End-of-life preparations among LGBT older Canadian adults: The missing conversation

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Abstract

LGBT older adults are more likely than their heterosexual peers to age with limited support in stigmatizing environments often poorly served by traditional social services challenging their preparedness for end of life. Fourteen focus groups and three individual interviews were conducted in five Canadian cities with gay/bisexual men (5 groups; 40 participants), lesbian/bisexual women (5 groups; 29 participants), and transgender persons (3 interviews, 4 groups; 24 participants). Four superordinate themes were identified: (a) motivators and obstacles; (b) relationship concerns; (c) dynamics of LGBT culture and lives; and (d) institutional concerns. Several pressing issues emerged including depression and isolation (more common among gay and bisexual men), financial/class issues (lesbian and bisexual women), and uncomfortable interactions with health care providers (transgender participants). These findings highlight the challenges and complexities in end-of-life preparation within LGBT communities.

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End-of-Life Preparations Among Canadian LGBT Older Adults:
The Missing Conversations

LGBT (lesbian, gay, bisexual, and transgender) aging research has grown significantly in recent years. Much of the research focuses on health consequences of the stigma and discrimination experienced by LGBT persons across the life course, though little has been written about end of life. Considering the unique historical contexts of current LGBT older adults' lives, an exploration of end-of-life concerns is timely and relevant.

Advance Care Planning: Addressing End-of-Life Ambivalence

Canada, like the U.S., is described as a death-denying culture (Northcott & Wilson, 2008). Socially reinforced barriers limit *personal* discussions and *experiences* of dying and death. Not only does evading conversations about end of life potentially preclude personal and interpersonal growth (Calhoun & Tedeschi, 2013), it also keeps death "in the closet"—along with hopes, fears, and wishes about one's end of life. Although most respondents to the 2013 Canadian Hospice Palliative Care Association (CHPCA) survey thought end-of-life planning was important, less than half had engaged in such conversations.

In surveys of older adults, Advanced Care Planning (ACP) rates have been modest (e.g., Schickendanz et al., 2009). Researchers and practitioners point to many barriers, including confusion about what ACP means and the implications of decisions rendered (Regence Foundation, 2011). Minority group factors (cultural, racial, gender/sexual orientation) may further intensify barriers, including access to resources (unequally distributed across groups), mistrust of the healthcare system (i.e., discrimination by service providers against those seeking services), as well as spiritual

and religious beliefs (e.g., body integrity and afterlife, autonomy, and fate) (Barnato, 2007; Carr, 2011).

Existing literature on end-of-life preparations focuses on product (e.g., completed Durable Power of Attorney for Health Care [DPOA-HC]) over process (e.g., information search, decision-making), often neglecting the *conversations* upon which ACP documents are predicated (Schickedanz et al., 2009). Such conversations are difficult to initiate and navigate (CHPCA, 2013). The focus on product limits the advance care planning process as a whole (Bischoff, Sudore, Miao, Boscardin, & Smith, 2013).

LGBT Older Adults and the Canadian Context

LGBT older adults in Canada and the US are disproportionately represented by those without the traditional heteronormative hierarchy of support. LGBT older adults are much more likely to live alone, be unpartnered, and have no children (e.g., de Vries, 2013)—the primary care providers to older adults. Relatedly, LGBT older adults report high rates of loneliness, isolation, depression, and disability (e.g., Fredriksen-Goldsen et al., 2013). Friends are more prominent in the lives of LGBT individuals (de Vries & Megathlin, 2009) but friendship networks lack the structure and support of kinship systems (Barker, 2002). Conversations about end-of-life care, difficult under traditional circumstances, face additional hurdles in these non-traditional circumstances.

Limited Canadian research on LGBT older adults and healthcare utilization (Brotman, Ryan, & Cormier, 2003; Brotman et al., 2007; Wilson, Kortes-Miller, & Stinchcombe, 2018) examining end-of-life issues concluded that being LGBT still strongly impacted conversations, noting barriers such as social isolation and exclusion, despite high levels of acceptance and support. A 2013 Pew report found that 80% of the

Canadian sample agreed that "society should accept homosexuality;" only Spain and Germany exceeded this percentage across the 39 countries studied.

Canada has taken important steps toward improving the context for LGBT individuals. In 1996, the Canadian Human Rights Act was amended to include sexual orientation as one of the prohibited grounds of discrimination (Government of Canada, 2018). Canada legalized same-sex marriage in 2005, the fourth country in the world to do so.

Statistics Canada has begun to include questions about sexual orientation in its national surveys. While preliminary estimates amongst those between the ages of 18 and 59 show 1.7% *identifying* as homosexual and 1.3% as bisexual (Statistics Canada, 2017), this is likely an under-estimate due to individuals' reluctance to identify as homosexual or bisexual and that numbers are often smaller than those reporting having same-sex sexual relationships.

More recently, the Canadian government has (a) apologized to LGBT persons for past mistreatment, (b) created a non-binary gender option on passports, and (c) passed anti-discrimination legislation for transgender persons (Reid, 2017). The Canadian government currently assumes an international voice in support of LGBT human rights across the Commonwealth and beyond (Reid, 2017). These are recent and powerful acts of support of LGBT persons. Nevertheless, research suggests legacy effects of the more discriminatory and exclusionary history of this community.

Method

We conducted focus groups organized by sexual orientation, gender, and transgender status. Focus groups are particularly useful in work with persons from

minority and disempowered populations (Hughes & Dumont, 1993, Kitzinger, 1994). Guided conversations provide for "complex dimensions to be revealed that are not accessed by more traditional methods and can identify cultural values and group norms as a result of the shared and common knowledge" (Robinson, 1999, p. 906). Importantly, this approach offered the additional benefit of serving as a model for participants to initiate discussions and foster potential support.

The sample comprised 93 community-dwelling LGBT persons aged 55 to 89 from five Canadian urban centers: Vancouver, Edmonton, Toronto, Montreal, and Halifax. Focus groups in Montreal (n=3) were conducted in French; the remainder in English. Ethics approval was received from the six universities involved in this study.

In pilot tests participants reported feeling most comfortable talking about issues in a same gender group and recommended that other groups be constructed similarly. Therefore, in each city, separate focus groups were conducted with (a) gay and bisexual men, (b) lesbians and bisexual women, and (c) transgender individuals (excepting Edmonton). Because very few bisexual individuals responded to the call for participation, they were included in the other groups, consistent with some previous research (e.g., Wilson et al., 2018). Also, scheduling and transgender participant availability resulted in three individual interviews being carried out, one each in Edmonton, Toronto and Halifax with transcripts coded in the same way as the focus groups. All respondents received a $25 gift card for participating.

Recruitment took place through community agencies, social media (e.g., Facebook), promotional materials in LGBT-identified venues (e.g., community centers), news reports in the LGBT and broader press, and by referral. Prospective respondents

were asked to email or call the research office in each of the five cities. Eligibility criteria were: (a) at least 55 years of age, (b) English or, in Montreal, French speaking, (c) living with one or more chronic conditions, (d) identifying as LGBT, and (e) having some Internet experience (a requirement given that a goal of the project was development of an interactive end-of-life planning website (see Beringer et al., 2017).

Sample

Thirty-nine gay and one bisexual men (GBM), 28 lesbians and one bisexual women (LBW), and 24 transgender individuals (including those who identified as gay, lesbian, bisexual, and heterosexual) participated in the focus groups or interviews (Table 1). Ages ranged from 55 to 89 years, with an average age of 69 which did not differ across groups. The only significant difference concerned number of children: over three-quarters of GBM had no children compared with fewer than half of LBW and one-third of transgender persons, $\chi^2(2) = 15.48$, $p < .001$. See Table 2 for additional demographic information.

--- Insert Tables 1 and 2 here ---

Focus Groups and Interviews

From September 2014 through March 2015, 14 focus groups and three interviews were held in mutually acceptable meeting spaces: five groups of GBM (one group in each city); five groups of LBW (one in each city); four groups of transgender persons (one in each city except Edmonton) and one interview in three cities (as noted above). Focus groups included between 2 and 15 participants, averaging six persons. (The size of each focus group is presented in Table 1; bisexual participants were included in the gay and lesbian groups; the transgender group sizes are reflected in the final column.) All focus

groups and interviews were audio-recorded with permission and transcribed verbatim. Focus groups averaged two hours (ranging from 90 to just over 120 minutes); interviews averaged 90 minutes (ranging from 45 to 100 minutes).

Each focus group had a facilitator with expertise in focus group and qualitative methodology and a research assistant taking notes to assist in the transcription. The semi-structured focus groups/interviews addressed concerns, preparations, and explicit plans for later life care (including conversations about end-of-life), and the role of community (formal and informal) in supporting and enacting such plans.

Data Analysis

Thematic analyses (Joffe & Yardley, 2004) of the focus group and interview transcripts, conducted by two or more coders to establish consistency, were accomplished by multiple readings and discussion of "codable units" with phrases or sentences that presented ideas related to the topic. Codes were derived inductively (e.g., in-depth discussion or multiple mentions). Decision trails made the codes assigned by individual coders transparent and assisted in the demonstration of consistency and trustworthiness (Noble & Smith, 2015). On each of the 17 transcripts, an average of 142 pieces of text were coded. The final codes from this process were used in subsequent coding. This secondary coding —the narrative equivalent of cluster analysis—was undertaken by two coders who grouped codes that addressed similar issues or ideas into categories. An average of 35 categories were created across the 17 transcripts. These categories were further grouped into overarching themes—topical areas that reflected the organizing structures and meaning of the content.

Results

Four broad themes were identified in the data: (a) motivators and obstacles, (b) relationship concerns, (c) LGBT culture dynamics, and (d) institutional concerns. These themes are arranged in order of relative salience from the participants' perspective. Most, but not all, themes were present in the discussions of all of the LBW, GBM, and transgender groups. Financial issues were not prominently raised by the GBM groups; trust and honesty issues were minimally mentioned by the LBW groups; the role and history of HIV/AIDS and the role of the church and religion were not prominently raised by the transgender groups. However, even when the same theme was expressed across LGBT groups, the manner in which issues were raised and considered often assumed a different form. These differences are highlighted in the following sections.

Motivators and Obstacles

A primary theme concerned issues that motivate and impede end-of-life preparations. This theme consisted of two categories: (a) reasons for and extent of formal document completion, and (b) interpersonal challenges to end-of-life discussion.

Reasons for and extent of formal document completion. A prominent topic of discussion was the extent to which individuals had completed formal end-of-life documents with a focus on the underlying motivators for such completion. Preparedness varied across and within groups, and most preparation focused on financial considerations (e.g., wills). One transgender man reported that he had been planning since a young age after being "advised by an old man not to wait until I was old and then say, 'I should have done it.'" Similarly, an LBW said that she had "been concerned with my own end of life since I was 8." In contrast, another LBW said that she was now "at the age where I am beginning to plan and to be more mindful of my health," whereas

several transgender respondents admitted the need to start planning and to have documents completed. Situated between these extremes of document readiness, many participants reported on the need to alter existing documents, many of which had not been updated since "the time of AIDS."

Across the groups, participants identified "push factors" associated with end-of-life document completion. One GBM said that he was "shocked into planning by the death of his friend," and another recalled "families of friends came in and took everything"—something he hoped to avoid. An LBW echoed this view having "seen first-hand what happens when a long-lost relative shows up and makes a claim on the estate." Several LBW and transgender participants spoke of health crises (e.g., cancer diagnoses, heart attack) prompting their completion of the necessary documents to provide direction and structure at life's end. Another transgender woman spoke of a friend who "was buried as a man; the female persona disappeared entirely," and she wanted to ensure this would not happen to her.

Transgender participants uniquely spoke of how other life needs and demands superseded end-of-life preparation efforts. Several reported that food and shelter and "the necessities of life take priority" such that "dealing with end-of-life is beyond their resource base"—financially and in other ways. Similarly, one GBM noted that he "was more concerned with living" than preparing for death, and another said that he "can't bring [him]self to act" for fear of a self-fulfilling prophecy (i.e., hurrying death). Several LBW and GBM noted the need to make others aware of the documents completed and help others get their affairs in order.

Interpersonal challenges to end-of-life discussions. Two interacting dimensions

comprise this category: the absence of someone to whom they can turn and the related absence of end-of-life conversations. A common refrain heard in all of the focus groups: "I have no one to turn to; who is going to look after me?" as posed, in this instance, by one of the transgender respondents mostly based on the emotional distance from family. In almost all of the focus groups, a related comment included a version of "having no one, there is nothing to discuss," as reported by one of the LBW.

One GBM noted: "I haven't thought through who would care; there has been no discussion—not even with myself." Participants from several of the groups described more general conversations about end-of-life plans such as "I posted something about it on Facebook" (as a transgender man said) to "I've had general conversations with friends about pulling the plug" (GBM). Several transgender participants added that they "don't have the appropriate language to have the complete conversation."

Several LBW described the "awkward conversations" in which they had engaged with "no resolution" and the "need for a catalyst to broach the subject." Partners were mentioned by LBW participants (not seen in other groups) including "inability to get my partner to talk about it" and "having no girlfriend now, I am not sure what to do—I may rely on my ex-partner." Transgender participants described the "divisions within the LGBT community" and how such divisions "may make it more difficult to have conversations across the community." Both GBM and LBW participants spoke of avoiding discussions about end-of-life care based on "modesty" or "shame in asking for help" or not wanting "to put friends out, to be a burden on anyone." One LBW added that she would accept personal care, "like wiping your ass," by a professional or a stranger, but not from a friend.

Relationship Concerns

The second theme concerned challenges in the relationships of LGBT individuals and the impact of such challenges on end-of-life preparations and concerns. Four categories comprised this theme: (a) ambivalent ties with families of origin, (b) chosen family strengths and challenges, (c) isolation and loneliness, and (d) trust and honesty.

Ambivalent ties with families of origin. Families of origin were often mentioned, most frequently in terms of estrangement and the limitations thereby imposed on end-of-life discussions. All groups mentioned families of origin as "distant" (the term most often used by GBM). One GBM said: "Generally speaking, a lot of us lost our families when we came out." LB and transgender women and transgender men similarly talked about rejection from their families of origin: "my family considers me extraterrestrial" (one LBW said); a transgender woman shared that "When your family can't accept you for who you really are, they are not really family." GBM had concerns about family involvement including "the invasiveness of my family after my [partner's] death."

However, some spoke of some family-of-origin involvement and their potential reliance on them "even if not the family we would want," as reported by one GBM. Another GBM expressed fear of his family of origin "turning their back on him" at a time when he needed them most. One transgender woman spoke of the conditional support of her son (who had asked that she attend his wedding as a man) and another of her partner claiming she was "lucky to have family" including the support of her ex-partner given that having "a long-term partner in the trans community is a rarity." Another transgender woman spoke highly of the support of her wife with whom she remained in contact (and

in relationship) throughout her transition. This woman now viewed her as a sister, noting that she "would rather have a live sister than a dead husband."

Siblings were mentioned frequently, particularly by GBM, as potential supporters later in life. Many LBW and GBM had cared for their aging parents, some of whom felt that they could "leverage this care for my parents" with siblings for their own care in later life. LBW participants mentioned their children more than those in other groups, even if not always favorably. Still, concern was expressed about not wanting "to saddle someone with all of this" and discomfort about asking family to engage in personal care. Finally, one LBW mentioned the important role of pets as both providers of emotional support and as a source of anxiety following the death of the participant (e.g., being unsure of who would care for the surviving pet).

Chosen family strengths and challenges. Chosen families were mentioned frequently but more frequently by GBM and LBW than by transgender participants. One GBM said "we invent family; there is the urge to create family." Several LBW spoke of how chosen families were there "through thick and thin." These families often included partners and former partners: "My ex would give up her job and her wife for a certain length of time" (LBW participant). Both LBW and GBM participants also spoke of the need to, and sometimes the experience of, developing friendships with younger persons "to be there" when required, recognizing the absence of intergenerational contact in the networks of LGBT persons. At the same time, these participants noted the difficulty in creating friendships and nurturing support and the limitations in what friends might do and what might be asked of them. For example, GBM and LBW participants reported that "friends have their own lives" and demands that cannot be easily set aside when care is

needed. Several LBW added that they would therefore wait "until the bitter end" to ask a friend to assist and would rather ask a stranger because they "don't want [their] friend to see them or remember them" as ill and in need.

The LGBT community was described as a potential source of support by both GBM and transgender participants. Several GBM described versions of the following: "the gay community will stand tall and be there—as we have done before" during the time of AIDS. Transgender participants thought that "trans communities come together out of necessity." Implied in this more equivocal community call, several transgender participants described how there was "no one to run interference" for them and that they have to look after themselves "and hope that when the end comes, the lights will just go out." Such absence of support may also underlie the infrequency with which chosen families were mentioned by transgender participants.

Isolation and loneliness. Transgender and LBW participants mentioned isolation based on negative interactions (e.g., "trans persons learn to isolate themselves"). All groups mentioned loneliness (e.g., "when you are old and trans, you get pretty lonely"), and being alone ("trying to live that secret makes for a very solitary existence"). Transgender participants linked part of their experience to the passage of time, noting that late-life "transitions lead to a life of struggle and isolation." GBM also raised the issue of time but often in the context of loss through AIDS: "Everyone is gone," said one GBM, referring to the many losses of friends to AIDS.

Trust and honesty. A relational concern found disproportionately in the discussions of transgender participants and GBM concerned the absence of trust and honesty. Transgender participants mentioned difficulty getting other transgender

individuals involved because of a generalized lack of trust. The groups often spoke of the need for safe spaces for transgender persons—often lacking—and the "need for somebody to rely on and trust implicitly in your life." GBM similarly spoke of ending relationships "because there was no honesty" and expressed concern about "being screwed over by younger persons" (referring to nieces and nephews) when care was needed and/or finances were concerned.

Dynamics of LGBT Culture and Lives

Participants drew attention to their lives as members of a stigmatized group as contributing factors to their preparations for end-of-life. Four categories comprised this theme: (a) the fragmented LGBT community, (b) disclosure, (c) the role and history of HIV/AIDS (articulated by the GBM and LBW groups), and (d) financial concerns (mentioned by LBW and transgender participants).

The fragmented LGBT community. Most groups spoke of factions within the LGBT community that challenge the search for, and receipt of care. GBM often raised the issue of ageism, particularly around intimate relationships and self-perceptions. They maintained that "[the] chances are slim of finding Prince Charming after 50" in this "pick up culture," and that "I worry that I am no longer attractive," and "no one wants to be the close and intimate friend of a 75-year-old." LBW participants also reported on the ageism they had encountered saying, "some of the younger people deliberately avoided speaking to us. It was like a curse. It hurts so much." Transgender participants declared that "younger persons transitioning today have access to different surgeries, hormones—[they] don't have the same experiences of having to pass." Several went on to say that younger transgender persons "don't have to apologize for who they are" and they were

"better at being proud." Transgender participants also felt that growing old was difficult to discuss with other transgender persons or within the LGBT community at large stemming from the "self-centered, egotistical, aesthetic orientation; the community tries to erase aging" (stated by a transgender woman).

Both LBW and transgender participants made specific references to divisions within the LGBT community. LBW suggested that the lesbian community was divided by marital history, with one participant exclaiming, "having been heterosexually married, you're [seen as] one of the breeders." LBW also spoke of a gay-male centric culture, with "more resources for men, not so much is available for women." Several women noted that the "gay village is male—it is a world of men;" "most LGBT help lines are staffed by men; where can you go to get help from other lesbians? We need someone who speaks lesbian." One LBW participant noted that she didn't "want to retire with a whole pile of drag queens;" others in her group agreed.

Transgender participants spoke of their different status within the LGBT community saying, "the reality is that gays and lesbians have the choice to come out, but someone with bodies that are different don't have the choice." Several reported in various ways that "the trans community and the LGB community are at loggerheads." Nevertheless, other LGBT individuals were also noted as a source of support, particularly by LBW. For example, one participant said that when she was ill, "my community stepped in and housed me, took care of me. The LGBT community is good about doing that kind of stuff."

Disclosure. All groups noted that disclosing their sexual orientation or gender identity, particularly within the medical environment, contributed to their limited end-of-

life planning and experiences. LBW and GBM participants expressed concern about "what to reveal" during medical appointments often disclosing their sexual orientation on "a need to know basis" for fear of stigma. One LBW reported that there "are times when I want to shout out 'I'm a lesbian,' but it can't be done—we can't talk about it. It is still taboo." GBM spoke of "having to live two lives—one open and one closed" with reference to health care contexts (likened to the military). Other GBM participants described living "compartmentalized lives" wherein individuals from various components of their lives did not know the complete person—or each other—with articulated implications for pulling together a community of care. Several GBM added that they would be "unwilling to go back in the closet for long-term care" even, as they could "see how that might be the solution for some."

The groups noted the broader context of guarded identities. Transgender participants expressed concern about the quality of life lived with such secrets (e.g., "what kind of life is that, always living a secret, always afraid of being found out?") while simultaneously expressing concern about revealing the secret. One person described how her peers were unhappy when a well-known trans woman publicly spoke about her surgery: "We did this so we could live as women, and now you are talking about it on TV. It was as though she revealed a secret."

Several transgender participants spoke at length about disclosure in medical settings noting "it is impossible not to 'come out' as a transsexual because your medical file follows you everywhere." One transgender participant said, "I don't want to deal with people looking at me for interest—to see what my vagina looks like." Another reported that her "greatest reason for having surgery was to ensure that her anatomy agreed with

the gender she was living;" she didn't "want to be in a nursing home with breasts and a penis." Concern over how a transgender person might be treated in long-term care and at life's end was present in much of this discussion, often expressed as "fear of staff treatment if one has not had the full surgery."

The role and history of HIV/AIDS. HIV/AIDS was mentioned often in the GBM groups and in some of the LGW groups. LBW noted both the community responsiveness to the crisis and the often-overlooked roles of women in the early years of AIDS. They noted how women "contributed greatly" but how "the reverse did not happen… men did not come forward for breast cancer" in the same way. GBM participants addressed the legacy of HIV/AIDS, including how their approach to aging and end-of-life was "colored by [the] losses" they endured and the "experience of HIV." One man poignantly noted that he "was out of practice with grief," having experienced so much grief in the early 1990s and less since then, until recently. Several men noted that they "had strong networks then" but that the "urgency went away and so did support groups." Several men also expressed that they "had never expected to live this long" or be dealing with these end-of-life issues again, now in old age.

Relatedly, GBM and LBW referenced issues of caregiving related to "the time of AIDS." Across the GBM focus groups, mention was made about having cared for someone with HIV/AIDS, mostly friends, neighbors, and partners; this was also true for LBW to a lesser extent. Several participants reported having been part of a care team for someone who died of AIDS. A portion of the discussion focused on some of the similarities in need for care of an aging gay and lesbian population, but without "the anger today as there was with HIV" leaving needs unaddressed, often hidden.

Groups spoke of the challenges and rewards of caregiving. Challenges included some specific activities required of a caregiver in relation to HIV/AIDS. One GBM said, for example, that his "line in the sand" was changing diapers. LBW participants described caregiving as a "complex," "difficult" experience, both physically and psychologically, particularly when "trying to maintain independence" for the person receiving care—and the caregiver herself. A GBM proclaimed that care for dying individuals was hard to do—and that he "may think twice" if someone asked him to do it again. One LBW participant, in a lighter manner, mentioned how "people do unexpected things—I never thought I would get a chance to see his dick repeatedly," referring to a gay man dying from AIDS for whom she cared at end of life. Harkening back to concerns about their own future, an LBW participant reported, "when I think of what I did for my partner, it scares the hell out of me that I don't have anyone I would feel comfortable asking for that kind of support."

Importantly, the rewards of caregiving were also (albeit less frequently) mentioned by LBW participants. They reminded each other that "caring for someone, although a tremendous task, can also provide joy." It was noted, "the person who is ill is still the same person with all of their traits—they are not just a burden."

Financial concerns. Both LBW and transgender participants addressed the financial challenges of their lives explicitly tied to their gender identity and/or sexual orientation. One transgender participant proclaimed that she was "less financially prepared than friends who didn't have an issue called 'being trans' that ruined—interfered with their life." Others drew attention to more systemic issues such as the "two-tiered system, where if you have the resources," you can be more fully engaged in

life (and prepare for end-of-life). Transgender groups mentioned underemployment, unemployment, and homelessness.

LBW participants similarly noted that "resources are fundamentally lacking for lesbians"—unlike GBM as several participants noted. Some financial concerns derived from "choices made in life that leave us relatively poor in old age" (e.g., engaging in poorly paid non-profit work). One woman expressed concern over her financial status following her partner's death saying, "I can't afford to stay in our house" after her death.

Institutional Concerns

The fourth theme focused on institutional issues comprising three categories: (a) social and health service barriers, (b) the (related need for) political action and advocacy, and, to a lesser degree (c) the role of the church and religion.

Social and health service barriers. GBM and LBW noted the lack of available LGBT-affirmative social and health services. One participant reported "as a gay person, I do not feel welcome at the hospital," whereas another noted "We have no support in traditional care systems." Transgender participants described the profound insensitivity of some healthcare providers; for example, one transgender participant spoke of being left with her breasts exposed on a hospital gurney in a hallway for a significant period of time. Several spoke of the misuse, sometimes intentionally, of gender pronouns by healthcare staff.

LBW and GBM frequently raised concerns about nursing homes or seniors' homes. GBM reported their unwillingness "to go back into the closet for long term care." LBW offered similar opinions, speaking of the "horror of having to wind up in care. . . and having to start again to pretend to find a gay joke funny." There were mixed feelings,

however, about LGBT-specific facilities. One LBW noted that she didn't want to be in an exclusively "gay senior's home—there's more to life than being gay;" whereas another LBW expressed her preference for a "facility geared to lesbians so she could be with others like [her]."

Political action and advocacy. Participants mentioned the need for political action and involvement, including education, the latter being more prominently mentioned by GBM and transgender participants than by LBW. GBM spoke of needing to "educate younger gay men" to be involved and create change. Transgender participants pushed for "bottom-up education" that is "directly relevant" for patients, given the reported absence of "government standards of care for LGBT persons." One participant noted that "transgender people must be life-long educators" for staff at all levels—and also for other residents of care facilities.

LBW participants were more likely to call for the government to "do its job." The "government is our employee," one said; "we should be getting what [our] taxes have paid for," said another. LBW participants proclaimed that the "LGBT community should push back and make changes" both externally (e.g., help governments change) and internally (e.g., make other LGBT people aware of their rights and responsibilities). Several LBW had fought for women's and sexual minority rights and reported that they were tired and frustrated by the fights. Still, many noted the need to remain involved politically: "we are bigger as a group."

Advocacy was a part of this discussion including the need "to advocate for others" (as one GBM said), particularly at times of ill health. One transgender woman said: "When sick, you can't really speak for yourself—you need an advocate, particularly

in such a vulnerable place." LBW agreed saying that the community needed spokespersons and advocates.

Role of church and religion. Churches were mentioned by GBM (two groups) and LBW (one group). They were seen to offer structure for community and social interaction, but with some trepidation—as was religion in general. GBM, for example, reported some fear that "others will use their faith against me" (as a GBM). One LBW noted that she "does not feel welcome in church because of its active role" against same-sex marriage. Nevertheless, she still found it difficult to sever her relationship with a community of which she had been a part for most of her life.

Discussion

This study describes the end-of-life concerns identified by a group of LGBT older Canadians and the manner in which such concerns were expressed and shared. Findings highlight the various sociocultural realities and financial challenges LGBT older adults experience in their preparations for end-of-life, including isolation, ambivalent ties with biological kin, and social challenges with friends and chosen family—speaking to both LGBT "culture" and the broader Canadian culture of these participants. While many of the findings were consistent with existing literature, differences in the issues identified by lesbians (and bisexual women), gay (and bisexual) men, and transgender persons were also noted, both in type and approach.

Issues and Barriers Common Across LGBT Groups

A common concern heard is a version of "no one is there for me." This "empty set" and its relationship to end-of-life planning is the overarching message of this study and corresponds with other reports identifying isolation and loneliness among LGBT

older adults (e.g., Fredriksen-Goldsen et al., 2013). In particular, gay and bisexual men and especially transgender persons (who report being forsaken by their partners and children in high proportions, see Cook-Daniels, 2015) articulate these concerns. The absence of others makes conversations about preparation and end-of-life concerns necessarily one-sided and understandably difficult to sustain.

Biological or families of origin, regarded as the most common occupants of the inner circles of heterosexual older adults (e.g., Cantor & Brennan, 1993), are often described as "distant." However, siblings represent an interesting exception to this pattern and suggest the need for further exploration. As often reported (e.g., de Vries & Croghan, 2014; Muraco & Fredriksen-Goldsen, 2011), friends or chosen family frequently "step up" to address the void created by a lack of connection with family of origin (Brotman et al., 2007). Nevertheless, friends also have competing demands challenging their availability to provide support (Almack, Seymour, & Bellamy, 2010). However, even when friend-caregivers are present, they are often not recognized within the health care system; furthermore, participants expressed reticence to "burden" their friends with their healthcare needs, as well as modesty—not wanting their friends to see them in such poor health, similar to the earlier research of Johnson (1983) in a heterosexual context. Still, friends sometimes serve as a stimulus for end-of-life preparations, often indirectly, through the health crisis of a friend or the behaviors of families at the time of a friend's death.

Many interpersonal challenges are linked to social stigma reported by LGBT older adults, (de Vries, 2015), including those experiences directly tied to LGBT status such as the reported "guarded identities" and the additional layer of minority stress

(Meyer, 2003). However, other experiences also include ageism, which is acutely felt among gay men (Bergling, 2004). In general, and both echoing previous Canadian research and offering poignant insight into the later life experiences of older LGBT Canadians, many aging-related services are viewed as not welcoming of sexual and gender diversity (Brotman & Ferrer, 2015) and concerns were expressed about assisted living and long-term care during perhaps the most vulnerable of times--end of life (Brotman et al., 2007).

Social stigma is not restricted to the broader heteronormative environment dominating the lives of these women and men. It also derives from what is described as ageist, male (white)-privileged, cisgender-centric LGBT environments. Such findings suggest that even within the progressive and "officially" inclusive Canadian political setting, work remains to redress the legacy of discrimination experienced by LGBT older adults. Moreover, experiences differ based on sexual orientation and/or gender identity.

Subgroup Particular Issues

Wilson et al. (2018) note that the "recognition of intersectionality and varying social locations is crucial to facilitating positive aging experiences and good end-of-life care" (p. 9). This study identified ways in which the groups of LGBT persons differed in their approach to end-of-life.

Lesbians and bisexual women. In addition to speaking strongly of the fissures in the LGBT community, there is a much stronger political and social justice perspective to the discussions of lesbian and bisexual women, including calling for the LGBT community to be a voice in the larger aging dialog. Several other authors have commented on the socio-economic differences between lesbians and gay men,

particularly in later life (e.g., Badgett, Durso, & Sneebaum, 2013); the women in this sample propose a work history basis for such differences.

In contrast to gay and bisexual men, lesbians and bisexual women are more likely to speak about their personal networks of support, mostly in favorable terms, and less likely to comment on loneliness and isolation. The role of ex-partners is especially noted—and supports the "really long-term relationships," and potential sources of support, lesbians reportedly experience (Weinstock & Rothblum, 2004), still meriting further exploration.

Gay and bisexual men. The legacy of HIV/AIDS is central to gay and bisexual men's discussions, with both individual (i.e., personal losses, end-of-life preparation) and collective (i.e., changes in the community) effects. From a social network perspective, some men see the need to repopulate their social worlds (even while they express some futility around this), particularly with younger persons who will be available when the times demand. Implicit in some of these discussions is a reference to a type of retraumatization, something rarely discussed in the literature and worthy of further study.

Being alone is identified as a major related problem (Fredriksen-Goldsen et al., 2013); several groups grappled with a response to the question of who would pick them up after a colonoscopy. This may well be related to trust and honesty (more pronounced in the discussions of gay and bisexual men and transgender persons), though further research is needed.

Transgender persons. Many issues experienced by GBM and LBW who are cisgender are also experienced by transgender persons, but frequently in a more extreme form (Persson, 2009), especially aloneness and loneliness. Similar to lesbians and

bisexual women, inadequate financial resources, unemployment and, for some, homelessness compromise transgender individuals' quality of life and preparation for life's end (Grant et al., 2011).

Transgender aging involves unique challenges. For example, transgender persons describe feeling separate from the LGB community by way of their "different bodies." Surgery further differentiates the experiences of transgender persons—in this case, from one another, consistent with other studies (e.g., Persson, 2009). All participants noted the need for education, but transgender persons in particular articulate the need for person-centered care—a call to action. Some of the more transgender-specific issues are elucidated in another paper (see Pang, Gutman, & de Vries, in press).

Limitations

Our LGBT focus group participants self-selected for an in-depth group discussion on end-of-life issues based on their (varying) readiness to speak to these issues. The lesbian participants, in particular, appeared to have a background rich in social activism, benefitting discussions but constraining representativeness. Bisexual women and men, transwomen, people of color, rural LGBT older persons, and those with more complex health and social care needs were under-represented. All of the focus group respondents identified as LGBT, again limiting participation to particular identity labels, similar to other studies (e.g., Fredriksen-Goldsen et al., 2013). More focused and innovative outreach to include these group should be considered in subsequent end-of-life studies.

Given this study's focus, it is not surprising that the focus groups were of various sizes. From a methodological perspective, such variations may influence the nature and breadth of the discussions undertaken by the focus group participants. The exact effects

of focus group size are unknown in this study but remain a consideration for pursuit in subsequent research.

Conclusion and Future Directions

This study reinforces and informs literature on LGBT aging and end-of-life considerations. Our data add important contextual information, offering a range of implications for both practice and research. Although the Canadian government has taken important steps in the last few decades to improve the social conditions in which LGBT individuals age, much work needs to be carried out at other micro, organizational, governmental, and macro levels. As Wilson et al. (2018) have noted, "creating social environments and health systems that are inclusive and facilitate quality end-of-life care is vital" (p. 29) in helping to support aging LGBT individuals—with work still to be done. Several explicit calls for greater involvement of government were noted above. This appears consistent with, for example, government-funded health care—with demands for more *focused* attention to the health and well-being of older LGBT persons.

It remains clear, for example, that missing in much of the end-of-life preparations taken by LGBT individuals are discussions about care options even where formal documents have been completed. Health care and other service providers are important conduits in initiating and navigating such discussions and subsequent research should examine the innovative ways in which such discussions have successfully taken place to help allay fears about end of life, including online (see Beringer et al., 2017) The consequences of ongoing and long-term stigma are prominently identified in LGBT individuals' experiences in both the treatment they have experienced in health-care settings *and* in the treatment they anticipate, reflecting a minority stress (Meyer, 2003)

experience. Issues of actual and perceived stigma and discrimination mandate attention in advancing our understanding of end-of-life conversations. More needs to be done to improve the psycho-social environments in which end-of-life conversations are oftentimes situated within the context of non-traditional family ties and communities. LGBT persons express particular concerns about the absence of others with whom to engage in end-of-life conversations and the absence of LGBT forums to support and encourage such discussions.

References

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

Badgett, M. V. L., Durso, L., & Schneebaum, A. (2013). *New patterns of poverty in the lesbian, gay, and bisexual community*. Los Angeles, CA: The Williams Institute.

Barnato, A. E. (2007). Are regional variations in end-of-life care intensity explained by patient references? A study of the US Medicare population. *Medical Care, 45,* 386-393. www.ncbi.nlm.nih.gov/pmc/articles/PMC2686762/

Barker, J. (2002). Neighbors, friends, and other nonkin caregivers of community living dependent elders. *Journal of Gerontology, 57,* 158-167.

Bergling, T. (2004). *Reeling in the years: Gay men's perspective on age and ageism*. New York, NY: Harrington Park Press.

Beringer, R., Gutman, G., & de Vries, B. (2017). Developing a web-based platform to foster end-of-life planning among LGBT older adults. *Gerontechnology, 16*(1), 48-55.

Bischoff, K. E., Sudore, R., Miao, Y., Boscardin, W. J., & Smith, A. (2013). Advance care planning and quality of end-of-life care among older adults. *Journal of the American Geriatrics Society, 61*(2), 1-12.

Brotman, S., & Ferrer, I. (2015). Diversity within family caregiving: Extending definitions of "who counts" to include marginalized communities. *Healthcare Papers,* 15(1), 47-53.

Brotman, S. B., Ryan, S., Collins, L., Chamberland, R., Cormier, D., Julien, E., & Richard, B. (2007). Coming out to care: Cargivers of gay and lesbian seniors in Canada. *The Gerontologist, 47,* 450-503.

Brotman, S., Ryan, B., & Cormier, R. (2003). The health and social service needs of gay and lesbian elders and their families in Canada. *The Gerontologist, 43,* 192-202. doi:10.1093/geront/43.2.192

Calhoun, L., & Tedeschi, R. (2013). *Posttraumatic growth in clinical practice*. New York, NY: Taylor & Francis.

Canadian Hospice Palliative Care Association. (2013, December). *What Canadians say: The way forward survey report*. Retrieved March 31, 2017 from http://www.hpcintegration.ca/media/51032/The%20Way%20Forward%20-%20What%20Canadians%20Say%20-%20Survey%20Report%20Final%20Dec%202013.pdf

Cantor, M. H., & Brennan, M. (1993). Family and community support systems of older New Yorkers. *Growing older in New York City in the 1990s: A study of changing lifestyles, quality of life, and quality of care, Vol. V.* New York, NY: New York Center for Policy on Aging, New York Community Trust.

Carr, D. (2011). Racial differences in end-of-life planning: Why don't Blacks and Latinos prepare for the inevitable? *Omega: Journal of Death and Dying, 63*(1), 1-20.

Cook-Daniels, L. (2015). Transgender aging: What practitioners should know. In N. Orel and C. Fruhauf (Eds.), *The lives of LGBT older adults: Understanding challenges and resilience* (pp. 193-216). Washington, DC: APA Press.

de Vries, B. (2013). LG(BT) persons in the second half of life: The intersectional influences of stigma and cohort. *LGBT Health 1*(1), 16-21.

de Vries, B. (2015). Stigma and LGBT aging: Negative and positive marginality. In N. Orel & C. Fruhauf (Eds.), *The lives of LGBT older adults: Understanding challenges and resilience* (pp. 55-72). Washington, DC: APA Press.

de Vries, B., & Croghan, C. (2014). LGBT aging from community perspectives: Challenges and opportunities. *Journal of Homosexuality, 61*, 1-20.

de Vries, B., & Megathlin, D. (2009). The meaning of friends for gay men and lesbians in the second half of life. *Journal of GLBT Family Studies, 5,* 82-98.

Fredriksen-Goldsen, K.I., Kim, H-J., Hoy-Ellis, C., Goldsen, J., Jensen, D., Adelman, M., &… de Vries, B. (2013). *LGBT older adults in San Francisco: Recommendations for the future*. Report prepared for the LGBT Aging Policy Task Force. Institute for Multigenerational Health: University of Washington, Seattle.

Fredriksen-Goldsen, K.I., Kim, H-J., Shui, C., & Bryan, A.E. (2017). Chronic health conditions and key indicators among lesbian, gay and bisexual older adults, 2013-2014. *American Journal of Public Health, 107*(8), 1332-1338.

Government of Canada (2018, Sept. 10). *Rights of LGBTI persons*. Retrieved from https://www.canada.ca/en/canadian-heritage/services/rights-lgbti-persons.html.

Grant, J. M., Mottet, L. A., Tanis, J., Harrison, J., Herman, J. L., & Keisling, M. (2011). *Injustice at every turn: A report of the National Transgender Discrimination Survey.* Washington: National Center for Transgender Equality and National Gay and Lesbian Task Force.

Hughes, D., & Dumont, K. (1993). Using focus groups to facilitate culturally anchored research. *American Journal of Community Psychology, 21,* 775-806.

Joffe, H., & Yardley, L. (2004). Content and thematic analysis. In D. Marks & L. Yardley (Eds.), *Research methods for clinical and health psychology* (pp. 56-68). New York. NY: Sage.

Johnson, C. L. (1983). Fairweather friends and rainy day kin: An anthropological analysis of old age friendships in the United States. *Urban Anthropology, 12,* 103-123.

Kitzinger, J. (1994). The methodology of focus groups: The importance of interaction between participants. *Sociology of Health and Illness, 16,* 103-121.

MetLife (2010). *Still out, still aging: The MetLife study of lesbian, gay, bisexual and transgender baby boomers*. New York, NY: The Mature Market Institute.

Meyer, I. H. (2003). Prejudice, social stress, and mental health in lesbian, gay and bisexual populations: Conceptual issues and research evidence. *Psychological Bulletin, 129,* 674-697.

Muraco, A., & Fredriksen-Goldsen, K. (2011). "That's what friends do": Informal caregiving for chronically ill midlife and older lesbian, gay, and bisexual adults. *Journal of Social and Personal Relationships, 28*(8), 1073-1092.

Noble, H., & Smith, J. (2015). Issues of validity and reliability in qualitative research. *Evidence Based Nursing, 18*(2), 34-35.

Northcott, H. C., & Wilson, D. M. (2008). *Dying and death in Canada* (2nd ed.). Peterborough, ON: Broadview Press.

Persson, D. I. (2009). Unique challenges of transgender aging: Implications from the literature. *Journal of Gerontological Social Work, 52,* 633-646.

Pang, C., Gutman, G., & de Vries, B. (under review). Later Life Care Planning and Concerns of Transgender Older Adults in Canada. *International Journal of Aging and Human Development.*

Pew Research Center (2013). *The global divide on homosexuality*. Retrieved from http://www.pewglobal.org/2013/06/04/the-global-divide-on-homosexuality/

Robinson, N. (1999). The use of focus group methodology—with selected examples from sexual health research. *Journal of Advanced Nursing, 29,* 905-913.

Reid, G. (2017, November). Canada sets international example in LGBTI rights. *The Globe and Mail*, Retrieved from https://www.theglobeandmail.com/opinion/canada-sets-international-example-in-lgbt-rights/article36157300/

Regence Foundation (2011). *Living Well at the End of Life: A National Conversation*. March 2011, www.regencefoundation.org/docs/FDRegenceNationalJournalSurveyResults.pdf

Schickedanz, A. D., Schillinger, M. D., Landefeld, C. S., Knight, S. J., Williams, B., & Sudore, R. L. (2009). A clinical framework for improving the advance care planning process: Start with patients' self-identified behaviors. *Journal of the American Geriatric Society*, *57*(1), 31-39.

Statistics Canada (2017, September 25). *Same-sex couples and sexual orientation—by the numbers*. Retrieved from https://www.statcan.gc.ca/eng/dai/smr08/2015/smr08_203_2015

Weinstock, J. S., & Rothblum, E. D. (2004). *Lesbian ex-lovers: The really long-term relationships*. New York, NY: Haworth Press.

Wilson, K., Kortes-Miller, K., & Stinchcombe, A. (2018). Staying out of the closet: LGBT older adults' hopes and fears in considering end-of-life. *Canadian Journal on Aging, 37,* 2-21.

Table 1.

LGBT Sample Distribution

	Gay Men	Lesbian Women	Bisexual	Other	Total
Cisgender					
Vancouver	15	12			27
Edmonton	5	2			7
Toronto	5	4	1 (Male)		10
Montreal	6	5			11
Halifax	8	5[a]	1 (Female)		14
Total	39	28	2		69
Transgender					
Vancouver	3 TM[b]	3 TW[c]		3 TW	9
Edmonton				1 TM[d]	1
Toronto	1 TM	3 TW	2 TW	1 TM 1 TW 1[e]	9
Montreal				2 TW	2
Halifax		2 TW		1 TW	3
Total	4	8	2	10	24

[a]One participant was transgender
[b]TM = Transman
[c]TW = Transwoman
[d]One transgender participant identified his sexual orientation as "other"
[e]One participant declined to identify a gender or a sexual orientation.

Table 2.

Group Characteristics

	n	% Single	% Living Alone	% No Children*	% No Caregiver
Gay and bisexual men	40	62	70	77	25
Lesbians and bisexual women	29	52	48	52	30
Transgender women and men	24[a]	67	50	26	29

[a]Four men identified as gay, eight women identified as lesbian, two women identified as bisexual, and 10 persons identified as heterosexual.
* $p < .001$

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