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SYSTEMATIC REVIEW

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The needs, preferences, and experiences of LGBT + people living with dementia: a systematic review with thematic synthesis

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Abstract

Background LGBT + people are disproportionately at an increased risk for developing dementia. Dementia can compound the impact of stigma and social marginalisation experienced by LGBT + people, and is likely to create barriers to accessing healthcare services. Understanding the needs, preferences, and experiences of LGBT + people with dementia will help support high quality individualised care. The aim of this review is to explore and synthesise the evidence on the needs, preferences, and experiences of LGBT + people with dementia.

Methods Systematic review with thematic synthesis. The search strategy combined concepts of gender and sexual minorities, and dementia. MEDLINE Complete, PsycInfo, CINAHL, and Academic Search Ultimate were searched until March 2024. Relevant published papers in the English language were included, regardless of design or type. Data were analysed using thematic analysis. Findings were discussed from a queer lens.

Results Out of 1537 initial titles, 16 papers were included. Majority were published in the UK ($n = 8$), followed by USA ($n = 4$), Canada ($n = 2$), and Australia ($n = 2$). Of 16 papers, two were empirical qualitative studies, one used a subset of qualitative data from a previous study alongside other sources (literature review, reflection, policy) for data analysis, and 13 papers were non-empirical. The experiences primarily focused on actual or anticipated discrimination, and how the lifetime experiences of oppression, trauma, and other stressors can impact on the experience of dementia. Many of the needs captured focused on safety and control in identity disclosure and expression, and access to love, intimacy, and social networks. In addition, maintaining personhood through institutional safety, psychological safety, and attachment through relationships and couplehood were highlighted. Data on preferences were not explicit.

Conclusion The robustness of the science is weak regarding the needs, preferences, and experiences of LGBT + people with dementia. Designing and implementing dementia-related policies through a queer intersectional lens, along with embedded cultural safety education programmes, are needed. Further research that includes the voice of LGBT + people with dementia coupled with healthcare professionals' perspective is needed.

Keywords Dementia, LGBT+, Personhood, Queer theory, Gender and sexuality diverse

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Introduction

The prevalence of self-reported cognitive impairment, and dementia related risk factors are higher among lesbian, gay, bisexual, transgender, and those who do not identify as cisheterosexual (LGBT+) people compared to cisheterosexual individuals [1, 2]. A cisheterosexual person is a person whose gender identity aligns with their sex at birth (cisgender), and who is attracted to the opposite sex (heterosexual) [3]. In this review, we use lesbian, gay, bisexual, and transgender (LGBT) and lesbian, gay, bisexual, and those who do not identify as cisheterosexual (LGBT+) to distinguish between papers that report on LGBT only from those that report on LGBT+. LGBT + people are more likely to be diagnosed with heart disease, depression, stroke, and substance use disorder among other illnesses compared to cisheterosexual people [4, 5], all of which increase the risk of dementia [6]. These health disparities are attributed to stress from discrimination and stigmatisation, placing the LGBT + person at a disadvantage due to intersecting forms of structural and socio-cultural inequalities [7, 8]. Discrimination and being unable to disclose a LGBT + status place older LGBT + people at a higher risk of experiencing loneliness and social isolation [9, 10]. Loneliness and isolation have been associated with adverse physical and mental health outcomes, increased mortality rate, and elevated risk for developing dementia [11, 12]. In addition, the onset of dementia can compound the impact of stigma and social marginalisation experienced by older LGBT + people, and is likely to create barriers to accessing healthcare services; causing the onset of dementia to go unnoticed and untreated [13, 14]. A recent scoping review examining health disparities among older LGBT individuals in the UK highlighted concerns about identity loss and the fear of developing dementia among older LGBT people [15]. In addition, persistent inequalities were identified in both physical and mental health, while social and formal care settings were found to significantly threaten identity and lifelong relationships of older LGBT people [15].

There is an emergent awareness of the importance of diversity in shaping the needs, preferences, and experiences of people living with dementia [16]. However, the diversity of sexual and gender orientation and its impact on the person living with dementia remain scant from the broader dementia literature. Two scoping reviews examined the lived experience of LGBT + people with dementia and their care partners [17], and the experiences of LGBT + older adults with dementia in long term care settings [18]. Similarly, another scoping review examined if dementia services and support organisations are meeting the needs of LGBT people with dementia [19]. To our knowledge and up to our search date (March 2024), no published systematic reviews have examined the needs, preferences, and experiences of LGBT + people living with dementia.

Table 1 PECO framework

Population	LGBT + people living with dementia
Exposure	Living with any type of dementia
Context	Any
Outcome	Needs, preferences, and experiences

In order to provide high quality individualised care for LGBT + people living with dementia, the aim of this review is to examine and synthesis the available literature to address the following review question: What are the needs, preferences, and experiences of LGBT + people living with dementia?

Methods

Review design

This review is rooted in constructionist ontology and subjectivist epistemology [20]. In a constructionist-subjectivist paradigm, knowledge is mutually co-produced, and is an outcome of the interaction between the researchers, and with the researchers and data presented in found literature [21]. Thematic synthesis was employed [22]. The benefits of thematic synthesis approach are that it can process ‘thin’ (descriptive) and ‘thick’ (analytical) data, provides an audit trail, and can be organised to answer the review question directly [23].

Search strategy and data sources

The review question was divided into defined population, exposure, context, and outcome (PECO) criteria as demonstrated in Table 1. PECO criteria help specify inclusion and exclusion criteria, define the review aims, further develop search terms, and facilitate the interpretation of research findings in relation to the review question [24, 25].

A preliminary scoping search was undertaken to become familiar with the common terms used to describe two concepts: dementia and LGBT+. The search strategy was then fully developed in collaboration with a faculty librarian using Medical Subject Headings (MeSH) and keywords for two concepts: Sexual and Gender Minority and Dementia. The two concepts were combined using the Boolean ‘AND’ operator. The preliminary scoping search revealed that there is little published literature on the topic of LGBT + and dementia. Therefore, keywords relating to needs, preferences, and experiences were not used to broaden the search output. The search strategy was adapted for each database based on its subject index or thesaurus term. Table 2 provides an example for search terms and strategy used for CINAHL database.

Four databases were selected: Medline Complete, PsycInfo, CINAHL and Academic Search Ultimate. The databases were searched until March 25, 2024.

Table 2 Key search terms used in CINAHL database

Concept	Search term used
Sexual and gender minority	((MH "LGBTQ + Persons+") OR (MH "Intersex Persons") OR (MH "Bisexuals") OR (MH "Gay Persons") OR (MH "Gay Men") OR (MH "Lesbians") OR (MH "Transgender Persons+") OR (MH "Transsexuals") OR (MH "Sexual and Gender Minorities+")) OR TI (LGB* OR Intersex* OR Bisexual* OR gay* OR lesbian* or transgender* or transsexual* or "gender and sexual minorit*" OR "sexual minorit*" OR "gender minorit*" OR homosexual* OR "same-sex" OR "same sex" OR queer) OR AB (LGB* OR Intersex* OR Bisexual* OR gay* OR lesbian* or transgender* or transsexual* or "gender and sexual minorit*" OR "sexual minorit*" OR "gender minorit*" OR homosexual* OR "same-sex" OR "same sex" OR queer)
AND	
Dementia	((MH "Dementia") OR (MH "Dementia, Vascular") OR (MH "Frontotemporal Lobar Degeneration") OR (MH "Lewy Body Disease")) OR TI (Dementia* OR alzheimer* OR parkinson*) OR AB (Dementia* OR alzheimer* OR parkinson*)

Table 3 Inclusion and exclusion criteria

Inclusion	Exclusion
English Language	Languages other than English
Any study design or type, including non-empirical published papers, such as commentary, discussion, and case reports	Papers that do not separate LGBT + from cisgender heterosexual individuals
Papers that address needs, preferences, and experiences of LGBT + people with any type or stage of dementia	Papers that only include or focus on LGBT + caregivers or caregivers of LGBT + people with dementia

Restriction was added for publications in the English language, but no restrictions were added for dates. Reference lists of retrieved articles and relevant systematic reviews that were identified during the search were scrutinised for further relevant papers.

Selection strategy

The inclusion and exclusion criteria are provided in Table 3. Needs, preferences, and experiences were operationalised in the context of dementia by physical, psychosocial and spiritual needs, preferences, and experiences. This operationalisation of the needs, preferences, and experiences is similar to a recent systematic review exploring the needs, preferences, and experiences of LGBT + people with serious illness [26].

After duplicates were removed, two reviewers (CC and JL) scanned the first 10% of titles and abstracts independently [27] and met to discuss any discrepancies, when necessary. The remainder of the titles were screened by one reviewer (CC). The same process was repeated for articles that were selected for full-text review. Accuracy and rigour of applying the inclusion criteria were facilitated by reflexivity, and discussing the papers with another reviewer [28]. Reflexivity was employed through journaling and informal debriefings among the reviewers. This facilitated an awareness of the subjective ideas of the reviewers, their position in the review process, and the effects this had on how the found literature was interpreted in relation to the inclusion and exclusion criteria.

Data extraction and thematic synthesis

Following full-text review, summary data and main characteristics of each included paper were tabulated using a spreadsheet (Table 4). Given the paucity of research in this area and that non-empirical papers were included in this review, the full text of each included paper (that is, any part of the paper), was considered for data extraction and thematic synthesis. The three stages of Thomas and Harden [22] approach were followed:

(1) Line by line inductive coding (free codes) of the full text using NVivo software (version 12).
(2) Consolidating the free codes developed in the earlier stage into related concepts to develop descriptive themes.
(3) Generating analytical themes that directly address the review question.

Quality appraisal

Concepts from realist evidence appraisals were applied to include relevance, richness (conceptually and contextually), and rigour [29]. This was achieved by assessing whether the non-empirical included papers contribute to answering the review question, conceptually or contextually. This is consistent with Thomas and Harden's thematic synthesis [22], which locates the notion of quality within the context of the review question instead of study design; that is, the hierarchy of evidence does not prioritise the study design but the ability of the study to answer the review question. As such, papers were not excluded on the basis of their quality [22].

Results

16 papers met the inclusion criteria and were included in the review (Fig. 1).

Table 4 Summary of characteristics and findings of included papers

Author(s), year & country	Paper type/design & population	Purpose	Findings
Empirical studies			
Barrett et al., 2015 [31] Australia	Two empirical qualitative studies comprising in-depth interviews with: • 30 LGT (living with dementia ($n=9$); same-sex partner ($n=6$)) • service providers ($n=6$)) Population: Lesbian, gay & transgender people	Explore the experiences & needs of LGBT people with dementia	• Many older LGBT people have lived at a time when LGBT people where criminalised & pathologised • LGBT people living with dementia do not lose their sexual orientation or gender identity, although dementia may change how sexual orientation is expressed • Dementia & associated cognitive impairment increase vulnerability to homophobic/transphobic family members, which can have adverse impact on how sexual orientation & gender identity are expressed • Loss of control over identity disclosure is an added stressor for LGBT people with dementia • Intimate relationships, friendships, & LGBT networks provide a safe space for LGBT people with dementia & may act as a buffer against discrimination • Actual & anticipated discrimination within services is a concern among LGBT people with dementia, which for some may result in resisting or avoiding care
McParland & Camic, 2018 [30] UK	Empirical qualitative study comprising 10 in-depth interviews with: • Couples living together ($n=7$). women ($n=4$) men ($n=3$) with same-sex partners • Gay man with dementia ($n=1$) • Lesbian with close friend ($n=1$) Population: Lesbian & gay people	Explore what it means for lesbian & gay people to experience dementia, & to understand these experiences within dyadic relationships	• Lesbian & gay people continue to experience homophobia & discrimination • Lesbian & gay people are subjected to a 'double stigma', relating to sexual orientation & dementia, which could threaten personhood • The stigma affected participants differently, where some became more isolated by choosing to manage alone while others decided to reach out & take action (e.g., by educating others) • Identity concealment decisions were shaped by anticipated & experienced discrimination • Relationships with significant others were as 'sheltered harbour', & important for maintaining personhood
Westwood, 2016 [32] UK	Four main sources for data analysis: • Literature review relating to ageing, gender & sexuality • A subset of data from 60 older LGB individuals aged 60 & over (including 36 lesbian & bisexual women) • Data from Dementia Services Equality Impact Assessment conducted by the author for a local authority previously • Author's insight Population: Lesbian & bisexual women	Explore the experiences of lesbian & bisexual women living with dementia from an intersectional lens	• Many LGB individuals are hesitant to engage with healthcare providers due to previous & current negative experiences, with implications on timely diagnosis & treatment • Lack of social support, especially access to intergenerational support • Fear of disclosing identity, especially in heteronormative formal care setting
Non-empirical papers			

Table 4 (continued)

Author(s), year & country	Paper type/design & population	Purpose	Findings
Adelman, 2016 [37] USA	Discussion paper Population: LGBT	Highlight the added stigma & other challenges faced by older LGBT people with Alzheimer's diagnosis	• LGBT older people with Alzheimer's diagnosis face double stigma & barriers to care • Older LGBT people with Alzheimer's fear that care providers may not be open to their relationship, being devalued, & receiving a lesser quality care due to their sexual orientation & gender identity • Planning ahead is crucial for older LGBT people to avoid delay accessing services & delaying diagnosis
Beehus-poteea & Badrakalimuthu, 2021 [34] UK	Case vignette, drawing from an observation of a transgender person with dementia Population: Transgender persons	Discuss challenges faced by transgender community in the context of dementia	• Past & present experiences of discrimination, prejudice, & stigmatisation lead to poor access & utilisation of healthcare services • Issues with gender-related behaviour among transgender people with dementia • Limited social support networks
Cousins et al., 2020 [44] UK	Non-systematic literature review Population: LGBT+	Produce an introductory summary of the challenges and considerations facing LGBTQ + people	• Older LGBT + people are more likely to have experienced stigma, discrimination and pathologisation of their LGBT + identity • LGBT people with dementia in care homes are at risk of discrimination • LGBT people fear accessing health services due to previous discrimination • Main concern for LGBT people with dementia is loss of self alongside a loss of LGBT identity • Older LGBT + people with dementia may live with hidden identities but out themselves due to cognitive impairments • Transgender people with dementia may experience challenges in being able to express individual gender identity • Early life memories, which become vivid as dementia progresses, might be traumatic for LGBT people • Transgender people with dementia may return to a time before they transitioned • Older LGBT people with dementia are more likely to be estranged from family of origin, with increased levels of social isolation and loneliness • LGBT + support networks are important buffers to the added stressors experienced by LGBT + people with dementia • Advance care planning may be adversely affected for LGBT + people with dementia as LGBT + significant others may be excluded from life-making legal decisions • Structuring care programmes around binary gender (male or female) undermines personhood for non-binary individuals
Duffy & Healy, 2014 [36] Australia	A reflection using four case examples from practice. Two cases relate to gay men living with dementia Population: Gay men	Explore case examples from social work practice in health & residential care settings that highlight complexities of working with LGBTI people	• Safety issues & risk of disclosing identity • Lifetime experience of discrimination • Challenges in formal care settings include discrimination from staff & service users, & anxiety over identity disclosure • Lack of social support & familial connections • Relationships changes & loss of connection with community of choice due to dementia • Unequitable legal rights & history of oppression • Need for advance care planning

Table 4 (continued)

Author(s), year & country	Paper type/design & population	Purpose	Findings
Fredriksen-Goldsen et al., 2018 [13] USA	1. Reviewing 10 core competencies for professional practice with LGBT older adults & families 2. Reviewing & analysing research findings from existing literature on LGBT aging & culturally competent practice in Alzheimer's disease & dementia care Population: LGBT	Develop competencies for specialised practice with LGBT older people living with cognitive impairment & dementia, as well as their families & caregivers	• Discrimination & identity concealment places the LGBT + person with dementia at an elevated risk for adverse physical & psycho-social outcomes • LGBT older people are more likely to be estranged from family of origin, not have children, & live alone • Historical, social, & cultural context negatively impact LGBT older adults living with dementia • Need for advance care planning in the context of limited social support • LGBT people exhibit strength in their ability to maintain a positive sense of identity & adapt to adversity
Harper, 2019 [38] UK	Discussion paper Population: LGBT+	Explore the needs of older LGBT + people with dementia, the role of legislation & regulation, & how healthcare professionals can provide support	• LGBTQ + people with dementia experience unequal rights, microaggression, & overlapping stigma, resulting in loneliness & lack of social support • Increased fear & self-regulation may be more common among older LGBTQ + people with dementia due to generational homophobia, leading to identity concealment • Older trans people with dementia face additional challenges related to recognising & maintaining a gender identity consistent with physical appearance & gender expression • Sexual development is often an unmet need for LGBTQ + people with dementia
Le Berre &Vedel, 2020 [42] Canada	Commentary paper Population: LGBT+	How national & provincial strategies related to Alzheimer disease & related disorders can be inclusive	• Stigma & discrimination resulting in limited access services • Fear of disclosing identity due to previous & current negative experiences • Fear of mistreatment & discrimination in formal care settings, especially for the transgender community • Experience of double stigma of dementia & sexuality
Marshall et al., 2015 [33] Canada	Case report, drawing from the biographical details and real-life clinical scenario of a transgender person with dementia Population: Transgender	Highlight the challenges encountered by a transgender person when they are no longer able to express a consistent gender preference due to dementia	• Gender identity ambivalence or 'confusion' due to cognitive impairment associated with dementia, creates "challenges" to staff • Inconsistent gender -related behaviours can magnify social exclusion & isolation, especially in formal care settings • Families of origin can infringe on gender expression
McGovern, 2014 [43] USA	Non-systematic literature review Population: LGBT	• Review the available knowledge on the experiences of older LGBT people with dementia • Promote care practices tailored to the needs & expectation of older LGBT people with dementia	• Loss of a LGBT identity coupled with a loss of self is a common concern for older LGBT people with dementia, rendering the LGBT individual doubly invisible • Life course events of discrimination, lack of recognition & rights, & personal histories of activism (e.g., Stonewall riots, Gay Rights movement) impact on current lived experience & political identity of older LGBT people with dementia • Cognitive impairment associated with dementia may result in forced disclosure of a LGBT identity, rendering the LGBT person with dementia more vulnerable to discrimination • LGBT support networks provide psychological safety

Table 4 (continued)

Author(s), year & country	Paper type/design & population	Purpose	Findings
Monks & Shaw, 2017 [39] UK	Discussion paper Population: LGBT	• Explore the issues & needs of LGBT people with dementia • Feedback from a workshop the authors ran to capture ideas for best practice related to LGBT people with dementia	• LGBT people face double discrimination, relating to their sexual & gender identify, & dementia • LGBT people with dementia are more likely to live alone, & less likely to have children • LGBT people with dementia are more likely to rely on formal care compared to heterosexual people • Families of origin may impede affirming-care for the LGBT person with dementia
Peel & Harding, 2016 [40] UK	Discussion paper drawing on three case examples Population: LGBT	Explore sociolegal needs & challenges relating to LGBT people with dementia	• Despite legal change protecting LGBT rights in the UK, discriminatory & prejudice practices still exist • Older LGBT people with dementia are likely to conceal their identity due to previous negative experiences & fear of discrimination • Older LGBT people are more likely to be admitted to formal care settings due to lack of familial support • Family of choice may be excluded from being involved in LGBT older adult lives by formal care services • Current heteronormative models of care hinder identity expression & recognition of family of choice for older LGBT + people with dementia • Advance care planning can protect facilitate identity & protect LGBT older people with dementia from homophobia & transphobia
Price, 2008 [41] UK	Discussion paper, which forms part of an ongoing small-scale, qualitative study Population: Gay & lesbian people	Explore the intersection of sexually minoritized identity, ageing, & cognitive impairment & the challenges this poses for social work professionals	• Psychological & personal safety is jeopardised for gay & lesbian people with dementia, due to loss of personal agency & control • Historical context relating to oppression, stigma & discrimination for lesbian & gay people may impact on current experiences • The heteronormative models of support hinder lesbian & gay people from raising issues & needs important to them
Scharaga et al., 2021 [35] USA	Case report, drawing from a real-life clinical scenario of a transgender person with dementia Population: Transgender persons	Evaluate whether applying normative data for men or women in neuropsychological evaluation for a transgender individual result in significantly different standard scores	• Identity concealment may increase distress among transgender older adults • The transgender case report highlighted social isolation, loneliness, limited social support, rejection from family, 'sadness', & anxiety among the transgender individual • Transgender individuals are more vulnerable to making poor health & financial choices due to lack of social support, avoidant coping strategies, discrimination, & limited access to care

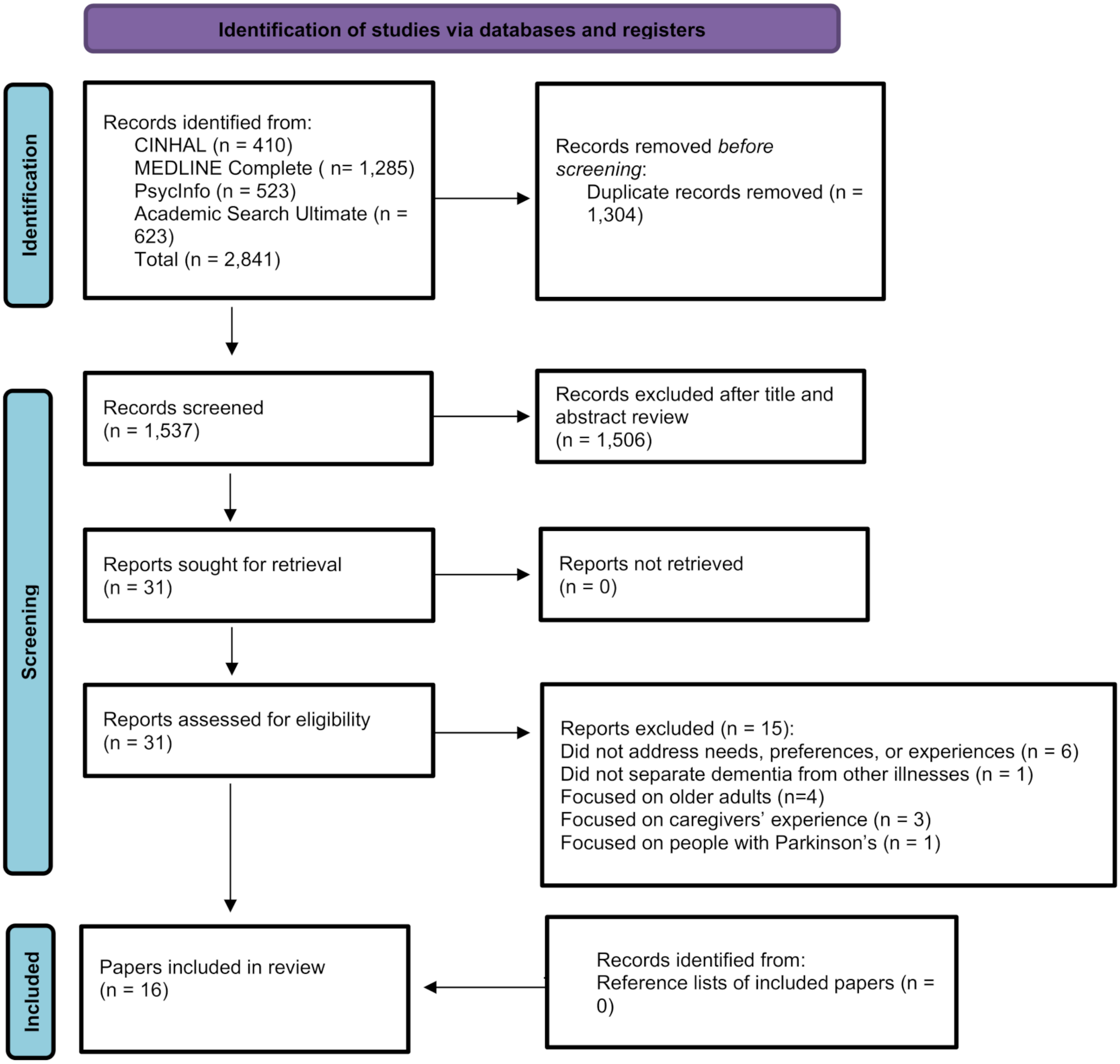

Fig. 1 PRISMA flow diagram of included papers

Overview of included papers

Table 4 provides a summary of the characteristics and features of the included papers. The majority of the included papers were published in the UK ($n = 8$), followed by USA ($n = 4$), Canada ($n = 2$), and Australia ($n = 2$). Of the 16 papers, two were empirical qualitative studies [30, 31] and one used a subset of qualitative data from a previous study alongside other sources (literature review, reflection, policy) for data analysis [32]. The remaining 13 papers were non-empirical papers. Three were case reports [33–35], which draw from real-life clinical scenarios and detailed biographies, and one was a reflection using case example from practice [36]. One paper reviewed and analysed findings from an existing research project (Age with Pride) and core competencies [13], and the remaining were either discussion [37–41], commentary [42], or non-systematic literature review [43, 44] papers. One of the discussion papers [41] was part of an ongoing small-scale qualitative study, and used excerpts from research participants in the discussion.

The four themes identified from the synthesis are:

1. Oppression, discrimination, and stigmatisation of the present are compounded by the past.
2. Maintaining "personhood": the intersection of LGBT + identity and dementia.
3. Access to love, intimacy, and social networks act as a buffer to the added stressors.

4. “Outed” by dementia: safety and control in identity disclosure and expression.

Themes

Oppression, discrimination, and stigmatisation of the present are compounded by the past

Understanding the lifetime experiences of oppression, discrimination, and stigmatisation that LGBT + people, especially older ones, have experienced is a crucial pre-requisite to fully understanding their experience of dementia [13, 34]. LGBT + people have been pathologised [32, 44] and criminalised [36, 45] based on their sexual orientation and gender identity. The included papers indicated how LGBT + people were denied services, rejected by their family of origin, and have been subjected to the harmful practices of conversion therapy [13, 32, 39, 44]. As a result, LGBT + individuals have learned how to hide their identities as a means of survival in a society that does not view a LGBT + identity as an accepted variation of human sexuality and gender identity [30, 32, 36, 38, 41, 44]. One participant in Westwood ([32], p. 11) explained:

> *'What if they [staff] took a dislike to me? I don't think many people here would understand it or accept it somehow.*

In the context of dementia, these lifetime experiences have shaped how LGBT + people view, react, and interact with the world around them [32, 41, 46].

The included papers appeared to show how previous experiences of trauma, oppression, and other stressors place the LGBT + individual with dementia at a disadvantage. The traumatic memories related to sexual orientation and gender identity are reactivated with dementia, resulting in anticipated discrimination and fear of accessing services [13, 32, 44]. These traumatic lifetime experiences have been associated with higher rates of adverse mental health and psychosocial outcomes, such as social isolation and depression, among LGBT + people compared to the general population [13, 31, 35, 42, 44]. Consequently, living in social isolation puts the LGBT + person with dementia at an increased risk of emotional and physical abuse due to institutionalised discrimination, which has been linked to cultural incompetence and unpreparedness of care services [43].

Despite the considerable socio-legal change that many countries have witnessed in relation to LGBT + rights, homophobia, heterosexism, and transphobia still exist in policies and practices [31, 38]. LGBT + people with dementia may continue to experience systemic discrimination by health and social care services, where their care needs, relationships and families, and histories are still not well understood and acknowledged [30, 31]. This is compounded by societal and personal biases against aging and dementia, leading to overt discrimination, unconscious bias, and microaggression [13, 32, 41, 43]. Dementia and associated cognitive impairment may result in stigma and heighten some of the devalued characteristics of aging, such as forgetfulness and diminished cognitive processing [13]. Therefore, societal and personal biases against aging, dementia, and gender and sexual minorities may intersect to further social marginalisation of and microaggression towards the LGBT + individual [13]. Microaggression rooted in heterosexism is experienced in the form of assumed heterosexuality, denying same-sex relationships, and linking a dementia diagnosis as an outcome of a sexually minoritised identity by care professionals and services [30, 31, 38].

Maintaining “personhood”: the intersection of LGBT + identity and dementia

The included papers indicated how losing a LGBT + identity due to overpowering heteronormative biases and culturally incompetent services, added to the ‘loss of self’ as a result of cognitive impairment is a major concern [30, 32, 33, 38, 39, 44]. Consequently, the LGBT + individual with dementia is at a higher risk of being rendered doubly invisible [32, 41, 43]. Dementia, unlike other chronic or life-limiting conditions, collapses the foundation of identity. This is an outcome of the gradual loss of the person’s individual and shared memories; their ability to create individual and shared meaning; and their capacity to construct a narrative reflective of their individual and shared identity as a result of the cognitive decline associated with dementia [31, 43]. For LGBT + people with dementia, sexual orientation and gender identity constitute a crucial part of their personhood. This is illustrated in Barrett et al. ([31], p. 35), where one participant described the suggestion that sexual orientation is lost because of dementia as ‘crazy’, adding that it is like saying:

> *‘...hippopotamuses turn pink when they get to age 70’, and that sexual orientation is not ‘a rinse colour that you put through your hair. It’s fundamental... to who you are and how you relate to people.’*

Fear of devaluing this core part of identity and self by care services and professionals is portrayed to be a challenging aspect of the illness for the LGBT + individual [36, 37, 45].

The included papers indicated that attachment through relationships and couplehood is essential in promoting personhood in dementia [30, 32, 34, 39]. However, older LGBT + people are more likely to be estranged from their family of origin, live alone, and have limited social network compared to cisheterosexual people [13, 32, 36, 38, 40]. Therefore, issues distinct to the LGBT + community such as social isolation and exclusion, discrimination, and familial alienation further threatens personhood and identity in the context of dementia. The current heteronormative models of care delivery, which provide the basis for institutional homophobia and discrimination, impede personhood preservation for the LGBT + person with dementia as illustrated in Westwood ([32], p. 10):

> *I live in an incredibly (sic.) amount of fear about my future. Not just as an older person. But as a gay older person. Institutions, they're very straight. My god I hope I don't have to go into a care home, I really do... When I think about it, I find it quite scary. It frightens me that I am just going to be invisible, a nobody, that I am just going to be lost. And what I would want to do is just die.*

This seems to be a particular concern as LGBT + people with dementia are more likely to require community or residential care due to differently structured social networks compared to their cisheterosexual peers, but less likely to have their identities affirmed as exemplified in one of the included papers:

> *'Everything is predominantly heterosexual orientated. Sheltered and residential housing is mixed with no provision for those who prefer the company of their own orientation. It's depressing to think I might end up in a home where I could be isolated because to disclose/talk about my life would lead to ostracization.' ([32], p. 10)*

This was attributed in the included papers to the potential belief held by some care services that LGBT + individuals lose their sexual and gender identity, where dementia becomes the primary identity of the person [32, 38, 44].

Other complexities highlighted in the literature are related to transgender individuals 'forgetting' that they have transitioned, intermittently exhibiting gender-related behaviour inconsistent with previous behaviour and associating with a different gender identity [33–35, 38, 44, 45]. The gender fluidity among transgender people living with dementia is portrayed as problematic in the included papers, where people are viewed as no longer capable of expressing a consistent gender expression or preference due to dementia. Moreover, the included papers highlighted how transgender individuals with dementia are particularly vulnerable to cisgenderist pressure from families of origin, who can infringe on gender expression added to a cisgenderist pressure from formal care services [31, 33].

Access to love, intimacy, and social networks act as a buffer to the added stressors

Access to love, intimacy, and LGBT + social support networks has been framed in the included papers as an important buffer to the additional stressors encountered by LGBT + people living with dementia [30–32, 36, 38, 40, 43]. It is recognised in the included papers that people with dementia can and do engage in positive intimate relationships, including sexual contact [13, 34]. However, sexual development is often an unmet need for the LGBT + person with dementia, mainly due to homophobia, resulting in misunderstood sexually disinhibited behaviour [38]. Intimate relationships and connections with the LGBT + community affirm sexual orientation and gender identity of the LGBT + person with dementia [31], maintain personhood [30–32], and are a protective factor against discrimination [31, 32] and other adverse psychosocial outcomes such as loneliness [34, 35].

Relationships with partners were conceptualised as "sheltered harbours" against the challenges associated with sexual orientation and dementia in McParland and Camic [30]. However, people living with dementia often experience relationship changes with families, partners, and friends [13]. These changes are particularly significant to older LGBT + people living with dementia, who are more likely to rely on partners and friends as the main source of support to navigate through the added challenges imposed by dementia, and a minoritised sexual and gender identity [13, 32]. For instance, one participant in Barrett et al. ([31], p. 38) compared her experience with the experience of a friend living with cancer who:

> *'...received incredible support.. but we don't get that. Dementia is a terminal illness, but we don't get that level of support.'*

Another participant suggested that her friends:

> *'...don't know what to do, so they stay away. '*

Connection to LGBT + social networks was particularly important as it provided a safe space to 'freely' be oneself [43], without having to justify, hide, or explain the lived experience of the LGBT + person with dementia [30]. It also provided a space for informal advocacy, ensuring that a LGBT + identity is respected in the context of dementia [32, 43, 44]. This was exemplified in Westwood ([32], p. 7) where one participant explained:

> *'I'm finding hospitals and things like that overwhelming. I'm vulnerable sometimes, not being able to fight my corner... And I wonder who is going to advocate for me when I am in that position? I am going to have to depend on other people. And I want*

> *those people I depend on to recognise my difference and acknowledge what that might mean to me.'*

"Outed" by dementia: safety and control in identity disclosure and expression

The cognitive changes associated with dementia were highlighted as a source of high levels of stress and anxiety among LGBT + people with dementia [30, 31, 40–42]. This was mainly attributed to fear of losing decision-making capacity to make an informed decision about whether it is safe, and how to disclose a sexual or gender identity in certain environments, rendering the LGBT + person with dementia doubly vulnerable [31, 32, 40, 41, 44]. Histories of oppression, stigmatisation, and discrimination may affect older LGBT + people's decision around identity concealment and healthcare access [13, 44]. For LGBT + people who have experienced discrimination in the past, they may be hesitant to access services, move out of the safety of their home to formal care settings [36], or choose to conceal their identity [30, 32] due to fear of recrimination or unfair treatment [36].

For the LGBT + person with dementia, safety and control in identity disclosure is jeopardised as autonomy and control become increasingly undermined by dementia [30, 32], and in some cases by the partners [31, 32]. In addition, the process of disclosing a LGBT + identity is never a one-off process but can occur continuously in different contexts, with the potential of experiencing multiple negative reactions, and can be highly stressful. This was demonstrated in one of the included papers, where one participant explained:

> *"... at the hospital, in the surgery, with social services, with domiciliary care, and heaven knows elsewhere, people ask us who we are. And the pain in the gut feeling you get as each time you make the choice about delivering the fundamental information about yourself. Some of us don't even get to make the choice. My own partner outed me on every available occasion by constantly kissing me." ([41], p. 1345)*

Other challenges highlighted in the included papers are specific to transgender people, where their bodies are revealed to strangers while receiving care, eliminating their ability to control which parts of their identity are disclosed and how they are shared [31, 45]. In addition, gender expression may vary because of dementia, where transgender people may revert to earlier states of gender expression because of cognitive impairment [45]. This is depicted as an added challenge for the transgender person with dementia, especially for those who have had a gender reassignment surgery and exhibit gender-related behaviour that is inconsistent with their transgender identity, such as during personal care [38]. This was exemplified in one of the included papers, where a transgender person with dementia who previously underwent male to female gender reassignment surgery:

> *'...presented with toileting behaviour that would identify her as male gender, for example standing to urinate as if using a urinal, interpreted as reversal towards biological gender identification.' ([34], p. 12).*

Moreover, gender expression may be imposed on the person with dementia by transphobic family members. For example:

> *'Edna (a trans woman with dementia who had transitioned 40 years earlier) was prohibited from presenting as female by her family who were embarrassed by her trans status.' ([31], p. 35)*

Discussion

The aim of this systematic review is to identify and synthesise the evidence that described the needs, preferences, and experiences of LGBT + people living with dementia. The experiences of LGBT + people with dementia primarily focused on actual or anticipated discrimination, and how the lifetime experiences of oppression, trauma, and other stressors can impact on the experience of dementia. Many of the needs captured focused on safety and control in identity disclosure and expression, and access to love, intimacy, and social networks. In addition, maintaining personhood through institutional safety, psychological safety, and attachment through relationships and couplehood were highlighted. Data on preferences were not explicit in the included papers. However, the need to explore preferences through advance care planning with a focus on enduring power of attorney, living and legal wills, advance care directives, and gender and care setting preferences as a mechanism to ensure safety and promote autonomy were highlighted.

Heteronormativity

All the included papers reported on the histories of oppression, and actual or potential discrimination and mistreatment by healthcare services. This is consistent with a recent report, documenting 486 reports of homophobic abuse in care settings in the UK [47], and findings in the broader LGBT + literature [17, 26, 48]. However, the findings from this review highlight how societal and personal biases against aging, dementia, and a LGBT + identity may intersect to further social marginalisation of and microaggression towards LGBT + individuals. This reflects how stigma and bias in healthcare settings create pervasive systemic inequalities for the LGBT + person; leading to additional stressors, fears and worries about discrimination, and negatively affecting help-seeking behaviours [26, 49–51]. Fear of mistreatment marks the presence and impact of heteronormativity and homo-/bi-/transphobia [52]. Heteronormativity is exhibited by assumptions of heterosexuality as the benchmark for sexual citizenship that pervade care provision and service planning [53]. In addition, it signifies the overpowering prominence of heterosexual life course in dementia discourse [54]. This ranges from day-to-day care-based conversations, public-facing and internal dementia-related organisational material, and material used by dementia campaign groups [19, 54]. Heteronormativity also underpins how the LGBT + person and their caregiver are located in their relationship to policy and legislation of welfare state, which are built on assumptions that align with heterosexual life experiences; excluding or inadequately addressing the unique biographical milestones of LGBT + persons and their chosen family [55, 56]. In this regard, heteronormativity provides a conceptual basis for critiquing dementia care services that goes beyond overt discrimination inquiries, to encompass a more subtle bias that supports a hierarchy of sexualities in the context of care provision [54].

Personhood and the psychosocial model of dementia

Many of the needs captured in the included papers were characterised by maintaining identity and personhood. The psychosocial model of dementia, such as the widely used Kitwood's model, has a potential in understanding the diverse sexual and gender identities in the context of dementia [57]. However, the concept of personhood remains problematic under the psychosocial model, which assumes that "*the key psychological task in dementia care is that of keeping the sufferer's personhood in being*" ([57], p. 269). This model has been critiqued for its ambiguity in affirming whether there is a fixed stable self, which may or may not remain constant through time, especially in advanced dementia [14, 58]. In addition, this model assumes personhood as a standing or status which is replenished through relationships and social connectedness, shifting the responsibility on 'others' to maintain it in the context of cognitive impairment [59]. As a result, it bestows an inferior position on the person with dementia [60], where personhood becomes a status that can only be conferred by 'others' [61]. In this context, it can be argued that the concept of personhood in the included papers is based on asymmetrical power relationship between those with dementia and those without dementia (others), which can overtly and indirectly produce forms of inequality [61].

Reconceptualising personhood and dementia from a queer lens

Reconceptualising personhood in the context of dementia from a queer lens has a greater emancipatory potential for the LGBT + person with dementia. Queer theory criticises the notion of a stable and fixed self, arguing that identity is fluid, unstable, emergent, and performative in relation to historically specific discourses [62]. In this respect, to have personhood, does not rely on being positioned within normative typologies, such as a man or a woman, and an abled or disabled body [63]. Therefore, queering dementia has the potential to subvert the cisheteronormative agentic system created for the LGBT + person with dementia [63]. The mainstream cisheteronormative discourse of successful aging and dementia obscures the experiences of LGBT + people with dementia [64]. Sandberg and Marshall ([65], p. 3) noted:

> *'Heterosexuality seems to be central to the making of successful aging futures, yet cannot stand alone as the promise of a happy later life. Notably, heterosexuality needs to be accompanied by able-bodiedness and able-mindedness to produce visions of a successful aging future.'*

Consequently, dementia, in itself, challenges the normative life course which imposes a social and temporal location on the person, and a familial reproductive futurity within a specific order: The person moves from childhood to adulthood, procreates, and then dies [62]. This ordered teleology is disrupted by dementia, where people with dementia are often viewed as 'childlike', and are therefore regarded as deviating from the cisheteronormative temporal logic, which is a key characteristic of reproductive futurity [66]. In this regard, dementia queers the normative notions of successful positive aging, temporality and futurity, and disrupts a normative life course, regardless of sexual orientation or gender identity of the individual [62, 67].

Dementia and transgender persons: an ageist and ableist discourse

The behaviour associated with cognitive decline in dementia is viewed as troublesome to cognitive normalcy, and is suggestive of cognitive abnormality [63]. This was particularly highlighted in the included papers involving transgender individuals [31, 33–35, 45]. This cognitive disability in dementia was conceptually framed differently in the different included papers. This ranged from forgetting that they have transitioned/re-transitioning, inconsistent gender related behaviours, gender ambivalence, and gender confusion. This perspective of 'gender confusion' has been critiqued as being ableist and ageist, where cognitive impairment is viewed as taking away agency and decision-making capacity from the transgender person [68]. While transgender individuals have long had to endure the cisnormative assumptions that their gender identity is illusive [69], older and disabled individuals are frequently framed within ableist and ageist gender norms, rendering the transgender older person with dementia as genderless [70, 71]. The normative standards of an individual's gender in terms of maleness and femaleness are based on youth and able bodies and minds, pushing those who do not fit within this restrictive normative criteria to the margins [68]. However, people with dementia who more closely conform to gender norms are at a lower risk of being stigmatised due to their cognitive impairment [71]. Hence, the dual dynamic of being older and disabled creates a double bind as illustrated by Baril and Silverman ([68], p. 124):

> *'They are both subjugated to forms of degenderization by others who see them as less masculine or feminine than younger able-bodied/minded subjects, and normatively constrained to continue to perform masculinity or femininity to avoid further ageist and ableist/cogniticist forms of violence.'*

In this respect, the included papers frame transgender people with dementia in a way that produces degenderisation, and exhibiting 'gender ambiguity' or 'gender confusion' is in turn reinforcing ableist and ageist discourse.

Implications

The need for change in dementia care for LGBT + people is two-fold: (1) promoting culturally safe services, and (2) actionable policy changes that challenge mainstream constructions of dementia to include people who do not fit within the cisheteronormative life course. Cultural safety refers to the ability to provide services that go beyond recognising disparities, with the aim of challenging systemic inequality [72]. It requires service providers give precedence to service-users' narrative, life histories, and safety needs; forge community alliances; reflect on the intrinsic power imbalances inherent in care provision, and how their values and beliefs influence service delivery [73, 74]. The background of the health and social care workforce is diverse, where many people may come from countries that still criminalise homosexuality or consider it sinful [75]. A recent report showed that abusive health and social care professionals are primarily influenced by religious or personal beliefs that being gay is a sin, crime, or both [47]. Therefore, there is a need for specific training and education for health and social care professionals to raise awareness, and promote safety in providing a service that is inclusive of LGBT + identities. The need for cultural safety for LGBT + people can be illustrated by the decompensation model [76], which builds upon minority stress model [77]. The decompensation model suggests that lack of cultural safety can result in high levels of stress among LGBT + people and that their coping reserve may no longer be effective; negatively impacting their health and wellbeing [76]. Therefore, the use of inclusive language and symbols that indicate environmental safety, such as rainbow lanyards, alongside culture shift may be an important compensatory mechanism. This in turn may promote a LGBT+-affirmative environment, a pre-requisite to achieving cultural safety.

Developing and implementing dementia-related policies from a queer intersectional lens can promote cultural safety and have the potential to address social and political determinants of health. A queer intersectional lens to policy analysis and development can be a useful tool to challenge heteronormative assumptions, that tend to put those who do not fit within the cisheteronrmative life course on the margins. In the context of dementia, this can help reframe familial kinships and social connectedness, forgetfulness and confusion, household and welfare benefits among other social positions to ensure policy improves outcomes for the LGBT + person with dementia. An initial step towards queer(y)ing dementia-related policy is through data monitoring [78]. Data monitoring relating to sexual and gender identity within dementia care services is a useful tool in helping understand the differences and challenges faced by LGBT + people; ultimately, informing service planning that addresses the needs of the groups being served.

There are several research implications. The voice of LGBT + people with dementia themselves is almost absent from the literature. There is a need to explore the needs, preferences, and experiences of LGBT + people with dementia. The need to investigate the perspectives and views of service providers and other stakeholders is needed to describe barriers to LGBT+-inclusive dementia care. This will help inform educational interventions to enhance knowledge and awareness among service providers. Aspects of intersectionality that relate to socioeconomic status, ethnicity, and culture among others were rarely discussed in the included papers. Therefore, research that explores the intersection of different forms of oppression experienced by LGBT + people with dementia, in the context of having multiple minoritised identities, is needed. In addition, research that considers diverse geographical locations, cultural contexts, and methodological approaches is needed.

Strengths and limitations

This review explores the needs, preferences, and experiences of LGBT + people with dementia. Most papers included in this review were non-empirical papers. This demonstrates that the robustness of the science relating to experiences, needs, and preferences of LGBT + people with dementia is weak. Given that the majority of the included papers were non-empirical, this highlights a significant gap in the evidence base, limits the generalisability of the findings, and indicates that we cannot draw firm conclusions from the results of the review. All the included papers were from the UK, Canada, Australia, and USA, where legal and institutional support for LGBT + people are relatively prominent. In countries that still did not legalise same-sex marriage/partnership, and the 65 countries that still criminalise homosexuality [79], the needs, preferences, and experiences of LGBT + people with dementia might be very different. As such, these findings may not be applicable to diverse sociopolitical contexts, especially in settings that did not legalise same-sex marriage/partnership or continue to criminalise homosexuality. Most of the included papers did not differentiate between the different sexual and gender identities. Such homogenising discourse has the potential to hide differences and inequalities between and among the different identities and masks a nuanced discussions about different types of intersectionality [80].

Conclusion

This review provides a comprehensive appraisal relating to the needs, preferences, and experiences of LGBT + people with dementia. The findings illustrate that the needs and experiences of LGBT + people with dementia are intersectional in nature, and require a critical lens to deconstruct the cisheteronormative narrative in dementia discourse. The voice of people living with dementia is still almost absent from the available evidence, and therefore, the preferences of LGBT + people with dementia are not explicit in the existing literature. Designing and implementing dementia-related policies through an intersectional lens, along with culturally safe dementia services, are needed. Further research that includes the voice of LGBT + people living with dementia coupled with healthcare professionals' perspective is needed.

Abbreviations

LGBT	Lesbian, gay, bisexual and transgender
LGBT+	Lesbian, gay, bisexual, transgender, and those who do not identify as cisheterosexual
PsyhcInfo	Psychological information database
CINAHL	Cumulative index of nursing and allied health literature
MEDLINE	Medical literature analysis and retrieval system online

Author contributions

CC, CW and NP made a substantial contribution to the concept and design of this work in acquisition, analysis, and interpretation of data. JL independently reviewed 10% of the retrieved papers and contributed to quality assessment. CC drafted the manuscript, and NP and CW reviewed it and provided detailed feedback. All authors read and approved the final manuscript.

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