

Research

Older LGBT Adults' End-of-Life Conversations: Findings from Nova Scotia, Canada

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Abstract: Although increasing research attention in North America is being paid to the health and social disparities experienced among older lesbian, gay, bisexual, and transgender (LGBT) populations, end-of-life (EOL) preparations among these populations are not yet well understood. This study explored older LGBT individuals' EOL preparations and service providers' perceptions of such provisions. In this qualitative study, we conducted three focus groups with 15 LGBT adults aged 60 and older who have at least one chronic health condition and live in Nova Scotia. We also conducted one focus group with four service providers. We identified four themes: (a) LGBT communities of care have changed over time, (b) difficulties in asking others for help, (c) hesitancy in thinking about end-of-life, and (d) varying views on the helpfulness of internet technology. The findings illustrate ongoing tensions between being "out" about one's sexual orientation or gender identity and being able to engage with social and health care providers in determining EOL planning.

Keywords: aging; bisexual; end-of-life concerns; gay; lesbian; qualitative methods; transgender

Introduction

The health and social needs of older lesbian, gay, bisexual, and transgender (LGBT) populations are increasingly becoming the focus of social and health care policies and programs. However, the end-of-life (EOL) preparedness of LGBT persons is less well understood. Recent data from Canada, the UK, and the US indicate that many older LGBT adults are insufficiently prepared for EOL decision-making due, in part, to perceived or actual homophobia or transphobia experienced in interactions with health and social care providers. Given this, and the fact that many older LGBT adults do not have a primary health care provider, and even where they do, they are often reluctant to “come out” to them about their sexual orientation or gender identity, discussions of EOL needs are often stymied (Brotman, Ryan, and Cormier 2003; de Vries 2017; Murray et al. 2012).

Additionally, current research indicates that many older LGBT adults experience social isolation, are more likely to be single, not have children or close relatives they can turn to for EOL needs, and not be “out” to their neighbours (Brotman et al. 2007; Colpitts and Gahagan 2016; de Vries 2013). These factors all serve to reduce the likelihood that older LGBT adults will have made EOL preparations such as drafting or updating a will, completing a medical directive, developing an emergency contact list, or having an LGBT-friendly online “community” to turn to for EOL information. However, few studies (see Wilson, Kortess-Miller, and Stinchcombe 2018 for an example) have actually addressed these issues in the Canadian context. The purpose of this study was to explore the extent to which a sample of older LGBT adults had undertaken formal EOL preparations, such as medical directives, wills, power of attorney, and advance care directives, or had engaged in more informal preparation (e.g., held conversations about who might provide care). Given the high usage of social media sites by LGBT persons (of all ages) (Pew Research Center 2013), this study also explored the role that internet-based

technology plays in helping to advance such conversations.

Methods

Our study was part of a larger national qualitative study that utilized a focus group methodology (Denzin and Lincoln 2011; Morgan 1997) in five Canadian provinces (Nova Scotia, Quebec, Ontario, Alberta, and British Columbia). Qualitative studies are “particularly relevant in exploring and explaining meaning of sexual- and gender-minority status in specific, local, and historical contexts of lived experience” (Institutes of Medicine 2011, para 82). We used focus groups to collect data because these groups are appropriate for exploratory research (Stalmeijer, McNaughton, and Van Mook 2014) and for research with hard-to-reach populations (Bonevski et al. 2014). Moreover, we also viewed this approach as key to the very topic being studied—the importance of talking about EOL issues with populations who are often absent from such discussions. This is particularly relevant to the Nova Scotia context given the dearth of LGBT-specific research and health-related policies and programming focused on the unique needs of LGBT populations (Colpitts and Gahagan 2016). In lieu of these LGBT-specific elements, access to and utilization of web-based social media and information resources can provide a means of connecting with the broader socio-political aspects of LGBT aging discourse and these were queried in our focus group discussions (Kia 2015; Paterson 2017).

We conducted focus group discussions with each of the following groups: (a) gay and bisexual men (referred to as the Men’s Group), (b) lesbians and bisexual women (referred to as the Women’s Group), (c) transgender individuals (referred to as the Transgender Group), and (d) local service providers (the Service Provider Group). The four focus groups were held separately (rather than having all participants in the same group) given that focus group research has emphasized the need for homogeneity in group background (Morgan 1997). Such

homogeneity can help people to feel more comfortable and safe with each other, “facilitating open communication and exchange of ideas” among participants (Stalmeijer, McNaughton and Van Mook 2014, 928). Furthermore, these different focus groups provided an intersectional approach to our study, which was particularly relevant when exploring the lived experiences of those who have been historically absent from health equity-related research (Bauer 2014).

For the first three groups listed above, participants were eligible if they: (a) identified with the sexual orientation or gender identity for each group, (b) were 60 years or older, (c) had two or more chronic health conditions or were caring for an LGBT person with two or more chronic health conditions, and (d) had some experience with using internet-based technology (e.g., email). The age threshold of 60 was based on literature about “accelerated aging” experiences within the LGBT community (de Vries and Herdt 2012) and the World Health Organization’s (n.d.) definition of aging populations. Caregivers, however, could be as young as 50 years of age, while service providers were required to be 18 years or older and from an agency providing services to older adults, including LGBT individuals.

The research protocol for this study was approved by the research ethics boards of each of the research team members’ respective academic institutions in advance of any data collection. We screened all participants for eligibility over the telephone prior to their participation. Informed consent was obtained through the telephone screening procedure and again before the start of the focus group discussions, when all participants signed a hard copy of an informed consent form and agreed to the focus groups being audio-recorded. Once recorded, the discussions were transcribed verbatim, with identifying information removed and pseudonyms used in place of participants’ real names; these pseudonyms are used below when participant quotes are included. All electronic and hard copy materials from the Nova Scotia portion of this study were

password protected and stored in a secure, locked cabinet at the researchers’ offices.

This article focuses specifically on the data from four focus group discussions held in Halifax, Nova Scotia (the largest city in the Atlantic region of Canada), which took place between October 2014 and February 2015. We used various methods to recruit participants, including the distribution of emails and social media announcements by LGBT community partners focusing on health and advocacy issues.

Prior to beginning the focus groups, participants completed a brief demographic questionnaire that included questions about what kind of EOL preparation they had engaged in and the extent of their use and level of comfort with internet-based technology. The focus group discussion questions centered on three key topics of interest to the national research team, and were in keeping with the mandate of the funding agency. First, we asked the individuals about their perceptions of the problems that older LGBT individuals face with regard to EOL care. Second, we asked them to discuss the roles that community and internet-based technology does and could play in EOL care preparation. We then carried out open coding with the assistance of MAXQDA software (a data management software for qualitative and mixed-methods research) and identified themes based on a review of the open coding.

Sample

The Nova Scotia participants included: (a) 8 cisgender men, all of whom identified as gay; (b) 6 women (5 identified as cisgender; 4 identified as lesbian; one identified as bisexual; one transgender woman identified as lesbian); (c) 2 transgender women (both with female partners; one identified as lesbian, the other as heterosexual); and (d) 4 service providers.

The following paragraph applies to the first three groups of participants only. Ages ranged from 59-69 (Women’s Group), 63-82 (Men’s Group), and 61-74

(Transgender Group). Forty-four percent reported their relationship status as single (and lived alone), 13% were in registered domestic partnerships, and 38% were in other types of unspecified relationships. Of the 13 participants who were in relationships, 2 of them were in relationships of less than two years. The remaining 11 participants were in relationships that ranged in duration from 6 to 66 years, with an average duration of 15 years. Close to one-third of participants had children (one woman, two men, and the two transgender women in the Transgender Group were all parents). Overall, participants were well educated and had a high level of being out to others as indicated in the self-reported measures in the demographic survey. There was a range of EOL preparation (e.g., 75% had prepared a will but only 25% had made any informal caregiving arrangements), and 86% reported being mostly or completely comfortable with using a computer.

The service providers' focus group consisted of one lesbian, one bisexual woman, and two heterosexual women. As a group, they estimated that between 7% and 60% of their clients were LGBT.

Findings

Our research team identified four key themes in the focus group data: (a) communities of care change over time, (b) LGBT individuals feel that it is difficult to ask people for help, (c) LGBT individuals are hesitant to think about EOL issues, and (d) LGBT individuals hold varying views on the efficacy of internet technology. The following section offers a summary of our key finding as well as methodological limitations and recommendations. Each theme is described below, with illustrative quotes.

Communities of Care are Changing over Time

Acknowledging that communities of care (ways in which care is organized or offered within LGBT contexts) are not static but rather are formed and

reshaped over time through a variety of life changes was a pivotal aspect of both LGBT social lives and EOL decision-making. For example, our participants noted that the person being cared for and the types of care they received yielded a certain configuration of "communities of care" that may not be related to families of origin. Being "out" about one's sexual orientation or gender identity further complicated and negotiated these situations. Factors such as relocation, retirement, and death of a partner often resulted in a reshaping of friendship networks. Specifically, the failing health of friends was seen to have a significant impact on reshaping communities of care. For example, the Men's Group noted that some of the friends they might have been able to rely on as part of their care community later in life had died of AIDS years earlier.

Participants described how the landscape of their care communities was changing at both the individual and broader structural levels. This was seen as bringing about some positive changes over time, however, there were also "*institutional biases [care workers are] going to have to work through*" and acknowledgement that "*it's just going to take some hard work to change attitudes*" about LGBT persons (Men's Group, Mitchell). It is noteworthy that one of the two participants in the Transgender Group expressed that they were not fearful of discrimination and stated, "*I don't feel we're as discriminated against as much as perhaps even 10 years ago or 5 years ago. Then I'll say to healthcare workers and healthcare agencies, if they have a healthcare worker that has a problem, then they shouldn't be a healthcare worker with their agency*" (Transgender Group, Cecile). This particular participant referred to herself as having an "*awful optimism*" due, in part, to transitioning later in life and the relief associated with shedding the burden of her earlier identity.

While there was a general acknowledgement among all participants that LGBT communities of care had changed over time, the Men's and Service Provider Groups talked more about this than the other two groups. A shift away from the urgency of the HIV health crisis experienced in the LGBT community in

the 1980s resulted in a perceived lack of current flashpoints to mobilize the community. For example, Bianca (Service Provider Group) said: *“When I began working in HIV/AIDS it was just before the really strong antiretrovirals came in . . . and I really witnessed levels of care, community care teams, working together. People from the community mobilizing . . . Gay men and lesbians coming together to care for people from their community . . . I’ve seen less and less of that.”*

In the Men’s Group, Kurt noted, *“We don’t have a voice. A unified voice is what we need.”* He further lamented the fact that the *“younger generations are not prepared to, I don’t think, to do the same thing that we were prepared to do.”* Brad agreed, saying, *“It’s a different generation.”*

Difficulty Asking People for Help

Although asking for help can be challenging for many older adults, our participants talked about not wanting to be a burden on others, particularly friends, neighbours, and family to whom they were not “out.” Additionally, our participants distinguished between personal care tasks and functional tasks. In the Women’s Group, for example, Nancy said, *“If someone had to wipe my butt that’s a different question but if they only had to drive me and take me home.”* Sharon agreed, saying, *“Yah, that’s just a drive, that’s an errand.”* Carol similarly noted that she would feel comfortable asking a man to drive her to an appointment, but not to come to her house to do more personal tasks for her. The functional tasks were seen as easier to ask other people to carry out.

Participants stated that having someone to rely on for help was also easier if they had a partner. For example, Cecile (Transgender Group), said: *“I’m fortunate in that having a somewhat younger wife who, statistically, we hope she would outlive me. So if I was to expire, I would expect her to take care of business, shall we say. . . . We have discussed it a little bit more.”*

However, many participants reported feeling anxious

about relying on others, and some felt very alone. In some cases, this anxiety stemmed from fear of involving biological family members in EOL decision-making and personal care: *“We’ve done the paperwork but our main concern is how invasive is my family going to be?”* (Men’s Group, Kurt). Keith talked about one friend that he could potentially rely on, but said that the friend was already very involved in caring for someone. He added, *“So in this city of 185,000 or whatever it is, I know one person—who’s up to his neck as it is”* (Men’s Group). Women appeared sensitive to the gendered contexts of caregiving in their lives and reported being *“more hesitant to ask other women to help us because we understand the financial inequalities”* (Women’s Group, Susan). In terms of paid care, the Service Provider Group discussed the distrust the LGBT community has regarding the healthcare system: *“LGBTIQ folks tend to have much less trust of healthcare. Whether it’s home care or whatever it is, healthcare in general, if you don’t trust that system, why would you want them in your home?”* (Bianca).

Hesitancy in Thinking about End of Life Issues

Many participants stated that they did not want to think about EOL issues. In the past, many had rallied around their friends and lovers to help them during the HIV/AIDS crisis. Currently, participants state that there is either an absence of EOL discussions (*“There’s tons of fear around it . . . I have no plan”*; Men’s Group, Owen) or end of life is seen as something far in the distance (*“I’d like to think that the end of life is fairly far away for me”*; Men’s Group, Nicolas), both of which were justifications for a delay in EOL preparations. As noted earlier, participants generally felt more willing to have plans in place if they had a partner because they were attentive to the caregiving and related demands that might be placed on their partner.

Service providers reflected on the fact that, in their experience, many LGBT individuals are not comfortable talking about their health with health care providers. HIV diagnoses were mentioned, as

well as how the stigma associated with various physical or mental health issues could make it difficult to talk about EOL issues: *“If somebody has underlying depression or anxiety then those decisions are probably much harder to grasp”* (Service Provider Group, Krista).

Additionally, both the Service Provider and the Transgender Group commented that transgender individuals might have different priorities later in life: *“In the trans community . . . they’re just trying to feel okay about where they’re at now. . . . Thinking about death and dying, they’re thinking about trying to live”* (Service Provider Group, Bianca). This focus on trying to live appears to be associated with the point in life where an individual “comes out” or transitions. Both of the Transgender Group participants were transwomen who had transitioned later in life (in their late fifties and mid to late sixties). Cecile said, *“It has been the furthest thing from my mind. I realize that at seventy-five, I perhaps should be prepared or thinking about EOL situations but, to be honest, I just don’t. I feel good”* (Transgender Group).

Varying Views on the Efficacy of Internet Technology

As part of this study, we asked if and how internet technology could serve to bridge information gaps and needs in relation to EOL preparedness among older LGBT adults. Participants reported using internet technology in various ways to try to connect with others, seek out information, and stay in touch with family. In keeping with the work of Kia (2015), use of the internet can serve dual purposes in helping to render the needs and issues of older LGBT persons visible while at the same time allowing for greater surveillance of these populations. On the positive side of internet-based technology, Cecile (Transgender Group) said, *“The internet is fantastic. It is my social circle, almost.”* Similarly, Nicholas (Men’s Group) said, *“I’ve used the technology to make a lot of new friends and to broaden my own perspective. And feel comfortable in my own skin. And to be around other gay men, which is not*

always easy to find, even in this relatively large city.”

In terms of perceptions of potential negative elements, participants’ perceptions and experiences with internet technology were, in many instances, related to privacy issues. For example, several participants commented on how they preferred to know someone in person before revealing private things to them through the internet. Nicholas (Men’s Group), for example, stated: *“I would do it face-to-face first and then maybe follow up online.”* Members of the Transgender Group, in particular, mentioned the fear of losing control over privacy: *“I would never get into a social media situation where you’re communicating in [sic] the masses . . . anywhere where your information is shared and you’ve got no control over it, I don’t like that. I’ll stay away from that”* (Pamela).

Regarding EOL preparations and the internet specifically, a number of participants from each of the focus groups reported that it would be helpful to have EOL information that was concise, accurate, and available for LGBT individuals in one location on the internet. For example, Mitchell (Men’s Group) said, *“I belong to a website . . . for people who are living with chronic conditions . . . but [one that was LGBT-focused] would also be a good site to chat about some of those EOL decisions as well.”* Members of the Service Provider Group noted that such web-based resources needed to be culturally competent: *“What is ‘power of attorney?’ What is that? So that people have that sense. And definitions of terms. What are some of kind of things you might want to consider? I think that would be great. I think that if it was in one place that was credible information that also was LGBTIQ-focused so that it was culturally competent, it spoke to the people”* (Service Provider Group, Bianca).

The perceived utility of seeking online EOL information varied among participants, with trust being a key factor. While there is a growing literature in relation to online communities in general, this topic is beyond the scope of this paper. However, as Kia (2015) and Paterson (2017) suggest, and as indicated by our participants, the potential for

unwanted or unintended consequences associated with the use of internet technologies, including the potential for “outing” and the fear of retaliation where one’s gender non-conforming identity intersects with more heteronormative organizations or services, has created caution around the ways in which information is exchanged.

Recommendations

Additional supports are required to meet the complex and often unique needs of older LGBT populations as they explore their EOL requirements. Recommendations to emerge from the data include the need to evaluate how well existing health and social care policies are working for LGBT populations, particularly as these individuals age (Auldridge, Espinosa, and SAGE 2013). Current provincial policies and programming directions on healthy aging and EOL do not specifically include LGBT populations despite the ongoing stigma and discrimination these populations face in accessing health and social care. As such, all government-funded health and social programs should undergo sex- and gender-based analyses to determine if and how they are meeting the needs of LGBT populations. Although general information is available to those on limited incomes, access to legal information and resources that speak to the unique considerations of EOL planning for LGBT populations is needed. This information needs to be readily accessible in web-based formats as well as paper-based or hard copy formats in health and social care facilities to ensure EOL preparations occur in a timely and nonjudgmental manner. In addition, training of the next generation of health care providers in culturally competent and gender-appropriate care for older LGBT populations is warranted (Beagan, Fredericks, and Bryson 2015; Fredriksen-Goldsen et al. 2015; Gahagan and Colpitts 2016). This training ideally requires “mainstreaming” both the EOL and LGBT health content into all core curricula rather than being offered as an elective.

Further, although not the focus of this paper, the gendered nature of caregiving emerged from the focus groups in that the gender normative expectations for caregiving remains largely on the shoulders of women. In particular, this sentiment was reflected in comments made by cisgender women who did not want to burden other women with their care needs at end-of-life. This has important implications for the ways in which health and social care providers or caregiving support services may for example, assign particular EOL caregiving roles to older lesbians without fully appreciating their unique and oftentimes isolated contexts.

Limitations

Although we made efforts to ensure a diverse sample of participants from the LGBT communities in Nova Scotia, the issue of willingness to “be out” about one’s sexual orientation or gender identity may mean that those who were less “out” would not self-select to attend the focus group discussions. This is not only a limitation of this study, but it is also an important factor to consider for future research related to older LGBT adults. For instance, we did not have any female-to-male transgender participants, and only one bisexual person and one woman of colour participated in our Nova Scotia-based focus groups.

Conclusion

The purpose of this article has been to draw awareness to EOL issues faced by a sample of older LGBT individuals living in Nova Scotia, Canada. While the complex issues faced by older adults may intersect across all individuals who are faced with EOL decisions, the unique experiences of our participants, which are shaped by stigma and discrimination and their effects on social networks, suggest that more needs to be done to ensure that health and social care policies and programs meet the needs of these communities. This is particularly important in the smaller, under-resourced and less LGBT-friendly regions of Canada such as those in Nova Scotia (Colpitts and Gahagan, 2016; Gahagan

and Colpitts, 2016; Gahagan and Subriana-Malaret, 2018). Although there is increasing mainstream awareness of “healthy aging” and “adding life to years” among health-research funding bodies, the actual supports needed by older LGBT individuals are, as was pointed out by our participants, largely absent. In addition to understanding overall offloading of health and social care responsibilities to LGBT communities, more research is needed to address gaps in existing approaches to EOL decision-making based on sexual orientation and gender identity. This work is currently championed in the US by research and health services organizations such as the Fenway Institute and SAGE (Auldridge, Espinosa and SAGE 2013; Reisner et al. 2015). In Canada, we see the rights and needs of LGBT individuals gradually being recognized in provincial policy and programs. In the Nova Scotia context, some advances have been made in relation to LGBT-specific structures within the existing public health system, such as PrideHealth (Capital Health District). However, Nova Scotia’s 2008 Personal Directives Act is based on heteronormative assumptions about caregiving, and fails to acknowledge intentional “fictive kin” (chosen families) (Nelson 2015).

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