literature frequently emphasised the importance of safe, appropriate communication. Best practice examples in this area include:

- o healthcare professionals can use open communication; for example, patient assessments should include appropriate questions about sexuality, gender and bodily diversity in plain language (Farmer & Yancu, 2015)
- o healthcare practitioners must respect and ensure patients' privacy, confidentiality and safety while facilitating disclosure. They can ensure access to appropriate treatments and support from diagnosis of a life-limiting illness to death and bereavement for people who are LGBTIQ+ and their loved ones (Hunt & Bristowe, 2019)

- o healthcare professionals can respect patients' right to disclose or not disclose. They should create opportunities for patients to self-disclose. It is not sufficient to wait for people to disclose their sexuality— people who are LGBTIQ+ should be made to feel welcome by challenging anti-LGBTIQ+ bias and adopting an LGBTIQ+ affirmative approach (Chidiac & Connolly, 2016)
- o healthcare providers can learn to be sensitive about how they request patients' information, including using inclusive and gender-neutral language (AGSEC, 2015)
- o healthcare professionals can ensure all paperwork, including information leaflets and intake/admission and consent forms, uses LGBTIQ+ inclusive language (Lowers, 2017).

## LGBTIQ+ inclusive health service policies and practices

An inclusive environment in all practices (hospitals, aged care facilities, hospices) is the first step to improving LGBTIQ+ patient care (Bristowe et al., 2017). An inclusive environment can be fostered through the clear statement of discrimination policies and procedures, the inclusion of LGBTIQ+ content in diversity and anti-discrimination training, increasing LGBTIQ+ visibility in materials (written and images), explicit markers of inclusion such as rainbow lanyards and pins, and partnering and engaging with LGBTIQ+ community groups.

The RTH in London is an example of an inclusive hospital:

Royal Trinity Hospice in London is a pioneering force within the sector in addressing LGBT inequality in end-of-life care and working to enable people to be themselves – as patients, carers and staff. The hospice established an LGBT Friends group to help shape service provision and has forged links with other local LGBT groups. Notably, Royal Trinity Hospice was the first hospice in the UK to be included in the 'Investors in Diversity Top 100 Index', and has introduced 'FREDIE' (fairness, respect, equality, diversity, inclusion, engagement) as part of the hospice's culture so that the workforce is more aware of legally protected characteristics in their patients and colleagues and more aware of their own unconscious biases. Within five months of its launch in February 2019, a staff survey found that 26% thought FREDIE had already made a difference. (Hospice UK, 2021)

### Inclusive clinical and non-clinical policies

The literature provided the following examples:

- appropriate equality and diversity policies explicitly include LGBTIQ+ reporting mechanisms and non-discrimination policies (Henderson & Almack, 2016). Organisations can create, implement and evaluate policies that require equal treatment of LGBTIQ+ patients, staff and visitors of all ages. These policies should be publicly available to all staff, patients, and families
- inclusive employment policies support the recruitment of LGBTIQ+ staff in palliative care spaces. Employment strategies recognise that preventing discrimination is key to staff retention. In one survey of palliative care providers (mainly physicians), almost half who identified as a sexual minority reported differences in how their institutions had treated them. Institutions that discriminate against LGBTIQ+ staff do the same to LGBTIQ+ patients (Stein et al., 2020)
- policies to include recognise the name and gender of transgender people, regardless of their legal status (AGSEC, 2015)

- specific guidelines and standards of care be instituted for transgender and non-binary patients in palliative and hospice settings. Guidelines and standards can include a 'trans-affirmative fluid approach' focused on the present moment and accompanying transgender people living with dementia in their daily or weekly moods, preferences and needs (Baril et al., 2020).

### LGBTIQ+ inclusive healthcare intake forms and documentation

Inclusive healthcare forms and documentation can help create a welcoming, inclusive and culturally sensitive environment. LGBTIQ+ inclusive healthcare intake forms, questionnaires, documentation and medical files help to ensure that LGBTIQ+ patients' sexuality, gender and bodily diversity are respected throughout end-of-life care.

The following approaches can help to create inclusive healthcare forms and documentation:

- intake forms acknowledge multiple family types and relationships and appropriate questions about sexuality, gender and bodily diversity (Farmer & Yancu, 2015)
- forms allow for more than two sexes and genders, multiple partners, and use the terms spouse/s and partner/s rather than husband and wife. These amendments to forms will signal acceptance of people who are LGBTIQ+ as well as unions other than marriage (Selix et al., 2020)

- educational brochures on LGBTIQ+ health topics be made available with other patient information materials (Daley et al., 2020).
- healthcare providers ask about sexual and gender minority status, gauging a patient's willingness to talk about it, asking early and often (Cathcart-Rake et al., 2020). Appropriate questions include considering medical necessity, avoiding the conundrum of desire to know versus gaining the necessary information to direct or guide healthcare. Appropriate questioning involves not asking overly intrusive questions (Cottrell, 2020)
- healthcare planning documents are written to ensure the individual's gender identity and expression is respected and maintained (Johnson et al., 2018)
- patient resource lists, flyers and information list specific LGBTIQ+ supports and inclusive mainstream resources and providers in the practice area (Cottrell, 2020)
- electronic health records allow listing legal names and chosen names, and more than one gender (if appropriate). Workarounds should be created if this is not possible (Selix et al., 2020).

## Case study

This case study is of Ivy, aged 67, trans lesbian:

'One trans woman facing a terminal diagnosis recalled how medical records with inconsistent names were dealt with sensitively by staff: 'I was in hospital, and somebody came along and drew the curtains and I thought "oh shit what's going on". She was the ward secretary or something and she said "I'm having problems matching up your file because you say you've had (name of condition) but we've got no record. The nearest we've got is a person of this name". So, I was able to say "Yes, that used to be me". So, she said "OK, that's fine I can combine them now". And I thought that's really enlightened, she hadn't even used the name but treated me for who I am now. A little bit of thought works wonders' (Almack, 2018 p.8).

## LGBTIQ+ inclusive data collection and research

More robust data and research is needed to support LGBTIQ+ palliative care initiatives. Data collection is not simply about box-ticking—it is a way to discover what and who matters to people who are LGBTIQ+ to receive high quality, person-centred end-of-life care (Cloyes et al., 2018). Clinicians learn about their patient's history, care goals, needs, and key relationships

through data. It is important to create a safe space for patients to share this information because of the historical, loaded nature of the questions and decisions related to LGBTIQ+ palliative and end-of-life care (Cloyes et al., 2018).

Inclusive data collection and research include:

- o assessing the effects of discrimination on health in LGBTIQ+ older adults receiving end-of-life care (AGSEC, 2015)
- o co-designing with people who are LGBTIQ+ (Daley et al., 2020) and community advocacy and support groups to solicit buy-in and gain knowledge of factors that affect the feasibility and priorities of LGBTIQ+ palliative care research
- o tailoring effectiveness studies to specific LGBTIQ+ patients (e.g., use of online support) (de Vries et al., 2019)
- o using patient surveys and evaluation forms to elicit feedback (Farmer & Yancu, 2015)
- o examining aged care, hospital, hospice and community palliative care providers' attitudes towards, experience and knowledge of LGBTIQ+ patients and caregivers, to inform communication and education strategies to improve provider attitudes and care outcomes (Cloyes et al., 2018)

- o contributing to larger data sets and research into national demographic characteristics by using the Australian Bureau of Statistics 2020 Standard on sex, gender, sex characteristics and sexual orientation (i.e., in Australia) (Johnson et al., 2018)
- o contributing to national conversations about LGBTIQ+ end-of-life care needs and care implementation strategies (MCCC, 2017)
- o the Australian Census, a five-yearly survey completed by all Australian households, does not ask questions to determine LGBTIQ+ status. Unsystematic data collection and community surveys render LGBTIQ+ people invisible in data informing end-of-life care design, delivery, and funding (Kaiser Health News, 2019). Other countries have stripped LGBTIQ+ data collection at a national level to marginalise LGBTIQ+ people and make them invisible from a public health policy perspective (e.g., America's Trump administration removed LGBTIQ+ focused questions from government funding scoping surveys) (Kaiser Health News, 2019).

## LGBTIQ+ inclusive counselling

Palliative and end-of-life care include providing psychosocial supports for patients and their significant others. Inclusive and culturally safe counselling can be beneficial for people who are LGBTIQ+. Examples found in the literature include:

- o inclusive counselling for LGBTIQ+ people with a provider who is LGBTIQ+ or LGBTIQ+ friendly can help prepare for a respectful death. Healthcare professionals should recognise that a bereaved same-sex partner may not receive the same support and recognition as a heterosexual partner (AGSEC, 2015)
- o Wheat and Thacker (2019) noted that counsellors hold power in the therapeutic relationship. As with counselling generally, a solid, trusting therapeutic relationship is vital for patient progress. The therapist must recognise their privileges and disadvantages, acknowledge their degree of familiarity with contemporary LGBTIQ+ matters and consult resources to refine their cultural sensitivity (Patlamazoglou et al., 2017)
- o mental health professionals can support their clients by showing 'cultural humility' regarding LGBTIQ+ culture, emphasising the unique individual, engaging in self-reflection, and employing active listening (Sprik & Gentile, 2019)

- o counsellors may benefit from applying a social work approach to recognise historical disadvantage's influences on LGBTIQ+ patients' presumptions, experiences, and healthcare and social care services. Social work principles can also be applied to LGBTIQ+ elders' end-of-life issues, including cultural, assessment and engagement principles. People who are LGBTIQ+ may benefit from more emphasis on the psychosocial aspects of death and dying more generally and more investment in social workers (Kaiser Health News, 2019)
- o culturally competent counsellors understand the unique end-of-life issues for LGBTIQ+ people and foster coping strategies, health-promoting behaviours, shifting perspectives about health and body, exploring spirituality for comfort (if appropriate for the individual) and end-of-life acceptance (Seelman et al., 2017)
- o patients may benefit from being offered referrals and information about specialist services—often available from local LGBTIQ+ switchboards—to promote continuity of care and reduce barriers (Valenti et al., 2020). Where in-person services are not available (e.g., in rural and regional areas), counsellors may provide support and maintain contact by phone and email (Arthur, 2015)

### **LGBTIQ+ inclusive bereavement support**

A narrative of struggle linked to visibility can be discerned from the stories shared... Over the years, many overcame barriers to affirm their sexual identity and introduce their partner to larger circles. For many, this movement of affirmation culminated in seeing their partners' death as an opportunity to formally name and honour them. This was a particularly proud moment because they found the strength to put aside their fear of rejection to pay tribute. It seems as if the time of their partner's death represented a peak in some of our participants' visibility, as if, at this moment in time, the relationship was still strong enough to support them through the challenge of honouring it. (Millette & Bourgeois-Guerin, 2020 p.71)

Bereavement support from practitioners who understand LGBTIQ+ experiences can be incredibly valuable for those processing the loss of a loved one. The following summarises key statements about bereavement support:

- o culturally competent and/or LGBTIQ specific bereavement programs can help a patient's chosen support network, including partners, carers and chosen family (Stevens & Abraham, 2019)
- o partners of people who are LGBTIQ+ require support during and after bereavement. Informal carers are likely to experience increased pressures

since their partners potentially access end-of-life care late or not at all. Healthcare providers and bereavement programs must recognise the increased risk for disenfranchised and survivor guilt for people who are LGBTIQ+. Bristowe et al. (2016) noted that the bereaved of LGBTIQ+ people might experience prolonged, heightened grief

- o Patlamazoglou et al. (2018) noted that some same-sex bereaved partners might not think their relationships, losses, or roles as grievors have been disenfranchised. Instead, they might have experienced valuable acceptance and support within social, familial and professional contexts or varying levels of support
- o it is important to recognise the impact of caregiving and bereavement on the chosen family's privacy (Stevens & Abraham, 2019). The bereavement experience of people who are LGBTIQ+ can be shaped by whether the relationship was disclosed and acknowledged into bereavement, including the impact upon needs and access to care (e.g., needing to disclose to access LGBTIQ+ inclusive care) (Stevens & Abraham, 2019)
- o although their experiences are under-researched, bereaved closeted people may not identify as part of the LGBTIQ+ community or may be closeted to some family members or social services, leading to less social support (Patlamazoglou et al., 2018).

### **Religious/spiritual and non-religious/non-spiritual supports around death and dying**

Religious/spiritual and non-religious/non-spiritual supports are important considerations in providing end-of-life care:

- o some LGBTIQ+ people need and value spiritual and/or religious support at the end-of-life. Others do not have religious or spiritual needs. LGBTIQ+ inclusive care respects the person's wishes when they access palliative care (Stevens & Abraham, 2019)
- o palliative and end-of-life care services may not always ensure LGBT patients and their families have the same spiritual needs as other patients (Allen & Craven, 2020)
- o Wheat and Thacker (2019) note that 'religious and spiritual resources are not set up to understand and value the needs of LGBTIQ+ people' (p. 234)
- o it is important not to assume that someone is not spiritual or religious simply because they are LGBTIQ+ (Cloyes et al., 2018). For example, many LGBTIQ+ people are actively involved in organised religion and find that this provides community and support systems (Furlotte, 2018)

- some individuals benefit from inclusive spiritual care. For instance, end-of-life chaplains may help LGBTIQ+ people with religious or spiritual needs (re)affirm the link between their religion and LGBTIQ+ identity. Chaplains may help patients and their partners explore the connection between spirituality, intimacy and sexuality and/or loss of sex drive, including unmet needs (Fair, 2018)
- there are few resources in hospice and palliative care that examine the direct connection for LGBTIQ+ elders between their sexuality and their spiritual lives. Additional resources in this space may be beneficial (Fair, 2021)

### Case study

Campbell and Catlett (2019) presented a case study of the spiritual needs of a transgender-identified elder in hospice care in the US. A hospice volunteer used skilful means as an artist to help a transgender woman express her spirituality in the last six months of her life. They created a book, *Little Star*, containing the patient's poetry, narratives, sketches and drawings. The book was published posthumously as a gift connecting her to family and friends and to leave a legacy to help others. In this case, the hospice volunteer was an advocate for spiritual expression and connection and provided care for the human spirit.

### Cues in the environment that increase inclusivity

Organisations can signal inclusiveness through various cues and simple changes in their environment. For example:

- prominently displaying non-discrimination policies that explicitly include LGBTIQ+ protections (Farmer & Yancu, 2015)
- freely sharing information on LGBTIQ+ persons' rights, including the right to decide on visitors (Farmer & Yancu, 2015)
- listing clinic services with LGBTIQ+ organisations, age providers, social media and community centres (Selix et al., 2020)
- adding rainbow flags or 'safe space' stickers at the clinic desk and on the organisation's website (note, the workplace culture and environment must be supportive and inclusive beforehand) (Farmer & Yancu, 2015)
- including explicitly LGBTIQ+ friendly imagery, health-related materials, artworks and LGBTIQ+ magazines and newspapers in waiting rooms, exam rooms and communal areas (Lowers, 2017)
- providing gender-neutral bathrooms and signalling accessibility, including wheelchair accessible gender-neutral bathrooms (Farmer & Yancu, 2015)
- addressing health inequalities and helping overcome the fear that people who are LGBTIQ+ may have when considering whether to access palliative care services (Furlotte, 2018).

### Legal support, including ACP

Legal support relates to conversations about legal issues, rights, legal decision-making, ACP and other legal documentation such as a person's Will. The literature references legal support as:

- often, people who are LGBTIQ+ receive end-of-life care that is incongruent with their wishes (Marsack & Stephenson, 2017). ACP can help people who are LGBTIQ+ feel more at ease about death and dying and can promote their autonomy in end-of-life care
- ACP can put in place health, legal and financial protections for people who are LGBTIQ+, their families and loved ones. Although legal protections are increasing, ACP is important because diverse relationships, genders, sexualities, and identities are not yet widely recognised or understood (Edmonds, 2020)
- ACP support can include facilitating sensitive conversations related to end-of-life care by healthcare, legal, social support professionals and other providers (Henry et al., 2019). Care providers' inclusion and acknowledgement of the partners of people who are LGBTIQ+ in critical discussions are key. A common barrier to ACP conversations is that the issue had not arisen. However, literature on ACP highlights the importance of completing ACP documents and engaging in discussions about ACP and end-of-life care before they are needed (Hughes & Cartwright, 2015)

- care providers may support patients to think about the physical location of a memorial service, choosing a place that is easily accessible for their support networks, in a venue with clear non-discrimination policies, messaging signage and affirming practices (Bristowe et al., 2016)
- LGBTIQ+ patients may also think about whether to include a spiritual element of choice if this resonates with them (Catalan et al., 2020). For example, end-of-life support for a transgender person may include compassionate spiritual or non-spiritual care, including planning funerals/remembrances.

### Telehealth or online support for patient and carers/chosen family

Telehealth and online support for patients have become common practices, especially in the wake of COVID-19. The literature refers to modalities specific to palliative care for people who are LGBTIQ+ including:

- in-person, telehealth and online programs and support groups can help LGBTIQ+ partners, chosen family, friends and rainbow families process grief in a supported way. Such programs may be particularly effective in rural and regional areas, although this requires further research (Maingi et al., 2018)
- online and/or in-person support groups may be useful for people who are LGBTIQ+ who have experienced child loss (Allen & Craven, 2020). Such groups



allow bereaved parents to ‘debunk’ the negative reactions they may have received from LGBTIQ+ and non-LGBTIQ+ people after a traumatic child loss. For example, informal social support networks may help bereaved parents by providing authenticity and a chance to be ‘in tune’ with their needs. These networks may offer practical assistance in ways that respect the bereaved LGBTIQ+ parents’ choice to accept or reject it

- o online social support groups can help older LGBTIQ+ people with end-of-life preparation (Paterson, 2017). Such support groups and chat rooms may help patients and carers find community and overcome social isolation, reduce stress, ask for advice, navigate personal discussions before opening up to loved ones and access support when they may be afraid to come out in their geographical region due to lack of safety. For instance, one research participant in Paterson’s (2017) qualitative research used the US’s ‘Lots of Helping’ and the UK’s ‘Talking Points’ to support people with dementia who are LGBTIQ+ and their carers.

### **Advocate/consumer representatives**

**'In Manchester, St Ann’s Hospice have adopted a multi-faceted approach in reaching out to trans people. This model includes building links with trans communities and partnering with local advocacy groups to provide support and education, thus enabling a voice for the trans community in terms of what’s important to them with regards to palliative and end-of-life care.'** (Hospice UK, 2021 p.21)

Advocacy and consumer representation can play a part in the whole of organisation change processes to address systemic and structural issues. This representation may be part of alternative modes of care delivery (e.g., community living coordinated by peers) (Rosa et al., 2020). Including older LGBTIQ+ and their advocates in advocacy and consumer representation is essential to developing research agendas that underpin social justice and systemic change in healthcare (Westwood, 2020).

Patients’ awareness of their rights can be advanced by advocacy and consumer representation and raising their awareness of their right to an advocate of their choice when receiving palliative care services. Advocates can check that staff are providing inclusive and appropriate care, listening to, recording and upholding end-of-life wishes, and recognising the specific end-of-life needs of LGBTIQ+ people. For example, advocates can assist

with end-of-life planning that is culturally relevant and appropriate to meet the needs of an Aboriginal and Torres Strait Islander LGBTIQ+ person, brotherboy or sistergirl (Australian Government Department of Health, 2019).

### **Summary of inclusive practices**

Inclusive practices incorporate:

- o providing referrals to LGBTIQ+ specific services and supports and general services to avoid segregation (e.g., LGBTIQ+ competent bereavement counsellor, carer supports) (MCCC, 2017)
- o working in partnership with LGBTIQ+ organisations and other healthcare organisations to raise community awareness of LGBTIQ+ inclusive palliative care, including community-based palliative care (Australian Government Department of Health, 2019)
- o creating a safe working environment for all LGBTIQ+ staff and service users, including supporting the ability of LGBTIQ+ staff to provide safe and inclusive care to LGBTIQ+ patients (Henderson & Almack, 2016)
- o requiring all clinical and non-clinical staff to undertake LGBTIQ+ inclusive training on the needs and concerns of people who are LGBTIQ+ receiving end-of-life care (including in-home care services) (Daley et al., 2020)

- o undertaking inclusive consultation for service design and strategy, including considering co-design methods (Henderson & Almack, 2016)
- o providing institutional community outreach and services responsive to community needs (Henderson & Almack, 2016), including outreach for LGBTIQ+ ACP
- o assessing the health service’s capacity to deliver LGBTIQ+ affirmative healthcare (e.g., applying Rainbow Tick certification) (Rainbow Health Victoria, 2021)
- o ensuring that partners and chosen family are included and recognised in clinical and non-clinical guidelines and policies (Australian Government Department of Health, 2019)
- o respecting an individual’s degree of openness in sharing information about being LGBTIQ+ (Stinchcombe et al., 2017)
- o ensuring clinician questions and written clinical forms ask questions in a manner that does not assume heterosexuality when asking about sexual behaviour or relationship status (AGSEC, 2015)
- o creating a culture of respect for older people who are LGBTIQ+ in supportive living situations (e.g., assisted living facilities, nursing homes), including LGBTIQ+ inclusive training for all workers (including doctors, GPs, social workers, nursing assistants, administration staff) (Javier & Oswald, 2019).



## Conclusion

### Other facilitating factors and strategies

The following strategies were mentioned less often in research about enabling LGBTIQ+ inclusive palliative care:

- co-design approaches (e.g., working with LGBTIQ+ people to design inclusive palliative care services) (Henderson & Almack, 2016)
- volunteer support programs specifically for LGBTIQ+ communities (AHCA, 2019)
- carer support, as distinct from bereavement support (MCCC, 2017)
- diverse staff, including a designated LGBTIQ+ liaison (Farmer & Yancu, 2015)
- public health strategies to reduce stigma and improve access to palliative care for people who are LGBTIQ+ and their loved ones (Hunt et al., 2019).

**The reviewed literature highlighted a range of societal and systemic barriers that directly result in discrimination against LGBTIQ+ people. The barriers most often mentioned were discrimination, distrust of healthcare providers, ageing and ageism, legal issues, reduced access to ACP, social isolation and healthcare providers' non-recognition of families of choice.**

The adverse effect of these barriers is profound when considering the higher incidence of minority stress that individuals most likely experienced over their lifetime. Previous negative experiences with general health care settings also directly affect LGBTIQ+ individuals' trust when engaging with services.

The literature outlines key facilitating factors to address barriers to safe, inclusive care. The four most commonly mentioned facilitating factors and strategies were in order: (1) LGBTIQ+ inclusive training for palliative care staff, (2) end-of-life decision-making support, (3) inclusive healthcare provider policies and (4) legal advice for end-of-life documentation.

Training of healthcare professionals was considered a key solution to reducing barriers for LGBTIQ+ people. The literature indicated that training should be supported by inclusive organisational policies, practices, forms and documentation. Despite these recommendations, there is a dearth of evidence about the effectiveness of this approach. Further, there is limited evidence about the success of online training targeted at health care professionals.

This review highlighted the need to develop, implement and evaluate the identified strategies and facilitating factors for enhancing inclusive palliative and end-of-life care for LGBTIQ+ people. Consistent data collection by healthcare providers is missing; this could add to the evidence base of how to meet LGBTIQ+ palliative care needs. Accurate data is an important way of influencing and informing policy.

It is important to note that some populations have not had their experiences fully explored in the literature. Most notably, people who are intersex are often included within an LGBTIQ+ context without important distinctions. People who are LGBTIQ+ and belong to multiple minority/diverse groups may have additional needs not explored in the current research.

Palliative and end-of-life care services are uniquely positioned to provide people who are LGBTIQ+ with affirming, safe, inclusive care at a challenging and vulnerable time in life. After a lifetime of being subject to discrimination and prejudice, the importance and impact of this can not be understated.

The next step is an investment in these facilitating factors, robust evaluation of strategies and further research of under-researched populations.

## Glossary of key terms

**Advance care planning:** 'Advance care planning is the process of planning for your future health care. It relates to health care you would or would not like to receive if you were to become seriously ill or injured and are unable to communicate your preferences or make decisions. This often relates to the care you receive at the end of your life. Advance care planning gives you the opportunity to think about, discuss and record your preferences for the type of care you would receive and the outcomes you would consider acceptable. It helps to ensure your loved ones and doctors know what your health and personal preferences are and that these preferences are respected' (Advance Care Planning Australia, 2021, para. 1-2).

**Advance care directive:** 'An advance care directive is sometimes known as a living will. It's something you create for yourself and involves documenting your preferences for future care. It can include your values, life goals and preferred outcomes, and directions about care and treatments. You can also formally appoint a substitute decision-maker in an advance care directive. The process of creating an advance care directive and the names of the required documents varies between states and territories. Advance care directives are legally binding and the preferences for health care that you document must be followed' (Advance Care Planning Australia, 2021, para 9).

**Asexual/ace:** 'A sexual orientation that reflects little to no sexual attraction, either within or outside relationships. People who identify as asexual can still experience romantic attraction across the sexuality continuum. While asexual people do not experience sexual attraction, this does not necessarily imply a lack of libido or sex drive' (Australian Institute of Family Studies, 2019, Glossary section).

**Bereavement:** 'Bereavement is the state of loss when someone close to an individual has died' (Psychology Today Australia, n.d. para 1).

**Bisexual/bi+:** 'A bisexual person is romantically and/or sexually attracted to people of their own gender and other genders. The term 'bi+' is also sometimes used to describe the multiplicity of bisexualities. The term multi-gender attraction (MGA) may also be used for those who experience attraction to more than one gender over a lifetime, regardless of self-identity or labels' (Victorian Government, 2019, *LGBTIQ+ inclusive language guide*).

**Brother boy:** See Sister girl/Brother boy.

**Cisgender:** 'A cisgender person is someone whose gender aligns with the sex they were assigned at birth—someone who isn't trans or gender diverse' (Victorian Government, 2019, *LGBTIQ+ inclusive language guide*).

**Cisnormativity:** 'assumes that everyone is cisgendered and that all people will continue to identify with the gender they were assigned at birth. Cisnormativity erases the existence of transgender/trans and gender diverse people' (Australian Institute of Family Studies, 2019, Glossary section).

**Chosen family:** See family of choice.

**Discrimination:** 'Discrimination happens when a person, or a group of people, is treated less favourably than another person or group because of their background or certain personal characteristics. This is known as "direct discrimination". It is also discrimination when an unreasonable rule or policy applies to everyone but has the effect of disadvantaging some people because of a personal characteristic they share. This is known as "indirect discrimination"' (Australian Human Rights Commission, n.d.).

**End-of-life care:** 'likely to die in the next 12 months (involving periods of exacerbated illness that may be reversible); and likely to die in the short term (within days to weeks), where clinical deterioration is likely to be irreversible' (Australian Institute of Health and Welfare, 2016, para 1-3).

**Enduring guardian:** 'An enduring guardian is a term used to describe the person you legally appoint to make decisions about your health and lifestyle in the event you cannot make these decisions for yourself. (NSW Trustee & Guardian, 2020b, para 1).

**Enduring power of attorney:** 'An enduring power of attorney is a legal representative that a person can appoint in advance to manage their assets and financial matters on their behalf. This role can become part of the caring role if the person you care for is no longer able to make certain decisions for themselves due to impaired capacity.

It does not mean that a person will lose control over their financial affairs, but gives an attorney formal authority to manage a person's financial affairs according to their instructions' (Carers NSW, 2020, para 1).

**Family of choice (also chosen family):** 'The person or group of people that someone sees as significant in their life. It may include none, all or some members of their family of origin' (Acquaviva, 2017).

**Family of origin:** 'The family (by birth, adoption, or informal kinship care) in which a person was raised as a child' (Acquaviva, 2017).

**Gay:** 'A gay person is romantically and/or sexually attracted to people of the same-sex and/or gender as themselves. This term is often used to describe men who are attracted to other men, but some women and gender diverse people may describe themselves as gay' (Victorian Government, 2019, *LGBTIQ+ inclusive language guide*).

**Gender:** 'Gender, on the other hand, is a person's internal sense of being a boy/man, a girl/woman, both or neither. Gender is socially constructed and culturally specific' (Tuazon-McCheyne, 2021).

**Gender expression:** 'All people express a gender. Gender expression is a person's outward gender presentation usually comprising personal style, clothing, hairstyle, makeup, jewellery, vocal inflection, and body language. Gender expression is typically categorised as male or female or androgynous' (Tuazon-McCheyne, 2021).

**Gender identity:** 'A person's deep-seated, internal sense of being a boy/man, girl/woman, both or neither. The gender with which they identify themselves' (Tuazon-McCheyne, 2021).

**Gender non-conformity/conforming:**

‘A person whose gender identity and expression is perceived as being inconsistent with the social and cultural expectations expected for that gender. For example, boys or men who are not “masculine enough” or are feminine or girls or women who are not “feminine enough” or are masculine’ (Tuazon-McCheyne, 2021).

**Gender presentation:** See gender expression.

**Gender questioning:** ‘Not necessarily an identity but sometimes used in reference to a person who is unsure which gender, if any, they identify with’ (Victorian Government, 2019, *LGBTIQ+ inclusive language guide*).

**Grief:** ‘Grief can be experienced in response to a variety of loss-related events, such as the death of a loved one, separation or divorce, the loss of a sense of safety or predictability, physical incapacity through disability, or the loss of one’s home or community due to disaster’ (Australian Psychological Society, 2022, para 1).

**Heteronormative/heteronormativity:** ‘the view that heterosexual relationships are the only natural, normal and legitimate expressions of sexuality and relationships, and that other sexualities or gender identities are unnatural and a threat to society’ (Victorian Government, 2019, *LGBTIQ+ inclusive language guide*).

**Heterosexism:** ‘describes a social system that privileges heteronormative beliefs, values and practice. Heterosexism provides the social backdrop for homophobic and transphobic prejudices, violence and discrimination against people with non-heteronormative sexualities and gender identities and intersex varieties’ (Victorian Government, 2019, *LGBTIQ+ inclusive language guide*).

**Heterosexual:** ‘A heterosexual or “straight” person is someone who is attracted to people of the opposite gender to themselves’ (Victorian Government, 2019, *LGBTIQ+ inclusive language guide*).

**Homophobia and biphobia:** ‘refer to negative beliefs, prejudices and stereotypes that exist about people who are not heterosexual’ (Victorian Government, 2019, *LGBTIQ+ inclusive language guide*).

**Homosexual:** an individual who is sexually and/or romantically attracted to the opposite gender. (Australian Institute of Family Studies, 2019, Glossary section).

**Hospice (also inpatient palliative care):** ‘Inpatient palliative care units (hospices) will care for you when staying at home is no longer an option. Hospice units are designed to feel as ‘homely’ as possible. You are always free to bring in items from home to make your stay more comfortable.’ (Australian Government Department of Health, 2020)

**Intersex:** ‘Intersex people have innate sex characteristics that don’t fit medical and social norms for female or male bodies, and that create risks or experiences of stigma, discrimination and harm’ (Intersex Human Rights Australia, 2021).

**Lesbian:** ‘A lesbian woman is romantically and/or sexually attracted to other women’ (Victorian Government, 2019, *LGBTIQ+ inclusive language guide*).

**LGBTIQ+:** ‘stands for lesbian, gay, bisexual, trans and gender diverse, intersex, queer and questioning as an inclusive umbrella abbreviation to encompass a range of diverse sexualities, genders and sex characteristics. When writing about LGBTIQ people it is best to use the term “communities”, as these are many separate and distinct communities within this umbrella term’ (Victorian Government, 2019, *LGBTIQ+ inclusive language guide*).

**Misgendering:** ‘an occurrence where a person is described or addressed using language that does not match their gender identity (GLHV, 2016). This can include the incorrect use of pronouns (she/he/they), familial titles (father, sister, uncle) and, at times, other words that traditionally have gendered applications (pretty, handsome, etc.). It is best to ask a person, at a relevant moment, what words they like to use’ (Victorian Government, 2019, *LGBTIQ+ inclusive language guide*).

**Non-binary:** ‘A person who is non-binary is someone whose gender is not exclusively female or male; while a person who is agender has no gender’ (Victorian Government, 2019, *LGBTIQ+ inclusive language guide*).

**Palliative care:** ‘person and family-centred care 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 goal is to optimise the quality of life’ (Palliative Care Australia, 2021, para 1).

**Pansexual:** ‘A pansexual person is someone who is romantically and/or sexually attracted to people of all genders, binary or non-binary’ (Victorian Government, 2019, *LGBTIQ+ inclusive language guide*).

**Polyamory:** ‘The word *polyamory* is based on the Greek and Latin for “many loves” (literally, poly many + amor love). A polyamorous person is someone who has or is open to having more than one romantic relationship at a time’ (Veaux, 2020, para 1).

**Power of attorney:** ‘A power of attorney is a legal document that gives a person, or trustee organisation the legal authority to act for you to manage your *assets* and make financial and legal decisions on your behalf’ (NSW Trustee & Guardian, 2020a, para 1).

**Pronoun/s:** ‘Pronouns are one way people refer to each other and themselves. Most but not all men (including trans men) use the pronoun “he”. Likewise, most but not all women (including trans women) use the pronoun “she”. Some people use a gender-neutral pronoun such as “they” (e.g., “Pip drives their car to work. They don’t like walking because it takes them too long”)’ (Victorian Government, 2019, *LGBTIQ+ inclusive language guide*).

**Rainbow family:** Rainbow families are families where at least one parent identifies as lesbian, gay, bisexual, pansexual, transgender, gender diverse, intersex, non-binary, queer or asexual (LGBTIQ+). Rainbow families include same-sex families and gender-diverse families. (Raising Children Network, 2020)

**Sex:** ‘Sex refers to a person’s biological and anatomical characteristics that are commonly categorised based on one’s Chromosomes, genitalia, reproductive organs, hormones, and, secondly sex characteristics. These characteristics are commonly understood and labelled as either *male* or *female* at birth’ (Tuazon-McCheyne, 2021).

**Sexuality:** ‘Sexuality or sexual orientation is defined as the experience of sexual and romantic attraction and behaviour’ (Tuazon-McCheyne, 2021).

**Sexual orientation: Sistergirl/Brotherboy:** ‘Terms used for gender diverse people within some Aboriginal or Torres Strait Islander communities. Sistergirls and Brotherboys have distinct cultural identities and roles. Sistergirls are Indigenous people who were classified male at birth but live their lives as women, including taking on traditional cultural female practices (GLHV, 2016). Brotherboys are Indigenous people who were classified as female at birth but who have a male spirit’ (Victorian Government, 2019, *LGBTIQ+ inclusive language guide*).

**Stigma:** Stigma is a major cause of discrimination and exclusion: it affects people’s self-esteem, helps disrupt their family relationships and limits their ability to socialize and obtain housing and jobs. It hampers the prevention of mental health disorders, the promotion of mental well-being and the provision of effective treatment and care. It also contributes to the abuse of human rights. (World Health Organisation, 2022, para 1)

**Transgender:** ‘The terms transgender and gender diverse are used to describe people whose gender identity does not align with the social expectations of the sex they were assigned at birth’ (Tuazon-McCheyne, 2021).

**Transphobia:** ‘refers to negative beliefs, prejudices and stereotypes that exist about transgender/trans and gender diverse people’ (Victorian Government, 2019, *LGBTIQ+ inclusive language guide*).

**Queer:** ‘Queer is often used as an umbrella term for diverse genders or sexualities. Some people use queer to describe their own gender and/or sexuality if other terms do not fit. For some people, especially older LGBTIQ people, “queer” has negative connotations, because in the past it was used as a discriminatory term’ (Victorian Government, 2019, *LGBTIQ+ inclusive language guide*).

**Will:** ‘A legal document with instructions for who you want to inherit your estate, care for your children, and be the executor of your estate when you pass away’ (NSW Trustee & Guardian, 2021, para 1).

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