

Non-Clinical Interventions to Reduce Inequities in Palliative Care for 2SLGBTQ+ People: A Narrative Review

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Abstract

Introduction: People who identify as Two-Spirit, lesbian, gay, bisexual, transgender, and/or queer (2SLGBTQ+) experience health disparities across the lifespan, including at end of life. Recently there has been recognition of the value of health promotion approaches to palliative care that address the social and structural determinants of a good death. Current reviews on 2SLGBTQ+ palliative care are primarily framed through a clinical, patient-provider level lens. **Purpose:** To understand how implemented and evaluated non-clinical interventions regarding palliative care for 2SLGBTQ+ people are described in the literature. **Methods:** A narrative review was conducted adhering to a systematic procedure. Six relevant databases were searched, and 1,547 records were screened by two independent reviewers. To be eligible for inclusion, studies had to describe one or more implemented and evaluated non-clinical intervention that addressed at least one inequity or barrier to palliative care for 2SLGBTQ+ people. Charted data was analyzed using inductive content analysis. The socio-ecological model (SEM) was used to critically examine findings. **Results:** Six studies were included for review. Examples of non-clinical interventions across various settings and multiple socio-ecological levels were noted. We identified four overarching themes to describe how non-clinical interventions reduce inequities in palliative care for 2SLGBTQ+ people. **Conclusion:** This review revealed gaps in interventions at organizational, community, and public policy levels. Future research should map efforts specific to the Canadian context and empower 2SLGBTQ+ communities to evaluate and report on the interventions they lead. A trauma-informed intersectional approach should be used in the design of interventions with and for 2SLGBTQ+ community members.

Keywords: 2SLGBTQ+, palliative care, end-of-life care, interventions, inequities

Introduction

People who identify as Two-Spirit, lesbian, gay, bisexual, transgender, and/or queer, plus others who identify with sexual and gender diversity (2SLGBTQ+), experience health disparities across the lifespan, including at the end of life. Minority stress negatively impacts 2SLGBTQ+ people's health, life expectancy, and health-risk behaviours (Hajek et al., 2023; Lick et al., 2013; Meyer, 2003). Minority stressors range from distal experiences such as discrimination to proximal experiences such as concealing identity or internalizing and anticipating stigma (Meyer, 2003). Each 2SLGBTQ+ population experiences distinct and layered forms of minority stress. Additionally, 2SLGBTQ+ populations face a greater risk for certain advanced cancers as well as other serious health conditions. A review by Quinn et al. (2015) identified seven cancer sites that may disproportionately affect 2SLGBTQ+ populations, including anal, colorectal, lung, breast, cervical, endometrial, and prostate cancers. 2SLGBTQ+ people experience significant barriers to cancer screening (Haviland et al., 2021). As such, many do not receive timely intervention and are more likely to be diagnosed with advanced illness (Quinn et al., 2015). In addition to cancer, alcohol and tobacco use (Schuler et al., 2018) and risk of cardiovascular disease (Caceres et al., 2022) are also higher among 2SLGBTQ+ people. For example, older sexual minority women are more likely to have arthritis, asthma, a heart attack, a stroke, multiple chronic conditions, and poor general health compared to the general population (Fredriksen-Goldsen et al., 2017). More than ever, given an aging population and disproportionate health risk, 2SLGBTQ+ people need access to quality palliative care (Javier, 2021; Stinchcombe et al., 2017; Wilson et al., 2021).

Palliative care is a type of care that maintains the dignity and quality of life of people with life-limiting illnesses by relieving physical, psychological, social, and spiritual suffering (World Health Organization [WHO], 2020). The WHO estimates that each year 56.8 million people globally need palliative care. 2SLGBTQ+ people access palliative care services late or not at all because of anticipated or actual discrimination (Haviland et al., 2021; Maingi et al., 2018; van Klinken & van Leeuwenhoek, 2023). Recent reviews on palliative care highlight 2SLGBTQ+ people's concerns around identity disclosure, legal protections, discrimination or mistreatment from providers, insufficient provider knowledge, and respect for chosen families (Haviland et al., 2021; Maingi et al., 2018). Many 2SLGBTQ+ people, particularly transgender and gender diverse people, are not confident they will be treated with dignity and respect as they lose their autonomy and functional independence at end of life (Rosa et al., 2023). 2SLGBTQ+ people's willingness to disclose their identity or access palliative care is further threatened as they are targets of rhetoric, violence, and policies from the "anti-gender movement" (Tunney, 2024). There remains an imbalance between 2SLGBTQ+ people's disproportionate need for palliative care and the complex array of barriers to palliative care they face.

Numerous recommendations have been published on how to improve palliative care for 2SLGBTQ+ people (e.g., Cloyes et al., 2018; Javier, 2021; Maingi et al., 2018; van Klinken & van Leeuwenhoek, 2023). These recommendations largely stem from clinical domains like oncology nursing (Cloyes et al., 2018; van Klinken & van Leeuwenhoek, 2023), palliative medicine (Lintott et al., 2022), or geriatric medicine (Stinchcombe et al., 2017). There appear to be no reviews on the implementation of recommendations in practice, except for one review by Robinson and Matamoros (2024) with findings restricted to interventions applied at the patient-provider level. There is a need to examine measured outcomes and impacts of interventions to understand whether and how they affect inequities in palliative care for 2SLGBTQ+ people (Cloyes & Candrian, 2021; Robinson & Matamoros, 2024). Creating meaningful and sustainable improvements in palliative care requires confronting the role of organizational, community, and policy dimensions in generating and maintaining disparities.

The value of health promotion approaches to palliative care that address social and structural determinants of a good death have been increasingly recognized since the seminal work of Allan Kellehear in 1999 (Kellehear, 2020; Sirianni, 2020). A good death occurs when individuals are enabled to die the way they want to, which requires the right care and support systems (Krikorian et al., 2020). Palliative care has been criticized for being too embedded in the mainstream health care system and for isolating serious illness, death, and dying as personal problems (Kellehear, 1999; Rosenberg & Yates, 2010; Sawyer et al., 2021). Health-promoting palliative care de-professionalizes palliative care, promoting it as a collective duty across sectors and communities (Kellehear, 1999). This has been recognized as a model that “promotes optimal health even in the presence of incurable disease” (Rosenberg & Yates, 2010, p. 206). Health promotion approaches have been named as a promising solution for issues of access, cost, and equity in palliative care (Sirianni, 2020).

Health promotion approaches to palliative care represent a category of non-clinical interventions that extend beyond patient-provider encounters to reduce inequities in care (Chen et al., 2018). These interventions could include cultural humility training, online tools, or a health care bill of rights (Canadian Virtual Hospice, n.d.; Maingi et al., 2015; Rhoten et al., 2022). While improvement in the clinical delivery of palliative care to 2SLGBTQ+ patients is critical, it is necessary to examine available non-clinical interventions to ensure access to a good death for all 2SLGBTQ+ people facing life-limiting illness. The purpose of our narrative review is to understand what is known in existing literature about implemented and evaluated non-clinical interventions regarding palliative care for 2SLGBTQ+ people.

Methods

We conducted a narrative review to answer the following question: How does the literature describe implemented and evaluated non-clinical interventions regarding palliative care for 2SLGBTQ+ people? Three objectives were outlined to address the research question: (a) to explore what and how non-clinical interventions reduce inequities in palliative care for 2SLGBTQ+ people, (b) to critically examine implemented and evaluated non-clinical interventions regarding palliative care for 2SLGBTQ+ people through a socio-ecological lens, and (c) to identify gaps in the existing literature as it relates to non-clinical interventions regarding palliative care for 2SLGBTQ+ people.

Given the emerging state of the literature on palliative care for 2SLGBTQ+ people, a narrative review is most suitable for this research. This review method was chosen to establish an overview of the literature on palliative care for 2SLGBTQ+ people. Narrative review methodology is useful for comprehensive appraisal of previously published studies and current knowledge gaps (Ferrari, 2015). Narrative reviews allow researchers to present a rich summary of what is known on a topic, along with interpretation and critique (Greenhalgh et al., 2018). The quality and rigour of narrative reviews may be enhanced by borrowing from elements of systematic review methodologies designed to reduce bias in study selection (Ferrari, 2015).

Search Strategy

We completed systematic searches of the following databases in June 2024: PubMed, Embase, Sociological Abstracts, Academic Search Premier, Gender Studies Database, and CINAHL. We consulted a health science librarian to develop the search strategy and examined the concept map used by Robinson and Matamoros (2024) in their review. Keywords and synonyms (Table 1) were searched using AND/OR operators. The unique search strategies for each database can be found in Appendix A. Reference lists of selected articles were scanned to identify additional studies.

Table 1

Keywords and Synonyms for Search Strategy

| Population: "2SLGBTQ+ people" | Key Concept: "Palliative care" |
|--|--|
| LGB* OR queer OR gay OR lesbian OR transgender OR bisexual OR 'two-spirit' OR homosex* OR 'gender minorit*' OR 'sexual minorit*' | 'End-of-life care' OR 'palliative care' OR 'supportive care' OR palliat* OR hospice OR 'home palliative care' OR 'terminal care' OR 'terminally ill' |

Inclusion and Exclusion Criteria

There was no restriction on publication date, country, or population age. Only studies in English were included, due to time and resource constraints that prohibited access to translation. Published full-text journal articles were considered for inclusion if they described one or more implemented and evaluated non-clinical intervention that addressed at least one inequity or barrier to palliative care or a related subdomain (e.g., hospice or end-of-life care) for 2SLGBTQ+ people. We defined "non-clinical intervention" as any intervention that does not focus on an individual health care provider and patient encounter in the clinical environment (Chen et al., 2018). Health promotion approaches and initiatives were considered within the scope of "non-clinical interventions."

Study Selection

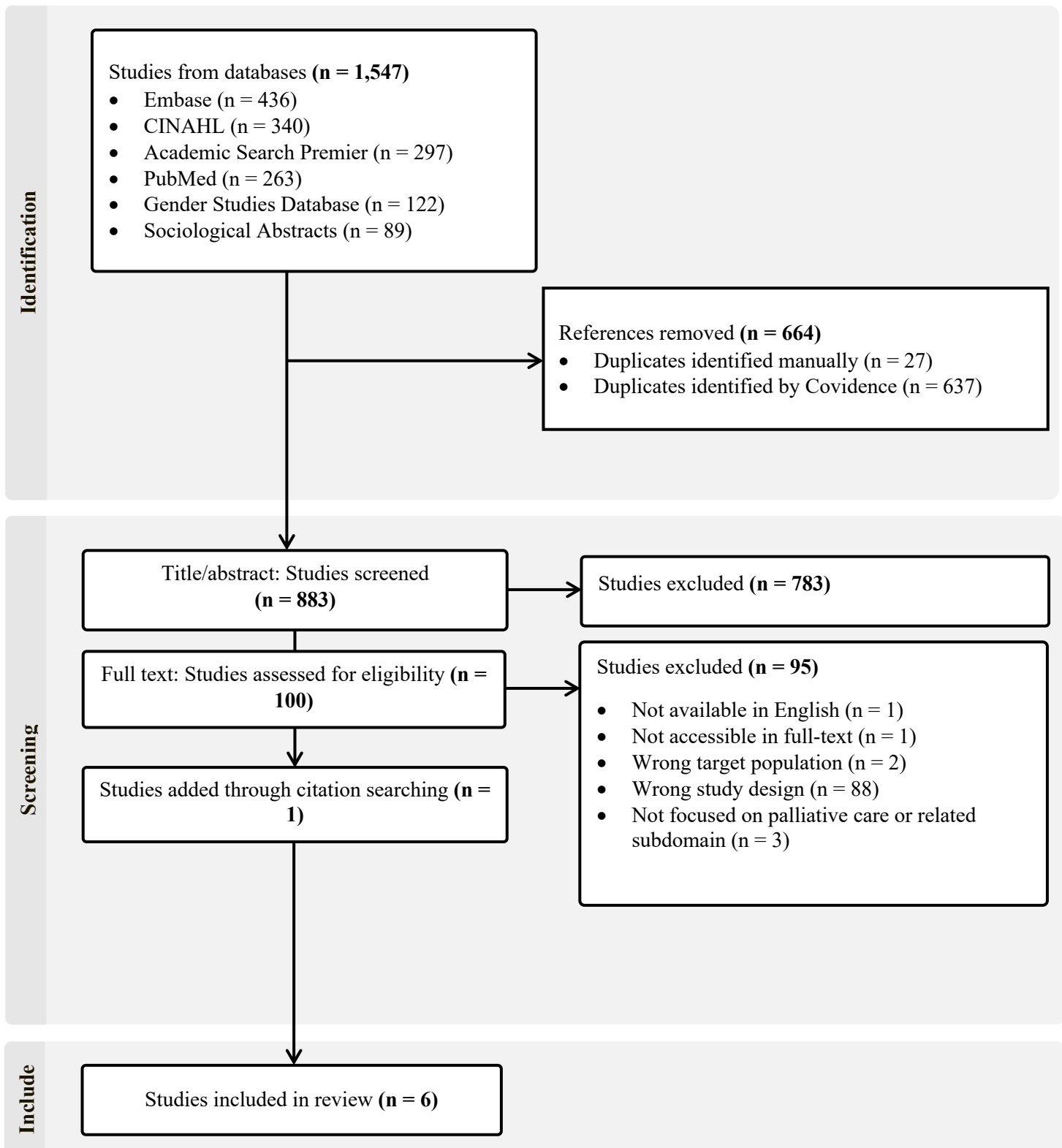
Our search strategy identified 1,547 records. We imported all records into Covidence (<https://www.covidence.org/>), where 637 duplicates were removed automatically and 27 were removed manually. Clear inclusion and exclusion criteria were developed (Appendix B). Titles and abstracts were screened independently by two reviewers against the inclusion/exclusion criteria. One hundred records were included for full-text review by two independent reviewers. Five studies were deemed eligible for inclusion in the review, and one additional study was identified through citation searching. A flow chart of the study selection process for this study is outlined in Figure 1.

Data Extraction and Synthesis

A comprehensive data charting form was developed by the research team to extract information relevant to the research question. Author, publication year, country of study, study population, study design, data collection method(s), study objective(s), intervention description, type of intervention, location/setting of intervention, target 2SLGBTQ+ population(s), inequities/barriers targeted, and key findings were charted in Microsoft Excel. Author GM extracted all data independently. We used descriptive statistics to describe study characteristics, and we used inductive content analysis (ICA) to thematically analyze the data. ICA has been identified as a method of qualitative content analysis well-suited for health-related research, particularly when the aim is to provide an answer relevant to policy or practice (Vears & Gillam, 2022). ICA involves five inductive stages in which qualitative text content is iteratively coded into categories or sub-categories (Vears & Gillam, 2022). After becoming familiar with the studies through reading and charting data, GM highlighted terms in the Microsoft Excel chart relevant to the research question. Highlighted terms were used to generate codes. Codes were then analyzed and organized into broad categories and sub-categories. Herein these categories are referred to as themes. Themes were debriefed with Author MN.

Figure 1

Flow Chart of Study Selection Process



In accordance with Vears and Gillam (2022), a theoretical framework was used to aid in the interpretation of the themes. McLeroy et al.'s (1988) socio-ecological model (SEM) includes intrapersonal, interpersonal, organizational, community, and public policy levels. The SEM is used in health promotion to emphasize how effective interventions must move beyond individually oriented behaviour change (McLeroy et al., 1988; Stokols, 1996). The SEM provided a strong framework for us to critically examine findings and identify gaps in the literature.

Results

Study Characteristics

We identified six studies in the final review. Publication dates ranged from 2013 to 2022. Two studies were conducted in Canada, and the other four were conducted in Ireland, Nepal, the United Kingdom, and the United States, respectively. Most studies used mixed methods and conducted questionnaires (n=5; 83%) and semi-structured interviews or focus groups (n=4; 66%). Two studies (33%) had a quasi-experimental design with pre-post-test evaluation. Table 2 outlines the types of interventions and target populations reported in the studies. While all (n=6) interventions aimed to impact palliative care for adults, two (33%) were tailored to older adults, and one (16%) was tailored to young men of colour who have sex with men living with HIV. The interventions evaluated in the studies include interdisciplinary provider training sessions (n=3; 50%); a volunteer community-based network of 2SLGBTQ+ older adults (n=1; 16%); a care and support centre (n=1; 16%); and a web-based platform for LGBT older adults (n=1; 16%). Half (n=3; 50%) of the interventions targeted multidisciplinary providers and the other half (n=3; 50%) targeted sexual and gender minorities. An overview of the characteristics of the six studies can be found in Appendix C.

Table 2

Overview of Types of Interventions and Target Populations

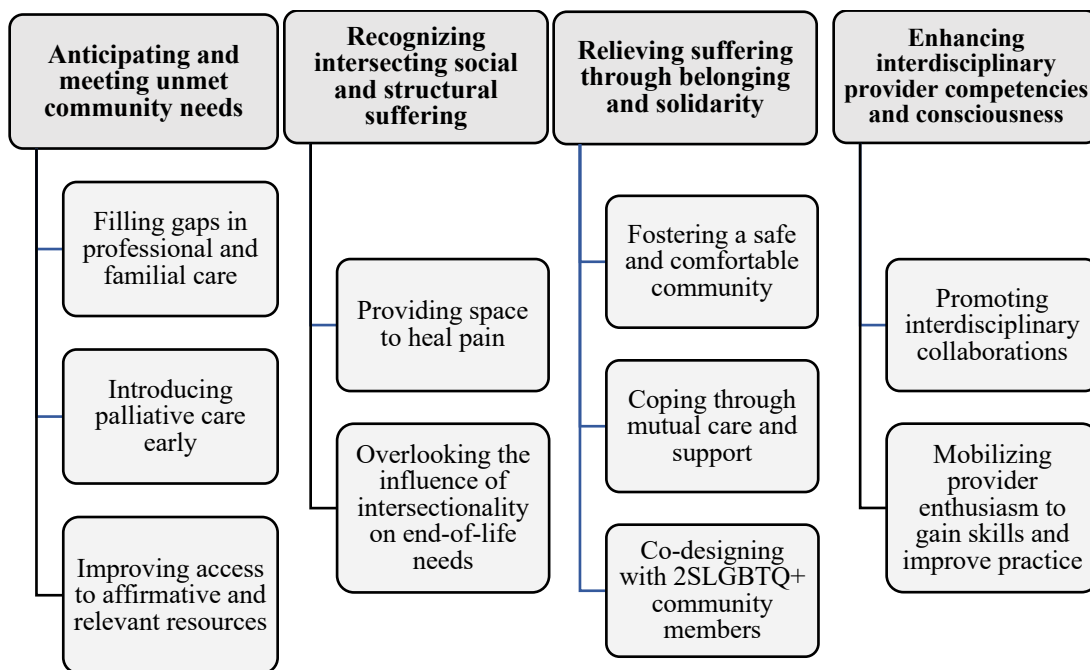
| Author(s), Publication year | Type of Intervention | Target Population |
|--------------------------------|---|---|
| Alexander et al., (2021) | Training on the early use of the palliative approach to care. All staff received 4-hour quarterly in-service workshops over 18 months, and a sub-group received 1–2-hour training sessions over a 5-month period | Multidisciplinary providers at HIV outpatient clinics |
| Baskaran & Hauser, (2022) | Palliative care and support centre organized by a non-profit organization. | LGBTQI+ people with terminal or chronic illnesses |
| Beringer et al., (2017) | Web-based platform including resource inventory on end-of-life care and planning | LGBT older adults |
| Chidiac et al., (2021) | 1.5-hour one-time training session | Multidisciplinary providers at four hospices |
| Grassau et al., (2021) | Volunteer community-based network focused on promoting affirming and safe care and community connection | LGBTQ2S+ older adults and allies |

| Author(s), Publication year | Type of Intervention | Target Population |
|--------------------------------|-------------------------------------|---|
| Reygan & D'Alton, (2013) | 50-minute one-time training session | Multidisciplinary providers at two hospitals and two hospices |

Through ICA, several themes and sub-themes were revealed. These themes reflect gaps in the existing literature and explore what and how non-clinical interventions reduce inequities in palliative care for 2SLGBTQ+ people. The four main themes include (a) anticipating and meeting unmet community needs, (b) recognizing intersecting social and structural suffering, (c) relieving suffering through belonging and solidarity, and (d) enhancing interdisciplinary provider competencies and consciousness. Figure 2 outlines the themes and sub-themes.

Figure 2

Themes and Sub-themes



Theme 1: Anticipating and Meeting Unmet Community Needs

The first theme pertains to how non-clinical interventions are developed in response to unmet 2SLGBTQ+ community needs.

Filling Gaps in Professional and Familial Care

It was evident in our review that non-clinical interventions fill gaps in practical, social, and emotional support generated from relying on the health care system and families of origin to meet the needs of 2SLGBTQ+ people with life-limiting illness. Baskaran and Hauser (2022) described how, in the care-and-support centre they evaluated, oftentimes family would be absent for patients' final moments, requiring staff to fill the void of caregiving and emotional support. While loneliness and alienation from support can be exacerbated at the end of life, Grassau et al. (2021) reported simultaneous experiences of "families of choice" stepping forward to provide informal caregiving. In 2SLGBTQ+ communities, the term "chosen family" is used to describe family-like groups of close friends, as opposed to legal or biological family members, who serve as essential social supports (Weston, 1991). Grassau et al. (2021) warn that informal caregiving should not be relied on to compensate for the failure of the health care system to care for people of non-cisgender or non-heterosexual identities.

Introducing Palliative Care Early

Multiple (n=4) of the interventions in our review involved either providing early access to palliative care (Alexander et al., 2021; Baskaran & Hauser, 2022) or introducing the concept of palliative care early on in the face of life-limiting illness (Beringer et al., 2017; Grassau et al., 2021). Alexander et al. (2021) found that 2SLGBTQ+ palliative care training enabled interdisciplinary staff to integrate palliative approaches into chronic disease management for young men of colour who have sex with men living with HIV. The palliative care centre in Baskaran and Hauser's (2022) study supported 2SLGBTQ+ people living with terminal and chronic illnesses, including predominantly those with HIV/AIDS. Beringer et al. (2017) and Grassau et al. (2021) reported on how workshops, film nights, panel discussions, or web-based platforms can encourage 2SLGBTQ+ older adults to engage in end-of-life planning and spark proactive conversations about end-of-life and aging.

Improving Access to Affirmative and Relevant Resources

Some (n=2) of the interventions in our review enabled 2SLGBTQ+ people to access information, booklets, posters, and videos that mirrored their identities and needs (Baskaran & Hauser, 2022; Beringer et al., 2017). For example, on the web-based platform evaluated by Beringer et al. (2017), videos were posted on topics like going back into the closet (i.e., concealing 2SLGBTQ+ identity) at the end of life. Beringer et al. (2017) found that an online inventory can be useful for 2SLGBTQ+ people to be confident accessing end-of-life planning and care resources that have been screened for genuine 2SLGBTQ+ friendliness. In the community network evaluated by Grassau et al. (2021), older 2SLGBTQ+ adults accessed resources for themselves and volunteered in long-term care, home care, community services, and seniors' centres to deliver sessions on frailty, chronic illness, and end of life for 2SLGBTQ+ people.

Theme 2: Recognizing Intersecting Social and Structural Suffering

This theme underscores the importance of recognizing intersecting social and structural causes of suffering as symptoms that should be attended to for 2SLGBTQ+ people with life-limiting illness.

Providing Space to Heal Pain

Many (n=3) studies described ways in which the non-clinical intervention attended to the impact of past and present trauma on suffering at end of life (Baskaran & Hauser, 2022; Beringer et al., 2017; Grassau et al., 2021). Grassau et al. (2021) reported that a trauma-informed intervention allows 2SLGBTQ+ people to work through the effects of past trauma—like abuse, the HIV pandemic,

and rejection from family of origin—on their current state of illness. Baskaran and Hauser (2022) described how a care-and-support centre treated experiences of systemic discrimination and oppression as social and structural causes of pain. One of the mechanisms for healing this pain was empowering 2SLGBTQ+ people receiving palliative care to engage in 2SLGBTQ+ advocacy efforts (Baskaran & Hauser, 2022). Beringer et al. (2017) described how a web-based platform for end-of-life planning and care was extended to respond to unique health care, housing, psychological, spiritual, and social concerns for 2SLGBTQ+ people.

Overlooking the Influence of Intersectionality of End-of-life Needs

Almost all (n=5) of the interventions in our review framed 2SLGBTQ+ people as a monolithic group (Baskaran & Hauser, 2022; Beringer et al., 2017; Chidiac et al., 2021; Grassau et al., 2021; Reygan & D'Alton, 2013). Chidiac et al. (2021) noted that one drawback to short or one-time training is the lack of ability to convey to providers the intersectionality and diversity present among 2SLGBTQ+ people. In Baskaran and Hauser's (2022) evaluation of a care-and-support centre, participants expressed a wish that staff would affirm the uniqueness of their individual identities, rather than treating them based on reductionist perceptions about who a "2SLGBTQ+ person" is. Participants in Grassau et al.'s (2021) study suggested that older gay men may be more likely to engage in opportunities for social connection than explicit emotion sharing (e.g., discussion group). The training program evaluated by Alexander et al. (2021) considered intersectionality between incarceration, mental illness, homelessness, employment, religion/spirituality, and social network for young men who have sex with men with HIV.

Theme 3: Reliving Suffering Through Belonging and Solidarity

This theme illuminates how non-clinical interventions can relieve suffering at the end-of-life for 2SLGBTQ+ people, specifically by fostering environments of belonging and solidarity.

Fostering a Safe and Comfortable Community

Whether online or in-person, the interventions described by Baskaran and Hauser (2022), Beringer et al. (2017), and Grassau et al. (2021) created a space for people to build community based on common needs, fears, and challenges at the end of life. Baskaran & Hauser's (2022) evaluation of a care-and-support centre revealed that new friendships were forged among fellow community members, which fostered a sense of support that was described as "therapeutic." Almost all providers and administrators at the care-and-support centre evaluated by Baskaran and Hauser (2022) identified as 2SLGBTQ+. In the community network evaluated by Grassau et al. (2021), consistent programs like discussion groups were identified as important for forming bonds and trust among members. Beringer et al. (2017) found that a web-based platform for end-of-life planning and care with signs of 2SLGBTQ+-friendliness (e.g., rainbow flags) and moderated interactive discussion boards can foster a supportive community for 2SLGBTQ+ older adults.

Coping Through Mutual Care and Support

A bi-directional process of both giving and receiving care was illustrated in three of the studies in our review (Baskaran & Hauser, 2022; Beringer et al., 2017; Grassau et al., 2021). In their study of a care-and-support centre, Baskaran and Hauser (2022) described how 2SLGBTQ+ patients provided peer-to-peer support by staffing a hotline for rural 2SLGBTQ+ community members to call with questions about their sexual orientation or gender identity. In the web-based platform evaluated by Beringer et al. (2017), 2SLGBTQ+ older adults showed a desire to extend support to others by sharing links on social media to 2SLGBTQ+-friendly end-of-life planning and care resources. Grassau et al. (2021) emphasized that while volunteer community-based networks aid in

preserving self-determination for 2SLGBTQ+ people at end of life, upholding this type of informal caregiving is tiring work that should be reinforced by formal and professional support.

Co-designing with 2SLBTQ+ Community Members

The majority of studies (n=5) reported on the involvement of 2SLGBTQ+ community members not just as recipients, but as active collaborators in the interventions (Alexander et al., 2021; Beringer et al., 2017; Chidiac et al., 2021; Grassau et al., 2021; Reygan & D'Alton, 2013). The community network described by Grassau et al. (2021) showed that palliative care interventions can draw on community development principles by designing initiatives with and for community members. Beringer et al. (2017) conducted town halls, focus groups, and an engagement process with 2SLGBTQ+ people to gather input for a web-based platform. In the training program evaluated by Reygan and D'Alton (2013), a 2SLGBTQ+-identified facilitator with lived and professional expertise was engaged. 2SLGBTQ+ people served as advisors to inform the design and implementation of the training programs evaluated by Alexander et al. (2021) and Chidiac et al. (2021). Chidiac et al. (2021) found that 2SLGBTQ+ people's participation on the project team was vital to ensure providers and leaders engaged with the 2SLGBTQ+ population and considered their needs.

Theme 4: Enhancing Interdisciplinary Provider Competencies and Consciousness

This theme relates to the impact of training programs as a non-clinical intervention to reduce inequities in palliative care for 2SLGBTQ+ people.

Promoting Interdisciplinary Collaborations

In all the studies that evaluated training as an intervention (n=3), staff from multiple disciplines participated (Alexander et al., 2021; Chidiac et al., 2021; Reygan & D'Alton, 2013). Alexander et al. (2021) described interdisciplinary team involvement as an essential component of delivering quality palliative care. The programs evaluated by Chidiac et al. (2021) and Reygan and D'Alton (2013) both comprised a presentation and interactive discussion. These were developed and adapted for providers/staff from diverse disciplines and intended to establish a foundation of collective awareness of the issues and needs of 2SLGBTQ+ people in the context of a life-limiting illness. The programs involved nurses, chaplains, physiotherapists, occupational therapists, health care assistants, doctors, counsellors or therapists, and social workers (Chidiac et al. 2021; Reygan & D'Alton, 2013).

Mobilizing Provider Enthusiasm to Gain Skills and Improve Practice

The impetus for most training programs was a lack of resources and education available to providers to develop the necessary skills and awareness to provide 2SLGBTQ+-inclusive palliative care (Chidiac et al., 2021; Reygan & D'Alton, 2013). Training programs enhanced providers' knowledge about 2SLGBTQ+ issues and needs, their confidence to provide palliative care for 2SLGBTQ+ patients, and their comfort using 2SLGBTQ+-related terminology and language (Chidiac et al., 2021; Reygan & D'Alton, 2013). Alexander et al. (2021) reported that training about the palliative care approach enabled those working in related fields, like HIV management, to incorporate cross-disciplinary skills to improve their practice. Chidiac et al. (2021) found training to be an essential approach to counter negative provider attitudes and assumptions about 2SLGBTQ+ patients. In the programs evaluated by Chidiac et al. (2021) and Reygan and D'Alton (2013), participants reported the training as useful for their practice and indicated that they would be interested in further training and would recommend it to colleagues.

Discussion

This narrative review reveals what is known about implemented and evaluated non-clinical interventions regarding palliative care for 2SLGBTQ+ people. After a systematic search and screening process, six studies were included. We employed the socio-ecological model (SEM) as a lens to critically examine the findings according to the research question and objectives.

Examining Results Through a Socio-Ecological Lens

McLeroy et al.'s (1988) SEM emphasizes that interventions must not focus solely on individually oriented behaviour change but should also target intrapersonal, interpersonal, organizational, community, and public policy levels. Interventions can span multiple interrelated SEM levels.

Intrapersonal

This level of the SEM refers to changing individual characteristics, such as knowledge, behaviours, attitudes, and skills (McLeroy et al., 1988). All (n=6) studies in our review involved interventions at this level. Half (n=3) of the studies focused on interdisciplinary provider training (Alexander et al., 2021; Chidiac et al., 2021; Reygan & D'Alton, 2013). Half (n=3) of the studies addressed the lack of practical end-of-life resources for 2SLGBTQ+ people (Baskaran & Hauser, 2022; Beringer et al., 2017; Grassau et al., 2021). Though intrapersonal interventions can be "criticized as superficial because they do not change structural forces that give rise to stigma," they are still valuable and oftentimes easier to implement (Cook et al., 2014, p. 103). Our review found that intrapersonal interventions can be useful to increase providers' understanding of and sensitivity toward 2SLGBTQ+ patients and to support 2SLGBTQ+ people in navigating inequities in end-of-life planning and care.

Interpersonal

This level of the SEM suggests that interpersonal relationships are an important source of social resources that mediate life stress and influence overall well-being (McLeroy et al., 1988). Three studies in our review revealed examples of harnessing existing social relationships and building up support networks to restore 2SLGBTQ+ people's self-determination over their palliative care experiences (Baskaran & Hauser, 2022; Beringer et al., 2017; Grassau et al., 2021). These interventions fill gaps in end-of-life care to care for more than the physical causes of suffering. Support networks create a reciprocal process of giving and receiving practical and emotional support. However, findings from Grassau et al. (2021) cautioned that it is not sustainable to rely on volunteer support networks in the absence of progress at systematic and structural levels, such as in the health and social care systems.

Organizational

This level of the SEM underscores the importance of organizational context for the scale and spread of non-clinical interventions. Non-clinical interventions require substantial human and financial investments to be sustained and are often incompatible with the goals and norms of health organizations (McLeroy et al., 1988). Our review found that most (n=5) non-clinical interventions regarding palliative care for 2SLGBTQ+ people did not target the organizational level. However, Baskaran and Hauser (2022) describe a palliative care centre funded and staffed by a 2SLGBTQ+ non-profit organization. Our review showed that training at organizations like hospices can contribute to a culture of understanding and interest in improving care for 2SLGBTQ+ patients (Chidiac et al., 2021; Reygan & D'Alton, 2013). This organizational culture shift could in turn spark the implementation of other 2SLGBTQ+-specific interventions.

Community

This level of SEM refers to partnerships among informal networks, institutions, and organizations (McLeroy et al., 1988). Our review found no examples of interventions regarding palliative care for 2SLGBTQ+ people that target the community level. Some (n=3) interventions fostered a sense of community through support networks, but these largely functioned in isolation from organizations and institutions and did not engage beyond 2SLGBTQ+ people, their caregivers, and allies (Baskaran & Hauser, 2022; Beringer et al., 2017; Grassau et al., 2021). Our review highlighted the importance of institutions and organizations to develop interventions with and for 2SLGBTQ+ communities (Alexander et al., 2021; Beringer et al., 2017; Chidiac et al., 2021; Grassau et al., 2021; Reygan & D'Alton, 2013).

Public Policy

This level of SEM refers to the power of public policy, procedures, and laws (McLeroy et al., 1988). Evident in our review is the lack of implemented and evaluated interventions at the policy level regarding palliative care for 2SLGBTQ+ people. Baskaran and Hauser's (2022) study provided a glimpse into how interventions could empower 2SLGBTQ+ patients to engage in advocacy efforts. Strong governmental or organizational policy is necessary to support the institutionalization of interventions and to address underlying social and structural drivers of inequities in palliative care for 2SLGBTQ+ people.

Gaps in Non-Clinical Interventions

There is a need for more interventions outside the clinical environment and patient-provider interaction. Our review found a substantial lack of implementation and evaluation of interventions regarding palliative care for 2SLGBTQ+ people. Without evaluation, it is difficult to assess whether recommended programs, policies, and practices are feasible, sustainable, and acceptable and whether they reduce the barriers and inequities 2SLGBTQ+ people face in palliative care. There are many factors that may contribute to interventions not being reported on or evaluated. This includes limited community organization resources and access to research expertise, a lack of dedicated funding and support for knowledge mobilization, and systemic marginalization of 2SLGBTQ+ populations in research.

Existing interventions fail to recognize the intersection of distinct social categories of identity (e.g., race, Indigeneity, socio-economic status, age, ability) across and between 2SLGBTQ+ populations. The literature echoes this finding, highlighting a need for interventions tailored to transgender and gender nonconforming people, as well as Two-Spirit, Black, and other 2SLGBTQ+ people of colour (De Jong et al., 2024; Robinson & Matamoros, 2024). Training interventions could be perceived as inauthentic and reductionist by 2SLGBTQ+ populations if they are done in the absence of organizational change (De Jong et al., 2024). Our review highlighted a gap in interventions at the organizational, community, and public policy levels. Addressing this gap is critical, as the power of intrapersonal and interpersonal interventions to tackle inequities could be stifled by deeply rooted social and structural factors.

Strengths and Limitations

To our knowledge, this is the first review study to provide an overview of existing implemented and evaluated non-clinical interventions for palliative care for 2SLGBTQ+ people. Our study is novel in its application of the SEM to map how existing interventions address inequities in palliative care for 2SLGBTQ+ people. The rigour and quality of this narrative review is enhanced by the systematic procedure that was established a priori to select and analyze studies (Ferrari, 2015; Rumrill & Fitzgerald, 2001). Screening was conducted by two independent reviewers. Our review examines the types, barriers, and benefits of interventions, and therefore does not conclude about

the effectiveness of them. Critical and quality appraisal of the included studies was not within the scope of this review. As only journal articles published in English were eligible for inclusion, studies published in other languages or other relevant literature could have been excluded. Work done by communities and organizations that may not be evaluated or reported in published literature could have been missed. As the studies in our review span a vast array of countries and cultures, not all interventions or findings may be transferrable to the socio-cultural and health system context of Canada.

Implications

This narrative review contributes to the inquiry into what and how interventions reduce inequities in palliative care for 2SLGBTQ+ people. Our review features literature about interventions that have been implemented in various settings and forms and across multiple socio-ecological levels. Our findings provide insight that could assist health administrators, researchers, and policy-makers in their efforts to reduce barriers to palliative care for the over one million people who identify as 2SLGBTQ+ in Canada (Statistics Canada, 2022). The information presented in this study could set the stage for future research on interventions for other equity-deserving groups who face disparities in palliative care (Bassah et al., 2024; Bowers et al., 2022). By focusing on interventions beyond the clinical environment and patient-provider interaction, our review contributes to the health-promoting palliative care field and applies a new lens in response to the need to improve palliative care for 2SLGBTQ+ people (Rosenberg & Yates, 2010; Sirianni, 2020). Our review elucidates how interventions that address social and structural dimensions of care promote access to a good death for 2SLGBTQ+ people facing life-limiting illness. The identified interventions model how palliative care can be de-professionalized to empower 2SLGBTQ+ patients and their communities to have ownership over their death and dying.

Recommendations for Future Policy, Practice, and Research

Canada-specific research, such as a grey literature review, is vital given inadequate national palliative care capacity that will likely exacerbate gaps in care for 2SLGBTQ+ people (Canadian Cancer Society, 2023). Future evaluative research could benefit from employing the SEM to assess, across multiple levels, if and how interventions improve palliative care for 2SLGBTQ+ people. Strengthening the evidence base on the outcomes of these interventions could support long-term human and financial investment. 2SLGBTQ+ people should be engaged in priority-setting, design, delivery, and evaluation of interventions. It is critical to ensure community groups and organizations have access to the knowledge and tools to report on the interventions they lead. For example, freely accessible evaluation guides have been developed to empower Compassionate Communities to evaluate the impact of their initiatives (Pallium Canada, 2025). Further, community groups and organizations can face barriers to reporting their work, as many journals still privilege academic and clinical research. There is a need to reframe what is considered valid research to ensure the impactful work and lived expertise of communities is disseminated broadly.

Employing a trauma-informed intersectional approach would ensure the impacts of distinct social categories of identity on end-of-life experiences are considered in intervention design, implementation, and evaluation (Shimmin et al., 2017). Health authorities, long-term care facilities, and hospices could review health equity frameworks and inclusion policies to ensure they contain best practices for 2SLGBTQ+-inclusive care. These organizations could modify and implement non-clinical interventions presented in our review. Providers and administrators may also refer to existing resources, anchored in evidence and lived expertise, to better serve 2SLGBTQ+ communities at end-of-life (Acquaviva, 2023; Canadian Virtual Hospice, n.d.; National Hospice and Palliative Care Organization, 2021).

Conclusion

Our review found six studies that reported on the implementation and evaluation of non-clinical interventions regarding palliative care for 2SLGBTQ+ people. Interventions that address social and structural determinants of inequities in palliative care for 2SLGBTQ+ people promote access to a good death. There is a gap in interventions at the organizational, community, and public policy levels. Future research should map efforts specific to the Canadian context and employ the SEM to evaluate implemented interventions. Future interventions should be designed and implemented using a trauma-informed intersectional approach and by centring 2SLGBTQ+ community members' distinct identities, needs, strengths, and lived expertise.

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Declaration of Ethics

Ethics application is not required for this study.

Conflict of Interest

The authors have no conflicts of interest relevant to this article to disclose.

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Author Contribution

GM conceptualized and designed the review, led the search and screening, led data extraction and interpretation, and drafted the initial manuscript. MN supervised the study and critically reviewed and revised the manuscript. All authors approved the final manuscript as submitted.

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Appendix A

Database Search Strategies

| | |
|---|---|
| PubMed | <p>("Palliative Care"[MeSH Terms] OR "Terminal Care"[MeSH Terms] OR ("end of life care"[Title/Abstract] OR "Palliative Care"[Title/Abstract] OR "supportive care"[Title/Abstract] OR "palliat*" [Title/Abstract] OR "hospice"[Title/Abstract] OR "home palliative care"[Title/Abstract] OR "Terminal Care"[Title/Abstract] OR "terminally ill"[Title/Abstract])) AND ("lgbt*" [Title/Abstract] OR "queer"[Title/Abstract] OR "gay"[Title/Abstract] OR "lesbian"[Title/Abstract] OR "transgender"[Title/Abstract] OR "bisexual"[Title/Abstract] OR "two spirit"[Title/Abstract] OR "homosex*" [Title/Abstract] OR "gender minorit*" [Title/Abstract] OR "sexual minorit*" [Title/Abstract] OR "Sexual and Gender Minorities"[MeSH Terms])</p> |
| CINAHL | <p><u>S1</u> TI (LGB* OR queer OR gay OR lesbian OR transgender OR bisexual OR 'two-spirit' OR homosex* OR 'gender minorit*' OR 'sexual minorit*') OR AB (LGB* OR queer OR gay OR lesbian OR transgender OR bisexual OR 'two-spirit' OR homosex* OR 'gender minorit*' OR 'sexual minorit*')</p> <p><u>S2</u> (MH "LGBTQ+ Persons+") OR (MH "Asexuality") OR (MH "Bisexuality") OR (MH "Homosexuality") OR (MH "Questioning Persons") OR (MH "Gender Identity")</p> <p><u>S3</u> TI ('End-of-life care' OR 'palliative care' OR 'supportive care' OR palliat* OR hospice OR 'home palliative care' OR 'terminal care' OR 'terminally ill') OR AB ('End-of-life care' OR 'palliative care' OR 'supportive care' OR palliat* OR hospice OR 'home palliative care' OR 'terminal care' OR 'terminally ill')</p> <p><u>S4</u> (MH "Terminally Ill Patients") OR (MH "Hospice Patients") OR (MH "Palliative Care") OR (MH "Hospice Care") OR (MH "Terminal Care")</p> <p><u>S5</u> = S1 OR S2 <u>S6</u> = S3 OR S4 <u>S7</u> = S5 AND S6</p> |
| Academic Search Premier and Gender Studies Database | <p><u>S1</u> TI (LGB* OR queer OR gay OR lesbian OR transgender OR bisexual OR 'two-spirit' OR homosex* OR 'gender minorit*' OR 'sexual minorit*') OR AB (LGB* OR queer OR gay OR lesbian OR transgender OR bisexual OR 'two-spirit' OR homosex* OR 'gender minorit*' OR 'sexual minorit*')</p> <p><u>S2</u> SU (LGB* OR queer OR gay OR lesbian OR transgender OR bisexual OR 'two-spirit' OR homosex* OR 'gender minorit*' OR 'sexual minorit*')</p> <p><u>S3</u> TI ('End-of-life care' OR 'palliative care' OR 'supportive care' OR palliat* OR hospice OR 'home palliative care' OR 'terminal care' OR 'terminally ill') OR AB ('End-of-life care' OR 'palliative care' OR 'supportive care' OR palliat* OR hospice OR 'home palliative care' OR 'terminal care' OR 'terminally ill')</p> <p><u>S4</u> SU ('End-of-life care' OR 'palliative care' OR 'supportive care' OR palliat* OR hospice OR 'home palliative care' OR 'terminal care' OR 'terminally ill')</p> <p><u>S5</u> = S1 OR S2</p> |

| | |
|------------------------|--|
| | <p><u>S6</u> = S3 OR S4</p> <p><u>S7</u> = S5 AND S6</p> |
| Sociological Abstracts | <p><u>S1</u> title(LGB* OR queer OR gay OR lesbian OR transgender OR bisexual OR 'two-spirit' OR homosex* OR 'gender minorit*' OR 'sexual minorit*') OR abstract(LGB* OR queer OR gay OR lesbian OR transgender OR bisexual OR 'two-spirit' OR homosex* OR 'gender minorit*' OR 'sexual minorit*')</p> <p><u>S2</u> title('End-of-life care' OR 'palliative care' OR 'supportive care' OR palliat* OR hospice OR 'home palliative care' OR 'terminal care' OR 'terminally ill') OR abstract('End-of-life care' OR 'palliative care' OR 'supportive care' OR palliat* OR hospice OR 'home palliative care' OR 'terminal care' OR 'terminally ill')</p> <p><u>S3</u> mainsubject(LGB* OR queer OR gay OR lesbian OR transgender OR bisexual OR 'two-spirit' OR homosex* OR 'gender minorit*' OR 'sexual minorit*')</p> <p><u>S4</u> mainsubject('End-of-life care' OR 'palliative care' OR 'supportive care' OR palliat* OR hospice OR 'home palliative care' OR 'terminal care' OR 'terminally ill')</p> <p><u>S5</u> = S1 OR S3</p> <p><u>S6</u> = S2 OR S4</p> <p><u>S7</u> = S5 AND S6</p> |
| Embase | <p><u>S1</u> 'palliative therapy'/exp OR 'terminal care'/exp OR 'terminally ill patient'/exp</p> <p><u>S2</u> lgb*:ti,ab OR queer:ti,ab OR gay:ti,ab OR lesbian:ti,ab OR transgender:ti,ab OR bisexual:ti,ab OR 'two-spirit':ti,ab OR homosex*:ti,ab OR 'gender minorit*':ti,ab OR 'sexual minorit*':ti,ab</p> <p><u>S3</u> 'end-of-life care':ti,ab OR 'palliative care':ti,ab OR 'supportive care':ti,ab OR palliat*:ti,ab OR hospice:ti,ab OR 'home palliative care':ti,ab OR 'terminal care':ti,ab OR 'terminally ill':ti,ab</p> <p><u>S4</u> 'lgbtqia+ people'/exp</p> <p><u>S5</u> = S1 OR S3</p> <p><u>S6</u> = S2 OR S4</p> <p><u>S7</u> = S5 AND S6</p> |

Appendix B

Inclusion and Exclusion Criteria

| Inclusion | Exclusion |
|---|---|
| <ul style="list-style-type: none"> Published in English Published journal articles Full-text accessibility All countries and locations All ages 2SLGBTQ+ population(s) Directly focused on palliative care or a related subdomain Describes one or more non-clinical intervention regarding palliative care for 2SLGBTQ+ people The non-clinical intervention addresses at least one inequity or barrier to palliative care for 2SLGBTQ+ people or subpopulation The non-clinical intervention has been implemented and evaluated | <ul style="list-style-type: none"> Not published in English Grey literature, media articles, conference abstracts, protocols, books, book chapters, commentaries, and editorials. Studies that are not available in full-text Non-2SLGBTQ+ people as target population Studies that are not focused on palliative care or a related subdomain Studies that describe a clinical intervention (i.e., patient-provider level) Studies where the described non-clinical intervention does not directly address an inequity or barrier to palliative care for 2SLGBTQ+ people or subpopulation Studies that describe an intervention that has not yet been implemented or evaluated. |

Appendix C

Overview of Study Characteristics

| Author(s), Publication Year | Country | Design | Study Population(s) |
|--------------------------------|----------------|---|--|
| Alexander et al., (2021) | United States | <i>Mixed methods, quasi-experimental:</i> combined the use of pre-post-test questionnaire, interviews, and longitudinal chart reviews. | <ul style="list-style-type: none"> HIV-positive young men aged 18–35 years who have sex with men (yMSM) (n=197) Multidisciplinary providers |
| Baskaran & Hauser, (2022) | Nepal | <i>Mixed methods:</i> combined the use of questionnaire with semi-structured interviews. | <ul style="list-style-type: none"> LGBTQI+ patients (n=8) Multidisciplinary providers (n=5) Family/community members (n=2) Administrators (n=14) |
| Beringer et al., (2017) | Canada | <i>Mixed methods:</i> Phase 1 consisted of a series of focus groups to inform the design of a web-based platform. Phase 2 involved a town-hall meeting to solicit feedback about the platform. Next, platform traffic was monitored, and user feedback was also collected from social media and emails. | <ul style="list-style-type: none"> LGBT older adults Community organizations Health care providers |
| Chidiac et al., (2021) | United Kingdom | <i>Quantitative, quasi-experimental:</i> pre-post-test questionnaire. | <ul style="list-style-type: none"> Palliative care multidisciplinary providers (n=145) |
| Grassau et al., (2021) | Canada | <i>Mixed methods:</i> combined the use of semi-structured focus groups and demographic questionnaire. | <ul style="list-style-type: none"> 2SLGBTQ+ Ottawa Senior Pride Network members (n=9) |
| Reygan & D'Alton, (2013) | Ireland | <i>Mixed methods:</i> combined the use of questionnaire and interviews. | <ul style="list-style-type: none"> Oncological and palliative care multidisciplinary providers (n=201) |