



LAW COMMISSION OF ONTARIO  
COMMISSION DU DROIT DE L'ONTARIO

# **PERSPECTIVES ON THE FINAL STAGES OF LIFE FROM LGBT ELDERS LIVING IN ONTARIO**

**Improving the Last Stages of Life  
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## EXECUTIVE SUMMARY

This paper takes into account how the experiences of diversity, in particular age, gender identity, and sexual orientation, contribute to quality of care in the last stages of life. As Canada's population is aging, so too is our lesbian, gay, bisexual, and transgender (LGBT) community. Many of Canada's LGBT elderly at some point have experienced systemic and open discrimination, homophobia, and even criminalization, to the detriment of their psychosocial well-being. Health disparities experienced by LGBT individuals are well documented, and range from negative effects of stigmatization to reduced access to health care services. Furthermore, for older LGBT individuals, care networks are often made up of friends and neighbours (often referred to as "families of choice") as opposed to spouses and children, which can complicate the process of decision-making in the later stages of life, especially if they have not created powers of attorney.

In recognition of these unique contexts, the research team conducted a literature review and facilitated focus groups to address the following research goals:

- Describe LGBT elders' experiences with social isolation and its perceived impact on access to care and quality of life in older age and, in particular, the last stages of life;
- Identify system-level barriers to health care access and utilization among LGBT elders and their caregivers, especially in the last stages of life;
- Explore the hopes and fears for care in the last stages of life among LGBT elders and their caregivers;
- Assess LGBT elders' level of awareness regarding resources and policies in Ontario to support quality of life in the last stages of life;
- Propose system-level recommendations for integration of LGBT elders based on their perspectives and experiences; and
- Examine possibilities for advocacy support to facilitate a "good death" experience among this population.

For our literature review, which used a scoping review methodology, the team identified articles that focused on LGBT older adults and end-of-life care. The available literature on LGBT aging and the last stages of life bring to light a number of important findings. These key findings include:

- Older LGBT adults include friends in their chosen families and desire for them to play an active role in their care and end-of-life decision-making.
- Like their heterosexual peers, LGBT older adults have intimacy and sexual needs in the last stages of life but these needs often go unmet because of negative attitudes held by health and social workers.
- LGBT older adults are at greater risk of physical and mental health conditions in comparison to the general population. However, social support may mitigate some of these negative outcomes.
- LGBT individuals with dementia may be triply vulnerable to stigma and discrimination due to the intersection of age, cognitive status, and sexual identity.
- Lack of knowledge about end-of-life care planning options combined with lack of preparedness may place LGBT older adults at increased risk of a lower quality of care in the last stages of life.
- LGBT older adults fear discrimination within formal care settings and do not trust that the medical or legal systems will carry out their end-of-life wishes.
- Health and social service workers can play a critical role in contributing to a positive care experience for LGBT older adults in their families by becoming knowledgeable about the unique needs of this population and being unassuming and accepting of individuals' sexuality.

A limitation of the existing research in the area of aging and end-of-life for LGBT adults is that it primarily originates in jurisdictions outside of Canada with differing medico-legal contexts. Recognizing the unique social, political, and legal context in Ontario and to complement the existing knowledge base, twenty-three self-identified LGBT individuals between the ages of 57 and 78 participated in focus groups in three regions in Ontario. While there was rich discussion regarding commonalities pertaining to perceptions of end-of-life that apply generally to aging and older adulthood, through our analysis we highlighted the unique considerations that were raised regarding the impacts of the gender identity and sexual orientation of our participants.

As echoed in the literature, we found strong themes pertaining to isolation, fears and hopes, systemic barriers, lack of knowledge of laws and policies, and the need for greater advocacy. In particular, participants described their concerns about social isolation at the end of life given their unique family structures. They also identified the system-level barriers in Ontario that they felt affected their access to quality care and quality end-of-life services. These included a lack of data collection around sexual orientation and gender identity that contribute to the 'invisibility' of LGBT older adults. Additional challenges included access to inclusive or LGBT

positive primary care supports, heteronormative assumptions across the health and social care continuum, and a distinct lack of education and training resulting in systems and services that are not culturally competent and do not meet the needs of LGBT older adults.

A salient theme that emerged from our participants was a strong fear about having to hide their identity related to sexual orientation or gender should they require long-term care. While some participants had an understanding of the laws, policies and resources that might facilitate quality care and a good end-of-life experience, others expressed confusion, particularly around the medico-legal rights for LGBT older adults.

Integrating the research literature and the lived experience of our participants, thirteen recommendations are proposed in this paper as a 'Call to Action.' Responding to these recommendations would position Ontario as a leader for change. These recommendations encompass new directions for clinical practice, research, and law and policy, and taken together their implementation would lead to cultural competence in the area of LGBT aging across the health continuum, with the goal of improving end-of-life and quality death experiences.

Without considering the potential barriers experienced by LGBT elders in accessing care, law and policy reform will not reflect the needs of this growing population, contributing to further marginalization. This project is an important contribution that gives voice to a population that is not often heard in the health policy landscape. Furthermore, the project informs the scholarly debate on the human rights of sexual minorities and gender nonconforming individuals in older age and in the last stage of life.

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## I. INTRODUCTION

### A. Scope of the Problem

Canada's population is aging and so too is our lesbian, gay, bisexual and transgender (LGBT) community. It has been a difficult challenge to adequately measure the proportion of the older adult population that is LGBT as traditionally there has been a reluctance to self-identify.<sup>1</sup> Despite significant changes in the protection of legal rights and equal civil liberties for the LGBT community, all too many older adults who identify as LGBT have experienced discrimination.<sup>2</sup> The systematic and at times, overt discrimination, acts of homophobia and even criminalization associated with sexual orientation or gender identity has been linked to detrimental psychosocial well-being.<sup>3</sup> Research has shown that even subtle instances of homophobia and heterosexism within formal care systems can drive discrimination and create barriers for LGBT older adults.<sup>4</sup> Unfortunately the experiences of older LGBT individuals remain a gap in the research literature, policy landscape, and education and training of service providers.<sup>5</sup>

Despite broad research gaps, the health disparities experienced by LGBT individuals, such as negative effects of stigmatization to reduced access to health care services, are well documented.<sup>6</sup> Data from the United States have found that common concerns for older LGBT individuals included social isolation and loneliness, financial concerns, and access to healthcare.<sup>7</sup> More specifically, for individuals aged 60 to 75, 40% reported that their healthcare providers did not know their sexual orientations. Recent data collected in Ottawa, Ontario also highlights some of the challenges faced by the older LGBT community, including social isolation and the increased likelihood of living alone.<sup>8</sup> These data indicate that 58% of respondents planned to avoid admission to long-term care due to concerns such as lack of trust and fear of discrimination. Concerns around institutionalization were also highlighted in a report from Alzheimer's Australia, where older transgender adults indicated they would rather end their own lives before being admitted into a long-term care or nursing facility.<sup>9</sup>

In addition to facing health disparities, older LGBT individuals are less likely than their heterosexual peers to have spouses and children fulfill caregiver requirements, support them in navigating the healthcare system, and assist them to make decisions in the last stages of life.<sup>10</sup> Often, care networks of LGBT individuals are made up of friends and neighbours (often referred to as "families of choice") as opposed to spouses and children, which can complicate the process of decision-making in the later stages of life, especially if they have not created powers of attorney.

## **B. Theoretical Framework**

This research takes a life course perspective to identifying the needs of LGBT older adults.<sup>11</sup> As a theoretical framework, the life course perspective meshes longitudinal perspectives with traditional types of research allowing for an understanding of intersections and diverse trajectories of life. This perspective allows for a focus on the individual context and acknowledges historical and social influences such as those left behind by policy legacies and structural lags. The life course theory of aging recognizes the importance of social structures and historical context as well as individual experiences and meaning. It is structured by using the following key principles:

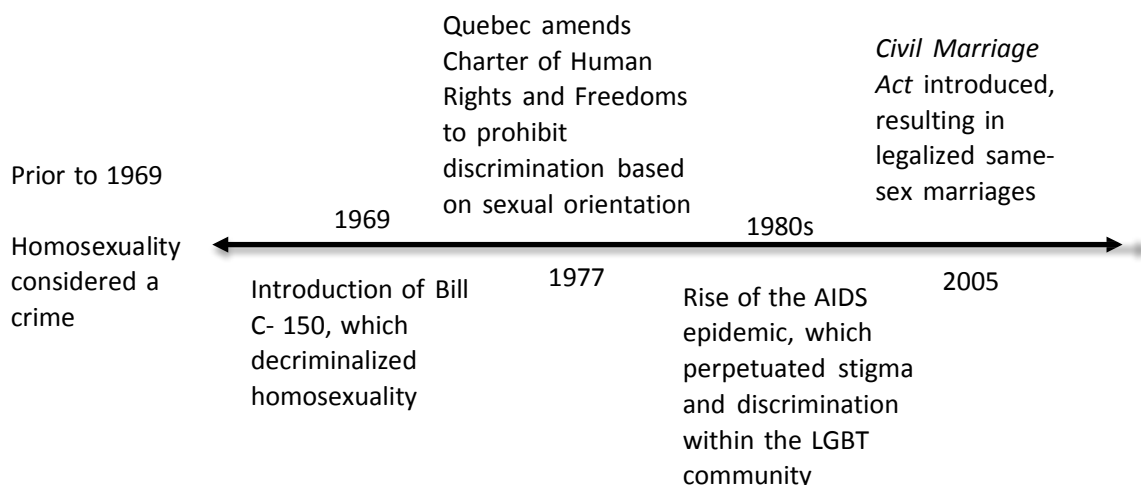
- 1) Lives are linked and interconnected to the relationships that influence them.
- 2) Social and historical context are important to the way an individual's life is shaped.
- 3) Transitions in life and the timing of such transitions are important in relation to their social contexts.
- 4) People have agency and are active in the construction of their own lives.
- 5) Aging is a lifelong process.<sup>12</sup>

The key principles of the life course theory are critical considerations for the study of older adults as well as persons who are approaching death and are thus used to guide this research.

## **C. Historical Context**

Aligned with the life-course theoretical perspective, Fredriksen-Goldsen and Muraco emphasize the need to document the historical context of older LGBT individuals as a critical component of understanding their lived experiences.<sup>13</sup> In Canada, the 1980's saw the rise of the AIDS epidemic and further perpetuated stigma among LGBT individuals, especially gay men. Indeed, many LGBT individuals of the baby boomer generation (i.e., those born between 1946 – 1964) and older faced stigma and overt discrimination, in some instances leading to abuse or forcing these individuals to live in secrecy. The gay rights movement did, however, gain momentum and in 2005 the *Civil Marriage Act* legalized same sex marriage. Below is brief overview of key moments in the Canadian historical context that should be considered in any research concerning the experiences and rights of LGBT individuals in Ontario.





Although the federal government recently tabled legislation to guarantee legal and human rights to transgender people, there remains a significant gap in legal protections related to gender identity with considerable jurisdictional variation.<sup>14</sup> This is reflected in the lived experience of discrimination for transgender individuals, with Ontario data showing that 73% of trans people have been made fun of, 39% have been turned down for a job, 26% have been assaulted, and 24% have been harassed by police.<sup>15</sup>

When considering the issue of healthcare and the last stages of life among LGBT individuals, it is critical to consider the unique historical and socio-political contexts within which individuals are situated.

#### **D. Goals and Structure of This Paper**

The available data make it clear that LGBT older adults and their caregivers face unique challenges with respect to health care and decision making in the later stages of life. Drawing from a life course theoretical perspective, the purpose of this research paper is to understand the lived experience of older LGBT individuals and their caregivers within the healthcare system in Ontario as well as highlight their concerns associated with the last stages of life.

In order to achieve this purpose, we first examine the available literature in the area of the last stages of life among LGBT individuals. Then, in the second part of the paper, we present findings from our new qualitative study of older LGBT Ontarians. Finally, we conclude the paper with a summary of our findings and recommendations to improve quality of care for LGBT older adults.

## II. REVIEW OF THE LITERATURE

The available literature in this area is varied in terms of methodological approach and specific area of focus. As a result, our literature review was executed using a scoping review approach where the goal is to map the literature on a particular topic, identify key concepts, and explore data sources.<sup>16</sup>

Electronic searches included articles published between 2005 and 2016 (i.e., 11 years) and used the following databases: AARP Ageline, Women's Studies International, Web of Science Core Collection (includes Social Sciences Citation Index), CINAHL, Medline, PsycINFO, PsycARTICLES, Cochrane Database of Systematic Reviews, Nursing & Allied Health Database. Additional resources were obtained by examining the references listed in retrieved articles and by searching Google. The search was first developed in Medline and then translated based on the search parameters for each of the databases.

### A. Existing Literature

The articles we identified were varied in terms of methodology and country of origin; the majority were observational in nature and originated from the United States and Australia. Several themes emerged from the review of included literature. These were identified as:

- social support and chosen family,
- intimacy,
- health status,
- fear of discrimination and lack of trust,
- lack of knowledge and preparedness, and
- cultural competence in the healthcare system.

We review each of these principal themes from the literature below.

#### **1. Social Support and Chosen Family**

The existing literature emphasizes the importance of family, friends, and communities for the well-being of older LGBT individuals. Research also highlights a role for *chosen family* (also referred to as *families of choice* and *lavender families*<sup>17</sup>) not only for providing social support and caregiving but also for end-of-life decision-making.

Chosen family refers to friends and community members who provide support, companionship, and love instead of biological relatives.<sup>18</sup> It is important to include 'loved ones' or 'family' as defined by the patient in the decision-making process for palliative and end-of-life care.<sup>19</sup> For example, findings from the MetLife survey, a cross-sectional study of 1000 US-based LGBT baby boomers, highlighted that respondents were highly involved in the provision of informal care for their families and that non-familial social networks play an important role as a source of social support.<sup>20</sup> Similarly, a small qualitative study of 15 older gay and lesbian adults in the United Kingdom described the complex nature of the familial relationships of participants' including a mix of biological and non-biological members.<sup>21</sup> The article suggests that LGBT individuals may prefer a close friend to have legal rights regarding their end-of-life care and decisions rather than a biological relative. The authors commented on the importance of social support for continued well-being amongst this population.

## **2. Intimacy**

Older adults continue to have sexual and intimacy needs in the presence of declining health and end-of-life care; this is true for heterosexual individuals as well as for queer-identified individuals. However, the needs of LGBT older adults within formal care settings may be overlooked because of heteronormative assumptions from health and social care workers, as well as fear of disclosure on the part of patients and families.

In a review of the literature on the palliative and end-of-life care needs of LGBT individuals, Griebing points out that sexuality is a core component of our experience as humans and deserves to be included in palliative care settings.<sup>22</sup> Declining health and the presence of terminal illness that accompanies end-of-life often has negative impacts on sexual functioning. Griebing indicates that existing literature shows that simple intimacy, physical closeness, and emotional connectedness often become more important than sexual intercourse among those in the last stages of life. The author draws many parallels between the needs of heterosexual and LGBT individuals close to end-of-life. An important distinction, however, is the experience of LGBT individuals with respect to the negative attitudes held by others. This may reduce an individual's willingness to communicate with health and social care professionals about their sexual and intimacy needs within care settings including hospice.

## **3. Health Status**

The existing research emphasizes the intersections between sexual minority statuses, physical and mental health, and the receipt of end-of-life care. In particular, declines in physical health typically accompany the last stages of life and there are often mental health consequences, such as depression.<sup>23</sup> In general, LGBT individuals are at a greater risk of negative physical and

mental health outcomes relative to the general population and these needs should be considered in the last stages of life.<sup>24</sup> Indeed, research suggests that these negative health outcomes among LGBT older adults may be partly mitigated by the presence of social support.<sup>25</sup> Thus, support from others is an important consideration for LGBT older adults including when entering into the last stages of life.

Aging is associated with an increased risk of cognitive impairment such as dementia and LGBT individuals with dementia may be triply marginalized within care settings due to the intersection of their age, cognitive status, and sexual identity, leading to poor quality care.<sup>26</sup> This is best evidenced in a literature review where McGovern identifies a lack of research on older LGBT individuals with dementia and, within the research that does exist, a particular invisibility of older transgender individuals.<sup>27</sup> The author argues that more research in the field is vital to providing appropriate health and social care to this community of older adults.

#### **4. *Fear of Discrimination and Lack of Trust***

A theme that emerged in the literature is fear regarding end-of-life including chronic disease and disability as well as fear of discrimination within medical and legal systems. More specifically, in a large study of 1,963 trans-identified adults that focused on later life and end-of-life preparations, Witten observed that participants expressed fear about potential late-life events and end-of-life needs.<sup>28</sup> These included concerns about legal requirements and care needs. Other research highlights the fears of discrimination due to sexual orientation within long-term care settings as well as fear over discriminatory care.<sup>29</sup>

Older LGBT individuals often have concerns about the medical system and distrust of health and social care providers. They have expressed anxiety about the possibility of receiving care from a provider who is homophobic.<sup>30</sup> In a small study of 19 gay and lesbian adults over the age of 50, many participants voiced anxiety over the possibility of social isolation and rejection during end-of-life care due to their sexuality.<sup>31</sup> Approximately half of the sample was against the idea of assisted living while over 80% of the sample was against the idea of living in long-term care. These latter concerns were due to apprehensions that staff would not be knowledgeable about lesbian and gay-specific issues.

However, the notion that all members in the LGBT community are distrustful of the healthcare system is not consistent across the literature. In fact, June and colleagues reported no differences between heterosexual women and lesbian woman in the state of Colorado (US) in terms of distrust of the healthcare system.<sup>32</sup> This latter finding may stem from regional

differences in attitudes towards healthcare and end-of-life and may also reflect jurisdictional differences in the availability of LGBT-friendly health services.

With respect to the legal system, LGBT individuals report distrust and fear that their wishes expressed in advance care planning will not be respected due to their sexual minority status.<sup>33</sup> This fear may originate from a lifetime of discrimination and/or experiences interfacing with the medico-legal system. Data from the US indicate that older lesbians report having struggled with policies that ignore their lifetime romantic partnerships and thereby deny them end-of-life decision making and access to death benefits.<sup>34</sup>

### **5. Lack of Knowledge and Preparedness**

Overall, the literature indicates that LGBT individuals lack knowledge about the legal provisions that can help ensure that their end-of-life decisions are respected. As such, few individuals have appropriately planned for end-of-life.<sup>35</sup>

A study that originated from Australia suggests that while a majority of LGBT individuals were aware of end-of-life care planning options, few of them had actually used these options.<sup>36</sup> When participants were presented with a fictitious scenario, only 27% of the sample was able to correctly identify who had the legal right to make treatment decisions for an unconscious person following a car crash. The findings also indicated that while 76% of respondents were comfortable with their healthcare provider raising end-of-life issues with them, transgender and closeted respondents were less comfortable having these conversations with their healthcare provider. Another study conducted by the same authors suggests that while advance care planning options have the potential to promote the rights of LGBT people at the end of life (insofar as it allows them to choose precisely who they would like to make decisions on their behalf), their levels of uptake approximate those of the general population.<sup>37</sup>

A survey of 1,963 transgender adults found that respondents had major concerns about end-of-life that were integrated with concerns about chronic illness and disability.<sup>38</sup> In general, the findings indicated that respondents were not prepared for major legal issues and events that take place in the last stages of life and reported fears about the future. In a follow-up study using the same database but focusing on transgender-identified lesbians, Witten similarly found that respondents were poorly prepared for end-of-life, not having planned.<sup>39</sup> The author suggests that few respondents were engaging in the process of advance care planning, including later life and end-of-life decision making.

Lack of education regarding the legal provisions for end-of-life decision-making among health and social care workers as well as among LGBT individuals has been cited as an obstacle to

improving care.<sup>40</sup> A particular challenge among healthcare providers in this Australian study was identifying a substitute decision maker in same sex partnerships according to their legal provision (i.e., the Guardianship Act). Thus, as echoed elsewhere in the literature, educating LGBT individuals as well as health and social care providers on existing legal provisions on treatment decision-making is necessary to prevent discrimination in the last stages and ensure quality of healthcare as well as the uptake of planning tools.<sup>41</sup> Taken together, these findings suggest that while there is broad awareness of end-of-life care planning options, LGBT individuals would benefit from more information through education efforts.

## **6. Cultural Competence in the Healthcare System**

Many LGBT individuals are presented with heteronormative assumptions when interacting with healthcare and social service providers and these assumptions in turn may contribute to a lack of trust towards the healthcare system.<sup>42</sup> Negative societal attitudes, discrimination, and homophobia shape end-of-life experiences for LGBT individuals and care providers need to consider these when offering care.<sup>43</sup>

Recent efforts have been made to develop educational materials for healthcare workers to address the needs of LGBT individuals.<sup>44</sup> Yet, as Aldredge and Conlon note, care providers often have a heteronormative outlook and lack of professional education on LGBT for palliative and end-of-life care.<sup>45</sup> These observations in the literature suggest that while there is effort to educate healthcare professionals, there may be barriers to accessing and implementing culturally competent care approaches that would facilitate inclusion of LGBT individuals in the last stages of life.

Communication between patients and healthcare providers remains a barrier in the provision of appropriate care for LGBT patients. A recent review of the recommendations for techniques to improve communication among care providers and recipients conducted by Lawton and colleagues suggests that clinicians can reduce barriers by having an open and affirming approach to interactions with patients and their families.<sup>46</sup> They suggest that clinicians should use inclusive language when interacting with patients. Additionally, clinicians should work to assure confidentiality, privacy, and professionalism in their interactions with patients.

Much of the research has focused on the role of health and social care workers in reducing barriers for LGBT older adults. Arthur completed a review of the literature which sought to ascertain whether current social, legal, and medical care is meeting the unique needs of the LGBT older adults.<sup>47</sup> The author suggests that health and social care professionals are not well prepared to work with LGBT older adults and that LGBT older adults have expressed concerns

and fear over discriminatory care. Arthur concludes that there is a widespread lack of recognition of the unique needs faced by LGBT older adults during end-of-life and palliative care.

Through a review of four case studies, Duffy and Healy explain that while successive generations of LGBT cohorts are being perceived in a more positive light by service providers, the current cohort of older-old (i.e., 85 years and older) LGBT individuals face the greatest number of barriers and that service providers who interact with this demographic should be particularly sensitive to their needs.<sup>48</sup> Other authors indicate that palliative care workers should focus on dignity, equality, and respect in order to improve the quality of service provided to LGBT individuals.<sup>49</sup> Kimmell argues that gerontologists can improve care to this demographic by recognizing how sexual orientation reflects an individual's experiences and that it is imperative that those working with older adults be unassuming and accepting of an individual's sexuality.<sup>50</sup>

Price suggests that service providers be educated in the issues specifically faced by these individuals such as social isolation from their biological families due to their sexuality.<sup>51</sup> It is also suggested that health care providers should be open to the possibility that caregivers of LGBT individuals may be members of the LGBT community themselves, and should also respect an individual's degree or lack of openness in sharing information about their sexuality. Price states that it is necessary to acknowledge the biases and barriers faced by lesbian individuals in terms of receiving adequate end-of-life care in order to improve end-of-life care. Price suggests that training healthcare providers to be aware of and knowledgeable about LGBT specific issues could improve the care that they receive.

Existing research suggests that efforts to train health and social care workers can effectively increase knowledge and awareness about issues facing older LGBT adults.

Porter and Krinsky, for example, held 4 training events in Massachusetts to determine the efficacy of LGBT aging competency training for service providers who work with older adults.<sup>52</sup> The results indicated significant improvements in the areas of knowledge, behavioral intentions, and attitudes towards the LGBT community following training. Specifically, results showed improved knowledge of policies (e.g., legal, financial, and health) and resources (e.g., informational, support, etc.) relating to LGBT individuals. Post-test results also indicated that participants felt more comfortable providing care to lesbian, gay and bisexual (LGB) individuals following training; however, they also felt less comfortable providing care to transgender (T) individuals. The authors attribute this discrepancy to the possibility that, after learning of the unique needs of this group, the participants did not feel as confident in their ability. These

findings show that LGBT-aging training is beneficial for service providers who are likely working with LGBT clients.

## **B. Summary of the Literature**

The available literature on LGBT aging and the last stages of life bring to light a number of important findings. These key findings include:

- Older LGBT adults include friends in their chosen families and desire for them to play an active role in their care and end-of-life decision-making.
- Like their heterosexual peers, LGBT older adults have intimacy and sexual needs in the last stages of life but these needs often go unmet because of negative attitudes held by health and social workers.
- LGBT older adults are at greater risk of physical and mental health conditions in comparison to the general population. However, social support may mitigate some of these negative outcomes.
- LGBT individuals with dementia may be triply vulnerable to stigma and discrimination due to the intersection of age, cognitive status, and sexual identity.
- Lack of knowledge about end-of-life care planning options combined with lack of preparedness may place LGBT older adults at increased risk of lower quality of care in the last stages of life.
- LGBT older adults fear discrimination within formal care settings and do not trust that the medical or legal systems will carry out their end-of-life wishes.
- Health and social service workers can play a critical role in contributing to a positive care experience for LGBT older adults in their families by becoming knowledgeable about the unique needs of this population and being unassuming and accepting of individuals' sexuality.

## **C. Limitations of the Existing Literature**

The results of this scoping review were useful in mapping the existing literature pertaining to LGBT aging and the last stages of life. The results were diverse in their methodologies yet many came to similar conclusions with respect to the concerns and experiences of LGBT older adults and end-of-life care. Overall, the literature demonstrates that LGBT persons entering the last stages of life face multiple challenges receiving quality care. These challenges include lack of confidence that the health care system will address their needs, fear of stigma and



discrimination, lack of knowledge about legal tools (e.g., advance care planning), and inadequate education for service providers, which, if adequate, could serve to mitigate discriminatory effects on LGBT individuals.

There are, however, limitations to the available literature. An important limitation to the above-cited research is that much of the data were collected in jurisdictions outside of Canada with differing medico-legal contexts. In particular, Brotman and colleagues collected data from participants in Canada whereas 6% of the sample described in Witten resided in Canada.<sup>53</sup> Indeed, some of the discrepancies observed in the literature may reflect geographic, cultural, or jurisdictional differences in the experiences of older LGBT individuals and their levels of comfort with the medico-legal systems. To some extent, these differences limit our ability to draw inferences about the experience of Canadian LGBT older adults and, more specifically, those residing in Ontario. Thus, there is a gap in the literature on LGBT aging and the last stages of life. In order to better understand the experiences of LGBT older adults with respect to the last stages of life, more Canadian-specific research is needed.

Additionally, this observation about limitations in the available literature is not unique to jurisdictional issues, as numerous articles included in this scoping review also call for more research in this area more generally.<sup>54</sup> Transgender individuals have unique and specific physical health needs (e.g., hormone replacement therapy). As such, transgender older adults represent a population for which knowledge about the aging experience and appropriate end-of-life care is especially lacking.

### III. FOCUS GROUPS

The available literature touching on the last stages of life among LGBT individuals makes it clear that this population faces some unique challenges. Yet, the majority of existing literature was conducted outside of Ontario. Indeed, Ontario is a unique jurisdiction with its own social, economic, and political diversity. As such, it was of interest to collect data on the last stages of life from older LGBT individuals living in Ontario.

Building on the review of the literature, three focus groups were held in order to:

- Describe older LGBT individuals' experiences with social isolation and its perceived impact on care access and quality of life in older age and, in particular, the last stages of life;
- Identify system-level barriers to health care access and utilization among LGBT older adults and their caregivers, especially in the last stages of life;
- Explore the hopes and fears for care in the last stages of life among LGBT older adults and their caregivers;
- Assess LGBT older adults' level of awareness regarding resources and policies in Ontario to support quality of life in the last stages of life;
- Propose system-level recommendations for integration of LGBT older adults based on their perspectives and experiences; and
- Examine possibilities for advocacy support to facilitate a "good death" experience among this population.

The focus groups were composed of between 6 and 9 participants and lasted approximately 1.5 hours each. The focus groups received approval from the Research and Ethics Board (REB) at the University of Guelph. All participants received an information letter and provided informed consent.

Focus groups were held in urban centres in Northern Ontario, Southern Ontario, and Eastern Ontario. The rationale behind holding focus groups in three locations across Ontario is to enhance the generalizability of the findings as well as to capture the experiences of individuals residing in urban settings with a large and organized LGBT presence as well as individuals residing in less-resourced areas with fewer available supports.

The recruitment for the focus groups was primarily achieved by working through our community partners and social media.

Audio from the focus groups was digitally recorded and transcribed. The transcriptions were analyzed using inductive thematic analysis.

## **A. Findings**

While there was rich discussion regarding commonalities pertaining to perceptions of end of life that apply generally to aging and older adulthood, through our analysis we are highlighting contributions that participants made which focused on their unique needs relating to gender identity and sexual orientation. As echoed in the literature, we found strong themes pertaining to isolation, fears and hopes, systemic barriers, lack of knowledge of laws and policies, and the need for advocacy supports. The lived experience of our participants in combination with the existing literature informs our recommendations for current policy and practice implications in the final section of this report.

### **1. Participants**

Twenty-three LGBT-identified individuals ranging from 57 – 78 years (mean = 67.39) participated in the study. Using a brief demographic questionnaire which included open-ended questions, participants were asked to self-identify their gender and sexual orientation. Participants were varied in their responses revealing diversity within gender identities and sexual orientations. In terms of gender, responses included: “Male”, “Female”, and “mostly woman but not feminine”. In terms of sexual orientation, responses included: “lesbian”, “gay”, “bisexual”, “two-spirit lesbian”, “ ? ”, and “bisexual to gay”. Participants identified their relationship status as: “partnered within a chosen family”, “single”, “partnered”, “married”, “single, divorced, grandfather”, and “partnered 41 years”.

During our discussions, several participants disclosed that they had previously been in long-term heterosexual relationships and had children. In response to a question about living arrangements, participants reported living with a spouse or partner and living alone. Working statuses ranged from: “long-term disability”, “retired – working part-time”, “retired”, “active volunteer”, “working full-time”, and “student”. The majority of participants reported having played a caregiver role at some point in their lives. Overall, the majority of participants reported a high level of education ranging from college diplomas to graduate degrees; however, not all participants had completed secondary school. Participants reported living with chronic diseases such as (Multiple Sclerosis, cancer, and HIV) but overall self-reported health was high.

## 2. Social Isolation

A key goal of this work was to build on the existing base of knowledge from the literature. Given the diversity in the social, economic, and political context of Ontario, we wanted to explore concepts from the literature and how they are or are not reflective of experiences of aging for LGBT individuals in Ontario. As noted earlier, concerns about social isolation and an increased likelihood of living alone were prevalent in the literature. Although many participants in our focus groups identified they had children, there were also strong concerns expressed by others about increased risk for social isolation as a result of having no children. As one participant noted:

I don't have children so nobody there is going to take care of me. I have good friends, they're not going to take care of me either I don't expect them to. So I'm feeling pretty alone. I don't have a partner. I'm pretty alone. And because of that I have been thinking of this a lot.

This uncertainty was reflected by another participant who recognized the importance of his current social networks but expressed fears about his potential risk for isolation in the future:

... is the network around me going to be strong enough and be there to support me, cause some... many of us may end up on our own even if we're in partnerships at the moment... and it's not always clear is there going to be a partner. We're not as connected to family as many cases, as lots of other people would be, not having, many of us, not having any children. So it's a question of is that road going to be a very lonely road, or am I going to have a very supportive network around me that helps me through that final journey.

While concerns about social isolation are not unique to LGBT older adults, our participants highlighted the diversity in their family contexts as being salient for this population. Furthermore, participants highlighted their sexual orientation when describing their worries for the future:

who's going to want to look after you? Who's going to want to look after me? Like... when you think about it, who's going to want to look after me, and who's going to want to look after a gay woman? You know?

As seen in the literature, anxiety about social isolation was not only about the later stages of life, but also specific to death and dying. The fears around social isolation and death were exacerbated for some individuals without partners and without biological families to advocate for them, as evidenced by the following participant who expressed,

When I'm dying I feel like I'm going to die alone. Without any power, so I just avoid that without even thinking about it. I tell my best friend [redacted] to fight for me like crazy. I wrote a will, at least maybe somebody will listen to my will.

Most participants had experience caring for others and they noted that being a caregiver could actually increase risk for social isolation, expressed by one participant when she noted:

... we raised children together, but looking after elders takes people out [of our community] and doesn't involve everyone else in the same kind of way... at least at present.

Again, while caregiving roles and the resulting risk of social isolation are not unique to LGBT older adults, Brotman and colleagues highlight that LGBT individuals are less likely to have spouses to fulfill caregiving requirements, which might have significant ramifications when the caregiving pool is smaller.<sup>55</sup> One participant, who described himself as a gay male, questioned if the caregiving journey and the risk of social isolation might be particularly unique for gay men, saying:

... the fact is that women tend to build their circles because of family and that ... easier than men do and men tend to be competitive and work oriented and that so when we get to later in life we don't have those natural circle in even using your family as support.

Despite this potential difference, participants also reflected on previous examples of success in building supportive networks among the gay community while recognizing barriers such as ageism that may influence social supports for older LGBT men:

... gay men are capable of doing this! I ran [a local caregiver program] in the age of AIDs... but I think there's an issue around gay men. There is ageism [it's] huge in the gay male community and I think that's very easily internalized.

The theme of social isolation was also discussed in the context of community settings. In particular, participants reflected on the risk for social isolation even within a group setting if they are not able to relate to their peers or feel accepted. Fears about long-term care are discussed in subsequent sections, however as noted below, social isolation within long-term care was also a concern for participants:

You have to have 3 meals a day with 3 other people. Cause they put 4 people at a table. So, this whole thing about isolation, if you're ... I don't know what scenario to give you. If you go back into the closet in a LTC home, okay you... what do you talk to

these other 3 people about? Because your life has been LGBT, so you're going to pretend you're straight? ... If you're an out-person then the home must be very careful of who they put you with. The homes are constantly reassigning tables, dining room seating. So, that's an important area to consider. How not to have that isolation, but have that acceptance.

### **3. System-Level Barriers**

Participants in the focus groups were attuned to system-level barriers and this was reflected in their discussions around social isolation, fears and hopes, and advocacy needs. These common threads weave together and highlight many of the systemic issues in the health and social care system that affect access and utilization among older LGBT older adults, especially in the last stages of life.

One such example included the complexity of the medico-legal frameworks, which can prevent people from enacting their wishes as they age and at the end-of-life.

I would want control. I do want control and I don't think it's going to be very easy to get. .... Getting a DNR piece of paper is extraordinarily difficult to get. The hoops you have to go through all of those kinds of things. So ... I'm pretty realistic about ...

Knowledge and awareness of policies and legal frameworks is discussed in detail below, however it is important to note that the system itself can create barriers to quality end-of-life care.

A prominent system-level barrier was related to the collection of demographic information, or a lack thereof, which can lead to the 'invisibility' of the LGBT population across the lifespan but in particular in late life. One participant reflected that he was told there were no LGBT individuals in a particular seniors community, and yet as he noted:

Well they're not being asked. ... I know what the form was for intake and it was not there ... And if it's not then it needs to go on there like any other public form like ... how do you identify. But this thing about acceptance is ... when you say we have no gay people here that's the façade that's the image you're projecting. There are LGBT people in every home, but in the past most of them are in the closet or back in the closet again ...

This gap in demographic information was a concern for multiple participants, with one pointing out that orientation and identity is only collected by one Local Health Integration Network (LHIN) in Ontario. As one participant eloquently stated:

Failure to collect epidemiological or demographic information is fundamental because they don't ... And so if you don't acknowledge the presence of people, it's difficult to get them rights.

The lack of inclusive demographic information goes beyond Ontario's jurisdiction and the healthcare system. Participants noted this was a gap in the recent Canadian Census:

Even our census didn't ask that question. ... I wasn't asked on the census whether you're gay or straight....

Reiterating the language of our participants, if you don't acknowledge the presence of people, it's difficult to get them rights. This invisibility also contributes to the heteronormative concentration within the training, education, policy and practices of the healthcare system. Heteronormative assumptions were common and most participants had personal experience of providers making improper assumptions about their sexual orientation. As one lesbian female participant described:

I had one physician who said, I went up to him not to long ago, couple months ago... and he said, well your husband should be with you on this matter and I said, I don't have a husband, I'm not interested in having a husband, something like that.

This was a common experience which was also shared by a gay male who spoke about his recent experience within a hospital:

And then if they were to ask you, well shall we call your wife [laughter], then there's a whole other issue there that you got to address.

The experiences of heteronormativity were also reflected in the strong desire shared amongst all participants to have access to LGBT friendly care, particularly primary care. Echoing the findings in our literature review, many LGBT older adults cite concerns about access, and for our participants this included access to a family physician both in terms of proximity and in terms of LGBT positive spaces. Participants expressed the value of a physician who either identifies as part of the LGBT community or is a strong ally.

There is a big difference [if] the doctor happens to be gay, I'm telling you, but it is like heaven sent this man knows the questions, he knows your struggles, and I know that we're not going to find a lot of gay doctors necessarily that identify themselves and do what our doctor does: take only LGBT clients, cause there's so many of us that need that kind of health, you know even for psychological help.

I guess I also really am concerned about I don't want my doctor to retire before I die because he happens to be good. But he's not the youngest one on the block either

and it's not an easy thought to think in later life finding a new doctor who understands what you've been through or the journey or maybe is even gay positive.

Participants also shared experiences of stigma and discrimination in their healthcare interactions. Anxiety about homophobic providers was a key concern identified in research by Rawlings and this resonated with our participants<sup>56</sup>:

I remember the doctor telling "I don't deal with people like you, you're HIV+, there's one place that you need to go, and this is it." And I felt alone, depressed, didn't have the resources until I was connected and I went to Dr. [redacted] and the amazing clinic, but to be told that was like heartbreaking. Totally awful.

The experience of stigma and discrimination was not unique to sexual orientation or HIV status. Participants also reflected on the unique challenges of receiving inclusive care for the transgender community:

... some pretty nasty stories about you know like trying to deal with the healthcare system and you know people... doctors just oh god... don't want to deal with that trans-vagina.

Fears about homophobia, stigma, and discrimination were also reflected in the significant discussions about the lack of inclusiveness in the healthcare system as a whole, but particularly within long-term care. Almost universally, participants described the lack of inclusivity as a barrier to receiving quality care at the end of life.

I'm actually more concerned about the process leading up to that point where there is a desire to die. When one – when people – reach the point of needing support or going into long-term care, the lack of support, especially for those of us that are LGBT... I don't think... I mean long term care right now does not have... doesn't believe in sex for example and certainly not in gay, lesbian sex – well sexuality – there's a severe lack in cultural competency in training for people who are going to be working in long term care, for policies, ... even though there are written policies written at the provincial level, I don't think any of it translate it into actual [use]... And the area I think is going to be the worst and will be the worst is for transgender individuals because you're gonna have workers finding somebody coming in whose physical body doesn't match their gender identity and I see that as ... a source of horrendous problems... I mean as it right now for transgender individuals, life is most difficult.

Participants were active in recognizing the barriers currently related to the inclusivity of long-term care but also had innovative ideas about a shift in culture, such as:



I think the model of GSAs (Gay Straight Alliances) which are now in almost every secondary school could be reconfigured to meet the same needs in long term care communities or retirement homes, maybe even hospitals or community health organizations. The Alliance, or whatever it could be renamed would be a representation of residents, especially LGBTQ identified ones, staff members and a board member perhaps. Family members of residents could even be included. They would be helpful and given responsibility in educating and bringing awareness of inclusivity and acceptance in the jurisdiction that they represent.

Fears about living in long-term care are discussed in more depth below, but a unique contribution to the literature that has emerged from our participants is related to systemic issues where religious organizations manage and lead long-term care facilities. This was discussed in each focus group and is a key access issue given that these facilities are part of the public system. The religious affiliations may contribute to a lack of inclusivity in the environment for LGBT residents and their families:

...he wound up in a, you know, [redacted religious institution] home which actually, despite the crucifixes on the wall, which would bother me, he got very good care, very good care. But I was ... and this was at the cost of him saying “don’t tell anyone I’m gay.”

In particular, in one region/focus group, participants discussed their concerns about the fact that many of the long-term care facilities are run by a Catholic organization and how this will be reflected in policy:

Let’s put that on the table right now ... I’m very frustrated and angry about faith-based approaches to anything regarding our health if you choose that and wish that. Cool. I’m sure there’s many places you can access, but to even consider it or think about being what I would call trapped or prisoned in a faith based institution makes me nearly apoplectic.

While participants had also had positive experiences within these institutions, they create potential system level barriers that are particularly unique to LGBT population.

All of the system barriers identified are closely linked to the stigma, discrimination, and heteronormativity that are prevalent within education and training. The lack of inclusive or culturally competent education emerged strongly from the data as a system-level barrier. Participants identified that this gap in education affects their access to quality care as they age and within end-of-life.

#### **4. Hopes and Fears for Care**

LGBT older adults have a number of hopes and fears as they consider their last stages of life and what the future may hold for them. Similar to what was found in the literature, participants spoke of a lack of confidence that the health care system will address their needs and that they will be able to maintain a sense of control and autonomy which is an integral part of how they prefer to approach their living. Most of the participants identified being in good health and were acutely aware that this could change in the future. This awareness is demonstrated in the following quote:

...I feel comfortable with where I am and right now my health is good and ... so ... I try not to worry about the future, but at the same time I am certainly aware of it, as everybody is, and looking at that loss of control that will happen

This fear of a loss of control was shared by a participant who articulated concern that choice and control are limited for individuals identifying as LGBT in long term care.

What I've observed you don't really get the choices you want once you're in a long term care facilities because typically now you're so compromised when you go in you don't have the opportunity to stop it before it's out of your control ...you're not necessarily going to have that ability to die with dignity

The lack of choice, control, and the associated ramifications, such as a loss of dignity, were described by a number of participants as a fear of being forced back into the closet. The closet represents being hidden for individuals who identify as LGBT. Being in the closet is an expression that is connected to a lack of disclosure of sexual orientation or gender identity, including aspects sexual identity and sexual behavior. Being forced back into the closet represents a fear of loss of autonomy, identity and freedom of sexual expression. Some participants shared that they had fought hard to get and stay out of the closet. They now feared that they were at risk of being coerced back into the closet towards the end of their lives in order to feel safe during a period in which they anticipated being vulnerable and lacking in power. This fear was shared by a participant who stated:

You've created spaces for yourself where you're comfortable then suddenly... somebody is gonna put you in the closet. I don't wanna live in a closet, I don't need to live in a closet, I'm not interested in a closet....

This participant went on to express that he had already done the work required to get out of the closet and now was fearful of the potential of needing to do it again.

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

The findings of this study reflect Griebing's research which reported that LGBT individuals have fears pertaining to the negative and heteronormative attitudes that are present in healthcare institutions such as long term care. One participant likened living in long term care to being in "Dante's Inferno." These fears resulted in a strong desire not to be institutionalized at the end of life. A participant describes this in the following statement:

I'm scared what's going to happen to us once we get older – or I'm getting older now- what if I got really sick and they had to put me in a long term home. I don't think I would ever want to go there.

The hope for quality care at the end of life expressed by the participants, like their fears, were not drastically different from heterosexuals in that they expressed a strong desire for control and autonomy. A participant demonstrates this hope in an expression of values:

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

Another participant speaks of his hope to be accepted, to be safe and not forced back into the closet, when he states:

... free from harassment of any nature, be it physical verbal mental, anything like that and knowing that you're accepted from everyone around you and no worrying about going back into the closet – ...after being out for over 20 years I couldn't go back unless there was marvelous wardrobe in there! There's no way I'm going back into the closet.

## **5. Awareness of Laws and Policies**

Individuals reported varying levels awareness of and comfort with laws, policies and resources in Ontario to support them in the last stages of life. Similar to what is reported in the literature, some participants reported confusion regarding their rights and the role of their families within healthcare decision-making and other areas as well as the roles of different organizations. While some participants reported having strong awareness about Ontario's medico-legal framework and being well prepared for the last stages of life, others reported confusion. One participant indicated confusion about whether families of choice could visit a hospitalized individual:

I read about this all the time in fiction that's based on reality. It's like anytime a person is hospitalized, maybe on an emergency basis, you always see people going to try to see them. And they're not allowed. They're not admitted because they're not family.

There was similar confusion among focus group participants regarding whether same-sex partners could be placed together within long-term care. One participant recounted an experience:

There was a colleague of mine who fought for their parents so that they could be together in the same room at the [redacted] and so she fought bureaucracy and got that changed. [Could] a gay or lesbian, or bi, trans couple ha[ve] been placed together like that if they wanted to? Like some couples, gay, straight, whatever don't want to be placed together, but some would. So could they?

As reflected in the literature, some participants had concerns that their loved ones would not be involved in their care or that their wishes would not be respected. Similarly, participants were confused by some of the laws in Ontario surrounding decision-making, long-term care, and end-of-life planning. One participant expressed their confusion:

That's a question I have, 'cuz we have living wills [sic] as well as a will for, you know, personal care. Is there any precedence of ... this isn't honoured. Should we be worried it wouldn't be honoured. Like if [redacted] went into the hospital or something would I still have the power to do not resuscitate?

Many participants in the focus groups had questions about how to navigate the healthcare system and about advance care planning and their rights. Conversely, others had worked extensively in care settings and openly shared their experiences and knowledge with the group. One participant who had experience working within the healthcare system suggested that:

Where I worked, you would ask people 'who is your chosen family? Who are those individuals that are important to you?'

In response to fears regarding discrimination in long-term care, another participant was aware of resources to make long-term care more inclusive to members of the LGBT community:

"There's ... a LGBT toolkit for long-term care."

The participants voiced many opinions about how to develop policies to promote inclusivity for LGBT older adults in the last stages of life. When asked about policy changes, one participant suggested that:

I think basically the policies of non-discrimination are in place, but it's working those out in all the different little aspects of life and then institutionaliz[ing] them.

Participants suggested that one method of ensuring that healthcare providers offer LGBT-friendly care would be to develop an accreditation process, a practice that one participant indicated is already being implemented in some jurisdictions:

I think it's still there, to be accredited with LGBT competence. [redacted] worked out an accreditation system themselves, but there's no reason ... why the LHIN couldn't say 'you want to be paid? We want to know people aren't being discriminated against.'

Among participants, the introduction of policies to guarantee inclusion and equitable treatment within healthcare as well as education of staff were cited as important means to facilitate competent care in the last stages of life.

## **6. *Fostering a "Good Death" Experience***

Many of the participants in our focus groups aligned themselves with ideas about the importance of advocating for the rights of LGBT individuals within society. Some participants had been advocates and activists during the early 1980s AIDS epidemic and continued to advocate for change and improvement for gay rights and freedoms today. The recognition that advocacy is important to facilitate a "good death" is supported in this statement from a participant:

I still share with you the desire to have control over my death. But I would be happy to be part of changing some of the ways that we saw engagement with one another through those frailties in life ...

And participants recognize that they may need to lead this advocacy movement once again, taking responsibility in leading change. This sentiment is shared in this statement:

"the children we've helped raised may or may not be in the position to advocate for us...."

Another additional quote from a participant expands on this concept:

I suppose it could be positive that we're the first wave that's going to be different because we've lived the life we have. So we do have an opportunity perhaps, responsibility, to try to make that different just by ourselves. And all this other stuff is

important too, but if we can try to carry on with not hiding that will sort of get a message or start something that hasn't been there before.

There is hesitation, however, to take the lead advocacy role in this area. Participants recognize that they may not be in a position to advocate to the best of their abilities or advocate as strongly as they would like as they predict finding themselves being tired, lacking energy and more vulnerable as they enter the final stages of life. Participants spoke of wondering who would take on this lead role as demonstrated in the following:

And it's exhausting. And I'm at the end of my life and I've done all that. Where are the people are going to pick this up and push it through the next level....We need more than just us, we've earned a rest for fuck's sake ...

Priorities for having a "good death" for the participants in this project included having control, maintaining a sense of community, feeling safe and having the freedom to express their sexuality. This is not unlike the general understanding of a good death which includes respecting the rights of the individual, ensuring the dying person is as comfortable as possible and in the company of people they love and care for.<sup>57</sup> Participants recognized that not everyone dies a good death. A number of participants had witnessed deaths that were not good from their perspective as described here:

I don't mean to die like some people we've known, That I would call terrible deaths, that is they slowly suffocated, a disease that goes on for a long time... it's quite inhumane and that's ... I feel I'd like to see that changed. A lot I think a lot would choose to die differently

Participants hoped that their death experience would be an extension of their life, including their advocacy work and efforts to live out of the closet. This desire is explained by the following participant:

So I'm going to die the way I'm living. I live in a normal neighbourhood and I do normal things. And if we go somewhere dancing we will dance in front of heterosexuals.

## **IV. A CALL TO ACTION: RECOMMENDATIONS TO POSITION ONTARIO AS A LEADER FOR CHANGE**

Key findings from our participants included highlighting the importance of community in end-of-life and fears about social isolation considering their unique family contexts. Further, system level barriers such as stigma, discrimination, and lack of education were pressing concerns. Fears about the lack of accessible and LGBT friendly long-term care institutions were a priority related to end-of-life. A dominant and reoccurring theme in all focus groups conducted was that LGBT older adults fear being forced back into the closet.

Overall participants identified themselves as educated and engaged. There was broad awareness of the resources and policies to support quality of care at end-of-life. At times there was confusion about the nuances of the legal frameworks for LGBT individuals that would support them in continuing their autonomous lifestyle. In considering possibilities to facilitate of a 'good death', education was identified as a driving force for change. This included system-level changes such as comprehensive social policy all the way through to education for improved clinical interactions at the bedside in end-of-life care.

Given our findings about the experiences of LGBT individuals in Ontario, it is recommended that cultural competence be systemically embedded into all levels of health and social policy and practice related to the last stages of life. This should be accomplished by implementing the following recommendations:

- Recognizing the need for increased advocacy and awareness of the experiences of older LGBT adults in Ontario.
- Increasing education about the needs of LGBT older adults at all levels of healthcare including social policy, acute care facilities, community care, and long-term care.
- Implementing education to shift attitudes and beliefs among individuals receiving care and their social networks. This includes the general public in an attempt to forge alliances between LGBT and non-LGBT communities.
- Increasing awareness needs to translate into cultural competencies which can be implemented and measured at the bedside of LGBT individuals as they enter the last stages of life and require more intense care.
- Making this population visible and ensuring needs are being met. Current administrative data collections systems (e.g., intake forms) should include questions about sexual orientation, the sex of a partner, and gender identity.

These data need to be collected in an inclusive and relationship-centred manner and patients should not be forced to disclose this information.

- Including rapport-building and opening space for communication around the range of sexual orientations and gender identity as a core competency of health and social care providers.
- Promoting environments that demonstrate openness and inclusivity. An example of this may be a rainbow sticker placed in a dominant position or including a rainbow symbol on a website.
- Valuing and including families of choice within the circle of care.
- Supporting LGBT older adults to navigate the complex medico-legal systems to ensure seamless transition throughout their continuum of care.
- Embedding the lived experience of LGBT older adults into educational approaches for healthcare providers to reduce stigma and discrimination.
- Eliminating institutionalized heterosexism by encouraging organizations to assess and modify their policies and practices using an LGBT/seniors lens.
- Promoting a research agenda that prioritizes the needs of LGBT older adults and includes the mobilization of knowledge.
- Developing leadership to prioritize research and knowledge mobilization, improving the quality of life and dying among older LGBT individuals.
- Providing advocacy and educational supports to ensure LGBT individuals and their allies are able to access and navigate legal frameworks to aid in advance care planning and end-of-life decisions.



## V. CONCLUSIONS

While LGBT older adults express concerns and confusion about medico-legal systems and end-of-life care, data from the academic literature and from focus groups suggest that there are numerous opportunities to reduce the occurrence of stigma and discrimination this community faces through a variety of means, especially educating health and social care workers. Moreover, among other measures recommended in our Call to Action, educating LGBT individuals and their families regarding advance care planning options will increase knowledge and preparedness for the last stage of life.

Many members of the LGBT community have faced a lifetime of systemic discrimination and it follows that they are hesitant to willingly enter into formal care settings. Despite experiencing discrimination, the existing literature suggests that LGBT older adults exhibit higher levels of resilience in comparison to their heterosexual peers.<sup>58</sup> Through the development of policy and implementation of programs that promote education and awareness about LGBT aging and the last stages of life, we can work towards ensuring appropriate care and a good death experience for all members of society, including sexual minorities.

## VI. ENDNOTES

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<sup>1</sup> Karen I Fredriksen-Goldsen & Anna Muraco, "Aging and Sexual Orientation: A 25-Year Review of the Literature" (2010) 32:3 Res Aging 372.

<sup>2</sup> David Haber, "Gay Aging" (2009) 30:3 Gerontology & Geriatrics Education 267.

<sup>3</sup> Haber, note 2.

<sup>4</sup> S Brotman, B Ryan & R Cormier, "The Health and Social Service Needs of Gay and Lesbian Elders and Their Families in Canada" (2003) 43:2 The Gerontologist 192.

<sup>5</sup> Anne K Hughes, Rena D Harold & Janet M Boyer, "Awareness of LGBT Aging Issues Among Aging Services Network Providers" (2011) 54:7 Journal of Gerontological Social Work 659.

<sup>6</sup> Elizabeth Price, "All but invisible: older gay men and lesbians: the sexuality of older people, and gay and lesbian sexuality in particular, is an issue that has largely been ignored in the nursing literature. But, says Elizabeth Price, older gay men and lesbians are becoming more vociferous about the health and social care services they have a right to expect" (2005) 17:4 Nursing Older People 16.

<sup>7</sup> "SAGE - Resources - Out & Visible (full report)", online: SAGEusa.org <<http://www.sageusa.org/resources/publications.cfm>>.

<sup>8</sup> Ottawa Senior Pride Network & Ipsos Reid, Housing Survey (Ottawa, 2015).

<sup>9</sup> Alzheimer's Australia, *Dementia, Transgender & Intersex People: Do service providers really know what their needs are?* (2014).

<sup>10</sup> S Brotman et al, "Access and equity in the design and delivery of health and social care to LGBTQ older adults: A Canadian perspective" in N Orel & C Fruhauf, eds, *The lives of LGBT older adults: Understanding challenges and resilience* (Washington, DC, US: American Psychological Association, 2014).

<sup>11</sup> V L Bengston, G H Elder & N M Putney, "The Lifecourse Perspective on Ageing: Linked Lives, Timing and History" in M L Johnson, ed, *The Cambridge Handbook of Age and Ageing* (Cambridge: Cambridge University Press, 2005) 493.

<sup>12</sup> V L Bengston, G H Elder & NM Putney, note 11.

<sup>13</sup> Fredriksen-Goldsen & Muraco, note 1.

<sup>14</sup> Egale Canada, "FAQ – About C-279 « Gender Identity Bill", online: <<http://trans.egale.ca/faq-about-c-279/>>.

<sup>15</sup> G R Bauer & A I Scheim, *Transgender People in Ontario, Canada: Statistics from the Trans PULSE project to inform human rights policy* (London, Ontario, 2015).

<sup>16</sup> Danielle Levac, Heather Colquhoun & Kelly K O'Brien, "Scoping studies: advancing the methodology" (2010) 5:1 Implementation Science 69.

<sup>17</sup> Deb Rawlings, "End-of-life care considerations for gay, lesbian, bisexual, and transgender individuals" (2012) 18:1 Int J Palliat Nurs 29.

<sup>18</sup> Shari Brotman et al, "Coming out to care: caregivers of gay and lesbian seniors in Canada" (2007) 47:4 Gerontologist 490.

<sup>19</sup> Tomas L Griebing, "Sexuality and aging: a focus on lesbian, gay, bisexual, and transgender (LGBT) needs in palliative and end of life care" (2016) 10:1 Current Opinion in Supportive and Palliative Care 95.

- <sup>20</sup> Metlife Mature Market Institute® 2 & The Lesbian And Gay Aging Issues Network Of The American Society On Aging, “Out and Aging: The MetLife Study of Lesbian and Gay Baby Boomers 1” (2010) 6:1 *Journal of GLBT Family Studies* 40.
- <sup>21</sup> K Almack, J Seymour & G Bellamy, “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” (2010) 44:5 *Sociology* 908.
- <sup>22</sup> Griebing, note 19.
- <sup>23</sup> Griebing, note 19.
- <sup>24</sup> Douglas Kimmel, “Lesbian, Gay, Bisexual, and Transgender Aging Concerns” (2014) 37:1 *Clinical Gerontologist* 49.
- <sup>25</sup> Blase E Masini & Hope A Barrett, “Social Support as a Predictor of Psychological and Physical Well-Being and Lifestyle in Lesbian, Gay, and Bisexual Adults Aged 50 and Over” (2008) 20:1–2 *Journal of Gay & Lesbian Social Services* 91.
- <sup>26</sup> Justine McGovern, “The Forgotten: Dementia and the Aging LGBT Community” (2014) 57:8 845.
- <sup>27</sup> McGovern, note 26.
- <sup>28</sup> Tarynn M Witten, “End of life, chronic illness, and trans-identities” (2014) 10:1 *J Soc Work End Life Palliat Care* 34.
- <sup>29</sup> Kimmel, note 24; Darren P Arthur, “Social Work Practice with LGBT Elders at End of Life: Developing Practice Evaluation and Clinical Skills Through a Cultural Perspective” (2015) 11:2 *J Soc Work End Life Palliat Care* 178; Brotman et al, note 18.
- <sup>30</sup> Rawlings, note 17.
- <sup>31</sup> Kristina M Hash & F Ellen Netting, “Long-term planning and decision-making among midlife and older gay men and lesbians” (2007) 3:2 *J Soc Work End Life Palliat Care* 59.
- <sup>32</sup> A June et al, “Views of Hospice and Palliative Care Among Younger and Older Sexually Diverse Women” (2012) 29:6 *American Journal of Hospice and Palliative Medicine* 455.
- <sup>33</sup> Paige Averett, Intae Yoon & Carol L Jenkins, “Older Lesbians: Experiences of Aging, Discrimination and Resilience” (2011) 23:3 *Journal of Women & Aging* 216.
- <sup>34</sup> Averett, Yoon & Jenkins, note 33.
- <sup>35</sup> Metlife Mature Market Institute® 2 & The Lesbian And Gay Aging Issues Network Of The American Society On Aging, note 20.
- <sup>36</sup> Mark Hughes & Colleen Cartwright, “LGBT people’s knowledge of and preparedness to discuss end-of-life care planning options” (2014) 22:5 *Health Soc Care Community* 545.
- <sup>37</sup> Mark Hughes & Colleen Cartwright, “Lesbian, gay, bisexual and transgender people’s attitudes to end-of-life decision-making and advance care planning: LGBT people and advance care planning” (2015) 34 *Australasian Journal on Ageing* 39.
- <sup>38</sup> Witten, note 28.
- <sup>39</sup> Tarynn M Witten, “Elder Transgender Lesbians: Exploring the Intersection of Age, Lesbian Sexual Identity, and Transgender Identity” (2015) 19:1 *Journal of Lesbian Studies* 73.
- <sup>40</sup> Colleen Cartwright, Mark Hughes & Tania Lienert, “End-of-life care for gay, lesbian, bisexual and transgender people” (2012) 14:5 *Culture, Health & Sexuality* 537.
- <sup>41</sup> Richard Harding, Eleni Epiphaniou & Jayne Chidgey-Clark, “Needs, Experiences, and Preferences of Sexual Minorities for End-of-Life Care and Palliative Care: A Systematic Review”

(2012) 15:5 *Journal of Palliative Medicine* 602; Lisa A Powell & Ruth Neustifter, “An Updated Social Context for Therapy with Elder Lesbian Couples” (2012) 24:3 *Journal of Feminist Family Therapy* 213.

<sup>42</sup> Griebing, note 19; Harding, Epiphaniou & Chidgey-Clark, note 41; Kevin Corbett, “Lesbian women and gay men found that nurses often assumed they were heterosexual, which led to feelings of discomfort and insecurity” (2007) 10:3 *Evidence-Based Nursing* 94.

<sup>43</sup> Rawlings, note 17.

<sup>44</sup> Griebing, note 19.

<sup>45</sup> Patti A Aldredge & Annemarie Conlon, “Reflections: Gay Men and Lesbians at End-of-Life” (2012) 8:2 *Journal of Social Work in End-Of-Life & Palliative Care* 113.

<sup>46</sup> Andrew Lawton, Jocelyn White & Erik K Fromme, “End-of-Life and Advance Care Planning Considerations for Lesbian, Gay, Bisexual, and Transgender Patients #275” (2014) 17:1 *Journal of Palliative Medicine* 106.

<sup>47</sup> Arthur, note 29.

<sup>48</sup> Francis Duffy & John Paul Healy, “A Social Work Practice Reflection on Issues Arising for LGBTI Older People Interfacing With Health and Residential Care: Rights, Decision Making and End-of-Life Care” (2014) 53:6 *Social Work in Health Care* 568.

<sup>49</sup> Rawlings, note 17.

<sup>50</sup> Kimmel, note 24.

<sup>51</sup> Price, note 6.

<sup>52</sup> Kristen E Porter & Lisa Krinsky, “Do LGBT Aging Trainings Effectuate Positive Change in Mainstream Elder Service Providers?” (2014) 61:1 *Journal of Homosexuality* 197.

<sup>53</sup> Witten, note 39; Brotman et al, note 18.

<sup>54</sup> McGovern, note 26.

<sup>55</sup> Brotman et al, note 18.

<sup>56</sup> Rawlings, note 17.

<sup>57</sup> Karen E Steinhauer, “In Search of a Good Death: Observations of Patients, Families, and Providers” (2000) 132:10 *Annals of Internal Medicine* 825.

<sup>58</sup> Jennifer Hillman & Gregory A Hinrichsen, “Promoting an affirming, competent practice with older lesbian and gay adults” (2014) 45:4 *Professional Psychology: Research and Practice* 269.