Older lesbian, gay, bisexual, transgender, queer and intersex peoples' experiences and perceptions of receiving home care services in the community: A systematic review

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Abstract

Background: Numbers of older lesbian, gay, bisexual, transgender, queer and intersex (LGBTQI+) people are increasing worldwide in line with the ageing populations of many countries. Most LGBTQI+ people want to remain in their own homes as they age, making it important to understand their experiences and perceptions of receiving home care. This systematic review aimed to examine older (over 60 years) LGBTQI+ people's perceptions and experiences of using formal home care services in the community.

Methods: The following six electronic databases were searched from the date of the first records until the first week of March 2020: MEDLINE; PsycINFO; Social Policy and Practice; CINAHL; SSCI; and ASSIA. Hand searches of the reference lists of the included studies and relevant reviews were also conducted. Only peer reviewed research published in English was included. There were no restrictions on study design. Finding were analysed using narrative synthesis. PROSPERO protocol registration identification number: CRD42020168443.

Results: Seven studies involving 169 participants were included in the synthesis. All were qualitative. Most participants were either lesbian women or gay men, with no studies investigation home care for transgender, queer, intersex or other sexual minorities. Fear of accessing home care services due to the perceived threat of homophobia and past negative experiences of discrimination were common. Some concealed any LGBTQI+ materials in their homes to try and hide their sexuality from home care workers. Despite fear of discrimination, lesbian women and gay men reported wanting and expecting the same level of care, dignity and respect as their heterosexual counterparts. Mandatory LGBTQI+ sensitivity training for home care workers was identified for reducing homophobia and increasing the inclusivity of service providers.

Conclusion: Older lesbian women and gay men fear or experience discrimination from home care workers, with some choosing to hide their sexuality causing stress and anxiety. Sensitivity training in the needs of older LGBTQI+ people should be considered by home care service providers as a way of reducing homophobic attitudes which may exist among some home care workers. Due to the paucity of studies and their focus on older lesbian women and gay men, more research is needed to explore the experiences of other sexual minorities receiving home care services who are represented by the LGBTQI+ umbrella term.

Key words: Sexual and Gender Minorities; LGBT; Aged; Home Care Services

What is already known about the topic?

- Older (over 60 years) lesbian, gay, bisexual, transgender, queer and intersex (LGBTQI+) people report homophobia, social exclusion and poor care provision when accessing long-term care services.
- However, older LGBTQI+ people increasingly want to remain in their own homes as they age, with maintaining social support networks and being wary of potential homophobia and heteronormative care home environments reported concerns. Therefore, there is a need to explore their experiences and perceptions of receiving home care services in the community.

What this paper adds

- Despite fear of discrimination, those lesbian women and gay men who utilise home care services expect to be given the same level of care, dignity and respect as heterosexual people.
- However, many older lesbian women and gay men fear accessing home care services due to the perceived threat of homophobia and past negative experiences of discrimination.
- Participants felt mandatory LGBTQI+ sensitivity training for home care workers would reduce homophobia and increase the inclusivity of home care services.

Background

Worldwide people are living longer, with one in five people projected to be aged 60 or above by 2050 (World Health Organisation [WHO], 2017). In the United Kingdom (UK), those of pensionable age are expected to increase from 12.3 million as of 2018 to approximately 15.9 million by 2043 (Office for National Statistics [ONS], 2019). However, as people age so too does their likelihood of living with disability (Melzer et al. 2015). More than a third of older people aged over 65 live with a long-term condition which negatively impacts on their quality of life (ONS 2013).

Many older people with long-term conditions living in their own homes in the community, rely on home (also known as domiciliary) care services to have their care needs met. It has been predicted that by 2020, almost 400,000 older people in England will be accessing home care services (Wittenburg & Hu 2015). Home care includes providing help with various tasks, including, for example: help with activities of daily living (e.g. washing; oral hygiene; dressing and eating); food shopping; providing meals daily (e.g. 'meals on wheels'); assisting with laundry; help with medication; and some social activities (Bottery et al. 2018).

The needs of older LGBTQI+ people

People who identify as lesbian, gay, bisexual, transgender, queer and intersex (LGBTQI+) not only suffer from significant health inequalities, such as an increased risk of mental illness and poorer access to health care services compared to heterosexual people (Williams et al. 2012), they are also not having their social care support needs met for a variety of reasons. A presumption by healthcare professionals that all people are heterosexual can cause distress when people are deciding whether or not to share their sexual or gender identities (Neville et al. 2015). Further, many fear being open about their sexual orientation due to discriminatory experiences from previous contact with some healthcare professionals (McCann & Brown 2019). Other research has found care staff working in the community lack knowledge specifically in the care needs of older LGBTQI+ adults, which they feel negatively impacts on the quality of care they provide to this already marginalised group (Kortes-Miller et al. 2019).

Although LGBTQI+ people may benefit from supportive LGBTQI+ communities and networks, they are more likely to be single, live alone, less likely to have children and less likely to see biological family members than heterosexual people (Almack et al. 2010; Guasp 2011). Further, some older gay and lesbian people experience their communities as exclusionary, therefore missing out on potential informal care support (Heaphy & Yip 2003). Given these diminished social and familial support networks, lesbian, gay and bisexual (LGB) people are more likely than heterosexual people to rely on social care services to have their healthcare needs met (Fredriksen-Goldsen et al. 2013; Fredriksen-Goldsen & Muraco 2010).

Inequalities and discrimination, whether perceived or lived, for older LGBTQI+ people in accessing social care services in the community have been reported (Kneale et al. 2019), with homophobia, heteronormativity, invisibility and denial of older people's sexual identity known concerns (Harding et al. 2012). These concerns and discriminatory experiences are becoming increasingly problematic, given the majority of LGBTQI+ people would prefer to continue living in their own homes, as opposed to residential care, as they age (Carr & Ross 2013; Kushner et al. 2013).

Experiences of LGBTQI+ in receiving care services

People who are LGBTQI + and live in care homes are increasingly being open about their sexuality with care staff and other residents, however, almost a quarter report it has had a negative impact on the care received (Government Equalities Office, 2018). Others experience social exclusion or marginalisation (Hayman & Wilkes 2016; Leyerzapf et al. 2018). Evidence also suggests that some care staff have heteronormative attitudes and working practices towards LGBTQI+ older people which further compounds their invisibility and inequality (Simpson et al. 2018). Further, poor LGBTQI+ awareness and homophobia among care home staff is a reported concern among residents, resulting in them concealing their sexual and gender identities through fear of being disliked and in order to feel safe (Manthorpe & Price 2005; Westwood 2015). Given the reported experiences of older LGBTQI+ people receiving homophobia in care home settings, there is an important need to explore whether these experiences occur when accessing other sources of formal care provision. Home care services provided in the community is one such service.

Aims and research questions

Whilst the experiences of older people receiving home care and the challenges they report have been identified in general (Sykes & Groom, 2011), the peer reviewed literature describing the perceptions and experiences of older LGBTQI+ people utilising these important social care services has not been synthesised and remains poorly understood. Therefore, this systematic review aimed to examine the published literature on older (over 60 years) LGBTQI+ people's perceptions and experiences of using formal home care services in the community to answer the following three research questions:

- What are the experiences or perceptions of older (over 60 years) LGBTQI+ people in using formal home care services?
- What impact (if any) do these experiences have on the physical and mental health of those utilising home care services?
- What are the barriers and facilitators to accessing these services?

Methods

This review followed Centre of Reviews and Dissemination (CRD) procedures (CRD 2009) and was reported using the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines (Moher et al. 2009). The research questions and search strategy were developed using the patient, intervention, comparison, outcome and study design (PICOS) process (CRD 2009). The review protocol was registered with in the International Prospective Register of Systematic Reviews (PROSPERO) database on 19th February 2020 and published on 23rd April 2020. At the time of registering the protocol, the electronic search strategy had been competed but the searches had not been carried out. The protocol registration number is: CRD42020168443 (Smith & Wright 2020).

Electronic search strategy

The following six electronic databases were searched from their first records until the first week of April 2020: MEDLINE, PsycINFO, Social Policy and Practice, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Social Sciences Citation Index (SSCI) and Applied Social Sciences Index and Abstracts (ASSIA).

Search strategies similar to that in Box 1 were designed dependent on the electronic databases listed above and their individual Medical Subject Heading (MeSH) terms. All key words and combinations were the same throughout the database searching. The MeSH terms used are reported in italics and key words with truncation, where appropriate.

Other sources searched

Reference lists of relevant literature reviews and the articles included in this review were hand searched. Experts in the field of research identified from the literature searches were contacted to identify other potentially relevant articles missed from the electronic searches.

Inclusion criteria

- Studies investigating formal home care experiences of LGBTQI+ people aged over 60
- Primary research published in peer-reviewed journals
- Studies published in English
- Quantitative, qualitative or mixed methods
- There were no date restrictions

Exclusion criteria

- Studies not about people who identify as LGBTQI+ or not possible to distinguish data from those who are LGBTQI+
- Studies where less than 50% of participants are aged over 60

- Studies about informal care (e.g. not paid for)
- Grey literature, opinion pieces, letters, commentaries or editorials
- Literature reviews

Box 1: Example search strategy conducted in MEDLINE

Concept	Search terms
Experiences/perceptions	*Patient satisfaction*, *personal satisfaction, quality of health care*, experience$, perception$, perspective$, facilitator$, barrier$, satisfaction, client satisfaction, care quality, quality of care
AND	
LGBTQI+	*Sexual and gender minorities*, *transgender persons*, lesbian$, transgender$, transsexual$; bisexual$, asexual$, gay, genderqueer, gender-queer, queer$, gender fluid, homosexual$, intersex$, gender-binary, non-binary, minority sexual, sexual minority, sexual orientation$, gender identit$, agender$, marginali?ed orientation$, men who have sex with men, women who have sex with women, non-heterosexual, pansexual, two-spirit$, third-gender, LGB, LGBT, LGBTQ, LGBTQI, LGBTQI+
AND	
Older people	*Aged*, *Aged, 80 and over*, older, oldest old, aged over 60, 60 years+, aged 60 and over, aged 60 and above, elder$, retired, retiree, senior citizen$, geriatric$
AND	
Home care	*Home care services*, *health services for the aged,* home care, homecare, domiciliary, home help$, home-aide$, in-home care$, community care, formal care

[a] $ denotes truncation (e.g. bisexual$ searches for: bisexual, bisexually and bisexuality)
[b] ? denotes use of wildcard
[c] italics signifies medical subject heading (MeSH) term

Study screening and selection

Following duplicate removal, both review authors independently screened the titles and abstracts to identify studies fitting the inclusion criteria. Both authors then scrutinised full texts of the selected articles. Where there was uncertainty about inclusion, consensus was achieved by discussion.

Data extraction and management

Data were extracted using standardised data extraction forms and subsequently entered into standardised tables. Data extraction included author details, year of publication, participant demographics, sample size, key findings related to LGBTQI+ perceptions and experiences of home care, and the authors' conclusions.

Quality appraisal

The quality of included studies was assessed independently by both study authors using the QualSyst review tool (Kmet et al. 2004). For qualitative studies, a maximum score of 20 can be achieved, with higher scores indicating greater study quality. Differences in quality scores between authors was small, with consensus achieved through discussion. Quality scores were not used to exclude studies, but were used to identify their strengths and weaknesses.

Data synthesis

Data were synthesised using a narrative approach (Dixon-Woods et al. 2005). Given the broad research questions and anticipated varied study types expected, narrative synthesis was an appropriate choice. This method is inclusive, allows integration of qualitative and quantitative data from a wide variety of sources and is descriptive and interpretive. A modified approach of conducting narrative synthesis reported by Popay et al. (2006) was followed. Briefly, the stages were: (1) a preliminary synthesis of the findings; (2) exploring relationships in the data; and (3) assessing the robustness of the synthesis.

Results

Electronic searches, conducted during the first week of April 2020, revealed a total of 209 articles before duplicate removal: MEDLINE – 34; PsycINFO – 45; Social Policy & Practice – 11; CINAHL – 76; SSCI – 33; ASSIA – 10. After duplicate removal, 146 unique titles and abstracts were identified. Examination of these titles and abstracts led to 29 full-texts being retrieved. Six fitted the inclusion criteria and were included in this review. Reference list searching of the six included studies and seven relevant reviews, found during the electronic database searches, was conducted. This led to a further 19 full-texts being retrieved, with one article fitting the inclusion criteria. Therefore, seven articles were included in this review. All the included studies were qualitative.

Of the 48 full-text articles assessed for inclusion, 41 were excluded for not investigating home care services (28); being a commentary, book chapter or dissertation (6); used the same data as an already included article (3); participants were aged on average under 60 years old (2); had too little relevant data (2). Two articles came close to inclusion, but were ultimately excluded after discussion between reviewers due to having too little relevant data (Pang et al. 2019; Smith et al. 2010). The Pang et al. (2019) study explores end of life care for older transgender people, but does not focus on home care. Most participants in this study had not received or considered home care and no quotes are presented which describe home care. Findings presented in a survey study by Smith et al. (2010) describe the needs and expectations of older

LGBT people, but is not focused on home care services. Full details of the process of including and excluding articles with reasons is available in Figure 1.

Three overarching themes were developed from the narrative synthesis: 1. Experiences and perceptions of older LGBTQI+ people receiving home care services; 2. Impact of home care services on the physical and mental health of older LGBTQI+ people; and 3. Barriers and facilitators for older LGBTQI+ people in accessing home care services. Quotes from the included articles are presented to illustrate the findings from the narrative synthesis.

Figure 1 here

Study details and quality

The seven qualitative studies ranged in publication date from 2010 to 2019, with six published from 2015 onwards. Five were conducted in North America (Butler 2017; Dunkle 2018; Furlotte et al. 2016; Grigorovich 2015; Stein et al. 2010) one in the United Kingdom (Willis et al. 2018) and one in Australia (Waling et al. 2019). All used a range of sampling, data collection and analysis methods (Table 2). Three used face-to-face interviews (Furlotte et al. 2016; Grigorovich 2015; Willis et al. 2018), two telephone interviews (Butler 2017; Waling et al. 2019) and two focus groups (Dunkle 2018; Stein et al. 2010). Analysis types varied but was commonly thematic (Grigorovich 2015; Waling et al. 2019; Willis et al. 2018) or based on grounded theory (Butler 2017; Dunkle 2018).

Study quality was generally high, with scores ranging from 60% (Stein et al. 2010) to 90% (Willis et al. 2019). Six of the seven studies scored 75% or above (Table 3). Most studies performed well when describing the rationale for their approach, methods and data analysis used. However, relationships with theoretical frameworks and researcher reflexivity were often poorly defined or missing.

Participant characteristics

There were 169 participants in total. The majority were lesbian women (106: 63%) or gay men (58: 34%), with five bisexual people (3%). One participant also self-identified as transgender. Ages ranged from 39 to 86, with the average and median ages of participants above 60 years old for all studies. Partnered/co-habiting status of participants was reported by all studies, with more partnered/cohabiting (109: 64%) than not. Six of the seven studies reported participant ethnicity, with the vast majority white (125: 92%), three were Aboriginal (2%), three African American (2%) and two Asian (1%). A further three participants did not disclose their ethnicity. Full participant demographic details are available in Table 1.

1. Experiences and perceptions of older LGBTQI+ people receiving home care services

Narrative analysis of the findings suggested that many lesbian and gay older people are fearful of accessing home care services due to the perceived threat of homophobia and past negative experiences of discrimination. Fear was reported across all seven included studies and leads many to not disclose their sexual orientation to home care workers, with a common strategy for concealing their sexuality including hiding (often referred to as 'de-gaying' or 'straightening up') anything in their household which could reveal their sexuality (Butler 2017; Dunkle 2018; Furlotte et al. 2016; Grigorovich 2015; Stein et al. 2010; Waling et al. 2019; Willis et al. 2018).

> "*I don't have anything* [LGBT related] *displayed. I put away some books that were lesbian connected; I just put them under other things.*" (Lesbian participant from Butler 2017)

The potential for discrimination, mistreatment and concern over receiving poor quality care were highlighted as reasons for taking this action. However, some had developed strategies to deal with this in advance, often by being open about their sexuality with care workers and home care providers with the expectation those with homophobic views would not be sent to their house (Butler 2017; Grigorovich 2015; Willis et al. 2018).

> "*I think right up front, I said, 'This is my wife,' and she said, 'Oh, good.' And that was about it. Just went on from there…*" (Lesbian participant from Grigorovich 2015)

Although some reported no homophobia, this was not the case for all. Negative comments about participants' sexuality, questioning the validity of their relationships, and care workers who would not return after learning of the participants' sexuality were described (Butler 2017; Waling et al. 2019). The questioning of the validity of participants same sex relationships and other prejudices was a cause of stress, leading some older lesbian and gay people to feel isolated and silenced (Grigorovich 2015). Those participants who were not currently experiencing homophobia from home care workers, often discussed receiving it in the past or knowing of someone else who had and fearing what may happen if a care worker holds homophobic views (Butler 2017; Furlotte et al. 2016; Grigorovich 2015; Stein et al. 2010).

> "*I'm afraid to have a stranger* [care worker] *in my home, someone who may be very anti-gay, and then what if they find out about my life and now they're in my home regularly, and could somehow take advantage or mistreat me?*" (Participant gender and sexuality not disclosed. Stein et al. 2010)

However, poor care provision and attitude of home care workers was not always related to participants' sexuality. For example, some reported 'lazy', 'dishonest', 'incompetent' and 'unreliable' care workers regardless of their views on sexuality or religious beliefs (Butler 2017; Furlotte et al. 2016).

Overall, the gay, lesbian and bisexual participants in these seven studies largely wanted and expected to receive the same level of care, dignity and respect as their heterosexual counterparts. With some participants reporting that LGBTQI+ specific services may not be needed if they were to be treated with the same respect and dignity as heterosexual people receiving home care (Dunkle 2018). However, through fear of discrimination and the perceived potential for receiving poor quality care, many hide their sexuality. Summaries of the findings and conclusions of each included article are available in Table 4.

2. Perceived impact of home care services on the physical and mental health of older LGBTQI+ people

The impact of home care experiences on the participants' physical and mental health was rarely reported directly. However, concerns about possible homophobia from home care workers was described as negatively affecting their emotional wellbeing. In particular, anxiety surrounding the potential for discrimination was described, whilst others talked about how stressful and emotionally draining it was to be constantly 'on guard' for potential threats or homophobic discussions (Furlotte et al. 2016; Grigorovich 2015; Waling et al. 2019).

> "*you listen to people talk, you listen to the jokes they tell, you listen to the comments they make, and you pretty quickly learn to assess the risk*." (Gay male participant from Furlotte et al. 2016)

Other sources of anxiety and emotional expenditure related to the potential for privacy being breached and the emotional strain of hiding their sexual identity from strangers coming into their homes (Stein et al. 2010; Willis et al. 2018).

> "*What would worry me is somebody who was an evangelical Christian coming in and suddenly realising they were in a gay environment and possibly saying or doing something and storming out and not coming up and creating a fuss—you don't want fuss as you get older*." (Lesbian participant from Willis et al. 2018).

3. Perceptions and experiences of the barriers and facilitators for older LGBTQI+ people in accessing home care services

Various facilitators to accessing home care services were identified. Having the option of gay or lesbian home care workers or those with LGBTQI+ friendly views, was perceived as important for increasing inclusivity and reducing feelings of anxiety over disclosure (Furlotte et al. 2016; Waling et al. 2019; Willis et al. 2018).

"*If you had to have a nurse who came in or people came in to shower you or people came in to assist you in some other way with daily living, you'd really want to be able to have a choice of people who were gay friendly*." (Gay male participant from Waling et al. 2019)

The need for mandatory LGBTQI+ sensitivity training in the needs of older LGBTQI+ people was emphasised, especially for reducing homophobia among home care workers and increasing the inclusivity of service providers (Butler 2017; Dunkle 2018; Furlotte et al. 2016; Grigorovich 2015).

"*They have to be educated to come into a lesbian home and feel comfortable. These people that come into your home must be educated in diversity. I would call ahead and ask and if they are not open to serving the lesbian community, I'd say no thank you*." (Lesbian participant from Dunkle et al. 2018)

Further, providing clear and obvious signs that services were LGBTQI+ welcoming was imperative to facilitate access, for example, showing same sex couples in advertising material or placing rainbow flags in prominent positions around home care provider premises (Butler 2017; Dunkle 2018). Heteronormativity of home care providers was therefore a barrier to access for some lesbian and gay participants.

Discussion

The findings of this systematic review have revealed significant gaps in awareness surrounding the experiences of older LGBTQI+ people accessing home care services in the community. Whilst there is a dearth of research on this topic generally, almost all that is available focuses on the experiences of lesbian women and gay men. The experiences and perceptions of bisexual, transgender, queer, intersex, asexual and other sexual and gender minorities represented by the LGBTQI+ umbrella term are currently missing. However, whilst no date restrictions were placed on the searches, all included studies were published within the last ten years, suggesting an increasing body of research is being conducted into LGBTQI+ experiences.

As older LGBTQI+ people are more likely than heterosexual people to rely on social care services (Fredriksen-Goldsen et al. 2013) and most would prefer to remain in their own homes as they age (Carr & Ross 2013) the findings of this review are of concern. Experiences of homophobia were commonly reported. Further, through fear of discrimination and the potential for receiving poor quality care, many chose to hide their sexuality. Similar findings have been reported previously with lesbian women and gay men accessing other social care services (Harding et al. 2012; Kneale et al. 2019), with fear based on past experiences of discrimination a common reason to hide their sexuality (McCann & Brown 2019). However, due

to the lack of research into the experiences of other sexual minorities it is not possible to infer whether they experience similar discrimination when accessing home care services.

Evidence suggests older LGBTQI+ people are becoming more open about their sexuality in long-term residential care settings, but this sometimes results in homophobia, marginalisation, social exclusion and has a negative impact on the care received (Government Equalities Office, 2018; Hayman & Wilkes 2016; Leyerzapf et al. 2018). Findings from this review suggest older lesbian women and gay men are experiencing, or perceive they will experience, similar negative consequences from disclosing their sexuality. Home care service providers should consider ways in which they can make home care more inclusive and reduce barriers to accessing these services. For example, showing gay couples in advertisements or placing clear signs they are gay friendly, such as the rainbow flag, on their premises. Further, care workers should consider bringing information on the care providers non-discrimination policy and LGBTQI+ inclusive materials on their first visit to the care recipients' homes. This could also help reduce anxieties and emotional burden some report surrounding the disclosure of the sexuality to home care staff.

High quality training for care workers has been shown to improve the quality of care and health of service users (Cooper et al. 2017). Therefore, future policy surrounding home care of older people should include requirements for service providers to deliver validated sensitivity training in LGBTQI+ care provision. This has the potential to decrease experiences of discrimination and improve perceived LGBTQI+ inclusivity, therefore reducing barriers to accessing home care services. However, research exploring LGBTQI+ sensitivity training for home care workers is needed to identify how it impacts on the experiences of older LGBTQI+ people using these important social care services.

Limitations

Despite a comprehensive literature search across six electronic databases, few studies exploring the home care experiences of older LGBTQI+ people were found. The findings of this review are principally relevant to white Western lesbian women and gay men only. Black and minority ethnic groups and other at-risk groups for discrimination, such as refugees; people with disabilities; or those with severe mental illnesses, may experience receiving and accessing home care services differently to the homogeneous participant group in this review. Overall, the paucity of relevant literature inhibits the robustness of the conclusions that can be drawn.

Only research studies published in English were included, which could have led to relevant papers being omitted. This decision was taken for pragmatic purposes (CRD 2009), however the findings are therefore biased toward Western English-speaking countries. Further, it is

reasonable to assume that the experiences of older LGBTQI+ people in countries where few legal protections exist may differ from those reported here.

The two authors of this review, a gay male and asexual woman are both white, cisgendered, non-disabled people from working class backgrounds. In recognising these characteristics, the study authors accept that the analysis and reported findings of this review may have been influenced by their social positions. The authors came to the review through a shared commitment to highlight social injustices and advocate for change in their work where they can. Cognisance of their situatedness enabled them to be open to experiences outside their frames of reference. For example, to think about the importance of research into intersectional experiences such as raced homophobia. Future systematic reviews on similar topics could potentially bolster their analysis by including authors from a diverse range of marginalised groups who may look for more multiple nuanced experiences in the data based on their worldview.

Although various strategies were used among the included studies to enhance rigor and trustworthiness, none reported reflexivity in the research process. Consequently, how authors potentially influenced the studies based on their own beliefs, judgements and practices cannot be explored. Therefore, we encourage researchers to include a discussion of reflexivity in their research investigating LGBTQI+ topics.

Future directions

With increasing numbers of older people being open about their sexuality and gender identity, it is essential to explore and understand how aged home care services can adapt to meet the needs of these groups. The studies presented focus largely on the experiences of white people at the younger end of the older age spectrum who are living in Western high-income countries. The experiences of older black and minority ethnic LGBTQI+ people, the oldest age groups (those over 80 years) and research conducted in low- and middle-income countries is needed. Further, whether it is appropriate to conduct research which groups older LGBTQI+ people together and reports their combined experiences should be considered. As Butler (2017) notes, differences in experiences could be masked by variations in gender and sexual identity.

No quantitative or mixed methods studies were identified during the literature searches. This an important area for future exploration, with the impact of poor home care on the mental and physical health of older LGBTQI+ people poorly understood.

Conclusions

Many older lesbian women and gay men fear or experience discrimination from home care workers. Some choose to hide their sexuality causing emotional strain and anxiety. However,

more research is needed to understand and explore the experiences of other sexual and gender minorities who are represented by the LGBTQI+ umbrella term. Mandatory sensitivity training in the needs of older LGBTQI+ people should be considered by all home care providers as a way of potentially reducing homophobic attitudes among home care workers and increasing the inclusivity of these important social care services. Improving access to home care services can be facilitated by improving the visibility of LGBTQI+ people in advertisements and including symbols highlighting inclusivity, such as rainbow flags, on service provider premises.

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We have no conflict of interest to declare.

References

Almack K, Seymour J, Bellamy G (2010). Exploring the impact of sexual orientation on experiences and concerns about end of life are and on bereavement for lesbian, gay and bisexual older people. *Sociology, 44*(5):908-924. DOI: 10.1177/0038038510375739.

Bottery S, Jefferson L, Bennett L, Hall P, Cream J, Dale V, Honeyman M, Birks Y, Bloor K, Murray R (2018). *Home care in England. Views from commissioners and providers*. Kings Fund: London.

Butler SS (2017). Older lesbians' experiences with home care: Varying levels of disclosure and discrimination. *Journal of Gay & Lesbian Social Services, 29*(4):378-398. DOI: 10.1080/10538720.2017.1365673.

Carr S, Ross P (2013). *Assessing Current and Future Housing and Support Options for Older LGB People*. York: Joseph Rowntree Foundation.

Centre for Reviews and Dissemination (2009). *Systematic Reviews: CRD Guidance for Undertaking Reviews in Health Care.* CRD: University of York

Cooper C, Cenko B, Dow B, Rapaport P (2017). A systematic review evaluating the impact of paid home carer training, supervision, and other interventions on the health and well-being of older home care clients. *International Psychogeriatrics, 29*(4):595-604. DOI: 10.1017/S1041610216002386.

Dixon-Woods M, Agarwal S, Jones D, Young B, Sutton A (2005). Synthesising qualitative and quantitative evidence: a review of possible methods. *Journal of Health Services Research & Policy, 10*(1):45-53. DOI: 10.1258/1355819052801804.

Dunkle JS. (2018). Indifference to the difference? Older lesbian and gay men's perceptions of aging services. *Journal of Gerontological Social Work, 61*(4):432-459. DOI: 10.1080/01634372.2018.1451939.

Fredriksen-Goldsen KI, Muraco A (2010). Aging and sexual orientation: A 25-year review of the literature. *Research on Aging, 32*(3):372-413. DOI: 10.1177/0164027509360355.

Fredriksen-Goldsen K, Kim H, Barken S, Muraco A, Hoy-Ellis C (2013). Health disparities among lesbian, gay, and bisexual older adults: results from a population-based study. *American Journal of Public Health, 103*(10):1802-1809. DOI: 10.2105/AJPH.2012.301110.

Furlotte C, Gladstone JW, Cosby RF, Fitzgerald KA (2016). "Could we hold hands?" Older lesbian and gay couples' perceptions of long-term care homes and home care. *Canadian Journal on Aging, 35*(4):432-446. DOI: 10.1017/S0714980816000489.

Government Equalities Office (2018). *National LGBTQI+ Survey: Research Report*. London: Crown.

Grigorovich A (2015). Negotiating sexuality in home care settings: Older lesbians and bisexual women's experiences. *Culture, Health & Sexuality, 17*(8):947-61. DOI: 10.1080/13691058.2015.1011237.

Guasp A (2011). *Lesbian, Gay & Bisexual People in Later Life*. Stonewall.

Harding R, Epiphaniou E, Chidgey-Clark J (2012). Needs experiences and preferences of sexual minorities for end of life care and palliative care: A systematic review. *Journal of Palliative Medicine, 15*(5):602-611. DOI: 10.1089/jpm.2011.0279.

Hayman B, Wilkes L (2016). Older lesbian women's health and healthcare: A narrative review of the literature. *Journal of Clinical Nursing, 25*(23-24):3454-3468. DOI: 10.1111/jocn.13237.

Heaphy B, Yip AKT (2003). Uneven possibilities: Understanding non-heterosexual ageing and the implications of social change. *Sociological Research Online, 8*(4):99-110. DOI: 10.5153/sro.864.

Kmet LM, Lee RC, Cook LS (2004). *Standard quality assessment criteria for evaluating primary research papers from a variety of fields*. Edmonton: Alberta Heritage Foundation for Medical Research (AHFMR), HTA Initiative HTA Initiative, 02(13).

Kneale D, Henley J, Thomas J, French R (2019). Inequalities in older LGBTQI+ people's health and care needs in the United Kingdom: a systematic scoping review. *Ageing & Society,* 1-23. DOI: 10.1017/S0144686X19001326.

Kortes-Miller K, Wilson K, Stinchcombe A (2019). Care and LGBTQI+ aging in Canada: A focus group study on the educational gaps among care workers. *Clinical Gerontologist, 42*(2):192-197. DOI: 10.1080/07317115.2018.1544955.

Kushner B, Neville S, Adams J (2013). Perceptions of ageing as an older gay man: a qualitative study. *Journal of Clinical Nursing, 22*(23-24): 3388-3395. DOI: 10.1111/jocn.12362.

Leyerzapf H, Visse M, De Beer A, Abma TA (2018). Gay-friendly elderly care: creating space for sexual diversity in residential care by challenging the hetero norm. *Ageing & Society, 38*(2):352-377. DOI: 10.1017/S0144686X16001045.

Manthorpe J, Price L (2005). Lesbian carers: personal issues and policy responses. *Social Policy & Society, 5*(1):15–26. DOI: 10.1017/S1474746405002691.

McCann E, Brown M (2019). Homelessness among youth who identify as LGBTQ+: A systematic review. *Journal of Clinical Nursing, 28*(11-12):2061-2072. DOI: 10.1111/jocn.14818.

Melzer D, Delgado JC, Winder R, Masoli J, Richards S, Ble A (2015). *The Age UK Almanac of Disease Profiles in Later Life A Reference on the Frequency of Major Diseases, Conditions and Syndromes Affecting Older People in England*. UEMS Ageing Research Group: University of Exeter.

Moher D, Liberati A, Tetzlaff J, Altman DG (2009). Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. *PLoS Medicine, 6*(7). DOI: 10.1371/journal.pmed.1000097.

Neville, S J, Adams, J, Bellamy, G, Boyd, M, George, N (2015). Perceptions towards lesbian, gay and bisexual people in residential care facilities: a qualitative study. *International Journal of Older People Nursing, 10*(1):73-81. DOI: 10.1111/opn.12058.

Office for National Statistics (2013). *General Lifestyle Survey: 2011*. [Accessed 19-01-2020] https://www.ons.gov.uk/peoplepopulationandcommunity/personalandhouseholdfinances/incomeandwealth/compendium/generallifestylesurvey/2013-03-07

Office for National Statistics (2019). *National Population Projections: 2018-based Statistical Bulletin*. [Accessed 21.01.2020] www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationprojections/bulletins/nationalpopulationprojections/2018based#changing-age-structure

Pang C, Gutman G, de Vries B (2019). Later life care planning and concerns of transgender older adults in Canada. *The International Journal of Aging and Human Development, 89*(1):39-56. DOI: 10.1177/0091415019843520.

Popay J, Roberts H, Sowden A, Petticrew M, Arai L, Rodgers M, Britten N, Roen K, Duffy S (2006). *Guidance on the conduct of narrative synthesis in systematic reviews*. Swindon: ESRC Methods Programme.

Simpson P, Almack K, Walthery P (2018). 'We treat them all the same': the attitudes, knowledge and practices of staff concerning older lesbian, gay, bisexual and trans residents in care homes. *Ageing & Society, 38*(5):869-899. DOI: 10.1017/S0144686X1600132X.

Smith LA, McCaslin R, Chang J, Martinez P, McGrew P (2010). Assessing the needs of older gay, lesbian, bisexual, and transgender people: a service-learning and agency partnership approach. *Journal of Gerontological Social Work, 53*(5):387-401. DOI: 10.1080/01634372.2010.486433.

Smith R, Wright T (2020). Older LGBTQI+ people: a protocol for a systematic review of their experiences of receiving home care services in the community. *International Prospective Register of Systematic Reviews*. Registration number: CRD42020168443.

Stein GL, Beckerman NL, Sherman PA (2010) Lesbian and gay elders and long-term care: identifying the unique psychosocial perspectives and challenges. *Journal of Gerontological Social Work, 53*(5):421-35. DOI: 10.1080/01634372.2010.496478.

Sykes W, Groom C (2011). *Older people's experiences of home care in England*. Manchester: Equality and Human Rights Commission.

Waling A, Lyons A, Alba B, Minichiello V, Barrett C, Hughes M, Fredriksen-Goldsen K, Edmonds S (2019) Experiences and perceptions of residential and home care services among older lesbian women and gay men in Australia. *Health and Social Care in the Community, 27*(5):1251-1259. DOI: 10.1111/hsc.12760.

Westwood S (2015). 'We see it as being heterosexualised, being put into a care home': gender, sexuality and housing/care preferences among older LGB individuals in the UK. *Health and Social Care in the Community, 24*(6):e155-e163. DOI: 10.1111/hsc.12265.

Williams H, Varney J, Taylor J, Fish J, Durr P, Elan-Cane C (2012). *The Lesbian, Gay, Bisexual and Trans Public Health Outcomes Framework Companion Document.* London: Public Health England. [Accessed 01/02/2020] https://www.london.gov.uk/sites/default/files/LGBT%20Public%20Health%20Outcomes%20Framework%20Companion%20Doc.pdf

Willis P, Raithby M, Maegusuku-Hewett T (2018). "It's a nice country but it's not mine": Exploring the meanings attached to home, rurality and place for older lesbian, gay and bisexual adults. *Health and Social Care in the Community, 26*(6):908-916. DOI: 10.1111/hsc.12616.

Wittenburg R, Hu B (2015) *Projections of Demand for and Costs of Social Care for Older People and Younger Adults in England, 2015 to 2035*. PSSRU: London.

World Health Organisation (2017). *Global Strategy and Action Plan on Ageing and Health*. Geneva: World Health Organization.

Table 1: Aims and participant demographic characteristics

Authors (Year published) [Country]	Aims	Participant numbers	Age in years Mean [median] (range)	Gender (%)	LGBTQI+ (%)	Ethnicity (%)	Cohabiting/ partnered (%)	Urban/rural
Butler (2017) [USA]	To explore the experiences of older lesbian women receiving home care services.	20	71.9 [71.5] (66-86)	20 women (100%)	20 lesbian women	20 white (100%)	5 (25%)	Both urban and rural
Dunkle (2018) [USA]	To explore what lesbian women and gay men know about services funded under the Older Americans Act (OOA).	31	65.6 NR (54-80)	16 women (52%); 15 men (48%)	16 lesbian women (52%); 15 gay men (48%)	27 white (87%); 1 Asian (3%); 3 not disclosed (10%)	22 (71%)	NR
Furlotte et al. (2016) [Canada]	To describe what lesbian and gay couples anticipate their experiences will be like with long-term care homes and home care services.	24 (12 couples)	63.5 [65] (39-75)	16 women (67%); 8 men (33%)	16 lesbian women (67%); 8 gay men (33%) [note: 1 also identified as transgender]	23 white (96%); 1 Chinese (4%)	24 (100%)	NR
Grigorovich (2015) [Canada]	To better understand the impact of sexual minority identity on lesbian women's experiences of home care services.	16	63.9 NR (55–72)	16 women (100%)	12 lesbian women (75%); 4 bisexual women (25%)	12 white (75%); 3 Aboriginal (19%); 1 African American (6%)	9 (56%)	Urban
Stein et al. (2010) [USA]	To identify the psychosocial challenges gay and lesbian older people face regarding long-term care.	16	NR NR (60-84)	12 men (75%); 4 women (25%)	12 gay men (75%); 4 lesbian women (25%)	14 white (88%); 2 African American (12%)	5 (31%)	NR

Waling et al. (2019) [Australia]	To explore perceptions and experiences of residential care and home care services, and the rationale behind current and future decision processes in accessing them.	33	68 [66] (60-80)	19 women (58%); 14 men (42%)	19 lesbian women (58%); 14 gay men (42%)	NR	22 (67%)	Urban (76%); regional (12%); rural (6%); unknown (6%)
Willis et al. (2018) [UK]	To examine the significance of home and place of lesbian, gay and bisexual adults aged over 50.	29	62 [61] (50-76)	19 women (66%); 10 men (34%)	19 lesbian women (66%); 9 gay men (31%); 1 bisexual man (3%)	29 white (100%)	22 (76%)	Rural (62%); urban (38%)

[a] NR = not reported (where possible, study authors were contacted to retrieve missing data)

Table 2: Study design and methods

Authors (date) Country	Study type and design	Sampling	Data collection	Data analysis
Butler (2017) [USA]	Qualitative, cross-sectional	Convenience	Telephone, semi-structured interviews	Constant comparative method of grounded theory
Dunkle (2018) [USA]	Qualitative, cross-sectional	Snowball and purposive	Face-to-face, focus groups	Principles of grounded theory
Furlotte et al. (2016) [Canada]	Qualitative, cross-sectional	Snowball and purposive	Face-to-face and telephone; active interviews	Constant comparative method
Grigorovich (2015) [Canada]	Qualitative, cross-sectional	Snowball and purposive	Face-to-face; semi-structured interviews	Thematic
Stein et al. (2010) [USA]	Qualitative, cross-sectional	Convenience	Face-to-face, focus groups	Open-ended coding
Waling et al. [2019) [Australia]	Qualitative, cross-sectional	Stratified random	Telephone, semi-structured interviews	Thematic
Willis et al. (2018) [UK]	Qualitative, cross-sectional	Purposive	Face-to-face; semi-structured interviews	Thematic

Table 3: Quality scores of included studies

	Butler (2017) [USA]	Dunkle (2018) [USA]	Furlotte et al. (2016) [Canada]	Grigorovich (2015) [Canada]	Stein et al. (2010) [USA]	Waling et al. [2019) [Australia]	Willis et al. (2018) [UK]
Question / objective **sufficiently described?**	2	2	2	2	2	2	2
Study design evident and appropriate?	2	2	2	2	2	2	2
Context for the study clear?	2	2	2	2	2	2	2
Connection to a theoretical framework/wider body of knowledge?	1	2	1	1	2	2	2
Sampling strategy described, relevant and justified?	1	2	1	2	1	2	2
Data collection methods clearly described and systematic?	2	2	2	2	1	1	2
Data analysis clearly described and systematic?	2	2	2	2	1	2	2
Use of verification procedure(s) to establish credibility?	2	0	2	2	0	2	2
Conclusions supported by the results?	2	1	1	1	1	2	2
Reflexivity of the account?	0	0	0	0	0	0	0
Total score out of 20 (%)	**16 (80%)**	**15 (75%)**	**15 (75%)**	**16 (80%)**	**12 (60%)**	**17 (85%)**	**18 (90%)**

[a] yes = 2, partial = 1, no = 0 (Kmet et al. 2004)

Table 4: Findings and conclusions

Authors (date) Country	Study findings relating to the experiences and perceptions of LGBTQI+ people receiving home care services	Authors' main conclusions
Butler (2017) [USA]	Four themes relevant to this review were identified: 1) level of disclosure; 2) experiences with homophobia; 3) evaluation of care received; 4) visions of ideal long-term services and support. Some lesbian women took steps to hide their sexuality by 'de-gaying' their home, thereby hiding anything which might highlight their sexuality. Others decided 'disclosure up front' was the best policy and were open about their sexuality with the home care providers. This was a way of setting boundaries up front to avoid them having care workers with homophobic views. Five of the 20 participants reported homophobia and discrimination when receiving home care. Examples included: difficulty in finding care workers who would stay after finding out their sexuality; care workers who used their religion to justify their homophobic behaviour; and a lack of caring behaviour. Although most described receiving good quality care, it came after numerous experiences of poor care and homophobia. Others described experiences of lazy, dishonest, incompetent and unreliable care workers. Receiving good quality, accepting, compassionate care was more important than having a lesbian care worker. Some would feel more comfortable disclosing their sexuality if services made clear they are 'gay friendly' in their marketing materials.	Care workers need extensive training in order to provide good quality and reliable care to older lesbian women. Older LGBT people need special consideration due to the fear they may have about receiving home care services based on the homophobia they may have received in the past.
Dunkle (2018) [USA]	Four themes relevant to this review were identified: 1) low expectations of a welcoming environment; 2) the importance of being out; 3) need for LGBT-specific services; 4) how to create inclusive services. Some participants talked about needing to 'straighten up the house' and hide items which may suggest their sexuality to the home care workers through fear of homophobia. Some described not wanting or potentially needing home care services due to the LGBT community taking care of each other. Others described that this is what they have always done, dating back beyond the AIDS epidemic of the 1980s.	Lesbian women and gay men generally expect an unwelcoming environment regarding in-home care services. However, not all LGBT people want LGBT-specific services, they want

	Home care services should have visible signs that they are inclusive of the LGBT community, if not this is a barrier to access for some as they view it as an unsafe space. Visibility was described as seeing same sex couples in advertisements and the rainbow flag on doors or windows of services providers. LGBT people would feel more comfortable in accessing these services and it makes for a more welcoming environment. LGBT sensitivity training for home care workers was described as essential due to the homophobia experienced by some older gay people.	what everyone else wants: to be treated with dignity and respect by services providers.
Furlotte et al. (2016) [Canada]	Four themes relevant to this review were identified: 1) discrimination; 2) identity; 3) expenditure of energy; 4) nuanced care. Participants feared covert discrimination, such as home care workers talking about them behind their backs. Covert discrimination also occurred when care providers assumed participants were heterosexual. Some felt that discrimination based on sexuality would be more likely to occur in rural areas, as opposed to more cosmopolitan city centres. Most had not experienced overt discrimination, but had heard from others about homophobic experiences or based their assumptions on past negative experiences. Some do not feel comfortable disclosing their sexuality to health care providers through fear of being discriminated against. Having multiple home care workers entering their home led to uncomfortable feelings, especially surrounding having to disclose their sexuality repeatedly. Having openly gay or lesbian staff members was described as a way of increasing inclusivity. Participants described emotional energy involved in hiding their sexuality from home care workers by trying to 'de-gay' their home. This was through fear they may not receive the same level of care as heterosexual people. Others talked about constantly observing or being on guard for signs their home care workers may discriminate against them, for example comments they make or jokes they tell. Participants wanted health care providers to respect their lifestyle and act in a natural way. They also described not wanting any special treatment, just the same standard of care, respect and dignity received by heterosexual people. LGBT sensitivity training may be useful.	Older lesbian and gay couples anticipating the need for long term care homes and home care services are concerned about future discrimination and complex challenges related to their sexual identity and couple-hood. They expect to have to expend emotional energy while experiencing the need for nuanced care.
Grigorovich (2015) [Canada]	Four themes relevant to this review were identified: 1) deciding to come out; 2) negative reactions to disclosure; 3) supportive reactions and gratitude; 4) maintaining vigilance. Most participants reported not disclosing their sexuality to home care workers and that most assumed they were heterosexual. However, one participant felt being open with their sexuality from the beginning was important, especially if they were worried about being 'found out' due to having LGBT items in their homes. Others based disclosure by gauging who they felt might be 'okay with it' and the need to do so. The need to monitor care workers	Sexual minority stress and heteronormativity negatively affects older lesbians' and bisexual women's home care experiences. Awareness of lesbian, gay, bisexual,

	reactions and deciding on the right time to disclose was described as emotionally draining. Past experiences of sexual minority prejudice and oppression or overtly homophobic violence and discrimination from health care workers providers influenced decisions not to disclose. One participant who had disclosed her sexual orientation talked about receiving demeaning comments from multiple home care workers. Others described more subtle experiences of prejudice, such as questioning the validity of their relationships. This was stressful and contributed to participants' feelings of isolation and being silenced. Several participants reported positive experiences and reactions from home care workers. These surrounded being accepting of their sexuality, being able to take part in jokes and having a positive attitude. Many participants worried about experiencing homophobia from home care workers in the future. This was due to the continued prevalence of homophobia in society and past experiences of discrimination. Needing to continually monitor care workers reactions and guard against potential homophobia was described as stressful and negatively affected their experiences of receiving home care. Mandatory training in sexual and gender diversity for home care workers was described as important.	transgender and queer people and sexual and gender diversity could be raised through mandatory educational and professional training for home care workers and agencies.
Stein et al. (2010) [USA]	One theme relevant to this review was identified: 1) views on being gay in the community Many participants explained they felt fear about disclosing their sexuality and being neglected or abused by the home care workers they depend upon. Those living in the community reported 'gay-related' rejection and stigma from health care providers. Reluctance to disclose their sexuality was often based on past negative experiences and discrimination. Being afraid of having strangers in their homes who may be homophobic was also reported. In particular the fear of home care workers somehow finding out about their sexual orientation and subsequently being mistreated was discussed.	It remains for the health care community to take heed of the need to become more culturally proficient with respect to the gay and lesbian community. Staff must become sensitised to and respectful of the needs of this population.
Waling et al. [2019] [Australia]	Two themes relevant to this review were identified: 1) perceptions and experiences of residential care and home care services; 2) poor quality care in residential care and home care services. Participants felt home care services did not provide a sense of community, which is important for lesbian and gay people who have had to build communities in order to be resilient against discrimination and violence. A safe environment was perceived as essential due to many LGBT people not having family support networks to advocate on their behalf. Community events or networking were not supported by home care services which led to some feeling isolated and frustrated.	While some concerns may be evident in heterosexual populations, others were specific to the impact of sexuality-based stigma. The identified concerns are likely to be useful for policy makers and service providers for ensuring that

	Whilst many had positive experiences of home care services, the high staff turnover led some to have concerns over needing to give instruction repeatedly as well as the possibility some home care workers may not be gay friendly. This was described as a 'rigmarole' which requires 'preparation' each time they get new home care workers. Using home care services was preferred to entering residential care settings as most wanted to stay in their own homes openly as gay men and lesbian women. Many talked about a preference for home care workers to be lesbian and gay friendly and to have that choice available to them.	services needed to support older age are inclusive and sensitive to the various needs of this population.
Willis et al. (2018) [UK]	One theme relevant to this review was identified: 1) ambivalence towards care services in the home, The prospect of needing to utilise home care services caused anxiety for participants. Most were concerned about the potential for home care workers being homophobic and the potential for privacy being breached in smaller, rural communities. Many participants were concerned with their sexual identity being visible in the home and sought to 'de-gay' their home, largely by removing and hiding lesbian and gay related books/DVDs, fridge magnets and rainbow flags. Some lesbian women discussed how they would prefer to receive support in the home from lesbian care workers or others who had previous experience caring for a lesbian or gay family member. Others talked about the importance of disclosing their sexuality from the outset to new carers as a way of screening out those and their agencies who were unsuitable.	An ageing in place agenda that is more aligned with the life histories of older LGB adults would promote peer networks and social connections between LGB adults to mitigate social isolation, be these virtual or physical connections.

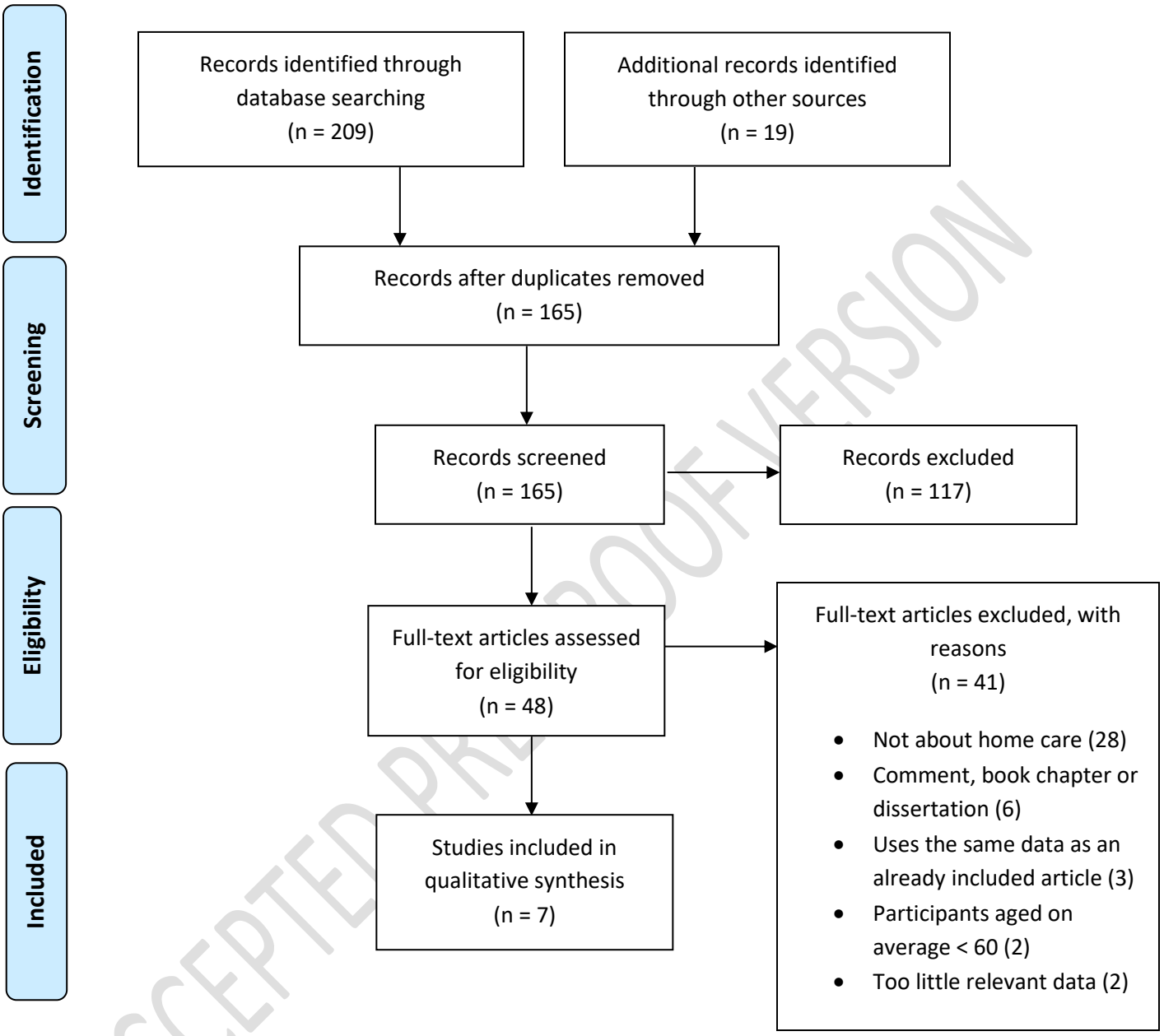

Figure. 1. PRISMA flow diagram showing the process of article identification and selection