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Hidden from sight - from the closet to the paywall:
A rapid evaluation of restricted and monetized access to
LGBTQ+ inclusive palliative, end-of-life, and bereavement care research

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Abstract

Introduction: LGBTQ+ people experience higher burdens of life-limiting illnesses, poorer health outcomes, and multi-level barriers to accessing palliative, end-of-life, and bereavement care. High quality evidence is needed to inform interventions to address these inequities, and inform inclusive practices and policies. Despite global initiatives to improve availability of peer-reviewed journal articles, the minority of research is open access (OA). We aimed to evaluate accessibility of literature related to LGBTQ+ inclusive palliative, end-of-life, and bereavement care.

Methods: A rapid review of the evidence regarding LGBTQ+ inclusive palliative, end-of-life, and bereavement care was conducted; OA status of identified articles was assessed. Articles from three published systematic reviews were included (2012, 2016, 2020). Review articles were updated using the original search and inclusion/exclusion strategies.

Results: 66 articles related to LGBTQ+ inclusive palliative, end-of-life and bereavement care were identified between 1990-2022. Of these, only 21% (n=14) were OA. Of the OA articles, 79% were published between 2017-2022, and 50% were published between 2020-2022, reflecting more recent shifts towards OA publishing.

Discussion: Health and social care professionals and policy makers rely on access to high quality evidence to inform their work. Failing to make articles related to the needs of LGBTQ+ people and populations open access risks further marginalisation and worsened inequities. Innovative journal policies and funding are needed to enable access, particularly for research that foregrounds the needs of marginalised communities. Where articles are currently behind paywalls, there is a need for accessible summaries or policy briefs to inform inclusive policy and practice.

Keywords: *sexual and gender minorities; SGM; LGBT; LGBTQ+; palliative care; hospices; death; key populations; end of life; bereavement; grief*

Key Message: This review aimed to evaluate accessibility of LGBTQ+ inclusive palliative care research. 21% of studies included were open access (n=66; 1990-2022). Accessible science is essential to dismantle structural injustices for LGBTQ+ people. Failure to make articles related to the needs of minoritized groups open access risks perpetuating and exacerbating inequities.

Introduction

Research from 27 countries reports that 8% of adults have a minoritized sexual orientation, and 1% identify as transgender or non-binary.¹ Lesbian, gay, bisexual, transgender, and queer or questioning (LGBTQ+) people worldwide face sociopolitical discrimination, violence, stigma, and bias throughout life,²⁻⁴ including in the palliative, end-of-life (EOL), and bereavement care contexts (hereafter referred to as palliative care).⁵⁻⁷ LGBTQ+ people experience disproportionately higher burdens of life-limiting illnesses, poorer health outcomes, and multi-level barriers to accessing equitable health and social care services.^{8,9} Systematic reviews of LGBTQ+ inclusive palliative care literature demonstrate unique needs (e.g., need for greater social support), experiences (e.g., fear of discrimination and mistreatment), and preferences (e.g., inclusion of chosen family/spouses/partners in decision-making), which must be addressed to improve care quality and outcomes for these populations.¹⁰⁻¹² However, greater accessibility to high-quality research is needed to inform interventions to alleviate inequities and improve person-centered health and social care services for LGBTQ+ people.^{2,13}

The open access (OA) publishing market was worth just over \$2 billion in 2022; a 24% growth from 2021.¹⁴ Of 8,590,194 Web of Science journal articles (2015-2019), roughly 43% were OA, with significant differences across fields (e.g., 21% in Humanities, 50% in Medical and Health Sciences).¹⁵ Global initiatives, such as Plan S,¹⁶ and international public health emergencies, like the COVID-19 pandemic, have all contributed to increases in OA publishing.

Access to high-quality science is essential to improve LGBTQ+ inclusive, evidence-based palliative care. Although health and social care professionals should ideally have access to methodologically robust, clinically relevant, and up-to-date publications to inform both practices and policies, most research is not OA. We sought to identify the proportion of LGBTQ+

inclusive palliative care research that was OA and provide implications for equitable access to research, evidence-based practice, health workforce capacity building, and the development and implementation of LGBTQ+ inclusive policies at local, national, and global levels.

Methods

Objective

To evaluate the accessibility of evidence related to LGBTQ+ inclusive palliative, EOL and bereavement care. An article was ‘accessible’ when the full text was available OA through online sources unaffiliated with institutional logins or journal subscriptions.

Review Design

Tricco and colleagues define a ‘rapid review’ as “*a type of knowledge synthesis in which components of the systematic review process are simplified or omitted to produce information in a short period of time.*”^{17,18} A rapid review design to capture evidence related to the OA status of LGBTQ+ inclusive palliative, EOL, and bereavement care was selected given both time and resource limitations,^{19,20} as well as the extensive systematic reviews previously conducted by the investigative team.¹⁰⁻¹² All articles included in these systematic reviews met inclusion criteria for the current review objective. Following evidence-based guidance for conducting rapid reviews,^{21,22} we aimed to ensure transparency and rigor on all aspects of the research process (e.g., search strategy, study selection, data extraction, synthesis).

Search Strategy and Data Sources

We assessed all articles that met inclusion criteria for and were previously appraised in three published systematic reviews in 2012,¹⁰ 2016,¹¹ and 2022.¹² Articles from all three systematic reviews were extracted into a table (n=48). Using an incognito internet browser and logged out of all institutional accounts, each article was searched to assess and record OA status.

The Harding et al.⁷ review included literature from 1993-2010 (n=12). The Rosa et al.¹² review was an update of the Harding et al.¹⁰ review and included relevant literature from 2010-2020 (n=13). We conducted an updated search for November 2020 – October 2022, replicating the search terms and databases that Rosa and colleagues¹² previously identified. Bristowe and colleagues¹¹ originally included 23 studies from 1993-2016; we conducted an updated search for April 2016 – October 2022 using their prior search strategy. The search strategy (i.e., terms and databases) conducted for each review can be found in the associated methods sections.¹⁰⁻¹²

Screening Process for Updated Searches

After uploading articles into Covidence and duplicates removing duplicates from the updated searches, one team member (HS) screened all titles and abstracts following inclusion criteria of the published reviews.¹⁰⁻¹² Each additional article selected for full-text review was verified for inclusion criteria by two of three reviewers (HS, DW, KB). Figure 1 shows a modified PRISMA flow diagram of the overall screening process.

Data Extraction

Based on internet search results, articles were identified as being OA or behind a paywall. Of the OA articles, we extracted year of first publication (including e-pub online ahead of print date), full journal citation data, journal type by field, country and country income classification (per World Bank classification)²³ of the corresponding author's affiliation, and country and country income classification of the study participants.

Results

Sixty-six articles related to LGBTQ+ inclusive palliative, EOL and bereavement care between 1990-2022 were identified. Of these, 21% (n=14) were OA (Table 1). 50% (n=7) were published in psychology, health research, public health, or health care quality journals. Of the

remaining OA articles, 21% (n=3) were published in condition-specific journals (e.g., cancer, AIDS), 21% (n=3) were published in palliative care journals, and the remaining 7% (n=1) was published in an LGBTQ+ specific journal.

Most OA articles on LGBTQ+ inclusive palliative, EOL, and bereavement care were published between 2017-2022 (79%; n=11). 50% (n=7) of all OA articles were published in or after 2020. The remaining 3 OA articles were published in 1996, 1999, and 2004, respectively.

Table 1 shows that 79% (n=11) of the OA articles' corresponding authors held primary affiliation in high-income countries (Ireland, n=1; United Kingdom, n=4; United States, n=6). Two articles' corresponding authors were based in upper-middle income countries (Brazil, n=1; South Africa, n=1) and one was in the lower-middle income country of Zimbabwe. One paper was led by authors based in the United States however participants were from a lower-middle income country (i.e., Nepal).

Discussion

To our knowledge, this is the first review to explore the OA status of LGBTQ+ inclusive palliative, EOL, and bereavement care research. Approximately 20% of these papers are OA, significantly limiting the availability of high-quality evidence for health and social care professionals, educators, researchers, and decision-makers. Results demonstrate a marked increase in relevant OA articles since 2017, mirroring international trends in OA publishing. However, the marginalization of LGBTQ+ people at all levels continues to escalate rapidly, requiring improved accessibility to evidence that drives inclusive practices and policies.

Paywalls leave end users and the public without key data to improve health and social care quality and delivery. Experts have recommended several strategies to ensure a diversity, equity and inclusion (DEI) conscious scholarly ecosystem through directly addressing OA

infrastructure.^{24,25} Examples include the training of all journal staff and editorial teams to identify and halt biases in peer review, paper acceptance, and editor processes; ensuring diversity (in the broadest sense) among editorial boards; focusing on the integration of DEI policies and procedures in OA publishing; and taking steps to increase research accessibility to low- and middle-income countries (LMICs) while also providing more cost-effective pathways for LMIC researchers to publish.²⁵

The current OA culture is significantly exclusionary. In a survey of 842 scientists from 64 countries, more than 60% of respondents noted cost as the most frequent barrier to OA publishing.²⁶ While most of the survey participants shared that their last publication was OA - whether due to funder mandates, institutional pressures, or OA only journal options - about 20% used personal funds to pay OA fees. Disappointingly, women and researchers in LMICs face the most substantial OA publishing barriers.²⁶ Our findings correspond, with only four OA papers including participants that live in LMICs (e.g., Brazil, Nepal, South Africa, Zimbabwe; table 1). As more journals move toward OA only publishing, innovative funding to promote inclusive scientific dissemination, particularly for research that invests in marginalized communities, will be essential to promote sustainable DEI models.²⁴

Additional multi-stakeholder implications exist. Health and social care professionals should seek support from partnering academic institutions, libraries, and professional organizations to access needed evidence – including data behind paywalls - and effectively translate high quality science to practice to measurably improve inequities. Health systems should prioritize funding for OA publications to ensure ready access to needed research for those under their employ. Policy makers should feel confident that all necessary evidence is available

to undergird policy development, implementation, and evaluation. Policies must be forged in collaboration with researchers and publishers to overcome access barriers to OA research.

Accessible science is a first step to combat discriminatory social realities for LGBTQ+ people worldwide. Sixty-five countries have laws that criminalize LGBTQ+ people and 12 have jurisdictions where the death penalty is either imposed or is possible.³ In the context of palliative care, LGBTQ+ people are particularly vulnerable to mistreatment, as agency and access to needed resources (e.g., social support) may be at risk.¹⁰⁻¹² This may be compounded by bias, stigma, and violence.⁵⁻⁷ Better access to science can directly inform inclusive health systems; policies that protect and enfranchise LGBTQ+ people and their families, spouses, and partners; and interpersonal professional-patient/family interactions grounded in respect, sensitivity, and humility. Fostering such inclusive environments can improve outcomes for all patients, their family caregivers, and the bereaved.

Disclosure/Conflict of Interest Statement:

RH discloses unpaid leadership roles, serving as a Trustee, Marie Curie UK (End-of-Life Charity); Co-Chair, African Palliative Care Association Research Network; British HIV Association (BHIVA) Standards Steering Committee Member; and Vice-Chair, Worldwide Hospice Palliative Care Alliance. These authors have no other conflicts to disclose. KB has received consulting fees from Gilead Sciences, honoraria from Hackensack Meridian Health and Memorial Sloan Kettering Cancer Center, and travel support from the European Association for Palliative Care.

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Figure 1. Article Screening Process.

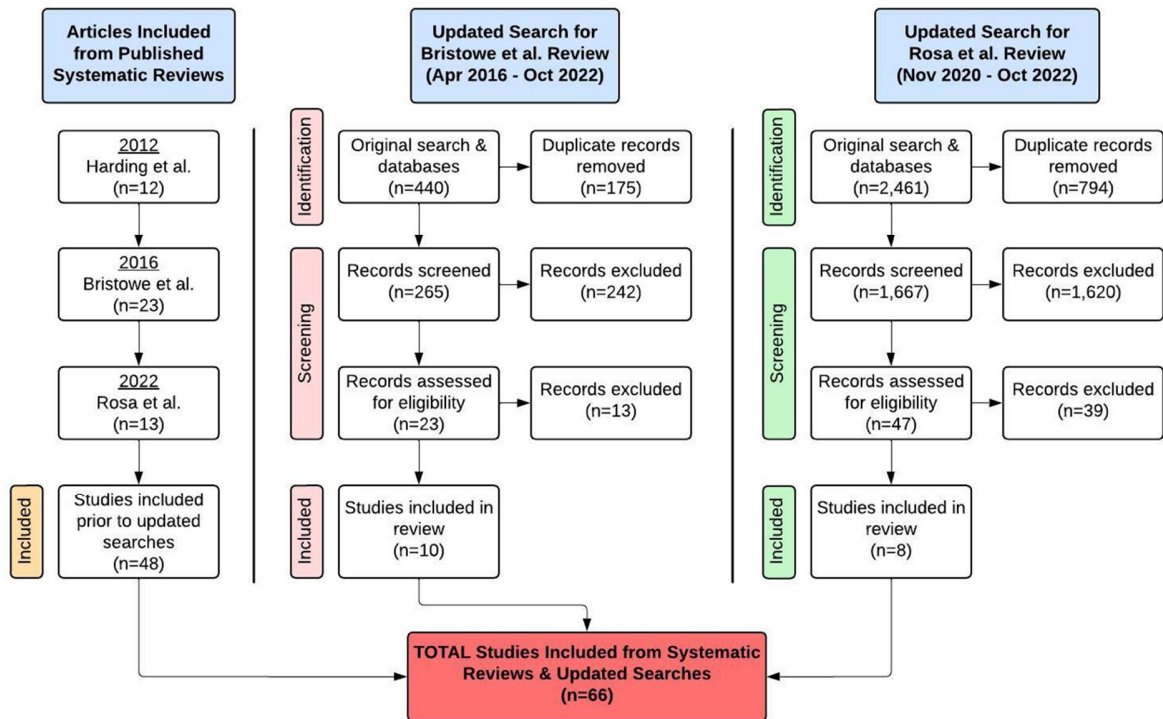


Table 1. Open Access LGBTQ+ Inclusive Palliative, End-of-Life, and Bereavement Care Articles.

Publication Year & Journal Type	Full Citation	Study Aim/s	Country of Corresponding Author	Country of Study Participants
****1996	Tedlie Moskowitz J, Folkman S, Collette L, Vittinghoff E. Coping and mood during aids-related caregiving and bereavement. <i>Ann Behav Med.</i> 1996;18(1):49-57. doi:10.1007/BF02903939	This prospective study of a cohort of human immunodeficiency virus positive (HIV+) and HIV negative (HIV-) caregiving partners of men with AIDS examined the contextual effects of caregiving and bereavement on coping and the association between coping and positive and negative mood during the five months leading up to their partner's death and the five months following their partner's death.	United States	United States
***1999	Curtis JR, Patrick DL, Caldwell E, Greenlee H, Collier AC. The quality of patient-doctor communication about end-of-life care: a study of patients with advanced AIDS and their primary care clinicians. <i>AIDS.</i> 1999;13(9):1123-1131. doi:10.1097/00002030-199906180-00017	To assess prevalence and quality of end-of-life communication between persons with advanced AIDS and their clinicians and to identify patient and clinician characteristics associated with this communication.	United States	United States
***2004	Boehmer U, Case P. Physicians don't ask, sometimes patients tell: disclosure of sexual orientation among women with breast carcinoma. <i>Cancer.</i> 2004;101(8):1882-1889. doi:10.1002/cncr.20563	The current study was undertaken to describe the disclosure of sexual orientation among sexual minority women with breast carcinoma.	United States	United States
**2017	Seelman KL, Lewinson T, Engleman L, Maley OR, Allen A. Coping Strategies Used by LGB Older Adults in Facing and Anticipating Health Challenges: A Narrative Analysis. <i>J Gay Lesbian Soc Serv.</i> 2017;29(3):300-318. doi:10.1080/10538720.2017.1310644	To explore how LGB adults (age 65 and older) cope with health challenges in late life while living in an urban area of the Southeast United States.	United States	United States

****2017	Arima AC, de Lucas Freitas J. The veiled bereavement: the experience of lesbians widows in a phenomenological-existential perspective. <i>Temas psicol (Trends Psychol)</i> . 2017;25(4):1467-1482. doi: 10.9788/TP2017.4-01Pt	To understand the experiences of lesbians widows according to an existential-phenomenological perspective.	Brazil	Brazil
*2017 (epub date)	Bristowe K, Hodson M, Wee B, et al. Recommendations to reduce inequalities for LGBT people facing advanced illness: ACCESSCare national qualitative interview study. <i>Palliat Med</i> . 2018;32(1):23-35. doi:10.1177/0269216317705102	To explore health-care experiences of LGBT people facing advanced illness to elicit views regarding sharing identity (sexual orientation/gender history), accessing services, discrimination/exclusion and best-practice examples.	United Kingdom	United Kingdom
*2019	Hunt J, Bristowe K, Chidyamatatare S, Harding R. 'So isolation comes in, discrimination and you find many people dying quietly without any family support': Accessing palliative care for key populations - an in-depth qualitative study. <i>Palliat Med</i> . 2019;33(6):685-692. doi:10.1177/0269216319835398	To examine the accessibility to, and experiences of, palliative care for key populations in Zimbabwe.	Zimbabwe	Zimbabwe
****2020	Catalan J, Ridge D, Cheshire A, Hedge B, Rosenfeld D. The Changing Narratives of Death, Dying, and HIV in the United Kingdom. <i>Qual Health Res</i> . 2020;30(10):1561-1571. doi:10.1177/1049732320922510	To reflect on a broad range of meanings around death within the historical UK epidemic, to examine how dying narratives shape contemporary HIV experiences.	United Kingdom	United Kingdom
***2020 (epub date)	Moloney C, Allen M, Power DG, et al. Assessing the Quality of Care Delivered to Transgender and Gender Diverse Patients with Cancer in Ireland: A Case Series. <i>Oncologist</i> . 2021;26(4):e603-e607. doi:10.1002/onco.13618	To retrospectively explore the quality of care and needs among an oncologist identified sample of transgender and gender diverse patients with cancer across three hospitals in Ireland.	Ireland	Ireland

****2021	Nguyen AL, Davtyan M, Taylor J, Christensen C, Brown B. Perceptions of the Importance of Advance Care Planning During the COVID-19 Pandemic Among Older Adults Living With HIV. <i>Front Public Health</i> . 2021;9:636786. doi:10.3389/fpubh.2021.636786	To assess advance directive completion, healthcare proxy, and attitudes toward advance care planning among older adults ages 50+ living with HIV during the COVID-19 pandemic.	United States	United States
****2022	Mange T, Henderson N, Lukelelo N. "After 25 years of democracy we are still stigmatized and discriminated against...": Health care experiences of HIV positive older black gay men in a township in South Africa. <i>J Pract Teach Learn</i> . 2022;19(1-2). doi: 10.1921/jpts.v19i1-2.1674	To explore the aging and health-care experiences of older gay black men in a selected township in the Cape Metropole, with the purpose of finding strategies to deal with their real life concerns.	South Africa	South Africa
*2022	Baskaran AB, Hauser J. Maya Ta Maya Ho (Love is Love): A Qualitative Study on LGBTQI+ Experiences in Hospice & Palliative Care in Nepal. <i>J Palliat Care</i> . Published online April 11, 2022. doi:10.1177/08258597221092896	To explore Nepali LGBTQI+ patients' experiences in hospice and palliative care.	United States	Nepal
****2022 (epub date)	Timmins L, Pitman A, King M, et al. Does the impact of bereavement vary between same and different gender partnerships? A representative national, cross-sectional study. <i>Psychol Med</i> . 2023;53(9):3849-3857. doi:10.1017/S0033291722000496	To compare bereavement outcomes for partners of same-gender and different-gender decedents.	United Kingdom	United Kingdom
****2022 (epub date)	Braybrook D, Bristowe K, Timmins L, et al. Communication about sexual orientation and gender between clinicians, LGBT+ people facing serious illness and their significant others: a qualitative interview study of experiences, preferences	To identify key stakeholders' experiences, preferences and best practices for communication regarding sexual orientation, gender identity and gender history in order to reduce inequalities in healthcare.	United Kingdom	United Kingdom

	and recommendations. <i>BMJ Qual Saf.</i> 2023;32(2):109- 120. doi:10.1136/bmjqs- 2022-014792			
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Table Legend:

*Published in palliative care journal

**Published in LGBTQ+ focused journal

***Published in disease-specific journals (i.e., cancer, AIDS)

****Published in psychology, health research, public health, or health care quality journals

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