How do Community-Dwelling LGBT People Perceive Sexuality in Residential Aged Care? A Systematic Literature Review

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Abstract

Objectives: To investigate what empirical studies report on the perceptions of community-dwelling LGBT adults regarding sexuality and sexual expression in residential aged care (RAC), and how their sexuality should be addressed in RAC.

Methods: Relevant papers were identified through electronic searches in Pubmed, Cinahl, Web of Science, and Embase databases; and by reference tracking and citation tracking. Data were extracted from included articles using a standardized data extraction form and were compared, related, and synthesized using thematic analyses. We evaluated the methodological quality of the studies.

Results: Eighteen articles were identified. Based on the perceptions of community-dwelling LGBT people, three major topics emerged regarding sexuality in RAC: (1) factors affecting LGBT people's perceptions, subdivided into (a) discrimination, (b) loss of sexual identity, (c) failure to acknowledge the same-sex partner, and (d) lack of privacy; (2) LGBT-specific RAC facilities; and (3) characteristics of LGBT friendly RAC facilities and caregivers.

Conclusions: LGBT people have clear perceptions about how sexuality and sexual expression is or should be managed in RAC. Despite the general increase in acceptance of sexual minorities, our analysis shows that many community-dwelling LGBT people still believe older LGBT residents are discriminated against because of their sexual orientation or gender identity. Taking into account these opinions is crucial for increasing accessibility of RAC to LGBT people and to ensure the quality of care provided to them.

Keywords: sexuality, aged care, nursing homes, perceptions, LGBT

Introduction

Although sexuality and sexual expression in residential aged care (RAC) has been a topic of growing interest among researchers, policymakers, and other stakeholders, it remains a controversial and awkward topic for many to discuss. Contemporary beliefs and understandings of sexuality in later life are fraught with a long history of sociocultural stereotyping (Gott, 2005; Weeks, 2002). Within our Western society, the stereotypical and ageist belief that older people are asexual and have no interest in sex at all is still influential (Bauer, Haesler, & Fetherstonhaugh, 2016; Hodson & Skeen, 1994; Weeks, 2002). The healthcare sector also does not always manage to escape this deeply ingrained prejudice (Addis, Davies, Greene, Macbride-Stewart, & Shepherd, 2009). Prejudiced attitudes of healthcare staff, relatives, and fellow RAC residents, for instance, might prevent residents from expressing themselves as sexual beings (Elias & Ryan, 2011; Mahieu & Gastmans, 2015; Mahieu, Van Elssen, & Gastmans, 2011). When it comes to accessing aged care services or entering a RAC facility, older lesbian, gay, bisexual, and transgender (LGBT) people often find themselves in a particularly challenging position, especially when ageist assumptions that the elderly are asexual go hand in hand with presumptions of heterosexism (Addis et al., 2009; Bauer et al., 2016; Brotman et al., 2007; Brotman, Ryan, & Cormier, 2003; K. Hash, 2006; Hughes, 2009; Knochel, Quam, & Croghan, 2011; Simpson et al., 2017). Under such circumstances, LGBT people risk suffering a sort of “double invisibility” (Addis et al., 2009; Brotman et al., 2003). They are furthermore vulnerable to dual discrimination; that is, discrimination on the grounds of their age and their sexual orientation or gender identity (e.g., homophobia, heterosexism).

The prospect of having their sexuality denied in later life might negatively affect the willingness of LGBT people to turn to RAC if needed or to disclose their sexuality when they

do enter a RAC facility (Addis et al., 2009; Knochel et al., 2011). Although LGBT people and heterosexuals face similar challenges and problems as they progress toward retirement age (Hughes, 2009), older LGBT people additionally are more likely to become socially isolated and to live alone than their heterosexual peers (Addis et al., 2009; Brennan-Ing, Karpiak, Seidel, & America, 2011; Hash, 2006; MetLife, 2010). Research furthermore indicates that LGBT people are more likely to constitute a family of choice, consisting of close friends whom they “consider family even though [they] are not biologically or legally related” (MetLife, 2010, p. 16). For some, these close families can be an important source of support and assistance (Hughes, 2010). Hughes (2010), for instance, illustrates how lesbian and gay Queenslanders mainly expect to rely on same-sex partners, or LGBT and heterosexual friends for emotional and social support as they grow older. Of the participants in the Hughes study, about 54% expected to receive physical support later in life from their partner. Approximately 36% counted on their LGBT friends for physical support in the future. Yet, since friend-centered support networks often consist of peers that are also facing the same challenges inherent to aging, their support might not sufficiently cover all care needs (Brennan-Ing et al., 2011). Moreover, LGBT people are less likely than heterosexuals to have children who may support them in later life (Brennan-Ing et al., 2011; Grigorovich, 2016; Hash, 2006). Therefore, LGBT people are more likely to be in need of RAC facilities than heterosexual people. However, for people from minority groups who have been subjected to discrimination in various life settings, being dependent on RAC might be perceived as a real threat (Hughes, 2010). In other words, LGBT people may have “gay-specific” concerns regarding the prospect of living in RAC facilities (Kottorp, Johansson, Aase, & Rosenberg, 2016), which could in turn result in specific preferences regarding the characteristics and the type of facility.

A better understanding of how community-dwelling LGBT people perceive sexuality and sexual expressions and how their sexuality should be addressed in RAC facilities is crucial, if

we want to increase the accessibility of RAC to sexual-minority people and ensure the quality of care provided them. After all, ailments of old age make them future consumers of RAC also. Hence, this paper provides a systematic review of empirical studies investigating the perceptions of community-dwelling LGBT people regarding sexuality and sexual expression in RAC, and how their sexuality should be addressed in RAC facilities. New insights are gained that advance our understanding about why elderly community-dwelling LGBT people may be reluctant to seek RAC.

Methods

Definitions

In this review, we refer to sexuality “as a social process that includes the quality of being sexual and sexual identification, whether gay, straight, bisexual, queer or ambiguous” (Simpson et al., 2017, p. p.248). Sexuality is considered to be multi-dimensional, “as constituted by biological, e.g. bodily sensations that we interpret as sexual; psychological, e.g. emotions and cognition; and cultural/social influences” (Simpson et al., 2017, p. 249). Sexual expression refers to the way in which people express themselves sexually.

Design

We carried out a systematic literature review following established procedures and PRISMA guidelines (Greenhalgh & Peacock, 2005; Liberati et al., 2009). This included a systematic search of the literature, the identification of relevant papers based on a predefined set of inclusion and exclusion criteria (Liberati et al., 2009) and an appraisal of the quality of reporting of the included papers. We used thematic synthesis (Thomas & Harden, 2008) to analyze the included papers.

Search Strategy

Following Greenhalgh and Peacock (2005), we combined various search methodologies in order to increase the efficacy of our search and paper identification process. Pubmed, Cinahl, Web of Science, and Embase electronic databases were used. The search took place on February 15, 2016. The search was not limited by articles' publication date. More information on this search can be found in Table 1. Our search strings were developed in close consultation with a librarian of the [ANONYMOUS]. These consisted of nested Boolean AND/OR searches with type of participant (LGBT people) and topic (residential aged care) as components. Search outputs were merged, and duplicates were removed before implementing title, abstract, and full-text screening. In order to identify relevant papers that might have been missed by the database search, the reference lists and Web of Science citation lists of all included articles were also searched. We updated our initial search results with a complimentary database search on August 18, 2017, this time limited to the years 2016-2017. Fig. 1 outlines the entire literature search and identification process, which follows the overall structure of the PRISMA flow diagram (Liberati et al., 2009).

[PLEASE INSERT TABLE 1 about here]

[PLEASE INSERT FIGURE 1 about here]

Inclusion/Exclusion Criteria

The screening process of candidate articles strictly adhered to a predetermined set of inclusion and exclusion criteria. [Author 1] and [author 2] assessed article eligibility in consultation with [author 3]. Disagreements about article inclusion were resolved by discussion and consensus.

Types of Studies

Publications reporting on empirical studies using a quantitative, qualitative, or mixed-method design were considered eligible for inclusion if they were published (1) as a journal article; and (2) in English, Dutch, French, or German. All articles fulfilling (1) and (2) were considered

regardless of publication date. Theoretical articles, overview articles, reviews, and editorials were excluded.

Types of Participants

We only considered articles reporting on studies that included community-dwelling LGBT adult participants who had no educational or professional links with healthcare, in general, and elderly care, in particular. Community-dwelling was defined as still living at home in the community. If both LGBT people and heterosexual people participated, only data of LGBT people were extracted for our systematic review. We specifically sought papers that reported on “outsider” perspectives from LGBT people considering future RAC residency and who were neither involved professionally nor financially in RAC. We excluded papers reporting on studies of perceptions of managers, administrators, and investors in continuous-care retirement communities, for example. Along the same line of reasoning, we excluded papers that reported on studies of older LGBT people already living in a RAC facility, even if they addressed the attitudes and experiences of these residents toward the sexual behavior of co-residents.

Types of Outcome Measures

Articles were included only if their study outcome measures were relevant to the perceptions of “outsiders” or community-dwelling LGBT laypeople regarding sexuality and sexual expression in RAC. Thus, we included papers in which the study outcome measures assessed so-called “attitudinal experiences.” Attitudinal experiences are those “that are not based on actual interactions. Instead, they are grounded in an imaginative ability, namely to identify oneself in a possible context and to identify the possible experiences one can have in that context” (Vandemeulebroucke, de Casterle, & Gastmans, 2017, p. 5). “Actual experiences” of older LGBT residents living in RAC facilities were not included. Articles were also excluded if their study outcome measures dealt with only sexuality and aging, in general, with no reference to

RAC and if the study outcome measures dealt with only long-term care planning with no reference to sexuality.

Search Outcome and Quality Appraisal

Our literature search yielded 18 journal articles that met our inclusion criteria. Ten of these studies used a qualitative research design, six studies used quantitative research methods, and two studies used a mixed qualitative-quantitative research design. The key characteristics of the included articles are described in Table 2.

[PLEASE INSERT TABLE 2 about here]

The qualitative studies were assessed by using the Critical Appraisal Skills Program (CASP) (Table 3). The quality of quantitative and mixed-method studies was assessed by using the tool developed by Hawker et al. (Hawker, Payne, Kerr, Hardey, & Powell, 2002) (Table 4). However, the quality assessment was indicative rather than evaluative and the methodological quality was not taken into consideration for the inclusion and exclusion of the studies.

[PLEASE INSERT TABLE 3 and 4 about here]

Data Extraction and Synthesis

A standardized data extraction form was used to collect relevant data from the included articles. It extracted the following elements: country in which the study was conducted; research aim, study design, setting, sample, data collection, and analysis; ethical considerations; and main results. [Author 1] and [author 2] extracted data, which were then carefully reviewed by [author 3]. Disagreements among the authors were deliberated upon until a consensus was reached.

This review's aim was to gain a better understanding of community-dwelling LGBT people's perceptions toward sexuality and sexual expression in RAC, and of their perceptions regarding how their sexuality should be addressed in RAC facilities. Thus, we employed an interpretive

approach using thematic synthesis inspired by Thomas and Harden (2008). This thematic synthesis comprised two stages. First, the articles were read repeatedly to obtain an overall understanding of the material. Second, relevant passages were isolated, summarized on the data extraction form, compared, related, and coded according to theme. Similar themes were grouped together. This inductive analysis produced three major descriptive themes. One of the themes was divided into four subthemes. These themes and subthemes were discussed among the researchers and were later used as an outline to structure the results section of this review. Coding and grouping the findings of the included articles were done manually.

Results

Characteristics and quality of Included Papers

Table 2 summarizes characteristics of the included articles. The 18 articles we analyzed originated from seven different countries: the USA (n=6), Australia (n=3), the UK (n=3), New Zealand (n=2), Canada (n=2), Ireland (n=1), and Sweden (n=1), and were published over a period of 14 years in 14 different journals. Different data collection methods were used. Nine of the 10 qualitative studies used interviews, while one used a focus group (Stein, Beckerman, & Sherman, 2010). The six quantitative studies used questionnaires. The two mixed-method studies used either questionnaires combined with interviews (Sharek, McCann, Sheerin, Glacken, & Higgins, 2015) or focus groups only (Kottorp et al., 2016). Study sample sizes ranged from 10 to 60 participants in the qualitative studies, 38 to 2269 participants in the quantitative studies, and 179 to 517 participants in the mixed-method studies. Participants were aged 18-92 years (mean: 36-66 years). Participants' sexual orientations varied among studies. Most papers reported that their participants were a combination of lesbian, gay, bisexual, and transgender persons (n=6); a combination of lesbian and gay persons (n=5); or a combination of lesbian, gay and bisexual persons (n=4). The remaining papers reported that their studies

included only gay (n=2) or lesbian (n=1) persons. Hence, most studies (n=15) included both male and female participants. Detailed characteristics of the included articles are in Table 2.

Table 3 and 4 summarize the quality assessment of the included studies. With only one exception (Robinson, 2016) all studies were proved to be valuable, meaning that they contributed to improve the existing knowledge on the topic, to identify new research areas, and to give indications for the practice. However, nine studies failed in reporting or describing the ethical issues. In fact, many did not indicate whether they obtain the approval from an ethics committee or the informed consent from the participants. Furthermore, all the articles assessed using CASP failed in considering their impact on the research, meaning that potential biases may have not been taken into consideration.

Factors Affecting LGBT People's Perceptions of Sexuality in Residential Aged Care

Our thematic synthesis identified several major themes. The first major theme was that participants raised common concerns that influenced their perceptions of sexuality in RAC. They had LGBT-specific concerns, along with the more common worries of aging, such as physical frailty and increased dependency. LGBT-specific concerns about RAC were discrimination on the basis of sexual orientation, loss of sexual identity, failing to acknowledge same-sex partners, and lack of privacy. These factors will be considered in turn.

Discrimination

According to Jackson et al. (2008), discrimination against long-term care residents on the basis of sexual orientation is believed to be a daily reality lived by LGBT people. A majority of the LGBT respondents (73.2%) in the study of Jackson et al. (2008) suspected discrimination. Chamberland (2003), Hash and Netting (2007), Johnson et al. (2005), Robinson (2016), and Westwood (2016) also reported this suspicion in their participants. Potential sources of discrimination in long-term care facilities were administrative staff (Johnson, Jackson, Arnette,

& Koffman, 2005); nursing staff (Hash & Netting, 2007; Johnson et al., 2005; Stein et al., 2010; Westwood, 2016; Willis, Maegusuku-Hewett, Raithby, & Miles, 2016); and residents (Chamberland, 2003; Johnson et al., 2005; Stein et al., 2010). Some gay participants interviewed by Robinson (2016) identify as potential sources of discrimination the religious and female-dominated setting of the nursing homes in Australia run by religious organizations. Furlotte et al.'s (2016) study of male and female same-sex couples in Canada showed that overt and covert discrimination can be distinguished. These couples reported not fearing overt discrimination, since the law protects them against this. They did, however, fear a more subtle form of discrimination that amounted to proxies for discrimination. Examples of this are disparagement, stigmatization, and presumptions of heterosexuality. Some respondents also anticipated increased vulnerability to discrimination in RAC due to the loss of socioeconomic “buffers,” like professional status, that would protect them in other contexts. Some of the analyzed studies indicated that the fear of discrimination and social isolation could turn nursing home admission into a daunting prospect for older community-dwelling LGBT people (Chamberland, 2003; Cronin et al., 2011; Hash & Netting, 2007; Sharek et al., 2015; Stein et al., 2010; Willis et al., 2016). According to Stein et al. (2010), Willis et al. (2016), and Furlotte et al. (2016), this fear might be rooted in previous personal encounters of homophobia experienced in healthcare.

Loss of Sexual Identity

Our thematic synthesis also identified loss of sexual identity as a subtheme affecting LGBT people's perceptions of sexuality in RAC. Some studies showed that the perception that nursing homes are heterosexual and LGBT unfriendly is correlated with a fear of losing one's sexual identity (Furlotte, Gladstone, Cosby, & Fitzgerald, 2016; Robinson, 2016; Westwood, 2016). Many participants predicted it would be difficult for them to express their LGBT identity in a heterosexual environment where most others lack similar experiences and interests (Furlotte et

al., 2016; Westwood, 2016). While some participants feared being forced back “into the closet” to avoid hostility, others indicated they would maintain their sexual identity and orientation regardless of the possibility of being discriminated against (Cronin et al., 2011; Furlotte et al., 2016; Jackson, Johnson, & Roberts, 2008; Johnson et al., 2005; Kushner, Neville, & Adams, 2013; Robinson, 2016; Sharek et al., 2015; Stein et al., 2010; Willis et al., 2016). One way they reported they might retain and express sexual identity was to maintain connections with the LGBT community. Conversely, participants losing these connections increased their concerns about risking identity loss (Furlotte et al., 2016).

Acknowledgement of Same-Sex Partner

An additional fear of LGBT people is that their same-sex partners will not be acknowledged as such by nursing home staff and, thus, will have no say in the care process (Furlotte et al., 2016; Hash & Netting, 2007; Hughes, 2009; McFarland & Sanders, 2003; Sharek et al., 2015). Some participants in the study of Hash and Netting (2007) were afraid that their wishes would be overruled by their partners’ biological family. Likewise, lesbian, gay, and bisexual (LGB) participants in Willis et al. (2016) feared becoming estranged from their partners in RAC. The same-sex couples interviewed by Furlotte et al. (2016) emphasized the importance of being acknowledged as a partner in a same-sex couple. Some voiced concerns about being denied the possibility of showing affection to each other in the common areas of a RAC facility, or fear that the partner would not be accepted and treated in the same way partners of heterosexual couples are. Others clearly indicated whether or not the partner would be acknowledged was a consideration in their decision to enter into RAC. Among those who consciously hide their LGBT identity, some reported being worried about being unable to maintain this pretense while residing in a nursing home (Sharek et al., 2015).

Lack of Privacy

The final subtheme our thematic synthesis identified as affecting LGBT people's perceptions of sexuality in RAC was lack of privacy. Older lesbian participants interviewed by Chamberland (2003) believed that the overall lack of privacy in residential care facilities would prevent LGBT residents from socializing with congenial peers or inhibit them from expressing themselves sexually. Along the same lines, LGB participants in the study conducted by Westwood (2016) expressed the need for a private place where they could be with their partners.

LGBT-Specific Residential Care Facilities

LGBT-specific residential care facilities are facilities reserved exclusively for LGBT residents. To our knowledge only few recent examples of such facilities have been recorded and no empirical studies on the actual experiences of older residents in LGBT-specific facilities have been conducted (Mahieu & Gastmans, 2015). And yet the second major theme emerged from the studies is related to LGBT-specific residential care facilities. Perhaps because of the fear of being discriminated against, an overwhelming majority of LGBT participants in the studies conducted by Jackson et al. (2008) and Johnson et al. (2005) (97.7% and 98%, respectively) supported the building of LGBT-specific residential care facilities. Chamberland (2003), Hash & Netting (2007), Hughes (2007, 2009), Neville & Henrickson (2010), Stein et al. (2010), Kushner et al. (2013), and Sharek et al. (2015) reported similar results. By contrast, McFarland & Sanders (2003) found that the importance attached to the possibility of building gay- and/or lesbian-specific residential care facilities to be limited. Only 8% of their lesbian and gay participants supported it. In Willis et al. (2016), about half of the participants expressed a preference for LGB-specific facilities. While the majority of the female participants in Westwood (2016) preferred a lesbian-only home, the majority of gay men preferred a non-LGBT-specific home. Nevertheless, the majority of participants believed they should have a choice between entering an LGBT-specific or non-LGBT-specific facility (Westwood, 2016).

When asked about their accommodation plans for later life, only 4.7% of the LGBT respondents in the study of Neville and Henrickson (2010) (Neville & Henrickson, 2010) chose to live in a general retirement facility, open to both LGBT and heterosexual residents. Many chose to stay at home or live with family (46.7% and 41.7%, respectively). If they could not remain independent, most respondents preferred moving to an LGBT-specific retirement facility. Living in a general retirement facility ranked second to last in desirability. LGBT respondents in Sharek et al. (2015) and Kottorp et al. (2016) strongly preferred to live at home as long as possible. Living in a nursing home was their least preferred option. These results are consistent with studies investigating the accommodation preferences of the older population in general. In a study on the preferred living arrangements in China, living in a nursing home was ranked last (Meng, Xu, He, Zhang, & Lin, 2017). Other studies confirm that older people prefer living at their own house or community as long as possible (Grimmer, Kay, Foot, & Pastakia, 2015; Matsumoto, Naruse, Sakai, & Nagata, 2016). Furthermore, Kottorp et al. (2016) and Robinson (2015) reported that LGBT older people share some concerns regarding ageing and nursing homes held by the general population (e.g. social isolation, loss of autonomy). They also elicited that LGBT people expressed gay-specific concerns regarding the prospect of living in RAC facilities, meaning that LGBT older adults have specific needs that have to be addressed when entering in nursing homes.

Older LGBT people's preference for an LGBT-specific assisted-living residence appear to be partially or totally unmet (Smith, McCaslin, Chang, Martinez, & McGrew, 2010). Lesbians and older lesbian/gay (LG) people (66 and over) especially seem to be concerned about the lack of available lesbian- and/or gay-specific residential care facilities (Hughes, 2009).

Opinions differed on how best to implement the ideal of a non-homophobic residential care facility. Some participants favored gender-specific facilities and others favored LGBT-specific facilities, housing both men and women (Chamberland, 2003; Westwood, 2016; Willis et al.,

2016). Many LGBT people nonetheless were skeptical about whether LGBT-specific residential care facilities can truly exist (Chamberland, 2003; Hash & Netting, 2007; Hughes, 2007; Kottorp et al., 2016; Stein et al., 2010). Thus, they faced a dilemma: Do I want to live in a non-LGBT-specific RAC facility and risk being stigmatized as being homosexual (Chamberland, 2003)? Or, do I want to live in a LGBT-specific RAC facility and keep my LGBT identity but with the risk of being in a “gay ghetto” (Hughes, 2007; Kottorp et al., 2016)? In the study of Kottorp et al. (2016), most of the participants preferred living in a LGBT house open to heterosexual people having the same values as LGBT people, or living in a house with areas and activities open to everyone regardless of orientation.

Characteristics of LGBT Friendly Facilities and Caregivers

The final major theme that emerged from our analysis related to the friendliness of RAC facilities and caregivers toward LGBT people. Rather than receiving preferential treatment, LGBT participants expected to be treated equally, like other residents, and with respect in LGBT friendly facilities (Hughes, 2007; Kushner et al., 2013; Furlotte et al., 2016; Stein et al., 2010). At the same time, participants strongly felt they should be acknowledged as LGBT individuals with specific needs and concerns (Furlotte et al., 2016). Some participants preferred LGBT people as caregivers in order to create a sense of inclusiveness (Furlotte et al., 2016; Kottorp et al., 2016). Participants also indicated the need for staff with specific LGBT competence (Furlotte et al., 2016; Kottorp et al., 2016). Indeed, not only should competent caregivers simply avoid prejudice, but they should also be respectful and empathic toward LGBT residents’ concerns (Furlotte et al., 2016). On the basis of these requests, LGBT people expressed the need to be understood and not be questioned about their sexual preferences and lifestyle (Kottorp et al., 2016).

Participants in the studies of Furlotte et al. (2016) and Robinson (2016) pointed out that the RAC facility as a whole should be more LGBT friendly and should have a deep understanding

and appreciation of the LGBT lifestyle, embedding this in the institution's care philosophy. However, in the study conducted by Jackson et al. (2008), LGBT people expressed doubts about whether facility policies on residents' rights even mentioned sexual orientation. Likewise, nearly 75% of the LGBT respondents in the study of Johnson et al. (2005) believed that long-term care facilities did not include sexual orientation in their anti-discrimination and residents' rights policies.

Knowledge and attitude training was often raised as a potential way to tackle the heteronormativity that is said to permeate our healthcare system (Furlotte et al., 2016; Jackson et al., 2008; Johnson et al., 2005; Kottorp et al., 2016; Sharek et al., 2015; Smith et al., 2010; Stein et al., 2010). In the study of Jackson et al. (2008), LGBT people argued in favor of staff receiving diversity and sensitivity training in order to increase their tolerance toward diverse sexualities. Similarly, Johnson et al. (2005) reported that 93% of their respondents, all LGBT people, supported diversity and sensitivity training for staff working at RAC facilities. Likewise, respondents in the study of Sharek et al. (2015) highlighted the importance of staff education to remove the presumption of heterosexuality and to increase staff's knowledge and awareness of LGBT issues. As for the acceptance of diverse sexuality within RAC facilities, Smith et al. (2010) and Stein et al. (2010) also endorse the importance of training and education.

Discussion

Our systematic review of the literature on perceptions of community-dwelling LGBT adults regarding sexuality in RAC shows that they have clear opinions on how this issue should be managed in RAC. Based on these perceptions, three major themes emerged from our analyses: (1) Factors affecting LGBT people's perceptions could be subdivided into concerns about (a) discrimination, (b) loss of sexual identity, (c) failure to acknowledge the same-sex partner, and (d) lack of privacy; (2) issues surrounding LGBT-specific RAC facilities; and (3) characteristics

of LGBT friendly RAC facilities and caregivers. Serious consideration of these themes can guide researchers, healthcare policymakers, and other stakeholders in providing the best care in an equitable way.

Methodological Discussion

Synthesizing study results that have heterogeneous methodologies and outcome measures is methodologically challenging (Whittemore & Knafl, 2005). To achieve scientific rigor, we clearly delineated our research aim, search strategy, and data extraction and synthesis especially well. The heterogeneity among the different studies was carefully documented and considered throughout the review process. Key differences are reported in the tables. Also, the relationship between the quality of the papers and the actual methodological soundness of a study in a paper we reviewed might be inconsistent or uncertain in a published paper. We took this into consideration as well during our analyses.

Our thematic synthesis provides in-depth insight into how LGBT people perceive and feel about sexuality and sexual expression in RAC, and about how their sexuality should be addressed. We note, however, that our findings may have limited generalizability, as almost all of the studies in the included articles were carried out in Western or Anglophone countries where LGBT-supportive legislation (e.g., same-sex marriages) was enacted some years before or after the studies were conducted. Future research conducted in other non-Western and non-Anglophone countries will determine whether our conclusions need modification.

Discussion of Substantial Findings

The 18 articles reviewed indicate that the topic of health equity for older LGBT people in RAC has increasingly gained importance during the last 10 to 15 years. More than 60% of the included articles we reviewed were published between 2010 and August 2017. The increase in studies likely reflects a cultural change, marked by an increased acceptance of LGBT sexualities

and enactment of specific laws protecting LGBT people's rights (Kollman & Waites, 2009). Although the included papers originate from a variety of countries, each with their particular political, socio-cultural, and legal background, all these had legalized same-sex marriages between 2003 and 2015. The only exception is Australia; still, civil unions of same-sex couples were legalized there in 2008.

Despite the increased acceptance of sexual minorities, many community-dwelling LGBT people still believe that older LGBT residents are discriminated against because of their sexual orientation or gender identity. Our literature analysis supports the veracity of anecdotes that LGBT people often do not relish the prospect of having to enter RAC. Discriminatory practices against older LGBT residents are believed to range from overt prejudice to more subtle forms of discrimination (Furlotte et al., 2016; Hash & Netting, 2007; Jackson et al., 2008; Robinson, 2016; Westwood, 2016). One part of Stein et al.'s (2010) study, reporting on the actual experiences of gay residents living in a RAC facility showed that also gay residents experience fear of discrimination. Specifically, the residents' group in Stein et al. (2010) identified three fears: "the fear that one's sexual orientation would result in less than equal care; the fear of having to deal with roommates who dislike gay people; and the fear of having to be careful not to offend others by being gay and so 'hiding their lives'" (Stein et al., 2010, p. 430).

Although not part of our formal analysis, studies involving nursing home managers, nursing staff, and heterosexual residents (Addis et al., 2009; Di Napoli, Breland, & Allen, 2013; Mahieu & Gastmans, 2015; Villar, Serrat, Fabà, & Celdrán, 2015; Willis, Raithby, Maegusuku-Hewett, & Miles, 2017) seems to indicate that fear of discrimination is, at least partly, grounded in reality. This literature indicates that the attitudes of nursing staff and heterosexual RAC residents toward sexual minorities are ranging from outright disgust to acceptance and support (Addis et al., 2009; Di Napoli et al., 2013; Mahieu & Gastmans, 2015; Villar et al., 2015; Willis et al., 2017). In Willis et al. (2017), the nursing staff and managers reported difficulties in

reconciling religious beliefs with expressing a sincere welcoming attitude toward LGBT people. Studies also reported forms of covert or unwitting discrimination, such as presumption of heterosexuality (Simpson et al., 2017; Willis et al., 2017). Such discriminatory practices are reported to have a specific impact on LGBT people health. Grigorovich (2015) reports that the quality of care provided to lesbian and bisexual women is often poor. Some of the included studies also report episode of bad-quality healthcare provision due to sexuality-based discrimination (Furlotte et al., 2016; Stein et al., 2010; Willis et al., 2016). Furthermore, actual experiences and concerns of discrimination in healthcare settings hinder the successful ageing in LGBT people (Caceres & Frank, 2016) and eventually the access to RAC services (Addis et al., 2009; Jihanian, 2013). LGBT residents seem to remain a largely “invisible” population within RAC for a variety of reasons, such as staff and residents’ discomfort in discussing sex-related topics (Gott, Galena, Hinchliff, & Elford, 2004; Mahieu & Gastmans, 2015; Saunamaki, Andersson, & Engstrom, 2010); the perceived private and intimate character of sexuality (Saunamaki et al., 2010); the presence of ageist and heteronormative assumptions (Frankowski & Clark, 2009; Saunamaki & Engstrom, 2014); and LGBT residents’ fear of disclosing their sexual orientation (Addis et al., 2009; Villar et al., 2015). Although the limited size of the sample impedes to generalize these results, it clearly indicates that further research is needed to assess whether and to what extent discriminatory practices toward LGBT people do exist in RAC facilities.

The perspectives discussed above suggest what might be done to change these in the future. A first step in creating a LGBT friendly environment, free from discrimination, would be to increase the “visibility” of LGBT residents and to remove the assumption of heterosexuality. Therefore, RAC facilities must make more serious efforts to train their staff and formulate new policy to address issues salient to elderly LGBT residents (“American Geriatrics Society care of lesbian, gay, bisexual, and transgender older adults position statement: American Geriatrics

Society Ethics Committee," 2015). The training should include good care practices (Grigorovich, 2016; Mahieu et al., 2011; Simpson et al., 2017) and education on specific aspects of the LGBT culture and history, such as the importance of same-sex partners and the link with the LGBT community or "family of choice" (Jihanian, 2013; Willis et al., 2017). Nursing home staff has to be trained to acknowledge the sexuality of the residents, the specific needs of LGBT residents, and differences within the LGBT community. They also need training on how to address possible discriminatory attitudes of heterosexual residents. An important element of training is proper language use: Nursing staff should learn what kind of terminology to avoid, as LGBT residents could perceive certain terms as being discriminatory (Jihanian, 2013; Grigorovich, 2016). An example of such enhanced training is the *Health Education About LGBT Elders curriculum* (HEALE), as described in Hardacker et al. (2014) (Hardacker, Rubinstein, Hotton, & Houlberg, 2014). The nurses and caregivers who received this training increased their knowledge of LGBT issues. In addition, anecdotal evidence shows that training increased the nurses' empathy for older LGBT residents.

Since nurses' attitudes toward the sexuality of elderly residents are also influenced by the organizational ethos of a facility (Mahieu et al., 2011), training should always be complemented with appropriate institutional policies. Nevertheless, many institutional policies do not properly address sexuality and sexual orientation (Grigorovich, 2016). Thus, policies that promote positive attitudes toward LGBT people and that enforce non-discriminatory practices are urgently needed (Jihanian, 2013; Mahieu et al., 2011; Willis et al., 2017). Positive leadership and constant monitoring ensures that policies and training are integrated in care practices (Willis et al., 2017). In order to be effective, LGBT-friendly policies, services, and training should be known by the community-dwelling LGBT population. Willis et al. (2017) indicate the involvement of LGBT volunteers living in the community as a way to improve and evaluate LGBT-friendly policies. Such volunteers could also function as a link between the RAC

facilities and the LGBT community helping to inform LGBT people about the new policies and programs in nursing homes. Furthermore, Simpson et al. (2015) advocate for a wider representation of LGBT people in the promotional material of RAC facilities. This could also contribute to promote LGBT friendly services, facilities, and policies.

Finally, the LGBT population is underrepresented in studies of aged care. Further research on the actual experiences of elderly LGBT residents in RAC facilities will help to accomplish the goals stated above (Addis et al., 2009; Mahieu et al., 2011; Simpson et al., 2017).

Participants had conflicting opinions about LGBT-specific nursing homes. Some strongly preferred to live in a LGBT-specific RAC facility where they expect to feel understood. By contrast, others feared a LGBT-specific RAC facility would be a “gay ghetto” failing in creating integration with the society. Two reasons might explain this tension in perspectives. First, sexuality and expression of one’s sexual identity vary greatly among LGBT people (Mahieu & Gastmans, 2015). Some LGBT people prefer to hide their sexual orientation and would therefore choose to live in a non-LGBT-specific RAC facility, while others prefer to openly express their LGBT identity, maintain close connections with the LGBT community and to live in an LGBT-specific facility.

A second reason that might explain the contrasting views is that elderly LGBT people might lack actual experiences with LGBT-specific nursing homes. Thus, their perspectives might be uninformed and guided by what they might imagine. Although the issue of LGBT-specific nursing homes is mentioned in 15 papers included in our review, only a few very recent examples of LGBT-specific nursing homes have been reported. In addition, we found no empirical studies on the actual experiences of older residents in LGBT-specific facilities (Mahieu & Gastmans, 2015).

These findings have implications for care practices and policymaking. Given that LGBT people have diverse opinions about LGBT-specific nursing homes, it seems logical that all RAC facilities (LGBT-specific and non-LGBT-specific) should implement an open and LGBT friendly culture. LGBT people do not expect to receive special or preferential treatment; our results show that they simply want to be treated equally. Moreover, they want their sexual orientation and lifestyle to be acknowledged.

Conclusions

This review reports on the perceptions of community-dwelling LGBT people on how sexuality and sexual expression should be managed in RAC. There is an urgent need to confirm these findings with studies of actual experiences of older LGBT residents living in LGBT-specific and non-LGBT-specific RAC facilities. Taking into account these perceptions and actual experiences is crucial in order to increase the accessibility of RAC to LGBT people and to ensure that they receive person-centered care.

References

Figure and Table Titles and Legends

Figure 1: Electronic search for literature identification and the selection process

Legends for Figure 1: None

Table 1: Electronic database searches

Legends for Table 1: None

Table 2: Summary characteristics of the studies reported on in the articles included in the literature review

Legends for Table 2: None

Table 3: Quality assessment of the included qualitative studies (CASP)

Table 4: Quality assessment of the included quantitative and mixed-method studies (Hawker et al., 2002)

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