

**Creating Visibility: Considering LGBT Older Adults in the Canadian
Caregiving Context**

by

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A Thesis

presented to

The University of Guelph

In partial fulfilment of requirements
for the degree of

Master of Science

in

Family Relations and Applied Nutrition

Guelph, Ontario, Canada

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ABSTRACT

CREATING VISIBILITY: CONSIDERING LGBT OLDER ADULTS IN THE CANADIAN CAREGIVING CONTEXT

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Lesbian, gay, bisexual and transgender (LGBT) older adults are at a greater risk of physical and mental illness when compared to heterosexual/cisgender older adults, largely due to stigma and discrimination. LGBT older adults may also avoid or delay seeking care from formal healthcare systems due to historical discrimination, increasing the demand on informal caregivers as this population continues to age. The current study aimed to explore LGBT older adults' (aged 65+) experiences with informal caregiving and healthcare services, contributing to the gap of Canadian research on this topic. The data of 50 participants were gathered using an online mixed methods survey and then analyzed using descriptive statistics and content analysis. The results indicate that LGBT older adults have unique needs in healthcare environments, especially in regard to their interactions with care providers. Participants had robust social networks, many of which contained other LGBT members with whom informal caring duties could be shared; however, the anticipated need of formal healthcare services remained. As LGBT older adults continue to age and subsequently may rely on more formal services, translating these results into policy and practice to improve their experiences is of utmost importance.

ACKNOWLEDGEMENTS

The support that I have received throughout this degree has been truly incredible. There were many occasions where the finish line seemed unreachable, and I wouldn't be crossing it without a community of strength and support.

To my amazing advisor and mentor, Dr. Kim Wilson. Thank you for the hundreds of meetings, emails, and informal chats, all of which you provided unparalleled guidance and support. Your kindness and ability to put my (usually stressed/anxious) mind at ease through validation and encouragement was always needed and appreciated. Thank you for introducing me to the wonderful world of qualitative research, sharing your expertise, and allowing me to grow and work alongside you in some incredible projects. I am grateful to have been mentored by such a remarkable researcher and teacher.

To Dr. Robin Milhausen, thank you for being a wonderful committee member. Thank you for your endless guidance and encouragement, dating back to my undergraduate days. Your insightful feedback and expertise were so valuable throughout my thesis development and writing processes. Your passion for research is inspiring.

To all of my participants, I am eternally grateful and honoured. Thank you for being so open and honest with me and for taking the time to provide me with such insightful data. I can only hope that I have done your words justice.

To my family, I cannot put into words how grateful I am for you all. I relied on and valued all of your support, in any and all forms: Breakfast visits, home cooked meals, an afternoon phone call. Thank you for keeping me grounded and for pushing me (gently) when I needed it. Thank you for encouraging me and always making it known how proud you are of me.

To Aidan, my rock. Thank you for being so dedicated to me and my process, for loving me even when it may have been hard to do so, and for being the true embodiment of a partner. From getting a puppy one month into my degree (shout out to Mowgli for endless snuggles and for getting me into forests and fresh air when I needed it most), to wedding planning, thank you for always putting us first and for encouraging me to do the same. I am honoured and grateful to grow alongside you and walk through life with you.

To my friends, far and near, thank you for always being only a phone call or text away and thank you for all of the humour, love, and support.

To my "FRAMily," thank you for the game nights, co-working sessions, and all of your endless empathy. Thank you for all of your advice and reassurance through this process. I am so grateful that I got to experience these last two years with such an incredible group of humans and researchers. I would not have been able to do this without you all!

It takes a village, and I had a great one.

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Introduction

Demographic characteristics of Canadians are shifting; Canada is now categorized as an aging nation, with an increasing proportion of older adults, specifically more than 10% of the population (Statistics Canada, 2016). As of the 2016 Canadian census, individuals aged 65 and older represented 16.89% of the population. It is proposed that 23% of the Canadian population will be over the age of 65 by the year 2030; this highlights the importance of considering aging by all disciplines and fields of practice (Battams, 2016; Torjman, 2015). Other demographic changes include Canadians having smaller families on average (Battams, 2016; Canadian Caregiver Coalition, 2013), and individuals having longer life expectancies (Shiu, Muraco, & Fredriksen-Goldsen, 2016). Additionally, disability rates are increasing (Fast, 2015; Fredriksen-Goldsen & Hoy-Ellis, 2007) in parallel to increasing rates and severity of chronic disease (Battams, 2016; Canadian Caregiver Coalition, 2013; Fredriksen-Goldsen & Hoy-Ellis, 2007; Torjman, 2015). Considering these changes, an increasing number of Canadians will need assistance, primarily sourced from informal caregivers (Barker, Herdt, & de Vries, 2006; Statistics Canada, 2013).

Older adults are heterogeneous in nature (e.g., varying sexual orientations, ethnicities, historical experiences, and abilities), requiring services and providers be responsive to these differences. Older adults are most often categorized in the literature as being a minimum of 65 years old, with some research choosing 50 as the age of inclusion (e.g., meta-analysis by Fredriksen-Goldsen & Muraco, 2010). The terms ‘aging individuals’ and ‘older adults’ will be used synonymously throughout this paper. One point of diversity among older adults is sexuality, which is often considered taboo (Brotman, Ryan, & Cormier, 2003; Furlotte, Gladstone, Cosby, & Fitzgerald, 2016). Broadly defined, sexuality “refers to the ways in which we experience and

express ourselves as sexual beings” (Rathus, Nevid, & Fichner-Rathus, 1993, p. 4). The construct of sexuality, as outlined by Fredriksen-Goldsen and colleagues (2014), is made up of three components that tend to be fluid across the life span: sexual identity, sexual attraction, and sexual behaviour. For the purpose of this paper, sexual identity will be the main focus. Sexuality remains important throughout the lifespan, requiring services, systems, and providers to consider older adults as sexual beings (Duffy & Healy, 2014; Stinchcombe et al., 2016; Stinchcombe, Smallbone, Wilson, & Kortes-Miller, 2017; Wilson, Kortes-Miller, & Stinchcombe, 2018). Ignoring or overlooking sexual orientation and gender identity (perception of oneself as female, male, neither, or integration of both; Human Rights Campaign, 2019) can be damaging, reinforcing the marginalization and invisibility of older adults (Brotman, Ferrer, Sussman, Ryan, & Richard, 2015; Brotman et al., 2003; Stinchcombe et al., 2016). Wilson and colleagues (2016) estimated the number of aging LGB adults using the 2011 Canadian Census data (Statistics Canada) with American population percentage estimates. Extrapolating from the most recent 2016 Census data, and considering the fact that LGB members make up 2-8% of the American population, it is likely that there are between 118,712 and 474,850 LGB older adults in Canada. Transgender older adults were not included in the estimates because census data was not available.

Fredriksen-Goldsen and Muraco (2010), after completing a thorough review of literature on LGBT older adults and healthcare, suggested four waves of research in the field thus far: disproving negative stereotypes, looking at psychosocial adjustments, identity development, and finally social support and community needs. Duffy and Healy (2014) suggested that future research needs to look at the rights of older LGBT individuals in policy and practice, and how to promote and improve their experiences.

Within this paper, I will review the current literature on general healthcare experiences of LGBT older adults, Canadian caregiving, caregiving and support systems among LGBT older adults, and relevant theoretical frameworks. The existing literature indicates that LGBT older adults face more challenges within broader healthcare settings; these challenges result in hesitancy to access formal services and a subsequent need for more informal care. Additionally, the informal caregiving context within Canada for the majority population is strained, with an increasing number of caregivers needed and minimal supportive resources available. However, the literature on both informal caregiving and LGBT older adults within the Canadian landscape is lacking. The current study aims to aid in understanding LGBT older adults' caregiving and care receiving experiences with healthcare and formal services, and the role of informal support in care and aging. The intent of this study was to fill the current gaps in literature, especially the Canadian literature, and inform and improve policy and practice. The literature review will be followed by an outline of the study methods and analyses, a thorough results section, and a concluding discussion.

Literature Review

The following section will summarize current literature regarding LGBT aging in relation to healthcare, caregiving, and support systems. This section will first introduce relevant terminology and discuss the history of LGBT rights in Canada and LGBT research. The following section will discuss the health discrepancies found between LGBT individuals and non-LGBT individuals, the context of social support among LGBT individuals, general healthcare service experiences for older LGBT individuals, the state of caregiving in Canada, and finally the state of caregiving among older LGBT persons. The 'Informal Caregiving in the Canadian Context' is supported only by Canadian literature, whereas the remainder of the

literature review is based on research from Canada, the United States, Australia, and the United Kingdom. This decision was made because of the lack of extant Canadian literature on the remainder of the subsections.

Historical Context and Terminology

First, the terminology that will be used throughout the following sections will be discussed. Broadly, sexuality encompasses the ways that individuals experience and express themselves as sexual beings. Within sexuality, sexual identity, commonly referred to as sexual orientation tends to be fluid in nature, no longer simply comprised of ‘straight’ and ‘homosexual’ dichotomous categories – rather, Coon (2003) suggests that sexual orientation can be considered on a spectrum, developing over time. For the purpose of this study, the acronym LGBT will be used to represent sexual identity terms (lesbian, gay, bisexual) and gender identity terms (transgender). Heterosexuality is the attraction to the other sex according to traditional binary categories of gender. ‘Heteronormativity’ is defined as the privileging of heterosexuality over all other sexual orientations and identities. Similarly, ‘cisnormativity’ is defined as the privileging of cisgender identities over all other gender identities (Brotman et al., 2007; Brotman et al., 2003). A person is cisgender if they identify with their sex as defined at birth.

The likelihood of and comfort associated with self-defining according to ascribed sexuality or gender categories may vary depending on aging cohort, as being ‘out’ is a new development for some older individuals (Furlotte et al., 2016). Barker and colleagues (2006) suggest that the older cohorts may be more comfortable with the term ‘homosexual,’ whereas younger generations have reclaimed the term ‘queer’. Given the historical stigma of the term ‘queer’ for the older generations, this term was used minimally in the current study. Fredriksen-Goldsen and Muraco (2010) suggest that strategies of disclosure and navigating sexual orientation/gender

identity vary across time according to the corresponding social context. Historically, individuals who grew up pre-liberation (term used to signify the Canadian liberations happening in parallel to the United States Stonewall era) would have experienced more obstacles to coming out (Brotman et al., 2003), and therefore could exhibit lower levels of disclosure and less visibility (Barker et al., 2006; Wilson et al., 2018). Generally, older cohorts came of age and lived in a time where homophobia was a societal norm, and where ‘deviant’ sexual or gendered behaviour was met with criminalization and pathologization (Brotman et al., 2003; Choi & Meyer, 2016; Coon, 2003; Fredriksen-Goldsen & Muraco, 2010; Grossman, D’Augelli, & Dragowski, 2007; McParland & Camic, 2016; Stein, Beckerman, & Sherman, 2010; Wilson et al., 2018). Therefore, LGBT older adults have faced a lifetime of victimization (Choi & Meyer, 2016; Duffy & Healy, 2014; Fredriksen-Goldsen & Hoy-Ellis, 2007; Stein et al., 2010). Although the social environment has become much more accepting, discrimination in policy and covert societal values favoring heteronormativity remain pervasive (Duffy & Healy, 2014). Defining the language that will be used throughout this research is important, given the diversity in language and identities within sexual and gender minority populations. Further, given the target population, it is important to identify and use appropriate language for older adults to ensure the comfort of the participants.

Political and Legal Changes

Canada is unique with regard to its LGBT history, both legally and politically (Brotman et al., 2015). Research on LGBT history in the United States of America (US) often considers the Stonewall riots to be pivotal moments (Fredriksen-Goldsen & Muraco, 2010). In Canada, the decriminalization of homosexuality in 1969, introduced in the form of Bill C-150 in 1967, was a pivotal moment in terms of LGBT history and advocacy (Brotman et al., 2015). Shortly after, in

1998, a Canadian-wide ban of sexual orientation-based discrimination occurred (Brotman et al., 2015). Later, in 2005, the Civil Marriage Act was created to allow for same sex marriage (Brotman et al., 2015). Political and legal changes demonstrate an increase in equality for all sexual orientations, with gender identity advocacy further behind (Brotman et al., 2015). However, in 2017, Bill C-16 was passed to “add gender identity and gender expression to the list of prohibited grounds of discrimination” (Bill C-16, 2017, “Summary”, para. 1). This historical consideration is especially important when looking at healthcare and caregiving considerations for older adults, as end-of-life rights and decision-making are undoubtedly affected by legal changes.

Health Disparities

Research and subsequent knowledge mobilization on healthcare and caregiving among LGBT older adults is especially important considering the health disparities found between LGBT individuals and their majority peers (e.g., Czaja et al., 2016; Stinchcombe et al., 2016). However, aging LGBT individuals are heterogeneous in nature, with individuals diverse in ethnicity, race, socioeconomic status, location, religion, and disability (Choi & Meyer, 2016). Additionally, regardless of perceived similarities, health status and development can vary significantly within cohorts (Fredriksen-Goldsen et al., 2014).

LGBT adults are at an overall greater risk of poor physical and mental outcomes due to their sexual orientation or gender identity, largely as a result of stigma and discrimination (Czaja et al., 2016; Stinchcombe et al., 2016). Victimization and internalized stigma are said to increase stress levels, which in turn result in higher mental health disparities (Choi & Meyer, 2016; Czaja et al., 2016; Stinchcombe et al., 2017; Wilson et al., 2018). This aligns with the minority stress

model, which states that experienced or expected stigma and discrimination due to minority status leads to higher stress levels and adverse health effects (Choi & Meyer, 2016).

The Aging with Pride: National Health, Aging, Sexuality and Gender Study, a longitudinal study on LGBTQ+ midlife and older adults, is the primary source of health and wellness data for the United States. Compared to those who do not identify as LGBT, LGBT older adults have poorer mental health, higher psychological distress, higher suicidal ideation, and more mental health disorders (Fredriksen-Goldsen et al., 2014). Poor mental health outcomes include loneliness, low self-esteem, internalized stigma, and victimization (Fredriksen-Goldsen & Muraco, 2010). Physically, LGBT individuals often have more complex needs, more physical limitations, and higher disability rates (Brennan-Ing et al., 2014; Fredriksen-Goldsen et al., 2014). Further, transgender individuals have poorer mental and physical health, specifically higher rates of depression, anxiety, and psychological distress, than non-transgender individuals (Choi & Meyer, 2016; Fredriksen-Goldsen et al., 2014).

Stinchcombe and colleagues (2018) published the first Canadian data on health disparities between LGB and heterosexual older adults using data from the Canadian Longitudinal Study on Aging (CLSA). These data suggest that disparities are found in chronic illness, mental health conditions, and health behaviours. Specifically, anxiety and mood disorders are diagnosed more in sexual minority males and females over 45 than their heterosexual counterparts. In terms of chronic disease, sexual minority females and males were more likely to report asthma than their heterosexual counterparts, and gay and bisexual males were more likely to have cancer. Lastly, lesbian and bisexual females were more likely to drink excessively and report past smoking habits, whereas LGB males were more likely to report current smoking habits (Stinchcombe, Wilson, Kortes-Miller, Chambers, & Weaver, 2018). An

increase in risk taking behaviours can be linked back to the minority stress model, as many of these behaviours may be a result of victimization and discrimination against LGBT individuals.

Regardless of the experienced stigma, LGBT individuals show the ability to cope through obstacles of adversity and display resilience (Brotman et al., 2003; Choi & Meyer, 2016; Fredriksen-Goldsen & Hoy-Ellis, 2007; Fredriksen-Goldsen & Muraco, 2010). It is suggested that this personal resilience in combination with community support results in positive adaptation to aging (Brotman et al., 2003; McParland & Camic, 2016). This phenomenon can be explained using the crisis competence model, which suggests that the methods used to successfully adapt to stigma early in life can be used to adapt to changes later in life, such as age-related changes (Fredriksen-Goldsen & Muraco, 2010).

Healthcare Access

In order to understand the caregiving context of aging LGBT adults, it is important to first review their experiences with healthcare and formal services in general. LGBT older adults face many of the same physical, emotional, and social age-related concerns as the general population; however, these issues are complicated by their gender identity or sexual orientation (Czaja et al., 2016; Hughes, Harold, & Boyer, 2011; Jackson, Johnson, & Roberts, 2008; Stein et al., 2010). LGBT older adults, as previously discussed, have psychological, physical, and mental disparities and more aging concerns compared to the majority population (Brennan-Ing et al., 2014; Grossman et al., 2007; McParland & Camic, 2016).

The unique needs and challenges of aging LGBT individuals are often not recognized in formal healthcare services, especially in end-of-life contexts (Cartwright, Hughes, & Lienert, 2010; Stein et al., 2010; Stinchcombe et al., 2017). This is due to the heteronormative and cisnormative nature of formal services and asexual assumptions of care providers, which are

especially pervasive in aging services, compared to general health (Brotman et al., 2003; Coon, 2003; Hughest et al., 2011; McParland & Camic, 2016; Stinchcombe et al., 2016; Stinchcombe et al., 2017; Wilson et al., 2018). The current healthcare offerings have been deemed inadequate to meet the unique needs of these populations (Brennan-Ing et al., 2014; Duffy & Healy, 2014; Fredriksen-Goldsen & Muraco, 2010; McParland & Camic, 2016). LGBT-specific services are better able to meet the needs of these aging individuals, especially with support (Choi & Meyer, 2016; Fredriksen-Goldsen & Muraco, 2010); however, these services are unavailable in many places (Brennan-Ing et al., 2014). The treatment of unique needs is complex, as outlined by Furlotte and colleagues (2016): a duality of need is desired by many older LGBT adults, in that they want to be treated the same as everyone else, but also want to be recognized for their unique identity and needs. This duality of care was echoed by long-term care workers in a study by Donaldson and Vacha-Haase (2016), where workers described a struggle between providing an equal standard of care versus specialized treatment: the authors suggest that ignoring the diversity of clients and treating all identically create an LGBT-blind perspective, which increases invisibility and marginalization.

LGBT individuals in general are less likely to access formal healthcare services as these services are often heteronormative and cisnormative in nature (Brotman et al., 2003; Cartwright et al., 2012; Coon, 2003; Hughes et al., 2011). McParland and Camic (2016) identified the older generation (65+) as the most fearful and the most at risk in terms of entering formal healthcare services. This may be attributed to their lifelong experiences with discrimination, and the expectation that discrimination would continue in services, as noted in Australian research (Duffy & Healy, 2014). Specifically, individuals may experience fear and mistrust of the healthcare system because of its history of discrimination and pathologizing (Brotman et al.,

2003; Brotman et al., 2015; Duffy & Healy, 2014; Fredriksen-Goldsen & Hoy-Ellis, 2007; Furlotte et al., 2016; Rawlings, 2012; Stinchcombe et al., 2016; Stein et al., 2010). Older LGBT adults may fear discriminatory or homophobic providers, and experience anxiety around receiving improper care or treatment as a result of their gender identity and/or sexual orientation (Brennan-Ing et al., 2014; Choi & Meyer, 2016; Czaja et al., 2016; Furlotte et al., 2016; Stinchcombe et al., 2016; Stinchcombe et al., 2017). Specifically, older LGBT adults expect to experience discriminatory practices and providers upon entering healthcare services (Brennan-Ing et al., 2014; Cartwright et al., 2012; Choi & Meyer, 2016; Hash, 2002; Hughes et al., 2011; Jackson et al., 2008). Therefore, LGBT older adults delay seeking care and/or avoid continuous care out of fear, resulting in later diagnosis and treatment (Brotman et al., 2003; Brotman et al., 2015; Choi & Meyer, 2016; Czaja et al., 2016; Harding, Epiphaniou, & Chidgey-Clark, 2012; Stein et al., 2010).

Because of heteronormativity and cisnormativity in healthcare, intake questions about sexual orientation or gender identity are often neglected, making disclosure difficult (Brotman et al., 2003; Stinchcombe et al., 2016; Wilson et al., 2018). There is considerable fear and discomfort about disclosing ones' LGBT identity upon entering healthcare services (Brennan-Ing et al., 2014; Cartwright et al., 2012; Czaja et al., 2016; Fredriksen-Goldsen & Hoy-Ellis, 2007; McParland & Camic, 2016; Wilson et al., 2018). Non-disclosure is used as a safety mechanism in this context, as a way of avoiding expected discrimination, poor treatment, and negative reactions (Brennan-Ing et al., 2014; Brotman et al., 2003; Choi & Meyer, 2016; Wilson et al., 2018). However, disclosure in healthcare environments allows for better visibility of health needs and the ability to provide better care, resulting in positive health outcomes (Brennan-Ing et al., 2014; Choi & Meyer, 2016; Duffy & Healy, 2014; Rawlings, 2012). Additionally, non-

disclosure further reinforces the invisibility of the aging LGBT individuals and their unique issues continue to remain unrecognized (Brotman et al., 2015; Rawlings, 2012).

The literature has outlined several specific barriers for LGBT older adults accessing healthcare including the need to advocate (e.g., Furlotte et al., 2016), lack of partner recognition (e.g., Brotman et al., 2015), expected discrimination (e.g., Fredriksen-Goldsen et al., 2014), negative reactions from professionals (e.g., Brotman et al., 2015), and geographic considerations (e.g., Cartwright et al., 2012). These barriers stem from the general hetero- and cis-normativity of services, creating an unsafe space for LGBT individuals. Furlotte and colleagues (2016) suggest that older LGBT adults fear that their ability to advocate for their needs would decline as their health status declined at the end of life. Partners and families of choice are often not recognized in formal services, especially in regard to end-of-life decision-making and planning (Brotman et al., 2015; Brotman et al., 2003). This is especially concerning considering that many LGBT older adults prefer their families of choice to have rights and abilities to make decisions over the recognized biological family (Stinchcombe et al., 2016). However, recognition of LGBT clients' relationships is crucial for quality care (Furlotte et al., 2016; Jackson et al., 2008). Non-recognition of partners and assumed heteronormativity are examples of covert discrimination or microaggressions, which results in an unsafe environment for LGBT individuals (Brotman et al., 2007; Fredriksen-Goldsen et al., 2014; Furlotte et al., 2016). Occurrences of overt discrimination, such as inappropriate or homophobic/transphobic reactions from healthcare providers, have also been noted (Fredriksen-Goldsen et al., 2014; Furlotte et al., 2016). Negative reactions may include hostility, harassment, excessive curiosity, pity, refusal of treatment, avoidance of physical contact, and condescension (Brotman et al., 2015; Brotman et al., 2003). In terms of geographic location, there are generally less LGBT services, more discrimination and

less disclosure, and an increased need for informal healthcare support in rural communities (Barker et al., 2006; Cartwright et al., 2012; Coon, 2003; Furlotte et al., 2016).

With regard to end-of-life care and formal caregiving options, it is important to note that there is considerable fear around entering long term care (LTC) due to expected discrimination (Choi & Meyer, 2016; Coon, 2003; Duffy & Healy, 2014; Furlotte et al., 2016; Hughes et al., 2011; Stinchcombe et al., 2016; Stinchcombe et al., 2017; Stein et al., 2010; Wilson et al., 2018). Specifically, LGBT older adults express fear around needs not being met, increased vulnerability, loss of independence, and a decreased ability to advocate for themselves (Brotman et al., 2015; Furlotte et al., 2016; Hughes et al., 2011; Stinchcombe et al., 2017). Many LGBT adults expressed the potential need to ‘go back in the closet’ in order to avoid discrimination and receive equal care (Brotman et al., 2015; Choi & Meyer, 2016; Duffy & Healy, 2014; Furlotte et al., 2016; Rawlings, 2012; Stein et al., 2010; Wilson et al., 2018). For transgender older adults entering LTC, non-disclosure or going back in the closet may not be possible, resulting in increased fear (Brotman et al., 2015). LGBT older adults expressed fear around interacting with other residents as well, specifically the inability to discuss their relationships or openly grieve the loss of partners (Choi & Meyer, 2016; Duffy & Healy, 2014; McParland & Camic, 2016; Rawlings, 2012; Stein et al., 2010). The fears that LGBT older adults express upon entering healthcare services and LTC is justified considering the historical and expected discrimination faced by this population – it is increasingly important to consider who will care for LGBT individuals and communities as they continue to age.

Social Support

Data from the American Aging with Pride study indicated that one element that has been shown to foster resilience and ameliorate health disparities and risks experienced by LGBT

individuals is social support (Erosheva, Kim, Emlet, & Fredriksen-Goldsen, 2016). Social support can be divided into three concepts: social networks, generally defined as webs of various relationships; support networks, relationships that provide emotional and concrete assistance; and care networks, combining informal and formal services that emerge to provide assistance for specific health or disability needs (Hughes & Kentlyn, 2011). Social support tends to look differently among LGBT individuals due to different life trajectories compared to the general population. Specifically, LGBT individuals are more likely to live alone, more likely to be single, and less likely to have biological children compared to the general population (Choi & Meyer, 2016; Czaja et al., 2016; Orel & Coon, 2016; Stinchcombe et al., 2016; Stinchcombe et al., 2017). Several studies suggest that risk of isolation is higher for LGBT older adults versus the majority population, especially for older adults who may experience a decrease in community contact later in life (Choi & Meyer, 2016; Stinchcombe et al., 2017). On the contrary, Brotman and colleagues (2003) suggest that total isolation among lesbian and gay older adults is a myth, in that many have created larger social networks than their heterosexual counterparts. However, the concern of future isolation by older LGBT adults has been noted (Stinchcombe et al., 2016; Wilson et al., 2018).

LGBT individuals often create families of choice, and support networks based on friendship, love, support, and companionship (Fredriksen, 1999; Fredriksen-Goldsen & Muraco, 2010; Orel & Coon, 2016; Stinchcombe et al., 2016; Stinchcombe et al., 2017). Families of choice, often comprised of partners, friends, co-workers, neighbours, and ex-partners, are considered to have the most important role in support for LGBT older adults (Brennan-Ing et al., 2014; Brotman et al., 2003; Fredriksen-Goldsen & Muraco, 2010; Furlotte et al., 2016; McParland & Camic, 2016; Rawlings, 2012; Stinchcombe et al., 2017). The involvement of

biological family or family of origin varies from uninvolved to complete mutual support; however, LGBT older adults are less likely to be functionally linked to their families of origin than the general population (Aronson, 1998; Brennan-Ing et al., 2014; Brotman et al., 2003; Coon, 2003; Fredriksen-Goldsen & Muraco, 2010; Gabrielson, Holston & Dyck, 2014).

Therefore, as means of social compensation (Barker et al., 2006), families of choice are fostered in order to supplement the support missing from biological family (Fredriksen-Goldsen & Hoy-Ellis, 2007; Gabrielson et al., 2014; Orel & Coon, 2016; Stinchcombe et al., 2017). Specifically, Erosheva and colleagues (2016) suggest that support with errands, advice, personal assistance, emergencies, and emotions are most often sought through close friends. Additionally, involvement in larger LGBT communities is also important for positive aging adjustment and outcomes (Brennan-Ing et al., 2014; Coon, 2003; Czaja et al., 2016; Fredriksen-Goldsen & Muraco, 2010; Gabrielson et al., 2014).

Involvement with LGBT communities is influenced by identity disclosure; specifically being 'out' is associated with more available support (Barker et al., 2006; Fredriksen-Goldsen & Hoy-Ellis, 2007; Fredriksen-Goldsen & Muraco, 2010), and more community ties and subsequent community support (Brotman et al., 2007; Choi & Meyer, 2016; Grossman et al., 2007). Additionally, involvement with LGBT communities can vary by age, with some older adults feeling that traditional LGBT communities do not adequately address their aging needs (Brotman et al., 2003). It is suggested that similar to the majority population, older LGBT adults may experience ageism in LGBT communities due to pervasive stereotypes and historical approaches toward navigating their identities (Brennan-Ing et al., 2014; Coon, 2003; Fredriksen-Goldsen & Muraco, 2010). A lack of support from community members and families of choice may result in higher levels of isolation and poorer health outcomes, as support serves as a

mediating factor for negative effects of stigma and discrimination (Barker et al., 2015; Brotman et al., 2015; Brotman et al., 2007; Choi & Meyer, 2016; Shiu et al., 2016; Stinchcombe et al., 2016).

Informal Caregiving in the Canadian Context

Unlike formal caregiving, informal caregiving is typically unpaid assistance that allows the care receiver to stay in a community setting, and is primarily provided by family, friends, and neighbours (Fredriksen-Goldsen & Hoy-Ellis, 2007). Informal caregiving is becoming more necessary in parallel to the changing Canadian landscape, specifically the increase in aging individuals and chronic disease, and changing family dynamics (Torjman, 2015). The number of people needing care is going to increase and an increased demand for informal caregivers will be seen in response (Aronson, 1998; Fast, 2015). Age-related needs are currently the most common reason for needing informal caregivers, (Canadian Caregiver Coalition, 2013; Statistics Canada, 2013) with most care for adults 65+ being provided informally (Fredriksen-Goldsen & Hoy-Ellis, 2007). Almost one-half of all Canadians (46%) have provided care for a long-term condition, aging need, or disability (Battams, 2016; Fast, 2015; Statistics Canada, 2013). The tasks that caregivers provide range from transportation and help with finances to personal care and administering treatments (Statistics Canada, 2013). Most caregiving roles are long-term, with 89% of caregivers reporting that they cared for more than 1 year, and 50% reporting that they cared for over 4 years (Canadian Caregiver Coalition, 2013; Statistics Canada, 2013).

Informal caregivers are a necessary piece in the healthcare system, as formal systems are already challenged to meet the growing demand for care and could not sustain adequate care without informal caregivers (Canadian Caregiver Coalition, 2013; Fast, 2015). The amount of care that informal caregivers provide is significant, providing more than 80% of care to

individuals with long-term conditions (Canadian Caregiver Coalition, 2013; Torjman, 2015). In fact, a study by Hollander, Liu and Chappell (2009) suggests that it would cost the Canadian healthcare system 25 billion dollars annually to replace the tasks and time provided by informal caregivers. Yet, the contribution of informal caregivers remains invisible and undervalued due to its unpaid and often obligatory nature (Torjman, 2015).

Family often provides informal caregiving, as a “landscape of care” exists in Western society, where providing and receiving care is second nature within a family context (Fast, 2015; Fredriksen-Goldsen & Hoy-Ellis, 2007; Statistics Canada, 2013). Within a hierarchy of care, informal caregiving by family is expected before formal or institutional care because of a sense of moral obligation and responsibility typically felt within families (Barker et al., 2006). The fact that 84% of caregivers are caring for biological family, with 48% caring for aging parents is therefore not surprising (Fast, 2015). Within the family, women are the most likely to perform the caregiving role in the general population (Fast, 2015; Statistics Canada, 2013).

Informal caregiving can be rewarding for the caregiver as well as the care receiver (Statistics Canada, 2013), with caregivers reporting that they felt a sense of purpose and nurturance and felt like better person as a result (Orel & Coon, 2016). Specifically regarding partner caregiving, some caregivers reported that being a caregiver enabled them to communicate love and commitment, and enhanced their relationship (Brotman et al., 2007; Hash, 2002; Fast, 2015). However, others reported that caregiving created tension in their relationship, conflict with jobs, a reduction in finances, isolation, loneliness, and depression (Hash, 2002). Coon (2003) suggests that caregiving can result in stress, physical and mental suffering, anxiety, fatigue, and caregiver strain. Caregiver stress can be mitigated by support, specifically when the support outweighs the demand of caregiving (Shiu et al., 2016). Economic costs to caregiving

include care labour, employment restrictions, and out-of-pocket expenses (Battams, 2016; Fast, 2015). Financial contributions of caregivers are significant, with an estimated 12.6 million dollars spent by caregivers in 2006 (Torjman, 2015), and 41% of caregivers reporting that they use personal savings in their caregiver roles (Canadian Caregiver Coalition, 2013). Financial spending can be especially damaging for low-income caregivers, who spend disproportionately more of their income on their caregiving role (Torjman, 2015). Financial support and general support services are difficult to attain—high demand and strict eligibility criteria means that these services are available “in theory, but not in practice” (Torjman, 2015, p. 8).

LGBT Informal Caregiving Context

Given the evidence on the hesitancy of accessing formal health services among LGBT individuals, informal caregiving may be more complex for LGBT older adults than majority populations. There is considerable fear among aging LGBT adults around who will provide their care in later life (Furlotte et al., 2016; Shiu et al., 2016), likely due to their previously discussed life trajectories and smaller caregiving pools as a result (Stinchcombe et al., 2016). Isolation risk may be higher for LGBT caregivers, as they may become separated from LGBT communities in their role (Hughes & Kentlyn, 2011; Rawlings, 2012). LGBT caregivers also provide more hours of care than the general population of caregivers, and therefore experience more role strain (Fredriksen, 1999). Additionally, due to the low access rates of formal healthcare services, there is increased demand from the informal caregiver to meet needs (Aronson, 1998; Brotman et al., 2007; Czaja et al., 2016; Gabrielson et al., 2014; Hughes & Kentlyn, 2011). The fear around accessing healthcare services is seen in caregivers as well as care receivers – Rawlings (2012) suggests that caregivers fear discrimination upon leaving their care receiver with formal services.

As seen more generally in the caregiving literature, a sense of love, obligation, commitment, and reciprocity exist as motivators for caregiving among LGBT individuals (Aronson, 1998; Brotman et al., 2007). Shiu and colleagues (2016) suggest that this mutual care may have originated in the HIV/AIDS epidemic, when biological families or origin families were often unwilling to provide care. Unlike among non-LGBT individuals, caregiving among LGBT persons is often performed by and for non-kin individuals (Grossman et al., 2007; Shiu et al., 2016). Additionally, caregiving duties are often shared and diffused through a wider network of support, namely LGBT communities (Brotman et al., 2007; Shiu et al., 2016). Also unlike the general caregiving community, gender roles are not as rigid and do not predict the caregiving division of labour among LGBT individuals (Aronson, 1998; Coon, 2003; Grossman et al., 2007; Hughes & Kentlyn, 2011; Stinchcombe & Wilson, 2018).

Often, heterosexual and cisgender individuals generally receive and provide care for biological family; whereas, LGBT individuals often receive and provide care for families of choice (Barker et al., 2006; Brennan-Ing et al., 2014; McParland & Camic, 2016). This being said, biological families can and do provide care for aging LGBT individuals, and tend to be supportive when they are present and functional in an LGBT individual's life (Brennan-Ing et al., 2014; Brotman et al., 2007; Fredriksen, 1999). However, in the majority of cases documented in the literature, LGBT older adults may be estranged or have concealed their identity from biological family, making care from origin families not an option (Aronson, 1998; Barker et al., 2006; Choi & Meyer, 2016). When biological family is absent, or even in the presence of biological family, families of choice fill the role of support and care (Barker et al., 2006; Brotman et al., 2007; Choi & Meyer, 2016; Fredriksen, 1999; Stein et al., 2010). Families of choice, specifically partners, friends, and neighbors, are deemed the primary caregivers and care

network for LGBT older adults (Brotman et al., 2007; Choi & Meyer, 2016; Czaja et al., 2016; Duffy & Healy, 2014; Hughes & Kentlyn, 2011; McParland & Camic, 2016; Stein et al., 2010; Stinchcombe et al., 2016). The importance of family of choice cannot be understated in the support and care of older LGBT individuals (Aronson, 1998; Barker et al., 2006; Hughes & Kentlyn, 2011; McParland & Camic, 2016). However, due to the non-biological relationship between caregivers and care receivers, their contributions receive even less recognition than biological or family caregivers (Brotman et al., 2007; Shiu et al., 2016). This may be due, in part, to the fact that non-disclosure of caregiver-care receiver relationships is common (Brotman et al., 2007).

The benefits of caregiving among LGBT individuals are similar to those of non-LGBT caregiving, in that personal growth, relationship strength, self-esteem, and self-efficacy are common experiences (Shiu et al., 2016). Compared to the non-LGBT caregivers, individuals caring for older LGBT adults tend to experience a higher risk of psychological and physical strain, depression, loneliness, poor nutrition, financial problems, job conflicts, less support, the effects of their own aging, and increased stress (Choi & Meyer, 2016; Fredriksen-Goldsen & Hoy-Ellis, 2007; Shiu et al., 2016). Additionally, LGBT caregivers experience a higher demand and less recognition and accommodation, and are therefore at greater risk for caregiver burden (Fredriksen-Goldsen & Hoy-Ellis, 2007; Shiu et al., 2016).

Unique challenges for caregiving among LGBT individuals have been outlined in some of the literature, and include the favouring of biological family, challenges with end-of-life decision making, and a lack of available support (Brotman et al., 2007; Brotman et al., 2015; Duffy & Healy, 2014; Fredriksen-Goldsen & Hoy-Ellis, 2007; Stinchcombe et al., 2017). Unique experiences for LGBT caregivers generally include the attitudes of service providers, the

challenge of identity disclosure, rejection from family, increased invisibility, and a lack of legal protection (Brotman et al., 2007; Hash, 2002; Fredriksen-Goldsen & Hoy-Ellis, 2007). A concern for both caregivers and care receivers is that biological family is often favoured over families of choice for decision-making in healthcare contexts, which may result in missed needs (Duffy & Healy, 2014; Harding et al., 2012). This occurrence reinforces the importance of creating advanced care plans for end-of-life care, as this allows the care receiver to dictate their wishes and ensure protection (Czaja et al., 2016; Fredriksen-Goldsen & Hoy-Ellis, 2007; Rawlings, 2012; Stinchcombe et al., 2017). However, the literature suggests that there is confusion and insufficient use of advanced care plans by LGBT older adults (Stinchcombe et al., 2016), and/or fear that their wishes would not be respected (Rawlings, 2012; Stinchcombe et al., 2017). Support is important for LGBT caregivers due to their increased stress, yet some evidence suggests that family and professionals were not willing to provide support during or after their caregiving roles (Hash, 2002). Additionally, traditional caregiving support groups were found to be unsafe for LGBT individuals, who felt uncomfortable disclosing their care relationship due to the heteronormative nature of the group (Brotman et al., 2007; Brotman et al., 2015; Harding et al., 2012; Shiu et al., 2016).

Rationale

Research indicates that older LGBT individuals may rely more on informal caregiving supports than non-LGBT individuals, because of stigma and discrimination in formal health care settings (Brotman et al., 2007; Czaja et al., 2016; Gabrielson et al., 2014; Hughes & Kentlyn, 2011). As such, “families of choice” are often on the front lines caring for aging LGBT persons (Brotman et al., 2007; Choi & Meyer, 2016; Fredriksen, 1999; Stein et al., 2010). However, research in this area is limited in several key ways. Primarily, the age of inclusion in studies with

older adults often deem 50 plus as an adequate cutoff for older adults, as identified in a literature review by Fredriksen-Goldsen and Muraco (2010). Yet, the literature also suggests that considerable cohort differences exist within the 50 plus age group, and that narrower age restrictions would be beneficial (Brotman et al., 2015; Choi & Meyer, 2016; Fredriksen-Goldsen & Muraco, 2010; Furlotte et al., 2016; Jackson et al., 2008). More Canadian literature is also needed on the topic of informal caregiving among LGBT older adults, as there is a gap in LGBT caregiving and end-of-life literature in Canada (Brotman et al., 2007; Stinchcombe et al., 2016; Stinchcombe et al., 2017; Wilson et al., 2018). The majority of aging LGBT caregiving literature is from the United States (e.g., Fredriksen-Goldsen & Muraco, 2010), Australia (e.g., Duffy & Healy, 2014), or the United Kingdom (e.g., McParland & Camic, 2016). Considering that the Canadian legal and political landscape differs from these other countries, it is important to gain a Canadian perspective (Brotman et al., 2015; Stinchcombe et al., 2016). Lastly, more diversity is needed in terms of participants recruited in order to ensure that policy and practice is being informed by a diverse and appropriate sample (Brotman et al., 2015). Multiple authors (e.g., Brotman et al., 2015; Choi & Meyer, 2016; Czaja et al., 2016) have suggested increased diversity in terms of social positions (ethnicity, race, ability, etc.) and geographic location (rural versus urban) is needed, and have highlighted the need to actively include more bisexual and transgender perspectives in sexual minority research samples. These limitations of the literature help to explain the necessity for this study.

Canada has made positive strides for LGBT rights; nevertheless, more work is needed in policy and practice in order to ensure an equitable aging experience for the diverse aging population. The fear and discrimination within healthcare against LGBT older adults coupled with the preferred assistance of families of choice indicates that these supports may be

increasingly responsible for informal care as the population continues to age (Barker et al., 2006; Brotman et al., 2007; Choi & Meyer, 2016; Fredriksen, 1999; Stein et al., 2010). Individuals who care for LGBT older adults are a critical part of the social fabric for LGBT individuals (Barker et al., 2006; Hughes & Kentlyn, 2011; McParland & Camic, 2016); therefore, caregiver needs and supports are important topics of investigation. The current study aimed to explore the experiences of LGBT older adults in terms of informal caregiving and care receiving, particularly in a Canadian context. Specifically, this study aimed to address the following research questions:

1. What are the needs of aging LGBT caregivers and/or individuals caring for LGBT older adults? (e.g., Support, accessibility, specificity of services, health and social care providers)
2. How can the formal healthcare system better meet the unique needs of informal LGBT caregivers/care receivers?
3. What is the role of support and/or families of choice in aging LGBT caregiving?

Theoretical Frameworks

This study used two guiding frameworks: the theory of intersectionality and the life course theory. The theory of intersectionality poses that the cumulative effects of one's social identities within their social context shape ones' lives and experiences (Choi & Meyer, 2016; Fredriksen-Goldsen & Muraco, 2010; Fredriksen-Goldsen et al., 2014; Furlotte et al., 2016). Within the current context, older LGBT adults experience the intersections of a minority aging identity as well as minority sexual identity, which can be combined with additional minority statuses depending on the individual (Coon, 2003; Fredriksen-Goldsen & Hoy-Ellis, 2007; Wilson et al., 2018). This theoretical perspective is useful in the creation of evidence-informed

policy, as makers need to ensure that changes are being made on behalf of all individuals rather than the voices of the most advantaged – in this context, considering the voices of LGBT older adults with additional marginalized identities will be important in the development of knowledge translation (Brotman et al., 2015).

The life course theory posits that social context, culture, and location as well as how time, historical period, and cohort shapes an individuals aging processes and life transitions (Fredriksen-Goldsen & Muraco, 2010). This theory helps to explain how and why individual differences and outcomes exist within cohorts (Choi & Meyer, 2016). The life course theory explores individual transitions and movement along a continuum, but also allows for consideration of current and historical influence (Wister & McPherson, 2013). Additionally, this theory highlights the fact that lives are linked: dyads, networks, relationships across generations and cohorts, and larger links between individuals/groups and the larger institutions in which we exist are all encompassed by the life course theory and all influence each other (Bengtson, Elder & Putney, 2005). However, the life course theory has some notable limitations; life trajectories are largely informed by the macro-environments and surrounding cultures in which a particular person exists, which Fabbre (2017) suggests are largely hetero- and cis-normative. Therefore, this theory is largely used in gerontological research to reinforce the idea that heterosexual/cisgender trajectories are the norm and can result in a lack of diversity recognition (Fabbre, 2017). This made the involvement of persons with several marginalized identities even more important in the context of this study, to help deconstruct the traditional trajectories of aging that have been largely informed by majority populations.

The combination of these theories allows for the exploration of individual differences over time and context as well as understandings of power and marginalization within society

(Brotman et al., 2015). These theories were used to inform the broad research questions, the survey questions, as well as provided a lens for data coding and analyses.

Method

Methodological Approach

Online surveys, comprised of qualitative and quantitative questions, were used to collect data for this study. Online surveys were chosen due to the somewhat sensitive nature of the content, as well as to increase accessibility and facilitate the cross-country nature of this study. Online surveys are beneficial in qualitative research as they guarantee consistent methods of questioning while still allowing for individualized responses (Braun & Clarke, 2013). Online surveys specifically allow for larger sample sizes and more geographic variability, which is important given our aim to include participants from across the country (Braun & Clarke, 2013). The open-ended questions were created as an ideal method to gain open and in-depth information about the needs, experiences, and overall state of caregiving among LGBT older adults. Demographic and descriptive questions were created in order to make quantitative comparisons by participant characteristics. Due to the online nature of this survey, the qualitative and quantitative questions served as an appropriate method for collecting a large amount of data from participants without the burnout that may be present with a strictly qualitative online survey. This study received ethical approval from the University of Guelph Ethics Boards (REB #18-11-010) on November 27th, 2018 (Appendix A).

Participants

I aimed to recruit a minimum of 35 participants, which falls slightly above the range (15-30 participants) indicated by Braun and Clarke (2013) as necessary to identify trends in qualitative data; more participants were desired due to the fact that both qualitative and

quantitative questions were used in this study. Inclusion criteria included restrictions for age; given my specific interests in aging, individuals were required to be aged 65 and older. Although some researchers use age 50 as their cutoff, there are significant cohort differences among LGBT+ older adults in terms of historical experiences and discrimination; accessing the lived experience of a more precise age group, specifically an older age group, was identified as an important goal for this study. Inclusion criteria also required participants to identify as LGBT (lesbian, gay, bisexual, and/or transgender); however, a note was added that individuals who use different descriptors for their identities were also welcome to participate. Lastly, participants needed to reside in Canada. The sampling methods were purposive, as the study aimed to explore a specific phenomenon within a specific Canadian subgroup.

Measures

I created the majority of the measures used in the survey; however, they were then reviewed and revised in collaboration with my advisory committee. The survey questions were informed by the literature (e.g., asking participants about their connection to the larger LGBT communities, as literature suggests that these connections have potential implications on aging outcomes). A review of the survey was conducted with my advisory committee members, as well as with a group of peers, to ensure appropriate presentation and content of the questions, for accessibility, spelling and grammar, and flow, and for understanding and clarity of the survey as a whole.

The survey included three screening questions, 12 demographic/preliminary questions, and 27 main content questions (Appendix B). The only questions that were not created researcher-created included three demographic questions (Appendix B, questions 6, 8, 9). Specifically, *An Inclusive Gender Identity Measure* by Hauptert, Pope, Garcia and Smith (2018)

was used for the demographic questions regarding gender identity, transgender status, and sexual orientation. The main content section contained questions about social support, caregiving and care receiving, healthcare experiences, and formal services/supports. These questions were left open-ended/qualitative where possible, to allow for participants to add in additional comments and experiences.

Recruitment

LGBT older adults are identified as a hard-to-reach population, especially given their history of discrimination (Braun & Clarke, 2013). Therefore, snowball sampling through online means or word-of-mouth recruitment was utilized. Specifically, recruitment occurred through the uploading of posters (Appendix D) to social media (i.e., Facebook, Twitter), which were available for viewers to share to their personal pages. Posters were also shared on LGBT+ Reddit forums. Lastly, the research project and recruitment poster were posted to/shared with LGBT+ organization pages.

Specifically, between December 3rd and 5th, 2018, the first round of survey dissemination occurred through a social media send out and Reddit posting. The recruitment poster and a small information blurb was posted to Facebook and Twitter and was later shared by peers. Several key influencers and organizations from LGBT communities shared the post on social media, allowing the survey to reach beyond our readily available networks. The same poster and informative blurb were posted on LGBT+ Reddit forums, specifically ‘r/ainbow’, ‘r/lgbt’, and ‘r/lgbtelders’. On December 20th, 2018, the study information and poster were approved and posted to Rainbow Health Ontario research page. A secondary social media posting was done on March 4th, 2019; community organizations (e.g., senior service agencies, caregiving organizations, etc.) were tagged on Twitter to facilitate further dissemination. Lastly, on

February 15th, 2019, contact was made with LGBT+ organizations (e.g., LGBT resource centers, LGBT older adult organizations) via email, specifically targeting western Canada. Western Canada was targeted at this time in hopes of increasing the geographic distribution of responses, specifically within Alberta and British Columbia where we had received limited responses. The survey was closed on March 31st, 2019 and all partial responses were recorded at this time.

Procedure

Surveys were created using Qualtrics software and were published online, accessible through a shareable link. Recruitment materials included a link to the online survey. Participants were first prompted with an information letter, instructions for completion, and a consent agreement prior to accessing the survey questions (Appendix C). Eligibility screening was embedded within the survey as required questions, all of which would only allow the participant to continue if they gave the appropriate response (e.g., responding ‘Yes’ to ‘Do you live in Canada?’). Demographic questions were also embedded within the survey. After completion of the survey, the participants were thanked for their time and participation, offered accessible support resources, and were provided contact information in case they had questions or concerns.

Data Cleaning

Data and responses were made anonymous via Qualtrics. The data cleaning process began with 66 individuals, all of whom agreed to participate in the survey through the online consent form. After the screening questions, 57 individuals were eligible to participate in the study. Of the 57 eligible participants, two individuals ended the survey immediately after the screening questions, and four individuals ended the survey part-way through or immediately after the demographic questions. Abiding by my ethics application, partial responses were recorded and used in the data analysis; however, participants that did not begin the main block of

survey questions (beyond demographics) were not included in the analysis. After an initial review of the data, I noticed a birth year of 1955 (age 63-64) was indicated in a demographic question, and this individual's data was removed due to inconclusive age status. This concluded the data cleaning process, resulting in 50 participants. The full data cleaning process can be found below (See *Figure 1*).

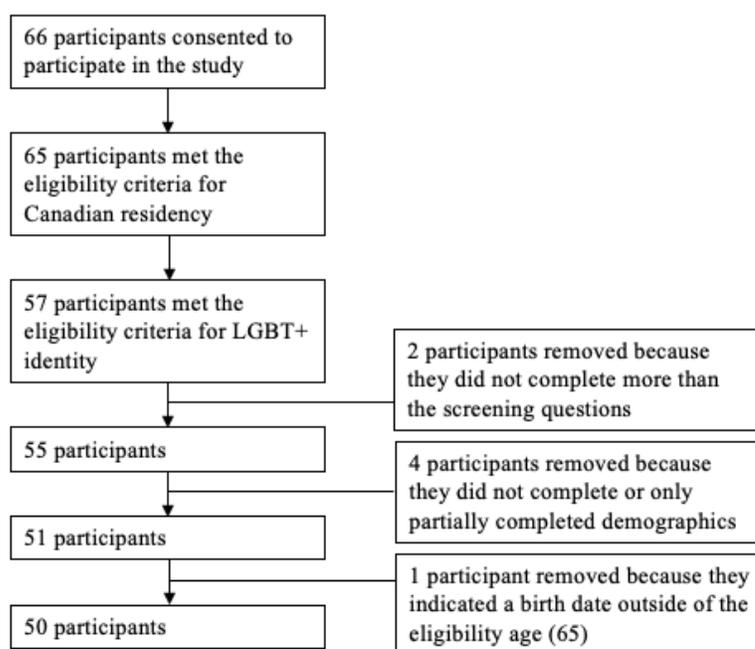


Figure 1. Data cleaning process, resulting in the final inclusion of 50 participants.

Analyses

Content analysis was used to analyze the qualitative survey data, systematically describing the phenomenon through sorting data into content-related categories (Elo & Kyngas, 2008). Specifically, inductive content analysis was used; inductive methods entail the creation of categories as data is read and processed, rather than the use of pre-constructed categories (Elo & Kyngas, 2008; Hsieh & Shannon, 2005). Content analysis is the process of systematically

determining themes and sub-themes from participant responses with the goal of understanding the overall phenomena and the contextual meaning of the data (Hsieh & Shannon, 2005).

The content analysis process began with downloading all of the data from Qualtrics. Once downloaded, the qualitative data was printed and read in depth several times to become fully immersed in the content and to quality check. All survey questions were then mapped onto the research questions, specifically sorting the survey questions based on which research question the survey responses would help to answer. A content analysis guide by Erlingsson and Brysiewicz (2017) was consulted, which describes four broad steps of analyses: familiarizing oneself with the data, dividing the text into meaningful units and subsequent combining of the units, formulating codes, and then developing categories and themes. For my analyses, after mapping the survey questions onto the research questions, the qualitative data was read once again, and preliminary units were developed (i.e., *“That they respect me and the fact that I have unique knowledge that might be useful to them”* into “respect me, I have unique knowledge”). The questions were then reviewed one at a time, line by line, adding in units and combining them as needed to create codes (i.e., respect, willingness to learn). Where applicable, codes were then collapsed and combined to create distinct categories and to avoid repetition between questions (i.e., moving respect into a category about interpersonal/personal efforts). Certain questions were also collapsed together by the similarity in codes and qualitative content (i.e., combining questions 34 and 43 about positive and negative experiences with a healthcare professional, respectively). Themes were created based on the content of the questions and combinations of codes and themes; themes were created to represent the underlying, interpreted messages of the participant data (i.e., interpersonal/personal efforts became ‘people who care have to care’).

Relevant verbatim passages were extracted from the data to accurately support the created themes and underlying codes.

The nature of this process was not linear, and the data were repeatedly reviewed and revisited at each stage to ensure that it was being accurately represented by the developed codes, categories, and themes. Content analysis was a feasible option due to the preciseness and consistency of the entire research process from data collection through reporting (Elo, Kääriäinen, Kanste, Pölkki, Utriainen & Kyngäs, 2014). To improve accuracy of the content analysis method, rigor is required in every stage of the analysis process: preparation, organization, and reporting of the data (Elo et al., 2014).

Descriptive statistics were used to analyze the quantitative survey data, specifically noting the mean (*M*), mode, standard deviation (*SD*), and range of responses where appropriate. These statistics were available through Qualtrics, specifically using the Report tool.

Results

Sample Characteristics

After data cleaning, the responses of 50 participants were used. Participant birth year ranged from 1935 (age 83-84) to 1954 (64-65) with a mean and median birth year of 1948 (70-71). Age ranges were included in brackets, as birth month was not provided and precise age at time of survey completion cannot be calculated. The sample included 29 male participants (58%), 20 female participants (40%), and one participant who specified their gender identity as 'transsexual' (2%). Of the 46 participants who answered the demographic question regarding transgender identity, two participants responded, 'Yes' (4.35%), one participant responded, 'Do not know' (2.17%), and the remainder responded 'No' (93.48%). Participants were able to select more than one option if applicable; the majority of participants identified as gay (41.43%),

lesbian (24.29%), and/or queer (14.29%), then same-gender loving (10%), bisexual (5.71%), asexual (2.86%), and/or pansexual (1.43%). See Table 1 for a summary of participant demographic characteristics.

All participants responded to the demographic question regarding partner status, with 24 married/living in common-law participants (48%), 17 single participants (34%), four widowed participants (8%), one divorced participant (2%), and one separated participant (2%). Three participants entered alternative responses to the partner status question: specifically, ‘annulled due to sexual orientation’, ‘web of relational connections’, and ‘part-time common-law’. The racial diversity of the participants was limited, with 47 participants who identified as Caucasian (94%), one participant identified as Metis (2%), one participant identified as Black (2%), and one participant responded with ‘Norwegian’ (2%). The majority of participants, 47 (94%) were of Canadian ethnicity, ten of which identified as French-Canadian (20%), and three of which identified as British-Canadian (6%). One participant identified with British ethnicity (2%), one participant identified as German (2%), and one participant identified as Mixed Euro (2%).

Geographic distribution across Canada was somewhat limited, with the majority (70%, 35 participants) of respondents residing in Ontario. Seven respondents were from Quebec (14%), three from Nova Scotia (6%), two from Manitoba (4%), two from British Columbia (4%), and one from Newfoundland and Labrador (2%). Within these provinces, 41 participants indicated that they live in an urban location (82%), and nine participants indicated that they live in a rural location (18%).

Table 1

Demographic Summary Table

| Demographic Item | Results |
|------------------|---------|
|------------------|---------|

| | | | |
|----------------------|--|-----------------------------|----------------------------|
| Birth Year | Range: 1935 (age 83-83) – 1954 (age 64-65) Mean: 1948 (age 70-71) Median: 1948 (age 70-71) | | |
| | Response | Number of Participants (n) | Percentage of Participants |
| Gender | Male | 29 | 58% |
| | Female | 20 | 40% |
| | Transsexual | 1 | 2% |
| Transgender Identity | Yes | 2 | 4.35% |
| | No | 43 | 93.48% |
| | Do not know | 1 | 2.17% |
| Sexual Orientation | Gay | N/A (select all that apply) | 41.43% |
| | Lesbian | | 24.29% |
| | Queer | | 14.29% |
| | Same-gender loving | | 10% |
| | Bisexual | | 5.71% |
| | Asexual | | 2.86% |
| | Pansexual | | 1.43% |
| Partner Status | Married/common-law | 24 | 48% |
| | Single | 17 | 34% |
| | Widowed | 4 | 8% |
| | Divorced | 1 | 2% |
| | Separated | 1 | 2% |
| | Other | 3 | |
| Race | Caucasian | 47 | 94% |
| | Metis | 1 | 2% |
| | Black | 1 | 2% |
| | Norwegian | 1 | 2% |
| Ethnicity | Canadian | 47 | 94% |
| | [French-Canadian] | 10 | 20% |
| | [British-Canadian] | 3 | 6% |
| | British | 1 | 2% |
| | German | 1 | 2% |
| | Mixed-Euro | 1 | 2% |

Participants were asked about their general health, to which most participants selected ‘very good,’ followed by ‘excellent’ and ‘good,’ and lastly ‘fair’, and ‘poor.’ Participants were

asked about their mental health, to which most participants selected ‘very good’, followed by ‘excellent’, ‘good’, ‘fair’, and then ‘poor’. See Table 2 for a health status summary.

When asked how the participants found the survey link, 25 participants (50%) named one specific pride organization, ten participants (20%) named Facebook, four participants (8%) mentioned friends and/or colleagues, five participants (10%) named groups/agencies and five participants (10%) mentioned email or other online means as the source of the survey link. The survey took participants an average time of 26 minutes to complete, with a range of seven minutes to one hour and 57 minutes.

Table 2

Health Status Summary Table

| | Response | Number of Participants (n) | Percentage of Participants |
|-----------------------|-----------|----------------------------|----------------------------|
| General Health Status | Excellent | 12 | 24% |
| | Very Good | 19 | 38% |
| | Good | 12 | 24% |
| | Fair | 5 | 10% |
| | Poor | 2 | 4% |
| Mental Health Status | Excellent | 18 | 36% |
| | Very Good | 20 | 40% |
| | Good | 9 | 18% |
| | Fair | 2 | 4% |
| | Poor | 1 | 2% |

Caregiving Needs

My first research question was, “*What are the needs of aging LGBT caregivers and/or individuals caring for LGBT older adults?*” In order to answer the research question regarding the unique needs of LGBT caregivers and/or carers of LGBT older adults, the survey questions found in Table 3 were used. The results for this research question suggested that although there are some healthcare similarities between LGBT older adults and their heterosexual/cisgender

counterparts, there are unique needs and wants by/for LGBT older adults in caregiving and care receiving roles.

Table 3

Survey Questions Used to Answer Research Question One

| Question # | Question Type | Question |
|------------|---------------|---|
| 32 | Quantitative | Indicate the extent to which LGBT caregivers have the same or unique needs from heterosexual/cisgender caregivers (scale) |
| 33 | Qualitative | Indicate the extent to which LGBT caregivers have the same or unique needs from heterosexual/cisgender caregivers (previous). Please explain. |
| 35 | Qualitative | As a patient, what is important to you when interacting with a healthcare professional? |
| 36 | Qualitative | As a caregiver, what is important to you when interacting with a healthcare professional? |

When asked about the degree in which LGBT caregivers' needs are similar to or different from heterosexual and/or cisgender caregivers, participants responded with a mean of 5.02 on a scale of one to ten ($M = 5.02$, $SD = 3.10$). Responses ranged from 0 (4 respondents), indicating that needs are the exact same, to 10 (5 respondents), indicating that the needs are completely unique. The most common response by participants, the mode, was 5 (7 respondents). These results indicate that, on average, participants felt that there were some similarities and some unique aspects of caregiving when comparing heterosexual/cisgender caregivers and LGBT caregivers. These results were further reinforced through qualitative responses, in which there was a fairly equal divide between respondents that felt as though the needs were the exact same and respondents that felt that the needs were unique. One participant responded, "Same...care is care," inferring that the needs of LGBT caregivers would not differ from those of heterosexual caregivers. On the other side of the spectrum, one participant responded, "Everything is different and unique, given that my core identity is 180 degrees away and separated from a heterosexual

core identity...” As seen in the quantitative responses, many individuals felt that although there were some similarities, there would be/are unique aspects to LGBT caregiving. One participant spoke on this middle-ground status, stating,

LGBT caregivers understand LGBT issues and can relate to the nuances involved.

Although we are human and share a lot of the same needs as Heterosexuals [sic], there is a shared history within the LGBT community that often is only understood by people who have lived with the fear and hurt of being "different".

Many participants noted considerations that would result in LGBT caregivers having unique needs: a background of oppression, heteronormative/cisnormative services, more complex navigation of services, advocacy efforts, and uncomfortable institutional settings. These factors would result in movement from having identical needs toward having unique needs in care settings; these factors are unique to LGBT individuals, in some cases LGBT older adults specifically.

Participants were asked what factors were important to them in both caregiving and patient roles when interacting with a healthcare professional. The codes and final themes for this question are summarized in Table 4. Two themes were identified in the qualitative responses provided: *Care is care: Basic rights* and *LGBT identities affect care: It takes more*.

Table 4

| <i>Question 35 and 36 Codes and Themes</i> | | |
|--|---------------------------------|--|
| Question(s) | Codes | Themes |
| Q35: As a patient, what is important to you when interacting with a healthcare professional? | Adequate care/treatment | 1) <i>Care is care: Basic rights</i> |
| | Identity | |
| | awareness/acceptance | 2) <i>LGBT identities affect care: It takes more</i> |
| | Listened to | |
| Q36: As a caregiver, what is important to you | Accessibility/language | |
| | Time/not rushed | |
| | Caregiver role/status awareness | |

| | |
|---|--|
| when interacting with a healthcare professional? | Partner respect/recognition Demeanor/comfort Respect Taken Seriously Willing to learn Professional/attentive Empathy/understanding Trust/openness/honesty Advocacy |
|---|--|

Care is care: Basic rights. When interacting with healthcare professionals, the *Care is care: Basic rights* theme describes experiences within care systems that could be generalized to the entire aging population. The codes within this theme were categorized together and represent experiences of basic rights within healthcare, and essentially a baseline of care for all aging individuals. This theme describes aspects of care that are expectations within heteronormative/cisnormative care systems. Participants mentioned several aspects of healthcare that are generally perceived as rudimentary within care settings. These included: adequate care/treatment, being listened to, not being rushed, provider comfort and demeanor, and respect. Several participants also noted the importance of having their concerns taken seriously as a patient, as well as having attentive and professional providers. As a potential caregiver, empathy and understanding were also considered important when interacting with a healthcare professional. Participant responses such as, “Quality health care for the patient, communication with the caregiver,” and “quality health care” exemplify this theme, in that these wants/needs represent basic expectations of healthcare professionals and healthcare contexts; these would be applicable to the entire aging population.

LGBT identities affect care: It takes more. As an LGBT older adult, there were several other factors identified as necessary and/or important in healthcare interactions that are not often considered as part of a baseline experience within heteronormative/cisnormative services. These

experiences are represented by the theme *LGBT identities affect care: It takes more*. This theme draws attention to the unique aspects of receiving or giving care for/by LGBT older adults within the current healthcare landscape. Codes were identified in both of the questions that asked about interactions with healthcare professionals in either a patient or caregiver role. Several codes were recurring, underscoring their importance: LGBT identity awareness and acceptance, a practitioner's willingness to learn, respect and communication with a patient's partner, partner role recognition as a caregiver, and an environment that supports trust, openness, and honesty. Additionally, several participants identified accessibility of information and language and advocacy as important when interacting with a healthcare practitioner. Specifically, having health information presented in an understandable and accessible way and using language that is respectful including preferred pronouns was identified as meaningful. As well, advocacy was identified as important, in that several participants noted the importance of being able to (patient) or having someone to (caregiver) advocate for their care quality and unique needs in care.

LGBT identity and awareness and acceptance were identified as important in both caregiving and patient roles, "That the professional know that I am gay and is comfortable with that..." Specifically, participants expressed that the ability to approach healthcare providers and healthcare environments as their authentic selves was important. A practitioner/provider's willingness to learn was also identified as important, with several participants indicating that they sometimes need to educate/provide information on their specific needs, "That they respect me and the fact that I have unique knowledge that might be useful to them." Partner recognition and respect was identified as important by participants in both caregiving and patient roles; as a patient, it was deemed important that their partner was recognized, involved, and informed, "I need them to respect me and also to treat my wife with the respect she deserves." As a caregiver,

the participants expressed the importance of having the healthcare provider acknowledge and appreciate their potential relationship with the care receiver, "...treats me with respect and understanding that I have a relationship with the person I am caring for." Partner recognition and respect was a frequently mentioned factor, indicating the importance of partner inclusion in the care process. The atmosphere was also noted as important, specifically desiring trust, openness, and honesty in their interactions and experiences with care and providers. One participant noted that within care environments, they desire being,

...able to speak openly and honestly about all of the circumstances of the persons I am helping regardless of the sexual orientation of the individuals involved. The sexuality of myself, OR the person being cared for should be irrelevant. Same sex partners should be treated in the same manner as opposite sex partners.

These results from the first research question demonstrate that although there are some similarities in caregiving/receiving among heterosexual/cisgender and LGBT older adults, there are unique considerations. This was reinforced by the qualitative responses, where many responses went beyond the *Care is care: Basic rights* theme to underscore additional important factors in care, *LGBT identities affect care: It takes more*. In response to the research question, "What are the needs of aging LGBT caregivers and/or individuals caring for LGBT older adults?" several factors were identified as important by participants: awareness and acceptance, willingness to learn, partner recognition, respect, and advocacy. All of these factors have been identified as unique factors/additional efforts for LGBT individuals in Canadian literature except for a practitioners' willingness to learn (Brotman et al., 2015; Brotman et al., 2003; Furlotte et al., 2016). This factor may have been identified in the current study as a result of the way the questions were asked, as this theme was more common in the question regarding being in a

caregiving role; historically, questions may have been asked about important aspects of care from a care receivers' point of view. Seeing as the majority of caregiving among aging LGBT adults is performed by friends or family of choice, the respondents may have had the opportunity to express their unique expertise of the care receivers' needs, "...I have unique knowledge that might be useful to them."

Healthcare System Improvements

My second research question was, "*How can the formal healthcare system better meet the unique needs of informal LGBT caregivers/care receivers?*" In order to answer the research question regarding formal healthcare system improvements for LGBT caregivers, the survey questions found in Table 5 were asked. Having established that the majority of the participants anticipated needing formal services as they age, participants spoke about the factors that would contribute to either a negative or positive experience in healthcare and which social positions would be most impactful on care quality.

Table 5

Survey Questions Used to Answer Research Question Two

| Question # | Question Type | Question |
|------------|---------------|--|
| 24 | Quantitative | Have you received/are you receiving informal unpaid care for a long-term condition, aging need, or disability? |
| 26 | Quantitative | Is this a current or previous care receiving role? |
| 27 | Quantitative | Have you been/are you an informal caregiver for an individual with a long-term condition, aging need, or disability? |
| 29 | Quantitative | Is this a current or previous caregiving role? |
| 34 | Qualitative | Think back to a positive experience with a healthcare professional. How did they show you that they care? How did they make you comfortable? |
| 43 | Qualitative | Think back to a negative experience with a healthcare professional. What actions or lack of actions did you find unpleasant? |
| 37 | Quantitative | As you grow older, do you anticipate needing any formal services/supports? |

| | | |
|----|--------------|--|
| 38 | Quantitative | What services do you anticipate needing? Select all that apply |
| 39 | Quantitative | In your opinion, how successful are the current services at meeting your needs? |
| 40 | Qualitative | As you grow older, what informal (social) support do you anticipate needing? |
| 42 | Quantitative | Place these in order of how much you believe they would impact the quality of care an individual receives in a healthcare setting (e.g., hospital, long-term care, clinic, etc.) |

Participants were asked whether they had received informal care for a long-term condition, disability, or aging need, to which four participants (8%) responded yes, and 46 participants (92%) responded no. Three of the four participants indicated that this was a previous care experience (75%), and one participant indicated that this was current care (25%).

Participants were also asked whether they had provided informal caregiving for a long-term condition, disability, or aging need, to which 25 participants (50%) responded yes, and 25 participants (50%) responded no. Of the 25 respondents who identified as having provided caregiving, only 22 responded to the follow-up question about whether this was a previous or current caregiving role: 11 participants indicated that this was a previous role (50%), and 11 participants indicated that this was a current role (50%). See Table 6 for a summary of this sample's caregiving and care receiving experiences.

Table 6

Caregiving and Care Receiving Experience Among Participants

| | Response | |
|------------------------|-----------------------------|--|
| Received Informal Care | No – 92% (46 participants) | |
| | Yes – 8% (4 participants) | Previous – 75% (3 participants) Current – 25% (1 participant) |
| Provided Informal Care | No – 50% (25 participants) | |
| | Yes – 50% (25 participants) | Previous – 50% (11 participants) |

Participants were then asked about whether they anticipated needing formal services/supports, to which 44 participants responded, 38 indicated yes (86.36%), and six indicated no (13.64%). When asked how successful the participants felt the current formal services in meeting their needs were on a scale of 0 to 10, participants responded with a mean of 5.89 ($M = 5.89, SD = 3.18$). The range of participant responses was from 0 (2 respondents), indicating services are unsuccessful in meeting their needs, to 10 (5 respondents), indicating services are very successful in meeting their needs. The most common response, the mode, was 8 out of 10. When prompted further, participants primarily anticipated needing transportation (26 participants) and specialized healthcare (26 participants), followed by housing (20 participants) and financial support (eight participants). Ten participants chose to add additional responses which can be grouped into homecare (six participants), peer/social support (two participants), and legal/financial support (one participant). See Figure 2 for a summary of responses for anticipated services needed. One participant specifically responded, “Extra help at home so I can age in place,” indicating the importance of adequate and inclusive home care for LGBT communities.

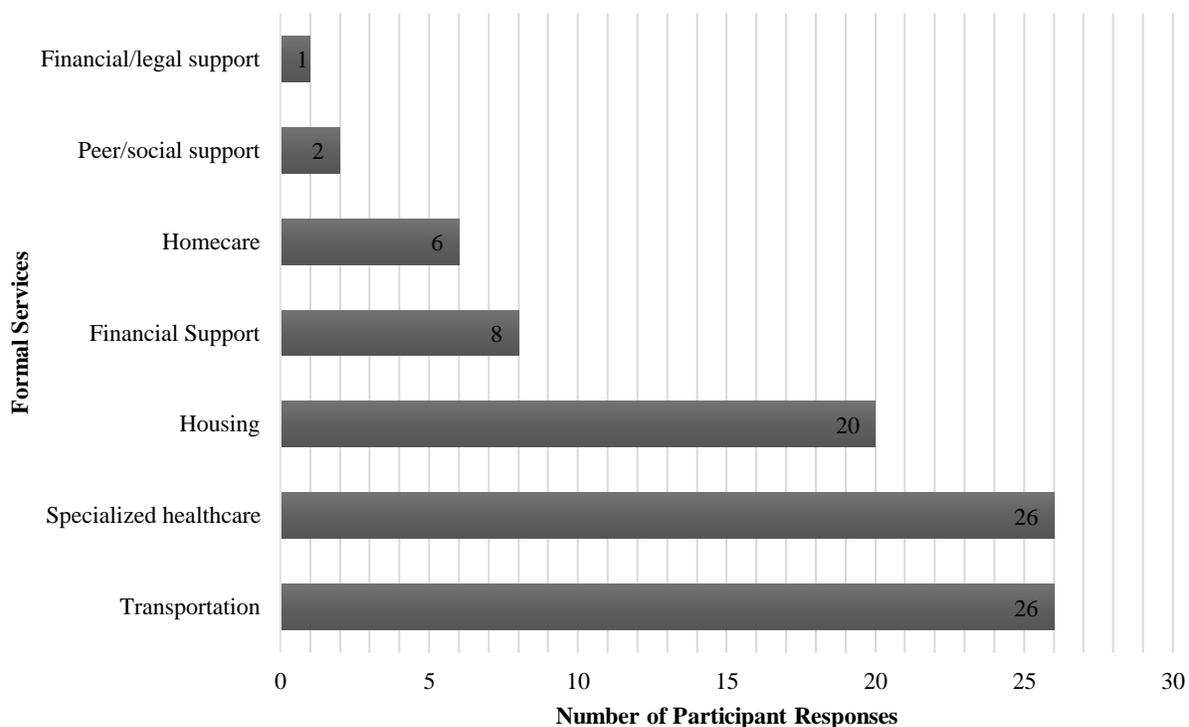


Figure 2. Anticipated types of formal services needed by participants.

Participants were asked to order a variety of social positions according to the degree in which they would impact the quality of care one would receive in a healthcare setting: age, (dis)ability, sexual orientation, gender identity, race/ethnicity, geographic location, socioeconomic status (SES), and language. Results are described by position/ranking, with position one indicating a perceived higher impact on care quality and position 8 indicating a perceived lower impact on care quality. The factors most frequently placed in positions 1, 2, and 3 can therefore be regarded as the most influential on care quality according to this sample; the factors most frequently placed in positions 6, 7, and 8 can be regarded as the least influential on care quality according to this sample. The factor most frequently placed in position 1 was age, with 23.81% of participants indicating age as the most impactful on care quality. The factors most frequently placed in positions 2 and 3 were (dis)ability (28.57%) and gender identity

(19.05%), respectively. The factors most frequently placed in positions 6 and 7 were geographic location (19.05%) and race/ethnicity (26.19%), respectively. The factor most frequently placed in position 8, therefore regarded as least impactful on care quality, was language (40.48%). This ranking question can also be explained using the mean (M) of each social position, with a lower mean (closer to 0) indicating a greater perceived influence on care quality and a higher mean (closer to 8) indicating a lower perceived influence on care quality (See Table 7). According to the mean values, age was perceived as the most influential on care quality and language was perceived as the least influential on care quality.

Table 7

Social Positions and Perceived Impact on Quality of Care

| Social Position | Mean (M), 0-8 |
|----------------------------|-------------------|
| Age | 3.74 |
| (Dis)ability | 3.43 |
| Sexual Orientation | 4.17 |
| Socioeconomic Status (SES) | 4.26 |
| Gender Identity | 4.33 |
| Geographic Location | 4.81 |
| Race/ethnicity | 5.48 |
| Language | 5.79 |

Participants were asked about the informal/social support that they anticipate needing as they continue to age, to which there were 38 varied responses. See Table 8 for a summary of the informal supports needed. Three participants indicated “social support” in general as important, and many other participants identified several specific types of social support: five participants indicated the importance of having people check in on them, seven participants indicated interaction and companionship as important, and three indicated the prevention of isolation

and/or loneliness as important. Friends and family were also a common response, with eight participants indicating this in their response, two of which identified LGBT-specific friends. Community and group membership were also identified as important, with 14 respondents indicating this source of support, three of which identified LGBT-specific groups. Six respondents anticipated needed housing and/or residency support, one of which identified a desire for LGBT-specific housing. Three respondents indicated an anticipated need of transportation or help getting around. Two participants indicated general emotional support as an anticipated need. Four participants indicated unique responses as anticipated needs: medically assisted death, remaining independent, experiencing issues already, and one participant indicated that they already have all that they anticipate needing.

Table 8

Anticipated Informal Supports Needed by Participants

| Informal Service Type | Number of Participant Responses (n) |
|---------------------------------|-------------------------------------|
| Social Support, Tasks | 18 |
| - Check-ins | 5 |
| - Interaction and Companionship | 7 |
| - Prevent Isolation/Loneliness | 3 |
| Friends and Family | 8 |
| - LGBT Friends | 2 |
| Community and Group Membership | 14 |
| - LGBT Groups | 3 |
| Housing/Residency Support | 6 |
| - LGBT Housing | 1 |
| Transportation/Getting around | 3 |
| Emotional Support | 2 |

To gain insight into the level of cultural competency in the current healthcare service offerings, the participants were asked about positive and negative experiences that they have had

with healthcare professionals. The overarching theme of these qualitative responses is *Quality care: The perfect storm*. Within this overarching theme, two subthemes were identified: *Institutional efforts toward accessibility* and *People who care have to care*. See Table 9 for a visual display of the codes, categorization, and themes used for this analysis.

Table 9

Question 34 and 42 Codes and Themes

| Question(s) | Codes | Themes and Categorization |
|--|--|---|
| Q34 Think back to a positive experience with a healthcare professional. How did they show you that they care? How did they make you comfortable? | No judgement Physical signs Gay-friendly/informed Homophobic experience/comments or fear Assumed heterosexual Not listened to | <i>Quality care: The perfect storm</i> - Gay-friendly/informed - Personalized care - Treatment quality a) <i>People who care have to care</i> - Time - Listening |
| Q43 Think back to a negative experience with a healthcare professional. What actions or lack of actions did you find unpleasant? | Poor/lack of treatment Given time Queer staff Poor demeanor/bedside manner No assumptions Mention partner Rushed Infantilizing/ageism Personalized care Listened to Respect Wait time Spouse not recognized Not listened to Demeanor Intake forms Indifference/invalidation Mirrored language | - Spouse Recognition - Demeanor - Identity Acknowledgement and Respect b) <i>Institutional efforts toward accessibility</i> - Intake forms - Queer staff - Physical signs |

Quality care: The perfect storm. This theme describes the practices that need to be present in order for LGBT caregivers and/or care receivers to access quality healthcare experiences. The ‘perfect storm’ component indicates that although not all of these factors need

to be present for caregivers/receivers to have a positive experience, all of these factors together represent an ideal experience according to the participants. This theme is positioned as overarching because although some of the qualitative responses were explicitly about quality of care, all of the responses and codes are ultimately part of a positive care experience in that institutional efforts and caring providers create quality care experiences. As stated, several participants explicitly referred to quality of care in their negative and positive experiences with healthcare. The qualitative responses indicated that treatment quality was of utmost importance, specifically the presence and quality of the healthcare treatment received. Within the positive experiences question, one participant noted that they have not had any interactions with a healthcare professional thus far, and another participant noted that they were unsure of whether their practitioner knew about their sexual orientation. Within the negative experiences question, one participant noted that they were asked not to come out by another professional due to the nature of their work (healthcare). Poor or lack of treatment was one of the most commonly noted issues by participants within this overarching theme, with one participant stating, “My new Dr (the other one sadly retired) asked if I was sexually active and you could tell from the look on her face she assumed I was not (I am).”

People who care have to care. This subtheme represents participant comments about professionals within healthcare, specifically that the individuals providing care need to demonstrate this care in their interactions with patients and caregivers. Within the previously discussed ‘perfect storm,’ quality healthcare workers make up the majority of the ideal healthcare scenario, with the majority of participant responses being about interpersonal/personal interactions. Several factors were noted by participants in both the negative and positive question; specifically, the factors seemed to exist on a continuum, in that one end of a factor’s

continuum was indicative of a negative healthcare experience and the other end was indicative of a positive experience. Time was one of the most common factors identified by participants, with “They took the time to explain,” at one end of the continuum and “Rushed. I was just a number,” at the other end. Feeling heard was also identified as an important part of the interpersonal healthcare experience, with one participant stating that their practitioner, “Talked but didn't listen...” Alternatively, another participant expressed a more positive experience with listening, “They listened to my feelings and wants and disires [sic].” An additional factor, spousal recognition, was identified by participants; on one end of this continuum, participants noted, “My doctor asked to meet my wife and often asks how my life is going in regards to our relationship,” whereas another participant spoke about the negative end of this continuum, “...treated my wife as if she wasn't there. He even asked if my husband was in the waiting room, twice. I think he was deaf.”

Identity acknowledgement and respect were noted as additional factors of importance by participants; on the negative side of the continuum, assumptions of heterosexuality were reported to contribute to a negative healthcare experience, “Presumption of my marriage to a woman, and then a near-dismissal of my partner when it was revealed that he was my husband not my wife.” Homophobic attitudes and comments would also occupy the negative end of this spectrum; one participant provided an unsettling homophobic account in care,

...one night, in hospital, 3 beds in a room, about 10 years ago. All night long, one of the patients would pretend to snore but would vocalize "fucking faggott" instead of a real snore sound. I complained but got only snickers from nursing staff. I was there for breathing difficulties and was on oxygen. They refused to put my bed in the hall. I grabbed my essentials [sic] and the oxygen and went to a hallway, fund [sic] an easy chair

and plunked myself down. I slept very little. I did complain to the hospital ombudsman and did get an apology letter.

On the positive end of this identity acknowledgement and respect continuum, mirroring patient language and using preferred pronouns were listed as part of a positive healthcare experience. The last important factor of care noted by participants within the *People who care have to care* subtheme was demeanor and comfort. On the negative end of the demeanor continuum, one participant noted their negative interpersonal experience with a practitioner, stating, "...stern, no bedside manner, talked to me as if he was reading from a text book, no smiles or comfort of any kind." In contrast, another participant recalled a positive interpersonal experience with a healthcare professional, "They acted in a warm, accepting manner that indicated that the fact that I was gay made no difference to them." These responses help to demonstrate the diversity of experience among LGBT older adults in healthcare services and display the need for consistent cultural competency training among health and social care providers.

Institutional efforts toward accessibility. Within the *Quality care: The perfect storm* theme, this subtheme represents participant-identified efforts that institutions can make to increase the accessibility and inclusion of healthcare facilities. Several factors were identified as important in creating a culturally competent experience for LGBT older adults: inclusive intake forms, LGBT representation on staff, and physical signs were provided as examples for working toward more accessible care. One participant seemed pleased with their experiences at their healthcare centre, described as, "a very inclusive organization ... LGBT-positive signs all over the place; LGBT people on staff; LGBT-inclusive client and intake forms/policies/outreach." Another participant stated, "Signs in [the] organization indicated willingness, competency," suggesting that visible efforts are important for the perceived capability and acceptance of the

institution. However, although an institution may present these physical signs of accessibility, the *People who care have to care* theme was coded substantially more in the participant data; this suggests that interpersonal/personal factors are the most significant indicator for healthcare experiences, and subsequently the quality of care that LGBT older adults receive.

The results from the first research question suggested that LGBT older adults have unique needs in care settings, making it important to determine how these unique needs can be better met by formal healthcare services. Although the majority of care is performed outside of formal care settings, one must consider the potential long-term consequences of informal caregiving; as stated in the caregiving literature, burnout is common and reliance on formal services for respite, support, or additional resources is likely. Given the fact that many LGBT older adults may be receiving care from/providing care to other aging individuals, the longevity of success in these arrangements may not be extensive, and formal services may be needed. As identified in the data, although only 50% of the sample has/are providing care, 86.36% of the sample indicated anticipating needing formal services at some point in their aging process. Regardless of the nature of the formal services these individuals anticipated needing, the *people* providing services were found to be the most important area for change toward inclusivity. Additionally, although not often desired, most LGBT older adults have experience with formal healthcare services and would be able to accurately anticipate what they would want/need as a caregiver or care receiver. The answers provided by the current participants are important to consider in caregiving and care receiving contexts, but also apply to all aging services. The participants within this sample identified specialized healthcare as an anticipated service they might require, yet housing and transportation were also noted; implementing these changes in

services outside of hospitals/healthcare alone would help to move formal services in a more inclusive direction.

In response to research question two, specifically regarding how the formal healthcare system can better meet the unique needs of LGBT caregivers/care receivers, participants identified the people/providers in care contexts as the most impactful on the quality of their experience. The *Quality care: The perfect storm* theme is comprised of adequate care/treatment, institutional efforts, and caring providers; however, caring providers were considered most impactful on experience quality by this sample. Giving adequate time, listening to the patient, recognizing/not making assumptions about a patients' partner/familial situation, acknowledging and respecting diverse identities, and performing duties with a caring and comfortable demeanor were all identified as important steps for practitioners or healthcare providers to implement in their interpersonal interactions. These results demonstrate the need for mandatory cultural change for healthcare providers and formal service workers in general.

The responses to the survey question regarding social positions and impact on care quality provided insights that could contribute to competency training; specifically, disability and age were regarded as the most impactful on care quality and these social positions should be of increased consideration in health and social care provider training. These results also demonstrate that, although there may be unique considerations in care in regard to the sample's sexual orientation and/or gender identity, there may be additional or even more pressing considerations regarding their age and/or disability status. These results reinforce the importance of considering an individual in their entirety, especially when they may hold several marginalized identities, and how their identities may impact their needs/wants from care settings, access to care, and historical experiences with care. It is important to note that this sample does

not accurately represent the Canadian population in terms of race/ethnicity, which may help to explain why language and/or race/ethnicity were regarded as the least impactful on care quality. Therefore, the factors that were regarded as most impactful on care quality may only be generalizable to individuals that closely identify to the social positionings of the current participants. Additionally, this sample was not asked about their disability status, and therefore we do not know if this is age-related disability or life-long/chronic disability and how/whether this would impact the perceived effect on care quality.

Support and Care in Caregiving

My third research question was, “*What is the Role of Support and/or Families of Choice in Aging LGBT Caregiving?*” In order to answer the research question regarding formal healthcare system improvements for LGBT caregivers, the survey questions found in Table 10 were asked. The results from research question three suggest that LGBT older adults have adequate social networks and connections to the larger LGBT+ communities, whom the majority of participants felt would assist in a caregiving role.

Table 10

| <i>Survey Questions Used to Answer Research Question Three</i> | | |
|--|---------------|--|
| Question Number | Question Type | Question Content |
| 20 | Quantitative | How much social support do you feel you have? |
| 41 | Qualitative | When you answered the previous question (How much social support do you feel you have?), which persons were you thinking about (e.g., your sister, your neighbour, etc.)? |
| 21 | Qualitative | How many people do you have in your social support network? (e.g., people that you can count on, people you could talk to if you had a personal issue, etc.). Please enter a number below. |
| 22 | Qualitative | As you age, how many people do you have in your social support network that would assist with daily tasks (e.g., meal preparation, chores, transportation to appointments, etc.) |

| | | |
|----|--------------|--|
| 42 | Qualitative | As you age, how many people do you have in your social support network that would assist you emotionally (e.g., listen to concerns, validate feelings, check in, etc.) |
| 23 | Qualitative | How many of these supportive individuals also identify as LGBT? |
| 25 | Qualitative | Who was/is the caregiver? What was the nature of your relationship with the caregiver (e.g., sister, neighbour, father, etc.)? |
| 28 | Qualitative | Who was/is the care receiver? What was the nature of your relationship with the care receiver (e.g., sister, neighbour, father, etc.)? |
| 30 | Quantitative | Indicate the extent to which you feel connected to LGBT+ communities |
| 31 | Qualitative | If you were to find yourself in a caregiving role, do you anticipate that members of the LGBT+ communities would help you (e.g., share some of the caregiving tasks, provide emotional support, etc.)? Please explain. |

Participants were asked to report on the degree of social support they felt they have on a scale of 0 to 10, to which participants responded with a mean of 6.94 ($M = 6.94$, $SD = 2.47$). Responses ranged from 0 (1 participant), indicating no/less social support, to 10 (7 participants), indicating high/more social support. The mode, or most commonly indicated response, was 8 out of 10 (14 participants). When asked to identify who their source(s) of social support was, the majority of participants identified several sources of support. Friends were one of the most frequent sources (36 respondents) with 3 of these respondents identifying LGBT-specific friends as sources of support. Ten participants responded broadly with “family” and without any further context the biological or non-biological nature of this cannot be determined. Several participants identified specific family members, with 11 identifying their partner, one identifying their in-laws, seven identifying nieces/nephews/grandchildren, eight identifying children, and 20 identifying siblings (brother = 5; sister = 12; broad/general = 3). Neighbours (9 participants) and community/groups (12 participants; 6 LGBT-specific) were also commonly identified as sources

of support. Additional sources of support included professionals/trainers (4 participants), work/colleagues (3 participants), church (3 participants), and government/courts (2 participants). Two participants responded with all/everyone, and three participants responded that they did not have any sources/geographically close sources of support.

Several social support questions were asked in an open-ended manner to allow participants to add any additional comments and/or create a custom range of numbers. For analysis, ranges were created for each individual question in order to encompass the ranges/responses given by participants in an organized fashion. When asked how many people the participants have in their social network, most identified between 5-10 people (29 participants), followed by 1-4 people (12 participants), 11-20 people (4 participants), and 21-30 people (3 participants). Two participants identified their network as considerably larger, with “300 plus” and “over 500” people in their network. Participants were then asked how many individuals in their support network that would assist with daily tasks such as meal preparation and transportation; Most participants responded with 1-4 people (24 participants), followed by 5-10 people (13 participants), 0/none (7 participants), 11-20 people (1 participant), and “25+” (1 participant). Two participants were unsure, two participants indicated professionals as sources for this role, and one participant gave a vague response (e.g., several). When asked about individuals who could provide emotional assistance, most participants indicated between 1-4 people (21 participants) or 5-10 people (21 participants), followed by 11-20 people (3 participants), 0/none (1 participant), “25+” (1 participant), and “41” (1 participant). One participant provided a vague response (e.g., a few). When asked how many individuals in their support network also identified as LGBT+, most participants responded between 1-4 people (21 participants), followed by all/almost all (9 participants), none/0 (8 participants), 5-10 people (8

participants), and 11-20 people (2 participants). One participant identified “about 40” individuals in their network as LGBT+, and one participant identified “half or more” of their network as LGBT+. The majority responses for these questions are available in Table 11.

Table 11

Quantitative Social Support Network Responses

| Question | Response | Number of Participants (n) |
|---|----------------|----------------------------|
| Q21: How many people do you have in your social support network? | 0/None | 0 |
| | 1-4 | 12 |
| | 5-10 | 29 |
| | 11-20 | 4 |
| | 21-30 | 3 |
| Q22: How many people do you have in your social support network that would assist with daily tasks? | 0/None | 7 |
| | 1-4 | 24 |
| | 5-10 | 13 |
| | 11-20 | 1 |
| | 25+ | 1 |
| Q42: How many people do you have in your social support network that would assist you emotionally? | 0/None | 1 |
| | 1-4 | 21 |
| | 5-10 | 21 |
| | 11-20 | 3 |
| | 25+ | 1 |
| Q23: How many of these supportive individuals also identify as LGBT? | 0/None | 8 |
| | 1-4 | 21 |
| | 5-10 | 8 |
| | 11-20 | 2 |
| | All/almost all | 9 |

In the caregiving portion of this study, when asked about previous or current caregiving or care receiving experience, participants were asked about who provided or received the care. Of the four participants who had received/were receiving informal care, two mentioned professionals (care team, personal support worker, nurse, housekeeper), and three mentioned family/friends (son, partner, housemates, neighbours) as having provided their care. Of the 22 participants who had provided/were providing informal care, ten indicated having cared for more than one person. Most participants identified the care receivers as friends (12 participants),

followed by mother (7 participants), father/fathers-in-law (5 participants), partner (5 participants), “family” (1 participant), aunt (1 participant), and board member (1 participant). Several participants included qualitative remarks such as “Early on in AIDS crisis.....tons of support,” and “Close friend with stage 4 cancer ... I am her 'person'” to give context to their caregiving relationships.

Participants were asked about the extent to which they felt connected to LGBT+ communities, and of the 45 responses, the mean connection was 6.29 on a scale of 0 to 10 ($M = 6.29$, $SD = 2.80$). Responses ranged from 0 (1 participant), indicating no connection to LGBT+ communities, to 10 (11 participants; mode), indicating a high connection. When asked if participants anticipated help from LGBT+ communities if they were to become a caregiver, most participants felt that yes, they would receive help (18 participants, 40%). One participant included potential reasoning for this support,

We have all been part of care teams during the HIV crisis. We understand the needs of responding to the members of our community when they are in crisis of any sort...I have shared my home with many many gay men and a family of choice has developed. These chosen family members will be there and have told me so.

Another participant identified LGBT+ communities as the “only source I would trust” and felt as though they would receive help. Nine participants (20%) indicated that they believed they would receive help with stipulations, such as only emotional support, only some people, or distance-dependent support. Six participants (13.33%) were unsure as to whether they would receive support from LGBT+ communities, with one participant indicating that, “it would be a hit or a miss with any of that support...there is nothing certain.” Seven participants (15.56%) responded that they do not believe they would receive help from LGBT+ communities, with one

male participant explaining, “I am married to a woman, so I am seen as Heterosexual. Hence, I am invisible to the gay community.” Four participants (8.89%) noted that they did not understand the questions and/or did not provide an appropriate response.

In response to research question three, “*What is the Role of Support and/or Families of Choice in Aging LGBT Caregiving?*” the sample felt as though they had adequate support (approx. 8/10 on the scale), with most identifying friends as their main source of support. In terms of the size of participants’ networks, most identified between 5-10 people, however this number dropped to 1-4 people when asked who could/would provide tangible assistance with tasks as they age. Most of the sample reported caring for friends followed by mothers, which is supported by the CLSA data on caregiving among LGB individuals (Stinchcombe & Wilson, 2018). As mentioned in response to research question two, the longevity of aging care networks may be dependent on the age and health status of individuals in this network. Within the current sample, most participants were aged 70-71 years old, which is relatively young considering that Statistics Canada (2019) predicts a life expectancy of 82.1 for Canadians as of 2017. Additionally, approximately 45% of the sample who had/were providing care reported having cared for more than one person, demonstrating the high demand for LGBT caregivers and preferred care networks. Formal services need to be improved in order to offer support or relief to LGBT caregivers in order to help reduce burnout and subsequently increase the longevity of these preferred support networks.

The results regarding connection to the larger LGBT+ communities also support those of the previously discussed CLSA data. In the present sample, participants indicated an above average connection to the community (6.29/10 on the scale), with most indicating a very strong connection (10/10 on the scale); participants in the CLSA data also indicated a high level of

support from the larger LGB communities (Stinchcombe & Wilson, 2018). Participants also indicated that they felt as though individuals from the larger LGBT communities would provide help to them in a caregiving role, outlining the importance of informal support outside of traditional biological/kin confines. The older adults in the current study have demonstrated that, regardless of being rooted in necessity or choice, they have successfully created caring networks. However, the longevity of these networks and the potential strain/burnout on the members must be considered; if formal networks were more inclusive and competent to meet the unique needs of LGBT older adults, perhaps these networks could become rooted more in choice/desire than necessity and safety. As noted in previous research questions, care provider training, adequate care/treatment and institutional efforts are needed. Furthermore, we need to consider the larger systems at work in care environments and which families/networks are valued and recognized; in order to provide the necessary support/relief to LGBT caregivers, these larger systems need to be designed in a way that values the diversity of care networks.

Summary

In summary, my first research question was “*What are the needs of aging LGBT caregivers and/or individuals caring for LGBT older adults?*” The results from this research question suggest that LGBT older adults have unique needs within care environments as both caregivers and care receivers; these needs include awareness and acceptance, a practitioners’ willingness to learn, partner recognition, respect, and advocacy. The second research question was “*How can the formal healthcare system better meet the unique needs of informal LGBT caregivers/care receivers?*” The results from this question suggest that quality care for LGBT older adults is comprised of adequate treatment, caring providers, and institutional efforts. Of these three influential factors, caring providers were identified as having the most impact on

whether a care experience was negative or positive. Specifically, the following factors were identified as areas of improvement for healthcare providers: Giving adequate time, listening to the patient, recognizing/not making assumptions about a patients' partner/familial situation, acknowledging and respecting diverse identities, and performing duties with a caring and comfortable demeanor. The third research question was "*What is the Role of Support and/or Families of Choice in Aging LGBT Caregiving?*" The results from this research question suggest that the LGBT older adults from this sample have adequate support networks and significant connection to the larger LGBT communities; although these preferred networks have been established, the majority of the sample anticipated needing formal services in the future, reinforcing the importance of making improvements to the cultural competency of healthcare and services in general.

Discussion

The purpose of this study was to explore the experiences of LGBT older adults in regard to caregiving, care receiving, and accessing formal services. I specifically aimed to answer three research questions: "*What are the needs of aging LGBT caregivers and/or individuals caring for LGBT older adults?*", "*How can the formal healthcare system better meet the unique needs of informal LGBT caregivers/care receivers?*", and "*What is the role of support and/or families of choice in aging LGBT caregiving?*" To answer these questions, the survey responses of 50 LGBT+ older adults were analyzed using descriptive statistics and content analysis. The results suggested that compared to their majority peers, LGBT older adults have additional, unique needs/wants in care environments. Further, experiences with providers and social care workers were identified as the most important factors in determining the quality of a care experience. Lastly, the LGBT older adults in this sample were identified as having adequate social networks

and connection to the larger LGBT communities. These results reinforce the importance of implementing more inclusive practices in formal services, specifically regarding caregiving and social care, as the older adult population continues to age.

Demographics. As previously stated, Barker and colleagues (2006) suggested that older adults may be less comfortable with the terminology ‘queer,’ due to its discriminatory connotation throughout history. For this reason, ‘LGBT’ was used in all study materials rather than the most current ‘LGBTQIA2+¹’ acronym. However, the sexual orientation scale used in the survey, developed by Hauptert, Pope, Garcia and Smith (2018), provided queer as an option and the results suggested that 14.29% of the sample identified with this term. Although we did not ask about comfortability with this term, many participants found this survey online or through an LGBT+ organization, where they may have had the opportunity to become more comfortable with this terminology. These findings provide insight for future research in this field, in that more current language may be successful in recruitment materials.

The majority of participants rated their overall health and mental health as ‘very good’ (38% and 40%, respectively) or ‘excellent’ (24% and 36% respectively). Stinchcombe and colleagues (2018), in the previously discussed CLSA study, suggest that LGB older adults tend to have poorer mental health, health behaviours, and chronic illness when compared to their hetero- and/or cis-gender counterparts. However, some similarities are visible between the current sample and the CLSA sample, in that the older CLSA age groups (65-74, 75-85) had the highest self-rated mental health. This phenomenon is interesting given the higher likelihood of chronic illness as age progresses; however, this trend demonstrates the resilience of LGBT older adults. Although the present study did not have a population of majority peers to compare with,

¹ This acronym represents lesbian, gay, bisexual, transgender, queer, intersex, asexual, and 2-spirit identities.

the participants' self-rating of health was generally positive. This is also visible through the participants' discussion of caregiving, in that only 8% of the sample had been on the receiving end of care. The levels of general and mental health of this sample may be a result of the resiliency and adaptation of these older adult populations (Brotman et al., 2003; McParland & Camic, 2016). Additionally, the majority of the participants reported adequately sized social networks, which has been linked to better health outcomes for LGBT older adults (Erosheva, Kim, Emler, & Fredriksen-Goldsen, 2016).

Caregiving needs. The overarching finding from the first research question is that the baseline, *Care is care: Basic rights* experience is not inclusive enough to meet the needs of LGBT older adults in caregiving/receiving roles. The baseline experience was identified as the minimum standard of care within formal services that could be generalizable for the entire population, including factors like adequate care/treatment and respect. These results reinforce the existing literature on LGBT older adults in healthcare settings, in that LGBT older adults do in fact have unique needs and considerations in care environments (Brennan-Ing et al., 2014; Duffy & Healy, 2014; Fredriksen-Goldsen & Muraco, 2010; McParland & Camic, 2016). The notion that healthcare/care environments are not meeting the unique needs of LGBT individuals has been described in past research (Brennan-Ing et al., 2014; Duffy & Healy, 2014; Fredriksen-Goldsen & Muraco, 2010; McParland & Camic, 2016); however, this has not been explicitly reported within Canadian contexts.

Several factors were identified as important by participants in both caregiving and care receiving, including awareness and acceptance of their LGBT+ identity, a practitioner's willingness to learn, recognition and respect of one's partner, advocacy, and overall respect. All of these factors, except for willingness to learn, have been identified in Canadian literature as

important for healthcare access by LGBT older adults (Brotman et al., 2015; Brotman et al., 2003; Furlotte et al., 2016). However, different factors were identified in the LGBT caregiving literature as being barriers to inclusive care; including the favouring of biological family over chosen family/partners, legal concerns regarding end-of-life decision making, and a lack of inclusive support resources (Brotman et al., 2007; Brotman et al., 2015; Duffy & Healy, 2014; Fredriksen-Goldsen & Hoy-Ellis, 2007; Stinchcombe et al., 2017); these factors were not noted by participants in the current study. I believe that this is due to the context that the questions were presented in, specifically participants in this study having been asked about both caregiving and care receiving experiences. For example, much of the literature discusses the factor of advocacy in older adulthood in the context of being unable to advocate for one's own needs and the accompanying fear (Furlotte et al., 2016); however, many of the participants in this study spoke about advocacy in the context of caregiving, specifically being able to advocate for other LGBT older adults in care.

Healthcare System Improvements. One of the most impactful findings from research question two was the *Perfect storm* concept, in that participants identified factors that could impact the quality of their care experiences. Specifically, participants noted quality care, institutional efforts, and caring health and social care providers. One piece of the institutional effort subtheme was the use of inclusive intake forms, which have been identified in the literature as important in fostering identity disclosure and subsequent comfort and care quality for LGBT older adults (Brotman et al., 2003; Stinchcombe et al., 2016; Wilson et al., 2018). With regard to practitioners and providers, historical instances and/or fear of covert and/or overt discrimination have been noted in the literature (Brotman et al., 2007; Fredriksen-Goldsen, 2014; Furlotte et al., 2016). The findings from this study are valuable in that they provide tangible steps

for health and social care providers to work towards more inclusive care. Specifically, the following factors were identified by current participants as important: giving adequate time, listening to the patient, recognizing/not making assumptions about a patients' partner/familial situation, acknowledging and respecting diverse identities, and performing duties with a caring and comfortable demeanor.

Previous literature suggests that LGBT older adults may delay or avoid seeking care due to fear of discrimination (Brotman et al., 2003; Brotman et al., 2015; Choi & Meyer, 2016; Czaja et al., 2016; Harding, Epiphaniou & Chidgey-Clark, 2012; Stein et al., 2010). However, 49 of 50 participants had reported a negative or positive experience within formal healthcare settings, indicating that they were accessing formal care. Considering the overall health status of the sample, these results indicate that the respondents may be proactive rather than reactive in terms of seeking healthcare. Additionally, 86.36% of the sample indicated anticipating needing formal services at some point in their aging process. Looking at the characteristics of the current sample, the majority of participants did not belong to additional marginalized positions beyond age and sexual orientation; therefore, this group of participants may have greater access to and comfort within formal services than individuals with additional marginalized identities, who are not represented in the current sample. The limited diversity of the sample is also highlighted by responses to the question regarding social positions and care quality. Geographic location was identified by participants as one of the least impactful social positions on care quality; however, the literature suggests that rural communities have significantly less adequate formal services and more discrimination than those in urban areas (Barker et al., 2006; Cartwright et al., 2012; Coon, 2003; Furlotte et al., 2016). This ranking makes sense in the context of the sample of participants, with only 18% of the sample having identified as living in a rural community.

Support and Care in Caregiving. Brotman and colleagues (2003) suggest that the notion of LGBT older adults being more isolated than their majority peers is a myth, which seems to hold true for the current sample of participants given their adequately sized social networks. Although the literature suggests that LGBT older adults are less likely to be linked to their biological family than their majority peers (Brennan-Ing et al., 2014; Coon, 2003; Fredriksen-Goldsen & Muraco, 2010; Gabrielson, 2014), twenty participants noted their siblings as part of their social networks. However, friends remained the most commonly indicated response when asked about the individuals that comprised the samples' social networks. Erosheva (2016) echoes this in their work, in that friends were regarded as the first source of tangible and emotional support for LGBT older adults. Social and community support were identified as important to this sample, with most feeling an adequate connection to the larger LGBT+ communities. The participants from the CLSA data also indicated a high level of support from the larger LGB communities (Stinchcombe & Wilson, 2018). Connection to and support from the community has been linked to positive aging outcomes and adjustment, which may help to explain the high average health status among these participants (Brennan-Ing et al., 2014; Coon, 2003; Czaja et al., 2016; Fredriksen-Goldsen & Muraco, 2010; Gabrielson et al., 2014).

With regard to caregiving, most participants reported caring for friends (54.54%) if they had indicated a caregiving role in the past or present. This finding aligns with previous literature, in that caregiving by and for LGBT older adults is most often done by/for families of choice and friends (Barker et al., 2006; Brennan-Ing, 2014; McParland & Camic, 2016). The literature also suggests that some caregiving may occur by/for biological family, which was demonstrated in this sample with the second most common care receiver being mothers of the participants. The caregiving reported by this sample also reinforces the notion that LGBT caregivers are in high

demand (Brotman et al., 2007; Czaja et al., 2016; Gabrielson et al., 2014; Hughes & Kentlyn, 2011), with 45.45% of the caregiver participants having cared for more than one person.

Fredriksen (1999) suggests that informal LGBT caregivers have higher levels of role strain and more hours of care than their majority peers due to increased demand. This underscores the importance of improving formal health and social care services for respite or assistance, reducing the burnout and demand of LGBT caregivers.

Theoretical Discussion

Two theories served as guidance for the formation of my research questions, survey questions, and analyses: life course theory and the theory of intersectionality. The life course theory suggests that individuals must be considered in their social and cultural contexts, in the context of their relationships and cohorts, and over the course of history and time. As previously noted, the historical discrimination experienced by LGBT older adults is important in considering their likelihood and desire to access formal healthcare services. Several participants spoke about historical discrimination, with one participant stating, “I fought the fight for my rights in the 80’s, I don’t want to fight for my rights again in my 80’s.” Life course theory suggests the importance of recognizing the diversity of experiences among cohort members and among individuals in general. As previously stated, Fabbre (2017) suggests that life course theory discourse is often informed by majority populations in gerontological literature. However, the life course theory can serve as an appropriate lens for these findings due to the theory’s focus on heterogeneity of older adults and the impact of historical and social contexts on accessing care. These findings help to reinforce the concept of diversity in aging, as the participant responses were so varied in regard to the way that they navigate services and systems; In the qualitative results, several participants indicated aging concerns that were directly related to their

sexual orientation and/or gender identity, yet some participants explicitly stated that their sexual orientation and/or gender identity was not relevant to their aging experience.

The life course theory also suggests the importance of considering individuals in their linked lives (the bi-directional impact of relationships and connections; Stinchcombe et al., 2016), which came out strongly in the participant responses. Some participants overtly stated the intentional and necessary co-creation of aging LGBT networks, with some individuals noting their experience with the AIDS crisis as a motivation. These responses also reinforced the importance of considering diversity in life trajectories. Historical discrimination and the larger hetero- and cis-normative culture that we live in have resulted in diverse life progressions and considerations for LGBT older adults. LGBT older adults may have experienced different accessibility and eligibility than the standard of majority populations; the results have demonstrated this phenomenon specifically in access to health and social care. In general, the participants had relatively robust social networks that were created to foster care and caregiving when needed. In line with the life course theory and the natural progression through life transitions, furthering the longevity of these networks is crucial for the continued wellbeing of LGBT older adults.

The theory of intersectionality is important to use in the creation and navigation of research with and for marginalized populations as it recognizes the additive oppression that individuals experience within various social positions. As previously stated, it is important that the experiences of those with several marginalized identities are at the forefront of informing policy and practice. In the context of the current sample, there was a lack of diversity in regard to several social positions; however, the participants of this sample belong to minority aging and sexuality groups. It is evident through several of the qualitative responses, specifically from the

LGBT identities affect care: It takes more theme, that regardless of the lack of additional marginalized identities, these participants are still not experiencing an appropriate quality of care. Therefore, their marginalization is evident through their noted experiences. This justifies and requires further work in this field to gain the additional insights of LGBT older adults with additional marginalized identities. In terms of which social positions were most indicative of care quality for this sample, age and disability were regarded as most impactful.

Strengths and Limitations

Strengths. The results from this study will contribute to the larger body of research regarding caregiving/care receiving among LGBT older adults, which is limited within Canada. Considering these results within the Canadian context is important given Canada's unique history with LGBT individuals and Canada's distinct healthcare system. The results provide unique contributions to the LGBT aging literature, specifically regarding healthcare and social care workers' interactions with aging LGBT populations; the importance of having a practitioner or provider that is willing to listen and learn from LGBT older adults regarding their needs is a unique contribution to Canadian literature. Additionally, giving time, listening, recognizing partners and families, being non-assumptive, and having a positive demeanor are all participant-identified factors that are important in care and could be translated into practice and training. Regarding the survey itself, the participants completed the survey quicker than anticipated, as the majority of participants completed the survey in under 30 minutes rather than the anticipated 60 minutes. This serves as support for the use of online survey methods with older adults, counteracting assumptions that online methods would not be successful with a sample of older adults. This being said, although we did not receive feedback regarding difficulties with the survey, we cannot make definite conclusions about the ease of use of the online survey for the

current sample or know who was unable to participate given the online methods. Additionally, although the sample was limited in terms of diversity, the participants' ongoing concerns with formal systems enforces the importance of translating these findings into improved practice.

Limitations. The primary limitation of this study is the lack of diversity of the sample that participated. One of the goals of this study was to attain a diverse sample in order to be able to understand and gain the insight of individuals who likely experience(d) the most problematic treatment within formal services. The sample was limited in terms of race, ethnicity, and gender identity, with most of the participants identifying as Caucasian, Canadian, and cisgender, respectively. This lack of diversity is visible in the question regarding the perceived impact of social positions on care quality; race/ethnicity, language, and gender identity were not included in the top three most influential factors and we cannot know whether this is due to the participants' lack of marginalized experience in these social positions. An additional goal of this study was to have a geographically diverse Canadian sample, however 70% of the sample was from Ontario. After thorough reflection, the goal of having geographic and characteristic diversity were likely unmet due to a lack of purposeful recruitment; individuals with additive marginalized identities and/or individuals in more remote geographic locations may be more difficult to reach without intentional, targeted recruitment. Additionally, in terms of online recruitment via Reddit forums, this method may have been more successful if the forum moderators had been contacted rather than posting from a personal/unrecognized account.

Lastly, upon analysis, I identified several questions that could have been rephrased for clarity and also noted areas where additional questions may have been advantageous. Specifically, questions regarding whether participants had children, and a question regarding disability status would have been helpful to include in the demographic block of questions. The

use of more validated measures and scales (e.g., a social network scale) may have been helpful for attaining data that could be readily compared to existing literature.

Future Research

Future research in this field should aim to recruit increasingly diverse samples, particularly Black, Indigenous, and people of colour (BIPOC), and participants from a wider range of geographic locations. Additionally, prior research suggested that the use of ‘queer’ and/or other more recent terminology from the LGBTQIA2+ communities may be problematic for older adults, yet several older adults self-identified as queer; therefore, using more diverse terminology and recruitment methods may result in more diverse sexual orientation and/or gender identity sampling for future research. As noted in the theoretical discussion, gaining the perspectives and lived experiences of individuals with several marginalized identities is important to further improve recommendations for policy and practice. Additional methods of research may also be beneficial, particularly interviews, as some of the qualitative responses provided could have been further nuanced and deepened in a face-to-face interaction.

Specifically, face-to-face interactions would result in more immediate feedback and could allow for more clarification, follow-up questions, and potentially a stronger rapport with participants.

In regard to content, research on LGBT older adults’ experiences with and/or anticipation of long-term care environments. This suggestion was put forward by a participant when asked if they had any additional feedback, “I would like to see more research about impact of sexual orientation on life in a long-term care facility. Being open versus going back into the closet. Discriminatory behaviour from staff and other residents.” An additional participant noted curiosity about staff training in long-term care, and several other participants noted long-term care as a particular concern.

Additionally, conducting research specifically with LGBT caregivers/care receivers would provide insight into experience with formal services in caring roles and where improvements may be necessary. As this was an exploratory study into this topic, inclusion criteria did not require that participants have experience in caregiving/care receiving.

Implementation: Moving from Research to Practice

As one participant urged, “Begin as soon as possible to work on programmes that can deal with some of the problems that are already well known.” Another participant states, “Direct action to implement programs... A NEW VIGILANCE is needed, if peace of mind is the goal of planners, researchers, and the LGBT+++COMMUNITIES, are to THRIVE well into their future.... all of us together.” Creating policies and practices that can improve the lives of LGBT older adults as they continue to age is of utmost importance, and the results from this study provide some guidance for meaningful recommendations. Ultimately, recommendations for policy and practice should be developed in partnership with and for the LGBT+ communities; those directly affected by policy and practice changes should have the opportunity to provide active feedback and insight on their needs and wants in order to improve their lived experience.

To improve practice in healthcare, the results from the survey questions on negative/positive experiences with care can be useful; specifically, implementing institutional changes/efforts and improving the quality of experiences with healthcare providers. The participants suggested that queer staff, inclusive intake forms, and physical signs of acceptance would help to demonstrate institutional effort. Brotman and colleagues (2015) support these methods and expand to suggest that institutional inclusivity may also include outreach to LGBT+ communities and taking the initiative to share their inclusive efforts. When possible, institutions

should also offer LGBT-specific resources and services, particularly support services for LGBT caregivers/caregivers of LGBT older adults.

To improve LGBT older adults' experiences with healthcare providers, which was identified as most impactful on care quality, training must be implemented. Furthermore, fostering empathy and promoting understanding and caring in daily interactions is needed from health and social care workers. Providing a safe and non-judgemental environment for LGBT older adults to be open and honest is an important first step in increasing safety and decreasing invisibility for this population. In terms of policy development, enforcing mandatory anti-oppression training and education would be an appropriate method of improving the comfort and accessibility of services for LGBT older adults. Specifically, education on structural and historical inequalities as well as population-informed education on the unique needs and wants of LGBT older adults would improve healthcare provider's culturally competent knowledge. The results from this study have provided some population-informed recommendations for providers, specifically information on what a positive experience with care providers may require.

LGBT older adults deserve improvement in the services that they access and deserve adequate and culturally competent care, as is provided to heterosexual/cisgender older adults. As older adults continue to age, institutions and health and social care providers must be able to adapt and recognize the great diversity of these populations. The long-term wellbeing of LGBT older adults and their care networks is dependent on the improvement of formal services for support and respite when needed, and these services require improvement before assistance is comfortable and accessible.

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Appendix A



RESEARCH ETHICS BOARDS

*Certification of Ethical Acceptability of Research
Involving Human Participants*

APPROVAL PERIOD: November 27, 2018
EXPIRY DATE: November 26, 2019
REB: G
REB NUMBER: 18-11-010
TYPE OF REVIEW: Delegated
PRINCIPAL INVESTIGATOR: Wilson, Kimberley (kwilso01@uoguelph.ca)
DEPARTMENT: Family Relations & Applied Nutrition
SPONSOR(S): N / A
TITLE OF PROJECT: Creating Visibility: Considering LGBT Older Adults in the Informal Canadian Caregiving Context

The members of the University of Guelph Research Ethics Board have examined the protocol which describes the participation of the human participants in the above-named research project and considers the procedures, as described by the applicant, to conform to the University's ethical standards and the Tri-Council Policy Statement, 2nd Edition.

The REB requires that researchers:

- Adhere to the protocol as last reviewed and **approved** by the REB.
- Receive approval from the REB for any **modifications** before they can be implemented.
- Report any **change in the source of funding**.
- Report **unexpected events or incidental findings** to the REB as soon as possible with an indication of how these events affect, in the view of the Principal Investigator, the safety of the participants, and the continuation of the protocol.
- Are responsible for **ascertaining and complying with all applicable legal and regulatory requirements** with respect to consent and the protection of privacy of participants in the jurisdiction of the research project.

The Principal Investigator must:

- Ensure that the ethical guidelines and approvals of facilities or institutions involved in the research are obtained and filed with the REB prior to the initiation of any research protocols.
- Submit an **Annual Renewal** to the REB upon completion of the project. If the research is a multi-year project, a status report must be submitted annually prior to the expiry date. Failure to submit an annual status report will lead to your study being suspended and potentially terminated.

The approval for this protocol terminates on the **EXPIRY DATE**, or the term of your appointment or employment at the University of Guelph whichever comes first.

Signature:

Date: November 27, 2018

Stephen P. Lewis
Chair, Research Ethics Board-General

Appendix B

Caregiving Among LGBT Older Adults

Q1 Do you live in Canada?

Yes (1)

No (2)

Skip To: End of Survey If Do you live in Canada? = No

Q3 Are you aged 65 or older?

Yes (1)

No (2)

Skip To: End of Survey If Are you aged 65 or older? = No

Q4 Do you identify as LGBT+ (lesbian, gay, bisexual, transgender)? *We recognize that you may use other language within these communities*

Yes (1)

No (2)

*Skip To: End of Survey If Do you identify as LGBT+ (lesbian, gay, bisexual, transgender)? *We recognize that you may use ot... = No*

End of Block: Screening Questions

Start of Block: Demographic Questions

Q5 What is your birth year? _____

Q6 What is your gender identity?

Man (1)

Woman (2)

Non-binary (e.g. genderqueer, genderfluid) (3)

Agender (4)

Another identity not listed: please specify (5): _____

Do not know (6)

Choose not to answer (7)

Q8 "Transgender" describes people whose gender identity or expression is different, at least part of the time, from the sex assigned to them at birth. Do you consider yourself to be transgender?

Yes (1)

No (2)

Do not know (3)

Choose not to answer (4)

Q9 Which of these sexual orientations fit for you? (choose all that apply)

Asexual (1)

Bisexual (2)

Straight (heterosexual) (3)

Gay (11)

Lesbian (4)

Pansexual (5)

Queer (6)

Questioning or unsure (7)

Same-gender loving (8)

An identity not listed: please specify (9) : _____

Prefer not to disclose (10)

Q10 What is your current marital/partner status?

Single (1)

Married / Living with a partner in a common-law relationship (2)

Widowed (3)

Divorced (4)

Separated (5)

A status not listed: please specify (6) : _____

Q11 In general, how would you describe your health?

Excellent (1)

Very good (2)

Good (3)

Fair (4)

Poor (5)

Not listed: please specify (6): _____

Q12 In general, how would you describe your mental health?

Excellent (1)

Very good (2)

Good (3)

Fair (4)

Poor (5)

Not listed: please specify (6): _____

Q44 Which province/territory do you reside in?

Alberta (1)

British Columbia (2)

Manitoba (3)

New Brunswick (4)

Newfoundland and Labrador (5)

Northwest Territories (6)

Nova Scotia (7)

Nunavut (8)

Ontario (9)

Prince Edward Island (10)

Quebec (11)

Saskatchewan (12)

Yukon (13)

Q13 Do you reside in an urban or rural area?

Urban (1)

Rural (2)

Remote (3)

Q14 Please identify the race(s) that you most identify with (e.g., Hispanic, Asian, Caucasian, etc.):

Q15 Please identify the ethnicity that you most identify with (e.g., Canadian, French-Canadian, Guatemalan, Persian, etc.):

Q16 How did you hear about this survey?

End of Block: Demographic Questions

Start of Block: Block 2

Q17 As you think about aging, what is most important to you? Is there anything particularly relevant to your sexual orientation and/or gender identity?

Q20 How much social support do you feel you have?

0 1 2 3 4 5 6 7 8 9 10

0 indicates less support, 10 indicates more support ()



Q41 When you answered the previous question (How much social support do you feel you have?), which persons were you thinking about (e.g., your sister, your neighbour, etc.)?

Q21 How many people do you have in your social support network? (e.g., people that you can count on, people you could talk to if you had a personal issue, etc.). Please enter a number below.

Q22 As you age, how many people do you have in your social support network that would assist with daily tasks (e.g., meal preparation, chores, transportation to appointments, etc.)

Q42 As you age, how many people do you have in your social support network that would assist you emotionally (e.g., listen to concerns, validate feelings, check in, etc.)

Q23 How many of these supportive individuals also identify as LGBT?

Q24 Have you received/are you receiving informal unpaid care for a long-term condition, aging need, or disability?

Yes (1)

No (2)

Skip To: Q27 If Have you received/are you receiving informal unpaid care for a long-term condition, aging need, o... = No

Q26 Is this a current or previous care receiving role?

Current (1)

Previous (2)

Q25 Who was/is the caregiver? What was the nature of your relationship with the caregiver (e.g., sister, neighbour, father, etc.)?

Q27 Have you been/are you an informal caregiver for an individual with a long-term condition, aging need, or disability?

Yes (1)

No (2)

Skip To: Q30 If Have you been/are you an informal caregiver for an individual with a long-term condition, aging n... = No

Q29 Is this a current or previous caregiving role?

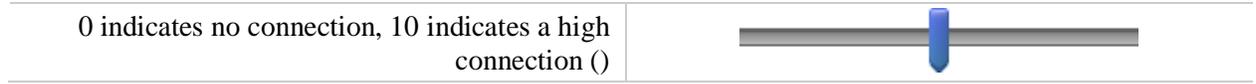
Current (1)

Previous (2)

Q28 Who was/is the care receiver? What was the nature of your relationship with the care receiver (e.g., sister, neighbour, father, etc.)?

Q30 Indicate the extent to which you feel connected to LGBT+ communities

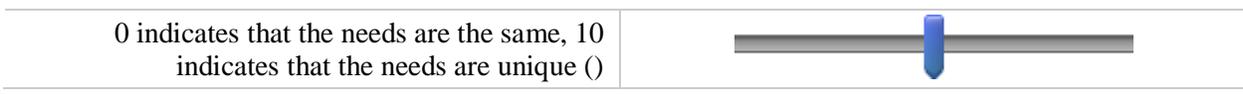
0 1 2 3 4 5 6 7 8 9 10



Q31 If you were to find yourself in a caregiving role, do you anticipate that members of the LGBT+ communities would help you (e.g., share some of the caregiving tasks, provide emotional support, etc.)? Please explain.

Q32 Indicate the extent to which LGBT caregivers have the same or unique needs from heterosexual/cisgender caregivers.

0 1 2 3 4 5 6 7 8 9 10



Q33

Indicate the extent to which LGBT caregivers have the same or unique needs from heterosexual/cisgender caregivers (previous).

Please explain.

Q34 Think back to a positive experience with a healthcare professional. How did they show you that they care? How did they make you comfortable?

Q43 Think back to a negative experience with a healthcare professional. What actions or lack of actions did you find unpleasant?

Q35 As a patient, what is important to you when interacting with a healthcare professional?

Q36 As a caregiver, what is important to you when interacting with a healthcare professional?

Q37 As you grow older, do you anticipate needing any formal services/supports?

Yes (1)

No (2)

Skip To: Q40 If As you grow older, do you anticipate needing any formal services/supports? = No

Q38 What services do you anticipate needing? Select all that apply.

Transportation (1)

Specialized healthcare (2)

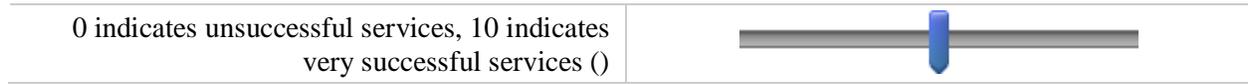
Financial support (3)

Housing (4)

Other(s): (5) _____

Q39 In your opinion, how successful are the current services at meeting your needs?

0 1 2 3 4 5 6 7 8 9 10



Q40 As you grow older, what informal (social) support do you anticipate needing?

Q42 Place these in order of how much you believe they would impact the quality of care an individual receives in a healthcare setting (e.g., hospital, long-term care, clinic, etc.)

- _____ Age (1)
- _____ (Dis)ability (2)
- _____ Sexual orientation (3)
- _____ Gender identity (4)
- _____ Race/ethnicity (5)
- _____ Geographic location (e.g., rural, urban, etc.) (6)
- _____ Socioeconomic status (7)
- _____ Language (8)

Q43 My research interests are on caregiving among aging LGBT individuals. Is there anything else you want me to know?

End of Block: Block 2

Appendix C

**Information Letter**

Title: Creating Visibility: Considering LGBT Older Adults in the Canadian Caregiving Context

You are invited to participate in a research study conducted by Dr. Kimberley Wilson, Dr. Robin Milhausen, and Haley Watson from the Department of Family Relations & Applied Nutrition and University of Guelph, Canada.

Inclusion Criteria

You must meet the following set of criteria in order to participate in this study: you must identify as an LGBT+ individual (acknowledging the diversity in preferred terminology), you must reside within Canada, you must be at least 65 years of age, and you must be able to read, write, and understand the English language.

Purpose of the Study

Given the aging Canadian population, the number of individuals needing care is gradually increasing. Research suggests that social networks and care might look different between diverse groups of individuals. The researchers of this study are aiming to explore what caregiving/care receiving and the general state of care looks like among LGBT older adults. The data from the study will be analyzed and summarized to fulfill a Masters-level thesis, with the goal of then publishing the data to an academic journal. The goal of this study is to use the results to build on the existing research in this field as well as to inform government-level policy and practice through strategic dissemination to better meet the needs of LGBT individuals.

Procedures

If you choose to participate in this research study, the questionnaire will begin immediately pending consent. The survey will take approximately 60 minutes to complete, but please take as long as you need. The survey will begin by asking demographic questions, followed by questions on your caregiving and care receiving experiences, your social networks, your anticipated needs as you age, and your experiences with formal supports/settings. Please note that the study should be completed in one sitting. This means, you would not be able to start the study at one time and come back to finish the questions at a later time.

Participation & Confidentiality

Your participation in this study is completely voluntary, and you are under no obligation to access or complete this study. You may choose to skip any questions by selecting the next arrow.

You may withdraw at from the study up until the completion and submission of the survey without any penalty. If you would like to withdraw from the study, simply close your internet browser and any/all data will be erased. Due to the anonymous nature, please note that after the submission of your survey, your data will not be identifiable and the researchers will not be able to withdraw your data from the study.

Every effort will be made to make sure that all data collected is held securely. We will never share your personal information with anyone else.

Please note that confidentiality cannot be guaranteed while data are in transit over the Internet. However, all collected data will be stored on a password-protected, encrypted laptop that is stored in a secure location.

Potential Benefits

The benefit may not be direct, but you will have the opportunity to inform research that could later affect policy or practice. You may also have the opportunity to reflect on your own experiences and values related to care and aging and may begin to think more about your future health and care.

Potential Risks

Some people may find some of the questions about caregiving/care receiving, or sexual orientation/gender identity uncomfortable or upsetting to answer. You may choose to skip any questions you would prefer not to answer or stop participating in the study at any time. If you experience any discomfort during the study, you are encouraged to contact your family doctor, a mental health professional in your area, or the researchers (contact information is provided below). We have also provided information for resources that you may find helpful.

If, at any point during the study, you feel upset, you are encouraged to contact a local crisis line, call emergency services, or go to your local Emergency Department.

To find a helpful resource in your area please visit:

Immediate help: Toll free 1-833-456-4566

Crisis Services Canada
5th Floor, 439 University Avenue, Toronto, ON M5G 1Y8
(437) 317-4488

Canadian Mental Health Association (CMHA)
Contact/find your local CMHA at <https://cmha.ca/find-your-cmha>.

Potential Benefits

Although there is no direct benefit to you for participating in this study, you may find the provided resources helpful. Additionally, findings from this study can help us to better understand the experiences of LGBT older adults, which can lead to improved advocacy efforts, policy, and practice. It is our hope that this research can be mutually beneficial, in that the researchers can gain crucial information for the field, but also of equal or higher importance is to apply this knowledge back to the community. If you are interested in receiving a summary of the findings, please contact the study researchers. We would be happy to share the findings with you.

Ethics & Contact Information

This project has been reviewed by the Research Ethics Board for compliance with federal guidelines for research involving human participants. If you have any questions regarding your rights and welfare as a research participant in this study (REB #18-11-010), please contact: Director, Research Ethics; University of Guelph; reb@uoguelph.ca; 519-824-4120 ext. 56606. You do not waive any legal rights by agreeing to take part in this study. If you have any questions after the completion of the study, you may contact Dr. Kimberley Wilson.

Please save and print a copy of this information letter to keep for your records.

Thank you for your participation.

| | |
|--|---|
| <p>Dr. Kimberley Wilson Assistant Professor Dept. of Family Relations & Applied Nutrition University of Guelph Guelph, ON N1G 2W1 kim.wilson@uoguelph.ca 519-824-4120 ext. 53003</p> | <p>Haley Watson MSc Student Researcher Dept. of Family Relations & Applied Nutrition University of Guelph Guelph, ON N1G 2W1 hwatso04@uoguelph.ca</p> |
|--|---|

Clicking on 'I Consent' at the bottom of this page indicates that I understand the information provided and agree to participate in this research.

I consent to participate

I do not consent to participate

Appendix D



**UNIVERSITY
of GUELPH** 

Participants Wanted!

Do you identify as LGBT? Are you aged 65+? Do you live in Canada? If so, we would love to hear from you!

A Master's candidate at the University of Guelph is conducting a study about LGBT older adults' experiences with aging, health, and care.

**Interested?
Access this link to fill out the (~60 minute) online survey:**

**[https://tinyurl.com/
CreatingVisibility](https://tinyurl.com/CreatingVisibility)**

**Researcher Contact:
Haley Watson
hwatso04@uoguelph.ca**

University of Guelph REB#: 18-11-010