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A rapid review of end-of-life needs in the LGBTQ+ community and
recommendations for clinicians

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A rapid review of end-of-life needs in the LGBTQ+ community and recommendations for clinicians

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Abstract

Background: Lesbian, gay, bisexual, transgender, and queer plus (LGBTQ+) adults face challenges accessing end-of-life care. Understanding the experiences of LGBTQ+ persons within the end-of-life context is crucial in addressing their needs and supporting equity at end of life.

Aim: Review recent literature documenting the experiences of LGBTQ+ adults nearing end-of-life, identifying needs, barriers to care, and translating this into clinical recommendations.

Design: A rapid review design was chosen for prompt results. The process was streamlined by limiting the literature search to peer-reviewed articles, dissertations, theses, by date and language. Data collection used a predetermined set of items based on Meyer's Minority Stress and Bronfenbrenner's Ecological Models including participants' voices, needs, and barriers. Thematic analysis of collected data was conducted and presented results in a narrative summary.

Data Sources: We searched six electronic databases (PubMed, Medline, ProQuest Dissertations and Theses A&I, ProQuest Dissertations and Theses, Open Access Theses and Dissertations, CINAHL, and Google Scholar) for articles published from 2016 to 2020.

Results: We included and appraised for quality 33 articles. We uncovered three latent themes: systemic barriers, a lack of lived experience within the literature, and treatment of LGBTQ+ as one homogeneous group.

Conclusions: The hybrid Meyer's Minority Stress and Bronfenbrenner Ecological model elucidated how stressors and social contexts may impact LGBTQ+ adults when accessing end-of-life care. Incorporating LGBTQ+ cultural competence training into continuing education and ensuring that LGBTQ+ individuals participate in the development of end-of-life care programming may better attend to the needs of this population.

Keywords

LGBTQ+, LGBTQ, end-of-life care, aging, palliative care, long-term care, rapid review, health services needs and demands

What is already known about the topic?

- LGBTQ+ adults' cumulative experience of discrimination over the life course has led to a distrust of and reluctance to access healthcare
- LGBTQ+ adults face challenges accessing end-of-life care
- No recent reviews (2016–2020) examine needs/barriers to end-of-life care for the LGBTQ+ community using Meyer's Minority Stress Model and the Bronfenbrenner's Ecological Model as a single framework

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What this paper adds

- Significant gaps in end-of-life care remain and future research should focus on the lived experience of LGBTQ+ older adults as less than half of the review study participants were LGBTQ+ individuals with direct lived experience (as either a patient or informal caregiver) in end-of-life care
- Systemic barriers perpetuate a heteronormative culture that assumes or rejects individuals' sexuality and gender preferences
- The tendency to treat LGBTQ+ individuals as a homogenous group does not acknowledge that the distinct subgroups operate within a context of intersecting identities and social determinants of health
- It is imperative to consider the complexities involved in making health systems LGBTQ+ affirmative. Changes must be perceived as authentic among LGBTQ+ individuals to be effective

Implications for practice, theory, or policy

- Understanding the relationship between the different experiences of LGBTQ+ adults in the end-of-life context is crucial to address the specific needs of each sub-group within this community and support access to end-of-life care to all
- The programming of services in end-of-life domains needs to ensure that LGBTQ+ individuals (and their support systems) are included as stakeholders
- Incorporating LGBTQ+ cultural competence training and follow-up into healthcare providers' continuing education which also involves a commitment to long-term self-reflection of implicit biases, implemented in tandem with organizational wide processes may better attend to the needs of this population

Introduction

According to the World Health Organization,¹ the number of adults aged 60 years and older in 2019 was one billion; by 2030 this is expected to increase to 1.4 billion. Consequently, there will be a concomitant increase in the number of older Lesbian, gay, bisexual, transgender, queer (LGBTQ+) people, and a corresponding increase in the number of them needing end-of-life care.²

The LGBTQ+ community has faced historical discrimination, oppression, and persecution by religious institutions, state, and medical authorities.³⁻⁷ While social movements have fought for the rights of persons who identify as LGBTQ+, historical and vicarious trauma, and ongoing inequities have implications for health, health care access and delivery.^{4,7,8} Research during the Acquired Immunodeficiency Syndrome crisis in the 1980's reported that gay men experienced discrimination, mistrust of hospice and palliative care, estrangement from families, and difficulty accessing their partners and chosen family.^{9,10} Transgender adults have also suffered micro and macro aggressions throughout their lives from almost all facets of society. Many trans individuals face extreme discrimination from healthcare staff which results in hesitancy and unwillingness to access health-care services.¹¹ This includes a reluctance to enter long-term care facilities, fearing they would need to conceal their marginalized sexual and/or gender identities.^{12,13} Accordingly, this population often chooses to remain "invisible" within the healthcare system resulting in unmet healthcare and end-of-life needs.^{14,15} Violence, abuse, and discrimination experienced within these social situations can accumulate stress over time, resulting in long-term health deficits, as

suggested by Meyer's Minority Stress Model.^{16,17} LGBTQ+ adults face challenges accessing end-of-life care (including hospice, palliative, and long-term care).¹⁸⁻²⁰ Simultaneously, healthcare professionals report difficulties in providing end-of-life care for LGBTQ+ patients regarding palliative care referrals, culturally competent care, psychosocial assessment, spiritual assessment, and bereavement.²¹

The end of life is a universal and unavoidable human experience. However, not all experiences are met with dignity, respect, and acceptance. It has been noted that "there is little unanimity on what constitutes a 'good death' and the appropriate societal responses to this issue of delivering culturally relevant and sustainable forms of end-of-life care in different settings are not subjects of broad agreement" (p. 72).²² Varied notions on what constitutes a good death brings up the question of what constitutes end-of-life care and what is a good end-of-life experience? For the purposes of this review, the concept of end-of-life care is based upon the National Institute on Aging which views end-of-life 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.²³ We determined that operationally defining "good" would be impractical as "good" is a subjective evaluation. Thus, this review focuses on examining the needs and barriers that impact the end-of-life care experience of LGBTQ+ adults.

Understanding the relationship between the different experiences of LGBTQ+ persons within the end-of-life context is crucial to address their specific needs and support equitable access to end-of-life care services. While previous reviews have identified discrimination and inequitable care

faced by LGBTQ+ in health care settings and identified a number of unmet needs faced at end-of-life, studies either focused strictly on cancer care,²⁴ were not specific to end-of-life care,⁶ or did not include barriers in its search.¹⁵ Therefore, we looked at barriers with the perspective that they could be factors formed throughout the life course. Furthermore, Stinchcombe et al.,¹⁵ stated that much of their inferences were limited by the current state of the literature at the time and encouraged continued research in this area, specifically incorporating a life course perspective to allow for an understanding of the personal histories and historical context in which this population is situated. To the best of our knowledge, no recent reviews (2016–2020) specifically explored both the barriers and unmet needs of this population during their end-of-life care experiences, while incorporating the life course perspective.

Our study is part of a larger project that aims to optimize the inclusion of the LGBTQ+ community with hospice and palliative care services. In order to provide decision-makers with timely results, a rapid review approach was chosen. Rapid reviews are an emerging type of literature synthesis which streamlines traditional review processes to provide end-users with results in a reduced timeframe and support decision-making in healthcare.²⁵ Our rapid review was conducted in 3 months and was guided by the question: What are the healthcare needs and barriers that impact LGBTQ+ adults end-of-life care as identified in the recent literature?

Methods

The use of rapid reviews can reduce the time required for a traditional review to less than six months.²⁶ Our approach followed the working definition of rapid review and design recommendations outlined by Tricco et al.²⁶ We also followed the reporting guidelines described in the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews Checklist²⁷ we adapted for the rapid review (Supplemental Material—Appendix 1).

Protocol and study selection

We defined a priori how to streamline the review process following Tricco et al.²⁶ design recommendations and the steps included: limiting the literature search to peer-reviewed articles, dissertations, and theses obtained online (no grey literature, no contact with authors); limiting inclusion criteria by date (January 2016 to February 2020) and language (English, French, and Portuguese according to the language proficiencies of the research team) having one person screen articles and another verify screening; and presenting results in a narrative summary after thematic analysis of abstracted data. While the focus of the rapid review is on adults aged 55+, we

determined that searching by specific age ranges/groups would be counterproductive as the definition of “older adult” varies considerably in the literature. We created a protocol to guide our rapid review, which is summarized in Supplemental Materials Appendix 2.

In February of 2020 we conducted an electronic search of the literature in PubMed, Medline, ProQuest Dissertations and Theses A&I, ProQuest Dissertations and Theses, Open Access Theses and Dissertations, CINAHL, and Google Scholar. We hand searched the cited literature in included full articles. Search terms included: (lesbian OR gay OR bisexual OR transgender OR queer OR intersex OR “two spirit” OR LGBT*) (death OR dying experience OR “nearing the end of life”) AND (palliative OR hospice OR end-of-life OR long-term care) AND (older adults) (health care). An example of the full search applied to the PubMed database is described in Supplemental Materials Appendix 3.

Manuscripts were included if they described findings relevant to LGBTQ+ adults and provided data related to hospice, palliative, long-term, assisted living, and/or end-of-life care. Articles providing information from the perspective of healthcare providers, patients, and/or families/informal caregivers were included. One reviewer (LL) conducted screening and exclusion of abstracts which was verified by a second reviewer (RB). All full texts (61 articles) were independently assessed by two reviewers (LL and RB). Excluded were any studies that could not identify the older LGBTQ+ adults’ specific concerns. Literature reviews without a description of the methodology, commentaries, briefings, editorials, perspective/opinion articles, and literature not available via interlibrary loan were also excluded. Disagreements about exclusion of full texts were discussed by the team (LL, RB, AD, HD) until consensus was reached, and reasons for exclusion were recorded. Thirty-three articles (54% of assessed manuscripts) were included. Figure 1 summarizes our search and selection process.

All articles were assessed for quality by three members of the team (AD, LL, and HD) who independently used validated tools depending on the type of articles: Mixed Method Appraisal Tool,²⁸ or Health Evidence Quality Assessment Tool—Review Articles.²⁹ Quality assessments were discussed when disagreements existed until consensus was reached. No articles were eliminated based on quality appraisals.

We collected data for predefined sets of items using a standardized Excel spreadsheet. Definition of items was informed by Meyer’s Minority Stress^{16,17} and Bronfenbrenner’s Ecological Models.^{30,31} An ecological perspective, such as the one proposed by Bronfenbrenner’s model,^{30,31} offers a good framework to analyze the social situations LGBTQ+ persons encounter by considering the multifaceted relations between individuals and the contextual systems they interact with.³² This type of framework has been used in exploring many subjects such as, physical activity interventions³³; public mental health research³⁴;

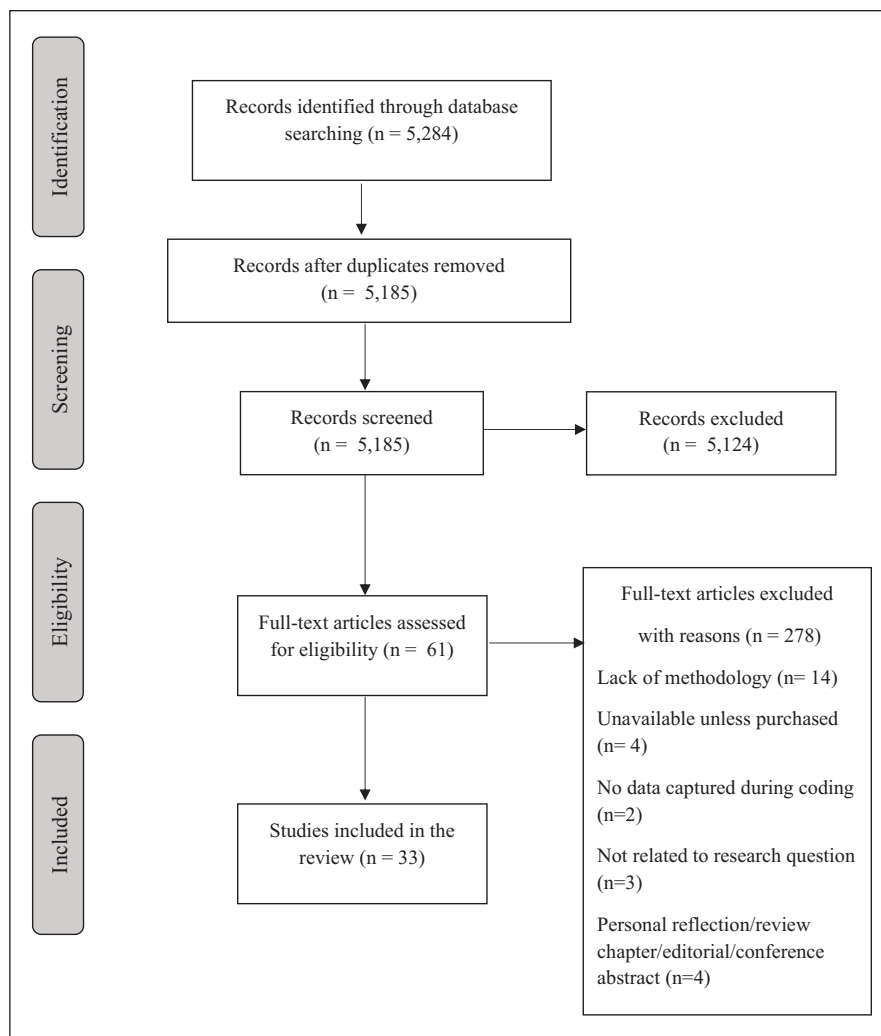


Figure 1. Study flow diagram.

and stigma in relation to men who have sex with men.³⁵ We used this framework to facilitate the understanding of the “dynamic interplay among persons, groups, and their socio-physical milieu” (p. 283).³⁶ Meyer’s Minority Stress Model^{16,17} was integrated alongside Bronfenbrenner to provide context for explaining the unique and adverse stressors (such as enacted, felt and/or internalized stigma) related to LGBTQ+ sexual minority identities and how these stressors negatively impact end-of-life experiences.

The form was pilot tested on three articles followed by a discussion to clarify discrepancies. Table 1 summarized the general characteristics we collected, and Table 2 summarizes the occurrence of the specific items we looked for in each article. LL and AD abstracted data from each article, which was verified by RB. Thematic analysis of abstracted data followed the framework proposed by Braun and Clarke,³⁷ who distinguish between two thematic levels: semantic and latent. We conducted a semantic analysis coding the semantic content (explicit surface meaning) of the data. This process was followed by a

latent analysis, where the entire team looked for underlying ideas and assumptions within the data. All data was synthesized narratively based on Tricco et al.²⁶ Popay et al.,³⁸ in their seminal article providing guidance on the conduct of narrative synthesis for systematic reviews, states that: “Thematic analysis, a common technique used in the analysis of qualitative data in primary research, can be used to identify systematically the main, recurrent and/or most important (based on the review question) themes and/or concepts across multiple studies” (p. 18). Although we have not conducted a systematic review, we judged it appropriate to use thematic analysis as a tool to synthesize our data.

Results

Most included articles reported findings from qualitative research studies.^{13,15,19–21,40–57,59–61} Roughly half of the studies were conducted in the United States^{21,41,43,45,47–49,54,56,57,59,62–64}, 10 in Canada.^{15,40,46,51–53,55,60,65,66}

Table 1. Demographic characteristics and quality assessments of included articles.

Author information	Study location	Funding	Sample information	Research design	Quality assessment tool and score
Willis et al. ¹³	United Kingdom (UK)	Comic Relief (charitable funding agency)	N = 37 HCP's, managers, and community advisors	Qualitative	MMAT—High Quality
Stinchcombe et al. ¹⁵	Canada (CA)	Law Commission of Ontario (LCO)	N = 25 articles related to health care and EOL needs of LGBT older adults and chosen family	Qualitative	Health Evidence—Moderate Quality
Hunt et al. ¹⁹	Africa	Open Society Foundations Open access for this article was funded by Kings College London	N = 60 key population adults N = 12 HCP's, palliative care representatives, and members of supportive organizations	Qualitative	MMAT—High Quality
Bristowe et al. ²⁰	UK	Marie Curie Research Grants Scheme, grant MCCC-RP-14-A17159	N = 23 qualitative and quantitative articles reporting bereavement experiences of lesbian, gay, bisexual, and/or trans* partners	Qualitative	MMAT—High Quality
Stevens and Abraham ²¹	United States (US)	Not specified	N = 2 individual self-identified as male and his spouse	Qualitative	MMAT—Moderate Quality
Simpson et al. ³⁹	UK	The National End of Life Care Programme and The School of Health Sciences (internal grant), University of Nottingham	N = 187 HCP's, care managers	Quantitative Descriptive	MMAT—High Quality
Sussman et al. ⁴⁰	CA	Not specified	N = 32 LTC home administrators interviewed N = 25 LTC administrators at a two-day meeting	Qualitative	MMAT—High Quality
Putney et al. ⁴¹	US	Simmons College President's Fund for Faculty Excellence, grant number 230059	N = 50 self-identified LGBT adults	Qualitative	MMAT—High Quality
Waling et al. ⁴²	Australia	Australian Research Council, grant number LP160100221	N = 33 self-identified older lesbian and gay adults	Qualitative	MMAT—High Quality
Boggs et al. ⁴³	US	National Institutes of Health (NIH)/National Center for Advancing Translational Sciences (NCATS) Colorado CTSI Grant Number UL1 TR000154	N = 154 individuals self-identified as transgender or gender-nonconforming	Qualitative	MMAT—High Quality
Bristowe et al. ⁴⁴	UK	Marie Curie Research Grants Scheme, grant MCCC-RP-14-A17159	N = 40 self-identified LGBT individuals and carers	Qualitative	MMAT—High Quality
Dotolo ⁴⁵	US	Not specified	N = 57 self-identified LGBTQ caregiving partners	Qualitative	MMAT—High Quality

(Continued)

Table 1. (Continued)

Author information	Study location	Funding	Sample information	Research design	Quality assessment tool and score
Wilson et al. ⁴⁶	CA	LCO	N = 3 focus groups comprised of 6–9 participants	Qualitative	MMAT—High Quality
Butler ⁴⁷	US	Not specified	N = 20 individuals self-identified as lesbian (includes four partners)	Qualitative	MMAT—High Quality
Campbell and Catlett ⁴⁸	US	Not specified	N = 2 hospice volunteer and patient	Qualitative	MMAT—High Quality
Dunkle ⁴⁹	US	Not specified	N = 31 self-identified as lesbian or gay	Qualitative	MMAT—High Quality
Hafford-Letchfield et al. ⁵⁰	UK	Comic Relief (charitable funding agency)	N = 18 community advisors, care home managers, and senior managers	Qualitative	MMAT—High Quality
Kortes-Miller et al. ⁵¹	CA	Not specified	N = 23 self-identified as LGBT	Qualitative	MMAT—High Quality
de Vries et al. ⁵²	CA	Canadian Frailty Network (formerly known as the Technology Evaluation in the Elderly Network)	N = 93 community-dwelling LGBT persons	Qualitative	MMAT—Moderate Quality
Pang et al. ⁵³	CA	Canadian Frailty Network, CAT2013-21	N = 24 transgender older adults	Qualitative	MMAT—High Quality
Caceres et al. ⁵⁴	US	National Institute of Nursing Research training grant [T32NR014205] to B.A.C.	N = 19 studies examining long-term care perspectives of health care providers (HCP's and individuals)	Qualitative	Health Evidence—Moderate Quality
Furlotte et al. ⁵⁵	CA	Arts Research Board of the Social Sciences and Humanities Research Council (SSHRC). The first author received a Doctoral Research Award (2012–2015) from the Institute of Aging of the Canadian Institutes of Health Research.	N = 12 self-identified same-sex couples	Qualitative	MMAT—High Quality
Lowers ⁵⁶	US	Staff development award from the American Institutes for Research	N = 30 self-identified LGBT adults	Qualitative	MMAT—High Quality
Seelman et al. ⁵⁷	US	National Institutes of Health Loan Repayment Program for Health Disparities Research through the National Institute on Minority Health & Health Disparities.	N = 9 self-identified LGBT adults	Qualitative	MMAT—High Quality

(Continued)

Table 1. (Continued)

Author information	Study location	Funding	Sample information	Research design	Quality assessment tool and score
Willis et al. ⁵⁸	UK	National Institute for Social Care and Health Research (NISCHR), Welsh Government 2011–2013 (SCRA/10/03)	N = 121 HCP's N = 20 LGB stakeholder representatives	Mixed Methods	MMAT—High Quality
Hinrichs and Christie ⁵⁹	US	Not specified	N = 2 self-identified lesbian and spouse, N = 1 HCP interdisciplinary team	Qualitative	MMAT—High Quality
Kortes-Miller et al. ⁶⁰	CA	Supported by the Retired Teachers of Ontario Foundation	N = 18 HCP and support staff	Qualitative	MMAT—High Quality
Westwood ⁶¹	UK	Not specified	N = 60 self-identified older LGB adults	Qualitative	MMAT—High Quality
Pelts and Galambos ⁶²	US	University of Missouri, Interdisciplinary Center on Aging, via a Research Enrichment and Dissemination grant	N = 60 long term care (LTC) staff	Mixed Methods	MMAT—High Quality
Smith et al. ⁶³	US	Not specified	N = 57 HCP's	Quantitative Descriptive	MMAT—High Quality
Stein et al. ⁶⁴	US	Borchard Foundation Center on Law and Aging	N = 865 HCP's, social workers, and chaplains	Mixed Methods	MMAT—Moderate Quality
Gahagan and Subirana-Malaret ⁶⁵	CA	Not specified	N = 283 self-identified LGBTQ respondents (individuals and HCP's)	Quantitative Descriptive	MMAT—High Quality
Kcomt and Gorey ⁶⁶	CA	Supported in part by an Ontario Graduate Scholarship	N = 8 studies related to End of Life (EOL) preparatory behaviors among LGBT people	Quantitative Descriptive	MMAT—High Quality

MMAT quality assessments were scored as follows: more than 2 “No” or “Can’t tell” responses were considered of low quality, assessments that received 1–2 “No” or “Can’t tell” responses were considered of moderate quality, assessments that received all “Yes” ratings were deemed to be of high quality. Health Evidence Assessment scoring was as follows: a total score of 4 or less was of low quality, a total score of 5–7 was of moderate quality, and a total score of 8–10 was deemed to be of high quality.

Two reviewers (A.D. and L.L.) separately (to reduce bias) read and scored the articles. Upon review of the assessments, any disagreement related to scoring was then taken to a third reviewer (H.D.) who read the articles in question and provided input.

Table 2. Rapid review articles, themes, categories, and codes.

Author and date	Participant voice		Needs				Barriers						
	HCP	LGBTQ+ person	Traditional family	Chosen family	Inclusivity	Social support	Stigma	Losses	Internalized	Positive marginality	Advocating voice	Social isolation	Distrust of the healthcare system
Willis et al. ¹³	*				*								
Stinchcombe et al. ¹⁵	*			*	*							*	
Hunt et al. ¹⁹	*				*				*			*	
Bristowe et al. ²⁰				*	*							*	*
Stevens and Abraham ²¹	*			*	*				*		*	*	
Simpson et al. ³⁹	*			*	*				*		*	*	
Sussman et al. ⁴⁰	*			*	*				*		*	*	
Putney et al. ⁴¹	*			*	*				*		*	*	
Waling et al. ⁴²	*			*	*				*		*	*	
Boggs et al. ⁴³	*			*	*				*		*	*	
Bristowe et al. ⁴⁴	*			*	*				*		*	*	
Dotolo ⁴⁵	*			*	*				*		*	*	
Wilson et al. ⁴⁶	*			*	*				*		*	*	
Butler ⁴⁷	*			*	*				*		*	*	
Campbell and Catlett ⁴⁸	*			*	*				*		*	*	
Dunkle ⁴⁹	*			*	*				*		*	*	
Hafford-Letchfield et al. ⁵⁰	*			*	*				*		*	*	
Kortes-Miller et al. ⁵¹	*			*	*				*		*	*	
de Vries et al. ⁵²	*			*	*				*		*	*	
Pang et al. ⁵³	*			*	*				*		*	*	
Caceres et al. ⁵⁴	*			*	*				*		*	*	
Furlotte et al. ⁵⁵	*			*	*				*		*	*	
Lowers ⁵⁶	*			*	*				*		*	*	
Seelman et al. ⁵⁷	*			*	*				*		*	*	
Willis et al. ⁵⁸	*			*	*				*		*	*	
Hinrichs and Christie ⁵⁹	*			*	*				*		*	*	
Kortes-Miller et al. ⁶⁰	*			*	*				*		*	*	
Westwood ⁶¹	*			*	*				*		*	*	
Pelts and Galambos ⁶²	*			*	*				*		*	*	
Smith et al. ⁶³	*			*	*				*		*	*	
Stein et al. ⁶⁴	*			*	*				*		*	*	
Gahagan and Subirana-Malaret ⁶⁵	*			*	*				*		*	*	
Kcomt and Gorey ⁶⁶	*			*	*				*		*	*	

No articles in Portuguese or French were included. Almost all articles (31 out of 33) included data obtained through interviews and/or focus groups. The 33 articles reviewed captured data from four groups of participants: health care practitioner ($n = 15$), LGBTQ+ person ($n = 24$), traditional family ($n = 2$), and chosen family ($n = 6$). These totals exceed 33 because 15 articles captured multiple voices. Articles were appraised to be moderate to high in quality. Table 2 summarizes the general characteristics of the included articles, and the quality assessment results.

Semantic analysis

Semantic analysis focused on identifying the participant's voice and followed with an exploration of barriers to end-of-life care in the LGBTQ+ community. Table 2 summarizes the semantic themes and sub-themes.

Latent analysis

Our latent analysis identified three themes: systemic barriers, lack of lived experience within the literature, and the tendency to group LGBTQ+ as one monolithic population.

Systemic barriers

Systemic barriers^{30,31} occur at the *Systems Level* (representing systems, institutions, and services) and the *Individual Level* (characteristics directly impacting those seeking care) and combined, provide a barrier to LGBTQ+ wishing to access end-of-life care.

Governing laws and institutional policies were a systems-level barrier with an impact on end-of-life care. Types of policies that provided barriers included the expense of insurance and care,⁴¹ end-of-life legal protection and documentation,^{15,42} marriage recognition laws,²¹ gender recognition laws,⁴³ anti-discrimination policies,^{20,44} and policies on surrogate decision-makers and non-traditional family arrangements.^{45,46} Geographical and/or local culture of social acceptance was identified as another systems-level barrier impacting LGBTQ+ members' experience at end-of-life.^{21,45,47–51} For example, a culture of social acceptance increased the chances of LGBTQ+ being treated fairly, despite the availability of relationship recognition laws,^{45,49} but a culture of "don't ask, don't tell" led to unmet healthcare needs.⁵⁰ Inadequate resources available for LGBTQ+ people^{48–53} makes resource availability another systems-level barrier. For example, bereavement support is sometimes not provided for non-biological families,⁴⁸ and challenges in finding appropriate care force some LGBTQ+ individuals to travel far distances to find a culturally competent provider.^{49,53} One article found that between distinct groups of the LGBTQ+ community (e.g., gay versus transgender), resources were

inequitable.⁵² Diminished socioeconomic status positions some LGBTQ+ members to face urgent and pressing issues in their lives (such as financial instability) and may inhibit one's ability to focus on future and/or end-of-life care planning.^{41,52,53} As such, lower socioeconomic status functions as a systems-level barrier. Heteronormative assumptions at the interactional level function as the most prominent, individual-level systemic barrier.^{20,51} This manifests as covert homophobia e.g., health care practitioner's avoiding topics on sexual identity and sexual orientation, and/or ignoring the specific needs of LGBTQ+ patients⁵⁰; and as overt homophobia e.g., the refusal to acknowledge relationships with same-sex partners,^{20,44,47} and intentional misuse of gender pronouns.⁵²

Lack of lived experiences within the literature

An analysis of the study participants in the reviewed literature displayed that less than half were LGBTQ+ individuals with direct lived experience (as either a patient or informal caregiver) in long-term and/or end-of-life care. Nineteen articles reported on the healthcare practitioner experience and/or were expressed in the "voice" of an LGBTQ+ person recounting someone else's experience with the end-of-life care system.^{19,21,41–43,45–47,49,51,53–58,62,65,66} The stories retold from peers indicated a high distrust of healthcare practitioners. While they provide insight into the perceptions of end-of-life care in LGBTQ+ adults they do not capture a complete landscape.

Tendency to group LGBTQ+

Out of the 33 articles reviewed only 11 distinguished distinct groups (e.g., lesbian, gay, bisexual, transgender, and queer) within the LGBTQ+ community.^{21,42,43,48,49,52,53,57,59–61} The majority applied results generically to the LGBTQ+ community. Some of the articles collected participants' gender preference and sexual orientation data separately yet described results collectively to LGBTQ+ participants.^{41,51,56} Interestingly, the lesbian, gay, bisexual group was the focus of the majority of articles that did differentiate between groups.^{42,47,49,57,59,61}

Discussion

Main findings

We explored the end-of-life experiences of LGBTQ+ adults to identify the unique needs and barriers to end-of-life care. Our findings show that LGBTQ+ adults face many barriers at end of life, many of which are systemic and present throughout the life course. These barriers perpetuate a heteronormative culture which can negatively affect end-of-life care and the

end-of-life experience. Our review also revealed gaps in the literature which warrant a closer look at how research and services are designed. Below we divide our discussion of findings into two parts: (1) the lack of lived experience in the literature and the tendency to collate LGBTQ+ subgroups warrant an exploration of codesign of end-of-life care research and services and (2) the compounding stressors throughout the life course experienced by LGBTQ+ adults affect the end-of-life care experience, necessitating the need for implicit bias education to deliver authentic inclusive care.

Lack of lived experience in the literature and the tendency to amalgamate LGBTQ+ subgroups. A sizable number of studies identified portrayed the voice of LGBTQ+ persons, yet most of the data did not come from people with direct end-of-life care lived experience, either as a patient or a caregiver. Oftentimes we found articles to report what is akin to hearsay evidence—“. . . some pretty nasty stories about—you know, like trying to deal with the healthcare system and, you know, people. . . doctors just oh god. . . don't want to deal with that trans-vagina.”⁴⁶ Due to a lack of patient voice, these stories may not capture an accurate representation of the end-of-life care landscape, but they do reveal an interesting gap in the research considering the voice of end-of-life healthcare providers was well represented. We speculate that the perceived fear of having to “go back into the closet” is a reality and fear of being “outed” may impact LGBTQ+ persons’ (with lived experience) willingness to participate in these types of research. Study participants may be afraid to be their authentic selves due to discrimination and microaggressions experienced throughout the life course, and as a result may feel forced to adopt a heteronormative persona. This is in accordance with a systematic review on sexual orientation disclosure by LGBTQ+ people in healthcare settings which determined that fear of poor treatment and reaction to disclosure was a prominent barrier to the disclosure.⁶⁷ Furthermore, if participants directly had experience with end-of-life care or not, many of the articles (21 out of 33) showed a pattern of distrust with the healthcare system over the life course.^{13,15,19,21,41–43,45,47–49,52–59,61,65,66}

The literature also revealed the tendency for studies to combine subgroups within the LGBTQ+ community and not explore their unique needs and/or experiences. This finding aligns with a review on transgender aging, which found that there were two types of articles; ones that were LGBTQ+ aging-related (or lumped aging) and those that were specifically related to transgendered aging.¹¹ Fredriksen Goldsen and de Vries⁶⁸ note that the “heterogeneity of LGBT older adults across populations, countries, and cultures highlights the important role of intersectionality in the lives of LGBT older adults” (p. 321). We must acknowledge that these distinct groups operate within the context of intersecting identities and

social determinants of health such as race/ethnicity, socioeconomic status, education etc., which are elements that individually and collectively impact the experience of receiving healthcare.

Perhaps this collation of subgroups and lack of lived experience in the literature is indicative of gaps in how research is designed and conducted. If so, what are the implications of this research approach on policy and clinical practice? Work by Westwood⁶⁹ explores the implications associated with research that takes a collectivized approach to LGBT+ aging. Six key problems which impact policy and practice were uncovered: (1) Homogenizing language and phrases; (2) Uneven representation of subgroups; (3) Thematic over-representation of sexuality; (4) Non-intersectional analyses; (5) Thematic under-representation of gender; and (6) Inaccurate reporting of data. She explains that when we approach LGBTQ+ aging research in a collectivized manner, it can mislead policymakers and service providers into thinking that everyone under this umbrella shares the same views, needs, and concerns. It can also lead to the under-representation of subgroups. For example, Witten⁷⁰ notes that while LGBTQ+ aging is discussed, the “unique needs of the transgender-identified and gender non-conforming-identified populations are still very much overlooked” (p. 63).

The implications of research are large as it sets the stage for what, and how, policies, programs, and services are created. Researchers should not only strive to engage LGBTQ+ persons for research priority setting and design, but the patient engagement strategy should incorporate a trauma-informed intersectional analysis to disrupt the idea that this group is homogenous and to approach opportunities for co-design.⁷¹ While it may be challenging to recruit members of the LGBTQ+ population due to distrust and discrimination, Fredriksen-Goldsen et al.⁷² have outlined competencies and strategies for culturally competent health and human service practice for LGBTQ+ adults and state that “an initial first step in this process is to communicate with LGBT older adults that the agency or program seeking their input is LGBT-affirming” (p. 15). It is also suggested that by recruiting LGBTQ+ adults as partners in the development of the mission and delivery of programs/services, their voices will be at the core of the programming. We argue that this step is crucial to design end-of-life care services that are non-discriminatory, authentic, and address the needs of this population.

Barriers, microaggressions across the life course and the need for implicit bias training and LGBTQ+ affirming care. To further guide our analysis of the results, we applied an integration of two frameworks: Bronfenbrenner’s Ecological Theory of Human Development^{30,31} and Meyer’s Minority Stress Model^{16,17} as seen in Figure 2. at the end of life. Below we briefly summarize each framework before explaining how we combined them.

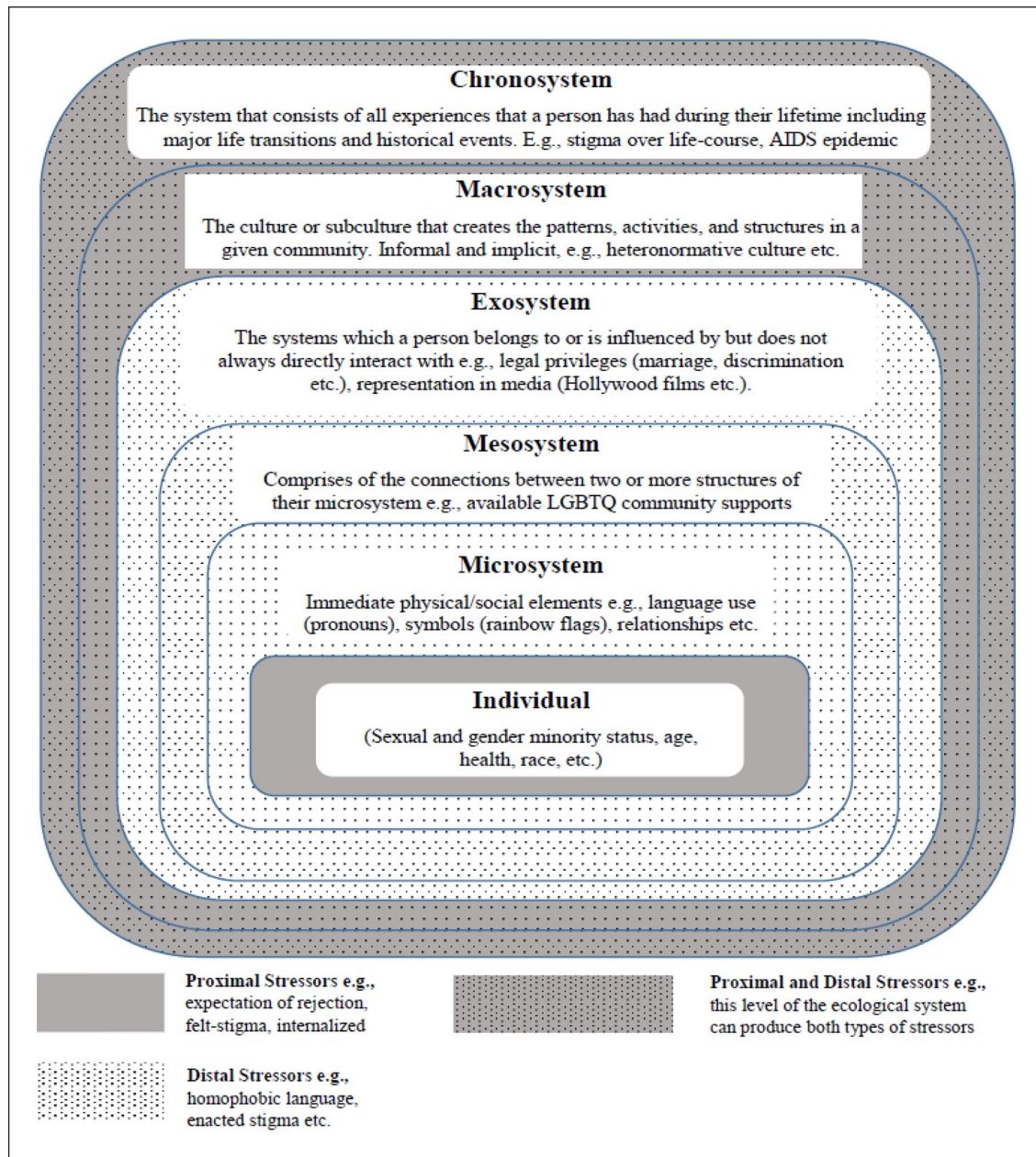


Figure 2. Proposed integrative framework using Bronfenbrenner’s and Meyer’s models to support the understanding of the experiences of LGBTQ+ persons at the end-of-life.

In Bronfenbrenner’s^{30,31} framework, human development is considered a complex system of relationships impacted by multiple levels of environment or “systems.” Individuals and processes are central to human development; the individual meaning *the person* and how their characteristics impact social interactions across the lifespan, and *processes* being the continuous reciprocal interactions between the individual and others, objects, and symbols in their immediate environment. Bronfenbrenner outlines five systems where such processes occur, the microsystem, mesosystem, exosystem, macrosystem, and chronosystem.^{30,31}

Meyer’s^{16,17} model suggests that difficult social situations cause stress for sexual minority individuals which may negatively affect health. Meyer differentiates between general, distal, and proximal stressors; general stressors being those that affect all people; distal minority stressors being those related to one’s sexual orientation such as discrimination and violence; and proximal stressors being those that are felt internally, due to recognition of being a member of and identifying as a sexual minority (expectations of rejection, concealment of one’s identity, and internalized homophobia).

By combining the two models, we can illustrate how stress experienced by a sexual minority member interacts and mediates at each system level. Our integrated framework provides a novel lens in understanding how many factors, not just those directly related to care, contribute to the end-of-life experience by acting as stressors, and how they impact the individual at different levels of their environment. We suggest that it is important to examine the varied contextual relationships, in order to better understand LGBTQ+ needs and barriers in terms of end-of-life experiences.

The first level in Bronfenbrenner's^{30,31} framework is the microsystem and refers to the complex relationships between an individual and their immediate setting. Our review included long-term care homes, hospitals, and clinics as components of this immediate setting. Interactive elements include those which enhance one's experience of inclusion, such as the use of inclusive pronouns (language) or the display of rainbow flags (symbols). Many of the participants in the studies we reviewed highlighted the importance of having LGBTQ+ friendly symbols imbued authentically, and that inclusiveness should be more than an act of checking boxes. Participants highlighted they could distinguish between authentic and inauthentic attempts at inclusivity, which affected their sense of belonging. Sadly, perceived inauthentic attempts at inclusivity appear to perpetuate a continued pattern of distrust of healthcare systems thereby also acting as distal stressors.

The mesosystem also impacts the individual directly but is composed of the interactions which occur between two or more system levels. The mesosystem can be enduring, such as an ongoing relationship with a family physician, or a one-time event such as the registration process for admission to a care facility. Moving from a familiar community to a health care setting may involve moving to a heteronormative environment. Our findings suggest that distal stressors are created when an environment does not provide a sense of belonging or social support.

The exosystem includes environments (informal and formal social structures) that individuals are a part of but do not always interact with on a regular basis. In our case, the broader health care system, mass media, and agencies of government may be considered examples of the exosystem. Our findings highlighted how system-level barriers such as government and institutional policies (or lack thereof) shape an LGBTQ+ individual's experience at end of life. Lack of protective policies such as discrimination or marital laws impact an individual's safety in these settings^{73,74} and create additional distal stressors. Furthermore, enacted stigma is often exacerbated when institutions lack anti-discrimination policies and/or other protocols to protect LGBTQ+ individuals.⁷⁵⁻⁷⁷ Blake and Hatzenbuehler⁷⁸ argue that anti-discrimination law "must be better tailored based on the evidence of who is affected

by stigma, as well as where and how stigma occurs, or it will be a poor tool for remedying stigma, regardless of its level of enforcement" (p. 500).

The macrosystem refers to the culture and/or subculture that creates patterns, activities, and structures in a community. It is informal and implicit. The local culture that an individual inhabits can be even more powerful to the LGBTQ+ experience than the existence of policies and protocols. Our review identified that the feeling of being stigmatized (or anticipation thereof) was frequently cited by LGBTQ+ participants and can manifest as both proximal and distal stressors. For example, even where LGBTQ+ discrimination laws exist, an environment possessing a more conservative culture may predispose the community to have more homophobic tendencies. Cummings et al.⁷⁹ found that "non-discrimination policies do not, of themselves, create an educated and inclusive environment" for clients/patients (p. 517). A proactive approach must be taken by "providers to learn about LGBT+ issues" and create an environment where LGBTQ+ people are "part of the fabric of the place, not just a tolerated minority" (p. 517).⁷⁹ Laws can be developed to protect the rights of LGBTQ+ individuals, but if they are interpreted and enforced at the macrosystem level with mission statements that state *we respect the rights of all our residents and treat everyone the same*; then such policy effectively perpetuates the invisibility of LGBTQ+ within the system by erasing their individuality and unique needs.

Lastly, the chronosystem refers to the historical circumstances that affect the contexts of the other systems. Many LGBTQ+ persons receiving end-of-life care have experienced minority stress over the life course. We can expect that these cumulative negative experiences act as a source of both distal and proximal stressors which may result in the general pattern of distrust of healthcare systems. As discovered, this can occur whether the participants had direct experience with end-of-life care or not.

It is important to consider the complexities involved in making health care systems LGBTQ+ affirmative. Not only are an array of measures required, but they must be perceived as authentic to be effective. This is further complicated as change is required across varying systemic domains. For example, on an individual level, LGBTQ+ cultural competency training may serve to improve interpersonal exchanges between LGBTQ+ residents and staff, but the effectiveness of such transactions may be limited if heteronormativity dominates the resident culture. While diversity and inclusion training are gaining momentum in healthcare organizations and can help to reduce forms of homophobia and transphobia, nuanced and subtle microaggressions still suggest to LGBTQ+ folks that their experiences, and identities are pathological, abnormal, shameful, and unwelcomed.⁸⁰ Staff who are not trained in recognizing and mitigating implicit bias may unintentionally harm or trigger existing traumas.⁸¹

Furthermore, breaking the heteronormative worldview which lends to such microaggressions requires a level of self-reflection, personal responsibility, and commitment to life learning and practice.⁸⁰

The variety of stressors throughout the life course experienced by LGBTQ+ adults coupled with microaggressions in health care settings create a compounding negative effect on the end-of-life care experience. Inauthentic attempts to showcase LGBTQ+ support while not having the systems to support true LGBTQ+ affirmative care may be even more harmful. Future education should consist of inclusion training but also involve a commitment to long-term self-reflection of implicit biases, implemented in tandem with organizational-wide processes that support addressing the unique needs of this population. Addressing the needs and barriers explored in this review is needed if we wish to elevate our nascent LGBTQ+ sensitivity into the realm of true authenticity and inclusion.

Strengths and limitations

One of the main strengths of this review was that this work was successful in providing an update of the end-of-life barriers and needs of LGBTQ+ adults and identified barriers to end-of-life care. Secondly, the rapid review design permitted evidence to be gathered and synthesized relatively quickly while adhering to a systematic methodology. However, although we searched articles in three languages, we may have excluded valuable studies that were published in other languages. The decision to include only peer-reviewed articles may have meant that we omitted relevant research which had not yet made it to publication. Furthermore, theses and dissertations that were not freely available may have also contained significant information. While rapid reviews reduce the time required for a traditional review, components of the systematic review process are simplified or omitted, and poor quality of reporting is one major pitfall for these types of review.²⁵ We addressed this issue by recording and reporting our approach in detail, allowing the reproducibility of our research. Furthermore, many articles included in our review were qualitative studies potentially limiting the generalizability of our results. On the other hand, the quality of the research included was generally high, which suggests good validity and reliability for our findings.

What this study adds

The joint use of Meyer's^{16,17} Minority Stress Model and Bronfenbrenner's Ecological Model^{30,31} to understand the healthcare needs of LGBTQ+ persons at the end of life was effective in identifying potential practice changes to better support this population:

- (1) Incorporating consistent LGBTQ+ cultural competence training into one's continuing education regime including (but is not limited to) recognizing

and de-escalating conflict related to sexual orientation, positionality/critical reflection of the clinician, positive communication, and relationship building.

- (2) Programming of services in end-of-life care domains needs to ensure that members of the LGBTQ+ community are included as key partners in these processes.
- (3) Attention to the different sub-groups within this community is paramount; there is growing evidence that these sub-populations face diverse barriers and possess varied end-of-life care needs and experiences.
- (4) Organization-focused actions, such as policy and procedure reviews, need to be conducted in partnership with the LGBTQ+ community and after broad LGBTQ+ cultural competence staff training.
- (5) The combination of Meyer's Minority Stress and Bronfenbrenner's Ecological Models provides a novel lens in examining how various contextual and individual systems interact over the life course, and what effect the systems may have on an LGBTQ+ adult.

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Supplemental material

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