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# Palliative care service provision and use among 2SLGBTQIA + individuals: a scoping review

Anna De Jong<sup>1</sup>, Kyle Swerhun<sup>1</sup>, Peter Brink<sup>1</sup> and Lynn Martin<sup>1,2\*</sup>

## Abstract

**Context** Health inequities exist across the healthcare continuum, significantly impacting 2SLGBTQIA + individuals. Palliative care presents unique challenges for sexual and gender minorities due to socio-cultural, psychological, and systemic barriers. The objective of this scoping review was to synthesize existing research on palliative care use among 2SLGBTQIA + individuals and identify common themes in the literature.

**Methods** A literature review was conducted, focusing on articles published between 2010 and 2023 from the PubMed and CINAHL databases. Arksey and O'Malley's methodological framework for scoping reviews was applied to guide the review process.

**Results** A total of 31 studies were identified. A significant portion of the research originated in North America, with little research from outside the USA. Palliative care and end-of-life care were most used to describe care, though these terms were often not clearly defined. All studies included a focus on sexual and gender minorities, but there was considerable variation in the terminology used and a noticeable paucity of literature specifically addressing the needs of transgender and gender non-conforming individuals, or use of an intersectional approach in analysis. Key themes identified in the literature include discrimination in palliative care settings, disenfranchised grief experienced by care partners, and a lack of training in palliative care settings concerning the unique needs of 2SLGBTQIA + people utilizing palliative care services.

**Conclusions** People identifying as 2SLGBTQIA + experience unique inequities in accessing and using palliative care services. To address these challenges, future initiatives should focus on developing identity-affirming palliative care settings, enhancing respect and support for care partners and found family, and ensuring healthcare providers are properly educated to provide care to this community. Future research is also needed that considers more diverse samples, as well as the impact of intersecting identities on the specific needs and challenges they face at end-of-life.

**Keywords** 2SLGBTQIA +, LGBTQ +, Palliative care, End-of-life care, Health inequities

## Background

Health inequalities exist across the continuum of care, and gender identity/sexuality is not exempt from these inequalities. The acronym 2SLGBTQIA + includes sexual and gender minorities who are Two-Spirit, Lesbian, Gay, Bisexual, Transgender/Trans, Queer/Questioning, Intersexual, Asexual/Aromantic/Agender and all others [1].

Palliative care, a specialized medical approach aimed at improving the quality of life for patients with

\*Correspondence:

Lynn Martin  
lmartin@lakeheadu.ca

<sup>1</sup> Department of Health Sciences, Faculty of Health and Behavioural Sciences, Lakehead University, Lakehead University, 955 Oliver Rd., Thunder Bay, ON P7B 5E1, Canada

<sup>2</sup> Centre for Education and Research On Aging and Health, Lakehead University, Thunder Bay, Canada



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serious illnesses, is a critical component of healthcare [2]. However, for individuals identifying as part of a sexual and gender minority, the experience of receiving palliative care is often uniquely challenging [3]. These challenges stem from a confluence of socio-cultural [4], psychological [5], and systemic factors [6] that have historically marginalized sexual and gender minority communities within healthcare systems. Even today, basic human rights are not universally afforded to those beyond the heterosexual, cisgender majority.

The experience of 2SLGBTQIA+ individuals in palliative care is embedded in the recognition that sexual and gender minority individuals often face distinct health disparities and barriers to accessing appropriate healthcare services [3, 7]. For example, Sexual and Gender Minorities (SGM) have been reported to seek cancer screening less frequently than non-SGM counterparts, highlighting the disparities in preventive care utilization within this population [8]. These disparities are not merely clinical but are deeply intertwined with broader issues of social justice, equity, and human rights. The historical context of sexual and gender minority as it relates to healthcare marginalization, is characterized by discrimination, stigma, and lack of understanding from healthcare providers, and has profound implications for how palliative care is delivered and received. In exploring this relationship, it is crucial to acknowledge the diversity within the 2SLGBTQIA+ community itself. Factors such as age [9], race [10], socioeconomic status [11, 12], and geographic location [13, 14] intersect with 2SLGBTQIA+ identities, further influencing healthcare experiences and outcomes. Additionally, the evolving nature of societal attitudes towards 2SLGBTQIA+ people, along with advancements in legal and policy frameworks, plays a significant role in shaping the healthcare landscape for these communities.

A better understanding of the current knowledge on palliative care use among sexual and gender minority people is crucial due to the unique health disparities and systemic barriers this group faces. While previous reviews have identified discrimination and unmet needs experienced by 2SLGBTQIA+ people in palliative care settings, these have primarily focused on cancer care [15, 16] and did not utilize a comprehensive review method [17]. This scoping review aimed to the current knowledge on palliative care use among 2SLGBTQIA+ people and identify common themes in the literature. It also considers the terminology used to describe populations and services received, as well as the approaches to create the knowledge.

## Methods

The 5-stage methodological framework for developing a scoping review, as proposed by Arksey and O'Malley [18], was utilized: (1) identification of the research question,

(2) identification of relevant studies, (3) study selection, (4) charting the data, and (5) collating, summarizing, and reporting the results.

In collaboration with a Librarian, PubMed and CINAHL databases were searched for full-text peer-reviewed original research articles (i.e., grey literature was excluded) published in English between January 1, 2010 and September 13 2023 (date of the search) using the following search terms: “ ‘sexual minori\*’ OR ‘gender minori\*’ or ‘sexual and gender minorities [MeSH Terms]’ AND ‘palliati\*’ OR ‘end-of-life’ OR ‘end-stage’ OR ‘life-limiting’ or ‘palliative care [MeSH Terms]’ ”. Grey literature was excluded. Searches were identical in both databases, with the exception of the use of MeSH Terms, which are not available in CINAHL.

Titles and abstracts were independently screened by the two first authors to assess articles for eligibility criteria; any conflicts were resolved by the last author. The information extracted from each included country in which the study was conducted, study aims, study design, target population, population-related definitions, setting, recruitment method/data source, participant characteristics, study findings, and terms used to refer to the target population and care received. We also reviewed author-identified study limitations and next steps for research.

## Results

### Study selection

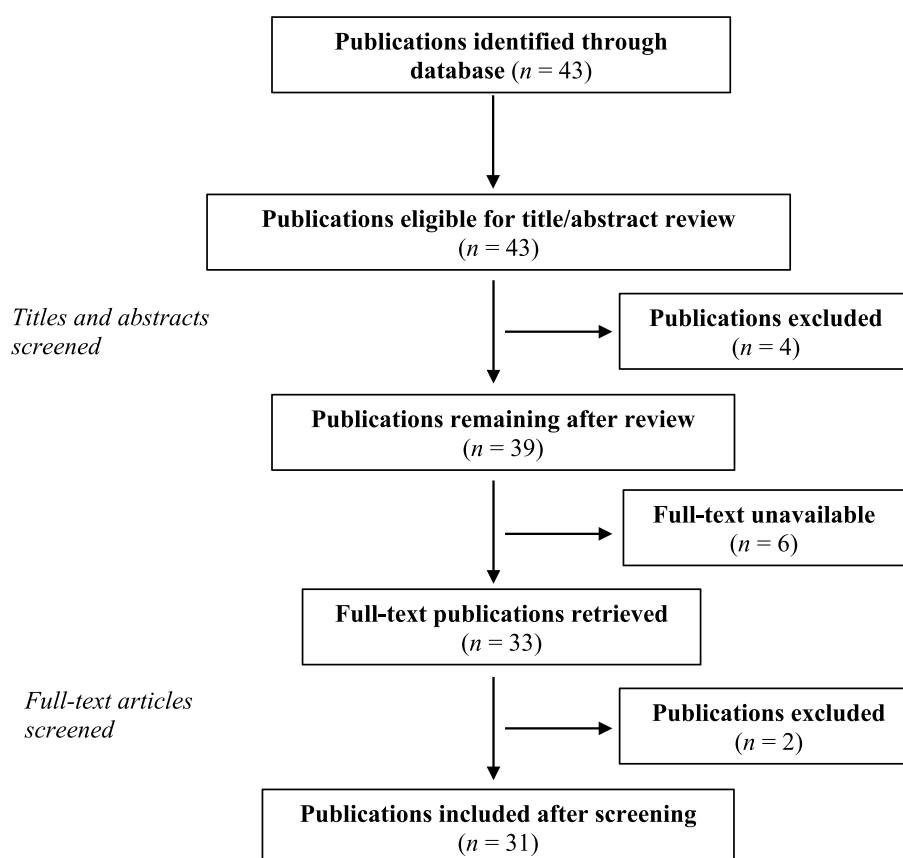
Initially, 43 unique articles were identified and after full-text review, data was extracted from 31 articles. Figure 1 shows the search results using the PRISMA Flow Diagram Tool. Most articles were excluded because they did not focus on palliative or end-of-life care and/or the population of interest.

Table 1 presents the key elements of the data extracted from reviewed articles.

### Study design, setting, and samples

The thirty-one articles reviewed included research publications ( $n = 15$ ) [3, 19–22, 24, 25, 27, 29, 34–36, 39, 40, 42], informal literature reviews ( $n = 11$ ) [4, 5, 23, 26, 30–33, 38, 41, 43], and formal literature reviews ( $n = 5$ ) [15–17, 28, 37]. Research articles varied in study design, with the majority using mixed methods ( $n = 6$ ) [3, 19, 22, 24, 34, 36] or qualitative designs ( $n = 6$ ) [20, 21, 27, 35, 40, 42]. There were three quantitative studies [25, 29, 39].

Original research studies were conducted in community [3, 21, 24, 27, 36, 42], hospital [22, 25, 40] or hospice [29, 35] settings, though some were conducted in multiple settings [20, 39]. One study was conducted with professionals in PC organizations [19]. Overall, sample sizes ranged from a single participant [40] to 867 participants [22], with mixed methods studies having the largest



**Fig. 1** Flowchart of search results

samples on average. Authors reported on a variety of characteristics, including age [3, 20, 22, 24, 25, 27, 29, 39, 42], sex [22, 34], gender [19, 25, 27, 35], gender identity [20, 34–36], sexual orientation [19, 25, 36, 39, 42], marital status [24, 27, 34], race/ethnicity [20, 24, 25, 29, 34–36], education [25, 34, 42], occupation [19, 39], income [24, 25, 29], rural/urban status [19, 34, 36], religion [19], and disability status [25, 36].

#### Geographic representation

Among original studies, half of the publications ( $n = 9$ ) came from the USA [19, 21, 25, 29, 34, 35, 39, 40, 42]. Research publications also came from Australia ( $n = 3$ ) [22, 27, 36], Canada ( $n = 2$ ) [3, 24], and the UK ( $n = 1$ ) [20].

#### Terminology – target population

While all studies focused on sexual and gender minorities (SGM), the terminology used to describe the target populations varied greatly. The majority of studies focused on LGBTQ [4, 5, 23, 26, 36, 40, 41, 43] or LGBTQ+ [3, 17, 29, 30, 37, 38] populations, though studies focused on LGBT individuals [15, 20, 27, 28, 39] were also common.

Some focused on specific subgroups [19, 21, 24, 41, 42], while others used the broader term SGM [16, 33–35]. One study used the term LGBTI [22] and another LGBTQIA [32].

#### Terminology—care/services

Almost all publications used either "palliative care" ( $n = 15$ ) or "end-of-life care" ( $n = 10$ ) when describing care. Only three studies provided a clear definition of "palliative care". Two studies used the World Health Organization's definition: "an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual," [15, 36]. One study defined palliative care in terms of "improv[ing] patients' quality of life by alleviating physical and emotional distress, demonstrating compassion and emphasizing dignity, especially during the transition towards end-of-life" [32].

Similarly, only three of ten studies defined "end-of-life care". One study described it in terms of the end-of-life

**Table 1** Key elements of data extraction

| References                      | Country   | Design                              | Target population                 | Study setting                | Sample size | Sample characteristics  | Care/Services                                    |
|---------------------------------|-----------|-------------------------------------|-----------------------------------|------------------------------|-------------|---|--|
| [3] Kortés-Miller et al. (2018) | Canada    | Mixed methods                       | LGBTQ+                            | Community                    | 23          | Age   | EOL  |
| [4] Sprik & Gentile (2020)      | N/A       | Commentary                          | LGBTQ                             | N/A                          | N/A         | N/A   | EOL  |
| [5] Javier (2021)               | N/A       | Review                              | LGBTQ                             | N/A                          | N/A         | N/A   | Palliative/Palliation                            |
| [15] Haviland et al. (2020)     | N/A       | Review                              | LGBT                              | N/A                          | N/A         | N/A   | Palliative/Palliation                            |
| [16] Cloyes et al. (2021)       | N/A       | Review                              | SGM                               | N/A                          | N/A         | N/A   | Palliative/Palliation; hospice; EOL              |
| [17] Lintott et al. (2022)      | N/A       | Rapid Review                        | LGBTQ+                            | N/A                          | N/A         | N/A   | EOL  |
| [19] Berkman et al. (2023)      | USA       | Mixed methods                       | Transgender                       | PC Organizations             | 865         | Gender; Sexuality; Occupation; rural/urban; religion                        | Palliative/Palliation; hospice                   |
| [20] Bristowe et al. (2017)     | UK        | Qualitative                         | LGBT                              | Hospital, Hospice, Community | 40          | Age; Self-described identity; ethnicity                                     | Advanced/End-stage/Serious/Life-limiting illness |
| [21] Candrian & Cloyes (2020)   | USA       | Qualitative                         | Lesbian                           | Community                    | 1           | N/A   | EOL  |
| [22] Cartwright et al. (2017)   | Australia | Mixed methods                       | LGBTI                             | Hospital                     | 867         | Age; Sex  | EOL  |
| [23] Cloyes et al. (2018)       | USA       | Review                              | LGBTQ                             | N/A                          | N/A         | N/A   | Palliative/Palliation; EOL                       |
| [24] Dube et al. (2021)         | Canada    | Quantitative                        | Gay men                           | Community                    | 7           | Age; Marital status; Race; living arrangement; annual income                | Advance care planning                            |
| [25] Grill et al. (2021)        | USA       | Quantitative                        | sexual minorities                 | Hospital                     | 223         | Age; gender; race; sexual orientation; education; income; disability income | EOL  |
| [26] Higgins & Hynes (2019)     | N/A       | Commentary                          | LGBTQ                             | N/A                          | N/A         | N/A   | EOL  |
| [27] Hughes & Cartwright (2015) | Australia | Qualitative                         | LGBT                              | Community                    | 305         | Age; gender; identity; marital status                                       | Advance care planning                            |
| [28] Kcomt & Gorey (2017)       | N/A       | Review                              | LGBT                              | N/A                          | N/A         | N/A   | EOL  |
| [29] Kemery (2021)              | USA       | Quantitative                        | LGBTQ+                            | Hospice                      | 122         | Age; income; race; LGBTQ status   | Hospice  |
| [30] Liantonio et al. (2023)    | USA       | No specific design really described | LGBTQ+                            | N/A                          | N/A         | Not reported  | Palliative/Palliation                            |
| [31] Lippe et al. (2023)        | N/A       | N/A                                 | transgender, gender nonconforming | N/A                          | N/A         | N/A   | Palliative/Palliation                            |
| [32] Lutz & Ehrlich (2022)      | USA       | Commentary                          | LGBTQIA                           | N/A                          | N/A         | N/A   | Palliative/Palliation                            |
| [33] Maingi et al. (2018)       | USA       | Review                              | SGM                               | N/A                          | N/A         | N/A   | Palliative/Palliation                            |

**Table 1** (continued)

| References                   | Country   | Design          | Target population | Study setting                                 | Sample size               | Sample characteristics   | Care/Services                                |
|------------------------------|-----------|-----------------|-------------------|---|---------------------------|--|--|
| [34] Reich et al. (2022)     | USA       | Mixed methods   | SGM               | Community                                     | 603                       | Sex; SGM status; race/ethnicity; marital status; health insurance; education; remoteness | Advance care                                 |
| [35] Reynaga et al. (2022)   | USA       | Qualitative     | SGM               | Hospice                                       | 48                        | Gender; Gender identity; Sexual orientation; Race  | Hospice                                      |
| [36] Roberts et al. (2022)   | Australia | Mixed methods   | LGBTQ             | Community                                     | 222 surveys; 6 interviews | Sexual Orientation; Gender identity; urban/rural; cultural diversity; disability status  | Palliative/Palliation                        |
| [37] Rosa et al. (2022)      | N/A       | Review          | LGBTQ+            | N/A   | N/A                       | N/A  | Palliative/Palliation                        |
| [38] Rosa et al. (2020)      | USA       | Opinion article | LGBTQ+            | N/A   | N/A                       | N/A  | Palliative/Palliation                        |
| [39] Stein et al. (2020)     | USA       | Quantitative    | LGBT              | Hospice (hospital, home), Hospital, Community | 865                       | Age; Occupation; sexual orientation; gender identity                                     | Palliative/Palliation                        |
| [40] Stevens & Abrahm (2019) | USA       | Qualitative     | LGBTQ             | Hospital                                      | 1                         | N/A  | EOL  |
| [41] Tapper (2023)           | USA       | N/A             | LGBTQ             | N/A   | N/A                       | N/A  | Palliative/Palliation; advance care planning |
| [42] Thomeer et al. (2017)   | USA       | Qualitative     | LG                | Community                                     | 90                        | Age; Education; Sexual orientation; Duration of relationship; Presence of children       | EOL  |
| [43] Wakefield et al. (2021) | N/A       | Editorial       | LGBTQ             | N/A   | N/A                       | N/A  | Palliative/Palliation                        |

preparation behaviours i.e. "discussed with a primary caregiver; discussed with a significant other, family member, friend, or another substitute decision-maker; completed a will; completed a living will and/or appointed a health care proxy" [28]. Thomeer and colleagues spoke specifically to informal/formal decision-making at end-of-life: "informal conversations with loved ones about future care and end-of-life preferences and the creation of formal end-of-life plans via living wills, healthcare proxies, and other legal documents" [42]. The last study described EOL care as "living with a life-limiting and/or chronic illness that requires home care, assisted living, long-term care, and/or hospice palliative care" [17].

Each of the four publications using the term "advanced care" provided clear definitions. Three defined it in terms of advance care planning, which focuses on discussing and documenting values and wishes for future medical care [24, 27, 34], whereas Bristowe and colleagues defined

"advanced care" as care provided to those with advanced illness and potentially in their last year of life [20].

Only two studies used the term "hospice" to describe the care given. Kemery defined hospice care as providing comfort to the terminally ill and their families [29], while Reynaga and colleagues did not define the term [35].

### Key findings

Several themes emerged from the content of the publications reviewed, including: (1) discrimination, fear, and stigma (2) disenfranchised grief of found family, and (3) HCP knowledge, experience, and training.

### Discrimination, fear, and stigma

Many studies spoke to the experience of discrimination, fear, and stigma when accessing palliative care [3–5, 15, 17, 19, 20, 25, 26, 32, 34, 36–39, 41, 43] as well as prior experiences of discrimination and stigma within the healthcare system. Research has shown that people are

less likely to access screening services for life-limiting illnesses due to these fears and are consequently more likely to develop advanced disease as a result of such delays [26, 43]. Further, individuals fear that stigma will impact their experiences within the palliative care setting, including a lack of respect for their identity, wants, and decisions [34]. Forced "outing" is one of the most common fears people face when contemplating accessing palliative care. This is especially dangerous for people who may have support persons or caretakers unaware of their sexual or gender identity; in such cases, forced "outing" potentially threatens the individual's support network [4]. A recent case study based in the USA highlighted the discrimination faced by a lesbian couple in a palliative care setting [21]. When the couple's married status was revealed to health care providers (HCPs), care declined rapidly, and the person's needs were ignored. Only when the person's spouse began referring to herself as a "friend" or "emergency contact" did care improve [21]. Discrimination and abuse from HCPs can also extend to friends and family, making caretaking even more difficult than it already is [23].

Research has also shown that HCPs are aware of heteronormative assumptions, homophobic behaviours, and discrimination are common in palliative care settings [20, 39]. Stein and colleagues [39] reported that more than half of HCPs in their study knew that individuals from sexual and gender identity minority groups were more likely to experience discrimination. Berkman and colleagues found that 21.3% of HCPs reported witnessing disrespectful, inadequate, or abusive care towards transgender people, and of these, 85.3% said that transgender people were treated in a disrespectful manner [19].

#### ***Disenfranchised grief of found family***

Individuals often face barriers in palliative care with regards to found family, described as individuals who have close familial bonds but do not share a biological connection, and can include close friends and partners or spouses [15, 22, 39]. A USA-based study found that 15% of HCPs had witnessed the treatment decisions of spouses and partners be disregarded in the palliative care process [39]. Cartwright and colleagues [22] reported that even though Australian law dictates that a same-sex partner is a lawful substitute decision-maker, two-thirds of HCPs indicated that the adult child or ex-husband should make medical decisions [22]. Advance care planning is a tool that can be used to legally protect individuals and their families from potential discrimination [27, 28, 40, 42], and research suggests that they are better at communicating wishes with family and preparing legal documents [28] and are more likely to have these in place

[42]. In some cases, formal advance care planning documents are the only assurance for people and their families that the person's wishes will be respected [40].

As found families are not always viewed with the same validity as biological families, their bereavement needs are often either overlooked or disregarded [20, 22, 23]. As an example, one study reported that a same-sex partner who had referred to themselves as a "friend" to ensure better care from HCPs did not receive proper bereavement support after her partner's death, as HCPs were unaware of her true status [21]. The partner was unable to access 2SLGBTQIA+-specific resources without a referral and was left to experience her grief with little help. The authors also reported that most bereavement support groups operate under a heteronormative framework and, as such, are likely to feel unsafe [21].

#### ***HCP knowledge, experience, and training***

A theme that appeared frequently throughout the literature review was a lack of population-specific knowledge, training, and experience among HCPs working with sexual and gender minority groups. Mainstream palliative care is based on a heteronormative framework that does not account for the unique needs of this population [3, 5, 15, 17, 20, 23, 26, 33, 43]. For example, HCPs often use heteronormative language when addressing individuals, which could invalidate their gender identity [38]. In a UK-based study, participants noted that HCPs in both palliative and non-palliative care settings either assumed their gender identity or disregarded their preferred pronouns, making it difficult for them to engage with HCPs [20]. Another study found that HCPs in hospice care settings often use "normalizing" language, which positions the individual as cisgender. "Individualizing" language, which emphasizes the importance of historical context for personalized care, was the least common language framework used by HCPs [35].

Many HCPs do not understand the importance of found family and confidentiality regarding identity disclosure. In a Canadian-based study, participants indicated that mainstream palliative care options do not understand the importance of the LGBTQ community. The potential loss of community upon entering a formal palliative care setting is concerning for some, and some participants noted that HCPs working within palliative care do not take these concerns seriously [3]. Many people would prefer to have either population-specific palliative care settings or increased accessibility to LGBTQ staff within palliative care settings to make their experiences more comfortable [3, 33, 34]. In fact, a case study found that providing affirming care and using the preferred identity label improved communication between the individual and



his hospice care team [40]. There is a need for inclusive training for HCPs working within palliative, hospice, and end-of-life care settings which acknowledges the lived experiences of LGBTQ individuals within society, as well as population-specific community resources for caretaking and bereavement [3, 5, 17, 21, 23, 26, 30, 31, 33, 40].

#### Author-identified study limitations

A number of study limitations were noted. Regarding previous literature reviews, authors suggested that findings may not be generalizable to all SMGs based on their inclusion and exclusion criteria [15, 17, 28]. Generalizability was also questioned based on the fact that most articles reviewed originated in Western and predominantly white countries [37].

The most common limitation identified in original studies was related to the study samples. Some authors noted that a small sample size limited the generalizability of findings [20, 24, 25, 35], while others noted that convenience sampling and recruitment methods may have limited heterogeneity within samples [3, 27, 29, 36, 39]. Several studies also discussed limitations in data collection and measurement tools. For example, some grouped all identities as “sexual and gender minority” [3, 34]. Other studies discussed a lack of depth in data collection methods [19], low response rates [22], and questioned the validity of measurement tools in the study population [29]. Overall, samples were relatively homogenous, with a noticeable lack of representation from racial/ethnic minorities and transgender/gender non-conforming people [19, 20, 24, 34, 35, 39, 42].

#### Author-identified next steps

Among the literature reviewed, the most common next step identified was developing training for HCPs concerning the population-specific palliative care needs [15, 17, 20, 21, 26, 32, 35–37, 43]. Bristowe and colleagues [20] suggest that training could include teaching HCPs appropriate ways to reference sexual orientation in conversations with individuals as well as root sources/causes of discrimination within health care settings. Inclusive communication skills and appropriate language use (i.e. use of proper pronouns) were also referenced as important [21, 36]. Some authors also discussed the need for resources for HCPs struggling with their own bias. For example, Reynaga and colleagues [35] suggest linguistic resources may be helpful in allowing HCPs to identify bias in the language they use. Overall, there is a need to collaborate with 2SLGBTQIA+ communities when developing training regarding population-specific palliative care needs [17, 35, 36].

Another common next step identified was further research on the lived experiences of 2SLGBTQIA+ people using palliative care services and their family/caretakers themselves; several studies focused on the perspectives of HCPs [19, 20, 22, 29, 35, 36, 39]. Future research should also focus on recruiting broader samples, including racial/ethnic minorities, transgender and gender non-conforming people, and people with intersecting identities [21, 28, 29, 32, 37]. In addition, this work should focus on distinguishing the different experiences of distinct identities within the LGBTQ+ community [17, 29, 39].

#### Discussion

This scoping review identified three prominent themes regarding palliative care use among 2SLGBTQIA+ groups. These trends included experiences of discrimination and fear, a disregard for found family and their grief, and a lack of population-specific training/experiences among HCPs. Discrimination experienced in palliative care settings by 2SLGBTQIA+ people can result in unaddressed or poorly managed symptoms [26], psychological distress [15], and an overall distrust of palliative care [5]. Moreover, the fear of facing discrimination can cause people to delay or avoid seeking palliative care, which further exacerbates their health conditions, diminishes their quality of life and leads to feelings of isolation, anxiety, and depression [15]. Refusing to acknowledge the unique experiences of 2SLGBTQIA+ people within palliative care can be just as harmful as discriminatory behaviours. When 2SLGBTQIA+ people are treated in the same manner as cisgender/heterosexual people in palliative care settings, HCPs may inadvertently maintain discriminatory attitudes that create an environment where 2SLGBTQIA+ people do not feel safe or comfortable expressing themselves or disclosing crucial information about their health and well-being [25, 26, 35]. As such, 2SLGBTQIA+ people end up receiving a poorer quality of care that does not consider the context of their sexual/gender identity.

Discrimination can extend to the partners and caretakers of 2SLGBTQIA+ people receiving palliative care, leading to further isolation as many 2SLGBTQIA+ people do not have supportive relationships with biological families [26]. The bereavement and grief of 2SLGBTQIA+ individuals' caretakers and partners are also impacted by the bias and discrimination experienced within palliative care settings [20, 37]. 2SLGBTQIA+ people may choose not to disclose their relationship to a caretaker/partner, and if they do disclose such a relationship, it may not be acknowledged by HCPs. Whether a relationship was disclosed/acknowledged can have legal ramifications for caretakers and

partners and impact access to bereavement resources [20, 43]. Even when resources can be accessed, they may not be appropriate due to the heteronormative and cis-normative frameworks they are built on. Of the literature reviewed, there was a notable lack of research from countries other than the USA. There are several cultural and healthcare system differences between the USA and Canada, so findings from the USA may not be applicable in a Canadian context. For example, regional disparities in healthcare access, varying social attitudes, and legal protections in Canada may differ from those in the USA. Conducting research within Canada can help identify specific gaps in knowledge and service provision, leading to the development of more inclusive and palliative care practices that are sensitive to the needs of the Canadian 2SLGBTQIA+ community.

Further, the use of inconsistent definitions for palliative/EOL care can lead to a fragmented understanding of the unique experiences of 2SLGBTQIA+ people using palliative care. Research findings can become difficult to compare and synthesize when standardized language is lacking, and the development of specific guidelines and knowledge translation may also be hindered [44, 45].

Finally, there was a noticeable lack of information regarding two-spirit, asexual, and intersex individuals in the literature reviewed. There was also an apparent lack of population-specific information in those studies which referenced transgender people, with only two studies specifically focusing on transgender and gender-nonconforming individuals [19, 31]. In addition, there is a tendency to universalize the experiences of 2SLGBTQIA+ people rather than acknowledging the differences in palliative care needs among subsets within the 2SLGBTQIA+ community [17]. Homogenizing 2SLGBTQIA+ experiences can result in inadequate policies and HC services that fail to meet the specific needs of these subsets [17, 46].

## Implications

There is a critical need for additional studies that explore the experiences, needs, and preferences of 2SLGBTQIA+ people using palliative care services, as well as that of their caretakers and partners. Specifically, there is a need for large-scale studies with more diverse samples. Research that explores the experiences of those with intersecting identities is especially important. In the literature reviewed here, samples were homogenous and lacked representation from other marginalized groups (e.g. race, ethnicity, and socioeconomic status). Individuals with intersecting identities will likely face additional layers of discrimination and barriers to palliative care use. It is essential for researchers to sample from populations with diverse identities to ensure equitable representation

in research. It is also necessary for future research to focus on diverse subsets within the 2SLGBTQIA+ community. There is a noticeable lack of research concerning transgender and gender non-conforming individuals [19, 20, 39]. In addition, the experiences of those with differing identities within the 2SLGBTQIA+ community are often lumped together [17]. It is important for research to focus on the differences in experience among different 2SLGBTQIA+ groups.

Next, there is a need for more interventional research that focuses on system change. Most of the studies reviewed were exploratory research studies that aimed to understand the perspectives of 2SLGBTQIA+ people using palliative care, their caretakers and partners, and HCPs. This research has advanced the field of palliative care and understanding of the disparities 2SLGBTQIA+ people face; however, it is critical that future research be dedicated to identifying evidence-based interventions that improve the quality of care provided to 2SLGBTQIA+ people. This could include research regarding HCP training programs and identity affirmation policies. It is important that individuals be involved in research processes in order to promote trust building and ensure that proposed solutions are 2SLGBTQIA+-informed.

Lastly, the development of HCP training programs focusing on the needs and preferences of 2SLGBTQIA+ individuals within palliative care settings is needed. Research suggests cultural humility, rather than cultural competency, may be effective in improving interactions between HCPs and 2SLGBTQIA+ individuals in palliative care settings. Although cultural competency can have moderate impacts on HCP attitudes and knowledge, the term competency implies that HCPs can become fully competent, which oversimplifies the experiences of 2SLGBTQIA+ people. In comparison, cultural humility focuses on self-reflection, active listening, and mutual respect. This form of education can be complicated, as it requires ongoing participation in education by the HCPs [4]. Developing comprehensive training programs can also be challenging as research does not often distinguish between the differential experiences of those within the 2SLGBTQIA+ community. Experiences are often lumped together, and as a result, training programs may not provide accurate information on how to approach care for specific individuals (i.e. transgender people) [17]. Suggestions for best practices moving forward include developing training programs founded on cultural humility and acknowledging the different experiences of all 2SLGBTQIA+ subsets.



## Conclusion

Sexual and gender minorities face significant challenges in palliative care settings, many of which are rooted in experiences of discrimination, fear, and stigma. Yet these challenges are not solely specific to healthcare settings. Sexual and gender minorities are often faced with discrimination and/or marginalization in all aspects of life. Stigma may heighten their apprehension about palliative care, as they fear their identity, desires, and decisions might not be respected. Heteronormative assumptions and homophobic behaviours are unfortunately still prevalent in palliative care environments, and healthcare providers are often aware of this discrimination. This awareness underscores the need for a more inclusive and understanding approach in palliative care settings, and the creation of welcoming environments. A critical trait of this inclusivity is the recognition of 'found family' – where individuals who are not biologically related, form close bonds with sexual and gender minority persons. These relationships, often including partners, close friends, and spouses, play a significant role in the lives of sexual and gender minority individuals but may be overlooked in palliative care settings.

Additionally, a recurring theme in the literature is the lack of specific knowledge, training, and experience among healthcare providers in addressing the needs of persons from sexual and gender minority groups receiving palliative care. There is a need for inclusive training for health care providers that not only acknowledges the lived experiences of sexual and gender minority individuals but also integrates population-specific resources for caretaking and bereavement, ensuring a palliative care environment that is truly respectful and accommodating of all identities.

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## Authors' contributions

LM conceived the study. AD and KS developed the search strategy and conducted the literature search. AD and KS extracted and screened articles. AD completed data extraction. AD, KS, and LM reviewed the analysis process. AD, PB, and LM were involved in writing the manuscript. All authors approved the final version of the manuscript.

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## Availability of data and materials

Not applicable.

## Data availability

No datasets were generated or analysed during the current study.

## Declarations

### Ethics approval and consent to participate

Not applicable.

### Consent for publication

Not applicable.

### Competing interests

The authors declare no competing interests.

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