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Dying in Long-Term Care: Perspectives from Sexual and Gender Minority Older Adults about Their Fears and Hopes for End of Life

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ABSTRACT
As lesbian, gay, bisexual, transgender, and queer (LGBTQ+) communities age, many individuals expect a need to enter the long-term care system toward the end of life. Not unlike most aging Canadians, this anticipation is met with concern and fear. However, previous research suggests that older LGBTQ+ individuals have unique fears often related to personal safety and discrimination. This qualitative study examined the hopes and fears of older LGBTQ+ adults considering long-term care as they face end of life. Data were collected from three focus groups in Ontario, Canada, and analyzed using inductive thematic analysis. Specific and frequent reference to fear of entering long-term care homes was common across all focus groups, as participants anticipated: social isolation, decreased independence and capacity for decision-making, increased vulnerability to LGBTQ+-related stigma as well as exposure to unsafe social and physical environments. The results from this study, therefore, emphasize the need for palliative care specialists and long-term care home staff to address the unique health needs of older LGBTQ+ adults nearing the end of life in order to work toward allaying fears and creating supportive and inclusive long-term care environments.

KEYWORDS
Aging; end of life; LGBT; long-term care; Canada

Introduction
Older lesbian, gay, bisexual, transgender, and queer (LGBTQ+) adults experience increased social isolation and concerns as they enter the later stages of life (Brotman, Ryan, & Cormier, 2003; Cartwright, Hughes, & Lienert, 2012). This may be due in part to their membership as a marginalized population that becomes more hidden and invisible as they age.
LGBTQ+ older adults face particular challenges in health and social care provision as they have expressed little confidence that they will receive appropriate, inclusive, and unbiased treatment within these systems (Brotman, Ryan, & Meyer, 2006; Stein, Beckerman, & Sherman, 2010). As LGBTQ+ communities age, many individuals express concern that they will need to enter the long-term care (LTC) system in order to have their care needs met (Furlotte, Gladstone, Cosby, & Fitzgerald, 2016). Not unlike most aging Canadians this prediction is met with concern and fear. However, aging LGBTQ+ individuals have unique fears, which are often related to personal safety and discrimination (Arthur, 2015; Furlotte et al., 2016).

In Canada, long-term care (LTC) homes serve individuals, often older adults, who require ongoing formal support to complete activities of daily living. In Ontario, the average LTC resident is 83 years old and has multiple medical comorbidities (Canadian Institute for Health Information [CIHI], 2017). Approximately 50% of Canadian LTC residents die each year (CIHI, 2017) and, as such, LTC homes are commonly providing end-of-life care (Marcella & Kelley, 2015), a trend that is also being observed in other industrialized countries (Parker, 2014). In addition to being in greater demand, residential LTC facilities (also known as nursing homes) in Canada have become more complex care environments (Hirdes, Mitchell, Maxwell, & White, 2011).

In recent years, there has been a shift in conceptualizations of LTC such that LTC homes are being viewed as places that recognize the continued role for older adults in the community and that emphasize the importance of the concept of personhood in the delivery of care (Williams, Hadijstavropoulos, Ghandehari, Yao, & Lix, 2015). Such models maximize the ability for older individuals to make decisions about their care, including where and how they choose to die (McCormack et al., 2015). These models of care should also account for the needs of diverse populations of older adults. Yet, evidence suggests that, in Canada, approaches to healthcare are not meeting the needs of LGBTQ+ individuals (e.g., Sinding, Barnoff, McGillicuddy, Grassau, & Odette, 2010). Furthermore, research has shown that formal care providers lack educational opportunities to address those needs (e.g., Daley & MacDonnell, 2011) and that older LGBTQ+ individuals face barriers that prevent them from accessing care (e.g., Grigorovich, 2016).

Like many parts of the world, Canada’s population is aging, as are members of minority populations. Estimates suggest that approximately 395,000 older adults in Canada currently identify as lesbian, gay or bisexual (Wilson, Stinchcombe, Kortes-Miller, & Enright, 2016). In line with the movement toward person-centered models of care within LTC, it is critical
to gain an understanding of the unique needs of diverse populations, including LGBTQ+ individuals, around end of life.

In a recent qualitative study on the formal care needs of older lesbian and gay couples in Canada, Furlotte et al. (2016) found that participants expressed concerns about covert discrimination within formal care, the potential risk of disclosing one’s sexual identity, and the desire to be around other gay and lesbian people within LTC. Participants also anticipated that they would need to expend a lot of energy to ensure their well-being within LTC and that they yearn for, what the authors refer to as, nuanced care, involving mutual comfort among residents and care providers.

While Furlotte et al.’s (2016) interviews were not specifically focused on end-of-life care, the themes align with other work in the area of LGBTQ+ aging and end of life. In a recent scoping review of 25 scientific articles on healthcare and end-of-life needs of LGBTQ+ older adults, Stinchcombe, Smallbone, Wilson, and Kortes-Miller (2017) found that older members of the LGBTQ+ community feared discrimination within formal care settings, were often distrustful of healthcare providers and desired culturally competent healthcare that involves fictive kin. The scoping review also found some discrepancies in the literature with respect to older LGBTQ+ adults’ experiences, which they suggest reflect geographic, cultural, or jurisdictional differences.

Few studies have collected data on LGBTQ+ aging and end of life in Canada, highlighting an important gap in our knowledge of how to provide person-centered end-of-life care in LTC homes (e.g., Brotman et al., 2003, 2007; Furlotte et al., 2016; Wilson et al., 2018; Witten, 2014). Collecting data on the perceptions of LGBTQ+ older adults on LTC and end of life is critical to informing inclusive educational initiatives dealing with institutional care and end of life, including palliative care programs in LTC. The purpose of this qualitative study, therefore, was to examine the fears and hopes of older LGBTQ+ adults considering the potential of admission to LTC, as they face the end of their lives. The data were collected though focus groups in three different cities in Ontario, Canada.

**Methods**

**Procedure**

The data presented in this study were collected as part of a broader study examining the aging experience of older LGBTQ+ adults and their hopes and fears for the end of their lives (detailed in Wilson, Kortes-Miller, & Stinchcombe, 2018). Ethical approval was received from the University of Guelph’s Research Ethics Board (REB). The recruitment for the focus
groups was primarily achieved through collaboration with community based LGBTQ+ organizations and/or support groups and snowball sampling, where the research team and collaborators encouraged participants to refer other potential appropriate participants to the study (Patton, 1990). Although it was not a requirement for participation, a majority of the participants had either formal or informal affiliations with the collaborating community organizations. To increase the reach of the study, to those who may not have been connected to the collaborating community organizations and/or support groups, additional recruitment occurred through social media platforms (i.e., Facebook and Twitter). Each of the participants received an information letter and consented to participate in the study. Incentives to participate in the study included reimbursement for travel and parking costs. No participants withdrew from the study.

Three focus groups were conducted in urban centers in Northern, Southern, and Eastern Ontario, Canada. These three locations were chosen in attempt to garner a wide variety of perspectives from individuals residing in urban settings with a large and organized LGBTQ+ presence as well as individuals residing in less-resourced areas with fewer available supports.

All participants received an information letter and provided informed consent. The focus groups comprised of between six and nine participants and lasted approximately 1.5 h in duration. A member of the research team (K.K.-M.), previously trained in interviewing and group facilitation, conducted the focus groups.

Audio from the focus groups was digitally recorded and transcribed. The team gathered qualitative data using a semistructured guide that included questions about participants use of the healthcare system, relationship with healthcare providers, social supports, barriers to care as well as experiences of aging and considerations for the end of life. The questions were intended to encourage open-ended responses in alignment with the life course theoretical perspective (Bengtson, Elder, & Putney, 2005). As originally described in Wilson et al. (2018, p. 24), the focus group guide consisted of the following questions:

1. What kind of things do you consider when you think about the later stages of your life?
2. What rewards do you anticipate?
3. What challenges?
4. What kind of unique needs do older LGBT adults have?
5. Please describe how you use the health care system presently.
6. How would you describe your relationship with your health care providers?
7. What is done well for you?
8. What could be done better?
9. Please describe any barriers you may face preventing you from getting the kind of care you would like.
10. What do you hope for at the end of your life?
11. What fears or concerns do you have?
12. What resources are you aware of for LGBT elders nearing the end of their lives?
13. What policies (social, government, financial) are you aware of that support or hinder LGBT elders nearing the end of their lives?
14. Is there anything else you would like us to know?
15. Would you feel comfortable using video technology to share your personal experience and story?
16. If you had one wish for your end-of-life experience, what would it be?

Participant characteristics

Qualitative data were gathered from 23 participants whose ages ranged from 57 to 78 years (mean = 67.39) and who identified as part of the LGBT² community. A brief demographic questionnaire with a series of open-ended questions was utilized. This questionnaire asked participants to self-identify their gender and sexual orientation through two open-ended questions. Through examination of participant responses, participants in this study identified their gender as “male,” “female,” “two-spirit,” and “transgender.” Self-reported sexual orientation included: “gay,” “lesbian,” “two-spirit lesbian,” “bisexual,” “bisexual to gay,” and (?). Participants reported their relationship status as: participants reported: “single,” “single, divorced, grandfather,” “partnered,” “partnered for 41 years,” “partnered within a chosen family,” and “married.” Several participants also identified during focus group discussions that they had been in heterosexual, long-term, partnerships, and/or marriages that resulted in children. Participant responses to living arrangements included, “living with a spouse or partner,” and “living alone.” For the most part, participants were highly educated, as responses varied from graduate degrees to college diplomas; while some participants reported having not completed secondary school. In general participants reported that their health was “good,” and included that they were living with the following chronic illnesses: cancer, HIV, and multiple sclerosis.

Analysis

The data were analyzed using an inductive thematic analysis approach (Braun & Clarke, 2006). Members of the research team first familiarized
themselves with the data, reading transcripts from the focus groups in their entirety, while noting references to potential emerging categories. Next the team engaged in collaborative analysis and began to identify themes. Given that the scope of this particular analysis included end of life and LTC, review of the transcripts was limited in order to focus on these particular topics. Constant comparison was employed to guide coding, categorization, and theoretical sampling. In the final analysis phase, the researchers reread the data and extracted samples that best demonstrated the four final themes. To enhance trustworthiness and ensure agreement and accuracy, members of the research team reviewed all coding within the data abstraction process and thematic analysis. This process resulted in the themes outlined below.

**Results**

Four major themes organized the findings of this research project: (1) strong fears, (2) social isolation, (3) concerns about dependence, and (4) safe and inclusive spaces. These themes will be examined below with corresponding quotes from participants in the study.

**Strong fears**

In accordance with the findings of Furlotte et al. (2016), participants in this study voiced concerns about stigmatization and discrimination from healthcare providers and healthcare systems, loss of social conditions and community as well as a lack of ability to advocate and navigate health and social systems as they age. Similarly, the notion of feeling at-risk in disclosing sexual orientation and/or gender identity (i.e., the point of transition and/or sex assigned at birth) was expressed across participants, as many perceived LTC as not being a welcoming or safe environment for the LGBTQ+ community. For instance, when asked what kinds of things come to mind when the participants considered the later stages of life and/or end of life, one participant responded:

[I hope to be living] in a safe environment. Free from harassment of any nature, be it physical, verbal, mental, anything like that and knowing that you’re accepted from everyone around you and not worrying about […] going back into the closet— I…after being out for 20 years I couldn’t go back unless there was a marvellous wardrobe in there [laughing]. There’s no way I’m going back into the closet.

The data suggest that older LGBTQ+ adults are burdened with the stress of assessing LTC environments for risks of discrimination and rejection, as they fear that they may be forced to silence parts of their identities in order to protect themselves and appease others. While participants frequently
expressed fears of being forced back into the closet, in order to maintain a hidden identity, one participant described that if she were to enter LTC, she would need to compromise her sexual identity in order to receive appropriate care:

So I mean in a way you’re kind of thinking well, “I’ll have to go back into the closet”… I’ll be straight, you know… in order to be in a home, to be looked after […]

Similar sentiments have been echoed in other research conducted in Canada, as older gay men and lesbian women who have been open and out about their sexual identity with others often find themselves having to go back into the closet, once they begin to acquire health care services (Brotman et al., 2003). Such findings extended to this study, as participants shared instances where homophobia and heterosexism appeared to be common experiences in their healthcare encounters. This was demonstrated by one participant who expressed the following:

[T]he assumption is that you’re heterosexual. So you’re going to have a husband and a wife. So if there’s an activity that’s even scheduled to take place in a long-term care facility it’s going to be kind of the women will do this, the men will do this, [like] couple’s nights… Even if [my partner and I] were to go into a facility, would it possible to be sharing a room where you hear them talking about having a husband and wife…

Another participant who encountered issues of heterosexist assumptions with a health care practitioner described similar fears. However, this participant also recognized that they may be experiencing even greater discrimination within health systems due to the layering of multiple marginalized social positions. While this participant describes the phenomena as, “double whammy,” it has also been referred to as “double disadvantage” and/or the “multiple jeopardy” theory (e.g., Purdie-Vaughns & Eibach, 2008):

I was not a straight person, so… I felt like I didn’t matter to him… I felt really shitty after I came out of there […] And I know it happens to people like me, First Nations, and it’s even more against me because I’m two-spirit person… I have more double… whammy or whatever you want to call it, because of who I am.

The compounding effects of occupying multiple social positions also extends to trans older adults, as studies have demonstrated how transphobia and cissexism, more specifically, have been perceived as negatively impacting their end-of-life care (e.g., Cook-Daniels, 2015; Witten 2014). Fears of this form of discrimination were evident for one participant who described the possibility that some trans folks may feel it necessary to revert to the sex they were assigned at birth, in an attempt to protect themselves from undue harm:
I’ve certainly heard some horror stories about trans people in care facilities having to revert to their birth gender to avoid harassment, discrimination, and so on.

However, maintaining a hidden identity may not be possible, as another participant explained:

[F]rom a completely sort of practical standpoint, it’d be difficult for me to pretend I wasn’t transgender. My body is not ... boobs... and that stuff. So it’d be pretty difficult just from a totally sort of practical standpoint...

These fears were expressed regarding treatment from healthcare providers but also extended toward the community that older adults could be potentially residing with should they be admitted into LTC. This led to a discussion about the need for LTC homes to be designed specifically for the provision and care of the LGBTQ+ community. The response to this idea was mixed, as some participants felt that it would never happen due to a lack of healthcare resources as well as the view that all people should learn to integrate. Fears of judgment from others were expressed as in the following quote from a participant:

I’m going to speak about not [being] in favour of integration [of straight and LGBTQ+ individuals in homes], because I don’t trust the general populace who will also be in that place ... not to judge.

Participants from this study were requesting affirming care and support, so that they may live out their later years free from the discrimination and exclusion that they advocated against for most of their lives. As one participant explained:

I mean it’s just so ironic that you’ve created the life and have some comfort and thrive and then imagine that ... there’s a whole other place where we are going to do the same work in. I mean I don’t have the energy to ...

While another participant spoke of how a person’s geographical location will play a role in the quality of care a person may receive, and the importance of maintaining allies:

[M]uch worse is true in the North and I really think that we need to not leave that only to people on reserve, and off-reserve, or living in the North, to advocate. I mean imagine if you’re queer on the reserve. You’re in big trouble. You’re in really big trouble. So there’s a long way to go.

In sum, these participants are fearful that such resources will not be readily available for when they need them most, that is, when they are nearing the end of their lives.

Social isolation

Social isolation and loneliness among older people is a significant concern for older adults and an important area for policy and practice. It is of
particular concern for older LGBTQ+ adults who find themselves further isolated, if they do not have strong biological family ties or large social networks as they age. Trepidation in terms of increased social isolation was expressed by one participant, who shared:

I’m lonely cause my partner died. And that doesn’t look very good… once you get older you’re seen by society as like not being … not even a person…

Another participant who had experience working in a LTC home and had been caring for a family member at the time of the focus group, shared how social isolation is prevalent in LTC homes:

I’ve been in many, many homes over the years and toured new homes, I don’t know of any personally myself where you can identify. And maybe there were and they didn’t bother which is good because why out… you won’t want to ostracize or isolate people...

Participants also described anticipating that their social networks and support systems will change and become smaller as they age. Some participants questioned whether their social networks could attend to their end-of-life needs:

I find isolation could be a barrier to end-of-life care… You feel alone where you don’t want to necessarily go to your friends or you don’t want to bother them… and you’re living with, for example, depression, anything like that and it gets only worse and worse and… [there is] no one that you’re comfortable reaching out to.

While others recognized that with age they may become completely void of social supports (e.g., family, friends, partners, etc.), and as such, those who are alone are particularly at risk of having their own quality of life spiral downward. For example, one participant reflected on an experience in which he realized the vulnerability of aging alone and without a support:

Life changes immediately, you know […] and] if you’re alone, who do you call?

In such cases, participants revealed that they might be forced to rely on institutional care. In particular, one participant touched on the issues of narrowing social networks and the resulting isolation, while comparing living in a LTC facility to the literary depictions of the nine circles of hell:

Becoming isolated as well, which seems to happen fairly incrementally […] I think the spectre of nursing homes is my idea of Dante’s Inferno really. [My Mother] was in a nursing home […] and I would see the other residents] yearning to get out of the double locked doors […] I think about 200 people [were in the nursing home] and at any given day, I don’t think I ever saw more than 6 visitors.

While on the contrary, one participant distinguished that in circumstances of extreme social isolation near the end of life, LTC could have the potential to offer a positive, social influence:
Although sometimes if you’re alone by yourself, going into a home actually heals the person because you’re now with people. They belong. They can identify. We can make it for LGBTQ people as well, that can identify. Living alone, isolated, 92 years old in a little apartment, putting yourself on the fifth floor, no air conditioning, and [then] you’re put into a home. That can sometimes revive peoples’ health […] So then, let’s make that as accommodating, as wonderful, for all of us in the home, if we ever get there, as we can.

Similarly, later on in the discussion, another participant returned to this idea of being isolated and needing support from others that acknowledges the uniqueness of the individual:

[W]e need somebody else getting invested in who we are and how we’re going to die. And I’m only speaking for myself…

**Concerns about dependence**

Participants in the focus groups expressed concerns about becoming dependent on their care providers and the healthcare system, as they anticipate that the aging process will strip away their capacity for decision-making. In response to being asked about what comes to mind when they consider aging and end of life, one participant said:

[W]ell this dependency, lost autonomy, the… the lack of ability really to make one’s own decisions. Losing control over one’s self, one’s environment.

Participants spoke about the need to be self-sufficient and independent throughout their lives and how that may change, as they require formal care.

I think the thing that really troubles me when I think about it is the loss of independence on many levels. And… I guess I’ve always been pretty fiercely independent and the fact of not having your own room [in long-term care] …

While another participant also discussed concerns about losing control at the end of life as well as the impact that would have on friends and family:

To not have that kind of control. And to have your children or family and friends have to go through that. It’s scary.

Participants spoke about wanting to be able to make decisions and maintain quality of life, even as they enter formal care and approach the end of their lives. One participant who expressed the following supported this concern:

And that’s what I value, a quality of life and having some control over my quality of life. And I don’t want to give that up and have no quality of life when I’m ready to die.
Safe and inclusive spaces

Focus group participants spoke about their desire to feel safe within healthcare environments, including LTC homes. Participants primarily spoke about social environments that would not accept or acknowledge their identities and feared that they would not receive appropriate care. One participant suggested that non-LGBTQ+ individuals might be judgmental, which could contribute to a lack of safety within LTC:

Will I be in a stigma-free environment? … Will I be able to be a gay man and … if I have to be in an institution and … will [I] see proper care, [and] not [have to] go back into the closet?

While another participant made note of the invisibility some LTC institutions demonstrate toward LGBTQ+ populations, as he shared the following:

What worries me now though is sometimes you approach retirement homes and nursing homes to… inquire and they say “we don’t have any gay people here” […] can you imagine living there and being gay and they say “oh we don’t have any” or trans people.

There was also discussion about how aspects of the physical environment can contribute to a sense of safety, or lack thereof. Some participants spoke about the role of visual symbols on the walls of institutions and how they impacted their sense of security. One participant discussed visiting an older family member in a LTC home:

The first thing that I noticed was the crucifix and I felt so uncomfortable. And every time I came in I thought, “I’m not even staying in this room and I feel uncomfortable.”

Participants also spoke about ways that formal care settings show they are an inclusive space by displaying certain symbols. In particular, rainbow flags and stickers came up in discussions as a means to show that spaces were welcoming to LGBTQ+ individuals. One participant spoke about looking for health services on the Internet and noted that:

If they had… you know, a rainbow sign… you know, everyone would be welcome and it would be much easier.

Similarly, another participant proposed a solution for promoting safe environments for LGBTQ+ older adults:

[Y]ou need to make sure you have an environment where LGBTQ+ people will feel accepted, comfortable, acknowledged and not have to go back into the closet in order to be there … I’ve seen that there are signs in some that say “Gay Friendly” in [redacted name of LTC home]. They had something there.

Focus group participants desired LTC spaces that are inclusive, safe, and where they would be treated fairly by healthcare providers and other
residents. They highlighted the role of symbols in contributing to a sense of threat as well as symbols that contribute to a sense of safety and security.

**Discussion**

This study showcased the fears and hopes of older LGBTQ+ individuals as they consider entering into formal care settings and navigating their end of life. This study yielded several noteworthy findings. In particular, in all three geographic regions, there was a common fear that encompassed entering into LTC homes. Participants perceived entering into LTC homes as leading to the potential for: social isolation, decreasing their independence and capacity for decision-making, increasing their vulnerability to negative beliefs and perceptions related to their LGBTQ+ identity as well as exposure to unsafe social and physical environments. Participants expressed that they had ‘worked hard’ throughout their lives to advocate for their recognition, autonomy, and safety and were concerned that the aging process and admission to formal care would result in a decrease in their quality of life until they die. Focus group participants were also cognizant that they would experience functional losses throughout the aging process and they desired the opportunity to continue to make decisions and to retain quality of life in formal care settings. While these concerns have been expressed by non-LGBTQ+ older individuals in the literature and seem to be common themes around aging and transitioning into formal care, these participants’ concerns were unique in that, as a result of their minority status, they had cultivated a sense of independence and interdependence on their LGBTQ+ and allied communities. The idea of a loss of independence combined with interfacing with majority communities within formal care settings was particularly troubling for focus group participants. Likewise, focus group discussions revealed that due to the complexities of their lived experiences, older members of the LGBTQ+ community had unique health needs that were linked to their sexual and/or gender identities. Participants were concerned that these health needs would not be appropriately addressed.

Over the last decade, despite the establishment of policy directions to support the aging population, there remain concerns among diverse populations regarding equitable treatment in formal care settings, particularly in LTC homes. These findings echo those of other research studies in Canada that found that older LGBTQ+ may be at risk for social isolation (e.g., Brotman, Ryan, Jalbert, & Rowe, 2002; Ottawa Senior Pride Network [OSPN] & Ipsos Reid, 2015) and that they desire culturally competent, or nuanced, care that allows them to feel safe and confident in the care they receive within an institution, as they face the end of their lives (e.g., Furlotte et al., 2016).
The findings from this study highlight the need to ensure that LTC homes exhibit inclusive social and physical environments that are safe for diverse residents, including LGBTQ+ individuals. Safety can be conveyed through positive symbols that resonate with community members, including rainbow stickers or flags, as was mentioned by participants. Similarly, given their lived experiences, some symbols may be threatening to residents and care workers could offer, when possible, to remove symbols that make residents feel uncomfortable (e.g., a crucifix). LTC home staff and administrators should be mindful to display inclusive symbols only if aspects of the social environment truly reflect inclusion. A commitment to enhancing the social environment for older sexual and/or gender minorities could also be reflected within the care facilities’ vision, values, and priorities that explicitly focus on diverse populations. Similarly, care providers and LTC home administrators should have access to training programs that equip them to provide nuanced care for LGBTQ+ residents at end of life.

This study unearths some important considerations for providing care to LGBTQ+ individuals at the end of their lives; however, it is not without limitations. In particular, this study was conducted in three sites in Ontario. In Canada, healthcare is a provincial responsibility and it is reasonable to speculate that views about care and end of life may differ in other parts of the country. Second, the participants’ demographic data were not linked to the focus group discussion, nor did we include a focus group question that requested participants to disclose their sexual orientation and/or gender identities during the discussion. Consequently, we were unable to further distinguish participant voices by sexual orientation and/or gender identity, unless it was explicitly stated in the discussion. Evidence suggests that older LGBTQ+ adults have unique needs at the end of life (Stinchcombe et al., 2017); future research should examine the specific end-of-life needs of older LGBGTQ+ adults in relation to their specific identities (e.g., lesbian, bisexual, gay, trans, etc.). Third, while the recruitment materials sought to hold focus groups with individuals 60 years and older, the average age of the final sample was young (mean age of 65 years) relative to the Canadian population of older adults. Older cohorts may have unique perspectives that were not captured here. A related limitation is that only individuals residing in the community participated in this study and, as such, the data reflects the fears and hopes around LTC homes and end of life rather than actual experiences in LTC. Thus, future research should make efforts to capture the lived experiences of older LGBTQ+ individuals and their support networks in formal residential care settings in Canada.

As the culture of LTC homes in Canada evolves to serve individuals with more complex co-morbidities and to include formal end-of-life care, it is
imperative to equip administrators and staff with educational opportunities to serve diverse communities. While attitudes toward LGBTQ+ individuals in Canada have become more inclusive in the last decade, older sexual and gender minorities represent a segment of society who may be at greater risk of experiencing the negative impacts of aging leading to poor quality of life. Many members of this demographic advocated for themselves and their communities during a historical period where they may have faced stigma and discrimination with potential employment and legal consequences (Brotman et al., 2003; Brotman et al., 2015; Dentato, Orwat, Spira, & Walker, 2014). As such, there is a moral imperative to support these individuals whose struggles led to a freer society as they experience losses associated with age and require formal care.

As LTC homes across Canada begin to develop formal palliative care programs, it is important to address the unique health needs of LGBTQ+ seniors and work toward allaying fears and creating supportive and inclusive environments. The data presented here may be used to support educational initiatives for LTC home staff and palliative care specialists as well as help to establish professional competencies to promote equitable and nuanced care for LGBTQ+ older adults at the end of their lives.

Notes

1. The life course theoretical perspective emphasizes the socio-historical contexts, relationships, transitions between life stages as well as the timing between these transitions and individual agency, as important factors that influence experiential and behavioural differences between individuals, groups, and cohorts.

2. The acronym “LGBT”, rather than “LGBTQ+”, was used at the time of recruitment.

References


