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Palliative and end-of-life care needs, experiences, and preferences of LGBTQ+ individuals with serious illness: A systematic mixed-methods review

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Abstract

Background: Lesbian, gay, bisexual, transgender, and queer/questioning (LGBTQ+) individuals experience discrimination throughout the care continuum, including during serious illness and at end of life. High-quality palliative care requires that health professionals deliver individualized services that reflect the needs, experiences, and preferences of LGBTQ+ persons.

Aim: To identify and appraise existing evidence related to the needs, experiences, and preferences for palliative and end of life care among LGBTQ+ individuals with serious illness.

Design: Data-based convergent synthesis design reported per the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines.

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Declaration of conflicting interests

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Supplemental material

Supplemental material for this article is available online.

Data sources: PubMed, Embase, Cochrane CENTRAL, PsycINFO, CINAHL, and Scopus from January 1, 2010 to November 6, 2020.

Results: Of 4875 results captured, 69 articles underwent full-text review and 13 were retained for analysis. Most studies were from North America with trans individuals represented in 10 of 13 studies. Needs ($n = 6$) included increased social support, institutional safety, economic and legal supports, and advocacy to mitigate health barriers. Experiences ($n = 12$) were driven by fear and worry associated with discrimination/stigma, providers' hetero-/cisnormative assumptions, homophobia and transphobia, social isolation, and an undignified death. Preferences ($n = 6$) pertained to inclusion of chosen families in decision-making, disclosure of LGBTQ+ identity based on safety of the clinical environment, and a desire to maintain autonomy.

Conclusions: The robustness of the science has improved regarding the needs, experiences, and preferences of trans individuals. Actionable, inclusive policies coupled with sustained and integrated cultural sensitivity training for health workers are mandatory. Interventional research is critical to enhance tailored palliative care for LGBTQ+ people and their chosen families.

Keywords

Sexual and gender minorities; bisexuality; palliative care; palliative medicine; hospices; terminal care; terminally ill; death; critical illness; catastrophic illness

Background and rationale

The inequities experienced by people with minoritized sexual and gender identities, such as lesbian, gay, bisexual, transgender (trans), and queer/questioning (LGBTQ+) individuals, span multiple domains.¹⁻⁴ Health research demonstrates that LGBTQ+ people have higher risks of several life-limiting and life-threatening conditions when compared to the general population,⁴⁻⁶ including but not limited to cardiovascular disease^{7,8} and cancers.^{9,10} Disproportionate adverse biological outcomes are empirically linked back to minority stress.¹¹

To ensure person-centered care and promote value concordant decision-making, palliative care teams should understand what and who is important to the individual receiving care.¹² Identification of persons' social support is important as it may come from outside biological families of origin (e.g. families of choice).^{5,13} Consideration of an individual's sexual and interpersonal wellbeing and respect for their gender identity are components of holistic care.¹⁴ However, heteronormative and cisnormative biases (both conscious and unconscious) may lead to this aspect of care being overlooked for LGBTQ+ people.⁵ Older LGBTQ+ individuals report a fear of being open about their sexual orientation,^{15,16} while trans people face additional concerns about receiving care appropriate to and respectful of their gender identity during life and after death.¹⁵ Trans individuals are also less likely than LGB people to engage in end of life planning such as willwriting or appointing a healthcare proxy.¹⁷

Among LGBTQ+ people, discriminatory experiences, as well as the fear of bias, can negatively impact access to services and the provision of adequate care.^{8,18-20} For example, during the COVID-19 pandemic, LGBTQ+ people reported significantly lower use of telehealth for mental healthcare, lower rates of primary healthcare provider

access, and overall lower well-being when compared to non-LGBTQ+ individuals.^{21–23} LGBTQ+ people may fear or experience heteronormativity, cisnormativity, oppression, and/or discrimination^{15,16} in residential care settings by staff. Home-based care may be feel unsafe if LGBTQ+ people are unsure of their health provider’s attitudes toward their identities.²⁴ These factors may lead to an avoidance of planning for such transitions and, in turn, exacerbate the challenges LGBTQ+ individuals may face in old age and/or at end of life. LGBTQ+ persons’ spouses or partners may face disenfranchised grief as their loss may be ignored, minimized, or demeaned by others.,^{16,24}

A 2012 systematic review highlighted the needs, experiences, and preferences of LGBTQ+ people in the context of end of life and palliative care.¹⁹ A subsequent scoping review identified barriers to quality palliative care for LGBTQ+ people with cancer.²⁵ Given the urgent challenge of developing evidence-based responses to meet the needs of LGBTQ+ people with life-limiting and life-threatening illness, we performed an update to the 2012 review (Harding, Epiphaniou and Chidgey-Clark, 2012) to identify and appraise existing evidence for the needs, experiences, and preferences of LGBTQ+ individuals with serious illness. The implications of this review are critical to guide future research, policy, health education, and measurable improvements in clinical practice for LGBTQ+ people and their chosen families.

Methods

Objectives

We sought to systematically synthesize the quantitative and qualitative literature to update a previous systematic review on this topic¹⁹ and answer the following questions: (1) what are the palliative and end of life needs of LGBTQ+ individuals with serious illness, (2) what are the palliative and end of life experiences of LGBTQ+ individuals with serious illness, and (3) what are the palliative and end of life preferences of LGBTQ+ individuals with serious illness.

Review design

We conducted an integrated convergent synthesis review, specifically following a data-based convergent synthesis design.²⁶ This design allowed for concurrent analysis of both qualitative and quantitative evidence using the same synthesis method and allowed us to broadly describe individual studies while also grouping main findings in response to the research questions (e.g. needs, experiences, preferences).²⁶ Our protocol is registered in the International Prospective Register of Systematic Reviews (PROSPERO; CRD42020218305). All procedures adhered to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines.²⁷

Search strategy and data sources

Six databases were selected: PubMed (via National Library of Medicine’s [PubMed.gov](https://pubmed.ncbi.nlm.nih.gov/)), Embase (via Elsevier’s [Embase.com](https://www.embase.com/)), Cochrane Central Register of Controlled Trials/ Cochrane CENTRAL (via Wiley’s Cochrane Library), PsycINFO (via Ovid), Cumulative Index to Nursing and Allied Health Literature (via EBSCO), and Scopus (via Elsevier). The

search strategy was developed in PubMed by a research informationist (KG) in collaboration with the research team using Medical Subject Headings (MeSH) and keywords for two concepts: Sexual and Gender Minorities and Palliative Care. Concepts were combined with the Boolean AND operator, and restrictions were added for English language and publication dates in or after 2010, the year when the data from the last systematic review was captured. The Cochrane Handbook filter was used to exclude animal-only studies.²⁸ A second research informationist performed a Peer Review of Electronic Search Strategies (PRESS), and edits were implemented.²⁹ The search strategy was then translated to the other databases using available filters and controlled vocabulary. For a complete strategy, see the accompanying PubMed search displayed in Supplemental Material. The databases were searched on November 6, 2020. Results were entered in Covidence, a web-based software platform for systematic review development that includes the deduplication of uploaded records.³⁰

Selection strategy

Table 1 provides inclusion and exclusion criteria. Studies of any design were considered eligible for inclusion if they focused on the palliative care and/or end of life care needs, experiences, or preferences of LGBTQ+ individuals who were receiving palliative care and/or had a serious illness. This review is aligned with the following definition of serious illness: “Serious illness carries a high risk of mortality, negatively impacts quality of life and daily function, and/or is burdensome in symptoms, treatments or caregiver stress. This includes conditions not advanced or high dependency/low function that carry a degree of clinical uncertainty.”^{31,32} Needs, experiences, and preferences in the palliative context were based on the previous approach by Harding et al.¹⁹ in their 2012 systematic review on this topic and operationalized by psychosocial, physical, or cultural needs; interpersonal, institutional, or health or social care experiences; and preferences for care delivery, individual and chosen family communication, care plan logistics, and sexual orientation and gender identity disclosure.

Studies that included caregiver or bereavement experiences were only included if they also included the perspective of LGBTQ+ individuals receiving palliative care or with a chronic illness. Those that evaluated needs, experiences, and preferences of LGBTQ+ individuals retrospectively from the perspective of family or caregivers were excluded, as were studies that did not disaggregate LGBTQ+ from heterosexual or cisgender participants. Additionally, those that focused on hypothetical fears about end of life or advance care planning were excluded if they did not include participants who had a serious illness. Studies not available in English, case studies, editorials, conference abstracts, reviews, chapters, and active clinical trial abstracts were excluded.

Screening process

After duplicates were removed, titles and abstracts were reviewed by two independent reviewers for initial eligibility. When necessary, discrepancies were discussed with the first (WER) and second (KER) author. Each article selected for full-text review was reviewed for inclusion criteria by two independent reviewers. Excluded studies were also assigned a

reason for exclusion. Discrepancies in inclusion and reasons for exclusion were discussed with the first (WER) and second (KER) author.

Data extraction

Following full-text review, we extracted pre-specified information from the final set of studies that remained for inclusion in the systematic review using a spreadsheet template developed for previous systematic reviews^{33–35} (see Table 2 for study information categories extracted).

Data synthesis and analysis

Extracted information was then synthesized by the first (WER) and second (KER) authors to produce descriptive information characterizing the studies (e.g. method, participant demographics), as well as themes: needs, experiences, and preferences. These themes were selected so findings were in line with those from Harding et al.¹⁹ Each study was discussed by the first (WER) and second (KER) author and findings were categorized by these three themes based on consensus.

Quality appraisal

To assess methodological quality of studies that met eligibility criteria, we used a modified version of the Downs and Black study quality checklist³⁶ given our inclusion of both qualitative and quantitative papers, as well as intervention trials and exploratory studies. The checklist evaluated five fields with a “yes/no” response: (1) study aim/hypothesis/objective clearly stated; (2) main outcomes to be measured clearly described in introduction or methods section; (3) patient characteristics clearly described; (4) main findings clearly described; (5) sampling strategy/recruitment plan clearly described. Qualitative studies were also evaluated for their use of reflexivity around social location and personal experiences and beliefs, a common approach to identifying and reducing bias in qualitative analysis and interpretation.³⁷

Results

Search yield

The search strategy yielded 4875 records. After 2103 duplicates were removed, a total of 2772 records were uploaded for screening. Of these, 69 articles underwent full-text review and 13 studies met the inclusion criteria and were retained for analysis. A PRISMA Flow Diagram (Figure 1) shows the number at each stage: Identification, Screening, Eligibility, and Included.²⁷ All 13 studies reviewed (100%) satisfied all five study quality indicators; one article (8%) had previously published their recruitment and sampling approach in a separate manuscript.³⁸ Five of the seven qualitative studies explicitly included a reflexivity statement and efforts to reduce research bias.^{39–43}

Origin of data and study designs

Reported data were collected from Canada ($n = 5$),^{38,41–44} United States ($n = 5$),^{45–49} UK ($n = 2$),^{39,50} and Zimbabwe ($n = 1$).⁴⁰ There was a total of two quantitative studies,^{44,45} seven

qualitative studies,^{38–43,50} four mixed methods,^{46–49} with three being secondary analyses of a larger mixed methods survey.^{47–49} Of note, the mixed methods survey respondents were predominantly from the United States (81%), but included respondents from a total of 24 countries.

Study populations

Studies described LGBTQ+ identities within samples using different parameters. Two papers recruited men who have sex with men,^{39,45} seven recruited LGB, LGBT, or LGBTI samples,^{38,40–42,44,46,50} four papers focused on participants of all sexualities and gender identities.^{43,47–49} Few studies specified participant sex traits (e.g. intersex),^{40,50} included a broader range of gender identities (e.g. genderqueer, trans-blended),^{42,49} or captured sexual orientation identities beyond LGB and heterosexual (e.g. pansexual, asexual).⁴⁷

Several serious and/or chronic conditions were included in study samples. Two papers focused on men with HIV.^{39,45} Three studies included HIV among other cancer and non-cancer diagnoses, such as multiple sclerosis, renal failure, lung disease, neurological conditions, stroke, or mental health or substance use disorders.^{42,46,50} Five studies included participants with one or more nonspecified chronic health conditions or life-limiting illnesses^{38,40,41,43,44}, three papers included participants who had a chronic illness or disability (nonspecified).^{47–49} A summary of the studies can be found in Table 2.

Needs (N = 6 studies)

Palliative and end of life care needs were emphasized throughout many of the studies.^{38,41–43,46,50} Lack of consistent social support and economic stability,^{41,43,46,50} as well as supportive institutional environments^{38,42} created the context for many expressed needs. The need for varying types of safety and policy protections through advocacy was explicit.⁴¹

In Bristowe et al.'s study, LGBTQ+ participants reported that there may be additional and/or different considerations related to person-centered care needs when compared to heterosexual and cisgender populations, such as social support structures and additional legal concerns.⁵⁰ Data from several studies reflected a need for social support through solidarity within a given LGBTQ+ group and the need for a close support person and/or caregiver within a social network of chosen family and community connections.^{41,43,46} Social and institutional factors—such as seeking LGBTQ+ only versus mixed population nursing homes; lack of intergenerational contact; economic, housing, and food insecurity; and trans individuals expressing the need to be self-reliant due to a lack of community—all informed needs for additional social support.^{41,43}

Study participants communicated worry about dependence, informing a heightened need for self-sufficiency and increased coping skills, such as finding comfort in spirituality.^{42,46} A study by de Vries et al. also showed that even in the context of supportive community, participants often avoided discussions about end of life or felt shameful in sharing the full burden of their intimate physical needs with friends or family.⁴¹ The same participants acknowledged not knowing who to speak with about end of life issues, a “need for a

catalyst” to broach uncomfortable conversations, and the need to find the right language to fully address issues of concern.⁴¹

Some studies spoke to the need for an increased sense of safety in institutions and throughout service delivery.^{38,42} There was a need to see LGBTQ+friendly symbols (e.g. pride flags) within health systems that indicated safety,⁴² as well as a need for a moderating presence on virtual or internet support platforms to promote a sense of emotional safety.³⁸ In addition to physical safety markers, a study that explored the perspectives of sexual and gender minoritized adults about their fears and hopes for end of life highlighted the need for affirming care to prevent social isolation and feared discrimination and stigmatization at the end of life.⁴²

Pang et al. described unique considerations about trans participant needs.⁴³ Trans individuals who transitioned later in life expressed the need to make up for lost time that was exacerbated by older age and chronic illness.⁴³ This study also emphasized that mitigating everyday concerns of trans marginalization and discrimination (immediate needs) often prevented these participants from preparing for end of life and advance care planning (future needs).⁴³ Additional studies that focused on trans individuals’ needs echoed the unique considerations at the intersection of being trans, older, economically insecure, and unprepared for end of life decision-making, all underscoring the need for additional health worker cultural sensitivity and communication training.^{47–49}

Finally, one study’s findings specified the need for advocacy through political action, community education (e.g. of younger populations), and advocacy to address health service inequities, enhance safety for LGBTQ+ people during healthcare interactions, and mobilize social change.⁴¹

Experiences (N = 12 studies)

A diverse range of experiences of LGBTQ+ persons in the context of palliative and end of life care were described throughout the studies.^{38–45,47–50} Experiences regarding institutional and service barriers and stressors,^{41,43,50} as well as fears and worries about encountering discriminatory and/or harmful behaviors from health workers were explicit.^{40,42,47–49} Studies described differences in experiences across LGBTQ+ identities (e.g. LGB as opposed to trans) and for individuals with minoritized intersectional identities.^{48,49}

In a study of men who have sex with men positive for HIV,⁴⁵ there was a strong correlation between an early outpatient palliative care approach (e.g. not reserved for end-of-life) and increased quality of life, although these study findings were potentially confounded by the once-daily HIV treatment introduced during the same measurement period. In Catalan et al.’s qualitative study,³⁹ the impact of changes to HIV treatment was also noted. A sample consisting of 26% men who have sex with men talked about how perceptions and attitudes toward death had shifted over time with the introduction of HIV antiretroviral medications.³⁹ Gay men with HIV in the sample shared that frequent exposure to high numbers of poor-quality deaths was both traumatic and angering. Many had lost their peer groups due to HIV and some preferred to have their feelings related to death “locked away in a sense.”³⁹

Bristowe et al. described a number of experiences among LGBTQ+ persons, including service level or interactional barriers/stressors (e.g. heteronormative assumptions and homophobic/transphobic behaviors), invisible barriers/stressors (e.g. historical context of criminalization/pathology, fears, and experiences of discrimination), and prior experiences of discrimination or violence in response to sexual/gender identity disclosure that informed future social interactions. Fears of discrimination were notably exacerbated with medical frailty.⁵⁰

These findings reflect Pang et al.'s⁴³ and Kortess-Miller et al.'s⁴² studies that emphasized trans experiences of social isolation, disconnection from the broader LGB communities, and mixed experiences/perceptions of health systems (e.g. concern about institutionalized living/treatment, misgendering, and vulnerability in the context of diminished capacity).

de Vries et al. led a qualitative study with older LGBTQ+ adults regarding end of life preparations with four overarching themes that described their experiences.⁴¹ First, motivators and obstacles related to documentation issues and interpersonal factors were identified as informing end of life conversations. Second, there were several varied relationship concerns regarding families of choice and families of origin, experiences of social isolation, and viewing of trust and honesty as a challenge in relationships, particularly within the trans community. Third, experiences of a fractured LGBTQ+ community, historical influence of HIV/AIDS, and financial instability informed end of life preparations. Finally, several service and health barriers and institutional concerns directly impacted the experiences related to chronic illness in this sample.

Experiences, worries, and fears of discrimination and stigma were common. One lesbian participant in a study by Hunt et al. described not having symptoms adequately addressed and fears of an undignified death.⁴⁰ Of 384 trans or gender non-conforming participants in a paper by Walker et al. only 12.8% expressed "100% confidence" that they would be treated with dignity and respect by healthcare professionals as they aged; 13.3% endorsed "no confidence"; most reported having "a little confidence" (18.8%), "a moderate amount of confidence" (24.2%), or "a good amount of confidence" (22.9%); and 8.1% said they were unsure how much confidence they had in healthcare professionals.

There were varied experiences in preparing for end of life and advance care planning. Witten's analysis of trans adults with a chronic illness showed that the population was poorly prepared for many of the legal concerns related to end of life, with only 42.6% making preferences known through a will and 30.9% through a durable power of attorney.⁴⁸ Another study found that LGBTQ+ persons in a partnered relationship were more likely to have completed advance care planning documents and participated in advance care planning discussions, while those with children were less likely to have completed documents.⁴⁴ In this sample, most participants were single and lived alone, trans participants were more likely to have children, and about 50% of all participants reported having chosen family.

Witten's study on the intersection of aging, bisexual identity, and trans identity showed a statistically significant higher prevalence of trans bisexual respondents with both a chronic illness and a disability when compared to trans lesbian participants, "supporting

the argument that there are multiple complex subgroups within the global trans-identified population.”⁴⁹

Preferences (N = 6 studies)

LGBTQ+ individuals had a diverse set of preferences for disclosure and exploration of their sexual and gender identity based on their own personal and historical experiences,⁵⁰ and dependent on their circumstances and stigma.⁴¹ Some preferred the involvement of their family of origin even if challenging and despite a fear of ultimately being abandoned,⁴¹ while others made explicit a preference for partners to be acknowledged and included in critical health discussions.⁵⁰ de Vries and colleagues found that some older LGBTQ+ Canadian adults had a preference to not be seen or remembered as ill by friends.⁴¹

A study by Kortess-Miller et al. showed that LGBTQ+ older adults endorsed a desire to make decisions and maintain their quality of life, as well as a desire to be cared for in safe and inclusive environments.⁴²

Pang et al.’s findings highlighted preferences of trans older adults in particular and showed some were focused on dealing with the “day-to-day” challenges of caring for oneself while simultaneously coping with a chronic medical condition and/or economic instability. Those who were gender transitioning late in life expressed a preference to prioritize transitioning-related concerns over age-related and/or end of life issues.⁴³ Some trans participants expressed a preference for suicide over a loss of functional independence or autonomy and/or due to fear of mistreatment in health settings.^{48,49} In a survey of 1963 trans adults, the minority of those with a chronic illness had a will or a durable power of attorney (42.6% and 30.9% respectively).⁴⁸

Discussion

In this systematic review, we identified and appraised evidence that described the palliative care and end of life needs, experiences, and preferences of LGBTQ+ individuals with a serious illness. Notably, representation of trans individuals in the literature has increased substantially since Harding et al. published the first systematic review on this topic.¹⁹ In fact, the 2012 review reported that no papers met inclusion criteria specific to trans individuals. Most of the papers in this review described gender identity in addition to sexual orientation for study participants and the majority reported findings specific to trans persons.^{38,40–44,47–50} Several papers provided additional specificity in assessing LGBTQ+ identities and/or sex traits either through open-ended questions or survey options during data collection (e.g. two-spirit, gender non-conforming, asexual, etc.).^{40,42,47,49,50}

Overall, palliative and end of life needs of LGBTQ+ participants in the studies focused on social support, institutional safety, economic and legal supports throughout the care continuum, and advocacy in the community, in health and social care settings, and in policy to address health access barriers and make tangible steps toward more inclusive care.^{38,41–43,46,50} Many of the experiences captured in the literature were characterized by fear and worry largely associated with a pervasive culture of discrimination and stigma, the heteronormative and cisnormative assumptions of health workers, being on the receiving end

of homophobic and transphobic behaviors, social isolation which worsened in the context of aging, losing autonomy, or being trans, and concerns about confronting an undignified death.^{38–45,47–50} The preferences of LGBTQ+ individuals pertained to the inclusion of chosen families in decision-making and care planning, disclosure of their sexual orientation and/or gender if clinical environments were perceived as safe, and a strong desire to maintain functional independence and agency.^{41–43,48–50}

Many study participants reported either anticipated or actual bias, discrimination, or mistreatment from healthcare professionals.^{40–43,47–50} Fear and worry about discrimination reflects the pervasive structural and interpersonal stressors experienced by LGBTQ+ individuals described in the literature.^{4,7,11,17–20,25,51} Indeed, one recent survey of 865 hospice professionals found that 23.7% and 21.3% had witnessed inadequate or abusive care of LGB and trans individuals respectively.⁵² However, fear of mistreatment also reflect the lack of concrete and measurable efforts by the larger palliative care field to communicate and advocate a message of inclusive care. Many study participants in the studies reviewed expressed a lack of confidence that they would be treated with dignity and respect as they lost functional independence, agency, and autonomy.^{40,47,48}

Although not part of this current systematic review, the needs, experiences, and preferences of LGBTQ+ individuals' chosen family members also require further exploration and interventions to promote inclusive care. Specifically, policies are needed to mitigate marginalizing treatment, ensure consequences for health workers who demonstrate discriminatory behaviors, actively dismantle heteronormative and cisnormative assumptions about family relationships and dynamics, and respectfully and consistently engage chosen family in decision-making and end-of-life care planning.^{50,53} The bereavement of LGBTQ+ individuals' partners is affected by the acknowledgment of their relationship during life and the time surrounding death, potential legal and financial challenges, LGBTQ+ targeted bias, and stigma associated with the negative legacy of HIV and AIDS.⁵¹

This review illustrates improved recognition that the LGBTQ+ community is not a monolith as evidenced by increased visibility of trans and other underrepresented LGBTQ+ groups in the scientific discourse, which has been reflected in other literature syntheses.⁵⁴ Nevertheless, the unique social needs, experiences, and preferences among other gender non-conforming individuals (e.g. gender non-binary, gender fluid, gender queer) with serious illness remain under-researched compared to those of LGB people and need further exploration.⁴⁹ In fact, study findings suggested that trans individuals often feel isolated from the broader LGB community.^{41,43} The needs, experiences, and preferences of these groups will additionally vary significantly based on intersectional identities (e.g. racialized and LGBTQ+ identities),^{55,56} personal, generational, and historical experiences,⁵⁰ and social and political determinants of health,^{57,58} as well as the ability of health professionals to provide person-centered care for LGBTQ+ individuals through enhanced knowledge and empathic communication.^{50,59}

Implications

The needs for change in the field are two-fold: (1) institutional policies should be in place to substantively address overt instances of discrimination and abuse and (2) inclusive care

practices promoting dignity of all LGBTQ+ care recipients and chosen families must be more widely implemented. Effective anti-discrimination policies and inclusive environments and practice can create a safe space for LGBTQ+ people to disclose sexual orientation and gender identities, leading to holistic, person-centered care for individuals and groups across the sexual orientation and gender identity spectrum.^{24,60,61}

Health systems and health professionals across disciplines need to assume accountability for creating cultures that promote person-centered and holistic palliative care. Safety and support for the needs, experiences, and preferences of LGBTQ+ persons must be pervasive, consistent, and go beyond performativity. In other words, displaying symbols that denote environmental safety (e.g. a rainbow flag) without an accompanying culture shift of inclusivity is insufficient and potentially harmful. Such changes have the potential to alleviate fears and worries regarding discrimination, as well as engender trust between LGBTQ+ persons, health professionals, and health care systems during the inherently vulnerable experiences inherent to serious illness and end of life.

Addressing the social and political determinants of health through advocacy efforts can effect change at the policy level to protect the welfare and wellbeing of LGBTQ+ persons who may be socially isolated or economically insecure. For example, in 2016 the American Department of Health and Human Services announced Section 1557 of the Affordable Care Act, which offers a level of protection against discrimination on the basis of several characteristics including gender identity, intersex status, and sexual orientation.⁶² The 2019 US Equality Act strengthens this further, but LGBTQ+ people are still at risk of being denied access to several services, including health care facilities and nursing homes in over half of US states.^{63,64} In the UK, the Equality Act 2010⁶⁵ protects from discrimination on the basis of multiple characteristics including sexual orientation, gender reassignment, and gender identity. The related public sector Equality Duty (section 149) requires public authorities show due regard for advancing equality between people who share protected characteristics and those who do not, and the elimination of discrimination, harassment, and victimization based on the same characteristics. The 2011 report from the American Joint Commission Institute of Healthcare Improvement focused on advancing effective communication, cultural competence, and person-centered care for LGBTQ+ individuals and groups and encouraged accredited hospitals to develop related LGBTQ+-inclusive processes and policies.⁶⁶ LGBTQ+-specific guidance for end of life care was also developed by the independent regulators of health and social care in the UK.⁶⁷ However, there is much work to be done to promote widespread adoption and implementation of such policy changes, particularly given the evidence in our review that continues to show fears and worries related to discrimination.

There are several research implications. First, there is a critical need for large-scale studies that explore the palliative and end of life needs, experiences, and preferences of all LGBTQ+ groups, as well as their chosen families, from time of diagnosis with a serious illness to bereavement (i.e. the entire spectrum of palliative care). Most of the studies in this review were qualitative and exploratory in nature, providing rich data despite limited sample sizes. Although these exploratory investigations advance the field, there is also a need for more investment in research funding that will support multilevel interventional

studies to make changes in the system at large.⁶⁸ Additional needs will include an educated and diverse research team, including members of LGBTQ+ groups, a focus on participant safety and trust building, and both community-based participatory research and participatory action research approaches to engage LGBTQ+ stakeholders and promote change through improved LGBTQ+-informed designs.

Next, rigorous investigations that explore the needs, preferences, and experiences of diverse subsets of the LGBTQ+ community (e.g. LGB, trans and gender non-conforming, queer/questioning, asexual), while recognizing the inherent differences among LGBTQ+ groups, is essential. Research that explores the intersectional burden of stressors related to having multiple minoritized identities experienced by individuals who identify as both LGBTQ+ and/or a member of other marginalized group (e.g. race, culture, ethnicity, socioeconomic status) is key to ensuring representation in research and, ultimately, equitable care. This goal will also become increasingly possible as health systems continue to create and strengthen accurate and respectful sexual orientation and gender identity (SOGI) data collection mechanisms. Institutional and system-level factors that prevent the acquisition of SOGI data should also be studied and disseminated to increase scholarly awareness of barriers to high-quality palliative care practice and research. Some studies only included either sexual orientation (e.g. LGB) or gender (e.g. trans) minoritized identities,³⁸ as opposed to accounting for individuals who were members of both minoritized sexual and gender identities (e.g. trans bisexual persons).⁴⁹ It will be necessary for researchers to intentionally sample from populations with these “both/and” intersectional identities to more rigorously describe needs, experiences, and preferences. In addition, concerted efforts should be made to accurately document cisgender identity where appropriate as a component of sociodemographic data collection to ensure that cisnormative assumptions are not unintentionally perpetuated. In many of the studies included in this review, “cisgender” was assumed or not reported where participants were not trans.^{38,42}

Finally, there is a need for additional studies that evaluate the perspectives and experiences and knowledge of healthcare professionals from multiple disciplines and settings to quantify and describe barriers to LGBTQ+ inclusive palliative and end of life care. These findings would inform clinical education interventions to increase knowledge of LGBTQ+ palliative care needs, experiences, and preferences, and enhance cultural competence for LGBTQ+ groups. Given the higher risks of several serious illnesses among LGBTQ+ populations, and advances in law and health policy, it could be assumed that the healthcare workforce receive appropriate training to support equitable care for LGBTQ+ people. However, other recent studies demonstrate that culturally sensitive professional training and practice have been inadequate and integration into medical curricula inconsistent.^{69–71} Furthermore, it is unclear whether the current and often elective provision of such training is effective in improving practice.^{72,73} Regardless, many health and psychosocial care professionals lack the knowledge and confidence in providing LGBTQ+ inclusive care.^{74,75} The best available evidence regarding practice recommendations should continue to be synthesized and appraised to meet health professionals’ educational needs to best support the provision of holistic palliative and end of life services for care recipients and chosen families in various social contexts.^{52,59,76–78}

Strengths and limitations

Articles included in the final review were predominantly from Western countries with majority White populations who were highly educated. Although these articles met inclusion criteria, additional literature analyses should investigate and integrate findings from palliative care and LGBTQ+ literature in languages other than English, as well as non-empirical and grey literature that may address similar population experiences in other unrepresented countries and cultures. Diversifying future study designs and analyses will address potential sampling and reporting biases that limit generalizability and future intervention design.

Our analysis focused on the palliative and end of life care needs of people with serious illness and did not include studies exclusively focused on caregiver, partner, or family bereavement or dyadic experiences. Members of our team have systematically appraised LGBTQ+ partner bereavement experiences previously.⁵¹ Additional analyses should explore the bereavement experiences of chosen families more broadly while accounting for a common experience of disenfranchised grief among LGBTQ+ groups.^{25,79}

During our full text review phase, there were several studies excluded that addressed advance care planning and end of life preparations of LGBTQ+ individuals who were not diagnosed with serious illness (e.g. well individuals). The exclusion of these articles from the current review somewhat limits the generalizability of our current findings. However, Witten highlighted the need to separate these groups for the purpose of this appraisal, showing statistically significant differences between trans persons with a chronic illness and a will compared to trans persons without a chronic illness who had a will.⁴⁸ Nevertheless, there is growing literature on advance care planning, aging-related concerns, and end of life preparation among LGBTQ+ persons who are not currently diagnosed with a serious illness, which also requires systematic appraisal and further investigation.

Conclusion

Our systematic review provides the first comprehensive appraisal of the needs, experiences, and preferences for palliative and end of life care for LGBTQ+ persons with serious illnesses in a decade.¹⁹ Findings demonstrate an increased focus on trans persons and a greater understanding of the fears and worries of LGBTQ+ individuals and groups pertaining to discriminatory behaviors and systemic barriers to care. Intervention studies should focus on enhancing both clinical and community-based supports that will mitigate social isolation and economic precarity for LGBTQ+ people and populations. Needs, experiences, and preferences varied across care delivery settings (e.g. hospital, home services, long-term care) and require further investigation to ensure and enhance LGBTQ+ safety. Additional research is critical to understand the role of multiple minority stressors on LGBTQ+ people receiving palliative and end of life care and the education needs of multidisciplinary health workers to improve outcomes.

Demonstrable and measurable change is needed to ensure that every person—regardless of sexual or gender identity—receives humanizing care that enhances their quality of life while effectively and consistently alleviating serious health-related suffering in palliative

and end of life settings. There remains a dire need to generate substantive evidence and implement and evaluate clinical improvements that will ensure the dignified living and dying of LGBTQ+ persons at all stages of illness accompanied by the active inclusion of their chosen families.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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References

1. Mendos LR. State-sponsored homophobia 2019: global legislation overview update. Geneva: ILGA World, 2019.
2. Chiam Z, Duffy S, Gil MG, et al. Trans legal mapping report 2019: recognition before the law. Geneva: ILGA World, 2020.
3. Schuler MS, Prince DM and Collins RL. Disparities in social and economic determinants of health by sexual identity, gender, and age: results from the 2015–2018 National Survey on drug use and health. *LGBT Health* 2021; 8: 330–339. [PubMed: 34101498]
4. National Academies of Sciences, Engineering, and Medicine. Understanding the well-being of LGBTQI+ populations. Washington, DC: The National Academies Press, 2020.
5. Stinchcombe A, Smallbone J, Wilson K, et al. Healthcare and end-of-life needs of lesbian, gay, bisexual, and transgender (LGBT) older adults: a scoping review. *Geriatrics* 2017; 2: 13. [PubMed: 31011023]
6. Hudson-Sharp N and Metcalf H. Inequality among lesbian, gay, bisexual, and transgender groups in the UK: a review of evidence. London: National Institute of Economic and Social Research, 2016.
7. Caceres BA and Streed CG. Cardiovascular health concerns in sexual and gender minority populations. *Nat Rev Cardiol* 2021; 18: 227–228. [PubMed: 33510362]
8. Rosati F, Williams DP, Juster R-P, et al. The cardiovascular conundrum in ethnic and sexual minorities: a potential biomarker of constant coping with discrimination. *Front Neurosci* 2021; 15: 619171. [PubMed: 34093107]
9. Saunders CL, Meads C, Abel GA, et al. Associations between sexual orientation and overall and site-specific diagnosis of cancer: evidence from two national patient surveys in England. *J Clin Oncol* 2017; 35: 3654–3661. [PubMed: 28945501]
10. Quinn GP, Sanchez JA, Sutton SK, et al. Cancer and lesbian, gay, bisexual, transgender/transsexual, and queer/questioning (LGBTQ) populations. *CA Cancer J Clin* 2015; 65: 384–400. [PubMed: 26186412]
11. Flentje A, Heck NC, Brennan JM, et al. The relationship between minority stress and biological outcomes: a systematic review. *J Behav Med* 2020; 43: 673–694. [PubMed: 31863268]
12. Giusti A, Nkhoma K, Petrus R, et al. The empirical evidence underpinning the concept and practice of person-centred care for serious illness: a systematic review. *BMJ Glob Health* 2020; 5: e003330.
13. Sprik P and Gentile D. Cultural humility: a way to reduce LGBTQ health disparities at the end of life. *Am J Hosp Palliat Med* 2020; 37: 404–408.

14. Griebing TL. Sexuality and aging: a focus on lesbian, gay, bisexual, and transgender (LGBT) needs in palliative and end of life care. *Curr Opin Support Palliat Care* 2016; 10: 95–101. [PubMed: 26780525]
15. Valenti KG, Jen S, Parajuli J, et al. Experiences of palliative and end-of-life care among older LGBTQ women: a review of current literature. *J Palliat Med* 2020; 23: 1532–1539. [PubMed: 32835594]
16. Kneale D, Henley J, Thomas J, et al. Inequalities in older LGBT people’s health and care needs in the United Kingdom: a systematic scoping review. *Ageing Soc* 2021; 41: 493–515. [PubMed: 34531622]
17. Kcomt L and Gorey KM. End-of-life preparations among lesbian, gay, bisexual, and transgender people: integrative review of prevalent behaviors. *J Soc Work End Life Palliat Care* 2017; 13: 284–301. [PubMed: 29252156]
18. Lisy K, Peters MDJ, Schofield P, et al. Experiences and unmet needs of lesbian, gay, and bisexual people with cancer care: a systematic review and meta-synthesis. *Psychooncology* 2018; 27: 1480–1489. [PubMed: 29462496]
19. Harding R, Epiphaniou E and Chidgey-Clark J. Needs, experiences, and preferences of sexual minorities for end-of-life care and palliative care: a systematic review. *J Palliat Med* 2012; 15: 602–611. [PubMed: 22401314]
20. Meads C, Hunt R, Martin A, et al. A systematic review of sexual minority women’s experiences of health care in the UK. *Int J Environ Res Public Health* 2019; 16: 3032. [PubMed: 31438599]
21. Phillips C How covid-19 has exacerbated LGBTQ+ health inequalities. *BMJ* 2021; 372: m4828. [PubMed: 33727244]
22. Ruprecht MM, Wang X, Johnson AK, et al. Evidence of social and structural COVID-19 disparities by sexual orientation, gender identity, and Race/ethnicity in an urban environment. *J Urban Health* 2021; 98: 27–40. [PubMed: 33259027]
23. Buspavanich P, Lech S, Lerner E, et al. Well-being during COVID-19 pandemic: a comparison of individuals with minoritized sexual and gender identities and cis-heterosexual individuals. *PLoS One* 2021; 16: e0252356. [PubMed: 34101746]
24. Cloyes KG, Hull W and Davis A. Palliative and end-of-life care for lesbian, gay, bisexual, and transgender (LGBT) cancer patients and their caregivers. *Semin Oncol Nurs* 2018; 34: 60–71. [PubMed: 29306523]
25. Haviland K, Burrows Walters C and Newman S. Barriers to palliative care in sexual and gender minority patients with cancer: a scoping review of the literature. *Health Soc Care Community* 2021; 29: 305–318. [PubMed: 32767722]
26. Hong QN, Pluye P, Bujold M, et al. Convergent and sequential synthesis designs: implications for conducting and reporting systematic reviews of qualitative and quantitative evidence. *Syst Rev* 2017; 6: 61. [PubMed: 28335799]
27. Page MJ, McKenzie JE, Bossuyt PM, et al. Updating guidance for reporting systematic reviews: development of the PRISMA 2020 statement. *J Clin Epidemiol* 2021; 134: 103–112. [PubMed: 33577987]
28. Higgins JP, Eldridge S and Li T. Including variants on randomized trials. In: Higgins JPT, Thomas J, Chandler J, et al. Oxford, United Kingdom. (eds) *Cochrane Handbook for Systematic Reviews of interventions* 2nd edition. Cochrane, 2019; 569–594.
29. McGowan J, Sampson M, Salzwedel DM, et al. CADTH methods and guidelines: PRESS peer review of electronic search strategies: 2015 guideline explanation and elaboration. Ottawa, ON: CADTH, 2016.
30. Veritas Health Innovation. Covidence systematic review software. Melbourne: Veritas Health Innovation 2022.
31. Kelley AS. Defining “serious illness”. *J Palliat Med* 2014; 17: 985. [PubMed: 25115302]
32. Kelley AS, Covinsky KE, Gorges RJ, et al. Identifying older adults with serious illness: a critical step toward improving the value of health care. *Health Serv Res* 2017; 52: 113–131. [PubMed: 26990009]

33. Atkinson TM, Andreotti CF, Roberts KE, et al. The level of association between functional performance status measures and patient-reported outcomes in cancer patients: a systematic review. *Support Care Cancer* 2015; 23: 3645–3652. [PubMed: 26314706]
34. Roberts KE, Walsh LE, Saracino RM, et al. A systematic review of treatment options for grieving older adults. *Curr Treat Options Psychiatry* 2019; 6: 422–449. [PubMed: 32754423]
35. Singer J, Roberts KE, McLean E, et al. An examination and proposed definitions of family members' grief prior to the death of individuals with a life-limiting illness: a systematic review. *Palliat Med* 2022; 36: 581–608. [PubMed: 35196915]
36. Downs SH and Black N. The feasibility of creating a checklist for the assessment of the methodological quality both of randomised and non-randomised studies of health care interventions. *J Epidemiol Community Health* 1998; 52: 377–384. [PubMed: 9764259]
37. Berger R Now I see it, now I don't: researcher's position and reflexivity in qualitative research. *Qual Res* 2015; 15: 219–234.
38. Beringer R, Gutman G and de Vries B. Developing a web-based platform to foster end-of-life planning among LGBT older adults. *Gerontechnology* 2017; 16: 48–55.
39. Catalan J, Ridge D, Cheshire A, et al. The changing narratives of Death, dying, and HIV in the United Kingdom. *Qual Health Res* 2020; 30: 1561–1571. [PubMed: 32507074]
40. Hunt J, Bristowe K, Chidyamatara S, et al. 'So isolation comes in, discrimination and you find many people dying quietly without any family support': accessing palliative care for key populations - an in-depth qualitative study. *Palliat Med* 2019; 33: 685–692. [PubMed: 30859906]
41. de Vries B, Gutman G, Humble, et al. End-of-life preparations among LGBT older Canadian adults: the missing conversations. *Int J Aging Hum Dev* 2019; 88: 358–379. [PubMed: 30871331]
42. Kortess-Miller K, Boulé J, Wilson K, et al. Dying in long-term care: perspectives from sexual and gender minority older adults about their fears and hopes for end of life. *J Soc Work End Life Palliat Care* 2018; 14: 209–224. [PubMed: 30457453]
43. Pang C, Gutman G and de Vries B. Later life care planning and concerns of transgender older adults in Canada. *Int J Aging Hum Dev* 2019; 89: 39–56. [PubMed: 30997824]
44. de Vries B, Gutman G, Soheilipour S, et al. Advance care planning among older LGBT Canadians: heteronormative influences. *Sexualities* 2022; 25: 79–98.
45. Alexander CS, Raveis VH, Karus D, et al. Early use of the palliative approach to improve patient outcomes in HIV disease: insights and findings from the care and support access (CASA) Study 2013–2019. *Am J Hosp Palliat Care* 2021; 38: 332–339. [PubMed: 32851870]
46. Seelman KL, Lewinson T, Engleman L, et al. Coping strategies used by LGB older adults in facing and anticipating health challenges: a narrative analysis. *J Gay Lesbian Soc Serv* 2017; 29: 300–318. [PubMed: 30568396]
47. Walker RV, Powers SM and Witten TM. Impact of anticipated bias from healthcare professionals on perceived successful aging among transgender and gender nonconforming older adults. *LGBT Health* 2017; 4: 427–433. [PubMed: 29111876]
48. Witten TM. End of life, chronic illness, and trans-identities. *J Soc Work End Life Palliat Care* 2014; 10: 34–58. [PubMed: 24628141]
49. Witten TM. Aging and transgender bisexuals: exploring the intersection of age, bisexual sexual identity, and transgender identity. *J Bisex* 2016; 16: 58–80.
50. Bristowe K, Hodson M, Wee B, et al. Recommendations to reduce inequalities for LGBT people facing advanced illness: ACCESSCare national qualitative interview study. *Palliat Med* 2018; 32: 23–35. [PubMed: 28502218]
51. Bristowe K, Marshall S and Harding R. The bereavement experiences of lesbian, gay, bisexual and/or trans* people who have lost a partner: A systematic review, thematic synthesis and modelling of the literature. *Palliat Med* 2016; 30: 730–744. [PubMed: 26944532]
52. Stein GL, Berkman C, O'Mahony S, et al. Experiences of lesbian, Gay, bisexual, and transgender patients and families in hospice and palliative care: perspectives of the Palliative Care Team. *J Palliat Med* 2020; 23: 817–824. [PubMed: 31916901]
53. Rosa WE, Banerjee SC and Maingi S. Family caregiver inclusion is not a level playing field: toward equity for the chosen families of sexual and gender minority patients. *Palliat Care Soc Pract* 2022; 16: 26323524221092459.

54. Lintott L, Beringer R, Do A, et al. A rapid review of end-of-life needs in the LGBTQ+ community and recommendations for clinicians. *Palliat Med* 2022; 36: 609–624. [PubMed: 35176932]
55. Damaskos P, Amaya B, Gordon R, et al. Intersectionality and the LGBT cancer patient. *Semin Oncol Nurs* 2018; 34: 30–36. [PubMed: 29325815]
56. Westwood S, Willis P, Fish J, et al. Older LGBT+ health inequalities in the UK: setting a research agenda. *J Epidemiol Community Health* 2020; 74: 408–411. [PubMed: 32086374]
57. Matthews AK, Breen E and Kittiteerasack P. Social determinants of LGBT cancer health inequities. *Semin Oncol Nurs* 2018; 34: 12–20. [PubMed: 29373163]
58. McDermott E, Nelson R and Weeks H. The politics of LGBT+ health inequality: conclusions from a UK scoping review. *Int J Environ Res Public Health* 2021; 18: 826. [PubMed: 33478019]
59. Banerjee SC, Walters CB, Staley JM, et al. Knowledge, beliefs, and communication behavior of Oncology Healthcare Providers (HCPs) regarding lesbian, Gay, bisexual, and transgender (LGBT) patient health care. *J Health Commun* 2018; 23: 329–339. [PubMed: 29521575]
60. Lecompte M, Ducharme J, Beauchamp J, et al. Inclusive practices toward LGBT older adults in healthcare and social services: A Scoping Review of quantitative and qualitative evidence. *Clin Gerontol* 2021; 44: 210–221. [PubMed: 33357121]
61. Brooks H, Llewellyn CD, Nadarzynski T, et al. Sexual orientation disclosure in health care: a systematic review. *Br J Gen Pract* 2018; 68: e187–e96. [PubMed: 29378698]
62. Baker KLGBT protections in affordable care act section 1557. *Health Affairs Blog*. 2016.
63. Gonzales G and Gavulic KA. The Equality Act is needed to advance health equity for lesbian, gay, bisexual, and transgender populations. *Am J Public Health* 2020; 110: 801–802. [PubMed: 32374685]
64. MAP. Why we all need the equality act now. Boulder, CO: Movement Advancement Project, 2021.
65. Act Equality 2010 Ch. 15. UK2010. The National Archives on behalf of HM Government.
66. Commission JAdvancing effective communication, cultural competence, and patient- and family centered care for the lesbian, Gay, bisexual, and transgender (LGBT) community: a field guide. Oak Brook, IL: The Joint Commission, 2011.
67. CQC. A different ending: addressing inequalities in end of life care - lesbian, gay, bisexual or transgender people. Newcastle upon Tyne: Care Quality Commission, 2016.
68. Bosse JD, Jackman KB and Hughes TL. NINR funding dedicated to sexual and gender minority health: 1987–2018. *Nurs Outlook* 2020; 68: 293–300. [PubMed: 32138976]
69. Smith SD, Rowan NL, Arms TE, et al. An interdisciplinary approach to enhancing health knowledge and cultural awareness with LGBT older adults. *Educ Gerontol* 2021; 47: 79–85.
70. Tollemache N, Shrewsbury D and Llewellyn C. Que(e)rying undergraduate medical curricula: a cross-sectional online survey of lesbian, gay, bisexual, transgender, and queer content inclusion in UK undergraduate medical education. *BMC Med Educ* 2021; 21(1): 12. [PubMed: 33407394]
71. McCann E and Brown M. The inclusion of LGBT+ health issues within undergraduate healthcare education and professional training programmes: A systematic review. *Nurse Educ Today* 2018; 64: 204–214. [PubMed: 29510349]
72. Jur ek A, Downes C, Keogh B, et al. Educating health and social care practitioners on the experiences and needs of older LGBT+ adults: findings from a systematic review. *J Nurs Manag* 2021; 29: 43–57. [PubMed: 32881171]
73. Lindsay S, Rezai M, Kolne K, et al. Outcomes of gender-sensitivity educational interventions for healthcare providers: A systematic review. *Health Educ J* 2019; 78: 958–976.
74. Arthur S, Jamieson A, Cross H, et al. Medical students' awareness of health issues, attitudes, and confidence about caring for lesbian, gay, bisexual and transgender patients: a cross-sectional survey. *BMC Med Educ* 2021; 21(1): 56. [PubMed: 33446197]
75. Nowaskie DZ, Patel AU and Fang RC. A multicenter, multidisciplinary evaluation of 1701 healthcare professional students' LGBT cultural competency: comparisons between dental, medical, occupational therapy, pharmacy, physical therapy, physician assistant, and social work students. *PLoS One* 2020; 15: e0237670. [PubMed: 32790797]

76. Caceres BA, Travers J, Primiano JE, et al. Provider and LGBT individuals' perspectives on LGBT issues in long-term care: a systematic review. *Gerontologist* 2020; 60: e169–e83. [PubMed: 30726910]
77. Maingi S, Bagabag AE and O'Mahony S. Current best practices for sexual and gender minorities in hospice and palliative care settings. *J Pain Symptom Manag* 2018; 55: 1420–1427.
78. Maingi S, Radix A, Candrian C, et al. Improving the hospice and palliative care experiences of LGBTQ patients and their caregivers. *Prim Care* 2021; 48: 339–349. [PubMed: 33985709]
79. Shepherd BF, Brochu PM and Stripling AM. Hidden grief is complicated: identity concealment as a minority stressor and relational-cultural barrier among bereaved sexual and gender minoritized elders. *Psychol Sex* 2021; 1–18.

What is already known about the topic?

- LGBTQ+ individuals face social inequities that lead to decreased health service access, increased morbidity across several illnesses, poor health and quality-related outcomes, and disease-related mortality.
- LGBTQ+ individuals and their chosen families have specific health needs that require appropriate, accessible, and person-centered palliative and end-of-life services.
- Evidence-based recommendations encourage healthcare professionals to explore the sexual and gender identities of individuals with respect, avoid heteronormative and cisnormative assumptions, and recognize the importance of including an individual's partner and chosen family in decision-making and care planning processes.

What this paper adds?

- Evidence regarding the palliative and end of life needs, experiences, and preferences specifically for trans persons has increased substantially over the past decade, from zero papers reported in a 2012 systematic review on this topic to 10 papers that included trans individuals as a population demographic in this review.
- In addition to worrying about clinician discrimination, several studies reflected LGBTQ+ participants' explicit concerns that they would not be treated with dignity or die in a dignified manner aligned with personal values. Some trans participants preferred death or suicide to a loss of functional independence.
- Greater visibility of trans individuals in studies highlighted insufficient services to address the social, legal, and ethical domains of palliative care for these groups (e.g. housing, economic instability, long-term care needs). Trans participants felt at increased risk for social isolation and disconnection from the broader lesbian, gay, and bisexual community.

Implications for practice, theory, or policy

- Cultural humility training is essential alongside actionable policy changes to ensure respectful collection of data and create care environments that are safe for LGBTQ+ persons and chosen families to disclose identities and relationships.
- Large-scale studies are needed that ensure a diverse representation of individuals across the LGBTQ+ spectrum and include the perspectives of multidisciplinary health professionals to identify systemic barriers and promote inclusive LGBTQ+ palliative and end of life care.
- Intersectional identities—including among people with both minoritized sexual and gender identities—should be assessed throughout clinical

encounters and research studies to account for multiple minority stressors that likely inform cumulative impact on palliative and end of life needs, experiences, and preferences.

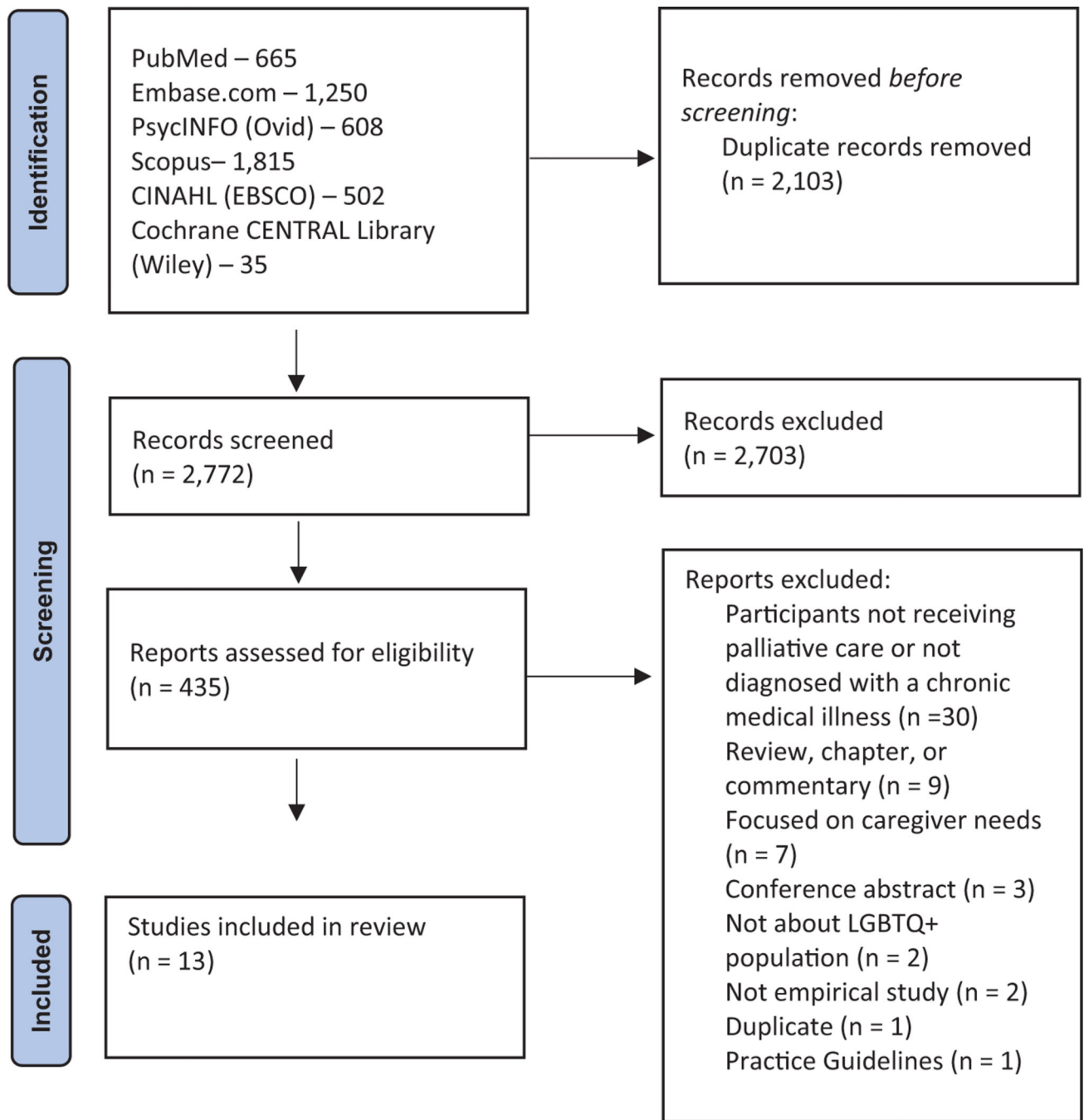


Figure 1.
PRISMA flow diagram.

Table 1.

Inclusion and exclusion criteria.

Inclusion criteria	Exclusion criteria
<ul style="list-style-type: none"> English language, full-text available from January 1, 2010 to November 6, 2020 	<ul style="list-style-type: none"> Languages other than English or full-text unavailable
<ul style="list-style-type: none"> Qualitative and quantitative studies in peer-reviewed literature 	<ul style="list-style-type: none"> Grey literature, editorials, opinion pieces, conference abstracts, and non peer-reviewed studies
<ul style="list-style-type: none"> Participants who are LGBTQ+ and have a serious illness 	<ul style="list-style-type: none"> Sole focus on caregiver or bereavement experiences
<ul style="list-style-type: none"> Studies that address the palliative and end of life needs, experiences, and preferences of LGBTQ+ individuals with serious illness 	<ul style="list-style-type: none"> Studies that did not disaggregate LGBTQ+ participants from heterosexual or cisgender individuals
	<ul style="list-style-type: none"> Advance care planning or hypothetical end of life studies if participants did not have a serious illness

Summary of studies.

Table 2.

Study	Methods	Population	Study aims	Measures	Main findings	Implications
Alexander et al. ⁴⁵	Quantitative-quasi experimental, longitudinal	$N = 197$ ($n = 112$ intervention, $n = 85$ control); HIV positive y MSM attending HIV outpatient clinics in Maryland and HIV outpatient health workers; age: $M = 29$ years, $SD = 3.9$ years; 78% Black, 6% White, 9% Hispanic, 2% Other, 5% Multiracial	Assess the impact, acceptability and applicability of training staff on ePA to optimize patient outcomes in behavioral health and QoL	Life Events Scale, CES-D-SF, Global and Summary QoL	<ul style="list-style-type: none"> • 45% of participants had experienced 3 or more serious adverse events • Significant association between the number of life events encountered and probable depression and alcohol problems • QoL increased in patients who received ePA 	ePA may be used in HIV outpatient settings to promote patient engagement and quality care
Beringer et al. ³⁸	Qualitative	$N = 43$ ($n = 15$ gay and bisexual men, $n = 12$ lesbian and bisexual women, $n = 9$ transgender persons, $n = 7$ service providers); patient participants had at least one chronic health condition; Canadian; age: $M = 67.6$ years, $SD =$ not reported; race/ethnicity not reported	Obtain feedback on the development of a web-based platform for older LGBT individuals to receive support and information on EOL topics	Focus group interviews about the website	<ul style="list-style-type: none"> • In the first 16 months of the website launch 1684 “authentic users” (user visiting the site for 11–1801+ seconds) • Focus group participants reported a need for a moderated and safe web environment • Focus group feedback on website was generally positive 	LGBT-friendly resources may improve EOL planning and health care
Bristowe et al. ⁵⁰	Qualitative	$N = 40$ LGBT individuals across the UK ($n = 19$ gay, $n = 1$ homosexual, $n = 1$ gay and intersex, $n = 14$ lesbian, $n = 2$ bisexual, $n = 2$ lesbian and trans, $n = 1$ friend of trans woman) with advanced illness ($n = 21$ cancer, $n = 16$ non-cancer, and $n = 3$ both a cancer and a noncancer condition); age: $Med = 59$, range = 27–94; $n = 34$ White British, $n = 4$ White Other, $n = 1$ Black British, $n = 1$ African-Caribbean	To explore health-care experiences of LGBT individuals with advanced illness	Semi-structured interviews	<p>Five main themes:</p> <ul style="list-style-type: none"> • Person-centered care needs that may require additional/different consideration for LGBT people (including different social support structures and additional legal concerns) • Service level or interactional barriers/stressors (heteronormative assumptions and homophobic/transphobic behaviors) • Invisible barriers/stressors (historical context of pathology/criminalization, fears and experiences of discrimination) • Service level or interactional facilitators (acknowledging and including partners in critical discussions) • Fears of disclosure due to past discrimination 	<p>Recommendations were made for providers serving LGBT individuals:</p> <ul style="list-style-type: none"> • Avoid using heterosexually framed or assumption-laden language • Demonstrate sensitivity in exploration of sexual orientation or gender history • Respect individuals’ preferences regarding disclosure of sexual identity or gender history • Carefully explore intimate relationships and significant others, including biological and chosen family (friends) • Explicitly include partners and/or significant others in discussions • Make clear statement of policies and procedures related to discrimination • Include content regarding LGBT communities in training on diversity and discrimination • Increase LGBT visibility in materials (in written content and images) • Provide explicit markers of inclusion (e.g. rainbow)

Study	Methods	Population	Study aims	Measures	Main findings	Implications
Catalan et al. ³⁹	Qualitative	<i>N</i> = 51 (<i>n</i> = 13 MSM; other sexual orientations not reported) participants had to have had personal or professional experience with HIV-age not reported; 90% Caucasian, 6% African/Afro-Caribbean, 4% South East Asian/Indian	Explored experiences with living with HIV	Semi-structured interviews	Themes included: <ul style="list-style-type: none"> • Death as traumatic and energizing • "Lazarus" phenomenon, meaning the impact of showing improvement as medications advanced Living with HIV amidst a death denying culture 	lanyards or pin badges) <ul style="list-style-type: none"> • Initiate partnerships and/or engagement with LGBT community groups <p>Authors recommend palliative care be integrated into the care of those with HIV to normalize the dying process and facilitate patient-centered care</p>
de Vries et al. ⁴¹	Qualitative	<i>N</i> = 93; LGBT older adults from Canada with at least 1 chronic health condition (<i>n</i> = 39 gay cismen, <i>n</i> = 28 lesbian ciswomen, <i>n</i> = 1 bisexual cisman, <i>n</i> = 1 bisexual ciswoman, <i>n</i> = 4 gay transmen, <i>n</i> = 6 lesbian transwomen, <i>n</i> = 2 bisexual transwomen, <i>n</i> = 10 other; age: <i>M</i> = 69 years, range = 55–89 years; race/ethnicity not reported)	Study examined end-of-life concerns among LGBT adults through interviews and focus groups	Interviews and focus groups	Four themes were identified: <ul style="list-style-type: none"> • Motivators and obstacles: documentation completion reasons and interpersonal challenges around EOL discussions (absence of a person to turn to and absence of the conversations occurring) • Relationship concerns: ambivalent ties with family of origin, chosen family strengths and challenges, isolation and loneliness, trust and honesty • Dynamics: of LGBT culture and lives fragmented LGBT community, disclosure, role and history of HIV/AIDS, financial concerns • Institutional concerns: social and health service barriers, need for political action and advocacy, role of church and religion 	Findings highlight sociocultural realities and financial challenges LGBT older adults experience in their preparations for EOL, including isolation, ambivalent ties with biological kin, and social challenges with friends and chosen family
de Vries et al. ⁴⁴	Quantitative	<i>N</i> = 91 (<i>n</i> = 40 gay/bisexual men, <i>n</i> = 27 lesbian/bisexual women, <i>n</i> = 7 transmen, <i>n</i> = 17 transwomen) from Canada with at least 1 chronic health condition; age <i>M</i> = 67.78, <i>SD</i> = 6.9; race/ethnicity not reported	Study examined relationship between relationship status, adult children, chosen family and demographic characteristics on EOL document preparation and discussions	„Availability of Social Support,” ACP Documents and Arrangements Index, EOL Care Discussions Index	<ul style="list-style-type: none"> • 71%–85% identified friends as those they could rely on, with family the next most common • 2/3 participants had completed will, 1/2 power of attorney, 1/2 a living will, 19% had prepaid funeral plans • 43% reported having had care discussions with family, 39% with friends, 32% with partners, 17% with health care professionals, 18% with other professionals • Relationship status and number of children were significantly correlated with completing ACP documents and arrangements • Participants generally poorly prepared for EOL decisions. • LGBT participants more likely to be single, living alone and to have more health problems. 	Findings demonstrate a need for attention to initiating ACP discussions with LGBT older adults and intentional connecting to EOL resources
Hunt et al. ⁴⁰	Qualitative	<i>n</i> = 72; Participants in Zimbabwe included LGBTI people and other sexually non-conforming people and health and palliative	To identify the attitudes and experiences of sex	Focus groups	<ul style="list-style-type: none"> • Only one LGBTIQI person with a life-limiting illness included. Participant reported symptoms being untreated and 	Care negatively affected by discriminatory beliefs and practices

Study	Methods	Population	Study aims	Measures	Main findings	Implications
Kortes-Miller et al. ⁴²	Qualitative	care providers and representatives of support and program agencies ($n = 3$ with life-limiting illness, only one identified as lesbian); age not reported; race/ethnicity not reported $N = 23$; LGBT Q+ elders from Canada (demographics not broken down); participants living with cancer, HIV or multiple sclerosis (breakdowns not reported); age: $M = 67.39$ years. Range = 57–78 years; race/ethnicity not reported	workers, sexual minorities, and health and palliative care providers regarding accessibility and quality of palliative care Study examined fears and hopes of LGBTQ+ participants regarding long-term care at the end of life	Focus groups	experience of undignified death. • Study overall noted in population experiences of discrimination, increased risk of painful, undignified death. Findings included participants having strong fears about discrimination and stigmatization: social isolation, concerns about dependence, safe and inclusive spaces	The findings from this study highlight the need for long-term care homes to be inclusive and safe for diverse residents through adding positive imagery (e.g. pride flags) and removing potentially offensive imagery (e.g. crucifixes)
Pang et al. ⁴³	Qualitative	$N = 24$ ($n = 6$ self-identified trans men [$n = 4$ gay, $n = 2$ straight] and $n = 18$ trans women [$n = 2$ bisexual, $n = 8$ straight] with at least one chronic condition); age: $M = 70$ years, Range = 55–89 years; all participants White Canadians	To understand how older adult members of trans communities perceive their late life and end-of-life care needs and what steps they are taking to address these needs	Focus groups and interviews	Three primary themes emerged: • “Dealing with the day-to-day” reflecting economic precarity and transitioning in later life • Fractures and support within family and community • “There’s a huge gap between principle and practice” reflecting mixed experiences and perceptions of healthcare services	Finding highlight the impact of daily life challenges and distinctive social support circumstances of older trans individuals
Seelman et al. ⁴⁶	Mixed Methods	$N = 9$; 8 participants had chronic illness ($n = 5$ cisgender men, $n = 4$ cisgender women, $n = 1$ same-gender-loving, $n = 1$ “likes having sex with women,” $n = 1$ “mostly gay,” $n = 6$ gay or lesbian [breakdown not specified]); age: $M = 71$; range = 65–77; $n = 6$ White/Caucasian, $n = 3$ African American/Black	The purpose of the study was to understand the health challenges LGB individuals face in later life and coping strategies used	Semi-structured interviews	Themes included: • Health challenges: sudden shift in wellness, dealing with comorbidities for years • Coping strategies: engaging in health-promoting activities, shifting perspectives about health and body, trusting in spiritual comfort, and accepting rather than resisting the EOL; social support essential	Study largely identified themes associated with coping with illness in older LGB populations
Walker et al. ⁴⁷	Mixed methods	$N = 384$ Global, English-speaking, transgender-identified adults ($n = 33$ masculine, $n = 130$ feminine, $n = 12$ androgynous, $n = 71$ transgender, $n = 28$ transman, $n = 51$ transwoman, $n = 14$ two-spirit, $n = 45$ other; $n = 114$ heterosexual, $n = 22$ gay, $n = 68$ lesbian, $n = 68$ bisexual, $n = 24$ asexual, $n = 17$ celibate, $n = 12$ pansexual, $n = 20$ questioning, $n = 16$ refused to be labeled, $n = 23$ other); individuals with chronic illness and/or disability (total numbers not reported nor were results disaggregated); age: $M =$ not reported, range = 51–55 years 100 (26.0%)	Study data from the “Trans MeLife Survey on Later Life Preparedness and Perceptions in Transgender-Identified Individuals”; examined impact of anticipation of bias from healthcare professionals on successful aging	Online survey with a mix of dichotomous, Likert-scale questions and open-ended questions	Anticipated bias, social support network size, and disability status significantly predicted participant perceptions of successful aging • 32.1% reported no or a little confidence they would be treated with dignity and respect by professional as they age • 47.1% moderate to good and 12.8% 100% confident • Larger social support networks and higher levels of confidence that a healthcare professional will treat them with dignity and respect as a TGNC person at EOL were associated with	Fears of and actual discrimination may impede quality of life and healthcare for aging transgender individuals

Study	Methods	Population	Study aims	Measures	Main findings	Implications
Witten ⁴⁸	Mixed methods	56–60 years 120 (31.3%) 61–65 years 91 (23.7%) 66–70 years 42 (10.9%) Over 70 years of age $n = 31$ (8.1%); $n = 350$ White, $n = 2$ Black, $n = 4$ Hispanic or Latino, $n = 2$ Native American or First Nations, $n = 10$ multiracial, $n = 16$ other $N = 1963$ Global, English-speaking, transgender-identified adults (14% masculine, 26% feminine, 3% androgenous, 5% gender queer, 1% gender bender, 14% transgender, 2% third gender, 13% transman, 11% transwoman, 2% transbended, 3% two spirit, 1% questioning; 25% heterosexual, 7% gay, 14% lesbian, 18% bisexual, 4% asexual, 3% celibate, 8% pansexual, 4% questioning, 6% refuse to be labeled, 1% omnisexual, 9% other); 30.1% with chronic illness, 27.1% with disability; age: 18–30: 19%, 31–40: 14%, 41–50: 20%, 51–60: 27% 61–70: 16% Over 70: 4%; 85% Caucasian, 3% Hispanic, 3% multiracial, 2% Black, 2% Asian, 1% First Nations, 4% other	Study data from the “Trans MeTLife Survey on Later Life Preparedness and Perceptions in Transgender-Identified Individuals”; examined end-of-life and chronic illness experiences and preparation	Online survey with a mix of dichotomous, Likert-scale questions and open-ended questions	<p>participant perceptions of successful aging</p> <ul style="list-style-type: none"> Quantitative and qualitative data were grouped under religiosity, spirituality and faith; social support; chronic illness and disability; pension and retirement; legal paperwork; paying for later and EOL; later life fears; and death and dying 30% of respondents overall reported not being sure of who would care for them in old age or in illness Themes of free responses included experiencing discrimination by caregivers, fears of cruelty and abuse, fears of homelessness, dementia and of not being allowed to live their lives as their true selves 	<p>Importance of facilities and providers being educated and prepared to meet the need of growing population of trans-identified older adults</p>
Witten ⁴⁹	Mixed methods	$N = 147$ bisexual, transgender-identifying adults; 31.6% with a chronic illness; 18–30: 11.6%, 31–50: 40.8%, and 51 and older: 47.6%; 89.7% Caucasian, 3.4% biracial/multiracial, 1.4% Arab and Hispanic	Study data from the “Trans MeTLife Survey on Later Life Preparedness and Perceptions in Transgender-Identified Individuals” on EOL and later life concerns, plans, and preparations experiences and needs of trans bisexual adults	Online survey with a mix of dichotomous, Likert-scale questions and open-ended questions	<ul style="list-style-type: none"> The number of trans-bisexual respondents who had a chronic illness and a disability was statistically greater than those who identified as trans-lesbian, supporting the argument that there are multiple complex subgroups within the global trans-identified population. 27.9% had completed a will, 22.4% had completed a living will, 15.6% durable power of attorney 50.8% had “tried to talk about my own death with other people” Respondents identified who they would discuss EOL care with: partner/spouse (34.7%), nobody (31.3%) and friend (17.7%) 	Findings highlight the unique intersection of trans and bisexual identities in older adults and related needs around EOL planning, as well as points of resilience in this population

ACP: advance care planning; ePA: early use of a palliative approach; EOL: end of life; HIV: human immunodeficiency virus; MSM: men who have sex with men; QoL: quality of life; TGNC: transgender and gender nonconforming; yMSM: young men of color who have sex with men