Later Life Care Planning and Concerns of Transgender Older Adults in Canada

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Abstract
While the particular health-care concerns of transgender people have been documented and transgender aging is an emerging area of scholarship, little is known about planning for later and end-of-life care among transgender older adults. As part of a larger project, focus groups and interviews were conducted with 24 transgender older adults (average age 70 years) living in five cities in Canada exploring their concerns and explicit plans for later life care. Three primary themes emerged: (a) “dealing with the day-to-day” reflecting economic precarity and transitioning in later life, (b) fractures and support within family and community, and (c) “there’s a huge gap between principle and practice” reflecting mixed experiences and perceptions of health-care services. These themes suggest that effective promotion of care planning among older transgender persons requires an appreciation of the daily exigencies of their lives and the extent and nature of social support available to them.

Keywords
transgender, aging, later life/end-of-life care, social support, long-term care

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Introduction

Later life and end-of-life care planning and concerns of trans\(^1\) older adults has not been an area of significant academic inquiry to date. Popular literature and media representations, however, provide a common script of fear regarding later life care. Fears of mistreatment in care facilities, namely nursing homes, have been captured in interviews with trans older adults and service providers in U.K. and U.S. articles, noting the lack of acceptance of diverse bodies and potential challenges of navigating gender-segregated spaces (Godfrey, 2016; Perry, 2015). Fears about “going back into the closet” in long-term care homes are shared among LGBTQ (lesbian, gay, bisexual, transgender, and queer) older adults in Canada as well as reported in mainstream press articles (Ibbotson, 2018; Purdon & Palleja, 2018) and academic literature (Brotman, Ryan, & Cormier 2003; Wilson, Cortes-Miller, & Stinchcombe, 2018).

Coupled with these fears are reports of poor health in the modest research literature on the experiences of older trans persons. For example, Fredriksen-Goldsen, Kim, Barkan, Muraco, and Hoy-Ellis (2013) found that transgender older adult participants had significantly poorer physical health, higher rates of disability and depressive symptomatology, and greater perceived stress than the nontransgender LGB older adult participants; other U.S.-based research reports that relative to cisgender older LGB and heterosexual adults, transgender older adults had higher rates of psychological distress, including higher rates of internalized stigma (Hoy-Ellis & Fredriksen-Goldsen, 2017). Witten (2016) has written extensively on transgender aging, noting, in particular, on the invisibility and family isolation that trans older adults may face. Further studies have observed the unique barriers to accessing health care and the isolation and lack of support that many trans older adults face (Hébert, Chamberland, & Enriquez, 2012; Persson, 2009).

More commonly, however, discussion of the particular situations of trans older adults is folded into commentary regarding LGBT older adults more generally. For example, scholars have articulated how LGBT older adults, and especially trans older adults, are more likely to be living alone, aging without partners, and without the support of children, who are understood to be the typical primary caregivers of older adults (de Vries, 2013). Scholars have pointed to concerns about elder abuse and violence both from within and external to the LGBT community (Cook-Daniels & Munson, 2010). While such findings provide valuable insight into the general, mostly U.S.-based landscape in which LGBT older adults are aging, and some of the particularities of trans experiences and the existing and potential limits of heteronormative care institutions in relation to them, their application to the Canadian context has not yet been established. This is especially significant in terms of differing rights trajectories and the organization of health care in Canada compared with other countries.
Canadian Literature and Context

Canadian researchers have observed how the health and care needs of LGBT older adults are both different and more numerous than among the general population and are often overlooked in mainstream health care and social service provision. Less is known about trans older adults’ perspectives toward later and end-of-life care planning, recognized as a significant area of concern for LGBT communities (Kimmel, 2014; Witten, 2016). In similarity to the United States (e.g., Hughes & Cartwright, 2014), this is an area that has only just begun to be explored.

To date, much of the Canadian scholarship on LGBT older adults has focused on care experiences and concerns. Studies have illuminated, for example, challenges navigating home care services and demands for affirmation of their identities from service providers among older lesbian and bisexual women (Grigorovich, 2015), and among caregivers challenges patients face in coming out to caregivers (Brotman et al., 2007). Other research has documented the emergence of LGBT inclusivity strategies in the home care sector and offered specific recommendations on improving quality of care (Daley & MacDonnell, 2016; Sussman et al., 2018). While published studies concerning trans older adults are limited (Hébert et al., 2012), there is a small yet growing body of research around trans health. This research has documented the health challenges and systemic barriers that trans people face, including barriers to accessing trans-inclusive and trans-affirmative health-care and social services (Bauer et al., 2009; Bauer, Zong, Scheim, Hammond, & Thind, 2015).

In general, a challenge to framing a Canadian context are the significant jurisdictional differences with respect to health and social services across Canadian provinces and territories. The organization of health-care and social services is also differentially distributed across levels of government—municipal, provincial, and federal. The same is true of LGBT or trans-affirming supports and services which also vary greatly within and between provinces. Yet, there are key commonalities that are tied to the historical period through which Canadian older adult trans persons have lived, and the current political and legislative climate in which they are now aging that may help us to understand their experiences.

Like other nations, Canada is experiencing population aging. In 2016, nearly 6 million Canadians were aged 65 years or older; by 2036, it is estimated that seniors will number over 9.5 million, making up between 23% and 25% of the Canadian population (Statistics Canada, 2018). Both governments and the private sector are recognizing the need to increase health-care services to meet the needs of this burgeoning and increasingly diverse seniors population, while commentators stress the higher spending this may necessitate (Jackson & Clemens, 2013). Community organizations and advocacy groups have recognized a need to create social spaces and programs for LGBT older adults (e.g., QMunity, 2015; The 519, 2019) and have endeavored to learn more
about their particular requirements through national consultation processes (e.g. Egale Canada, 2019). The LGBT older adult population is also on the federal government’s radar as part of seniors issues, as reflected in publications focused on social isolation among LGBTQ seniors (Government of Canada, 2018) and equity concerns in provincial seniors’ strategies (Sinha, 2013).

In tandem with population aging, LGBT rights and recognition in Canada have undergone significant shifts over the past five decades. This includes the decriminalization of homosexuality (in 1969), the extension of adoption rights to same-sex couples, and official sanctioning of same-sex marriage (nation-wide in 2005). Sexual orientation became prohibited grounds for discrimination in the Canadian Human Rights Act in 1996 and, in 2017, gender identity and expression were added (Government of Canada, 2017). Sex designation can be changed on legal documents, including birth certificates, and as of 2017, gender neutral birth certificates and passports have been issued. Furthermore, in Canada, grassroots and community-based efforts have led to increased awareness of the general need for trans-affirming health-care and social services. Some publically funded transition-related care is currently available. For example, in Ontario, Canada’s largest province, sex reassignment surgery is insured with prior approval from a physician or nurse practitioner (Government of Ontario, Ministry of Health and Long-Term Care, 2016).

Still, despite these advances, Canadian-based research has documented that health-care challenges and systemic barriers still exist for older adult members of trans communities, and little is known about how they perceive their late life and end-of-life care needs nor what steps they are taking to address these needs. This research was designed to address this knowledge gap.

Method

In 2015–2016, a series of focus groups and a small number of interviews were conducted with 93 LGBT older adults living in three broad regions of Canada. The 24 transgender participants are considered here. A broader analysis and comparison across LGBT groups appears elsewhere (de Vries et al., 2019).

The focus groups and interviews were designed to present environments of safety and the comfort of speaking among peers, with the awareness that every individual would come with their own set of experiences and that differences exist within communities. A central goal of this research was to better understand the later life planning experiences of older LGBT persons, including the issues involved as well as barriers and facilitators to effective planning.

Due to the small numbers of participants in some of the study sites (where participant numbers ranged from one to nine) and a related concern of compromising anonymity, we have grouped the data into the three regions of Canada mentioned earlier. The overall research team comprised investigators
and research assistants from across provinces, in addition to numerous community partners at each research site (with a total of over 20 community partners).

Recruitment and Focus Groups

All study participants were recruited by reaching out through community and partner organizations and through key informants. Recruitment announcements and project descriptions were also placed in relevant websites and newsletters, primarily distributed by the groups mentioned earlier (i.e., Qmunity in Vancouver; the 519 in Toronto; Egale, for national exposure). Participants were asked to contact the research assistant in their region for eligibility, consent, and inquiries. For recruitment of trans participants key informant referral proved particularly important, as individuals heard about the study through existing networks and trusted sources.

Research assistants conducted screening interviews by telephone, and eligible participants were invited to attend the focus group, or if that was precluded, to participate in an interview. Inclusion criteria were age 60 years or older, English or French speaking, reporting at least one chronic condition, and some Internet experience (geared to a secondary objective of the larger project which was to investigate the role of technology in older LGBT adults’ later life care planning). Participants were given a $25.00 gift certificate in recognition of their participation.

Focus groups and interviews were conducted in community spaces. These included conference rooms provided by local community centers and a private room in a public library. They were led by the principle investigator, co-investigators, or research assistants in each of the three regions and were approximately two hours in duration. Three of the 24 participants were interviewed individually to accommodate their availability. All focus groups and interviews were audio-recorded with the consent of participants and were later transcribed.

The focus group questions relevant to this analysis concentrated on eliciting discussion around concerns, preparations and explicit plans for later life care (including conversations about care, current, and future) and the role of community (both formal and informal) in supporting and enacting such plans. Guiding questions included Who are the people with whom you would talk about hopes, fears, plans for the future? How do you stay connected with these individuals? With whom have you had explicit discussions about care? What are these conversations like? What would encourage people (you) to have such explicit discussions?

Participant Demographics

In total, 6 self-identified trans men and 18 trans women participated in the trans-specific focus groups and interviews. These included 5 participants from Eastern Canada, 9 from Central Canada, and 10 from Western Canada. Among trans
men, four people identified as gay and two as straight, while among trans women eight identified as lesbian while two identified as bisexual and eight as straight. The participants ranged in age from 55 to 89 years, with a mean age of 70 years. All participants were White Canadians of European descent, who resided in or in close proximity to the five urban centres where the study was conducted (Vancouver, Edmonton, Montreal, Toronto, and Halifax).

Table 1 provides information concerning participants’ familial and friend relationships and living arrangements. As can be seen, a majority (65%) were single at the time of response, while the average number of friends participants reported having was 3 to 4. Seventeen participants, or 71%, reported having children. A range of living arrangements were reflected in the sample.

### Data Analysis

All focus groups and interviews were audio-recorded and transcribed verbatim by research assistants. This narrative material was then analyzed using inductive thematic analysis, guided by constructivist grounded theory (Charmaz, 2000; Strauss & Corbin, 1998). Data analysis assumed several stages. After multiple initial readings of the transcripts, two individuals (the third author and a research assistant) identified codable materials—text that was characterized by key or recurrent points of discussion. Upon agreement of codes, a subset of transcripts were coded by both individuals to establish comfort and facility with the process. Independent coding of transcripts followed, with frequent consultation between individuals and resolution of discrepancies. Final codes reflect the consensus of both individuals.

A second-order analysis of these codes was undertaken by the lead author. The transcripts and codes were reviewed multiple times and used to inform superordinate themes—themes that reflect both the breadth of the codes and integrate

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**Table 1.** Participant Relationships and Living Arrangement.

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<thead>
<tr>
<th>Relationship status</th>
<th>Eastern Canada (5)</th>
<th>Central Canada (9)</th>
<th>Western Canada (10)</th>
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<tbody>
<tr>
<td>Single</td>
<td>3</td>
<td>6</td>
<td>6</td>
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<tr>
<td>Partnered (including legal, common-law, and committed)</td>
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<td>3</td>
<td>4</td>
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<thead>
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<th>Living arrangement</th>
<th>Eastern Canada (5)</th>
<th>Central Canada (9)</th>
<th>Western Canada (10)</th>
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<tbody>
<tr>
<td>Alone</td>
<td>1</td>
<td>4</td>
<td>6</td>
</tr>
<tr>
<td>With partner</td>
<td>2</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>With others (including family and friends)</td>
<td>1</td>
<td>3</td>
<td>1</td>
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<table>
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<tr>
<th>Have children</th>
<th>Eastern Canada (5)</th>
<th>Central Canada (9)</th>
<th>Western Canada (10)</th>
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<tr>
<td></td>
<td>3</td>
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<table>
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<tr>
<th>Average number of friends</th>
<th>Eastern Canada (5)</th>
<th>Central Canada (9)</th>
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them into more parsimonious, higher level characterizations. A second individual was presented these themes and justifications and through discussion and further conceptualizations, final themes were determined; these are presented later.

**Results**

Most participants had not given much thought to later and end-of-life care and had no concrete plans in place. Thus, focus group conversations served as a platform where people began to form ideas, musing aloud, and adding onto other perspectives as discussions unfolded. Participants also highlighted reasons why they had not given later and end-of-life care much thought. From these conversations and the process described earlier, three key themes emerged: (a) “dealing with the day-to-day”: economic precarity and transitioning in later life, (b) fractures and support within family and community, and (c) mixed experiences and perceptions of health-care services. We found no meaningful variation on themes based on gender identification or geographic region.

**“Dealing With the Day-to-Day”: Economic Precarity and Transitioning in Later Life**

Many participants expressed a focus—even a demand—on dealing with the present and the day-to-day, precluding specific thought being given to later and end-of-life concerns. This perspective stemmed mainly from two intertwined areas: economic precarity and the experiences of transitioning later in life.

Speaking from her own experience, and generalizing to others in trans communities, one participant linked concerns over economic precarity with a more pervasive insecurity:

... we struggle so much with our everyday lives, of where we’re going to eat, where we’re going to sleep, we’re under-housed, we’re underemployed ... whether our teeth hurt or whether we’re being attacked, just our everyday, everyday lives that it’s really really difficult to plan ahead, especially, in fact it’s not even on the radar for many people ...

She describes how immediate concerns, such as where to eat or sleep, coupled with the potential for trans phobic violence, may circumscribe planning for the future. While she acknowledged her privilege as a White, English-speaking, university-educated and able-bodied person, noting that while she has found empowerment to tackle some of these circumstances, others differently positioned face greater challenges in doing so. While she had made a will some 30 odd years ago that she knows needs updating, this was not top of her mind especially, as she emphasized, she does not have much wealth to leave.
A focus on day-to-day living was similarly noted by those transitioning later in life. Participants spoke of changing social conditions that enabled them to both recognize themselves and to take steps toward their desired realities of expressing their gender. Yet, the dimension of coming out and transitioning later in life present both opportunities and challenges. One participant, who in her words had *switched over* later in life, related the constraints placed on her gender expression by pathologization earlier in her life. When asked during the interview about later and end-of-life care planning she chuckled, responding, 

End-of-life care! I haven’t planned for it just yet, I’m still trying to get caught up on what I missed out on when I was younger. I know it happens to other people but I haven’t been worrying about it for myself just yet.

This participant shared the sentiment of living on unexpected time and a desire to focus on new aspects of her life over focusing on the ending that aging is taken to represent. At the same time, she continued to reflect on the constraints of her economic situation: she had struggled throughout her life to gain and maintain paid formal employment, a situation she attributes directly to what she termed her gender dysphoria and to employment discrimination. At the same time as desiring to *catch up* on what she missed out on, she is currently living in poverty and continues to seek employment as an older trans woman.

Another participant’s reflections expand on the concerns over employment and transitioning later in life:

I don’t know, I think ... trans community is tough. There’s a group of trans people that transition later in life, for all kinds of reasons, after their spouse dies, or a divorce, or the kids have grown up, or a million reasons, right. They transition late in life ... successful living is very complicated. They’re not going to pass, they’re not going to get employed very often, it’s just, and it might be easier inside of the larger cities, but in other places, life is very difficult when you transition late in life.

She speculated that if a person is in the process of transitioning, experiencing alienation, and dealing with health and employment issues, end-of-life planning may be of relatively low priority. In counterpoint, another trans woman with a longer trajectory of paid formal employment commented on the relative privilege she has been given, that of coming out after her working life. Now retired, she has savings and a pension and is able to support herself and imagines a secure future with her partner.

**Fractures and Support Within Family and Community**

Conversation around potential later and end-of-life care circumstances and plans highlighted both the fractures within and support from family and
community. Participants named a mixture of people present in their support systems, including children, partners, ex-partners, younger siblings, and close friends; several also mentioned having no one.

For those who have maintained relationships with spouses, ex-spouses, or children from previous marriages, those individuals remain point people in current support networks and were named as part of any discussions around later and end-of-life care. For example, one trans man and his partner had made their wills, and he had appointed her as his power of attorney. The immediate impetus behind this formalization was a surgery at age 60 years.

One trans woman identified her wife, who has been with her through her transition, as the person who would be able to care for her, and described her partnership thus:

... that would most definitely be Z. ... there’s definitely having somebody that you obviously can rely on and trust implicitly as part of your life ... That is a huge thing to have but something that affects not just the transgender population but I mean any kind of senior citizen ... They have to have somebody to drive them home, even a simple thing like an eye exam or a more serious thing like a colonoscopy. When you have somebody as part of your life, as part of your support system, whether we like to recognize it or not, it is. Certainly Z. is part of my support system, for day-to-day living. She cooks, I do the dishes. How would I manage without her, you know? ...

One participant shared how while she was there to provide care for her mother in her old age, she herself has no one.

... she had me to kind of run interference for her, but hey, there’s nobody out there to run interference for me I’ve gotta look after myself and hope that when the end comes the lights will just go out and I won’t have to be in this declining phase, where I’ve got to depend a whole lot on somebody else. Because there is nobody else out there, right, at the moment ... I have a fair sized extended family but I’m kind of disconnected from them and, there’s no children, you know, to look after me ... so, that’s the way it is.

Others described a social network composed of many friends and community connections. Yet, among these participants, individuals struggled to identify a close person who they would feel comfortable calling upon to care for them in times of need. Difficulty forming close friendships and exclusion from a broader LGBT community were cited as key contributors to this. One participant discussed the difficulty of making close friendships, even when well connected to community:

... I’m well known in this city and I’ve got lots of friends ... but most of them would be friendships that would be related to my role in the community, right?
So if I think about, I’ve lived here now for two and a half years . . . and . . . beyond family and the people that helped me move in and my landlord, the only person who has ever been in my home, in that two and a half years, has been another trans woman, and that’s because I had her look after my pets when I was away. So, you know, I don’t have a strong social network either. And I’m well known.

Relating rejection from family members with difficulty making friend and community connections, another participant shared:

I’ve found it difficult because I appear very masculine, and then my background . . . I don’t have family to rely on, sort of excommunicated a number of years ago, they won’t accept the feminine side so, you know, as I’m getting older, sure, there’s a worry about I don’t, you know, from my lifestyle, I really haven’t made any close friends . . . ”

This participant alludes to fractures within trans and LGBT communities, as others also expressed community divisions. For example, one participant discussed the dwindling of an LGBT seniors group and expressed that while there is a large trans contingent in his LGBT community there are not many community spaces where trans people are welcome. Yet, at the same time, community organizations were named by multiple participants as sources of support and connection. These perspectives highlight the diverse and ambiguous ties that participants described, and a general identification of lacking in family, friend, and community support they may currently desire or need in the future.

“**There’s a Huge Gap Between Principle and Practice**: Mixed Experiences and Perceptions of Health-Care Services

Finally, participants expressed mixed experiences and perceptions of health-care services, contributing their perceptions of what may or may not be available and accessible later and at the end of life. While participants did relate some positive experiences in health-care institutions, experiences shared were mainly negative ones.

For example, one participant shared his experience of calling multiple physicians before finding one that would take him.

And I had just put it right out there . . . I said, I’m trans and I need a doctor or a GP [general practitioner], I’m post-op . . . I just need a GP. And it took 42 doctors before I found one that would take me as a patient. And they were not, they were not, ah, they were very blunt and bold, you know, oh sorry we don’t treat people like you, you know. And so, it’s like, really? So, yeah, it’s a very different world to walk in.
Particularly pertinent to later and end-of-life care concerns, among participants there was an expressed fear of institutionalized living (i.e., long-term care) and how they would be treated particularly as they may depend on others for personal care. While one participant shared a positive experience with a home care provider, most had not received home care or long-term care yet or had formed perceptions of these services. One participant with experience in the health-care sector reflected:

... there’s a huge gap between principle and practice, as we all know. You could say you’re trans friendly, queer friendly, but does it happen in practice and how are these things enforced? And when you’re in a home for [the] aged you’re very vulnerable regardless, even if you’re not trans or intersex or two-spirit or gender queer, but if you are, even more so, and if you haven’t had full surgical transition and your body looks different—I had surgery but I still have scars ... And so even though it’s supposed to be trans-friendly, the people there could freak out ... even if they may not do anything blatant, there’s still that subtle Othering that goes on ... if your body’s different you have no choice. If you have a nurse there or personal support worker, they’re going to know at some point. So there’s a vulnerability around that ...

Another participant described past negative experiences of being mis-gendered by medical professionals, and emphasized the impact of this especially when one is in diminished capacity and cannot as effectively advocate for oneself. Further reflecting on this vulnerability, another participant expressed:

... we may be confident when we’re okay, at whatever age we are, but then when something happens and then it’s a total stranger that’s gonna be disrobing us, or bathing us, then, you know particularly if things aren’t particularly congruent or, you know like that, right, then suddenly strangers and that person gets put on the spot and you have to deal with their emotional response, however they try to be courteous, and we’re often much more sensitive when we’re that vulnerable ... I’m very confident as a man 24/7 but in the eventuality that someone’s going to be looking after me as I age, and if I lose mobility, then that’s ... a real concern ...

These were reflections which pinpointed both specific concerns about living in long-term care homes and vulnerability in relation to healthcare institutions as gender nonconforming people.

Discussion

Trans older adults bring to their later lives wide-ranging experiences and perspectives. While our study sample of 24 people is not representative of the great diversity among trans individuals and communities in Canada, participants’
reflections and ideas highlight and illustrate several areas for further analysis and advocacy. We focus on several key points in the discussion later.

Inherent in the first identified theme is a sense of immediacy and focus on living in the present. These were related to the significant insecurity that some trans people face in ways that directly impact their abilities, and desires, to think about and plan for later and end of life, and, for those transitioning later, a sense of the present as a new beginning they wanted to dwell within.

As some participants expressed, immediate concerns related to their experiences of marginalization and discrimination over life courses remain primary and at the forefront of their daily life; with these concerns later and end-of-life care planning were not priorities. Such focus on immediate needs and living in the moment precluding action toward advance care planning has also been found among other structurally vulnerable populations in Canada (Stajduhar et al., 2019). Significantly, participants linked employment issues—unemployment and employment discrimination—with other insecurities such as personal safety and housing stability. Potential for workplace discrimination against trans individuals is documented, stemming interactively from transphobia and the effects of health issues on abilities to work (Namaste, 2000). Housing has also been found to be a particular challenge for trans people of all ages (Abramovich, 2012; Pyne, 2011), and affordable housing is an increasingly pressing issue in major Canadian urban centers that particularly affects older adults (Weeks & LeBlanc, 2010). From this perspective, initiatives to combat poverty and provide greater trans-affirming affordable housing—in turn promoting greater security—may be considered an important part of a holistic promotion of later and end-of-life care planning. While discrimination on the grounds of gender identity or expression is now prohibited in the Canada Human Rights Act, ongoing efforts to combat workplace discrimination and promote employment equity may likewise enable future generations greater assurances and resources to consider later stages of life.

Furthermore, as participants described, when there is a sense of starting life anew, thinking about later and end-of-life care planning, let alone taking active steps toward this, is not front of mind. An acute perception of time left to live is one shared among trans older adults in other research, for example, as Fabbre (2014) shows how transitioning later in life was linked to a heightened immediacy of temporal horizons and opportunities to embrace more authentic selves. Initiatives to promote later and end-of-life care planning conversations among trans older adults must be sensitive to these transitions, as what may be commonly regarded as later life is not uniformly experienced; indeed, later life may bring significant new beginnings. Conversations about such planning and promotion of steps such as executing wills and powers of attorney, can, for example, use language that focuses on what individuals desire in the future horizons of their lives as part of more general planning strategies.
The roles of family, friends, and community in the lives of trans participants suggest both challenges and opportunities for fostering supportive connections for later life. Notably, close family members continue to serve an important place in the lives and support networks of a number of our trans participants, findings which contrast with the predominant focus on fracture with family reported in the literature (Kimmel, 2014). Given the roles that close family members may play in care, this suggests that policies and initiatives to support trans older adults in later life, including planning for it, must also be attuned to the needs of partners, children, and other primary caregivers with whom they are in interdependent relation.

Yet, not all participants have that family support, and among these participants, there was a noticeable lack of a strong social support network. Social isolation must also be considered along a longer trajectory of the discrimination and violence that members of trans communities have faced. Furthermore, even where participants described an active social life in their chosen communities, this did not necessarily correlate with the presence of close friends, and the importance of friendship among LGBT older adults is well acknowledged (de Vries & Megathlin, 2009; Witten, 2016). This presents a challenge and an opportunity for communities, as participants’ experiences show a need not only to create more trans-affirming spaces in mainstream health services but also within broader LGBT community spaces where fragmentation and exclusion exists. While trans people have been organizing for decades, trans communities’ distinct issues have only gained more widespread and mainstream visibility in recent years, and trans persons have historically been excluded from many gay and lesbian spaces and networks. Creating more trans-affirming community spaces and social events, and fostering intergenerational spaces where people of all ages can intermingle, may help to facilitate further opportunities to connect.

Finally, the make-up of social support networks raises the question of who will be there to support trans people as health needs intensify, and points to the role that government-provided health-care and support services will likely play in the later and end-of-life care for many. Long-term care emerged as a significant area of concern among participants in their thoughts about later and end-of-life care, and it is clear that trans-affirming home care and long-term care services are and will become crucial to serve aging trans persons. While research has documented the fears that LGBT people face regarding home care and long-term care, including complex decision making around coming out and experiences of micro-agressions (Connolly, 1996; Furlotte, Gladstone, Cosby, & Fitzgerald, 2016), there are no available empirical studies of the experiences of trans older adults in these settings. The apprehensions that trans participants in our study expressed were significantly around the physical exposure and vulnerability that comes with personal care (e.g., help with bathing).

At one level, this points to the specific need for education and training among service providers from front-line staff to managerial levels in providing
trans-affirming care, such that, for example, bodily integrity is recognized and trans residents are consistently addressed with pronouns and names of their preference. Furthermore, fostering long-term care environments where workers and residents alike feel valued and where care workers have time to develop rapport with residents may facilitate further mutual trust and personal understanding. While planning for later life involves individual effort and decision-making, it is also an issue of recognizing interdependencies and creating social conditions in which trans older adults are enabled to have greater security in their present lives.

**Strengths and Limitations**

The focus group and interview format was a successful means of promoting conversation among participants and eliciting active reflections on later and end-of-life care planning and concerns. Community partnerships and key informants, such as community leaders, proved vital in connecting with trans community members. We were able to reach a sizable number of participants, over a wide age range, with different economic means, and varied family and support system situations. Thus, our study offers a valued and often missing perspective to the existing literature which mainly focuses on the perspectives of lesbian, gay, and bisexual older adults.

The sample, however, reflected a predominantly White demographic of English or French speakers, residing in or near urban centers, and necessarily *out* to some degree. Underrepresented in this study were people of color, people from Indigenous communities, including those who may identify as two-spirit, and people who live in rural and remote areas. As per study design, recruitment information asked specifically for trans men and trans women. This could have been read as exclusionary and prohibited other gender nonconforming and non-binary individuals who do not identify with these terms from participating. We likely did not reach the most isolated individuals, including those with no connection to LGBT community networks, the very ill, or those living in institutional settings such as long-term care homes.

**Future Directions**

Future research should endeavor to involve a greater diversity of trans and gender nonconforming older adults, including those groups which our study did not reach. Canadian-based research regarding trans aging and later and end-of-life care planning would particularly benefit from learning from the perspectives of two-spirit people and trans people of color, as well as individuals with different immigration trajectories. Focus upon the experiences of trans masculine individuals is another avenue for critical inquiry, underrepresented in our sample and in research on gender diverse populations more generally.
(Cook-Daniels, 2017). Finally, given the dynamism of the linguistic landscape of trans and gender nonconforming communities (Witten, 2016) and as the terminologies used by people to describe their gender identities and expressions are wide-ranging and change, researchers can continue to consider ways to define and inclusively identify the groups they hope to reach.

Conclusion

With an aging population, governments at municipal, provincial, and federal levels, social service agencies, and communities have turned their attention to older adults as a demographic for whom care must be planned. As these conversations take place, it is critical to ensure that issues that affect trans older adults are brought to the fore. This project was, in part, an effort to promote these conversations about later and end-of-life care, highlighting perspectives of a multiply marginalized group toward a greater understanding of an increasingly diverse older population.

Authors’ Note

Brian de Vries and Gloria Gutman are principal investigators of this study.

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Note

1. Trans is used to refer to the transgender umbrella term and used to encompass those with a broad spectrum of gender identities and expressions that do not conform to their birth-assigned sex.
References


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